# Chapter 18 Participatory Action Research as a Core Research Approach to Health Promotion



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#### **Key Concepts Definitions**

- *Participation*: active involvement in decision-making by all stakeholders on an equal basis paying attention to potential power differences
- Co-creation of knowledge: collective activity where different ways of knowing and understanding reality are brought together in the process of research inquiry
- Reflexivity: exploring and questioning unarticulated perceptions and understanding by all involved in the process including underlying social and political issues

#### 18.1 Introduction

The last half-century has seen increasing social inequities which have created a range of health issues that health promotion research seeks to explore and address. However, the practice of research can potentially reinforce the status quo and

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recreate the very same social injustices that underpin those health challenges, by marginalizing still further the groups it wishes to serve. It can do this by continuing to privilege dominant voices in terms of whose knowledge is valued and how knowledge is created. Given the ethical values underpinning health promotion as a practice (Carter et al., 2012; Mantoura & Potvin, 2013; Springett, 2001) it is crucial that health promotion research, itself also a practice, follows a set of ethical principles that reflect the values of health promotion which emphasize equity, empowerment and capacity building, as well as participation itself. Participatory action research (PAR) is such an approach and is becoming increasingly popular in health promotion research.

PAR has long and rich global traditions and a tapestry outside health promotion which can be drawn on (Abma et al., 2019 p. 10). Central to these traditions is an emphasis on research practices that encourage relationships, participation, dialogue, reflection and also the active involvement of all people affected by the health issue in focus, in the process of research, including deciding the research question itself. In this, it shares many characteristics with indigenous research. Indeed, one might argue that contemporary participatory action research is a re-remembering of older more holistic ways of knowing, one that is particularly relevant in the context of systems thinking and ecological awareness (Berkes, 2017; Hall, 2014; Peltier, 2018). It cannot be emphasized too strongly here that PAR is an approach to research and *not* a research method or methodology. This is an important distinction to make. It is often interpreted as a type of qualitative research, but it is quite possible to do participatory epidemiology and other forms of participatory quantitative research. (Bach et al., 2016). PAR's many strands to its inheritance, including terminology and theoretical basis, reflect the contexts in which the approach developed. For example, in the US this approach in health promotion is usually referred to as Community Based Participatory Research (CBPR) (CF Chap. 20 of this volume) reflecting the unique position of public health and a specific tradition of civic engagement in the form of community organizing in that country (Wallerstein & Duran, 2017) The emphasis has been on formalized partnerships between academic institutions and communities and less on direct grassroots involvement of marginalized groups or those that adopt indigenous values and principles. (Jordan & Kapoor, 2016).

Outside the health sector, in Latin America, Africa and Asia, PAR emerged from concerns for both the persistent inequalities in power and resources and the processes that keep the poor in communities oppressed and dependent, seen as an outcome of colonialism and the primacy put on Western science. (Jackson & Kassam, 1998; McTaggart, 1991; Fals-Borda, 1987) PAR has been seen as a way of challenging these dominant ways as to how knowledge is produced and acted on in order to bring about social change. (Bradbury & Reason, 2008) This challenge that has also been spearheaded within Western management science through the development of action research, a form of inquiry that uses the experience of trying to improve some practical aspect of a real situation as a means for developing our understanding of it. Over time the different traditions from both the North and South became the basis of participatory action research, which was first coined by Orlando Fals-Borda (1987) as the descriptive noun.

This brief history of PAR is important because within the research literature, while there is an emerging consensus on the basic characteristics of PAR, there has always been some tension both within health promotion and beyond between the more pragmatic end of the spectrum (informed by Western models) and what has come to be known as emancipatory or transformative participatory research (which reflects the social justice intention). (Lykes & Mallona, 2008; Jordan & Kapoor, 2016) It is the latter which has synergy with the principles of health promotion, while it is the former that is often the most practised.

