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Applying Participatory Health Research Elements in Rural End-of-Life Research: Reflections on Conducting In-Depth Interviews With Participants on Sensitive Topics

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Key words: rural; palliative care; participatory health research; participatory data collection: in-depth interviewing; sensitivity; vulnerable population; reflexivity

Abstract: The "Living Loving Dying" research project aimed to improve end of life and bereavement care for people caring and dying in rural areas. The data were provided by people who had experienced caring for someone until his/her death, while living in an area of low population and geographical isolation. Undertaking data collection on such a sensitive topic, from people still vulnerable from the impacts of death and grief, requires the use of particularly sensitive research methods. It is also important that participants feel their voices are heard and that they are contributing to positive change for others. In view of this we positioned people to participate as community-partners and utilized a descriptive qualitative design with participatory elements in the data collection method of in-depth, semi structured interviewing. The non-hierarchical relationship between researchers and community-partners were key influences for using participatory elements in this research with a vulnerable population. In this article we reflect on the pragmatic and ethical considerations that the application of this method has for rural end-of-life research.

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1. Introduction

Irrespective of where someone dies, quality end-of-life care for patients and their carers needs to be germane and relevant to the needs of their particular cultural and geographic areas (HART, LARSON & LISHNER, 2005; RAINSFORD et al., 2017). For those who choose to die (or care for someone) in a rural or remote region, the provision of palliative care presents particular challenges (BAKITAS et al., 2015; RAINSFORD et al., 2017). Palliative care in rural health is a largely under-researched area (RAINSFORD et al., 2017). Capturing the underrepresented rural voice of terminally ill people and their caregivers is central to understanding the challenges involved in this care and, in turn, ensuring that care is optimal. The choice of research methods to reflect this experience is equally a key consideration. [1]

The choice of study methodology in palliative care research is fraught with challenges. These include high attrition rates due to physical deterioration, fatigue, the burden of participation (SHANMUGASUNDARAM & FARRELL, 2015) and ethical concerns associated with engaging the terminally ill (STEVENS et al., 2003) and/or bereaved family members (KOFFMAN et al., 2012; PAYNE & FIELD, 2004). In order to address these issues it has been suggested researchers should foster methodological approaches which capture the complexity of the terminally ill person and family palliative care needs, and decide the best means of meeting these needs (PALLIATIVE CARE AUSTRALIA, 2000). In recent years qualitative methods have been used in palliative care research to understand the perspectives of the patient and carer (AOUN & KRISTJANSON, 2005; STIEL et al, 2010). In particular, action research approaches have been increasingly supported for enabling practice development and generating knowledge in the fields of palliative care and aged care (HOCKLEY & FROGGATT, 2006). Participatory approaches as a form of action research are more frequently used in public health end of life care[1] research as they target and recognize the "hidden public," i.e., those not directly receiving services but equally affected, such as family and local community members (SALLNOW, TISHELMAN, LINDQVIST, RICHARDSON & COHEN, 2016). [2]

Participatory health research (PHR) is also known as critical action research, practitioner action research, appreciative inquiry, and systemic action research. Regardless of which of these terms is favored, the shared aim is that the research empowers people to generate change and knowledge through a cooperative and reflective process (FREIRE, 1972). This style of research as a method of social inquiry dates back some 50 years, and its use for this purpose is widely accepted (BAUM, 2016). It is firmly established in the field of education and has recently become more commonplace in social and health care (HOCKLEY, FROGGATT & HEIMERL, 2013). What distinguishes participatory research from more traditional research paradigms is that it is collaborative and works with participants in order to effect practice or organizational change

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[1] Public health end of life care is a health promotion approach to end of life care whereby the community is a vital partner in providing quality health care at the end of life (PUBLIC HEALTH PALLIATVE CARE, 2015).

