Towards a tinkering participatory research method in mental health

Olav Tangvald-Pedersen and Rob Bongaardt

Faculty of Health and Social Sciences, University College of Southeast Norway, Kongsberg, Norway

ABSTRACT
The current agreement that evidence-based practice is a merger of research evidence, clinical expertise and patient preferences has made service user involvement and participant research not only acceptable, but also called for and desired. However, what user involvement and participant research entails, and how best to implement it, is contestable and ideologically rooted. In this paper, we describe three different ideologies, a liberal, an emancipatory and a caring ideology, and we present their concomitant methodological solutions and preferences. Finally, we outline a tinkering participatory research method by borrowing from the above-mentioned ideological views. We would claim that this method balances well between the demands of scientific rigour and the expectations of ideological and social relevance.

ARTICLE HISTORY
Received 8 September 2015
Accepted 2 July 2016

KEYWORDS
Care; consumerism; emancipation; ideology; methodology; participant research

Introduction
The current agreement that evidence-based practice is a merger of research evidence, clinical expertise and patient preferences (Spring 2007) has made service user involvement and participant research not only acceptable, but also called for and desired (Staley, Kabir, and Szmukler 2013). As a result, the quest for methodological research designs that take scientific rigour, clinical expertise and patient preferences into account has been intensified (Levant et al. 2008). Moreover, since this quest is taking place in an age of service user emancipation and empowerment (Staddon 2013; Sweeney 2009; Wallcraft, Amering, and Schrank 2009), all inputs stemming from these three sources should count as equal sources of knowledge in a scientific study. In other words, these sources of knowledge are regarded not as disparate and hierarchically ranged entities, but as parallel and complementary. In this sense, scientific research is conceived as being guided by prevailing human interests rather than an ideal of an impersonal mechanization of the research process through standardized methods (Kitcher 2001; Szmukler 2009). This also means that research projects are conducted on the middle ground shared between research purposes, available research methods and ideological regulations of those involved (Dehue 2010; Gustavsson 2004).

This article examines the methodological middle ground that we designed in one of our research projects in the mental health field involving user participant researchers. The project is financed by Extrastiftelsen in Norway, a national lottery allocating parts of its financial profit to NGOs committed to research in mental health. One such NGO is Mental Helse (Mental Health), a special interest group for mental health service users. One important ideological demand of Mental Helse is that mental health service users should participate in research projects. In that respect, the project is committed to the principles of democratic and ‘well-ordered science’ (Kitcher 2001, 117), which requires transparency.
in allocation and management of financial resources, a thorough explanation of the moral constraints influencing the aims and means of the project, and finally a declaration on who will benefit from the results of the research. Kitcher’s second demand – in this case, the moral, ideologically defined sphere that requires user involvement in the means of a project – made us highly conscious of the interdependency between ideology and research methodology. We found that research methodology, though often seen as a distinct ingredient of scientific research, is not always self-sufficient and independent of human interest and ideology. As Dehue (2010, 25) points out: ‘methodology is a form of output, … methods and techniques of social-scientific research, intended in first instance for colleagues, also find a market as aids in the questions, plans, or decision making of third parties’. Therefore, as Dehue has shown, methodological standards vary according to external factors such as ideological constraints, dominant social groups and scientific self-attribution.

The purpose of this article is twofold: to present an overview of three methodological standards and their respective dependency on three different ideologies or voices that advocate for user involvement and participant research; and to share our experiences of designing a solution given these three voices. The three ideologies we describe are a liberal, market-based ideology, a survivor led and emancipation-based ideology, and a health-care and education-based ideology. These three voices all stress the necessity of user involvement and participation, but differ rather radically in their scientific purpose and methodological preferences. We will untangle some strands of thinking by pairing up the liberal voice with a consultative research design, the survivor voice with an emancipatory research design and the caring voice with a cooperative research design.

In what follows, we first describe the liberal voice, secondly the survivor voice and thirdly the health-care voice. Our starting point is the mid-eighties when the liberal voice made itself felt (Keat, Abercrombie, and Whiteley 1994), and thereby encouraged the two other voices to intensify their engagement in the field of mental health. Hence, we do not present the voices in order of their chronological appearance, but are led by the dialogue that was inspired by mid-1980s liberalists (cf. Crossley and Crossley 2001; Rissmiller and Rissmiller 2006). For each voice, we first present the overall ideology and then how it engages with research method.

As ‘participant observers’ more than ‘dedicated contestants’ in the debate between these three ideological voices, we do not feel obliged to take a stand pro or contra. Nevertheless, in the final section we will describe our endeavour to implement participant research. We will do so to illustrate one possible process of creating a middle ground between the demands of user involvement ideology, research purpose and methodological rigour.

