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Using participatory and creative methods to facilitate emancipatory research with people facing multiple disadvantage: a role for health and care professionals

Debbie Kramer-Roy*

Occupational Therapy, Brunel University London, Uxbridge, UK

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Participatory and creative research methods are a powerful tool for enabling active engagement in the research process of marginalised people. It can be particularly hard for people living with multiple disadvantage, such as disabled people from ethnic minority backgrounds, to access research projects that are relevant to their lived experience. This article argues that creative and participatory methods facilitate the co-researchers' engagement in the research process, which thus becomes more empowering. Exploring the congruence of these methods with their professional ethos, health and care professionals can use their skills to develop them further. Both theory and practice examples are presented.

Keywords: participatory research; creative methods; ethnicity; multiple disadvantage; health and care professions; occupational therapy

Points of interest

- People who face disadvantage for more than one reason – in this case due to disability and ethnicity – tend to find it more difficult to take part in research activities.
- Their views and experiences are therefore not as often heard and addressed.
- Practical and creative research methods can make it easier for them to express themselves and to take more control of the research process.
- Using the example of an occupational therapy researcher using participatory action research, health and care professionals are encouraged to consider how these research methods match their professional skills so that their research and professional practice can influence each other positively.

Introduction

Participatory and creative research methods are a powerful tool for enabling the active engagement in the research process of marginalised people. It can be particularly difficult for people living with multiple disadvantage, such as disabled people

*Email: Debora.Kramer-Roy@brunel.ac.uk

from ethnic minority backgrounds, to have access to research projects that are relevant to their lived experience, and to feel empowered to actively contribute to these.

This article will argue that health and care professionals benefit from reflecting on how these research methods may be congruent with their profession so they can use them to enhance their profession's emancipatory potential as well as using their profession's strengths to support the research process.

The author is an occupational therapist and this discussion is based on her research experience; in particular, a participatory action research (PAR) project that sought to explore the support needs of Pakistani families with disabled children living in the United Kingdom. The full methodology and findings from this PhD study have been reported on elsewhere (Kramer-Roy 2012, 2010) and this article will focus on how the creative and participatory methods used contributed to the co-researchers' engagement in the research process and how they perceived this affected them.

More recently, hands-on workshops for occupational therapists confirmed the closeness-of-fit between this research methodology and the ethos of, and contemporary developments in, the profession of occupational therapy.

The first part of this article will briefly describe the decisions made by the author regarding the chosen research methods. To this end, a number of concepts stemming from previous experience and theory will be presented. These include: the importance of recognising the complexities of living with multiple types of marginalisation; the need for emancipatory disability research (EDR), especially when working with people who face multiple types of marginalisation; the way PAR can meet EDR's criteria; contemporary developments in, and definitions of, occupational therapy and occupational science; and the congruence between occupational therapy and PAR.

Following this, examples will be presented of actual creative and participatory methods and activities used, including how they were designed or chosen and how they facilitated individual reflection, sharing, planning for action, the construction of rich data and the reporting of findings.

The following section will demonstrate the emancipatory potential of the methods employed by researchers from any professional background. It argues that making the congruence between their profession and these methods explicit has the potential to enhance the emancipatory role of their profession as well as enabling them to use their professional skills to carry out the research well. The argument will be illustrated by applying this to how occupational therapists can implement contemporary approaches within their profession and contribute to meaningful research outcomes when working with marginalised populations.

Finally, the benefits of using creative and participatory methods with people facing complex marginalisation will be summarised, leading to implications for future research practice.

Living with multiple forms of marginalisation

More than two decades ago Stuart (1992) drew attention to the 'simultaneous oppression' that black disabled people faced in society; an oppression, he argued, that separates them from all other groups, including white disabled people and able-bodied black people. Stuart argued that this does not simply constitute 'double disadvantage' – one related to ethnicity and one related to disability – but that the

interplay between the two types of oppression compound each other to create a unique and complex experience of marginalisation, consisting of issues such as limited individuality, resource discrimination and isolation within the black community.

While a number of researchers appear to have taken Stuart's recommendation to construct 'a separate and distinct identity for black disabled people' (1992, 187) to heart, the number and range of studies remains limited and outside the central focus of disability studies.

Heer, Rose, and Larkin (2012) emphasise the limited research into cultural factors influencing the experiences of families caring for a disabled person. They present an experiential–contextual framework of disability to help visualise and understand how the 'minority experience' interacts with services which are still largely based in the medical model, on the one hand, and the range of barriers encountered in society based on negative attitudes to disability and the physical environment, as explained by the social model, on the other. Heer, Rose, and Larkin (2012) point out that neither the social model nor the medical model on its own can capture the lived experience of any disabled person, but particularly those from minority populations. For example, the medical model is based on western conceptions which do not tend to correspond with traditional interpretations of disability more common in South Asian communities. Similarly, barriers based on language, institutional racism and stigma within ethnic minority communities can be helpfully conceptualised from a social model perspective, but this is not commonly done within the Disability Studies literature.