#### 18.2 The Essence of Participatory Action Research<sup>1</sup>

There are now a number of excellent textbooks that detail ways in which a PAR project can be developed, their different standpoints being found on the continuum of pragmatism and emancipation. Box 18.1 outlines eleven common principles identified by the International Collaboration for Participatory Health Research (ICPHR) together with a twelfth added by Trickett and Beehler (2017) drawing on ecology. Rather than specify the steps in the process our intent here is to emphasize some key elements that mark out its essence that distinguish it from other approaches to health promotion research.

### Box 18.1 Characteristics of Participatory Action Research (based on International Collaboration for Participatory Health Research (ICPHR) (2013) and Trickett & Beehler, 2017)

#### **Participatory Action Research:**

- is participatory;
- is locally situated;
- is a collective research process;
- processes are collectively owned;
- aims for transformation through human agency and empowerment;
- promotes critical reflexivity;
- produces knowledge which is local, collective, co-created, dialogical, and diverse based on an extended epistemology of multiple ways of knowing (e.g. tacit, presentational, propositional, and practical);
- strives for broad impact;
- produces local evidence based on a broad understanding of generalizability;
- follows specific validity criteria;
- is a dialectical process characterized by messiness,

<sup>&</sup>lt;sup>1</sup>For more details, see also International Collaboration on Participatory Health Research position papers 1–3 http://www.icphr.org/position-papers%2D%2Ddiscussion-papers

#### 18.2.1 The Primacy of Participation

It has been argued that given the multidisciplinary history of PAR, this research approach cannot be confined to a narrow set of epistemological principles (Rahman & Fals-Borda, 1991). Indeed, this plurality is also a potential for strength (ICPHR, 2013) However, it could also be argued that the participatory principle that underpins PAR reflects a particular paradigm, given that a research paradigm is a set of underlying assumptions about the world and how it should be studied. (ICPHR, 2013; Guba and Lincoln 1989; Kuhn, 1962) That primary underlying assumption is that participation on the part of those whose lives or work is the subject of the study – or in the case of health promotion, their health – fundamentally affects all aspects of the research. Their participation, therefore, should be in all stages of the research process, from deciding the focus of the research and determining the research question through to dissemination of the research findings. An example of a tool developed to illustrate this is shown in Table 18.1. It is research "with" not research "on." Detachment is not an option.

#### 18.2.2 A Matter of Co-Creation

This means in particular that those who label themselves as researchers are not considered the over-riding experts, but more humbly see themselves as bringing a certain type of experience to *a co-labouring process* that leads to the *co-creation of knowledge* in a manner that is not only practical, but also collaborative and empowering. It is a collective activity through which different ways of knowing are brought together in an inquiry process that *intertwines research*, *learning and action* in a *continual emergent process* of feedback and change. (Fig. 18.1).

**Table 18.1** Levels of Participation and Stages of the Research Process: a tool for reflection (based on Cook et al., 2017 and modified by ICPHR)

Level (based on Cornwall,		Designing research	Generating	Data	Report	Dissemi-		
2008)	focus	methodology	Data	analysis	writing	nation	Action	Other
Co-option								
Compliance								
Consultation								
Co-operation								
Co-learning								
Collective Action								

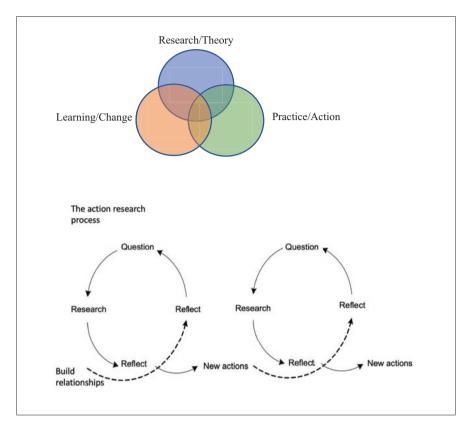


Fig. 18.1 The integration of research learning and change in the action research process