The liberal voice

From a liberal service user point of view, the welfare system, with its concomitant distribution of public services, is perceived as undemocratic, ineffective and disempowering (Beresford 2002; Sweeney 2009). It is undemocratic because it deprives people of the right to choose on their own. It is ineffective because no incentives exist to encourage improvement of the services, and, ultimately, it is disempowering because it undermines the independence and self-governance of the individual. For too long the welfare state system and services have been guarded and administered by experts who decide what public services have to offer, and whom to offer them to. Now the time has come, the liberals emphatically plead, to hand authority over to the consumers (Keat, Abercrombie, and Whiteley 1994). A just, democratic and efficient distribution of services must base itself on the aggregate of choices made by all of its actors, not on judgment-based decisions executed by selected bureaucrats alone. This implies transforming the ‘social services from a welfare agency run by professionals, allegedly too much in their own interests, to a customer-centred organization run by professional managers’ (McLaughlin 2009, 1104). In other words, the mental health system and other service systems must be transformed from closed and expert driven systems to open and transparent market systems. The mental health service system must change its modus operandi from being an expert agency distributing charities to the deserving poor, to working as in a market, distributing ‘health commodities’ based upon the
principles of supply and demand. Within a rationale of marketing and consumerism, service users and their organizations are no longer needy recipients of scanty goods, but imperious customers demanding proper ‘mental commodities’ based on their own needs. Mental health workers on the other hand are to lose their privilege as service monopolists and should act as competitive merchandisers offering their goods. Beresford (2012, 26) express the rationale in this way: ‘Consumerism starts with the idea of buying the goods and services we want, commodifying our needs, instead of making collective provision of them, to secure rights and entitlements.’

Within the logic of the market, customer and merchandiser are equal and interdependent (Smith 2001). Only together can they develop, renew and customize the services and commodities offered. Thus, participation and consultation between the two is not only necessary, but it is also democratic, efficient and empowering. It is democratic by means of adjusting the services to incoming needs. It is efficient and innovative because of the need to renew and improve the services/commodities offered in order to be a product in demand, and it is empowering by means of joint consultation and the right to choose. This implies that service users and professionals must consult each other in the process of accommodating and renewing the mental health services.

In terms of research, this implies involving the service user as an advisor and consultant ‘in framing research questions, identifying outcomes relevant to service users and selecting study instruments’ (Pollard and Evans 2013, 43). Further involvement in the research process, however, is unrealistic because ‘data collection and processing methods employed often require specialized knowledge and skills’ (Pollard and Evans 2013, 43). However, involvement by consultation is only one way of engaging consumers in the research process. In their review of research projects involving consumers, Oliver et al. (2004) distinguish between projects based on consultation, collaboration and user control, respectively. Despite these levels of involvement, Oliver et al. (2004, 103) nonetheless conclude their report with: ‘Productive methods for involving consumers require appropriate skills, resources and time to develop and follow appropriate working practices.’ In other words, regardless of various levels of user involvement, research methodology is of utmost importance, and ought to stay within the domain of academic researchers. So to sum up, methodological rigour is vitally important, and participant researchers can at most help to refine the relevance of a research project, but never steer it since their methodological skills are too vague and imprecise.

Survivors, whom we will now describe, voice a quite different view and approach to the nature of mental health, the mental health-care system and, consequently, to the implementation of user involvement and participation in mental health research.

The survivor voice

Survivors see themselves as having survived the mental health-care system and are living despite, not because of, the system, which has failed to be of any help (Plumb 2011). For survivors, the consumerist model is simply not radical enough. The disability activist and academic Oliver (1992) argues that the main problem with the consumerist model is its illusion of equality and common cause, and any suggestion of a common interest between system users and system providers is a simplification and a falsification. From a survivor’s point of view, this ‘falsification’ is expressed as a simplistic, medical dogmatic and repressive epistemology of mental illness (Bentall 2009). Focusing on mental illness mainly as an individually embedded impairment in need of medical care conceals the social aspect of mental illness, and even worse, it may hurt those inflicted (Wilson and Beresford 2002). In a survivor perspective, the problem lies with the present mental health system and the services it offers, as these services are unwanted, devastating and oppressive (Plumb 2011). Survivors perceive themselves not as active service users, but as coerced and involuntary service recipients. Plumb (2011, 6) puts it in this way: ‘[t] is not that we don’t experience difficulties or need support, but that our difficulties lie in hurt, oppression, a refusal to fulfill prescribed roles … and society’s response to these.’ What is needed, she continues, is ‘a more widespread shift away from talk of “illness”, “disorder” or “defective mechanisms” (chemical imbalances) to talk of distress or dissent’ (6).
From a survivor’s perspective, then, what is needed is not medical treatment of physiologically embodied mental impairments, but help to defeat and overcome social contempt, oppression and discrimination in order to live independent lives (Reeve 2015). Thus, the survivor voice urges for agitation rather than for consultation. Survivors want to be a revolutionary counterforce that emancipates haunted minority groups from discriminating and disabling social barriers (Oliver 1986; Oliver and Sapey 2006) and from oppressive conventions and values that function as the building blocks for self-image and society (Campbell 2009; Shildrick 2012). Furthermore, they warn against what they consider to be the guiding star of the consumerist model, the personalization and concomitant transference of responsibility for one’s own health and recovery process. McWade, Milton, and Beresford (2015, 308) put it this way:

Personalisation has been implemented through a free market ideology that has seen the dispossession and even some deaths of disabled people. It is ‘time to talk’ and not in the way the establishment wants us to, with individualised and neatly packaged tales of recovery.

