

Working Title: Exploring the Concept of Moral Distress with Community
Based Researchers: An Australian Study

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Abstract

Community based research (CBR) refers to an applied research methodology that is conducted in community settings in partnership between academic and non-academic participants in research. This article reports on a series of in-depth interviews conducted with 11 Australian CBR researchers between 2008-2009 designed to explore whether university employed community based researchers experience the particular phenomenon of ‘moral distress’ or feelings of helplessness to act in accordance with one’s moral values due to systemic or institutional constraints. Study results found that the CBR researchers experienced unavoidable moral distress at varying levels of intensity related to blurred boundaries between settings, participants and stakeholders. Based on the outcomes of this study further research and enhanced professional development and training practices are recommended.

Key words: community based research, moral distress, qualitative, proximity, boundaries

Abstract word count: 116

Body of paper word count: 4751

Body word count (plus appendices): 5197

Background

Over the past two years since the election of the new Federal Labour Government Australian universities have seen expanded funding and imperatives to conduct research in partnership with communities that directly experience or shape significant social challenges (see ARC, 2007 & 2009). This is particularly the case in research relating to Indigenous communities that have undergone a long history of colonialist research and intervention in Australia (see Kendall et al, in press). With this renewed shift toward community-based research (CBR) the authors argue that Australian universities also need to push for enhanced research training and support for responsive and responsible research in and with communities. A key but under-recognized element of this preparation lies in preparing researchers to work in settings that may be morally challenging. It appears that CBR practitioners from all disciplines may have a lot to learn from colleagues in the social services professions in this domain.

While there is a clear and well-justified focus in existing literature on protecting and empowering non-academic community participants in research there is little in-depth research that deals with potential harm that may come to academic researchers in the course of their work. As researchers engaged in community based research in Australia, the research team has experienced both personal and professional challenges as a result of their research-related roles and responsibilities in communities. It was in response to one particular incident the team experienced in 2008 that the researchers began to look for existing research and strategies that could prepare them to work in close proximity to and in partnership with non-academic community members, particularly those who experience significant vulnerability. This initial search included a review of the relevant scholarly literature and an

environmental review of existing university level training options for CBR. This initial review plus a subsequent series of 11 in-depth interviews with active university employed CBR researchers in South East Queensland, Australia was funded by the Research Centre for Clinical and Community Practice Innovation at Griffith University.

The exploratory study was based on three basic observations arising from the research team's reflections on their experience as CBR researchers:

1. That researchers often receive very little training or support to conduct community based research that involved direct and prolonged contact with community participants – even when those community participants were potentially vulnerable due to, for example, social and geographical isolation or marginalization;
2. That other professions such as social work, human services, and community nursing who had frequent contact with community members *in situ* (i.e. in their homes and communities) in the way that CBR researchers did had advanced frameworks for practice and professional health and safety where researchers typically had none;
3. That the phenomenon of 'moral distress' that is now well-documented in nursing appeared to be relevant for colleagues in CBR who experienced specific challenging incidents in the course of their work or periods of burnout and disillusionment after prolonged exposure to entrenched social problems their community colleagues experience.

Because the authors could not find any previous studies that linked moral distress to CBR they adapted Corley et al's model of moral distress in nursing. Corley et al. (2001, 2002) concluded that unresolved moral issues related to moral distress were

associated with high staff turnover, reduced job satisfaction and burnout among nurses, particularly those situated within an unresponsive organizational setting. A small amount of research also documented negative impacts on patients due to nurses' attempts to reduce their own moral distress (e.g., distancing, justifying, distorting). Although moral distress was also a potential motivator of learning, growth and change, there were few strategies available to manage its negative consequences. Jameton (1984, in Corley et al., 2001, p. 251) defined moral distress as:

'...painful feelings that occur when, because of institutional constraints, the [practitioner] cannot do what he or she perceives to be what is needed. Such feelings involve perception of moral responsibility and of the degree to which a person views herself or himself as individually responsible or as restricted by circumstances'.