#### 18.2.3 The Potential for Change and Transformation

PAR is also a capacity building process which has the potential to be a transformative experience for all those involved. Implicit is an ethical principle that something of value to all emerges from the process. For capacity building to happen, two elements need to be included, dialogue and critical reflection. Kemmis (2006), drawing on Habermas (1987, 2003) and others, talks of the need to create *communicative spaces*. In these spaces, through dialogue and iterative critical reflection, people make meaning together through listening to each other and sharing their knowledge and experience, by telling their stories (including quantitative data) and through a process of active questioning of the taken for granted about the way they think and act. A critical consciousness is developed among all those involved that is, changes in perceptions, beliefs, abilities and sense of self (Freire, 1970; Stanley et al., 2015; Gaventa & Cornwall, 2006).

#### 18.2.4 Relationships at the Centre

Authentic participatory action research is profoundly relational. This means time is spent building trust between co-researchers, making space for listening and dialogue and adopting research methods that engage the whole person, moving beyond text in some instances to arts-based methods, but always aware that methods are a way of eliciting ways of knowing. It is also important to be aware how power can affect relationships and to find ways of increasing equity between those engaged in the research inquiry, particularly ways that encourage the silenced to have their voices heard (Suopajärvi, 2017; Wallerstein et al., 2019; Call-Cummings et al., 2020) Taking time to build the relationships and trust is the foundation of good quality PAR. It is like a long-term capital investment, in this case in social capital, meaning the greatest returns are likely to come over long periods. There is evidence to suggest, however, when greater time is spent setting the scene for participatory research, the process of embedding research and its effects goes much quicker and without glitches later on down the line (Jagosh et al., 2012; Abma et al., 2019). Locally generated data provides information that has more meaning and relevance and contributes immediately to action or some change unlike a conventional traditional knowledge translation process in which research (data generation) and action are separate activities.

#### 18.2.5 A Non-Linear Process

The process is an emergent one, rather than being a clear-cut process with defined stages. Each iteration of the research builds on previous cycles to move forward, changing the research question as needed. Since this involves relationships, it is a messy process and can initially be destabilizing, especially for those who are historically held up as the experts. Indeed, messiness is fundamental to dialectal nonlinear process. This requires the seasoned health promotion researcher or practitioner to be comfortable with sitting with ambiguity, confusion and even conflict as these are fundamental to the process of learning. (Kolb, 2014; Cook, 2009).

#### 18.2.6 Local Knowledge and Context Have Value

PAR is grounded in everyday life, so the knowledge produced by PAR is local in scope, dialogical, co-created, and reflective of multiple perspectives. It is inherently contextual with the potential to produce local theories, or as Winter (2002 p. 144) puts it. "... an account of a specific situation that gets sufficiently close to its underlying structure to enable others to see potential similarities in other situations." This leads to a different definition of generalization from that currently used in the health

sciences which seeks to replicate standard health promotion interventions whatever the context. Rather, the intent is to generate accumulated local evidence to maintain and strengthen local action, while transfer to new settings is about using PAR to explore local conditions and how they replicate or differ from experiences elsewhere.

#### 18.2.7 Quality Is About Adherence to Ethics

Finally, quality in PAR is a function of its ethics, its values and principles (Banks and Brydon-Miller 2018; Abma et al., 2019; Lather, 1986). Thus, its validity criteria are additions to Guba and Lincoln's (1989) concepts of trustworthiness, commonly used in qualitative research. These criteria include participatory, intersubjective, catalytic, empathic and reflexive validity. Participatory validity refers to the extent to which all project members can take an active part in the research process to the fullest extent possible (Reason & Bradbury, 2001). Intersubjective validity is the extent to which the research exploration is viewed as meaningful and credible to relevant stakeholders from a variety of different perspectives (Springett et al., 2011). Catalytic validity represents the degree to which the research can create new possibilities for social action. Intersubjective validity is related to catalytic validity in that the research has to be meaningful for those involved and to build ownership for action. Empathic validity is whether the research has increased empathy among those who were engaged in the research together (Dadds, 2008) often through the way spaces for dialogue have been created. Finally, reflexive validity is the awareness of one's own frames of reference and the continual questioning thereof, as well as reflections on power and other relations. (May and Perry 2017; Janes 2016).