From a survivor perspective, joint efforts and consultation with professionals, which the consumerist model encourages, is not the right way to go. From a survivor’s point of view, the kind of participation the consumerist model invites service users to is little less than tokenism and seduction. The consumerist model disregards the mismatch in epistemic power between users and professionals; it refuses to discuss who is controlling the financial means, and who is dictating the terms of production (cf. Fricker 2007; Oliver 1992). Thus, the model gives the upper hand to the mental health system, and thereby implies a great risk of making survivors the weakest part in a detrimental partnership between the user apparatus and the established mental health system. That this fear may not be unfounded is pointed out by El Enany, Currie, and Lockett (2013, 24) who state that ‘through a combination of self-selection by those wanting to be involved, and professionals actively selecting, educating and socializing certain users, unrepresentative involvement occurs’. In other words, user organizations risk ending up under the thumb of the system they were supposed to oppose, and user involvement thereby degenerates into tokenism, doing little less than reinforcing and legitimizing an old fashioned and repressive service system. Beresford and Boxal (2013, 74) say it in this way: ‘Service users getting involved in conventional consultative and participatory processes based on consumerist ideology can find themselves sucked into reinforcing the ideas, agendas and concerns of dominant traditional medicalised individual interpretations of their experience.’

From a survivor perspective, real involvement and participation demand free, strong and independent special interest groups (cf. Barnes 1999; Cowden and Singh 2007), and participation in research implies much more than taking part in the refinement of the existing health-care system by means of different sampling and evaluation techniques. According to Stone and Priestley (1996), emancipatory and participant research implies a rejection of the medical model of illness and distress, and a dismissal of the scientific idea of neutrality and objectivity. As participant/survivor research has the practical purpose of being emancipatory and self-empowering for those who are disabled/mentally distressed, survivor organizations demand that disabled/distressed people control the means of scientific production. Personal experience should be given a voice that transcends the individual and expresses collective demands. Methodological plurality should serve that purpose, not as an objective technique to be applied, but as a mouldable means in the hands of users (Oliver 1992, 1997). So to sum up: methodology is secondary and subjugated to rightful political aims put forward by those inflicted by the unjust oppressive system.

The health-care voice

Betwixt and between consumers and survivors, we find health-care professionals. They voice their concern about the relative neglect of care in the perspectives of survivors and consumers alike. Seen from their point of view, the need for proper care is neither commensurable with the ideal of free market choice, nor with the demand of taking active part in a collective and emancipatory
counter force. Being in need of care and being in a state of making deliberate choices and considerations are simply not the same. These are distinct modes of being in the world, subjected to two different kinds of modus operandi, namely a logic of care and a logic of choice, consideration and management, respectively, as Mol (2008) has argued.

When one suffers from a disease, what one primarily needs is conscientious care and the facilities to recover, not the individual right to make deliberate choices. In Mol’s view (2008), the form of interplay within a health related care situation is quite distinct from the interplay within a market. The interplay within a market is brief, businesslike and clearly defined; it is a clear-cut transaction. It is all about buying and selling. The interplay within a care situation on the other hand is ongoing, ethical and developmental; it is a compound, complex and enduring relationship. Thus, whereas the relationships in a market are atomistic and run by a logic of choice, relationships in a care situation are symbiotic and run by a logic of care. Following Mauss (2002), Mol further argues that taking part in a servant-patient relationship is not like taking part in an individual and transactional exchange of goods where one uses money to buy a certain health service and, by the same token, also redeems oneself from any further social obligations. On the contrary, Mol (2008) claims, being part of a servant-patient relationship is tantamount to being part of a collective and total service system, a system allowing the patient the right to receive, but also the ability and expectation to reciprocate what is given in one way or another. Whether one is a public servant or a patient, one partakes in a lasting chain of gift exchanges, and gifts, unlike commodities, are encumbered with the commitment to reciprocate.

Indeed, paramount in the process of recovering from severe mental illness is the right to reciprocate, quite simply because the principle of reciprocity puts the patient on equal footing with the servant, without neglecting the fact that it is the representative of the servant system who is obliged to act first (Borg and Kristiansen 2004). From a more technical stance, commitment and reciprocity also fit the logic of care. Being a patient often means being in need of a long-lasting and coherent treatment plan and not in need of a detached and single-minded health service. Mol’s (2008) core argument is thus that best treatment is not a sellable and ready-made quick fix product, a detached commodity, but a piecemeal, experimental and ongoing tinkering activity between patient, family and health-care providers. The overall responsibility for this tinkering activity, however, is not dual and mutual. It is the service system and its representatives that unambiguously bear the responsibility to make tinkering work.

