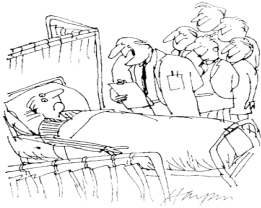


Shared Decision Making in Mental Health

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"When we want your opinion, we'll give it to you"

BMJ 2003; 327: 864



"I'M SORRY DOCTOR, BUT AGAIN I HAVE TO DISAGREE"

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www.glasbergen.com



“More and more patients are going to the Internet for medical advice. To keep my practice going, I changed my name to Dr. Google.”

Decisions about treatment...

Are not just medical decisions...

...Medical decisions are also personal decisions...

Shared Decision Making

- There are two experts in the consultation
- I am an expert on me and what matters in my life
- The best treatment decisions *for me* are made collaboratively with my doctor/care co-ordinator
- When decisions are also personal decisions, shared decision making is an ethical imperative

Shared Decision Making - a definition

Shared decision making is defined as decisions that are shared by health professionals and clients, informed by the best evidence available and weighted according to the specific characteristics and values of the client.

What is a good decision?

Patient centred decision is defined as the extent to which it reflects the considered needs, values and expresses preferences of a well informed client.

Sepucha KR, Fowler FJ, Mulley AG (2004) *Health Affairs*.

'No decision about me without me'



- 'Ambition is to achieve healthcare outcomes that are among the best in the world.'
- 'This can only be achieved by involving patients in their own care, with decisions made in partnership with clinicians, rather than by clinicians alone.'
- 'We want the principle of 'shared decision-making' to become the norm: *no decision about me without me*.'

... not just adults of working age

- Older adults have a strong desire for involvement in decision-making as do younger adults. Both age groups similar in their desire for information to aid in decision-making.
- Both age groups also preferred a collaborative role with a psychiatrist for medication decisions, an autonomous role for decisions related to psychosocial interventions, and a passive role with their primary care provider.
- Older and younger adults express similar decision self-efficacy

O'Neal et al (2008) American Journal of Geriatric Psychiatry

What would you do?

Let's say you are struggling with psychosis:

- Would you be willing to use a psychiatric medicine to gain symptom relief, but also gain 30 or 40 pounds as a result of using the medicine?
- Would you personally be willing to use a psychiatric medicine that put you at risk for cardiometabolic syndrome?
- Would you risk developing diabetes and consider that to be a reasonable trade off for reduction in symptoms?
- Would you be willing to postpone having a baby or starting a family in order to take a medication that offered you some symptomatic relief?

Shared Decision Making

- Conceptually, shared decision making falls between two extreme approaches to decision making: the paternalistic and the autonomous decision models.
 - In the traditional, paternalistic model, the doctor assesses what is best for a particular client, based on scientific evidence and clinical judgment, and makes the decision.
 - In the autonomous decision model, the client is presented with information, weighs the information, and makes the choice unilaterally.

Compliance Vs Shared Decision Making

- Medication management often conceptualised in terms of strategies to increase compliance or adherence
- For people with long-term conditions using medication is a dynamic journey, not a static event
- Compliance is an inadequate construct - it fails to capture the dynamic complexity of autonomous clients who must navigate decisional conflicts in learning to manage conditions over the course of years or decades
- Compliance is rooted in medical paternalism and is at odds with principles of recovery focused practice and evidence based medicine

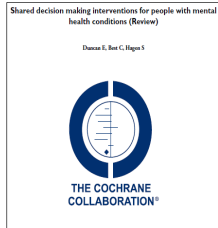
Personal medicine (Deegan, 2005)

- Self-initiated, non-pharmaceutical strategies to improve wellness (e.g. self management) and avoid unwanted outcomes e.g. hospitalisation.
- Personal medicine includes activities and interventions that give life meaning and purpose, and promote a sense of accomplishment.
- When medications enable people to pursue activities they are perceived as a valued tool in the recovery process.
- However, if medications interfere with personal medicine, so clients cannot engage in valued social roles and activities, the medications are viewed as blocking the recovery process and are often rejected.
- Insistence on compliance in such situations is experienced by people as countertherapeutic and unhelpful.

Few medical treatment decisions involve a clear best choice

- SDM assumes that two experts should collaborate in making complex medical decisions.
 - The doctor brings expertise in understanding the problem, the possible interventions, and the potential benefits and risks of alternatives.
 - The client brings expertise related to understanding their individual values, goals, supports, and preferences.
- Shared decision making acknowledges two kinds of expertise and requires the two experts to explicitly establish consensus on what the problem is, what the treatment goals are, and how they will know when the goals have been met.

Systematic review: SDM (2010)



- Two studies included. N=518
- Primary outcomes:
 - one reported statistically significant increases in user satisfaction, the other study did not.
- Secondary outcomes:
 - Interventions to increase SDM increased doctor facilitation of user involvement in decision making, and did not increase consultation times
- No firm conclusions can be drawn.