#### 18.2.8 PAR in a Non-Participatory World

Despite the contemporary clamour for participatory deliberation and a knowledge democracy (Budd Hall, 2019; Lafont, 2019) institutional practices and structures in which and with which health promotion practitioners and participatory researchers work remain fundamentally non-participatory. This results in tensions between the ideal and the reality in the form of constraints on how research is practised and the level of participation possible. Although research and project grant funding agencies in several countries increasingly require applicants to demonstrate partnerships, they also require that the research question and methods and the health promotion initiative to have been firmly established upfront, allowing little scope for an emergent process. They do little, on the other hand, to monitor the authenticity of the partnerships demanded. Moreover, funding for research is often separate from funding for a so-called "intervention" which runs counter to the intertwining of research learning and change and demanding innovative and creative workarounds by those seeking to undertake this type of research. Too often, health promotion funding

focuses on service delivery and short-term individual change rather than on the building blocks of long-term community development and social change. Furthermore, nearly all funding agencies tend to have preestablished areas which they and those who hold the power prioritize, often focusing on disease categories or lifestyle imperatives and not on local concerns.

When participation is not properly understood or implemented, it can merely reinforce the status quo and be ameliorative rather than transformative (Ledwith & Springett, 2010, p. 15). Various writers have attempted to identify different levels and modes of participation either as a ladder or a continuum (e.g. Arnstein, 1969; Cornwall, 2008) and while various forms of participation are valid at different times during the research process and depend on context, this has all to be reflected upon and negotiated. There is a significant difference between the notion of participation versus being a manipulated consumer, to be consulted when everything has already been decided such as research focus, research question and the research approach. This is a passive role, as opposed to being actively involved and engaged in all stages of the process. Only real involvement can lead to the changes in consciousness that forms the backbone of this type of research at its best. What is at stake is a change in the power differentials regarding decision-making in contexts that are often structured around an institutional base created in the late nineteenth and early 20th century and unsuited for contemporary systems thinking or researching "wicked problems." (Brown et al., 2010) While there have been some marginal shifts in the last twenty years in some countries, research bodies, including ethics committees, still find it difficult when communities want to drive the direction of research, judging proposals according to the status quo as to what constitutes quality and robust research.

When it comes to publication too, many research journals, particularly in the health sciences, successfully eliminate from publication, the relational dimensions that are key both to effective health promotion and participatory action research. (Harris et al., 2015; Harris et al., 2018; Abma et al., 2019). While there has been an exponential recent rise in the number of published papers identified as PAR, some projects remain hidden behind the use of traditional approaches and descriptors of those approaches (Lenette et al., 2019). I. Others masquerade as PAR, the best including some form of quality participatory methods but the worst fall well within the tokenism on the ladder of participation. The latter is potentially damaging, because if something that claims to be participatory and actually is not, this can lead to an undermining of trust in PAR as an approach, further confirming that the voices of the people who feel marginalized are not being heard or paid attention to. Illich (1975) talks about the iatrogenic² effects of medical treatment but we also need to be alert to iatrogenic effects of participatory "greenwash" in health promotion research.