This implies that professionals’ responsibility to improve care requires a practice grounded in an open-mindedness and sensitivity towards the patient’s lifeworld experiences, so called lifeworld-led health care, to use the term coined by Todres, Galvin, and Dahlberg (2007; see also Dahlberg, Todres, and Galvin 2009). This kind of health care rests on a philosophy of existential phenomenology and hermeneutics (Gadamer 1996; May, Angel, and Ellenberger 1958; Svenaeus 2000), stressing the importance of acquiring knowledge about the totality of lived experience of those who suffer, and not only experiences concerning deviance and pathology. Dahlberg, Todres, and Galvin (2009, 268) express it in this way:

> Within a perspective of lifeworld-led care we need knowledge that understands both the freedoms and vulnerabilities of peoples’ journeys as they struggle with different health related conditions. We also need knowledge of the possibilities for vitality, movement and peace; the deeper existential horizons and potentials that are possible.

In other words, from a health-care point of view, acquisition, development and implementation of knowledge are primarily meant to qualify the health-care worker to do a better job, not to make the individual services more efficient, commoditized and cost saving, nor to emancipate the patient. Health care is a tinkering activity involving patients, professionals and relatives (cf. Mol 2008), thus implying a form of knowledge that is sensitive to the tone of voice of those in need of care.

Central to the health-care perspective, then, is to improve the ability of health-care workers to be aware of the voice of the other, and to adjust their caring practice to this. It is argued that one way of
building this competence in ‘awareness of the other’ is by applying phenomenological principles of research (Galvin and Todres 2011; Giorgi 1985; Todres and Holloway 2004). Phenomenological research, with its emphasis on concrete life-world experiences, seems to be well suited for participant research. However, the status of the participants as researchers is ambiguous within phenomenological research. Davidson (2003), for instance, regards user participants as vital and important storytellers, but not as skilled phenomenologists. He writes:

Contrary to the constructivist views of Piaget and Kelly, we do not view people as going about their everyday lives as if they were untrained but naturally intuitive scientists. […] Nor do we view people as lay phenomenologists, reflecting on and trying to determine the structural elements of their own experiences. (Davidson 2003, 62)

For phenomenological researchers such as Davidson, participation and involvement on the part of the users is important insofar as they can help academically trained researchers to track down the relevant themes and questions, take care of ethical issues concerning participants involved in the research, and contribute to the research process by telling their stories (Davidson et al. 2009).

Such a clear-cut distinction between researcher and participants in the research process is not always present in phenomenological research. Finlay (2002) describes different ways of reflecting upon the source of data in phenomenological research (218):

Recognizing research as a co-constituted account, adherents of participative research argue that as research participants also have the capacity to be reflexive beings, they can be co-opted into the research as co-researchers. At the very least this involves participants in a reflexive dialogue during data analysis or evaluation.

Elsewhere she concludes by stating:

Given a multiplicity of appearances and meanings, surely a multiplicity of methods is also appropriate. Rather than being fixed in stone, the different phenomenological approaches need to remain dynamic and undergo constant development as the field of qualitative research evolves. (Finlay 2009, 17)

So to sum up: Methodology is a necessary yet flexible instrument, and the status of the participant as a researcher is indeterminate and open to exploration.

Table 1 below provides an overview of the three ideologies and the various aspects of research that they imply. In the following sections, we sketch our own approach, which incorporates aspects of all three stances.

Table 1. The relation between ideology, methodology and research design.

| Ideology       | Liberal                                                                 | Emancipatory                                                                 | Caring                                                                 |
|----------------|--------------------------------------------------------------------------|----------------------------------------------------------------------------|------------------------------------------------------------------------|
| Ontology       | Medical model: The disorder is located in the body                        | Social model: The disorder is caused by social conditions                   | Interactional model: The disorder is compounded by a blend of impairments and social conditions |
| Participant research because | Knowing the preferences of an influential customer leads to a better product Consultative and temporary | The survivor is oppressed and demands justice                               | The patient knows his/her situation best                                |
| Research design| Consultative Increased diversity and efficiency of the mental health system by means of choice and commodification of health services | Commanding, management of all parts of the project User-led                 | Ambiguous, imprecise and negotiable Collaborative                       |
| Purpose of research | Increased diversity and efficiency of the mental health system by means of choice and commodification of health services | Creation of a new health-care system by means of strong and independent special interest groups | Maintenance and improvement of care and education by means of tinkering activity and consensus making |
| Project owner | Health service groups Empirically based surveys and interviews           | Survivor groups Empirically based action research                          | Health service groups Phenomenological-based lifeworld-led descriptions |
| Preferred research methodology | Superior and imperative. Loyalty to well established methodological rules | Minor and subordinate. Loyalty to the political goals of the oppressed     | Contextual, but important. Loyalty to the tinkering activity of improving care |
| Research method viewed as | Superior and imperative. Loyalty to well established methodological rules | Minor and subordinate. Loyalty to the political goals of the oppressed     | Contextual, but important. Loyalty to the tinkering activity of improving care |
**Tinkering a middle ground**

We started this article by ascertaining that evidence-based practice has prepared the way for user involvement and participant research. Hopefully, we have now demonstrated the insight that the ideological vision of participant research influences the use of particular research designs and methods. Moreover, in accordance with Dehue (2010), we found that the particular ideological demands also influence the status of research method within a research project. In what follows, we primarily take issue with how method is used rather than with which method is used; we focus on methodological status more than on methodological form and heuristics.

