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Review Article

The "Insiders World": Participatory Action Research and Mental Health – The New Foundation of Social Inquiry

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Abstract

This paper explores the methodological introduction of participatory action research and the possibilities for engaging users and user groups in the research process. Before, we examine this, there is a contextual backdrop to understanding an historiography of mental health and its implications for researchers. Indeed, the nature and understanding of doing research "inside" the 'field' of mental health has predominantly taken on a privileged 'scientific' foundation and ethos which does not allow for sentient or existential reflection to the passionate disdain of many radical researchers. Indeed, the scientific 'medical model' is literally a global influence, business, practice and methodology – it has a perpetual permeation into all aspects of humanity. It portends that perceives mental illness, in particular, as related to physical, psychological and biological 'problems'. The paper deconstructs these assumptions and reveals that action research should be introduced to delve deeper into understanding health and stakeholder experiences.

Keywords: PAR, methodology, bio-medicine and theory

Introduction

The nature and understanding of doing research "inside" the 'field' of mental health has predominantly taken on a privileged 'scientific' foundation [1] and ethos which does not allow for sentient or existential reflection to the passionate disdain of many radical researchers most notably Laing [2] amongst a growing list. Indeed, the scientific 'medical model' is literally a global influence, business, practice and methodology – it has a perpetual permeation into all aspects of humanity. It portends that perceives mental illness, in particular, as related to physical, psychological and biological 'problems'. Such a model has been ethnocentric, Eurocentric and essentialist highlighting a lack of sensitivity to "people" and their interactions with other individuals, culture and society [3].

Mental illness has been seen as a 'medical problem', and this predominant perspective is evident through the language used by researchers, policy makers, mass media and the general public [4]. The master narrative of mental illness still begins and ends with the thorny problem of physical decline. The grand medical narratives of the body and mind hide the location of complex intersections of negative ideas about mental illness and 'madness' in occidental modernity [5]. Within the mental health field, there are relentless challenges because of power imbalances and the

desire for knowledge construction to be 'certain' and 'expert' due to the 'inspecting gaze' [6] on the part of professionals. It is important to recognise then that research is always a power process which takes place in a particular political and socio-economic context.

The dominance of the positivist paradigm in health research is securely embedded and likely to be difficult to jolt. Deductive forms of reasoning in the health field are well established not least due to their ability to provide insight through measurement of aetiology, prognosis and prevalence of illness, disease and health outcomes [7]. Surveying methods and Randomised Control Trials (RCTs) are popular mechanisms for assessing health improvement and decline; providing data that is practically used to inform decisions based upon efficiency and effectiveness of a given intervention. Such positivist approaches to data gathering and new knowledge generation have been heralded as a preferred approach on the basis of rigour and objectivity. Indeed, as authors such as Everest [8] concedes, there are copious concerns that qualitative methodologies are less favourable due to accusations of them being anecdotal, subjective and having little utility due to problems of replication. Conversely, though, authors such as Green et al. [9] cite the very real opportunities present to elucidate upon complex health issues through alternative methodologies. The supremacy of positivist paradigms (and their practical usefulness to determine human experience) in healthcare research remains an ongoing area of critical debate.

The hegemonic dominance of the closed perspective: positivism and researcher exclusivity

This paper faces up to the challenge of traditional research methodology and stresses the importance of a radically new approach entitled 'participatory action research' (PAR) to both applied research and inter-relationships between service users and providers. Anti-oppressive research methodologies have begun to emerge over the past decade or so to offer constructive alternatives to mainstream research which arguably tends to perpetuate rather than challenge social divisions by accepting taken-for-granted premises about social relationships [10]. It is also crucial in carrying out anti-discriminatory research to move away from pathological perspectives, to an understanding of mental health and power in professions being determined by discriminatory institutional processes, procedures and attitudes.

A major issue when carrying out social research is the relationship between the researcher and the research process, and the relevance of the researcher's personal experience. This approach is critical of the notion of scholarly detachment which involves 'removing' ourselves from the events and processes which we describe, and which does not consider how researchers cope with the actual experiences of the research process. As such, it challenges the view amongst the 'traditional' research community that personal experience typically is irrelevant to mainstream research, or is thought to contaminate research objectivity. As Powell [11] points out, acknowledging an emotional terrain contradicts positivist approaches where the investigator disembodies objective recorders of truth.

