Photovoice - an innovative research and intervention tool to promote personal agency and personal development

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Unfolding the experience of user participation in mental health services
“Nothing About Us Without Us”

Billy 002: Food stock at home.
User Participation in Mental Health Services

- What do the existing evidence on user participation (UP) in mental health services (MHS) tell us?
  - *Positive outcomes of empowerment* (Tambuyzer, Pieters, & Van Aidenhove, 2011) and *overall recovery* (Omeni et al., 2014).

- *Barriers to UP* (Borg, Karlsson, & Kim, 2009; McDaid, 2009; Patterson et al., 2009; Storm & Davidson, 2010).

- *Increasing desire to seek for a great influence in decision-making among service users* (Beckeret al., 2014).
A Collaborative Study on User Participation in Mental Health Services: East Meets West (2016)

Constructivist Grounded Theory (Charmaz, 2000 & 2006)

Academic researchers

Design

Data Collection

Data Analysis

Focus Groups
15 Participants

Individual in-depth interview
23 Participants

Photovoice
3 Participants

People with lived experience
Photovoice is a community-based participatory research (CBPR) strategy that:

- Provides people with cameras to photograph their perceived health and work realities (Wang, 1999).
- Allows professionals to capture the narratives and voices of marginalized groups (Mizock et al., 2014).
- Generates data that may not be easily accessed through traditional research methods (Cabassa, Nicasio, & Whitley, 2013).
Photovoice in Mental Health Research

- Participatory and action research is minimally implemented in Hong Kong’s social welfare settings (Shek, Lam, & Tsoi, 2004).

- The photovoice method has been applied to understand the experience of mental illness and recovery:
  - Cabassa et al. (2013)
  - Clements (2012)
  - Fleming et al. (2009)
  - Mizock et al. (2014)
  - Thompson et al. (2008)

- It has not been used to understand UP in MHS.
What are the aims of the study?

- To explore the experience of UP in mental health service in a non-Western culture through service users’ perspective.
- To examines the effects of photovoice as a community-based participatory research.
Who are the members of the researcher team?

- **Members of the community**: Mr. KS Chan, Mr. Patrick Cheng, Ms. KM Kwan & Mr. CO Lee

- **Academic researchers**: Prof. Samson Tse, Prof. Larry Davidson, Dr. Jessica Tang
How we designed the photovoice study?

- Adapted the nine-step strategy developed by Wang (2006).

- The collaborative research team worked out issues around:
  - Rationale of using photography
  - Focus of the topic
  - Choice and autonomy in participation
  - Informed consent and confidentiality
  - Literacy in using the digital camera
  - Pilot of the procedures
How we generated the data?

1st Meeting
- Introduction of the study
- Obtain consent, conduct basic training on photography, give trial photo taking assignment

2nd & 3rd Meeting
- Co-define the meaning of “user participation in mental health service”, group sharing of trial photos.
- Group sharing of photos taken in response to the meanings deliberated.

4th Meeting
- Individual sharing of photos taken in the field for attaining deeper narrative and discussion of the analysis with more time and space.
How we generated the data?

5th Meeting

- Group sharing of new photos taken on barriers and enables to user participation.

6th Meeting

- Evaluate the experience of the photovoice study in group.
- Discuss possible strategies to disseminate the findings.
How we analyzed the data?

18 photos were generated by the three participants.

- Thematic analysis conducted by the presenter.
- Reviewed by and discussed with members of the research team.
- Compared with the written narratives produced by the research participants.
- Agreed between the researchers and participants.

Tang, Tse & Davidson, 2016)
### What have we found?

**Characteristics of photovoice participants:**

<table>
<thead>
<tr>
<th></th>
<th>Winnie</th>
<th>Billy</th>
<th>Andrew</th>
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<tbody>
<tr>
<td><strong>Demographics</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Sex</td>
<td>Female</td>
<td>Male</td>
<td>Male</td>
</tr>
<tr>
<td>• Age</td>
<td>49</td>
<td>23</td>
<td>25</td>
</tr>
<tr>
<td>• Education level</td>
<td>Secondary school</td>
<td>Tertiary institute</td>
<td>Secondary school</td>
</tr>
<tr>
<td><strong>Mental illness experience</strong></td>
<td></td>
<td></td>
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<tr>
<td>• Lived experience of</td>
<td>Schizophrenia</td>
<td>Early psychosis</td>
<td>Schizophrenia</td>
</tr>
<tr>
<td>• Duration of illness</td>
<td>19 years</td>
<td>8 years</td>
<td>10 years</td>
</tr>
<tr>
<td><strong>Experience in MHS</strong></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>• Type(s) of service use</td>
<td>ICCMW, PsyOPD</td>
<td>ICCMW, PsyOPD</td>
<td>HWH, PsyOPD</td>
</tr>
<tr>
<td>• Form of involvement</td>
<td>Board member of a self help group</td>
<td>Peer support worker</td>
<td>Peer support worker</td>
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Experience of participation in mental health services

Core themes emerged from the photos:

- User perspective and power disparity
- Social inclusion
- Peer connection
- Shift of identity
- Personal responsibility and collaboration with staff
Experience of participating in the photovoice

- Exercises free will and autonomy
- Inclusion of users’ perspectives
- Acknowledges individualized expression
- Enhances Self-understanding
Experience of participating in the photovoice study

Extract from the fifth meeting:

**Winnie:** “This is participation. That means we are personally involved in the process ... This kind of process is pleasant. ... So compared to the questionnaire in which we only respond ‘agree’ or ‘disagree,’ or give a score, I think [the difference] to me is the participation. Yes.”

**Billy:** “I think there are things that numbers cannot represent. For example, on the notion of agreement, with “5” representing “highly agree. If to say very agree but have some reservation, then to select “4” or “5”? And does my “4” the same as your “4”? Or my “5” the same as your “5”? No one knows. Yes.”
Discussions

- User participation in Chinese culture
- Benefits and challenges of the participatory experience
What have we learned?

- UP entails partnership among service users, providers and peers.

- Photovoice as a CBPR:
  - Enhances personal agency.
  - Opens up new possibility for personal growth and development.
  - Gives access to unfold knowledge-by-experience.
  - Further application is recommended for the construction of experience-based knowledge within the mental health community.
  - More than a research method???

- 3Rs – Repositioning, Reciprocal, Reflexive

- 2Ms – Multiple-reality of knowledge, Mutuality
References


References


Q & A

Thank You!