The status we as researchers attribute to research method follows our preference for a lifeworld-led approach. A research approach that aims to understand and improve the lifeworld of patients makes us feel at home. That is because we also train mental health-care workers and want research outcomes to be relevant to their daily practice. How we hope to contribute to this is outlined in these final sections of the article. This section also illustrates that the mental health care field should not limit itself to just three ways to implement an ideology. Other ways are conceivable.

Our research approach is meant to be consistent with Kitcher’s (2001) point that a well-ordered research project answers to the moral demand of using a research method that aligns with the sponsors’ as well as users’ needs. Further, our methodological solution is analogous to Mol’s (2008) description of a tinkering practice of care. Thus, in this section we will outline and discuss our solution of how to tinker a research method. Of course, ‘tinkering a research method’ may have an inconsistent ring to it. Yet, it appears to be common practice in the natural and social sciences alike. Science studies, such as Gigerenzer’s (1987) study of statistical methods, show time and again that textbook research methods are typically compromises between several methods put together because they produce good results. Tinkering ‘presents small errors and large gains’ and can be seen as a process of trial and error, as Taleb (2013, 181) argues. A similar point is made by Polkinghorne (2006), arguing that slavishly following prescribed steps of a qualitative method discredits the scientist’s proficiency, and undermines the ability to yield unexpected, yet relevant, outcomes. We subscribe to this idea: to tinker a research method is congruent with the practice of research itself and in line with our ideology of lifeworld-led care. With reference to the overview in Table 1, we borrow from all three approaches as we collaborate with the user, deflate the status of method itself, and stay as close as possible to the lifeworld of patients.

Our way of thinking unfolds as follows: Mol (2008, 76) points out that the logic of care is incongruent with an argumentative style of reasoning; the tinkering nature of care fits better with a narrative style of reasoning. Narrative reasoning takes shape in a continuous dialogue between helper and patient. As different storytellers they can enrich each other’s understanding. This stands in contrast to the use of arguments, which easily leads to controversy, polarization and rejection of others’ points of view. What happens if we transfer this idea of narrative reasoning to the practice of collecting data, analysing data and reporting on findings? Can we create a research process that allows for dialogue between an academic and a user participant researcher that leads to growth of insight rather than to controversy; a research process that has rigour as well as relevance, ideological flexibility as well as conceptual coherence? Our experience is that the answer is a definite ‘Yes!’; which we will illustrate in the following description of how our research project unfolds. On the way we also indicate how the project is anchored in the different versions of participant research described above. Moreover, it illustrates the extent to which the project involved tinkering.

**A tinkering project unfolds**

As lecturers educating mental health workers, we are firmly embedded in the ideology of health care. As the mental health-care voice accords with being open-minded and sensitive towards other human beings’ lifeworld experiences, we set out to design a research project which concentrated on the following research question: ‘What are the essential themes of belonging to the workplace as
experienced by users of Norwegian mental health services? This question arose out of research revealing that a sense of belonging is a vital and inseparable part of a more comprehensive experience of good mental health amongst persons whose mental health has been challenged and, therefore, have received some kind of help from mental health services (Tangvald-Pedersen and Bongaardt 2011). In line with Kitcher’s (2001) principles of a well-ordered science regarding involvement, transparency and allocation of financial means, we consulted the Norwegian Center for Experience-based User Knowledge in Mental Health (Erfaringskompetanse.no), which is a Norwegian organization that collects mental health service user experiences as resources for research and development. We discussed with them how best to include users in the research project and how to improve the recruitment of participant researchers.

Once participant researchers were in place, the way of working together changed from consultation to collaboration. Through an ongoing dialogue with the participant researchers, the project took shape. When the proposal had found its final form and collaboration with user organizations was confirmed, the grant application was sent to Extrastiftelsen, the potential sponsor. They granted money for a Ph.D. research project, but only to support the academic researcher. This challenged the project, as it also needed to finance the participant researcher. The participant researcher took the lead to apply for an additional grant to cover her salary by creating a project within the project, emphasizing the relevance of participant research within larger research projects. Erfaringskompetanse.no granted a lump sum enabling the participant researcher to be involved part-time in the main project.

With the financial support in place, the next step concerned the collection and analysis of data. In collaboration, the academic and participant researcher recruited 17 informants via professional as well as user-led networks. These informants then shared their experiences of belonging to the workplace through interviews with the academic researcher or through written narratives based on an invitation to describe in as much detail as possible a situation or event in which they experienced a sense of belonging. All data were made available to both researchers.

