The Outcomes Assessment and Complexity Collaborative – OACC

A project on implementing outcome measures into palliative care across settings

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www.kcl.ac.uk/palliative
Declaration of interests

Academic institution: King’s College London

Working with the charity Hospice UK, and with Professor Kathy Eagar from Wollongong University

NOT working with any ‘for profit’ organisations

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OACC – what is it?

A collaboration in UK (London) to implement outcome measures into palliative care practice:

- develop and provide staff training to support the implementation of these outcome measures
- integrate health information technology to establish workable ways of capturing and processing outcomes data
- provide regular feedback of outcomes to the teams, using Quality Improvement Facilitators to directly improve patient and family care
OACC – what is it?

Now extending nationally across England

Very much in partnership with Hospice UK

- Also working with:
  Dr Bee Wee, National Clinical Director
  NHS England & Public Health England
  Palliative Care Funding Pilots
  Other partners

- An ‘open’ collaborative
Short term objectives

A **common set of outcome measures** to capture patient needs and outcomes

- measures which work hard for us (capture needs, complexity, outcomes and can deliver quality indicators)
- aligned with other national and other initiatives
  - national Palliative Care Clinical Dataset
  - Development Currency in England
  - Minimum Dataset (MDS)
Medium term objectives

To **implement the common set of measures** to capture patient needs, complexity, and outcomes

Work towards linked / pooled outcome data to better understand the population needs and outcomes

- to support evaluation of interventions
- to support quality improvement
- to enable realistic and meaningful benchmarking
Long term objectives

To regularly map casemix-adjusted outcomes across settings and services

To support quality improvement

PRINCIPLES THROUGHOUT:

Better care for patients and families

Inclusivity, patient- and family-centeredness, bridging evidence and practice
Why is this important?

• palliative care has relied on a combination of patient stories and the ‘drawerful of thank you letters’ as proof of a good job well done

• drive within the health system towards outcomes-based health care

• major financial constraints – UK faces up to a 25% health budget ‘gap’ by 2020

• will outcomes be imposed or will the speciality drive forward use of the best possible outcome measures?

1. good pain and symptom control
2. family support and reduction in burden on family
3. having priorities and preferences listened to and accorded with
4. achieving a sense of resolution and peace (time and support for preparation)
5. having well-coordinated and well-integrated care, with continuity of provision (not fragmentation of care e.g. avoiding not knowing professionals, having to repeat to different professionals, etc)
What outcome measures to use?

- **Phase of illness**
  - Australian modified definitions (good reliability)

- **Functional status**
  - Australia-modified Karnofsky Performance Scale
    - valid, reliable, in cancer & non-cancer, more discriminatory than ECOG or WHO performance status
    - (could also use ECOG or WHO but less discriminatory)
  - Barthel 10 item (for inpatients only)

- **Problem severity**
  - Integrated Palliative care Outcome Scale IPOS (+ Views on Care)
    - valid, reliable, sensitive to change, brief
    - (could also use ESAS or MSAS-SF but symptoms only)

- **Family caregiving strain and support needs**
  - 2 carer questions (+ Zarit Carer Interview)
Spell of care

Phase 1
Phase 2
Phase 3

1. Phase of illness
   - AKPS
   - IPOS
   - Barthel (IP* only)
   - Carer measures*

2. Monitor phase of illness daily or with each contact

3. AKPS
   - IPOS
   - Views on Care
   - Barthel (IP* only)
   - Carer measures*

4. AKPS
   - IPOS
   - Views on Care
   - Barthel (IP* only)
   - Carer measures*

5. AKPS
   - IPOS
   - Views on Care
   - Barthel (IP* only)
   - Carer measures*

* IP = Inpatient

* Carer measures as close to first assessment / admission or phase change or discharge as possible

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Practical issues – who records?