(REASON & BRADBURY, 2006). PHR offers opportunities for individuals, communities, and groups to actively contribute and participate in the process of research for practice change, and thus develop meaningful solutions that benefit themselves, others, and their wider community. "It regards participants as being knowledgeable about their own social realities and best able to re-articulate this knowledge as research evidence" (HIGGINBOTTOM et al. 2006, p.868). [3]

Action research models have been used effectively in various palliative care settings. HOCKLEY and FROGGATT (2006) used this approach in informing end of life care for older people in aged care homes. BLACKFORD and STREET (2013) assessed the feasibility of an advanced care-planning model in community palliative care in Victoria, Australia using the method. BRAZIL, KAASALAINEN, WILLIAMS and RODRIGUEZ (2013) worked with indigenous peoples using PHR to investigate issues of diversity in palliative care. SEALEY, BREEN, O'CONNOR and AOUN (2015) employed action research to develop a bereavement risk model for carers, and LARS, MOLANDER and INGER (2015) established guidelines for dealing with ethical issues for carers. REITINGER and LEHNER (2013) sought to understand the aspects of gender in two Austrian aged care facilities that provide palliative care. [4]

There are many ways of applying PHR methodology in any given setting, as it is a fluid process that can be adapted according to circumstances (BENNETT, 2004). BERGOLD and THOMAS (2012) suggest participatory elements should be embraced in research designs to gain a richer understanding of the situation under investigation and the people involved. The INTERNATIONAL COLLABORATION FOR PARTICIPATORY HEALTH RESEARCH [ICPHR], (2013) has established guidelines for applying the principles of the approach to suit the research setting. However, irrespective of the research situation one of the agreed strengths of the approach is the lack of clear distinction between the community-partners and researchers, which has the potential to lessen power imbalance, and generate individual and community competence to use research findings to encourage and effect practice change (MINKLER, 2013; MINKLER & WALLERSTEIN, 2013). The non-hierarchical relationship between researchers and community-partners and the flexibility of PHR were key factors in its use for our own research with a vulnerable population. A total allegiance to a PHR approach was not feasible because of the complexities of the remote location and vulnerability of the participants. Instead, our study merged standard qualitative methods with participatory elements for conducting research on sensitive topics. For the purpose of this article we have commenced with PHR literature (Section 2), and the various ways researchers have implemented a PHR approach with vulnerable participants. Following this is an overview of the research (Section 3) and a description of how we used PHR elements with vulnerable people in a rural setting. We then considered the different interview and research aspects we encountered (Section 4), and finally we offer a conclusion (Section 5). [5]

2. PHR Literature With Vulnerable Populations

The use of PHR with vulnerable populations is varied and diverse with the degree of participation sometimes limited to the data collection phases. For instance, the arts-based participatory researcher driven study by CONRAD and CAMPBELL (2008) with incarcerated adolescent boys in a young offenders facility involved the participants in the data collection process only. Their six-month project incorporated drama based activities to stimulate participant exploration, enabling them to depict their personal and collective stories in an art form. The researchers collected the many artifacts that emerged from the work such as scripts, music and drawings together with their field notes and reflexive journals for analysis. The researchers accept they did not adhere to ideal PHR principles given the participants' vulnerability and restricted access; however, they assert the work was informed by PR methodological principles and philosophy, and that it advocated on the participants’ behalf and respected them as creators of knowledge. [6]

In another study with isolated, incarcerated men, TURNER, PEACOCK, PAYNE, FLETCHER and FROGGATT (2018) investigated the "de facto life sentence" (p.161) of ageing, living with a terminal illness and subsequently dying in prison. Their three-phase study applied a PHR methodology, which included interviewing prisoners and staff to understand how anticipated deaths were managed. Conducting action cycles with staff and prisoners to identify changes to improve palliation followed this. Workshops were then held with stakeholders to distribute findings, and develop recommendations. Sixty-four participants were involved in the study. The majority were health care professionals, and employees of the criminal justice system, 17 prisoners took part, one nearing the end of his life. The findings shed light on palliation, end of life care and issues surrounding frailty and ageing in prisons, illustrating the flexibility of PHR in a complex setting. [7]

DOSSER and KENNEDY (2012, 2014) conducted two palliative studies in an acute hospital setting with vulnerable participants, using a PHR framework. They investigated support offered to family carers of people nearing the end of life, their experience of support following refining staff communication in the hospital unit and improving the hospital environment. The first phase of the study involved a qualitative phenomenological methodology to understand the complexity of experiences of bereaved carers and staff. Individual semi structured interviews were conducted with eighteen carers and three palliative care specialists. Five focus groups were also held with nursing staff and clinical support workers. The results determined what carers value and view as respect during the time of death. The second phase of the research comprised a two-day communication workshop with nursing staff, followed by meetings with five of the staff over four months to identify whether change had occurred in their communication practice. A short survey was distributed to the hospital ward team and relatives who were currently caring for a terminal relative to gauge their needs for a supportive space. The results of the research demonstrate an improvement in communication and an improvement in the hospital experience for carers. [8]

