



Measuring individual level outcomes in palliative care: why and how

21st Sept 2018

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Why and how?

Benefits & challenges ...

- What is an outcome measure?
- Why are outcomes difficult in palliative care?
- What makes a good outcome measure?
- What matters to children and young people, and their families?
- Benefits

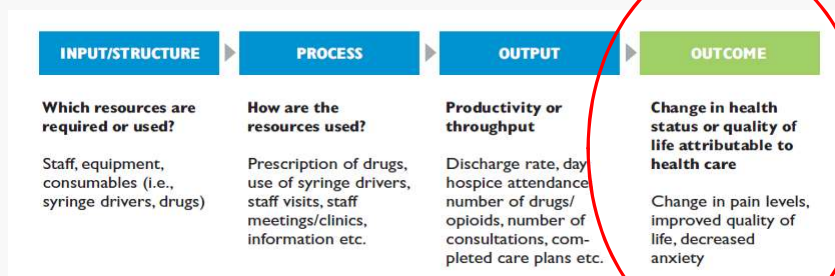
... and some of the challenges.

What is an 'outcome measure'?

- 'outcome' is often used in a lay sense to mean 'the result or consequence of something'
- in health care, 'outcome' derives from a systematic understanding of quality of care
- what is needed to deliver high quality care

So what is an outcome measure?

- way of measuring changes in a patient's health over time
- **Outcome** = "the change in a patient's current and future health status that can be attributed to preceding healthcare" (Donabedian 1980)



Why do individual-level outcome measures matter?

- Without them, we cannot know whether we are delivering best quality care or not
- Relying on 'thank you' letters (and complaints) is not enough
- We need to know – *systematically* – whether we are providing high quality care to all, in a timely and acceptable way, which is safe
 - Structure, process and output measures
 - Individual-level outcome measures
 - Experience measures
 - Safety indicators

Why are outcomes difficult in palliative care?

- not only survival ...
- different domains (not disease or procedure related)
- hard (not impossible) to measure, because of the qualitative nature of care
- will never represent all of care – not intended to
- need to include families too
- need to be aggregatable – problems with self-defined and with using solely goal-based measures
- context of declining health:
 - 'a positive difference' = preventing deterioration, maintaining normal, maximising quality of life, lessening impact of symptoms
- response shift

The challenge

- Say 100 children and young people (and their families) seen by a service
- 100 different stories of the impact of care
- Cannot be usefully aggregated
- How can the 'headlines' about care for these 100 be usefully combined, so as to:
 - Provide useful overall insight into the quality of care?
 - Identify areas of excellent care?
 - Identify areas which might need improvement?
- Reflecting the outcomes (or experience) of all, and including those without access to care?

Outcome measures distinct from experience measures...

- experience is important but fundamentally different
- outcomes and experience do not always run in parallel
- experience measures are 'a measure of the child and family's perceptions about ... the care they have received' (adapted from Coulter et al, 2009)
- not the same as satisfaction measures:
 - satisfaction with care may be one component of experience
 - satisfaction largely predicated on expectation

What is a quality indicator?

- norms, criteria, and standards used in determining the quality of health care (usually aggregated)
- 'explicitly defined, **measurable** item which reflects the quality of **structure, processes or outcomes** of care' (Campbell SM, 2003 & Donabedian 1988)
- a quality indicator requires explicit and defined components:
 - numerator e.g. number of children or young people with a particular concern, say pain
 - denominator e.g. total number of patients for whom this is assessed
 - norm or standard: for instance, at least 90% having a plan to address pain, and lessened pain as a result of the plan

Example:

- A 3 year old child with advanced life limiting illness is seen at home: holistic assessment undertaken; she has frequent episodes of crying and being unsettled (likely headache), poorly controlled fits, sleepiness possibly due to anti-epileptic medication. Family are at breaking point and need support. The team add analgesia, change anti-convulsant medicine regime, provide family support, and arrange respite care.
- **At review 3 days later, episodes of crying /unsettled much improved, fits better controlled. Respite care is planned for the following week.**

T1

T2

Example:

- Measure at **T1** :

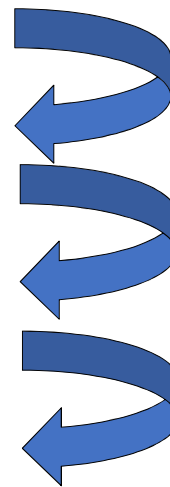
- assesses main **concerns**
- number, severity and interaction of issues = **complexity**
- if numerator/denominator/norm = **assessment-based quality indicator**

- Measure at **T2** , after interventions and support:

- change in e.g. symptom score or behaviour = **outcome** (change in wellbeing or health status)
- if numerator/denominator/norm = **outcome-based quality indicator**

At what level is data being i) collected and ii) used?