- Ideally patients themselves (Patient Reported Outcome Measures - PROMS) BUT
  - In palliative care many too ill or lack capacity to complete; ~60% hospice pts and ~15-25% community patients need help completing outcome measures (Etkind 2014).
- Proxy reporting (family or staff) is both necessary and useful (Kutner 2006)
- Therefore appropriate to use proxy measures
- Person-centred outcome measures (PCOMs) proposed in palliative care, instead of PROMs (Etkind 2014)
Practical issues – how to implement?

- Involve key people
- Prepare systems (especially IT)
- Preparing the team
- Training
- Starting to use the outcome measures
  - Go step by step, revisit training
- Feeding back data to inform care
- Understanding what is working and what is not
- Using the data to improve care
  - Also audit, service improvement, business case, appraisal, annual report, national data, funding, etc
Resources to support implementation

• In partnership with Hospice UK, the Cicely Saunders Institute has developed OACC Resource Packs (training and other support materials) to help palliative care services implement outcome measures

• Any palliative care team can purchase these Resource Packs at cost
  - King’s College London eStore (search ‘oacc’) or email oacc@kcl.ac.uk
Second edition published April 2015

Introducing the Outcome Assessment Complexity Collaborative (OACC) Suite of Measures

A Brief Introduction

Witt J, Murtagh FEM, de Wolf-Linder S, Higginson IJ, Daveson BA
A brief ‘How to Guide’ for implementing and using the OACC suite of outcome measures

Authors: Dawkins M and de Wolf-Linder S

Reviewers: Witt J, Murtagh FEM, Bunnin A, Taylor R
How does OACC fit with national work?

- Demographic data (ID number, initials, dob, gender, ethnicity)
- Start of episode of care:
  - Referral information (referral date, reason, family practitioner, setting, ‘ready’ date, start date, location, living alone, diagnoses, postcode, formal disability)
- End of episode of care:
  - ‘end date’, outcome, discharge destination, death
How does OACC fit with national work?

- OACC Outcomes data:
  - Phase of Illness
  - AKPS
  - IPOS-5

- Views on Care - 1Q
- 2 carer questions
- Who collected
How does OACC fit with national work?

- OACC Outcomes data:
  - Phase of Illness
  - AKPS
  - IPOS - full
  - Barthel (inpatients)
- Views on Care - 4Q
  - 2 carer questions
  - Zarit Carer Interview
  - Who collected
We have learnt 5 T’s about outcome measurement...

• IT
• Training
• Timing
• InTegration
• To go steadily …
We have learnt 5 T’s ...

• IT – sort out first and make it as simple as possible to enter outcomes data
• Training – not once, re-visit regularly, feedback outcomes collected to inform care
• Timing – when to capture outcomes
• InTegration – ensure clinical change drives outcomes capture and it is built into practice as much as possible
• To go steadily … better to go for good quality data and build this slowly …
Training on why as well as how

- hard (but not impossible) to measure – is only the ‘headlines’
- will never represent all of care – not intended to
- context of declining health:
  - ‘a positive difference’ may well be preventing deterioration, maintaining mobility, lessening the impact of symptoms, rather than improvement as such
Timing of measures

- ensure consistency in timing
- First assessment is easiest to capture
- Then fixed time versus Phase of Illness
- Phase of Illness has the advantage of following clinical changes
- Need to ensure Phase of Illness is working well first
Integration

• Delivering and improving clinical care is what motivates most staff
• Building into practice
• Streamlining outcome data entry to make it as easy as possible and to avoid duplication of effort
• Ensuring ‘live’ feedback and use of the outcomes data in:
  – day to day practice
  – MDM discussions
  – team case reviews and feedback sessions
  – discharge letters and other communications
In summary....

- The OACC project has made considerable progress
- Need to have a common set of outcome measures nationally (and perhaps internationally?)
- Need to align with national policy and initiatives at every stage in your own country
- A number of challenges, but ....
- ...considerable benefits to palliative care practice
- Collecting meaningful outcomes data strengthens palliative care in the context of wider health system
- Visit Cicely Saunders Institute stand for more information or to find out about OACC Resource Packs
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