The authors adapted Corley et al.'s model of moral distress (explored in further detail below) by drawing on existing literature from other social service research fields (e.g. social work and counseling) to expand their analysis of a range of 'symptoms' and forms of distress such as vicarious trauma. For example, researchers from other fields such as sexual abuse have reported a range of physiological and psychological symptoms related to work related distress and traumatization such as 'digestive problems; abdominal, back, and breast pain; skin problems; and sleeplessness – especially during the time of the interviews' (Rager, 2005, p23). Dunn (1991, p.90) also identified 'anger and powerlessness, which resulted in sleep disorders and other somatic complaints'.

Using this broadened conception of moral and more generalized distress, the study explored three key research questions, namely: (i) Do researchers conceive of CBR as a moral practice? (ii) Do CBR researchers report experiences of moral

distress? and (iii) What particular features of CBR cause distress? The authors provide preliminary answers to these three research questions in the course of the article.

Why study CBR researchers?

Existing literature indicates that close proximity between researchers and community participants is a defining feature of CBR. Community based research (CBR) is defined as ‘systematic inquiry, with the collaboration of those affected by the issue, for the purposes of education or effecting social change’ (George & Green, 1998 in Minkler et al., 2002, p. 14). CBR has the potential to produce high community impact because it collapses the processes of community consultation, research, and implementation into an ongoing action-oriented research design. This means that in CBR contexts research is not conducted remotely in universities and then “applied” to community contexts but is, rather, conceived, conducted, and implemented in community locations with community members as active decision makers and partners throughout the entire research process.

Hence CBR is “high stakes” research due to a number of factors including that: a) it involves significant personal and time commitments from communities and researchers alike; b) processes of research can have as big of an impact in communities as the final outcomes; c) it relies on the creation and sustaining of trusting interpersonal relationships between researchers and community members; d) it is dynamic, changeable, and ‘out of the box’ research due to the relational and situated nature of the research; e) the social change orientation of CBR and the typical topics covered (e.g. domestic violence and service planning) mean that there is often conflation between research, advocacy, and service provision practices and expectations for all involved. In many cases a university researcher can easily find

him or herself being asked to provide professional services such as counseling, advocacy, or medical advice in a research context. The researcher's in-depth interviews showed that separation of roles and contexts for practice can be particularly challenging for CBR researchers who have previous training in a social service or health discipline such as disability services, social work, youth services, or psychology. This is discussed further below as a key theme of the research.

Conceptual framework: Moral distress as an outcome of moral practice

The authors contend that Corley et al.'s (2002) discussion of moral distress assumes a conceptual framework of moral practice that is under-articulated in the original model. Framing CBR (or nursing) as a moral practice *overall* acknowledges that practitioners who experience moral distress do so because they see themselves as moral agents attempting to achieve an overarching moral "good" that is inherently linked to the purpose and nature of their practice (see Isaacs, 1998). In moral practices, individual practitioners care about their work and are committed to values that they seek to actualize via the conduct of research. As Minkler et al. (2002, p. 14-15) explained CBR can be regarded as a moral practice to the extent that it is 'committed to blurring the lines between the "researchers" and the "researched" and strengthening people's awareness of their own capabilities as researchers and agents of change'. CBR's focus on community participation asserts a strong value position that community participants should be involved in decision-making that affects their lives. Many CBR researchers are also "insider researchers" (Padget, 1998): that is, they have directly or indirectly experienced the phenomena they are researching. This has implications for the degree to which they perceive their work as being of value and, potentially, the degree to which they are vulnerable to distress in the context of

the research work.

The current study employed Corley et al.’s official definition of moral distress (included in the previous section) to define the phenomena the authors were looking for in CBR researchers reported experiences. In keeping with the exploratory nature of the research, the research team also expanded the definition to include any other ‘generalised form of stress or distress’ that our participants reported. They drew on existing literature of concepts such as vicarious trauma to be able to identify such ‘generalised’ forms of stress and distress. Hence they were able to identify researcher distress that resulted from “classical” moral distress (i.e. conflict of personal values with systemic or institutional values) plus other distress that was not necessarily related to value conflicts.

Corley et al.’s (2002) model of moral distress also demonstrates potential flow-on effects of practitioner distress for example to patients in the case of nursing practice (see Figure 1). Although flow-on effects to community participants was not the focus of the study, the research team included a question in the in-depth interview schedule that encouraged their participants to report any flow-on effects of their own distress that they had observed in community participants. This aided them in determining the appropriateness of the full Corley et al. model (illustrated in adapted form below) for potential later research.