Interestingly, all of the aforementioned studies were researcher initiated and included participants primarily in the data collection phases, and only one of the articles offered a rationale for this. It is assumed this was due to the vulnerability of the participants and the research environment which limited participation. Despite this, all of the studies illustrate how PHR can be adapted and utilized according to the restrictions of the setting and vulnerability of the participants. Irrespective of the degree of participation, the use of PHR informed the process and contributed to practice change. [9]

3. Overview of the Research

In this article, we reflect on our application of PHR elements in the data collection method in a palliative care rural health research project, the "Living Loving Dying" (LLD) project, which aimed to identify and understand factors that enable, sustain, modify and/or hinder access to adequate and appropriate palliative care in a rural area. Our practical and realistic application of PHR elements entailed understanding and addressing a series of ethical and pragmatic challenges, but nevertheless provided a rich insight into the conduct of palliative care research in rural areas. We hope that the sharing of this experience will be helpful for others who may be considering conducting research of this kind. [10]

3.1 Location of the research

The Tasman Peninsula where the research was situated is located 75km South East of Hobart, (the capital of Tasmania, a state of Australia) and covers 660 km^2. As with other rural areas of Australia, the population of the Tasman Peninsula faces a higher likelihood of ill health due to many factors, specifically, an above state average of people over 65 years (22.4%), and a high median age at 51 years (Tasmania 40 years) (DEPARTMENT OF HEALTH AND HUMAN SERVICES, 2016*).* Socio-economic factors impact of health and life expectancy, in the Tasman Peninsula are in the highest quintile; for instance, the average weekly income is one third lower than the state average, and the unemployment rate 4% higher (ibid.). In the survey a range of health risk factors has been found that were significantly higher than the state average: self-assessed health as fair or poor; psychological distress; insufficient physical activity. Multi-morbidity factors are also high, with 22.8% of persons aged 18+ reporting 4 or more chronic diseases (Tasmania 19.2%) (ibid.). Mortality is similarly higher, with prostate, cervical and lung cancers (WHITE, 2007) for residents of rural areas. [11]

3.2 The study

For the study we used a descriptive qualitative design with participatory action research elements for data collection. Semi structured interviews were conducted with community-partners who were carers of someone who had died from a life-limiting illness within the previous three years, or who were still caring for someone in the advanced stages of living with a terminal illness. A total of seventeen interviews were conducted with 19 participants, and in two instances two people were present, both of whom were partners. [12]

We developed a list of interview prompts (see Table 1) by modifying the quality of dying and death questionnaire (PATRICK, ENGELBERG & CURTIS, 2001), to provide minimal guidance in the interview and help concentrate the focus on different phases of the participants' experience, if required. This approach has precedence in the work of GERMAIN, MAYLAND and JACK (2016), who successfully incorporated the structure of the care of and dying questionnaire (MAYLAND et al., 2014) so as to direct their interviews with bereaved relatives to steer the focus of attention onto particular aspects of the dying event.

Interview Prompts
Discussing your feelings about dying/caring for someone who is dying (peace, fear, worry, dignity, respect)
Discussing your wishes for your/x's end-of-life care
Medical and nursing support
Informal supports
Being comfortable/uncomfortable
Medical intervention
Pain control
Having control over your daily activities
Controlling your end-of-life experience
Having energy to do the things you want or wanted to do
Spending time with loved ones
Spending time alone
Being touched and hugged by loved ones
Saying goodbye to loved ones
Finding purpose and meaning at the end-of-life

Table 1: Interview prompts based on the quality of death dying questionnaire [13]

Field notes were kept to record significant aspects of the interview, together with our impressions. All transcripts were transcribed by an external source and analyzed by the researchers. The study was approved by the University Ethics Committee #H16379. [14]

We drew from the work of BRAUN and CLARKE's (2006) inductive thematic analysis to frame the analysis. Once the interviews had been transcribed, the data were analyzed and the distillation of the data was ongoing until consensus was reached, and the research team was satisfied that the codes and themes were consistent with the research aims. The data revealed six major themes and 27 sub themes, which are illustrated in the following Table 2.

