Measuring outcomes in health settings – concepts to apply to community care

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Australian Health Services Research Institute
First National Workshop on the Measurement of Outcomes in Community Aged Care
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Overview

◆ What we mean by an outcome
◆ Why measure outcomes
◆ A brief introduction to our outcome centres
◆ How we measure outcomes in our outcome centres
◆ Benchmarking cycle
◆ What we have learned and how this applies to community care
Outcome

A change in an individual or group of individuals that can be attributed (at least in part) to an intervention or series of interventions

3 key ideas:
◆ change
◆ attribution
◆ intervention
Why measure outcomes?

- Fit with policy environment of personalised care
- Leads to improved quality
- Outcomes are an individualised measure linked to a person’s needs and goals
Outcomes, Needs and Goals

◆ individualised measure
◆ linked to a person’s needs and goals
Types of Need

- Normative need
- Expressed need
- Comparative need
- Felt need

(Bradshaw 1972)
Goals

- A simple statement /s
- The purpose of care
- People can have many goals
- A set of goals needs to be individualised and cannot be assumed
Types of Outcomes

- Maintenance outcomes
- Change outcomes
- Process outcomes
Level of Outcomes

- Consumer
- Carer
- Service provider
- System / program
Outputs and Need

◆ Measured outputs do not equate to meeting people’s needs
### Outputs vs Outcomes, Miller, 2008

<table>
<thead>
<tr>
<th>Service Led Output Focused</th>
<th>Outcomes focused</th>
</tr>
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<tbody>
<tr>
<td>Current tools encourage information gathering through standardised question and answer approaches to assessment, support planning and review</td>
<td>Decision making informed by semi-structured conversations with individuals in assessment, support planning and review</td>
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<tr>
<td>Tick box approach to assessment</td>
<td>Analytical skills involved in assessment</td>
</tr>
<tr>
<td>The person’s views may be included in decision-making</td>
<td>The person’s views/preferences are central to decision making</td>
</tr>
<tr>
<td>The person is viewed as a client, service user or patient</td>
<td>The person is a citizen with rights and responsibilities</td>
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## Outputs vs Outcomes (cont)

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<td>Where needs link to strict eligibility criteria, the assessor is required to maximise individual difficulties to access services</td>
<td>Outcomes allow preventive work to take place while services and resources are prioritised for those most in need</td>
</tr>
<tr>
<td>If the person is deemed eligible, identified needs are matched to a limited range of block provided services, resulting in service driven approaches</td>
<td>Identifying outcomes involve considering a range of solutions/strategies including the role of the person, family supports and community based resources</td>
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<td>Where needs are tied to eligibility criteria, preventive work</td>
<td>Outcomes allow preventive work to take place while services and resources are</td>
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<td>with people with low level needs may be excluded</td>
<td>prioritised for those most in need</td>
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<tr>
<td>Focusing exclusively on deficits and difficulties, and how</td>
<td>By focusing on strengths, capacities and goals, while mindful of limitations, the</td>
</tr>
<tr>
<td>needs are to be met, results in a focus on tasks and in services</td>
<td>role of the person is maximised. Services do things with people</td>
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<td>which do things to people</td>
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<td>Matching needs/deficits to services tends to result in static service delivery</td>
<td>Outcomes may change in the person’s life journey and so should be revisited</td>
</tr>
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<td>Where outcomes are identified, these tend to be professional or organisational outcomes e.g. improved nutrition, or avoid delayed discharge</td>
<td>Outcomes are what matter to the person, though often consistent with professional and organisational outcomes e.g. being able to get out and about.</td>
</tr>
<tr>
<td>Starting from what services are currently available restricts communication and limits options</td>
<td>Starting from the person’s priorities supports enabling relationships, creates clarity and identifies goals at an early stage.</td>
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How do you assess an ‘outcome’? Whose assessment counts?

*The Person*

- Stay at home as long as possible
- Function as independently as possible
- Have maximum confidence, choice and control
- Have friends
- Have things to do
- Come to terms with loss
- Be happy
How do you assess an ‘outcome’? Whose assessment counts? (cont)

The Carer

◆ Maximum wellbeing of person and carer
◆ Minimum carer burden
◆ Choice and control in determining services

The Provider

◆ Maximum improvement
◆ Minimum burden on the service system

The Payer

◆ Maximum improvement at minimum cost?
◆ Minimum burden on society?
Outcomes assessment can’t be a one-off event

◆ Need reassessment, based on a protocol:
  – Significant event (e.g., fall, carer crisis, hospital admission)
  – Pre-agreed time periods (e.g., 6 or 12 monthly)

◆ Types of outcomes at these points:
  – Alive or dead (level 1)
  – Better or worse (level 2)
  – Better or worse than expected (level 3)
  – Value for money (level 4)
Before and after

◆ Health outcome = difference in health status 'before and after' intervention.
  – grounded in an acute care paradigm in which sick patients receive treatment and, as a result, get better.
  – the way that clinicians (and consumers) typically judge the success of most health care interventions.