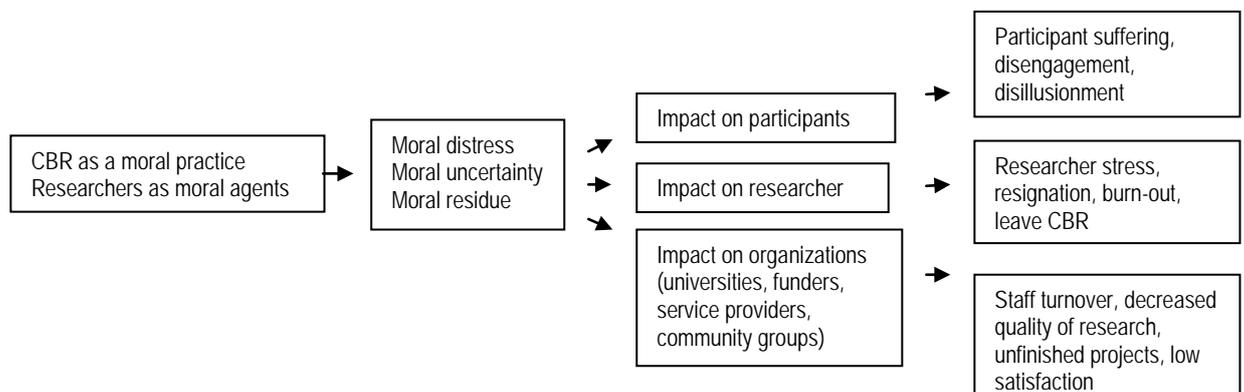


Figure 1. A theory of moral distress (adapted from Corley et al., 2002, p. 644)

Method

Data collection

In-depth interviews were conducted with 11 active CBR researchers from three different universities in South East Queensland, Australia. Ethical approval for the research was granted prior to the conduct of any interviews. Ethical review covered all three participating universities in the study. Participants were provided with an ethical consent information package via email prior to consenting to participate in the research. This was followed up with a phone call from the research interviewer confirming that they understood the consent package prior to scheduling a time for interviews to be conducted.

Semi-structured in-depth interviews were conducted either over the telephone (n= 7) or face-to-face (n=4). Telephone interviews were the preferred method of interview due to geographical distance between the research team and participants. Telephone interviews were also appropriate for this research given that researchers only analyzed participants' spoken accounts of their own distress i.e. manifestations of distress such as body language or facial expressions were not analyzed. Four interviews were conducted in person due to participant preference to participate in a face-to-face interview and manageable geographical distance for the interviewer to travel to the participant's location. Interviews ranged between 60 and 90 minutes, were recorded with permission and transcribed verbatim by a professional transcribing service soon after completion. The aims of the semi-structured interview were to explore: 1) the prevalence and severity of moral distress and uncertainty

among CBR researchers who work with vulnerable populations; 2) the health and wellbeing effects of moral distress and uncertainty on CBR researchers and 3) preferred means of supporting CBR researchers in their practice. Interviewees were asked to describe an experience in CBR that had really made an ‘impact’ on them – positive or negative; to describe any positive or negative impacts their CBR work had had on their health and wellbeing; and to identify strategies or processes that they thought would assist other CBR researchers to avoid distressing experiences in the future.

Sampling strategy

A stratified snowball sampling process was used to identify and select CBR researchers from three different universities in Queensland, Australia. Three different universities were targeted to explore whether or not organizational context would emerge as a significant factor in participants’ experiences of moral distress in the context of their research work. After potential participants were referred via the snowball method the research team selected participants to interview to provide representation across four levels of academic seniority i.e. PhD student, Lecturer, Senior Lecturer and Associate Professor/Professor¹ for each university. The snowball process commenced with the study team identifying potential participants known to be active CBR researchers through their own professional networks. This process generated an initial list of six CBR researchers across three universities. All of these six agreed to participate in the research. These participants were then asked to recommend other potential participants from their own professional networks. A

¹ Note that in Australia Associate Professor and Professor are deemed to be the highest level of academic appointment with lecturer being the initial level of appointment to the university for new PhD graduates.

further five CBR researchers were recruited through this method. The final sample was comprised of 11 active CBR researchers from three different universities, including four interviewees from “University 1” and four from “University 2”. After repeated attempts, we were unable to interview the desired number of participants (4) at “University 3” using the snowball sampling method. Data collection was concluded in August 2008 with only three interviewees from “University 3”.