Themes	**Sub Themes**
Dying at home	Positive and negative impact on families Responses by family members and communities Formal and informal resources: human and other Dying near home or in the city
Control	Lack of control Independence Carers taking control Will to live Controlling comfort and care
Difficult people, difficult relationships	Nature of the illness and pain History of difficult relationships Exposure of previously private family dynamics
Isolation	Personal or geographical Needing to drive and doing it badly Community connections Transport and accommodation Medical intervention: local health center, palliative care services, city hospital, other specialists, local general practitioner Allied health: nursing and home help
Grief and bereavement	Formal and informal supports (or lack thereof) Nature of grief Moments after death, funerals and wakes Coping strategies
Talking about dying	Between partners Between medical staff and patients With family and communities (especially in grief) With researchers

Table 2: Thematic analysis themes and sub themes [15]

3.3 Design considerations

In rural communities, the means and expertise for applied research to be conducted is frequently lacking. Hence, where research is conducted, external agencies are often engaged for this purpose (CONRAD & CAMPBELL, 2008; LeBLANC, WHEELER & ABERNATHY, 2010). Furthermore, patients, carers and bereaved carers are prone to habituate to the limitations of their geographical areas and typically do not have an awareness of public health end of life care.

For instance, the AUSTRALIAN INSTITUTE OF HEALTH AND WELFARE (2017) report states that people living in rural or remote areas have poorer access to, and use of health services compared with those living in metropolitan areas. Therefore they grow accustomed to their geographic isolation and often "make do" with the situation and do not consider how things might be different. Consequently, they are unlikely to question or challenge the provision of available services. [16]

PHR typically involves identifying an issue or experience that is shared by members of a community, the consequences of which are not always articulated but for which a solution is desired (CONRAD & CAMPBELL, 2008). The LLD project, however, was a researcher-initiated study and specific palliative care issues pertinent to the targeted rural community had not been voiced by the participants prior to initiating the research. The motivation for the research, triggered by a serendipitous conversation with a local practitioner, was the paucity of knowledge about palliative care services in the rural area concerned, together with the absence of a voice in this region. One of the stakeholders was directly involved in providing palliation and worked with the researchers throughout the design, post interview and analysis stages. The remoteness of the location and the vulnerability of the participants precluded involvement in the initial planning. [17]

An important and crucial consideration when conducting research with vulnerable populations is the need to protect participants from psychological harm and undue distress (HAWRYLUCK, 2004; McCOSKER, BARNARD & GERBER, 2001). In the LLD project, we deliberately sought to reduce participant burden by engaging participants primarily in the interview process. Instead, we focused on implementing the PHR principle of community-partners status in the in-depth interview process and otherwise minimizing their involvement. [18]

We were also sensitive to potential confidentiality issues owing to the small rural community and location. It became apparent from conversations with the community-partners prior to and during data collection that maintaining anonymity was vital. Rather than negotiate this with them, which often occurs in participatory research (SURMIAK, 2018), we were respectful of their concerns and preserved their confidentiality through coding and pseudonyms. We also upheld this in the write-up of the study and were cautious with how we wrote about their experiences so that they could not be identified. [19]

While there is broad agreement about the principles underlying the application of participatory research, the way in which these principles are implemented including the degree of community participation and community researcher participation varies (HOCKLEY et al., 2013). Given the restrictions of the research environment and the limited involvement of the community-partners, we were attentive to issues of participation and ethical concerns. Therefore we continually assessed our study according to how participatory we were during the data collection and if we had represented the community-partners' experiences meaningfully. In order to achieve this we drew from the work of CONRAD and CAMPBELL (2008) and REASON and BRADBURY (2006) and evaluated the research process according to relational qualities and relational practice, study outcomes and their significance, and the diverse ways of knowing. We were reflexive and considered the following: what was important, were the relationships respectful, were we ethical, had we been trustworthy, did we offer an equal voice, had we incorporated PR values, were the findings meaningful and essential, did we meet expectations and, ultimately, positively affect the wider rural community? [20]