Taylor-Ritzler et al. (2008) surveyed a large number of researchers (56 individuals and one group of 23) to identify the challenges and opportunities of conducting disability research with people from diverse ethnic groups in the USA, where this appears to be more common, or more commonly reported on, than in Europe. Key recommendations included forming partnerships with relevant community organisations, ensuring the research team includes disabled members from the ethnic group studied, and using participatory research methods that enable the researchers to share power with the participants at all stages of the research.

Richardson and Laird (2013) emphasised the need for the involvement of carers of disabled people from minority ethnic backgrounds. The findings from their interviews and focus groups exploring their understanding of and willingness to engage in research showed that carers are interested in participating if it leads to a practical beneficial outcome for themselves and those they look after. In addition, key barriers need to be addressed, including translation, gender sensitivity, flexibility in terms of timing, and practical help with caring for the person they looked after to free them up to participate. In other words, the recognition of the unique insight carers have to offer around informal care in minority ethnic contexts needs to be made concrete by overcoming the practical barriers to participation.

Among studies that have been undertaken with disabled people from ethnic minority backgrounds in the United Kingdom, a relatively large number of studies has drawn attention to the lived experience of disabled people from South Asian backgrounds. This is perhaps not surprising as over one-half of the immigrant population (7.5% out of the total 14.9%) in the United Kingdom is of South Asian origin (Office for National Statistics 2011). A picture of complex disadvantage emerges for some of the specific groups within this population; for example, the Pakistani community as described in the study presented in this article.

Pakistani families with disabled children

Compared with the overall population of the United Kingdom, the Pakistani community faces higher levels of poverty and unemployment, poorer housing (Nandi and Platt 2010), prejudice based on both racism and Islamophobia, and a lack of faith/culture-appropriate provision of social and leisure activities (Khan 2006). Pakistanis also have a higher incidence of self-reported ill-health, as compared with the British population (Equality and Human Rights Commission 2010). Limited English proficiency, particularly of women and of those living in areas with a large Pakistani community, also impacts on the ability to participate in society and access services (Modood 1997).

Furthermore, studies suggest a higher prevalence of childhood disability in the Pakistani community (Devereux et al. 2004; Morton et al. 2002). Although genetic causes, compounded by consanguinity, have been suggested as a factor in this increased incidence (Devereux et al. 2004), the causes are not fully understood and genetics only affect a small proportion of disabled children. Poverty and its associated disadvantaged position are likely to have a more significant effect (Reith 2001). The families of these Pakistani disabled children face the additional challenges of the high cost of raising disabled children, are less likely to receive benefits at the appropriate rates, and face more difficulty in accessing health and social care (Beresford 1995).

Although negative attitudes towards disability exist throughout society, some specific attitudes are seen in the Pakistani community, such as blaming the mother for the child's disability, a belief in disability as God's punishment and the subsequent lower levels of support received from the extended family and the community. These attitudes cause high levels of distress in the primary carers (usually the mothers) of disabled children (Bywaters et al. 2003; Hatton et al. 2004).

Key findings regarding the support needs of the families that participated in the current author's research included the need for recognition of the importance of faith in accepting the disabled child and dealing with negative community attitudes; the significant impact of (the lack of) belongingness on the well-being of the disabled child and their mother; the fundamental importance for professionals to build up a supportive relationship with the parents as persons in their own right; and the need for the social model of disability to be more explicit about the influence of religion and culture on the lived experience of disabled people from all backgrounds. These findings have been reported on in detail elsewhere (Kramer-Roy 2010, 2012).

The case for emancipatory disability research

In view of the complexity of the situation and the realisation that earlier quantitative and qualitative research had described rather than addressed the barriers faced by these families, the author looked for an alternative research paradigm. The critical or critical-emancipatory approach has been gaining in recognition, and its underlying ontology is that researchers need to take account of historical, social and political influences on human thought and action, and that social structures have historically served to oppress certain groups in society. In view of this position, critical approaches have emancipatory goals and seek to bring empowerment to these oppressed groups by exposing inequalities and giving voice, ultimately leading to positive social change (Henn, Weinstein, and Foard 2006).

EDR is clearly congruent with this alternative research paradigm. Oliver (1992) pointed out that much disability research over the preceding century had been experienced by participants – that is, disabled people – as a violation of their experience, as irrelevant to their needs and failing to improve their circumstances. Stone and Priestley (1996) added that the core of the problem was that disability research tended to take place ‘within an oppressive theoretical paradigm and within an oppressive set of social relations’ between the researcher and the participants, preventing the voice of the latter to be heard.

A decade later, Barnes (2002) summarised the key characteristics of EDR as follows:

- the control over all aspects of the research process should lie with the participants;
- the researcher must be accountable to the disabled community;
- the research should adhere to the social model of disability;
- the need for and validity of the concept of ‘objectivity’ (as demanded in the dominant research paradigms) should be questioned;
- any method may be used to achieve the research aims as long as the previous criteria are met (although qualitative methods are more commonly used);
- personal, lived experiences of disabled people may be a focus (if needed) as long as these are couched firmly within an environmental and cultural context;
- the research should have a meaningful practical outcome for disabled people.