The final sample consisted of two Professor/Associate Professors, four Senior Lecturers, two Lecturers and three PhD students. It was more challenging than expected to recruit Professor and Associate Professor level interviewees for the study via the snowball sampling method². Six participants were female and five were male. The two Professor or Associate Professor level participants in the study were both male whereas all the PhD students were female.

A significant number of interviewees (n=7) within this small sample could be classed as “insider researchers” (i.e. the researcher has personal experiences in common with the participants) either through: a) their cultural background; b) their experience as a person with disability or parent of a person with a disability; or c) some other affiliation with the research target population for example sexuality, migration experiences, or family member with a chronic disease. It was also noted that three interviewees described their family (e.g., parents) or a particular family member (e.g. brother) as significantly influencing their inclination or ability to engage in CBR. Three interviewees in this study were former school teachers.

Participants were engaged in research dealing with chronic disease, disability and/or mental health; refugee and migrant experiences; homelessness, public health

² This difficulty in recruiting more senior researchers may reflect the relatively small number of researchers who engage in sustained CBR throughout their career or career promotion variables associated with this style of research.

services and health promotion in Indigenous communities; community cultural development (Indigenous) and sexuality and aged care services.

Analysis

Several steps and methods were used to analyze interview data. Following each interview, the interviewer debriefed with one other colleague in the team, noting interesting features of the interview and how they related to moral distress. The interviewer noted any significant thoughts about the interviewee at the time of interview (e.g. he or she seemed very positive or upset, he or she confirmed thoughts from other interviewees, and so on). Interview transcripts were then analyzed in three consecutive phases over a period of approximately six months.

In the first phase of analysis, three members of the research team and a research assistant identified major themes in a sample of six transcripts. They followed Ryan and Bernard's (2003) prescribed method for inductive thematic analysis which focuses on identification of repeated experiences, frequently used metaphors, and indigenous experiences (i.e. experiences that are specific to one person or one cluster or type of interviewees e.g. women).

The initial meeting produced a preliminary list of major themes agreed upon by all raters. In stage two of the analysis process, the chief investigator then conducted in-depth thematic analysis of all transcripts and finalized a list of primary themes and sub-themes found in interview data using QSR NVivo software to aid in data management. In stage three, in-depth analyses of other significant features of the interview transcripts were conducted using matrices (tables) constructed in Microsoft Word. Matrices included columns which list broader qualitative features of the interviews including: (a) interviewee's use of metaphor; (b) critical incidents and

sources of reported distress; (c) reported positive and negative impacts of distress; (d) aberrant or unusual experiences of interviewees; (e) potential variables and categories related to the level of distress participants reported; (f) and an overall qualitative ranking of the level of distress experienced by each interviewee in relation to the critical incidents, issues, or impacts reported. Quotations and notes from each interview were added to the matrix in a row for each interviewee (see table below for example).

INSERT TABLE 1 ABOUT HERE

By including this data for each interviewee in the matrix we were then able to easily recognize patterns across the data. For example we noted that interviewees who had less experience in CBR reported more intense distress than those with more experience. Likewise, female interviewees were more likely to have a larger number of examples and quotations under the heading of blurred boundaries relating to private space and role confusion surrounding friendship with community participants than their male colleagues. These findings point to variables that should be investigated in future research.

Although a significant number of themes emerged from this process the focus of this paper is on the strongest themes that emerged from the data, namely: (1) *Expected distress*; (2) *Community Based Researchers as moral agents*; and (3) *Blurred boundaries*. The themes *Expected distress* and *Community based researchers as moral agents* highlight the ways that researchers conceived of their research as a moral practice and affirm the relevance of the concept of ‘moral distress’ for this branch of research practice. The theme of blurred boundaries was the most frequently

reported experience *across all interviewees*. It describes the primary sources of distress for interviewees reported in the study.

Themes are explored below using de-identified excerpts from the original transcripts. Other findings from the analysis process are described elsewhere (Sunderland, 2008). Appendices 1 and 2 include a full list of themes and sub-themes derived from the analysis.