3.4 Community-partner recruitment

As the LLD study focused on carers' and patients' experiences of palliative care, we sought community-partnerships from people who had been directly involved. We recruited eighteen eligible people who were carers of patients who had died at home in the past two years from a life-limiting illness, and one participant who was living with a life-limiting diagnosis and receiving palliative care at home in a rural area. Community-partners were recruited by means of a purposive sampling strategy, selected from GP records held at the Medical Centre by the research team, in consultation with the practice manager. All participants had received some level of support or care from the local Medical Centre. The local GP was associated with the local Medical Centre and a member of the research team, whereas the other three researchers were external to the Medical Centre and did not have any involvement there. Eligible participants were initially contacted by letter, outlining the study aims, methods, with an invitation to participate. Specifically, these people were offered a chance to work with us to influence change. The process of building rapport was initiated by taking care to write the initial recruitment letter in an informal and sympathetic style, and acknowledging the challenges inherent in caring for, talking about caring for and dealing with the subsequent death of someone close to them with a life limiting illness. For those who agreed to participate we followed up with a telephone call to discuss the study further and gauge their interest and availability for further involvement. Everyone we spoke to expressed an interest in interviews only and some specifically requested a telephone interview. Interviews were then organized with willing respondents. At the time of recruitment two other people who were living with a terminal illness and being cared for at home had agreed to participate but became too ill to take part. [21]

4. Interview and Research Elements

4.1 Building rapport

When collecting data through in-depth interviewing about the sensitive topic of death and grief, developing rapport with participants is key, along with establishing an informal and safe environment for the participants to share their experience, reflections and opinions. In qualitative studies the interview is an essential element for data collection and much significance is placed on this process, as key data and interpreted results emerge from this intimate conversation (FRITZ & VANDERMAUSE, 2018). Of the different styles of interview—be it individual or focus group—in-depth interviewing is the most appropriate and commonly used research method (MORRIS, 2015) for sensitive topics. It has been described as a dialogue between researcher and participant, focusing on the participant's insight of self, life and experience expressed in his or her own words (MINICHIELLO, ARONI, TIMEWELL & ALEXANDER, 1995) and was therefore used as the principal source for data collection in this study to allow us to gain insight into the participants "lived everyday world" (KVALE & BRINKMAN, 2009, p.29) of palliative care. [22]

Therefore, our process of building rapport continued as telephone conversations were made with the participants to arrange interviews, where participants were reminded taking part in the study was voluntary and they could talk as little and as much as they wanted to about the subject matter. The interviews were arranged at times and venues convenient to the community-partners—mostly in their own homes, which was their choice—and lasting approximately 60 minutes. The first two authors conducted the majority of the interviews, jointly, and in person, while two interviews were conducted via the telephone by request. Usually, we engaged in "small talk" at the beginning at the interview—about the participants' pets, their homes, the weather, food or gardening. This provided the participants with an opportunity to get to know us and gave them time to prepare for the interview. Of note, is that in the majority of interviews the participants also took measures to establish rapport with us, by providing hospitality through offering tea or coffee, baking a cake, or arranging morning or afternoon tea to share. [23]

During the interviews we continued to foster rapport by incorporating reciprocity, a feminist inspired reflexive tool used in research interviews (McNAIR, TAFT & HEGARTY, 2008), whereby we shared some of our feelings about the participant's experiences. Although feminist literature emphasizes the significance of establishing rapport (REINHARTZ, 1992), others view it as coercive rather than reassuring (PECKOVER, 2002). When participants are community-partners and their primary motivation for participating is to bring about change, the researchers’ role is to support them to do this, not to coerce into unwanted participation. Our PHR-informed position was to keep our own participation in the interviews to a minimum and enable the participants to take the lead and participate however they wanted to. For instance, on two occasions the participants had prepared for the interviews by writing about their experiences so they could discuss them. Our responsibility was to support, acknowledge and hear them. [24]