<sup>&</sup>lt;sup>2</sup> Iatrogenic effects are harmful effects such as disease inadvertently produced by a (medical) intervention

For health promotion, sitting as it does largely in public health, which historically has been driven by the primacy of approaches embedded in the medical model, any alternative approach represents a significant challenge to the status quo. This is not restricted to health science. In some countries, the social sciences continue to be focused on high-level theory building and social-structural issues; applied forms of research have not had equal status, receiving relatively little funding and often seen as not being research in the true sense (Altrichter and Posch 2007). Increasingly, this perspective is being challenged: firstly, by indigenous research, secondly by calls for the adoption of a participatory paradigm under the guise of participatory research or participatory action research, and thirdly by ecosystem critiques of current economic thinking in the light of climate change and increasing inequality. (Ledwith & Springett, 2022) There has also been pressure on researchers, in general, to be more accountable to the general public who indirectly funds most of their research, partly because of the increasing need to demonstrate research impact in an age of late neoliberalism. (Gray et al. 2018; Allweiss et al., 2020) At the same time, more vociferous groups such as those with HIV/AIDS, as well as indigenous people, have increasingly become disillusioned with the extractive nature of "traditional" research with "Not about us without us" becoming a common slogan in response to requests for research on their issues. (Bridges 2017).

### 18.3 The Challenges of Doing Participatory Health Promotion Research in Practice

While there is a strong case for adopting PAR approaches to health promotion research because it is more in line with the values and principles of health promotion, the actual practice is fraught with challenges. The following examples from two different contexts illustrate how some of the issues of trying to work in a participatory way in a non-participatory world plays out as the those involved strived to achieve quality as defined by the ICPHR. The first example provides a detailed account of the challenges and strategies to overcome some of the traditional expectations of research and who is involved in that research. The second describes a doctoral student's experience of starting and proceeding with a project under the constraints of university requirements.

## 18.3.1 Mental Health Promotion Research: Family-Based Positive Support (FaBPos): Attempting Participatory Research in the Health Sector

In health promotion research, the format and frameworks for judging the quality of research that dominate the perceptions of funders and research reviewers involve the expectation of anonymity, objectivity, replicability and large data sets pertaining

to the measurable. Research designed by distanced experts with additional contributions from those with lived experience can follow such pre-determined design processes as articulated in many research funding competitions. The implications for participatory action research (PAR) are, however, stark. As we have argued, PAR foregrounds relational engagement characterized by a shared approach to the generation of design and knowledge. These rub against frameworks seeking distance, objectivity and certainty as rigour (Cook, 2012; Lenette 2019; Maclure, 1990). The Family-Based Positive Support (FaBPos) study from the UK exemplifies many of the complications of researching in ways that challenge the ideologies, governance, bureaucratic and administrative structures that prevail. Highlighted below are some of the issues and consequences of just one, that of having to pre-determine a fixed proposal for the research design before the research process is underway.

The FaBPos project was envisaged as a participatory approach to investigating, through running a series of courses using Mindfulness/Acceptance and Commitment Therapy (ACT), the theoretical and practical underpinnings that would make such a course effective for family carers of adults with learning disabilities. Family carers with heavy and constant caring responsibilities are known to be more likely to suffer long-term stress caused by the unpredictable, and often socially difficult, behaviours of their loved ones. This is reinforced by the bureaucratic interface with the limited support available (Cook et al., 2019). Given the gap between service providers understandings of service delivery, and the dissatisfaction of those who receive services, traditionally dominant knowledge needed to be challenged by other knowledges to improve understandings of these practices and how these practices were conceptualized and carried out.

The idea behind the research emanated from a consultant clinical psychologist (Steve Noone) who had been exploring the use of Mindfulness and ACT for several years, in collaboration with an academic (Tina Cook: author). The project gained funding from the National Institute for Health Research (UK): Research for Patient Benefit stream and then navigated the ethical approval paths of both University-based and National Health Services (NHS) ethical governance. A fundamental challenge for the FaBPos project was that the application for funding, and governance processes, required the articulation of both the principal research question/objective and the proposed design and methodology, including being clear exactly what would happen to the research "participant," how many times and in what order, before we could engage with the people with whom we were to carry out the research (family carers).