For the analysis of the transcribed interviews and narratives, both common and different methodological entry points into the data at hand were identified. This was based on what the academic researcher and the user participant researcher considered their respective strengths; we tinkered our way towards the best division of labour. Both researchers opted for phenomenology as their basic stance. Phenomenology sets out to describe a person’s life world as experienced in everyday events. During the analysis process, one withholds theoretical or common sense assumptions about the experiences studied, and endeavours to let the phenomenon speak for itself. Upon entering the actual analysis of the transcribed interviews and narratives, cooperation between the researchers was deliberately paused; they each went their own way. The academic researcher applied Giorgi’s (2009) descriptive phenomenological approach, which focuses on creating a systematically derived, academically sound structure of specific human experiences. In our study, this so-called meaning structure issues from different descriptions of the same phenomenon (i.e. belonging to the workplace) as provided by the informants. The structure invokes constituent dimensions of the phenomenon such as ‘being invited into a work collective’, ‘the choice to participate in social activity’, or ‘vigilance concerning one’s identity as part of or separate from work colleagues’. In contrast to this, the participant researcher focused on a bodily sensed understanding of the same informants’ descriptions, making use of Todres’ (2007) embodied enquiry and Gendlin’s (2003) focusing technique. Instead of rewriting the experiences into an academically sound structure, the purpose of this way of working is to focus on ‘murky’ bodily felt senses, explicate these senses by means of images conjured up by words that catch ‘the crux of all that, the special quality that comes up from [the felt sense]’ (Gendlin 2003, 55). This ends up with creating a texture, which is a general but rich and experience-near description of the described phenomenon (cf. Todres 2007, 47). This texture’s purpose is to evoke, carry forth and empirically expound the bodily felt senses of the phenomenon. In our case, the texture extends the felt senses of ‘uncertainty’, ‘being in a state of limbo’ and ‘accommodating to expectations’, senses that gradually transform into senses of ‘relief’ and ‘settlement’. 
In the final stage of the research process, the academic and participant researcher resumed their collaboration. They compared and discussed their results to decide on written forms that present the content and message of the structure and texture in ways that fit the audiences to be addressed – that is, academic peers, user organizations or health-care professionals. Some audiences may be more interested in the meaning structure, which brings together the constituents of the experience as people have reported it, while for other audiences the texture is probably more interesting as it may call forth other dimensions and new insights amongst those who engage in reading it (Pethick 2015, 176). Thus, the tinkering model allows the academic researcher as well as the participant researcher to disseminate and present findings in line with their respective ideological goals. Moreover, the tinkering model begs for cooperation and co-authorship.

Conclusion

Our tinkering approach created a space for the participant researcher and the academic researcher to follow their respective courses of inquiry, thereby adopting different stances within participatory research. The approach also created space for transparency of the research process and dialogue about the intermediate and end results of the study. The researchers with their different backgrounds shared their analyses and findings during the process, largely following the methodological rules of their preferred approaches. They ‘broke the rules’, however, as they influenced each other’s working process through dialogue, narrating rather than arguing their way forward to a deeper insight into the phenomenon under study (i.e. the experience of a sense of belonging to the workplace).

In conclusion, we contend that tinkering user research participation advances beyond mere opportunistic eclecticism. Embarking on any research project guided by the principles of a well-ordered science (cf. Kitcher 2001, 117–135) implies involvement and negotiations amongst those concerned regarding the distribution of the financial means, the setting of the research agenda and the use of the research results. A tinkering research methodology views Kitcher’s principles of a well-ordered science as building blocks rather than limitations. Not unlike the caregiver who, in Mol’s (2008) conception, provides care by mixing and matching the resources of a situation to enable satisfactory processes and outcomes of care, the researcher draws on the specifics of the larger research situation to create the best possible research processes and outcomes – assuring both scientific rigour and social relevance.

Disclosure statement

No potential conflict of interest was reported by the authors.

Funding

This study was supported by Extrastiftelsen Helse og Rehabilitering [grant number 2012/2/0091].

Notes on contributors

Olav Tangvald-Pedersen is research fellow and assistant professor of mental health work.

Rob Bongaardt is professor of mental health. Their recent research concerns the experience of good mental health in the light of mental health promotion.

References

Barnes, M. 1999. “Users as Citizens: Collective Action and the Local Governance of Welfare.” Social Policy & Administration 33 (1): 73–90.

Bentall, R. 2009. “Roll Over Kraepelin.” In Mental Health Still Matters, edited by J. Reynolds, R. Muston, S. Heller, J. Leach, M. McCormick, J. Wallcraft, and M. Walsh, 16–23. Basingstoke: Palgrave Macmillan.
Beresford, P. 2002. "User Involvement in Research and Evaluation: Liberation or Regulation?" Social Policy and Society 1 (02): 95–105. doi:10.1017/S1474746402000222.

Beresford, P. 2012. "The Theory and Philosophy Behind User Involvement." In Social Care, Service Users and User Involvement, edited by P. Beresford and S. Carr, 21–36. London: Jessica Kingsley.

Beresford, P., and K. Boxal. 2013. "Where Do Service Users’ Knowledges Sit in Relation to Professional and Academic Understandings of Knowledge?" In Mental Health Service Users in Research: Critical Sociological Perspectives, edited by K. Boxal and P. Staddon, 69–86. Bristol: Policy Press.

Borg, M., and K. Kristiansen. 2004. "Recovery-Oriented Professionals: Helping Relationships in Mental Health Services." Journal of Mental Health 13 (5): 493–505. doi:10.1080/09638230400006809 x.

Campbell, F. K. 2009. Contours of Ableism: The Production of Disability and Ableness. Basingstoke: Palgrave Macmillan.