Ideally, building rapport with community-partners for our research would have incorporated small informal meetings whereby the study could be discussed and negotiated. However, we were realistic with what we could achieve owing to the confines of the research setting and susceptibility of the participants; we functioned according to the limitations of the situation (MELLOR, 1988). Interestingly, it is understood that community-partnership is positive for rural communities and crucial in health policy reform (COMMONWEALTH OF AUSTRALIA, 2012) yet the reality is very different. In a review of community participation in rural health research KENNY, FARMER, DICKSON-SWIFT and HYETT (2015) discovered that only a limited number of examples of participation in collaborative rural and remote health research exist. They suggest that meaningful involvement is not easy or straightforward, as rural communities are complex and it is naive to assume participation will be forthcoming (ibid.). In this instance inviting staff from the local medical center to participate as community-partners may have offered a link with the community and fostered greater participation. Participation from staff could have provided additional viewpoints, and further insights about palliation in the rural area could have been gained. [25]

4.2 Power and empowerment

As researchers who were currently or previously in clinical practice (one a nurse, one a psychotherapist, one a psychologist and one a general practitioner—identified on the information sheet), we were conscious of the obvious differences in circumstances. That is, we were conscious of being visitors to the participants' homes, that we were not immediately bereaved or providing end of life care for someone close to us, and knowing that we could walk away from the situation upon completion of the interview. In other words, we knew there was a power imbalance generated by differences in options. We were also cognizant of the fine line between researcher and bereavement counselor. During the course of the interviews with carers and bereaved carers, it became evident that many of the participants had not engaged in bereavement support or counseling prior to or following the death of someone they had cared for. Reasons for this included: not realizing a bereavement service existed; not knowing how to access such a service; not feeling they needed further support at the time; mistrust of sharing emotions with a stranger; and a perceived need to protect privacy in a small community. In many cases, the geographic isolation mirrored participants' lack of a psycho-emotional support system. [26]

Our PHR-informed response to both the power imbalance and to participants' lack of engagement with formal or informal support services in managing their grief and sadness was to empower the participants by situating the control of the interview in their hands, enabling them to direct the speed, content and direction of the process. This empowered them to have more control and involvement in this aspect of the research and particularly the researcher-participant relationship (ROSS, 2017). [27]

A key concern in conducting palliative care research is the protection of individuals who are especially vulnerable and susceptible to exploitation (LeBLANC et al., 2010). In this case, our concern was to avoid exploiting participants' vulnerability by inadvertently activating aspects of their emotional experiences and causing further distress. Locating the control of the interview with the participants circumvented this problem. It enabled them to decide what was discussed and how their knowledge was shared creating "moments of empowerment" (ROSS, 2017, §2). For example, one participant commenced the interview as soon as we arrived. We noted that she was not interested in any "small talk" before proceeding to express her concerns and anguish. When she had finished saying what she wanted to say we did not prolong the interview with any other questions we may have had and risk further distress. [28]

As researchers, the interview process was also an emotional experience. We were moved and our own vulnerability was activated from bearing witness to people's grief and their accompanying stories. Towards the end of one interview, one of the researchers became tearful which she acknowledged. Even though we were aware this could influence the interview, her tears felt appropriate and validating considering the depth of emotion being expressed. The community-partner continued with the interview and did not appear to be perturbed by the tears. Our vulnerability felt equalizing, dissolving any perceived sense of power inequality and possibly affording the community-partners further "moments of empowerment" (ibid.). [29]

4.3 Sensitivity

Death and bereavement are significant phases of life, and are considered sensitive subjects in health research (DAVIS, BOLDING, HART, SHERR & ELFORD, 2004; McCOSKER et al., 2001). They have the potential to trigger strong emotions such as shame, sadness, anxiety and distress (SIEBER & STANLEY, 1988), and can present challenges in in-depth interviewing for data collection (ELMIR, SCHMIED, JACKSON & WILKES, 2011; McCOSKER et al., 2001). Interviewing participants about sensitive subjects stems from the epistemological and ontological position that knowledge and truth can only be pursued from people who have experienced it (CROTTY, 1998). [30]