Discussion of major themes

Expected distress

When asked about their experiences of moral distress, it was notable that most of the CBR researchers interviewed for this research expected some degree of social or emotional discomfort *as a requirement of their work*. When interviewees described CBR they often referred to the inherent “complexity”, “difficulty”, and “challenging” nature of the research. Many of the researchers interviewed were involved in research topics that were extremely complex, challenging, and multi-faceted. For example, one interviewee jokingly said, “trust me to pick the hardest topic”. Echoing this sentiment, another interviewee stated, “...yeah I always pick the hard ones”. The locations of research are also often remote, are in current or former conflict regions, or feature living conditions that are substantially different to the researcher’s home life.

In addition to learning the basics of data collection and building relationships with community members, the CBR researchers often needed to learn complex cultural and community protocols for working with community members.

...that was one of the strong learnings that I had ... the Aboriginal people that I worked with also were confronted regularly by how they ought to position themselves. Even though there are different questions it's not as if you resolve

the issues of positionality in the field simply by being of the same cultural group that you work with....it revealed to me that this was more complex.

Although some insider CBR researchers already knew these protocols, they could still be rendered an ‘outsider’ via their new identity as a researcher in the community -- “...even though I’m Indigenous, I get to the communities and ... its like they don’t like to treat you nicely. They’ve already been burnt”. The emphasis of CBR is on building good relationships and trust with community members that can only emerge over time. Hence, by necessity and design, interviewees gave much of themselves interpersonally to the community they were working with. They enmeshed themselves in a complex web of interpersonal relationships, which, as interviewees emphasized, actually characterizes CBR. In many ways the experiences of blurred boundaries described above shaped researchers’ expectations of distress they might “legitimately” feel as a result.

Interviewees indicated that “you need to have thick skin” to do CBR work. A very experienced CBR researcher and remote health practitioner advocated for an “engaged disengagement” to protect both the researcher and community participants. He said that he often “steps back” from his current practice to reflect on the social history of the situation. This action allowed him to be both engaged and disengaged and enabled him to retain some perspective on the relationships he was forming. Although CBR researchers believed they needed to be resilient and establish deliberate boundaries to protect themselves, there was also a strong ethos that the researcher must be very open and responsive to communities. This juxtaposition of two apparently opposing orientations was a daily tension for interviewees and highlights the expectation of vulnerability that dominated their experience.

CBR researchers as moral agents

CBR researchers interviewed for this research do see themselves as moral agents who work toward a perceived good or moral outcome. For some interviewees the moral good they associate with their work is described as social justice activism. One interviewee indicated that he felt positive that he had been a small voice for change in the context of his research. For others, moral agency is about being an advocate for the marginalized groups they work with. Both insider researchers and other researchers indicated that they practiced or felt an obligation to uphold this type of moral agency. For example, one interviewee felt a strong responsibility to advocate for community member's copyright over original artworks when an industry partner asked to use a community member's artwork for corporate promotional purposes. In her words, "...[I] felt that something had to be said on the spot to protect the interests of the artists and the copyright of the image." [Interview 2] Likewise, another interviewee who worked with Indigenous communities also described a form of advocacy for the communities he works with. This interviewee described critical incidents where he intervened in other researchers' projects where he felt participants did not fully understand the intentions or proposed outcomes of the project (i.e. there was not informed consent). In some cases, this interviewee has prevented research projects from going ahead.

An interesting case was presented by one interviewee who described the extreme frustration she felt entering the corrections system to interview people with intellectual disabilities who had committed a crime. Her frustration was in some ways fuelled by the fact that she felt she could no longer advocate for the people she was interviewing in the way she could when she worked as a social worker. This

interviewee felt she had to passively observe what was going on rather than actively advocate for the people with disabilities she was interviewing. In her words,

...even in a social work capacity you have some way of ... dealing with it in that you're actually taking some kind of action to try and help people. Whereas, in a researcher role you don't get that same sense of -- personal satisfaction is not the word, like usefulness, you know, you feel like you can almost like raped a person and little stuff they've come out with and where do we go with this?...
...you just hope that something good will happen out of it...there's not that immediate feedback that you get from actually helping somebody [in social work practice], it's sort of delayed gratification [in research]. [Interview 6]

A number of interviewees also described mentoring other researchers, students, or community members as a form of moral agency in relation to their CBR work. The focus of mentoring for these interviewees had a number of purposes. For example: (i) supervising and mentoring post-graduate students who were undertaking CBR work; (ii) incorporating frameworks for practice they had developed via trial and error into their formal university courses in human services and other degrees; (iii) acting as an informal mentor and contact person for other researchers who wanted to do research in order to protect both the researchers and community members (e.g., in remote Indigenous settings); and (iv) mentoring Indigenous community members regarding their education prospects, career choices, and so on.