Cowden, S., and G. Singh. 2007. "The ‘User’: Friend, foe or Fetish? A Critical Exploration of User Involvement in Health and Social Care." Critical Social Policy 27 (1): 5–23. doi:10.1177/0261018307072205.

Crossley, M. L., and N. Crossley. 2001. "Patient’ Voices, Social Movements and the Habitus; How Psychiatric Survivors ‘speak out.” Social Science & Medicine 52 (10): 1477–1489. doi:10.1016/S0277-9536(00)00257-4.

Dahlberg, K., L. Todres, and K. Galvin. 2009. "Lifeworld-led Healthcare Is More Than Patient-led Care: An Existential View of Well-Being." Medicine, Health Care and Philosophy 12 (3): 265–271. doi:10.1007/s11019-008-9174-7.

Davidson, L. 2003. Living Outside Mental Illness: Qualitative Studies of Recovery in Schizophrenia. New York: New York University Press.

Davidson, D., P. Ridgway, T. Schmutte, and M. O Mol, A. 2008. The Authority of the Consumer. London: Routledge.

Dehue, T. 2010. Changing the Rules: Psychology in the Netherlands, 1900–1985. Cambridge: Cambridge University Press.

Duquesne University Press.

El Enany, N., G. Currie, and A. Lockett. 2013. A Paradox in Healthcare Service Development: Professionalization of Service Users. Social Science & Medicine 80: 24–30. doi:10.1016/j.socscimed.2013.01.004

Finlay, L. 2002. "Negotiating the Swamp: The Opportunity and Challenge of Reflexivity in Research Practice." Qualitative Research 2 (2): 209–230.

Finlay, L. 2009. Debating Phenomenological Research Methods. Phenomenology and Practice 3 (1): 6–25.

Fricker, M. 2007. Epistemico Justice: Power & the Ethics of Knowing. Oxford: Oxford University Press.

Gadamer, H. G. 1996. The Enigma of Health: The Art of Healing in a Scientific Age. Stanford, CA: Stanford University Press.

Galvin, K., and L. Todres. 2011. "Research Based Empathic Knowledge for Nursing: A Translational Strategy for Disseminating Phenomenological Research Findings to Provide Evidence for Caring Practice." International Journal of Nursing Studies 48 (4): 522–530.

Gendlin, E. 2003. Focusing. London: Rider.

Gigl, E. 1987. "Probabilistic Thinking and the Fight Against Subjectivity." In The Probabilistic Revolution. Volume 2: Ideas in Science, edited by J. Krüger, G. Gigl, and M. S. Morgan, 11–33. Cambridge, MA: The MIT Press.

Giorgi, A. 1985. "Towards a Phenomenologically Based Unified Paradigm for Psychology." In The Changing Reality of Modern Man: Essays in Honour of Jan Hendrik van den Berg, edited by D. Kruger, 20–34. Pittsburg, PA: Duquesne University Press.

Giorgi, A. 2009. The Descriptive Phenomenological Method in Psychology: A Modified Husserlian Approach. Pittsburgh, PA: Duquesne University Press.

Gustavsson, A. 2004. "The Role of Theory in Disability Research – Springboard or Strait-Jacket?" Scandinavian Journal of Disability Research 6 (1): 55–70.

Keat, R., N. Abercrombie, and N. Whiteley. 1994. The Authority of the Consumer. London: Routledge.

Kitcher, P. 2001. Science, Truth, and Democracy. Oxford: Oxford University Press.

Levant, R. F., N. T. Hasan, M. C. Roberts, and J. E. Barnett. 2008. "Evidence-Based Practice in Psychology." Professional Psychology: Research and Practice 39 (6): 658–662. doi:10.1037/0735-7028.39.6.658.

Mauss, M. 2002. The Gift: The Form and Reason for Exchange in Archaic Societies. London: Routledge.

May, R., E. Angel, and H. F. Ellenberger, eds. 1958. Existence: A New Dimension in Psychiatry and Psychology. New York: Basic Books.

McLaughlin, H. 2009. "What’s in a Name: ‘Client’, ‘Patient’, ‘Customer’, ‘Consumer’, ‘Expert by Experience’, ‘Service User’ – What’s Next?” British Journal of Social Work 39 (6): 1101–1117. doi:10.1093/bjsw/bcm155.

McMurry, B., W. Milton, and P. Beresford. 2015. "Mad Studies and Neurodiversity: A Dialogue." Disability & Society 30 (2): 305–309. doi:10.1080/09687599.2014.1000512.

Mol, A. 2008. The Logic of Care: Health and the Problem of Patient Choice. London: Routledge.

Oliver, M. 1986. "Social Policy and Disability: Some Theoretical Issues." Disability, Handicap & Society 1 (1): 5–17. doi:10.1080/02674648666780021.

Oliver, M. 1992. "Changing the Social Relations of Research Production?" Disability, Handicap & Society 7 (2): 101–114. doi:10.1080/02674649266780141.