As we were entering the world of the participants as community-partners, all of whom were grieving, it was imperative that we develop a trusting connection. SEIDMAN (2000) suggests a trusting relationship grows when there is a mutual interchange of information. For each interview we attempted to create an informal and relaxed atmosphere to enable the conversation to flow. We remained mindful of the sensitivity of each situation and took our cues about the pacing, timing, content and course of the interviews from the community-partners. For instance, one woman became very upset during the interview. We asked if she would like to have a break or stop and she did so, making cups of tea for us all. We drank tea, ate biscuits, played with the dogs, and looked at the garden, recommencing the interview when she felt ready to continue. [31]

4.4 Benefits of the community partners

Given bereavement theories and research outcomes that are concerned about engaging and interviewing the bereaved, we were cautious about inadvertently causing distress. However, we felt potential participants could make their own choices if we were judicious with our approach and their time. Likewise, we were confident that potential participants could be active community-partners. The LLD study findings echoed those of previous research in terms of the benefits of participation (BECK & KONNERT, 2007; DYREGROV, 2004). Most participants felt positively about contributing, given it had the potential to help others, i.e., it was seen to be valuable for them and typically not distressing. Some of the principal motivators for participation were altruism, appreciation, concern about the care provided and someone with whom to share their experience. There was a recurring theme throughout all of the interviews of a desire to participate for the benefit of others and to support the needs of the broader, local, rural community. [32]

Although most participants had little or no experience of counseling or bereavement support (the experience of talking about something private and personal with someone they did not know), they were forthcoming in describing their experiences. The interview provided them with a space to share their thoughts and experiences meaningfully (CISNEROS-PUEBLA, FAUX & MEY, 2004). At the conclusion of some of the interviews, participants thanked us, they stated that they were pleased to share their story and even commented that they felt better. This is consistent with the view that the retelling of an experience within the interview setting can assist in changing the storyteller's understanding and reconstruction of the event (RICHES & DAWSON, 1996). NEIMEYER (2001) suggests that restructuring is a common process following the death of someone significant which enables the bereaved to make sense of and find meaning in the experience, which is eventually integrated into a new narrative. [33]

Despite evidence that participatory methods can empower participants (ROSS, 2017) a thorough understanding of the possible benefits for bereaved relatives acting as community-partners in palliative care research is scarce (DYREGROV, 2004) and largely confined to studies involving the bereaved parents of children. ROBERTSON, JAY and WELCH (1997) as well as ROSENBLATT (1995) suggest that engaging bereaved relatives in research is unethical and has the potential to cause unnecessary harm. However, the experience of other researchers, including our own, is that relatives can benefit from their involvement provided suitable precautions, sensitivity and appropriate research methods are incorporated (GERMAIN et al., 2016; KOFFMAN et al., 2012). In a recent review of the impact of participation in end-of-life research on relatives' well-being, SINCLAIR and colleagues (2016) concluded that family members' understandings of the patients dying experience can offer useful insights to improve service delivery and support decision making. It provides an opportunity for, among other things, continuing a bond with the deceased (KLASS, 2006; VICKO, 1999), searching for a personal sense of meaning in the loss (NEIMEYER, 2001); and sharing their story, the personal narrative of their experience (WALTERS, 2000). [34]

4.5 Post-interview participation

Follow-up telephone calls were made to participants approximately two months post-interview, inquiring whether they wished to receive a copy of the interview transcript to review. During the telephone call, many reiterated that their experience of the interview was positive; one participant recounted how it allowed her to recognize that she was coping better than she thought. Another participant, also speaking positively about sharing her experiences during the interview, requested a copy of the transcript for the family as a memory of the relative who had recently died. Other participants preferred not to receive a copy of the transcript but were thankful for the opportunity to recount their experience in person. [35]

4.6 Role and needs of the researchers

GERMAIN et al. (2016) suggest that highly skilled researchers are essential in research of this kind in ensuring the provision of a safe environment, and in turn, engagement on the part of the participants. They advocate for researchers to have sensitivity and openness in equal quantities, together with a non-judgmental attitude to guarantee the safety of the participants. Furthermore, their research findings support the need for a methodological design with suitable degrees of sensitivity to support the bereaved. [36]

As a research team we all have many years of diverse and extensive experience working with people who have been coping with sensitive issues and complex circumstances. One of the researchers is a clinical psychologist and has worked for many years in clinical research, another is a general practitioner, one of the researchers is a former emergency department registered nurse and has been a social qualitative researcher and the other member of the research team is a practicing psychotherapist, registered music therapist and researcher working in palliative care. Given our backgrounds and experience we felt adequately equipped to carry out the research effectively and sympathetically. [37]