The degree to which interviewees in this study indicated that they felt morally *obligated* and *entitled* to take on active social justice, advocacy, and mentoring roles highlights the nature of CBR more broadly as a moral practice. It also highlights the degree to which CBR researchers feel *morally responsible for their research participants*. Again this is consistent with Corley et al.'s original model of moral

distress in nursing. The extent of researcher's personal commitment to their CBR work also indicates that it is a values-driven practice at many significant levels. As one interviewee explained, "...I think in this kind of area where you do have a personal commitment and you see a need, you know it seems reasonable to try and follow that up [through research]." [Interview 11] The authors hypothesize that such personal commitment to the communities they work with may also render CBR researchers more vulnerable to feelings of moral distress, uncertainty, and stress in the context of their research work.

Major causes of distress: Blurred boundaries

The most frequently occurring theme across all interviews was blurred boundaries. Interviewees shared numerous examples about how they experienced the blurring of boundaries in their CBR practice and how this contributed to feelings of moral distress and uncertainty. The key areas of blurred boundaries were: between public and private spaces for researchers and community members; between roles for the researchers e.g. researcher versus friend or service worker; and between accountabilities to different stakeholders in the research e.g., to community participants versus funding agencies and universities. These are discussed below.

Private and public spaces

A key reported site of blurred boundaries for female interviewees was "home". Several female interviewees reported feeling conflicted when community members asked to stay at their private home or visit for meals. The interviewees reported feeling conflicted because of a number of factors including: (a) they (interviewees) had previously spent time in community members' homes and shared meals with

them when doing research in community settings and felt obligated to reciprocate; (b) they felt that the relationship with the community member was blurred between a professional and personal nature and did not feel sure how to proceed socially; (c) researchers were wary of getting too close to research participants or declining social requests due to any impacts this would have on the research process and outcomes.

Interviewees reported that because their research work was based on strong trusted interpersonal relationships with community members, they did not want to offend them by declining a request to meet socially. One interviewee explained that she felt a strong sense of obligation to reciprocate the hospitality she had been shown while she was working in remote communities, but did not feel entirely comfortable doing so. This interviewee reported that community participants expected to stay at her home when they travelled to the city from their remote towns. She indicated that she had hosted some meals at her house but had not invited community participants to stay overnight.

Managing these blurred boundaries in practice was a significant challenge for CBR researchers. One interviewee commented, "...you're constantly having to work those boundaries and where does the research literature really talk about that?" [Interview 4]. Another interviewee reported feeling quite intense distress when she responded to a request from a community participant to stay at her home during a domestic violence incident. Domestic violence was the topic of the research they were both engaged in at the time. The interviewee reported that she went to pick up the community participant in the middle of the night and made arrangements for the community participant to sleep at her house. The interviewee then reported waking in the night thinking "*what have I done?!*"

Role boundaries

Role boundaries were also commonly blurred and relate to the above examples to the degree that interviewees were unsure if they were operating in a “friendship” role or a “professional” role in their relationships with community members. While conflicting feelings regarding community member access to interviewees’ homes was only reported by females in our study, both male and female interviewees frequently described the complexity of issues they faced in spanning the boundaries of their roles as “practitioner” roles and “researcher”. As one interviewee stated, “...you constantly have two caps on [practitioner and researcher]” [Interview 7].

