Qualitative approach to understanding experiences of compulsory care and treatment

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Cohort Study Background

- Millan Committee
- Mental Health (Care & Treatment) (Scotland) Act, 2003 (MHCT Act)
- Principles underpinning the 2003 Act
- National research programme
- Scottish Executive/Government commissioned
- Pathways model
### Pathways through Compulsion

Key Aspects of MHCT Act 2003

- New Mental Health Tribunals
- ‘Named person’
- Advance Statements
- Community-based compulsory measure
- Emphasis on social well being & development
Study Aims & Objectives

Main aim - To evaluate stakeholder experiences & views. Key objectives: -

1. To identify and describe operation and impact of MHCT Act
2. To examine service user journeys over 1 year
3. To examine interaction with other legislation
4. To assess success of well being measures
5. To evaluate against Millan principles
6. To make recommendations
Some of the Research Team
Partnership with Service Users

How Service Users Were Involved

- Research Proposal
- Research Advisory Group
- Developing Ethical practice
- Consulting User Groups
- Recruiting Team
- Partners in Research Team
- As Interviewers Co-researchers
- Data Analysis
- Lectures, Presentations

IN VOLVING SERVICE USERS
Research Methods

- Qualitative design:
  - Literature review
  - Telephone interviews
  - Face to face stakeholder interviews
  - In-depth interviews with SU
  - Focus groups/interviews with carers

- Different perspectives – SU, carers & professionals

- Two stages

- 2007 - 2009
What Some Interviewees Said…..

- It felt better that there was somebody there that understood”

- “If I was sitting with two officials I couldn’t be as relaxed, having a laugh as well as talking about these things”

- “Good that its also someone that’s been in a similar situation”
Service User Sample - Summary

- Sex – 67% men, 33% women
- Age (mean) – 40.5 years
- Youngest – 21 years
- Oldest – 63 years
- BME - 8%
- Learning difficulties & autism – 8%
- Most common recent experience – 35% community-based CTO
## Service Users Most Recent Compulsory Care Experience

<table>
<thead>
<tr>
<th>Category</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Short Term Order</td>
<td>7</td>
<td>14</td>
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<tr>
<td>Interim Order</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>CTO in hospital</td>
<td>13</td>
<td>27</td>
</tr>
<tr>
<td>CTO in community</td>
<td>17</td>
<td>35</td>
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<tr>
<td>Specialist Order – Criminal Justice</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Unclear at Stage 1</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>49</strong></td>
<td><strong>100</strong></td>
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Focus of Presentation

- Journeys Into Compulsion
- Participation
- Care & treatment
- Community-based compulsory care
- Feelings about compulsion
- Some Conclusions
Journeys Into Compulsory Care

- Complex, non-linear
- Diverse group
- Pre-compulsion
  - Start or escalation of serious MH issues
  - Stressful or traumatic events
  - Impact of social or environmental factors
  - Non compliance
  - Criminal justice system
  - Risk to self or others
Participation

Tribunals –

“I felt more involved. They asked me a question. I got a chance to talk you know and to ask questions, they asked how I was and what I thought. Before it was my doctor and the others talking you know, they didn’t give me any chance to talk.”

“I did get my tuppence worth, but it wasnae really worth anything”.
Participation - Advance Statements

- “What I’ve said...is that every effort should be made that I stay at home before being rushed into the [hospital], and every effort be made by non-drug methods, drugs being a last resort, and that I should have some say in what drugs I’m put on.”

- “If you get ill they’re just going to give you it anyway so it’s not worth nothing at the end of the day.”

- “Mine basically states that I don’t want any needles anywhere near me, that’s the bottom line. I suspect it won’t be worth the paper it’s written on.”

- “Regarding medication, they’re going to give you what they want to give you...What is the point, it’s wasting everyone’s time.”
“I put her as my named person instead of my mum. Her dad was manic-depressive so she can relate to me whereas my mum can’t. Plus there are things that I wouldn’t want my mum to know. If she’d seen half the things that have happened or I’d done she’d probably have a heart attack.”

“I just felt he (relative) was not speaking in my interests and perhaps I was mistaken. I think I named a good friend of ours after that.”
Participation - Access to Advocacy

“The advocate used to visit about once or twice a week. He'd be in and out helping me and he's researching the paperwork at the moment for this section order...It's pretty good that he's going on a fact finding mission for me.”

“I spoke to somebody from P in the past, and I didn’t have any result with them. I didn’t feel that they were going to make a difference.”
Care and Treatment

- “I've asked what the side effects are and nobody will tell me... The pills are upsetting the whole system, making you really ill but no, its ‘take these pills because you've got this mental illness and everybody who's got this mental illness has to have this pill'.”

- “The psychiatrist listened to what I had to say, not straight away but after I complained about it a few times then she decided to change my medication, see if it would make me feel any better and it did.”

- “I know I've got a care plan but I don’t know what’s in it. I see my RMO writing in it all the time but nobody has actually sat down with me like my key worker and told me what’s in it.”
Care and Treatment – Activities

“\textit{It's also very, very monotonous, there's nothing much to do here and it's nothing that I can really focus on doing. Like I'm an artist and if I had a drawing board or some proper materials to work with, and I could continue doing art and sketch people's portraits but at the moment I'm using printer paper and I only have biro pens to draw with.}”

“I think it would be a lot better if it wasn't all going to the gardens or woodwork or craft and design, that you were doing something constructive like learning a trade like brickwork or painting and decorating, mechanic or whatever.”
Community-based Compulsory Care

Limited in scope but -

- “It keeps me within the system and maybe being compelled to stay with it has benefited me…”
- *It’s been a good safety net if I have to go back into hospital.*

Resented

- “I want my own private life back. I don’t want people coming to my house like a bunch of Mormons and saying ‘oh you’ve got to do this today, you’ve got to do that today...’”
Feelings About Compulsory Care

- In retrospect, 52% felt it had been the ‘right thing’, “a necessary evil”
- 42% felt it unnecessary
- Complex – both resented as infringing human rights, and felt beneficial
- Hospital based detention disliked most
Some Conclusions

- Some improvements evident
  - Positive aspects of being listened to
  - Tribunals improved opportunity to have a say

- Listened to but not heard?
  - Limited evidence of concordance re treatment
  - Scepticism re Advance Statements

- Care and treatment limited
  - Lack of ownership of care plans
  - Drug based, not holistic

- Improvements in practice and services still needed