

BE WHAT YOU WANT TO BE

Compute or Communicate?
Exploring consumers' attitudes
towards routine outcome
measurement in mental health
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Outcome measurement

- Now a policy requirement throughout Australia
- As the name suggests the aim is to determine consumer outcomes as a result of the care and treatment provided by mental health services



Outcome measurement – the supporters

- facilitate consumer expression of meanings and experiences of care
- encourage clinicians to assess domains that they commonly overlook
- provide useful information to non-ward staff (e.g., educators, managers, researchers)
- assist consumer-staff communication
- promote staff self-reflection on practice



Outcome measurement: the detractors

- current outcome measures lack the precision and depth to be of real use to practitioners
- use of outcome measures has not been shown to improve consumer outcomes
- outcome measures currently used do not assess domains that are of primary interest to consumers



So let's go straight to the horse's mouth!

- Consumer views have been underrepresented in the discussions about outcome measurement
- Funded by ANZCMHN research fund



The study

- Two parts:
 - Focus groups with consumer members of PAT (Psych. Action and Training - a group convened by the Centre for Psychiatric Nursing - a collaboration between consumer educators and nurse educators with a strong interest in consumer perspective in mental health services.
 - Focus groups with consumers of mental health services (rural and metro Victoria)
 - Part 1 is the focus of this presentation



Method

- Reference group established
 - Consumer representatives
 - Research team
 - Senior nurse
 - Representative from ACMHN
 - Psychiatrist
- Reference group refined the scope of the study and developed the discussion stimulus for the focus groups



Discussion stimulus

- Two primary questions:
 - Does routine outcome measurement within Victorian mental health services satisfy the objectives of mental health service users?
 - What content, methods, and processes should be developed and implemented as part of a user-derived evaluation framework to be used alongside existing routine outcome measures in Victorian mental health services?



• Focus groups

- two focus groups of one to two hours
- Discussion questions presented as a broad basis for the interviews
- Facilitated by consumer researcher and research fellow
- Participants encouraged to raise any issues they considered relevant or important (regardless of discussion questions)
- And they had plenty to say ...



Findings

- Three main themes:
 1. Assumptions behind routine outcome measures (ROM)
 2. Consumer concerns with routine outcome measures, and
 3. Consumer Perspective: purpose, process and principles.



Assumptions behind routine outcome measures

- three main assumptions identified:
 1. ROM primarily designed to benefit the service by providing information to support the benefits gained as the result of service use;
 2. They suggest that positive outcomes for consumers are the result of service use and therefore do not consider other possible (external) contributing factors, and,
 3. They do not provide a basis from which the negative effects of the service system can be identified.



Benefit the service not the consumer

- ... when they [services] look at evaluation, they want to see whether it has had any benefit for you ... they want to make sure there's improvements in services and that services are actually doing something. So they do currently have tools in place ... to say the service has had an impact ... it is framed in terms of the benefits of the service.



If you're feeling better it's because of the service

- ROM provided the scope for services to take credit for positive outcomes without necessarily being able to clearly demonstrate what was responsible for the improvements, for example:
- *The assumption is that if people get better it must be because of the service, because that's the only thing that makes people get better, all the nice drugs and things, whereas in fact, people get better despite the service.*



If you're feeling better it's because of the service

- The participants emphasised the fact that they are continually influenced by far more than the existing service system:
- *... they [services] can't make the point that just because someone changes it's the service because increasingly people are using GPs, NGO's, families, support services, private therapists, massage.*
- Peer support was considered a critical factor that is not reflected in ROM



Getting better is because of us, not getting better is because of you

- Participants felt that where improvements were not evident the service was seen to have an 'escape clause':
- *Services generally think that 'we make things better', and if things are worse, well then it's the illness.*



Getting better is because of us, not getting better is because of you

- Participants referred to the damaging aspects of service use which were not reflected through the use of ROM, in one example:
- *An outcome for me, after having used services and being locked in seclusion, is now that I have claustrophobia, that's one of the outcomes for me is that I now can't be in closed rooms, and those kinds of outcomes are what need to be fed back to the service.*



Potential use of ROM

- Three main issues:
 1. could become the basis to decide access to or denial of services
 2. a sense that the real purpose of ROM was not disclosed to consumers, and
 3. the results of ROM were not used to feedback to consumers or to enact change.



Am I too well for a service?

- Some consumer participants expressed concern that ROM might be used to determine eligibility or otherwise for service:
- *What happens if I'm doing well, do I lose a service, for those who want it?"; "The DHS position is it's not going to be linked in that fashion"; "But the fear's there, and it could happen down the track.*



So what's it really all about?

- Participants expressed uncertainty about the real agenda for ROM, for example:
- *What's the intent of why are we filling out the outcome measures, is it to open a dialogue? Is it to get funding from DHS? Is it to precipitate change for the person? Whatever the intent of the tool is, then there's an honest communication about that.*



If I do something will you do something?

- Consumers felt frustrated at the lack of response by services to the findings from ROM, for example:
- *If I say, I think the service should spend more time doing this, and nothing ever happens of it, why would you say it again, consumers have been too much queried out. You do this satisfaction survey, and if you're expecting the change to happen, and don't see it, you're not going to fill in another one.*



Consumer perspective: purpose, process and principles

- Four main issues raised under this theme:
 1. the focus of outcome measures on symptoms rather than what is valued by consumers
 2. In consultation with consumers
 3. Consumer driven



What about what we think?

- Participants felt ROM predominantly focused on measuring symptoms as a way of determining success or failure, rather than being based on the factors consumers consider important:
- *By emphasizing service use, we're making an important point that it isn't just about individual pathologies, like "how depressed are you?" the focus is on something larger.*



Why not just ask us

- Clinicians should be encouraging consumers to directly communicate their concerns and therefore become more actively involved in their own care and treatment, as one participant stated:
- *Whoever's putting it [ROM] to the client, should be providing a forum where if the person wants to say to their face – it's rubbish ... and also the clinician has to actually listen to it and has to set up a plan of action that says, "yeah, I'm going to respond to that". Not, "let's hush hush, let's not deal with this one, put down the file..."*



If you want consumer participation then let us participate

- Evaluation of service effectiveness should be consumer driven:
- *If we're evaluating something, it needs to come from us as consumers and it needs to be thinking about the relationship between the consumers and the people providing the service.*



Discussion

- ❑ Findings from this study support the view current ROM do not provide the sort of information consumers think is most important
- ❑ Designed for the benefit of services not consumers
- ❑ Concern about how ROM might be used to determine access to services or levels of funding



Discussion

- ❑ Positive changes do not necessarily reflect the contribution of mental health services
- ❑ Focus on positive outcomes, don't reflect the negative



Discussion

- ❑ Completing forms does not promote genuine communication
- ❑ No evidence that results from ROM result in change or improvement



Discussion

- ❑ Consumers should be actively involved in the evaluation of services (filling out forms does not equal active involvement)



A closing thought

- *When you're trying to find out if a service is hurting or helping, you should ask a consumer.*



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