◆ Of limited value in measuring the outcomes for people with protracted and chronic illnesses.
  – Some people have conditions that last a life time.
Outcomes: Before and After

The difference before and after the intervention

Outcome = 40 point improvement

Outcome =
40 point improvement
Measuring outcomes - before and after

- 2 or more points of time
- ‘Outcome’ is the difference between the two
- Two possible outcomes at these points:
  - alive or dead (level 1)
  - better or worse (level 2)
With and without

◆ Health outcome = the difference between the person's quality of life and health status if they had received no intervention (or another type of intervention) and that person's expected quality of life and health status with the intervention.

◆ Includes outcomes for both consumers and carers.
Outcomes: With and Without

The expected difference with and without an intervention

Outcome with this intervention is now either -20, 20, 40 or 50 points improvement, depending on what might have happened with no intervention or another type of intervention.
Measuring outcomes - with and without

◆ 2 or more points of time

◆ ‘Outcome’ is the difference between the two points in time, taking into account what might have happened without the intervention

◆ Four possible outcomes at these points:
  – alive or dead (level 1)
  – better or worse (level 2)
  – better or worse than expected (level 3)
  – value for money (level 4)
Why measure consumer outcomes?

◆ **For research and clinical learning**
  – What works for which consumers

◆ **To support communication**
  – Between service providers and across sector (common language)
  – Between service providers and consumers

◆ **For use in service delivery**
  – To assess and monitor consumer progress and outcomes
  – To demonstrate to purchasers that service provision is effective and value for money
A development cycle for outcomes assessment and benchmarking

But it’s a bit more chaotic in practice!
One off studies

Outcome studies

Culture Change
Routine measures

Outcome studies → Routine outcome measures → Culture Change
Establish systems

Outcome studies → Routine outcome measures → Routine outcome systems (training, data collection protocols & processes)

Culture Change
Measurement

- Outcome studies
- Routine outcome measures
- Routine outcome systems (training, data collection protocols & processes)
- Culture Change
- Performance measurement
Feedback

Outcome studies → Routine outcome measures → Routine outcome systems (training, data collection protocols & processes)

Culture Change

Feedback → Performance measurement
Benchmarking

**Outcome studies**

**Routine outcome measures**

**Routine outcome systems**
(training, data collection protocols & processes)

**Culture Change**

**Benchmark**
(use the data to identify best practices and then implement them)

**Feedback**

**Performance measurement**
The benchmarking cycle

Outcome studies

Routine outcome measures

Routine outcome systems
  (training, data collection protocols & processes)

Culture Change

Evaluate & refine (measures & systems)

Benchmark
  (use the data to identify best practices and then implement them)

Feedback

Performance measurement
Clinical registries & benchmarking initiatives

◆ Increasing evidence that clinical registries in acute and sub-acute care lead to improved clinical outcomes

◆ International momentum is gathering to develop new clinical registries as quality-improvement measures. (McNeil et al, 2010)
AHSRI clinical repository & benchmarking initiatives

◆ Australasian Rehabilitation Outcome Centre (AROC) Started in 2002. Participating services: 372

◆ Palliative Care Outcomes Collaboration (PCOC) Started in 2005. Participating services: 130

◆ electronic Persistent Pain Outcomes Collaboration (ePPOC) Started in 2013. Participating services: 33
PCOC and ePPOC
The Palliative Care Outcomes Collaboration (PCOC)

- Initiated by federal Department of Health
- Four university collaboration
- Scope is multidisciplinary specialist palliative care services (public, private and NGO) in Australia
PCOC collaboration

◆ Australian Health Services Research Institute University of Wollongong (Professor Kathy Eagar)

◆ Institute of Health & Biomedical Innovation Queensland University of Technology (Professor Patsy Yates)

◆ Department of Palliative & Supportive Services Flinders University (Professor David Currow)

◆ Cancer & Palliative Care Research & Evaluation Unit University of Western Australia (A/Professor Claire Johnson)
The electronic Persistent Pain Outcomes Collaboration (ePPOC)