#### (a) Participatory Design without "participants"

The characterization of family carers as "participants" rather than co-researchers by funders and commissioners looking for a more separated approach to research design and enquiry meant that family carers choosing to engage in the research process could not be involved in development and design of that research prior to the proposal and all ethical approvals being completed. The "Catch 22" is that the research had then gained approvals based on a design that might need to be changed. The FaBPos project employed several ways to ame-

liorate the consequences of this. The issue remained, however, that to gain funding meant curbing the fundamental nature of our work, not standing by PAR principles and as such, risking reducing its power and transformational effectiveness for family carers and services.

#### (b) Seed Corn Funding for Conversations with Family Carers

To enable us to have discussions with and gather information from family carers that could inform the research process, we sought monies from a small fund held by the NHS Trust that would ultimately host the proposed research. This paid for a research assistant who, over the next year, together with the academic researcher, talked with family carers about their experience of services and what they might hope for to support them in their caring role. This helped us (the first steering group – see below) better understand the key issues experienced by family carers, and the practical ways in which engagement in research might be possible for them given their complex lives before we drafted the research proposal. This consultation process was important in shaping a study that might be attractive enough for family carers to consider as worthy of their time, but also created its own tensions, specifically in terms of who designed the research.

#### (c) The First Steering Group

An initial steering group was convened consisting of three family carers, the initiating consultant psychologist, a research assistant, and the researcher. These three family carers were active in thinking about the design of the project, using the learning from the information gathering study and drawing on their knowledge and the knowledge of other carers in their personal circle. They also had a lot to contribute to how the study might contact people who were seldom heard. It was this steering group, all acting on a voluntary basis apart from the research assistant, that designed both a course outline and the research proposal submitted for competitive funding.3

#### (d) Processes for Reaching the Seldom Heard

Contacting the seldom heard<sup>4</sup> was another challenge exacerbated rather than supported by the processes of traditional research governances. Family carers were not "the patient" and so were not formally known to health services. Although healthcare practitioners who had visited their patients' family for many years often knew family carers well, this was not a formally accepted contact route. Advertising through social media was also seen as somewhat controversial by funders and ethics committees. It was, however, the route

<sup>&</sup>lt;sup>3</sup>Due to the time between starting the project design and the actual start date of the project, the three family carers did not go on to be part of the core project. For different, personal reasons, none were in a position, once the research finally gained traction, to be directly involved (although two sat on the next steering/advisory group).

<sup>&</sup>lt;sup>4</sup>For further discussion on the important topic of reaching the seldom heard, see Schaefer et al. (2020)

through family carer centres, local fora and organizations where people with learning disabilities attended, championed by family carers on the steering group that ultimately proved most successful in finding people interested in taking part.

#### (e) Family Requirements vs Prevailing Scientific Expectation

An outcome of consulting with family carers before designing the project was that, like the advice of the three family carers on the steering group, their suggestions and needs challenged the prevailing expectations in respect of research quality. The first was the need to be clear about the nature of "participants" in the study. Many were clear that they could not see the relevance of their details (age, gender, economic status, marital status etc.) being recorded and would not offer this for researchers. A second element many family carers were adamant about was, that if the study involved being tested, for example, the use of psychological tests relating to depression scales, or blood tests to check their before and after course stress levels, they would not take part. We had contemplated including such tests as a way of triangulating data more traditionally and "pleasing" the funders by having some "measurable" data included but this was removed. They also had strong views about the venue for the study and the time of day, the length of each engagement and their role in it.

#### (f) Family Carer Expectations and Learning Spaces

Family carers placed great importance on spaces for talking together and making their contribution. Central to their involvement in the study was that firstly, they had the opportunity to talk with other families, offer their experiences to help other families in similar circumstances, and to learn from other family carer experiences themselves. Secondly, they wanted services providers to listen and learn from them rather than, as one family carer described her experience of engagement with professionals, it being "all give [from the professionals] and no take."