In summary, Barnes states that ‘by definition, EDR should be judged mainly by its ability to empower disabled people through the research process’ (2002).

Compared with traditional research, research of this nature requires a radically different relationship between the researcher and their participants, who become co-researchers. This can be difficult to attain due to the participants’ marginalised status, and requires the researcher to be open and self-aware about their own values, priorities and interpretation of findings (Barton 2005).

The choice of participatory action research to achieve emancipatory disability research aims

When considering how to achieve the aims of EDR, the researcher looked for a method that would build on her professional skills, experience and ethos. PAR appeared particularly suitable, but first its aims and principles needed to be compared with those of EDR.

The basic method of action research is a ‘democratic process concerned with developing practical knowledge in the pursuit of worthwhile human purposes, grounded in a participatory worldview’ (Reason and Bradbury 2006, 1). The process involves a spiral of cycles, each of which consists of: planning; action; observation of the impact of the action; and evaluation of that action and its impact. The aim is to bring together discourse and practice through constructive (planning and acting) and re-constructive (observing and reflecting) processes, so that improvements in practice and understanding can be made systematically, responsively and collectively (Kemmis, McTaggart, and Retallick 2004).

More specifically, PAR is a form of action research that is firmly grounded in the critical-emancipatory paradigm. It is defined as an emancipatory practice aimed at

helping an oppressed group to identify and act on social policies and practices that keep unequal power relations in place (Herr and Anderson 2005). The lived experience and knowledge of the participants – identified as an oppressed group – are directly valued and central to the process, which seeks to be empowering and to produce knowledge and action that are directly useful for them (Reason 1994).

The ‘action turn’ and ‘ways of knowing’

Reason and Torbert (2001) offer an epistemological basis for action research within the critical-emancipatory paradigm. They point out that the debate about positivist and interpretive research methods is concerned with the latter taking a ‘linguistic turn’ away from traditional quantitative research. In the linguistic turn, reality is viewed as a human construction based on language, and qualitative methods are used to portray these constructions or even deconstruct taken-for-granted realities. Action research requires a further ‘turn’, described as the ‘action turn’ toward ‘studying ourselves in action in relation to others’ (2001, 2). This turn complements the linguistic turn and places ‘primacy on practical knowledge as the consummation of the research endeavour’ (2001). Reason and Torbert go on to identify four characteristics of action research (2001, 5–10): the purpose of enquiry is to forge a direct link between intellectual knowledge and moment-to-moment personal and social action; human knowing is participative, growing from collaboration with others; the action-based enquiry aims to create a better state or reality; and all knowing is based in ‘experiential knowing’ (i.e. sensing, feeling, thinking and attending to the world). Heron and Reason (1997) identified three further ways of knowing in addition to experiential knowing, which they identified as the most fundamental form of knowing. These three ways are: ‘presentational knowing’ or the intuitive grasp of the significance of how we experience and view the world, expressed in graphic, plastic, musical, vocal or verbal ways; ‘propositional knowing’ or knowing in conceptual terms that something is the case, expressed in statements and theories through language; and ‘practical knowing’ or knowing how to do something, demonstrated in skill or competence. Practical knowing fulfils the three prior forms of knowing, building on and synthesising them and bringing them to fruition. This article puts the value of presentational knowing into focus by demonstrating how inviting participants to use creative methods of expression leads to the development of all four ways of knowing described.

Finally, for PAR to be able to be transformative and emancipatory it is essential to ensure that the nature and level of participation is authentic, because being ‘involved’ in research – including PAR – does not automatically lead to emancipation. Unless the researcher consciously and conscientiously seeks to facilitate the co-researchers’ active participation and control over the research processes, PAR can be as oppressive as any other approach to research. The equal and collaborative relationship between all involved is instrumental in achieving the emancipatory goals of PAR (see Cornwall 1996).

Congruence of emancipatory approaches and professional roles

Health and care professionals may benefit from choosing research methods that are congruent to one’s professional ethos and approaches. Examples of this are readily found in social work research literature. For example, D’Cruz and Jones (2004, 2)

suggest that ‘social work research should be another social work method or approach, in addition to the more well-known case, group and community work that are seen as “traditional” or, for some people, “real” social work’. In line with this view, Stevenson (2010) reports on her research with young adults with Down syndrome, arguing that the development of a rights-based emancipatory methodology was an important aspect of her work. This involved the participants conducting interviews, presenting at conferences and becoming paid trainers in Down syndrome and disability issues.

Similarly within the profession of nursing, emancipatory research has been used to benefit nursing professionals as well as clients. Rose and Glass (2008) point out that emancipatory research in contemporary nursing practice has the potential to raise nurses’ awareness of and to reduce their marginalised and oppressed positions, thus creating opportunities for the advancement of professional nursing practice. Their study focused on the nursing role in palliative care, using story-telling as one of the methods and finding that participants’ improved position enabled them to provide enhanced emotional support to their clients. Irwin (2006) discusses the challenges and opportunities of using emancipatory approaches with children, giving examples of contextual factors that impact on children’s health, such as removing restrictions on parent visiting on children’s wards and children co-designing after-school care to enhance their well-being.