The introduction of PAR 'plugs firmly into' feminist scholars' belief that the 'personal' is the crucial variable which is present in each and every attempt to 'do research', and that consciousness and experience should be made explicit within the research, rather than being disguised through claims of 'objectivity' and 'science'. That is, the kind of person we are, our involvement and our knowledge, influence how we experience the research, and have a crucial impact on what we see and what we do [12]. By doing participatory work where we have a personal commitment, our academic and professional contributions are more likely to come out of a personal, creative, politically engaged self, one that has a social, and not just an academic purpose. Clearly the value position we hold as researchers influence the topics we seek to research, the kind of knowledge we're looking for to generate and the way we go about actually doing the research.

Faulkner [13] claims research findings from R.C.T are limited as they do not take into account the concerns of service users as an experiential source or reflect truly the complexity and participation of individuals and social

contexts. Recently, there has been an ambivalence within research and development (R&D) narratives spoken by the NHS: one the hand, is the presumption that random trial testing is the cornerstone of 'objective' research; on the other hand, the Department of Health concede "scientific basis for many interventions is uncertain" and collaboration with service users in research implementation will be a priority [14]. Central to this agenda would be enabling individuals and groups to gain some control of research studies [15].

Understanding Participatory Action Research

A variety of possible participation and involvement between service users and providers in the health field has emerged and is described as a ladder of power sharing Kemshall et al. [16] cite Arnsteins [17] model: citizen control, delegated power, partnership, placation, consultation, informing, therapy, manipulation. Currently, the driving forces which determine the level of participation stem from legal and professional mandates. However, these have been criticised as partial, ineffective and generally reflect the ideologies of welfare marketisation and consumerist models of participation where knowledge, power and resources remain with providers [16].

Within the disability research field, there is evidence of a small shift toward greater partnership and equality within the research process and reports of a first step toward an emerging emancipatory paradigm through genuine, albeit limited progress made in changing the social relations of research production [18]. In contrast, the mental health field is dominated heavily by positivist methods conducted solely by professionals. A handful of user-led research initiatives exist, but little appears in the way of research collaboration in between [13,19].

A strategic way forward with research was recently suggested by Faulkner et al. [20]: 'A marriage of two types of expertise is the essential ingredient of the best mental health care: expertise by experience and expertise by profession'. These authors assert that qualitative research conducted with service users examines issues that are relevant in establishing meanings behind people's actions. In contrast, quantitative findings (R.C.T.) may not take into account aspects of service users lives which could be vital in understanding an "individual's decision to continue treatment, remain in contact with services or indeed survive" [20].

Arguably, the nature of Participant Action Research (PAR) and its associated approaches could form the basis for the fertilisation of a research alliance based on experiential and existential understanding. This approach has been described as a style of research rather than a specific method, with a particular strength in both generating solutions to practical problems, and in its ability to empower. Biggs et al. [21] suggests that such an approach has three essential elements: its democratic impulse; its participatory character; its simultaneous contribution to social science and social change. This approach, therefore, is concerned with action-oriented activity in which ordinary people address common needs concerning their lives and through this process generate knowledge and communicate [22]. Using this approach provides the opportunity to legitimise the knowledge generated by people, thus challenging other (hegemonic) knowledge about mental health that has often been based on 'deficiency' and 'deficit', or abnormality (Faulkner).

Further, participatory action research is compatible with health promotion principles, which can be summarised as participation, partnership and empowerment [23]. A central tenet of health promotion is that individuals have the capacity to define their issues, concerns and solutions. If research is going to fulfil its commitments to mental health, then there needs to be a continuing dialogue between all stakeholders about the principles of democracy, participation and preferred knowledge. An interpretative approach to research will invariably produce differing perspectives that may lead to complexity and contradiction. PAR research, therefore, strives to: achieve mutual respect; be honest about our own objectives; be honest about what is in it for people; be clear that the research findings will be disseminated to policy makers to try to influence policy, which should have an

impact at a community level; and be able to acknowledge that some of the expected changes cannot be guaranteed [24].

Henceforth, participatory action research is inherently more subjective than many other forms of research, but this does not mean that the research will not be rigorously undertaken. In this research, rigour will be achieved through the fostering of a sense of responsibility, accountability, partiality and subjectivity rather than the standard application of rules as in more traditional research [25]. In practical terms this will mean, in part, working hard to achieve the trust of participants by understanding the vulnerability of some and the sensitivity of the topic. Informed consent, privacy and confidentiality are principles that will underpin the research as will the need not to mislead participants. Boundaries will also be established and continuously reviewed, and approaches to debriefing participants will be developed.