- Individual level
 - To inform the care of an individual child?
- Service level
 - Aggregated from all children receiving care
 - To shape and plan services
 - Quality improvement
- Population level
 - Who does not get access to care?
 - Whole population
 - Commissioning/research
- National and International level



Linking data in this way multiplies its value; but must start with individual level

What does this mean?

- The same data needs to:

- Drive improvements in clinical care
- Inform team working
- For annual reporting and review of service
- Potentially enable national collection of outcomes data
- Support *realistic and meaningful* benchmarking

Helps identify concerns more quickly and completely
Use of outcome measures improves detection of concerns and emotional wellbeing

Teams can plan workload based on objective criteria: level of complexity

Numbers of referrals, level of activity, BUT also the impact and effect of that activity

Important that we all use the same metrics and measures:
national data and outcomes set, benchmarking needs to be case-mix adjusted

Value of outcome measures

- Demonstrating impact of services on child (and family) wellbeing
 - At level of individual
 - At level of cohort / population
- Several other benefits:
 - Measuring quality and effectiveness
 - Quality improvement and assurance
 - Understanding value and efficiency
 - Describing the population seen (complexity)
 - Enabling much better insights into who is NOT seen
i.e. issues of access

What makes a good outcome measure for palliative care (Evans JPSM MoreCare guidance 2013)

- care and needs should inform them, not vice versa
- must be responsive to change over time
- capture important and meaningful data
- need to use 'proxy' data
- data collection time points need clear definition, to establish both baseline and follow up
- measures need to be psychometrically robust ...
- ...yet brief and not too burdensome

Psychometrically robust measures

Reliability - Does the instrument behave as expected? (go up when it should and down when it should, behave the same for everyone)

- Does the instrument produce the same results when repeated in an unchanged population?
- Inter-rater (comparison between two raters)
- Test-retest reliability (same results with repeated measurements in unchanged condition)

Bland JM, Altman DG. Validating scales and indexes.
BMJ, 2002; 324, 606-7

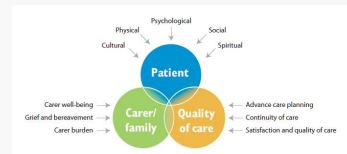
Validity – Does it do what it says on the tin?



➔ Face validity

➔ Content validity

➔ Construct and criterion validity



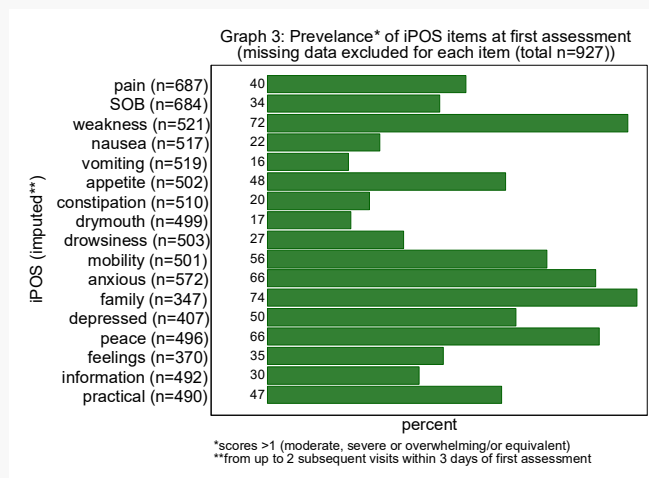
Responsiveness to change

If we cannot recognise the changes to the individual child/family's wellbeing in palliative care (i.e. the individual-level outcomes), we cannot assess whether we make a difference or not

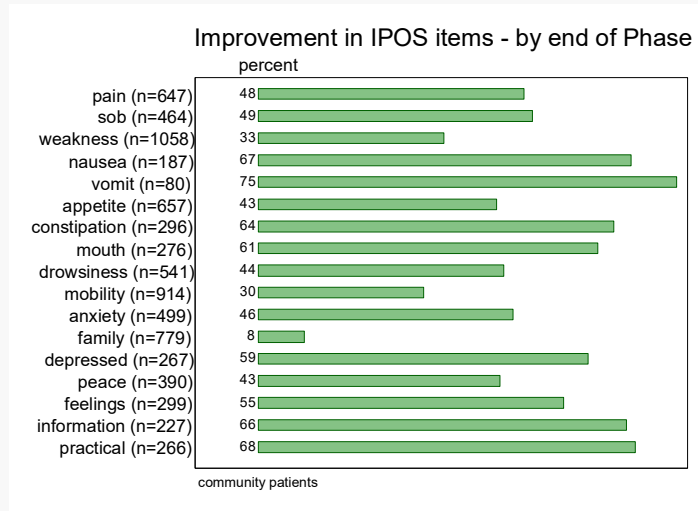
Some examples from the adult world

- Use at individual care level (not reported here)
- Use at aggregated level (whole cohort or population seen)
- Some examples...