Interviewees’ comments regarding dual roles in the research reflect the nature of CBR practice. In CBR the researcher is often endowed with a “hybrid” role: one that involves both personal and professional dimensions, expectations, responsibilities, activities, and impulses. For instance:

I think the greatest dilemma...the [community] saw me as a practitioner for years and I built my relationship and trust through being a practitioner. Then suddenly I was a researcher and I was able to do that research because of the trust I had developed... renegotiating the relationship...there was a sense that people never really quite understood, particularly [community members] who saw me as a sort of friendly practitioner... [Interview 7]

In one exceptional example, an interviewee experienced a brain injury when he intervened in a physical fight between two community members. His decision to intervene was based on his skills as a medical practitioner. The blurred line between his roles as a medical practitioner and as a researcher meant that he felt obliged to intervene. Similarly, another interviewee’s comments illustrated the tension many

CBR researchers felt between being engaged with communities and being an `objective` observer. In her words:

...there's a fine line you walk between being warm and friendly but also keeping the appropriate distance....there's no such thing as an objective observer in [community based] research. Once you're in the research project, you are in the project and you are a participant and your behaviour impacts on the whole project and everybody in it... [Interview 2]

Stakeholder expectations

Several interviewees also described significant tensions in balancing stakeholder expectations in CBR. This tension was created by the blurring of contexts within which the researcher was accountable (i.e., simultaneous accountability to the community, individuals within the community, the funding body, the university sector). This situation produces tensions for the researcher in terms of who holds power in the research relationship and in the overall research system. In the interviewee's words,

...to be a good researcher on the ground in a community you must be open to what the people, what outcomes they want from the research. Yet you must meet whatever the funding body is, their agendas -- which is totally different and often contradictory and there must be an appearance that you've performed well in all of that. [Interview 4]

For several interviewees there was a strong ethos that community members – particularly Elders and Chiefs who held official positions of authority – *should* have the upper hand in research-related decisions (e.g. regarding what can be published, whether the research will proceed, and what the topics of research should be).

So they trusted me as a practitioner but the moment I started saying, ‘we’d like to interview people for the purpose of writing a paper’, it was like – so you’re kind of stuck....it’s like, well gosh, I’m really upset that you think I’ll steal your knowledge after working with you for two years. Yet you have every right to believe that I’m going to steal your knowledge because plenty of researchers have been doing that for years.

Thus, the researcher is not just required to be “responsive” to communities, but is often required to de-prioritize his or her own preferences and the preferences of other stakeholders (e.g., funders, university) to ensure the research remains community-driven. Several interviewees’ reported feeling stuck or powerless when placed in this bind between various organizations and contexts they worked within.

Strengths and limitations of the study and suggestions for future research

The findings of this exploratory research suggest that: 1. CBR researchers do regard themselves as moral agents and they do expect some distress as a result of this way of working; and 2. The major source of moral distress is blurred boundaries (for example in the home for female researchers in particular, hybrid practitioner/researcher roles, accountabilities, and competing stakeholder expectations). The research also indicates that, at a conceptual-theoretical level, Corley et al.’s model of moral distress in nursing is highly relevant for CBR contexts.

Although it is not fully explored in this paper, interview data from this study indicated that female CBR researchers are more likely to report higher levels of distress than male researchers – particularly in examples of the blurred boundaries theme relating to private space (see Sunderland, 2008). Future research would need to factor in potential variances in the ways that male and female researchers perceive

their work and distress as a significant variable for inclusion. The fuller study also indicated that interviewees were severely underprepared to work in communities and that this is a significant cause of distress for early career researchers. Over time, experienced CBR researchers do develop a personalized 'framework for practice' that to some degree dilutes the potential for them to experience intense moral and other forms of distress as a part of the work (see Sunderland, 2008).

This exploratory study indicated that the university researchers interviewed were not aware of any significant distress community members experienced in the course of their shared research projects. This does not mean though that community members themselves did not experience distress. Future larger scale research should attempt to include community-based participants in CBR projects for a fuller analysis of flow on effects of researcher distress. This flow-on effect is included in Corley et al.'s original model of moral distress in nursing (2002).

The current study only included in-depth interviews and qualitative analysis of interview transcripts. It is possible to quantify CBR researchers' experiences and levels of moral distress using scales developed by Corley et al. (2001). These scales are now used for prevention of moral distress and associated burn out in nursing practice in some countries. A full-scale study of moral distress in CBR could include this dimension to the research with pre and post data collection surrounding any possible interventions in the form of professional development and support for researchers.