Our PHR informed approach during the data collection process was to create a relaxed and informal environment by briefly making the initial introductions, and obtaining written consent. We answered any questions the community-partners may have had prior to them talking about their experiences. We were conscious of remaining broadminded and non reactive throughout the interviews so that our responses did not impact upon the community-partners and their conversations. [38]

As the nature of qualitative research is the investigation of the participant's subjective experience, researching sensitive issues has the potential to impact the research team (ELMIR et al., 2011). It can be difficult for researchers to feel detached whilst hearing about distressing experiences, particularly if the researchers have similar lived experiences of the subject under investigation (DICKSON-SWIFT, JAMES, KIPPEN & LIAMPUTTONG, 2008). McCOSKER et al. (2001) suggest when conducting sensitive research that researchers develop a practice to safeguard against probable psychological impact. In order to minimize the emotional effects of data collection and working with the research data, we incorporated a number of strategies. For the data collection process we limited the number of interviews per day, we largely interviewed together to provide support for each other and share the responsibility. When coding the data, which we restricted to one day per week, we worked together not only to increase the validity and reliability of coding, but also to support each other, as it was easy to remember the emotions present during the interview, and the impact of bereavement on the community-partners. [39]

As we were interviewing in a rural area and time was spent travelling between appointments, we used this time to find balance between our roles as researchers and our emotional needs. We prepared for forthcoming interviews, reflected on and debriefed after each interview. We talked openly about how we felt and acknowledged if an interview experience had strongly affected us. We also ensured we took regular breaks, and we completed field notes during this time both collectively and individually. During the weeks of data collection and subsequent data analysis phases we often spoke of feeling emotionally drained. We recognized the need to do something distracting and lighthearted for ourselves as an antidote to the intensity of the process. [40]

4.7 Reflexivity

As researchers we were aware of the need to critically review the research process and evaluate our own attitudes, actions, emotions, roles and influences by choosing to employ a flexible, open participatory approach. As social-science and science-practitioners, we endeavored to collect the data while promoting empathy and emotional reflexivity throughout the interview process. Reflexivity is therefore a key component of the PHR approach. It is important that the researcher reflects on how he/she is situated in a certain social, political, and linguistic situation (ALVESSON, 2002; BORG, KARLSSON, HESOOK & McCORMACK, 2012). [41]

At the same time we were aware of the potential for our own vulnerabilities—e.g., memories of the deaths of people close to us—to be triggered, both during the interview and in processing the data, and for this to compromise the interview process and study findings (BORG et al., 2012). Hence, efforts were made to substantiate reflexivity by continually engaging with the data to ensure that themes and sub themes corresponded to our inquiry and not our own emotional responses. We kept field notes to record significant aspects of the interview, together with our impressions, which also served as a reflective tool. We further verified trustworthiness, credibility and integrity of the data by having an independent researcher confirm or reject identified codes, themes and sub themes against the transcripts. Participants were not asked to validate their interview transcripts, as some did not wish to receive copies of these, and we were conscious of participant burden. While it was accepted that we were carrying out a "gate keeping" role in protecting the participants, it was also felt that we had a duty of care given the sensitive nature of the interviews and, in some cases, participants' lack of emotional support. [42]

5. Conclusion

This research sought to improve end of life and bereavement care for people caring and dying on the Tasman Peninsula by understanding the experiences of those who received it. We were pragmatic and realistic about the restrictions of the research setting, specifically, the logistics of the rural location and safeguarding the vulnerable research population. The circumstances of this research afforded little opportunity to include the participants beyond the research interviews. Involving staff from the local medical center may have offered a link with the community, which could have fostered greater participation and added another dimension to the study. Nevertheless, despite the restrictions, our application of PHR elements enabled the participants to be positioned as community-partners to influence the interviews, have an audible and equal voice and share their experiences of rural palliative care. Multiple perspectives and viewpoints were heard and captured, providing a diverse picture of palliative care services in the area. This research illustrates how PHR elements can inform the conduct of research involving vulnerable study participants in a challenging setting posing significant ethical and logistic considerations. [43]

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