- Initiated by Faculty of Pain Medicine

- Australian Pain Society, PainAustralia and other stakeholders all involved in development and implementation

- Scope is multidisciplinary chronic pain management services (largely hospital outpatient) in Australia and New Zealand
How PCOC and ePPOC work

◆ Work with services to incorporate patient outcome measures into routine practice
◆ Provide ongoing support through training and assistance with IT
◆ Analyse the data and provide feedback on the results to individual services - reports every 6 months
◆ Facilitate benchmarking with other services
◆ Assist services with practice quality changes – Quality Improvement Facilitators (QIFs)
Approach to pain management

Pain management is core business in both palliative care and chronic pain management, however strategies and approaches differ

**PCOC**
- Aim is for patient to be pain-free
- Opioids are used routinely in clinical practice

**ePPOC**
- Aim is often to help patient live with the pain
- Goal is to minimise use of opioids
Validated tools used

PCOC
- PC Phase
- SAS
- PCPSS
- AKPS
- RUG-ADL

ePPOC
- Brief Pain Inventory (BPI)
- Depression Anxiety Stress Scale (DASS21)
- Pain Self Efficacy Questionnaire (PSEQ)
- Pain Catastrophising Scale (PCS)
Patient rating and proxy ratings

PCOC

◆ Varies by service and setting but about:
  – Patient – 50%
  – Family / carer – 40%
  – Clinician – 10%

ePPOC

◆ All assessment tools are patient rated (with parents rating young children)
Patient outcome measures - PCOC

- Time between ready for care and episode start
- Time in unstable phase
- Change in pain and symptoms (from start to end of phase)
  - Adjusted for client classification system
Unit of counting - PCOC

◆ Episodes of care broken up into Palliative Care Phases (stage of illness):
  – Stable
  – Unstable
  – Deteriorating
  – Terminal

◆ The ‘outcome’ is the change from the beginning to the end of each phase
Patient outcome measures - ePPOC

- Pain interference, intensity and frequency
- Mood and cognition
- Opioid and other drug use
- Health service utilisation (e.g. ED, hospital admissions)
- Ability to work/study
Unit of counting - ePPOC

◆ Outcomes measured from:
  – Referral to episode start
  – Episode start to episode end
  – Start to end of each treatment ‘pathway’ within an episode
    ♦ Group program, individual appointments
  – 3 months after discharge from the service
Benchmarking

- Service providers want to know how they are going compared to other service providers
- Need to compare similar service delivery to similar consumers (apples to apples, not oranges)
- Need for a classification system for consumers, more sophisticated than level of Home Care Package (e.g., low function, no carer, no cognitive impairment)
Benchmarking (Cont)

Need to provide opportunities for service providers to learn ‘best practice’ from each other, e.g.,
* confidential reports comparing one service’s results to similar services,
* benchmarking workshops, where service providers can meet with others to discuss improvements

Challenge of improving outcomes in a competitive tender culture
Benchmarking (Cont)

◆ Has led to significant improvements in performance in PCOC, ePPOC still in early stages
What we have learned

◆ More focus on consumer reported measures as the three centres have developed
◆ Sustainability depends on having clinically useful measures capable of routine collection
◆ Importance of measuring and reporting clinically significant change
◆ Importance of national approach and Quality Improvement Facilitators for quality improvement, not just for training
Outcomes in community care

- More complex environment
- More variability
- Availability and sustainability of carer is a critical factor
- Process of measuring outcomes in community care can build on the logic of health based outcome measurement systems
What to measure / when to measure?

- Information for outcome measurement should be a by-product of the information collected for care planning, not an additional piece of work.

- What is best practice care planning? i.e.: process, cycle, ‘phases of care’, what triggers a change in care plan, when to review etc.
What to measure / when to measure? (cont)

- What information is needed for ‘best practice’ care planning?
- Are we measuring outcomes for the care recipient, carer or the ‘carer dyad’ or a combination of all of these?
Conclusion

◆ The jury is in - measuring patient outcomes and benchmarking has been demonstrated to drive improvements in patient care

◆ There is much more to do in community care
  - Improving the evidence base
  - Implementing the evidence
  - Learning from each other
Further information

AHSRI - http://ahsri.uow.edu.au


References


◆ McNeil, JJ, Evans, SM, Johnson, NP and Cameron, PA (2010) “Clinical-quality registries: their role in quality improvement” MJA Vol 192, No 5, pp. 244-245