Although Fals Borda [26] identified thirty-five varieties, a basic tenet of (P.R.) is the facilitation of research processes which can lead to transformative changes at a personal and structural level. The principles of Whytes [27] hybrid, Participatory Action Research (P.A.R.) a fusion of qualitative philosophies and action research, describes how this is achieved through an exploration of the knowledge and experience of participants (co-researchers) who actively engage in all phases of the research, defining and investigating problems and collectively designing required action.

A guiding principle is that PAR is orientated toward cultural, ethnic and diverse lifestyle pluralisms which, in theory, would allow issues of gender and race to be addressed. The inherent value claimed is the possibility of getting to what Butt [29] called the `nitty gritty` of framing the right questions that are culturally unique to promote understanding based on experiences with a view to genuinely addressing emerging needs as part of the research process.

This assertion of the ontological primacy of being is derived from the principles of the Husserlian line of phenomenologists. Merleau Ponty [29] in his classic preface, argues "We must begin by re-awakening the basic experience of being in the world of which science is the second order expression". Underpinning Heron and Reasons [30] framework is the phenomenological theory that essences of lived experience can best be understood without imposing preconception.

In describing the philosophical basis for new paradigm inquiry, Heron also argues from the moral and political angle, " Knowledge fuels power...and the moral principle of respect for persons is most fully honoured when power is shared not only in the application of knowledge...but also in the generation of such knowledge" [31]. A step further is that the accumulation of knowledge, as an element of power, may become an instrument for change through what Stavenhagen [32] described as a creative, critical conscience to question and then modify social systems.

However, in sharp contrast, to this ideal liberationist strategy, the reality of the research context in the mental health field is summed up by Beresford et al. [33] who argue that service users are still seen as a source of empirical data rather than creators of their own theories. They attribute this to the continued dominance of psychiatric professions and service users/survivor's unequal relations with them.

The dynamics of P.A.R. are designed to examine and change the social relations of research collaboration and specifically allow for transformation at a very personal and politicised level. As such the nature of collaborative research would seem suitable to potentially address these inequalities, bringing up dilemmas with role function and anonymity [34].

Consequently, P.A.R. within the disability research field has been described as a somewhat revolutionary change process and as a precursor toward emancipation [35]. Although it has been advocated as a useful partnership approach within the mental health field, there are considerable challenges in attempting to change the power distribution toward service users [36].

Doing Action Research with Participation

The key question is how possible is it to implement PAR approaches? Current evidence in the UK mental health field of the pure application of PAR is non-existent with attempts ranging from tokenism to attempts at partnership [34].

Whykes [37] recently described the benefits of the service user research enterprise (S.U.R.E.) which was designed to "redress this power imbalance by providing training to service users in how to become collaborators". The early benefits reported are that research questions and outcomes have been altered based on user's expertise. However, the aim is not to train service users in research but to train service users and clinical academics in how to negotiate during a research programme. We would argue that this is not going far enough with a clear distinction still being made between users and clinical academics.

Smith and O Flynn [34] describe the use of participatory and emancipatory approaches in researching perspectives of different stakeholders (service users, staff) within a network of vocational initiatives for people diagnosed with mental illness. Personal gains reported include a range of communication skills, increased confidence, reciprocity and co-researchers feeling empowered "I know a vast amount more than I did before...it's given me the power I wouldn't have had otherwise" [34].

However, to gain funding and ethical approval a proposal had to be drawn up prior to the recruitment of co-researchers this was seen later as having a negative impact on breaking down power relations as research questions had already been formulated. Role confusion from participants was also highlighted. "Were they co-researchers, research subjects or service user representatives" [34]. The level of training and support required was underestimated which meant that the research skills of co-researchers enabled them to be only partially equipped to influence the study. These significant findings raise implications for the future use of qualitative strategies such as what constitutes effective research training, how much time does it take and who decides which `representative` service users will get it? Importantly, will funders accept research proposals from mental health service users?

Also, Dachler [38] commented that the gains and difficulties for participants were constructed from these authors' perspectives who gained political reality while alternative understandings from participants remain muted. This tends to be typical of research publications and raises the issue of the control of authorship.

These developments highlight a small step in an empowering direction but are a long way from the implementation of processes which may change the social and material relations of the research production or lead to any collective action to change systems as suggested by Oliver [39]. Evidence for this possibility through using (PAR) approaches has to be drawn from areas outside of the mental health field.

