Participatory Mental Health Research with Young People: Experiences and Lessons Learned

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Presentation purpose

- To present a conceptual framework for collaborating with young people with mental health needs in interpretive research
- To describe experiences working with young people with mental health needs in research
- To describe co-researchers’ roles and activities, and
- To examine challenges and effective strategies for collaborative research with young people.
Rationale for youth participation in research

Youth participation is believed to result in:

- Increased relevance of questions to the needs and concerns of youth and families;
- Improved cultural appropriateness of methods;
- Increased quality of data;
- More accurate interpretations and increased validity of findings;
- Wider dissemination of findings;
- More effective utilization of findings to guide programmatic improvements; and
- Empowerment of participants

(Carey, 2011; Smith, Monaghan, & Broad, 2002; Turnbull, Friesen, & Ramirez, 1998).
Participatory research: Pros and cautions

- Participatory research can claim ethical high ground by putting research participants at the center of study and sharing control over the process (Smith, Monaghan, & Broad, 2002)
- Carey (2010) encourages skepticism regarding service user participation in research and recommends caution about claims of benefits and unrealistic descriptions of emancipatory outcomes.
Ladder of Youth Participation

Youth-initiated, shared decisions with adults
Youth-initiated and directed
Adult-initiated, shared decisions with youth
Consulted and informed
Assigned but informed

Tokenism
Decoration
Manipulation

Adaptation of continuum of involvement

(Turnbull, Friesen, & Ramirez, 1998)

Level 1: Youth as Research Participants

Level 2: Youth as Advisory Board Members

Level 3: Youth as Occasional Reviewers and Consultants

Level 4: Researchers as Leaders and Youth as Ongoing Advisers

Level 5: Researchers and Youth as Co-researchers

Level 6: Youth as Leaders & Researchers

Typically does reflect PAR

Typically does not reflect PAR

Youth have greater decision making
Youth roles and influence in research and evaluations (based on Cousins & Whitmore, 1998)

- More involvement
  - Designing the study, analyzing information
  - Sitting on advisory board

- Less involvement
  - Reading draft reports
  - Less influence

- More influence
  - Interviewing study participants
  - More influence
Research methods

• Formation of Portland and Seattle research teams.
• Recruitment, hiring, and training of three youth (and two family member) research assistants.
• Recruitment of youth and young adults to participate in focus groups through contacts with family support organizations, community-based agencies, colleges, and personal contacts.
Recruitment of youth and family co-researchers

- Prepared job descriptions and recruitment materials
- Criteria: Young person aged 18-24 with history of mental health difficulties or experience of using mental health services and interest in MH research
  - Available for part-time employment
- Recruitment: Advertized in college publications and via web-site
- Hiring: Two female students in early 20s who met these criteria and one “mentee”.
Training of youth co-researchers

- Developed a training handbook that included:
  - A copy of the grant proposal that had been funded.
  - Copies of articles and chapters on qualitative research methods, including data collection and analysis.
  - Guidelines for ethical practices in research, including confidentiality, informed consent, how to respond if a research participant becomes distressed, etc.
  - A guide to conducting focus groups which had been selected by our advisory groups as the data collection strategy.
Training youth co-researchers

- The project leaders conducted face-to-face training sessions using the handbook as a guide
- Several sessions of role play to practice conducting focus groups
- Discussion of ethical dilemmas in research and how to address them
- Training in the use of data analysis software and basic SPSS training.
Data collection

• Twelve 90-minute focus groups with 59 youth and young adults (14-24) with mental health difficulties with questions focused on community integration.

• Youth and family co-researchers took lead roles in moderating groups, with Co-PIs and project manager assisting as note-takers, equipment monitors, etc.
Data collection & analysis

• Participants also completed a pre-focus group questionnaire and received $30; quantitative data were entered into SPSS for analysis.

• Focus group discussions were audio-taped, transcribed, and entered into qualitative analysis software.

• All team members participated in data analysis.

• After we established acceptable agreement on a portion of the transcripts, transcripts were coded independently by team members to identify common and unique experiences and perspectives of participants.
Roles/activities of youth co-researchers

• Advisory group consulted at the beginning and periodically throughout the project:
  – Gave feedback on methods, questions, analysis, findings, and dissemination strategies

• Youth co-researchers:
  – Assisted in wording questions.
  – Recruited focus group participants.
  – Mailed or e-mailed information about the project and informed consent materials.
Roles/activities of youth co-researchers

- Facilitated focus groups.
- Debriefed with PIs and project manager after focus groups.
- Transcribed some audio-tapes.
- Entered demographic data in SPSS.
- Participated in qualitative data analysis.
- Reviewed written report drafts and gave feedback.
- Co-presented findings at conferences.
Challenges of participatory approach

- Took more time – for training and debriefing
- Needed to take time to examine and resolve ethical dilemmas that came up
- Need for ongoing discussions of bracketing
- Youth co-researchers had other priorities at times
- One youth co-researcher struggled with her role and issues the work brought up for her – eventually quit
- Sometimes youth researchers expressed impatience at the slow pace of research and preparation of reports – wanted to use preliminary findings in advocacy for change
- Continuing concerns: Are we being participatory enough? Might we have stifled ideas, potential criticism?
Benefits of youth participation

• More relevant questions and probes
• Co-researchers created a relaxed, yet curious environment for participants to share experiences and views – we believe that participants were more comfortable and more forthcoming
• Increased participation in study – youth modeled skills for participants by setting focus group group rules
• Youth co-researchers were quick learners and very computer savvy.
Benefits of youth participation

• In data analysis, co-researchers noticed ideas that Co-PIs would have missed.
• Co-researchers learned new skills: greater comfort with research, developed skills in data collection and analysis, practiced public presentation skills at conferences
• Youth co-researchers continued their education (and one went to graduate school in public administration)
• PIs learned more about youth mental health experience and skills in collaboration
• More culturally grounded findings and overall, a better quality study.
Personal Reflection

- Impressed with the skills of youth co-researchers
- Strived to facilitate an egalitarian team with limited success: how to manage privilege and share power?
- Sometimes I felt impatience at time needed to explain research processes
- Sadness at the departure of a dissatisfied team member: What I could have done differently?
- Regret that we did not have $ or time to involve youth in later dissemination and advocacy
- Overall, more convinced than ever of the importance of participatory research with young people – more recent projects.
Recommendations for participatory studies

• Be clear and transparent about power dynamics in the research team, where the project leaders must:
  – Meet deadlines,
  – Be accountable to the funders,
  – Be responsible for achieving “academic” goals – publication!

• Continually examine and share power – in our study, everyone’s ideas were welcomed and taken seriously and most decisions were negotiated.

• Get to know each other as people – we needed more self-disclosure than with other colleagues

• Be patient

• Embrace the roles of teacher and learner throughout all stages – welcome ideas, questions, and challenges.
Revisiting Carey’s 2010 cautions

• Recognize limitations in empowerment
• Need to be explicit about action agenda or the lack thereof
• Need caution about claims of benefits of young people’s participation
• Need care to avoid “a different – and probably more sophisticated – type of exploitation” (p. 240).
References

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