Conclusions

The author's argue that moral distress and uncertainty in CBR are significant issues for universities, researchers, communities, and other bodies who fund research. The quotations included in this article also show that moral distress can have a significant

negative impact on individual researchers. Perhaps most importantly, this research highlighted that CBR is a very complex and difficult branch of research practice to undertake. As several interviewees indicated, CBR is “not like normal research” and that they *expect* to experience distress as a normal part of their CBR work. The most significant sources of distress reported by participants were around ‘blurred boundaries’ that are also, apparently, characteristic of CBR contexts and methods for research. The nature of CBR and its practitioners and participants sets it apart as being worthy of further study and, ideally, more systematic support from universities, ethics committees, and governments. Clearly, it is important to ensure that CBR researchers are properly and adequately protected and trained to carry out their practice to avoid negative outcomes for both researchers themselves, research participants, and research project outcomes. Future research could focus on trialing professional development and support and training processes to more adequately support researchers in this field.

Funding source: This research project was funded by a Research Centre for Clinical and Community Practice Innovation, Griffith University seed grant with matching funding from the Motor Accidents Insurance Commission of Queensland.

Acknowledgements: The research team would like to thank and acknowledge all community based researchers who were interviewed for this project. The valuable input of Anne-Marie Tripp in the research process is also acknowledged.

Conflict of Interest: None

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Table 1: Example of Interview Analysis Schedule

| <i>Interviewee</i> | <i>Categories</i> | <i>Critical incidents (sources of distress)</i> | <i>Qualitative ranking of overall distress reported</i> | <i>Themes</i> |
|--------------------|-----------------------------------------------------------------------|------------------------------------------------------------------------------------------|---------------------------------------------------------|--------------------------------------------------------------------------------------------|
| Interview 1 | Female Remote community Early career researcher (Lecturer A) | Unsolicited report of child sexual abuse in the course of research in community location | Medium | Blurred boundaries – research-professional “direct quotation 1” “direct quotation 2” |

Appendix 1: Themes emerging from first inter-rater meeting on sample of interview transcripts (n=6)

1. Boundaries

- a. Expectations of reciprocity
- b. Expectations of friendship
- c. Expectations of “fixit”
- d. Role boundaries e.g. researcher/social worker

2. Competing value systems and expectations

- a. Research - service provision e.g. social work
- b. CBR and university ethics
- c. CBR and university promotions system
- d. Researchers and industry partners

3. Support for researchers

- a. Practice base e.g. previous experience in social work, education
- b. Training
- c. Mentoring
- d. Supervision
- e. Emotional and mental health
- f. Safety
- g. Cultural in/appropriateness

4. Context of research work

- a. Intellectual disability
- b. Social work
- c. Corrections system
- d. Life story research

5. Mixed emotions

- a. Longer term rewards of conducting CBR justifies short term distress
 - b. Emotional challenges part and parcel of this kind of research
 - c. Uncertainty and ambiguity - relates to Boundaries (1) and Support (3) themes
6. Journey of learning
- a. Learning curve of researchers
 - b. Expansion of interest into other areas stemming from initial CBR work

Appendix 2: Themes refined by CI during in-depth analysis

1. Blurred boundaries

- a. Erecting boundaries between the researcher and community participants to protect oneself;
- b. Expectations of reciprocity from participants;
- c. Expectations of friendship from participants;
- d. Expectations of “fixit role” for researcher;
- e. Personal space – for example body and home;
- f. Practitioner versus researcher roles;
- g. Insider versus outsider.

2. Not like other research

- a. Complexity of CBR
- b. Close contact with participants
- c. Relational aspects
- d. Demands on the self
- e. Researcher as the research tool

3. Power and powerlessness

- a. Researcher has automatic power in relationship with community
- b. Community and cultural hierarchies have power e.g. elders and chiefs
- c. Researcher is powerless
- d. Community should have ultimate power

4. Expected distress: distress is part of this research

- a. CBR is complex
- b. Becoming thick skinned
- c. Downplaying distress
- d. Doubt and self critique

5. Journey of learning – metaphor theme

- a. Learning curve
- b. Developing personal frameworks for practice
- c. Role models
- d. Learning the hard way
- e. Helping others to learn from my mistakes
- f. Becoming a better person
- g. Rites of passage

6. Ethics and values

- a. Inappropriateness of formal research ethics for CBR
- b. Cultural ethics
- c. Personal ethics and values
- d. Safety

7. Systemic issues

- a. University research
- b. Research partners
- c. Legal issues

- d. Social and community services already in community
- e. Political climate
- f. Policy and funding