Oliver, M. 1997. "Emancipatory Research: Realistic Goal or Impossible Dream?" In Doing Disability Research, edited by C. Barnes and G. Mercer, 15–31. Leeds: The Disability Press.
Oliver, S., L. Clarke-Jones, R. Rees, R. Milne, P. Buchanan, J. Gabbay, G. Gyte, A. Oakley, and K. Stein. 2004. “Involving Consumers in Research and Development Agenda Setting for the NSH: Developing an Evidence-Based Approach.” *Health Technology Assessment* 8 (15): 1–148.

Oliver, M., and B. Sapey. 2006. *Social Work with Disabled People*. 3rd ed. Basingstoke: Palgrave Macmillan.

Pethick, S. 2015. *Affectivity and Philosophy after Spinoza and Nietzsche: Making Knowledge the Most Powerful Affect*. London: Palgrave Macmillan.

Plumb, A. 2011. “Distress or Disability: A Discussion Document.” In *Distress or Disability? Proceedings of A Symposium Held at Lancaster University, 15–16 November 2011*, edited by J. Anderson, B. Sapey, and H. Spandler, 3–12. Lancaster: Centre for Disability Research.

Polkinghorne, D. P. 2006. “An Agenda for the Second Generation of Qualitative Studies.” *International Journal of Qualitative Studies on Health and Well-Being* 1 (2): 68–77.

Pollard, K. C., and D. Evans. 2013. “Theorising Service User Involvement from a Researcher Perspective.” In *Mental Health Service Users in Research: Critical Sociological Perspectives*, edited by P. Staddon, 39–51. Bristol: Policy Press.

Reeve, D. 2015. “Psycho-emotional Disablement in the Lives of People Experiencing Mental Distress.” In *Madness, Distress and the Politics of Disablement*, edited by H. Spandler, J. Anderson, and B. Sapey, 99–112. Bristol: Policy Press.

Rissmiller, D. J., and J. H. Rissmiller. 2006. “Evolution of the Antipsychiatry Movement into Mental Health Consumerism.” *Psychiatric Services* 57 (6): 863–866.

Shildrick, M. 2012. “Critical Disability Studies: Rethinking the Conventions for the Age of Postmodernity.” In *Routledge Handbook of Disability Studies*, edited by N. Watson, A. Roulstone, and C. Thomas, 30–41. London: Routledge.

Smith, A. 2001. *An Inquiry into the Nature and Causes of the Wealth of Nations*. London: Electric Book.

Spring, B. 2007. “Evidence-Based Practice in Clinical Psychology: What It Is, Why It Matters; What You Need to Know.” *Journal of Clinical Psychology* 63 (7): 611–631. doi:10.1002/jclp.20373.

Staddon, P. 2013. *Mental Health Service Users in Research: Critical Sociological Perspectives*. Bristol: The Policy Press.

Staley, K., T. Kabir, and G. Szmukler. 2013. “Service Users as Collaborators in Mental Health Research: Less Stick, More Carrot.” *Psychological Medicine* 43 (6): 1121–1125. doi:10.1017/S0033291712001663.

Stone, E., and M. Priestley. 1996. “Parasites, Pawns and Partners: Disability Research and the Role of Non-Disabled Researchers.” *The British Journal of Sociology* 47 (4): 699–716. doi:10.2307/591081.

Svenaeus, F. 2000. *The Hermeneutics of Medicine and the Phenomenology of Health: Steps Towards a Philosophy of Medical Practice* (vol. 5). Dordrecht: Kluwer.

Sweeney, A. 2009. *This Is Survivor Research*. Ross-on-Wye: PCCS Books.

Szmukler, G. 2009. “Service Users in Research and a ‘well ordered science.’” *Journal of Mental Health* 18 (2): 87–90.

Taleb, N. N. 2013. *Antifragile: Things that Gain from Disorder*. London: Penguin.

Tangvald-Pedersen, O., and R. Bongaardt. 2011. “Tid og tilhørighet: Opplevelsen av god psykisk helse og dens implikasjoner for godt psykisk helsearbeid. [Time and Belonging: The Experience of Good Mental Health and its Implications for Good Mental Health Work],” *Tidsskrift for psykisk helsearbeid* 8 (2): 100–108.

Todres, L. 2007. *Embodied Enquiry: Phenomenological Touchstones for Research, Psychotherapy and Spirituality*. Basingstoke: Palgrave Macmillan.

Todres, L., K. Galvin, and K. Dahlberg. 2007. “Lifeworld-led Healthcare: Revisiting a Humanising Philosophy that Integrates Emerging Trends.” *Medicine, Health Care and Philosophy* 10 (1): 53–63. doi:10.1007/s11019-006-9012-8.

Todres, L. and I. Holloway, 2004. “Descriptive Phenomenology: Life-World as Evidence.” In *New Qualitative Methodologies in Health and Social Care Research*, edited by F. Rapport, 79–96. London: Routledge.

Wallcraft, J., M. Amering, and B. Schrank, eds. 2009. *Handbook of Service User Involvement in Mental Health Research*. Chichester: Wiley.

Wilson, A., and P. Beresford, eds. 2002. *Madness, Distress and Postmodernity: Putting the Record Straight*. London: Continuum.