The current author went through a similar reflective process to explore the congruence of emancipatory research, and in particular participatory and creative methods, with her own profession of occupational therapy.

Contemporary developments within occupational therapy and occupational science

The World Federation of Occupational Therapists defines occupational therapy as:

a client-centred health profession concerned with promoting health and wellbeing through occupation. The primary goal of occupational therapy is to enable people to participate in the activities of everyday life ... Occupational therapists work with people who are socially excluded owing to their membership of social or cultural minority groups as well as more traditional client groups. (2012b)

This definition takes occupational therapy back to its roots in ‘moral treatment’ which advocated a more humane treatment of people with mental health problems during the eighteenth and nineteenth centuries in the USA and the United Kingdom, offering opportunities to engage in purposeful occupation (Wilcock 1998). In the wake of World Wars I and II occupational therapy was drawn into more reductionist and impairment-focused health care and rehabilitation, becoming more aligned with the medical model. The struggle to maintain its holistic approach has always continued to an extent, but this was (and often still is) difficult to implement in clinical settings (Chapparo and Ranka 2005). However, a new discipline of ‘occupational science’ started to emerge in the 1970s, providing the theoretical basis for the recovery of occupational therapy as a profession that can facilitate individuals to reach their (occupational) potential through addressing social and environmental barriers as well as improving individual abilities. The importance of purposeful occupation in people’s lives is not limited to ‘maintaining’ themselves through productivity (e.g. work and education), self-care and leisure, but also has transformative potential

in terms of the opportunities it creates to choose and engage in occupations for the purposes of directing and changing personal or social aspects of life, with the aim of realising dreams and goals (Townsend 1997). It is through the ability to make choices about what to do and how to do it that people gain more control over their lives and health, and therefore participation in meaningful occupation has an important positive influence on health (Sinclair 2005).

Townsend and Wilcock (2004) identified occupation-related threats to health and well-being in terms of occupational injustice. These threats are described as ‘socially constructed, socially formed conditions that give rise to stressful occupational experiences’ (Townsend and Wilcock 2004, 251), providing a practical focus for emancipatory research as well as occupational therapy interventions. As a result of the growing theory of occupational science, the World Federation of Occupational Therapists (2012a) has issued a position statement on human rights, of which a key principle is that ‘people have the right to participate in a range of occupations that enable them flourish, fulfil their potential and experience satisfaction in a way consistent with their culture and beliefs’. An example of putting this into practice is the ‘Framework to Support Professional Participation in Community Development Projects’ developed by a working group of the European Network of Occupational Therapists in Higher Education, which proposes a collaborative and emancipatory approach to working with marginalised groups and communities (Zinkstok and Schiller, 2013).

The congruence between occupational therapy and participatory action research

Trentham and Cockburn (2005) observed that PAR is consistent with the values of occupational therapy and occupational justice in three ways. Firstly, PAR is a meaningful occupation in itself; that is:

when people ask questions, propose solutions, implement change and disseminate new knowledge they are participating in an occupational form that helps to develop the skills and knowledge necessary to take greater control over their own lives; in doing so, they promote their own health as well as the health of other community members. (Trentham and Cockburn 2005, 446)

Secondly, the approach that PAR takes to working as a team of co-researchers is congruent with the principles of client-centred practice, which is defined as ‘a partnership between the client and the therapist that empowers the client to engage in functional performance and fulfil his or her occupational roles in a variety of environments’ (Sumsion 2000, 308). Thirdly, in both occupational therapy and PAR ‘action’ and ‘collaboration’ are central, whether applied with individuals or groups. The successful outcomes of both processes depend strongly on the therapist or researcher’s openness to learn from their partners, rather than viewing themselves as the ‘expert’. In summary, occupational therapists’ values and skills are very helpful in conducting PAR, and conversely PAR is a very appropriate approach to researching the value and role of occupation in (disabled) people’s lives.

The methods used in the study and their contribution to the emancipatory outcomes

This research project involved all members of six Pakistani families with disabled children living in the United Kingdom in a PAR project that lasted one year. During

the exploratory phase, interviews and activities were carried out in each family's home, after which three action research groups, for mothers, fathers and non-disabled siblings respectively, met for eight sessions each. Meetings for all families together were held to facilitate communication across the groups and within the families, and to involve the participants in evaluation and analysis.

Conducting PAR does not necessarily require the use of creative activities to facilitate reflection and expression, and more often than not talking and discussion are the main modes of communication. However, there were a number of reasons for using creative methods in this project. Firstly, the group included children of a wide range of ages and abilities and using talk only would have been inappropriate and alienating for some. Secondly, despite the researcher's good command of the Urdu language, the sensitive nature of the research topic required a gentle and unrushed approach to each meeting. Symbolism and metaphor is quite prevalent in Pakistani culture and therefore a familiar way to explore ideas. On the other hand, in the Urdu language direct why questions are easily misconstrued as criticism of the *status quo* or the person rather than an invitation to reflect. The following subsections will describe examples of creative activities from the different stages and groups within project. The role of children as active researchers was reported on elsewhere (Kramer-Roy 2011).