In session one, course one, the facilitator started the session by *giving* information. Facilitators could, therefore, only draw on their personal view of what would be important for family carers to know. Family carer need for spaces to talk was clearly articulated in data from the pre-course enquiry. Reflecting on this, it can be seen that the transfer of knowledge from pre-course data to the facilitators had been the traditional version of knowledge delivery. While its sentiment had been understood and valued, its impact had been less transformational. Transformational learning was only experienced once the workshops started and family carers expressed their frustration with being talked at. It necessitated collaborative critical enquiry to forge practice, the process of participatory learning. The opportunity for this was denied by the processes for the research proposals that kept family carers at bay until the research started. Facilitators strongly believe that family carer critique of the

<sup>&</sup>lt;sup>5</sup>Whilst this was challenging at the proposal stage, it became somewhat more of an issue later when reviewers of the final report to funders, and reviewers of academic papers on the research, asked specifically for this information.

facilitation approach, established in a situation of honest and open exchange, was key to the disruption of their original plans for the course, and key to its success. As Lenette et al., 2019 point out "the dynamic and relational nature of PR means that there is seldom a 'right' way of proceeding...we are navigating shifting - and competing – opportunities, risks and agendas." It is, however, the process of creating communicative spaces for learning together, and the adaptability of the design in the light of iterative, critical, collaborative reflection, that lends PAR its skeletal strength. It is these processes that are yet to be widely valued by those seeking to commission and fund research. Ways of generating knowledge that incorporate the values of ambiguity and uncertainty, as opposed to pre-planned, pre-determined routes of certainty, challenge notions of meeting targets and replicability. The expectation in PAR that those with experience will be part of a process of researching and meaning-making, rather than subjects of the research questions and data analysis processes created by external experts, fundamentally challenges what it means to be a researcher and who has power and control over knowledge production.

#### 18.4 **Tensions Between Participatory Health Research** and Doctoral Timelines in Health Promotion

This example explores the promise and challenges of engaging in participatory health research as a doctoral health promotion student. Unlike the previous example, there was no pre-existing research proposal but scope to start from scratch. The challenge here was engaging others in doctoral research and how the timelines imposed by universities can inhibit the process. In 2013, I (KK) started my doctoral journey in health promotion with a particular interest in promoting equity in death, dying, loss, and care experiences. While the field of health promotion has historically focused on preventing disease, I was inspired by Antonovky's (1996) call for a salutogenic orientation to health promotion research and practice which is reflected in an emerging field called health-promoting palliative care that aims to re-build community capacity to support experiences of death, dying, loss, and care from social (vs. medical) lens (Kellehear, 1999; Rosenberg et al., 2014).

The first step I took in my participatory research journey was to explore: (i) whether any non-profit organizations in my city (Toronto, Canada) were working with health-promoting palliative care through a community capacity building approach; and (ii) whether any of these organizations may be interested in doing research together to learn about their approach to palliative care. In this initial exploration phase connecting with organizations, a common response to my email was a request for my full research proposal. However, as I was committed to engaging in a PAR process, whereby we would determine the focus of the research together. In hindsight, the common request from organizations for my full research proposal was likely a reflection of how organizations had been previously approached by researchers with fixed agendas. In time, I was able to connect with a local

hospice organization that had previously engaged in participatory research and was eager to co-develop a mutually beneficial research focus.