Barriers to Shared Decision Making

- Challenge to doctor autonomy
- Professional gift model
- Doctors not recognising preference sensitive decisions
- Evidence difficult to extract, interpret, communicate
- Logistics
- Lack of time
- "Patients don't want to participate"
- Literacy, numeracy challenges
- Need portfolio of appropriate decision aids

Barriers to achieving SDM in mental health

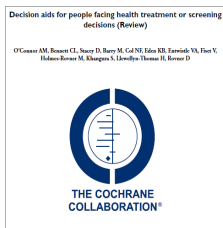
- SDM challenges the current norms and attitudes in services
- Assumptions that clients want to maintain current level of participation in decision making
- Clients will have various perspectives on the notion of participation in treatment decision making
- Many people (regardless of their mental status) are not comfortable making choices, particularly when there is little support and information
- Still identifying effective and feasible decision aid tools
- Peer specialists have the potential to serve as effective decision coaches, but we are only beginning to learn how to successfully include peers specialists as part of treatment teams

Delman et al, 2010

Decision Aids: Values clarification

- The presentation of medical information is only half of the equation in the decision aid. The second half of all decision aids includes values clarification.
- This is extremely important because no two people are exactly the same. When the exact same information is presented to two people, they might each choose a different treatment option based on what matters in their life.

Systematic review: Decision Aids (2009)



- **Review of 51 RCTs**
- Increase user involvement
- Improved user knowledge
- Balance, accuracy, consistency of information
- Clarify user values
- Improved agreement between values and choices
- Improve realistic expectations
- Lower decisional conflict
- Decrease number who are undecided

Currently there is only one decision aid for mental health....

Emerging evidence re MH and Decision Aids

- User-friendly, Internet-based software program which clients create a one-page computer-generated report for use in the medication consultation
- 662 times by 189 unique users from a young-adult and general adult case management team
- Focus groups with medical staff (n=4), clients (n=16), case managers (n=14), and peer-specialist staff (n=3) reported that the intervention helped to create efficiencies in the consultation and empower clients to become more involved in treatment-related decision making.

Deegan et al (2008) *Psychiatric Services*; and see Deegan (2010) *Psychiatric Rehab Journal*

CommonGround software



- CommonGround is a web-based software application that empowers people with psychiatric diagnoses to communicate with psychiatrists and to arrive at shared decisions about next steps in the management of their mental health conditions [Decision Aid].
- It was developed by and for people diagnosed with mental health problems.

What communication skills are required for effective SDM?

1. Define/explain problem
2. Discuss user's desired role
3. Present options
4. Discuss pros/cons
5. Explore user's values, preferences
6. Assess patient self-efficacy
7. Present doctor recommendations
8. Clarify understanding
9. Make or explicitly defer decision

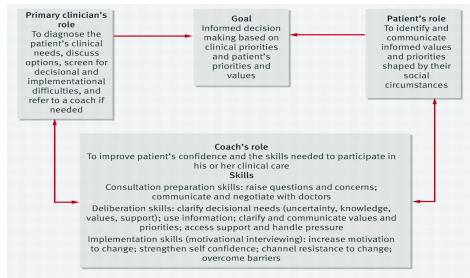
Adapted from Makoul G.(2006) An Integrative Model of Shared Decision Making in Medical Encounters. *PI Educ and Counseling*.

Which skills do clinicians most need to improve?

- Assessing users' values
- Asking about users preferred role in decisions
- Screening for decisional conflict
- Assessing support or undue pressure on user
- Increasing users' involvement in decision making

Légaré, 2006

Roles of coaching in shared decision making



O'Connor et al. (2008) *BMJ* 336:228-229

Other applications

- ECT?
- Psychological therapies?
- Going back to work / study and risk losing benefits?
- Self Directed Support / Personal Budgets?
- Treatment planning process (care plans, risk assessments/safety plans)?
- Smoking cessation?

When SDM is not useful

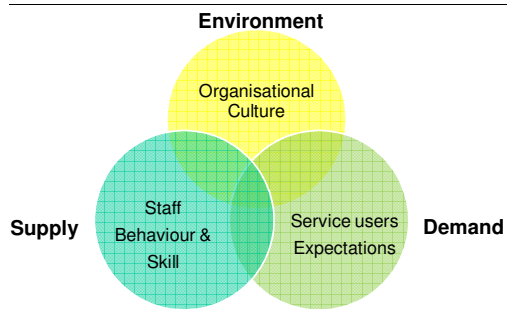
- In emergency situations
- In situations where a person lacks decisional capacity (e.g. advanced Alzheimer's, delirium)
- In these situations, advance directives or proxy decision making can be used.

However...

- Users' generally endorse a shared style of decision making but...
- They tend to focus on the relationship and affective components of decision making, rather than information gathering or deliberating options
- Users' may have a different view of decision making and may verbally defer to their care co-ordinator but remain silent about their preferences and wishes

Wollmann & Whitley, 2010

Where should we focus?



what are my **options**?

what are the possible **benefits and risks** of those options?

how **likely** are the benefits and risks of each option to occur?

www.ask3questions.co.uk

Bottom line

- People always want good information
- People want to feel listened to
- People want a say in things that affect their lives
- People have the right and ability to make decisions about their treatment

**Shared Decision Making assists
with all of the above**

Thank you

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