The exploratory phase

In addition to individual interviews with each person who was able to communicate verbally, all children were offered the opportunity to draw a picture of themselves doing their favourite activity. In addition to breaking the ice, and giving the researcher a first impression of the child's interests and abilities, it also surprised some of the parents to see their child express their ideas in a recognisable drawing – an early indication that creative methods can enable participants to express themselves clearly.

The second activity of interest at this stage was a disposable camera given to each family to take pictures of their daily lives, encouraging them to allow each family member to take some pictures. An important implication of handing over the camera was that the researcher clearly gave the families full control over the activity. In one family the activity triggered very rich story-telling about their life in the United Kingdom as well as in their Pakistani village. This was facilitated by the fact that this activity produced the first photograph ever in which their son with autism smiled. In another family the daughter with learning disabilities took most pictures and the pleasure and feeling of accomplishment helped her talk about her life animatedly. These parents were also surprised by their daughter's level of ability in this activity. While this was a one-off activity within this project and not a full form of Photovoice, its result is congruent with Povee, Bishop, and Roberts's (2014) findings of using this approach with people with intellectual disabilities.

These early activities demonstrated that the use of a meaningful age-appropriate occupation has the potential to facilitate the inclusion of disabled participants in the research process. This approach was therefore continued during the action research phase.

The women's group

In the first meeting of the women's group the researcher invited them to draw a picture expressing a metaphor representing their disabled child and/or their relationship with him or her. The aim was to give the participants some time to reflect on what to share with the others about their child in a more focused way than asking 'tell us something about your child'. In addition, having something for all to look at whilst she was speaking enabled each woman to feel more comfortable. Very interesting metaphors were drawn; for example, a beautiful but incomplete rainbow lighting up her parents' lives; an open book; an island in the sea; and a bright sun bringing energy as well as deep pain and worry (see Figure 1). One woman had difficulty drawing her metaphor (about the island), but the others instantly supported her in exploring her idea further and she was able to reject the idea that perhaps it was more like a boat as she felt he would never quite be able to 'connect with the mainland' (fitting in with mainstream society) and therefore an island was more appropriate. This activity set the group up well for being open in sharing their ideas, yet claiming and/or sticking to their own insights where appropriate throughout the project.

Another example explored an occupational science perspective on the mothers' lives with their disabled children. To this end the women each shuffled four coloured circles of paper (cut along one radius) representing one of the aspects of occupation as described by Wilcock (2006) – that is, doing, being, becoming and belonging – to form a pie chart showing how prominent each aspect was in their lives. The women readily understood this rather abstract concept, welcoming it as a new perspective on their complex lives, and found the physical activity of shuffling the circles as they reflected very cathartic. One woman realised that she was not allowed to 'belong' in her own right, but within her ethnic and family culture she was expected to 'sacrifice all' for her disabled child and the family as a whole and therefore to always be 'doing'. She realised this did not allow her to even think about what/who she might want to 'become'. However, in a more positive light, she also shared how for her 'being' was rooted in her personal faith that had grown through the difficult first years of her disabled child's life when she had met with much stigma and rejection within her community and when she had gradually realised that this child was not a punishment from God, but rather a gift, or blessing, that brought her closer to God. This activity facilitated the participants to become aware of and express propositional knowledge (see above) directly through an increasing recognition of shared challenges.

The men's group

The men's group was rather reluctant to engage in creative activities, and for the first meeting only one man brought two pictures of his disabled child (one with a happy memory and one with a sad memory) and these too had been selected by his wife last minute. The researcher therefore changed the activity to telling two one-minute stories about their child, one happy and one sad, which they were quite comfortable doing.

Another activity was a worksheet with a line-drawing of a man, with each body part representing certain types of skills or characteristics. For example, the shoulders represented responsibilities that weigh heavily, the hands represented practical skills