With this new connection demonstrating potential, I began the next and most significant phase of my participatory health research journey: the relationship building process. As PAR is a relational process, the initial relationship building lays the foundations for doing research together and influences the later stages of the PAR process as identified in Figure 2. We (the local hospice organization staff members and myself) used several different approaches to build our participatory research relationship and begin to focus the research. These approaches ranged from informal telephone calls, visits, and emails to learn about our different backgrounds and experiences (in this case, related to palliative care) to attending organizational meetings and events to co-writing grant applications together for funding. In particular, the process of co-writing a grant application was a tangible, focused project that helped to progress our planning together. However, one of the tensions I experienced as a health promotion doctoral student conducting PAR was between the time needed to meaningfully develop the initial participatory relationship with the 4-year timelines of a doctoral programme. As we (the local hospice organization and myself) were developing this relationship from scratch, it took over a year to build our research relationship at the organizational level. At this stage in the process, I had not been able to simultaneously begin to develop this same participatory research relationship at the community level. This is in part because I needed to build a level of trust with the local hospice organization before I would be invited to connect with members of their local community. While a significant amount of participatory work had been facilitated between myself and the local hospice organization for determining the focus of the research, this same participatory work was not facilitated at the community level. However institutional practice intervened through the imposition of university timelines on doctoral studies, necessitating the move on to the next phase of beginning to conduct the research. This eventually became a photovoice study exploring the characteristics of the community-based approach to palliative care alongside the volunteers and cared for within the community. (Kongats, 2020)

While members of the local hospice's community were eager to contribute their knowledge and experience to our research together exploring the nature and impact of health promotion approaches to palliative care, it remains unknown where the direction of the research may have headed had community members been involved in the focusing of the research question. Consequently, it also remains unknown how the impacts that emerged from our participatory health research project may have differed had there been different levels of community engagement before formally beginning the research.

Rather than seeing this project as a failure as it did not reach the "highest" levels of participation among all involved, using first-person inquiry and reflecting on my experience created an opportunity to reflect on "the variety of participatory engagements and the associated impacts that could be used by researchers" (Cook et al., 2017, p. 476). As health promotion researchers engaging in participatory processes in a "non-participatory" world, we must not get caught between being puritanical

about engaging PHR or not doing it at all (Klocker, 2012). "Rather, the road to 'doing research differently' has to begin somewhere" (Kesby et al., 2005, p. 145). Engaging in a reflective, first-person inquiry on my experience facilitating a PHR project was a valuable tool to bring to light some of the challenges with conducting PHR as a doctoral student. Such critical reflexivity can contribute to all such research not just at doctoral level.

#### 18.5 Reaping the Rewards of Participatory Action Research

Despite the challenges currently faced in doing health promotion research using a participatory approach, the potential rewards are profound. Not only do decisionmakers who have the power to make changes get to gain a better understanding of what works in local contexts because new voices are heard, but also action is actually taken because what the research reveals is more meaningful and relevant to people, timely, appropriate for the context, and potentially sustainable. (Jagosh et al., 2012; Viswanathan et al., 2004) Moreover, the cementing of relationships and understanding can lead to ongoing work in other areas beyond the original project. However, while there are pragmatic reasons for adopting an authentic PAR approach, one that does not treat people engaged in the research as objects but as living, thinking, knowledgeable human beings with whom to work, it is those relating to social justice and equity that are even more important. PAR engages in possibility, acknowledges the potential in people, and seeks empowerment and capacity building through the co-creational nature of knowledge generation in the research process and beyond. For those interested in contributing to changing the social relations that underpin health inequalities, it makes sense to practice research in a way that does not reinforces the existing power relations that created the problem in the first place. Thus, if one believes in social justice, democracy and social change for the better, then participatory approaches to research are a natural choice. At the very least there is the political and moral imperative that as owners of publicly funded research, citizens have a right to have a say in the research process. Fundamentally, it means furthering knowledge democracy (Hall & Tandon, 2017) within health promotion research, engaging in research practice that includes the heart as well as the head, and reasserting a balance that has been lost by the prioritization of Western approaches to science.

When starting participatory research you engage in a process that will leave you changed as a result. Everyone whom we have ever taught participatory research, and who has stayed with it, has said they cannot return to the way they did research before. Not everyone, of course, is comfortable with this type of research or can do it. That is fine. If you like structure, concreteness rather than ambiguity, prefer data to people, need predictability and control, then this is probably not for you. If you are open to change, are comfortable with not always knowing where things are going, like people, and above all have an innate belief in social justice and democracy and a faith in the humanity of people, then this may feel comfortable for you. (Abma et al., 2019 p. 18)

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