Emancipatory occupational therapy research and practice with marginalised ethnic minority clients.

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Overview

- Defining citizenship
- Pakistani families with disabled children
- Participatory Action Research
- Overview of methods and findings
- Thinking about your own opportunities
- Sharing stories
- Redefining OT’s role with ethnic minority (client) groups
I’m part of project on flight
I’m supposed to attain a great height.

But unfortunately I got stuck in a tree
So it looks like I am here for the night
Participatory Citizenship

- “Participation in civil society, community and/or political life, characterised by mutual respect and non-violence, and in accordance with human rights and democracy”.
- This is a RIGHT and a RESPONSIBILITY for each citizen.

Definitions on this and the next slide are taken from ENOTHE Citizenship Working Group’s document “Citizenship: exploring the contribution of Occupational Therapy”.
Participatory citizenship is expressed through the experience of belonging, by the doing of everyday occupations, by the sharing of activities/occupations with others, and by the contribution of occupations to the collective well-being and welfare of society.

Restriction of participation in occupations is also a restriction of citizenship.
Restrictions in Participatory Citizenship

The Pakistani community is one of the most disadvantaged in the UK:
- Higher levels of poverty and unemployment
- Poorer housing
- Higher incidence of self-reported ill-health and disability
- High rate of limited English proficiency
- Prejudice based on both racism and Islamophobia
- A lack of faith/culturally appropriate provision of social and leisure activities

Added challenge of childhood disability

- A higher prevalence of childhood disability in the Pakistani community
- High cost of raising a disabled child
- Less likely to receive disability benefits
- More difficulty in accessing health and social care

Specific issues in the Pakistani community:
- Blaming the mother for the child's disability
- A belief in disability as God’s punishment
- Lower levels of support received in the extended family and the community
- High levels of distress in disabled children and their primary carers (mostly mothers).

Are these families able to access the following? (see slide 4)

- the experience of belonging,
- the doing of everyday occupations,
- the sharing of activities/occupations with others
- the contribution of occupations to the collective well-being and welfare of society
Choice of research method

Participatory Action Research (PAR)

- 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 – i.e. it promotes citizenship!

- The lived experience and knowledge of the participants are directly valued and central to the process. PAR aims to produce knowledge and action that are directly useful to the participants and to empower them through the process of constructing and using their own knowledge

- The bundling of practical and academic knowledge in order to improve the situation

Congruence of PAR and OT (1)

- PAR is “consistent with the values of occupational therapy and occupational justice” and a particularly suitable choice of research approach.

- PAR is an occupational form that gives the participants an opportunity “to develop the skills and knowledge necessary to take greater control over their own lives; in so doing, they promote their own health as well as the health of other community members”

- Participants develop valuable life-skills, such as becoming more aware of their own behaviour, expressing views and opinions, working as a team, planning and decision-making.

Reference: Trentham and Cockburn (2005)
Congruence of PAR and OT (2)

- Working as a team of co-researchers is very congruent with the principles of client-centred practice:
  - respect for the person’s skills and insights
  - taking responsibility for one’s own choices
  - enabling participation
  - flexibility and
  - keeping in view the links between person, environment and occupation

The process of PAR

- A spiral of cycles
  - planning
  - action
  - observation of the impact of the action
  - Reflection on that action and its impact.

- A dynamic process

- Exploratory phase to identify issues first

The use of PAR in this study

- Exploratory phase in each family’s home – individual interviews, drawing, photography; observation of family interactions

- Followed by separate groups for men, women and children, in which they carried out their own action research cycles

- Meetings/parties to bring all families and the three group processes together
Key issues discussed in each group

- **Men:**
  - Noted negative attitudes in the Pakistani community
  - Asked Imams and scholars about Islamic beliefs and myths about disability

- **Women:**
  - Found the initial group meetings very supportive
  - Tried to set up a support group to include more Pakistani mothers

- **Children:**
  - Wanted “to understand our disabled siblings better so that we can help them to be happier”
Research activities

- Many different hands-on activities were used to facilitate reflection, thinking and discussion, leading on to planning and action.