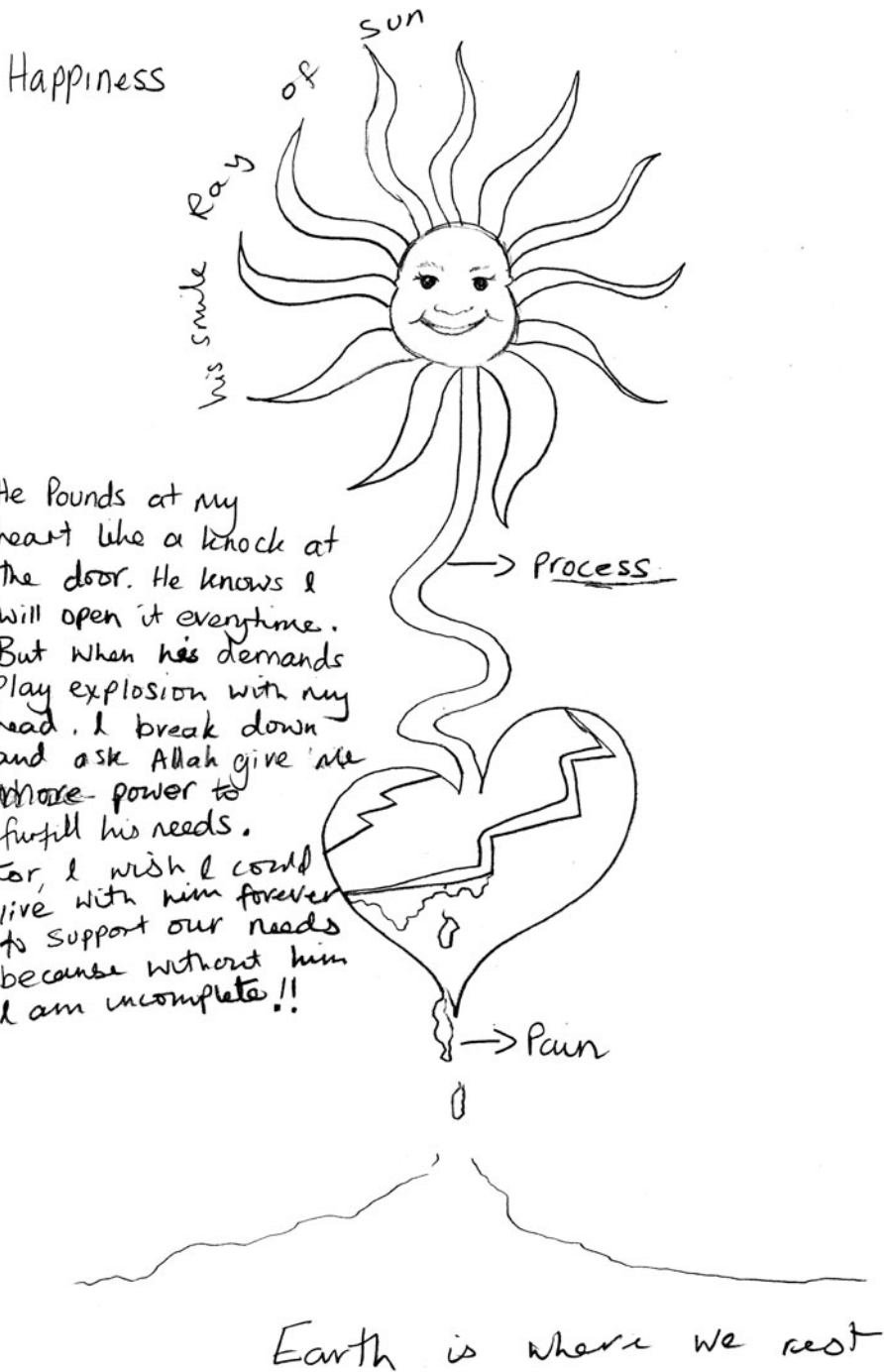


Figure 1. One mother's metaphor representing her relationship with her disabled child.

they were good at and the feet represented steps they could undertake to change their family life for the better (see Figure 2). This activity led to a very open and extended conversation about their role in the family and how they dealt with conflict and anger. This enabled the men to reflect on their father role and to open up to each other.

Before the project a number of people, including Pakistani women and non-Pakistani researchers, had expressed their doubts about Pakistani men engaging in the action research process in a meaningful way as ‘they would never talk about emotions or personal things’. Whilst meeting with them in the local Mosque (a public and neutral venue to meet with a female non-Muslim researcher) had already helped them to feel comfortable, this particular activity very clearly facilitated their openness and commitment to their own action research process, which involved them approaching their Imams to tell them what the Quran teaches about disability. This action helped them profile themselves as the proud father of a disabled child, approaching their religious leaders to request their support for the very first time.