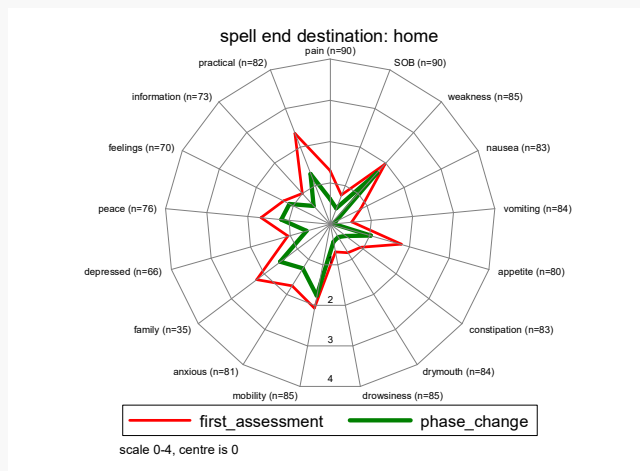
Distribution of mod/severe/overwhelming IPOS scores at start of care



% mod/severe/overwhelming changed to absent/mild by end of Phase (community)



Radial plot - easier to understand (N=90, discharged home from hospital)



A systematic review of quality of life measures for children and young people with life limiting conditions



Findings

- 3460 articles identified - 41 met the eligibility criteria
- Reported the psychometric properties of 22 health-related quality-of-life measures
- Evidence limited - at least half of the information on psychometric properties per instrument was missing
- Measurement error was not analysed in any and responsiveness to change analysed in only one study.
- Currently no 'ideal' outcome measure for use in paediatric palliative care.
- The domains of generic health-related quality-of-life measures are not relevant to all children receiving palliative care
- Important to continue work on outcome measurement in this field

Symptoms and concerns among children and young people with life limiting and life threatening conditions: A systematic review highlighting useful health outcomes

Eve Namisango Harding R, Bristowe K, Murtagh F, Abas M, Allsop M, Higginson IJ, Downing J.

Accepted for publication (2018): **The Patient - Patient-Centered Outcomes Research**

Aims

- i) Which outcomes (areas of wellbeing) matter to children and young people with life threatening or limiting conditions?
- ii) to develop a conceptual framework of health outcomes, meaningful for children and young people, which can inform the development of a person centred measure for this population

Results

- 13,567 abstracts were evaluated; 81 studies included.
- 58 (73.4%) studied cancer patients.
- A total of 3,236 children and young people, 2,103 family carers, 108 families, and 901 healthcare providers were included
- Children and young people not included in 30% of the studies, and a further 35% involved mixed samples of CYP and proxies.
- Findings were categorised and synthesised by domain, outcome themes and examples of outcome

Results

Physical wellbeing (n=62)

- Physical symptoms and symptom distress
- Function (what they could do)
- Treatment related concerns (especially side effects and treatment related pain)

Emotional wellbeing (n=65)

- Emotional aspects of illness, both positive and negative
- Behavioural (usual behaviours and change)
- Body image
- Self esteem
- Growth or maturing in emotion and development
- Being able to cope with illness and related matters

Social wellbeing (n=31)

- Relationships (family, friends)
- Perspective of others about themselves
- Doing normal (usual family and friends) activities
- Life values (what is important)
- Playing and having fun

Results

Spiritual/existential wellbeing (n=37)

- Worry about not being there / death
- Meaning of illness / why
- Connectedness with something wider or beyond

Other (n=28)

- Communication and information
- Decision making – having a part
- Care provision – who and when
- No money / financial concerns
- Having to be in strange environments

Implications

- Vary by developmental age, but overall consistency of domains
- Complex symptoms and related concerns remained a major theme
- Five main domains with sub-domains provide a useful framework
- However, children and young people not interviewed in 30% of the studies, and 35% were mixed samples of children and proxies,
 - low level of involvement in the research that should inform their care

Summary:

- Measuring outcomes is important
- **MUST** reflect the concerns of children and young people with life limiting illness (and their families) themselves
- Need to remember purpose: NOT a vehicle to deliver or reflect all of care, but simply 'headline' areas which – if used well – will reflect main impact of care for **every** child or young person
- No psychometrically robust measures
- (but work has started: 4 year EU-funded project)

Thanks to Eve Namisango and Christina Ramsenthaler



Thank you

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