- All family members took part, at home as well as in the groups.

- A few examples follow
Disabled children – photography

- Each family was given to take pictures of their daily lives.
- Afia (9) took a self-portrait with her favourite doll.
- Photographs elicited much animated story telling in several families.
Women - Being, Doing, Becoming, Belonging

- Four paper circles cut along the radius, each colour represents the importance of one concept:
- This mother showed how little she felt she was allowed to ‘belong’, or think about ‘becoming’ – she felt she was always ‘doing’ and that that was expected of her.
- Sense of ‘being’ was very important to her and had been influenced by her strengthened faith and resilience through raising her disabled child.

... and her child

- Contrast between the child’s belongingness within the immediate family and the lack of acceptance in the extended family and community, including the Mosque
  - an ongoing source of frustration and grief,
  - has significantly reduced the social contacts and support the family has
- For him to be allowed to ‘belong’ was paramount for his well-being
- He had little idea about what he might ‘become’ in the near or distant future.
HEAD:
thinking skills: what are you good at?

EARS:
who or what do you listen to?

SHOULDERS:
what responsibilities weigh heavily?

TRUNK:
how do you maintain balance in your life?:
home / work / relaxation / leisure

HANDS:
in what ways do you help family members?

BAG:
what things / resources do you have
or can you use?

FEET:
what is your foundation?:
e.g. values, worldview, etc.

what ‘HATS’ do you wear? (roles)

EYES:
what is your vision?

MOUTH:
language and communication skills

HEART:
social skills and network /
who is important to you?

HANDS:
what practical skills are you good at?

LEGS:
what steps could you undertake
to change life for the better?
Initially children were superficial and ‘too’ positive

Feelings cube had 3 positive and 3 negative feelings. After rolling the dice the child told a story about when they felt that way

(Gibbs et al, 2002, p72)
Story book

Possible titles offered:

- “What I would like my friends to understand about my brother”
- “Flip-sides: 3 things I both do and don’t like about my brother”
- “It’s not fair”
- “Once upon a time my brother…..”
- “Why?”
Time for your own ideas!

- Identify a ethnic minority client or population group in your context

- What are the restrictions in their “participatory citizenship”?

- How do you / could you facilitate this group’s participation in daily life / community / society?

- Present your ideas as a picture, poem, role play or any other creative / visual form.
Redefining OT?

- How do we conceptualise the role of OT in facilitating participatory citizenship?

- Keep in mind
  - Occupational science / justice
  - Occupational therapy practice
Some feedback from the participants

Noor (mother):
You got us a lot of things to think about and do – we didn’t only use it for your project, we could use ideas generally

Sadaf (mother):
My other children play more with Imran, like help him draw or play with the ball – he is happier than before.

Imtiaz (father):
The project clicked on my mind and I am still doing, and getting information

Gulzar (father):
I am more focused on understanding (him) and providing his needs

Aliya (13):
The purpose of the project was “for Pakistani siblings to communicate and not feel alone”

Inam (9):
We played, we organised the party and had fun
Some of my own reflections:

- Creative and non-verbal expression was particularly useful for those whose English was poor or who were least used to expressing their views verbally, as it made them aware of their often tacit views and feelings and of their ability to contribute to the group process.

- This PAR study has provided rich and detailed insight (*knowledge of the information kind*) into the support needs of Pakistani families with disabled children, the more fundamental insight (*knowledge of the wisdom kind*) has been around how we go about generating knowledge that is both valid and vital to the well-being of individuals, communities, and for larger-scale social change. Action research challenges the claims of a positivistic view of knowledge which holds that in order to be credible, research must remain objective and value free.

(Brydon-Miller et al, 2003)
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The full thesis is available on-line: http://bura.brunel.ac.uk/handle/2438/4377

References

- Equal Opportunities Commission (2004). Women and Men in Britain; Ethnic Minority