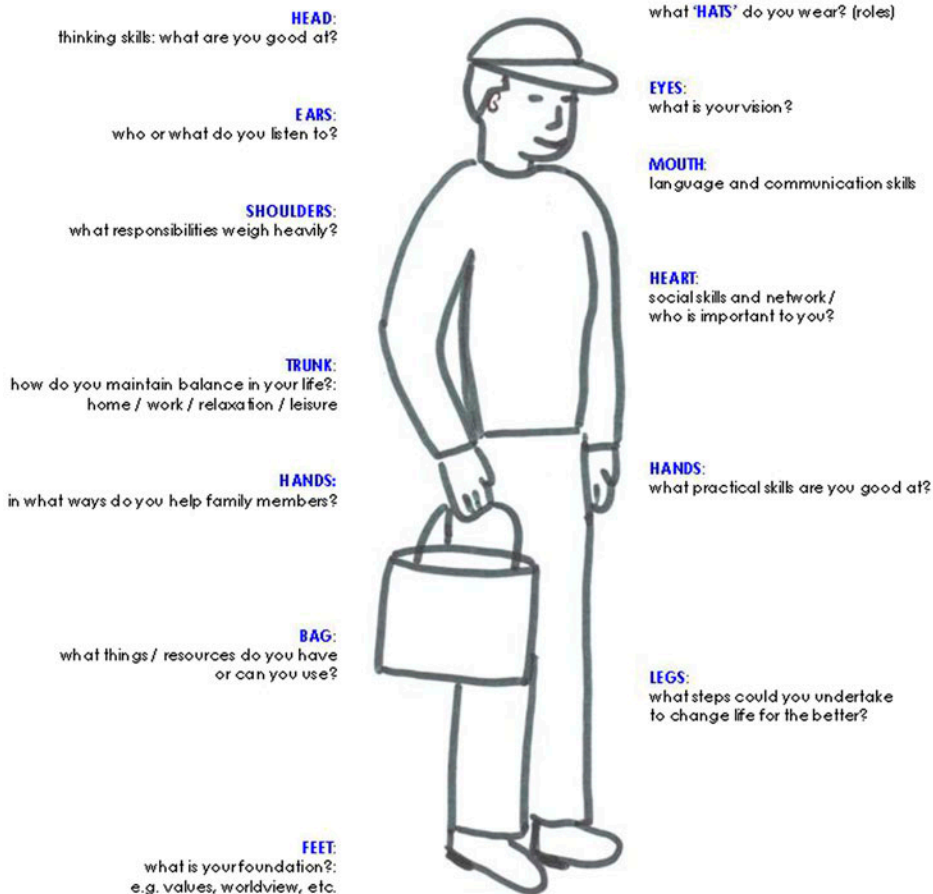


Figure 2. Worksheet developed for use by the men’s group to index views, skills and resources.

The children's group

Perhaps not surprisingly this was the group that most readily and frequently engaged in creative activities, both because at their age they felt freer to 'play' and because they needed a little more facilitation to express their feelings and ideas around disability as they had never been asked or expected to do so before. Consequently the children had been quite reticent during the exploratory phase, expressing only positive and rather superficial views. Therefore the first activity for the 'Kids' club' (as they liked to call it) was to complete a drawing of a sailing boat or butterfly to show things their disabled sibling was good at (on one sail/wing) and enjoyed doing (on the other). This provided a non-threatening way to start talking about their experience of living with a disabled sibling, as well as ideas for activities and food that would (and would not) be a good idea to have during the inclusive Eid Party they were invited to plan for all families together. The children referred back to this early set of activities regularly throughout the project including during the evaluation, when several children stated their pride and excitement at being able and trusted to plan the party.

However, in order to enable the children to acknowledge the more difficult aspects of living with a disabled sibling, a set of activities was then offered combining both positive and negative views. The first was to draw a 'Mr Men and Little Miss' character, first of themselves and then their disabled sibling. A brother and sister drew quite contrasting characters for their brother who has severe autism; that is, 'Mr Feely' because he loved to feel and smell his sister's hair and other things, versus 'Mr Slappy' because he often hit other members of the family. Following this the 'Feelings Cube', with symbols of six feelings (i.e. happy, proud, excited, sad, angry and embarrassed) was used as a dice, inviting the children to tell stories about a time their disabled sibling had felt that way or made them feel that way. This worked well as the children were allowed to 'pass' and thus felt free to choose stories they were comfortable telling, so that every child felt able to tell both positive and negative stories, both of which increased their realisation that they had much in common.

After one teenage boy had shared his idea that it was as if his brother with autism was trapped in the virtual world of a computer game, the children decided that their research aim was to 'understand our disabled brother and the different/virtual world he lives in better, so that we can make him happier'. To move towards that aim, the researcher offered story-telling and writing activities. Stories were read from *Views From Our Shoes* (Meyer 1997), a book of stories written by siblings of disabled children, which helped the children gain confidence that they could do the same. Following this one child spontaneously said she would write a story at home, and in the next meeting each child chose a title and book format to make their own stories.

All participants together

The Eid party the children organised early on in the research process built the children's confidence that they were able to consider their disabled sibling's needs so that they could be fully included in the party. In addition, it showed their parents that the children were able to express their appreciation for their disabled sibling in two ways; firstly, they made an Eid greeting card with a picture based on their

sibling's likes (personal appreciation); and secondly, they ensured there were activities that all disabled children could participate in and foods they enjoyed and were allowed to eat (practical appreciation).

The meeting at the end of the research process was a goodbye party as well as an evaluation event. Mothers made a picture on the theme of a Pakistani carpet, to show what aspect of the project they had enjoyed or gained from most. The children entered an art competition for which they made a picture to show something they had done or learned during the project. The entries were judged by everyone present in two ways. Everyone could write a positive comment on as many feedback sheets as they wished, and in addition everyone was given three stickers with which they could vote for the best three entries. Fathers participated in the activities on the day, one of which invited them to work with the children – a new experience for most – to make a giant 'snakes and ladders' game for which they thought of positive and negative disability-related messages.