Bernhard described a PAR approach as an emancipatory method to explore positive strategies for community survival with black men in the U.K. and Canada. Control of the research design, analysis, writing up and dissemination of the results remained with participants. Consequently, self-understanding and importantly self-determination was achieved through participants reporting a sense of individual and collective empowerment " I've been encouraged to do and act...thank you for the opportunity to talk about black men in a positive light" [40]. The author identified full participation as the key to facilitating changes. This occurred through the reflective processes of many members of the black community and allies coming together to create real strategies that enabled survival and success through social inclusion opportunities such as higher education and jobs.

This evidence clearly demonstrates the direct benefits of research collaboration to a marginalised community through enhancing knowledge, drawing on lived experiences and strengthening their power base to act. These positive outcomes arguably answer the fundamental axiological question of the value of research inquiry

paradigms in terms of human flourishing. Heron and Reason [30] highlight that human association is "authentic when it seeks the developmental emergence of autonomy and co-operation".

PAR: Challenges and Possibilities

A complex obstacle to participation emerges in relation to the imbalance of power differentials between mental health service users, interprofessional systems and structures. The power and status of professional cultures are based on the assumptions that staff know what's best [41]. Role security, financial and social rewards that `expert` health care status can bring are highly defended within the mental health industry [42].

Therefore, the integration of PAR approaches would require "systematic, philosophic, programmatic and role shifts that are substantial" [36]. These authors also highlight that service users who chose to participate would require considerable training and resources to acquire the knowledge to carry out research.

What is essential is a `commitment` to a fully collaborative process from power holders which, at present, is arguably lacking. Participation, as conceived originally by Friere [43], would mean the bold step of "acknowledging political structures and practices which disempower marginalised groups in society". Despite repeated calls and mandates for partnerships with service users, in reality, the opposite appears to be happening with recent mental health policy advocating a greater control role for psychiatric services [44].

Political assumptions and precedence that `the best scientific evidence` can only be derived from positivistic methods also indicate a desire for knowledge construction of assumed `certainty` from the expert side. The psychodynamics of this social role position have been defined as `anxiety reduction` on the part of power holders with research becoming `elastic' to suit dominant interests [45].

An Agenda for Change: PAR and Mental Health Research

The challenges that present themselves in advancing PAR in the field of mental health are considerable, but not insurmountable. The legacy of, and arguably the continuation of, power divides between mental health service users, and 'experts' requires careful consideration in moving an agenda of PAR forward. User controlled research has become an area of interest in the last decade, with the NIHR [46] suggesting that strategies must aim to: (i) empower, (ii) be part of broader social and political change, (iii) advance more equal relations of research production, and (iv) be based on social models of understanding and interpretation. These objectives are welcome. However, some further considerations are worthwhile.

At its core, PAR in the mental health domain should seek to challenge the 'traditional' and 'customary' discourse, policy and practice of researchers, policy-makers and politicians. There must be clear and unequivocal strategies in the development of research agendas and practice that seek to identify the roles and responsibilities of those in the research process. Further, there is a need to re-orientate consumers of research findings and analysis. While sentiments such as 'user voice', 'expert through experience' are crucial, what must not be maligned or set aside is the merit of service user research planning, coordinating, data analysis and dissemination. This is not to suggest that academia is redundant in the PAR process, on the contrary; rather it is assistive rather than authoritative.

A central task for the academy is to facilitate the cultivation of conditions whereby the credibility of PAR is promoted, and prejudices neutralised. Moreover, a challenge to the institutional conformity of research findings (and their merit) is a priority – indeed the worth of qualitative strategies of research and interpretative/phenomenological analysis remains paramount.

Conclusions

The article has attempted to illustrate fundamental issues of traditional methodology in researching mental health as well as to point to the nature of PAR as a forward-looking methodology. We agree with Faulkner [13] who states we need a "broader understanding of what constitutes evidence...in order that service providers and policy makers can respond to the needs and views of service users". However, given the policy emphasis on positivistic paradigm driven methods, it is arguable if we have reached the crucial stage of acknowledging the need to integrate (PAR) user centred approaches as legitimate inquiry.

The participatory principles of PAR which emphasise research processes that may have a transformatory affect in addressing power and social inequalities appear to be congruent with service users call for changes in research practice [20]. However, the powerful forces resisting change are arguably considerable and include resistance from professionals with uncertainty and fear being cited as dynamic factors that activate resistance [16,47]. There is also political resistance to seeing psychiatric patients as experts or partners in setting research agendas [33].

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