A final opportunity for working together arose by co-presenting at the 'Inclusion and Exclusion' conference in 2008 (organised by the Race Equality Foundation). One mother, two fathers and one child co-presented, and in addition the children's group and one other mother produced posters to present there. One father prepared the abstract beforehand and the presentation slides were started by another father and then added to by others (by email). This conference took place just after the project had ended and preparations for it were incorporated into feedback meetings of which the primary purpose was to present the data analysis back to the participants (member checking). The enthusiasm to be part of this presentation and the very positive feedback from the audience was testimony to the fact that the participants took ownership of the findings, were able to verbalise these well, and had gained a significant level of confidence to stand in front of an audience and speak about their difficult life circumstances. This activity facilitated the development of propositional knowing as the participants were actively analysing the findings and thinking through how to convey them to a new audience. I also demonstrated that their gradually taking control and ownership over their research process had eventually resulted in this confident presentation of their experiences to an external audience.

In their evaluation of the project, participants also indicated they had developed 'practical knowing' by implementing change in their family relationships and behaviour; for example, one father stated that he was now more focused on understanding and providing for his disabled son's needs, and a mother observed that her other children played more with her disabled son and that he was therefore happier than before. One of the children also said she now understood what her brother liked and did not like and why he felt left out sometimes, and that she now knew how to give him what he needed.

Exploring the potential of the methodology with other occupational therapists

To disseminate these research process-related findings, the author presented the importance of using participatory and creative methods with marginalised groups in a number of workshops for occupational therapists and students. The combination of linking the principles of this type of research to the contemporary theory and practice of occupational therapy and engaging the participants in group work to produce a creative activity relevant to a marginalised group they had worked with in the past

led to a broad range of products and ideas for both occupational therapy practice and research. The participants reflected on the need to move towards more occupation-based and emancipatory ways of working with their clients or participants, and away from impairment-based individual approaches. There were many examples of how more participatory and creative methods could be used within traditional settings to enhance their clients' or students' experience now and to potentially contribute to change over time. Others reflected on past situations, either successful in terms of the suggested approach or in need of improvement.

Examples of activities designed and carried out by participants at these workshops include: a poster showing how school children could prepare and lead a treasure hunt around the school grounds with various information points to engage their parents actively in encouraging healthier lifestyles for their children; a paper aeroplane with a word-gram, to represent how an occupational therapy school had given flight to the ambitions of a group of young ultra-orthodox Jewish girls who wanted to study occupational therapy but were severely restricted by a number of cultural issues; a paper house filled with affirming messages to be created and used by a client with agoraphobia to help her to leave her house more confidently; using the 'doing, being, becoming, belonging circles' activity with people with cardiac and pulmonary disease to identify occupations they can still participate in; and using circus skills with disadvantaged youth in Bulgaria to build trust and self-efficacy.

These workshops are an example of how researchers can contribute to their professional colleagues' understanding of the advantages of matching their research methods to their professional ethos and skills in order to develop appropriate and effective approaches to research.

Implications for researchers working with disabled people who face additional forms of marginalisation

There are a number of implications from this article.

Firstly, the article points out the need for recognition of the fact that marginalisation due to disability and ethnicity is not just a case of 'double disadvantage', but that it creates a unique and complex experience which therefore needs to be researched and addressed in its own right.

Secondly, PAR – which lends itself very well to the use of more accessible, creative research methods – meets the criteria for EDR very well. Furthermore, the cycles of planning, action, observing and reflection facilitate both the handing over of control over the research process to the co-researchers and the maintenance of a focus on achieving practical outcomes. This makes PAR particularly suitable for service providers seeking to involve carers and service users actively in the research process, especially those who face multiple disadvantage. In addition, the participatory and creative nature of activities can be applied in research as well as in increasing the level of participation and control of service users in the interventions they receive and the services they use.

Thirdly, the close fit between contemporary occupational therapy and PAR means PAR is a particularly suitable approach for occupational therapy research. It also means that occupational therapists are in a good position to take a lead role in developing suitable methods for research with disabled people, including those from ethnic minority backgrounds, to benefit researchers from any professional background. Examples were given of other professionals demonstrating how they

employed emancipatory approaches congruent with their professional ethos and skills.

Conclusion

This article has emphasised the importance of increasing research interest in populations who face additional reasons for marginalisation apart from disability. It has also demonstrated how the use of participatory methods can facilitate their full participation in the research process because it enables them to explore and express the complex issues they face through a combination of non-verbal and verbal methods; the concept of four ways of knowing is very helpful in understanding the research process and the development participants and researchers are enabled to experience through the use of participatory and creative methods.

Whilst this article points out that occupational therapists are particularly well equipped with their professional knowledge and skills to initiate this type of research, researchers from other professional backgrounds will be able to identify how it overlaps and interacts with the theory and practice they are experienced in. The most fundamental issue is that participatory and creative methods can contribute greatly to developing an equal and collaborative relationship between the lead-researcher and the co-researchers, which is particularly challenging when the co-researchers are facing multiple disadvantage. These methods can therefore enhance the outcomes of EDR.

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