How to build research capacity in palliative care?

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Learning Objectives

• Introduction to research in palliative care
• Discuss research capacity building
• Identify key research priorities
• Discuss the importance of getting the research question right.
• Generate a novel, interesting, specific and answerable research question.
Evidence based practise

- to develop, strengthen and implement, where appropriate, palliative care policies to support the comprehensive strengthening of health systems to integrate evidence-based, cost-effective and equitable palliative care services in the continuum of care, across all levels, with emphasis on primary care, community and home-based care, and universal coverage schemes

WHA May 2014
Evidence based practise

Why is it difficult in palliative care?

- Relatively new area
- Vulnerable patients and families
- High attrition
- Debate about ethics
- Lack of resources; human and financial
- Focus on service commitments
- Lack of academic centres and leadership
- Paucity of tools and methods
- Lack of incentives; opportunities, career paths
- Lack of a culture of evidenced based practise
Identification of research priorities

1. Have an idea
2. Explore that idea
3. Identify knowledge gap
4. Generate a research question
5. Design and carry out research
6. Publish and present
1. Ideas

• How to get ideas?
  • Pure inspiration (rare)
  • Critical reading of published papers
  • A conference or seminar
  • Observing patients
  • Speaking to other researchers
  • New technologies bring in new questions
  • A doubt raised by a colleague
2. Explore ideas

- Know the topic
- Know the problem
  - include observations and experience
- Know the current state of knowledge
  - think about data at your disposal
- What is the gap in knowledge?
  - literature review

- “It is not the answer which enlightens but the question” Eugene Ionesco
3. Identify knowledge gap

- In order to develop a *novel* question we need to do a literature search
- What is known about the topic:
- Areas for elaboration
- Unanswered questions
- Gaps in understanding
- How have similar questions previously been stated?
- What concepts/variables are associated with the problem?
3. Generate Research Question

- F – Feasible
- I – Interesting and important
- N – Novel
- E – Ethical
- R – Relevant

4. Design and carry out research

**Quantitative**
- Evidence is gathered systematically and is seen to be objective
- Normally it is numeric in nature
- Tends to focus on a small part of the human experience e.g. severity of pain

**Qualitative**
- Data is narrative
- Tries to address the dynamic, holistic and individual aspects of a phenomenon, within the context of those experiencing it.
- Rich in-depth information is collated e.g. meaning of pain
Identification of research priorities

Experience from Africa MPCU, PCAU and APCA

3 broad themes
1. Patient, family and volunteers
2. Health providers
3. Health systems
Evidenced based palliative care

Health systems integration

■ How to integrate palliative care within a government and academic institution?
■ How to foster and support a culture of evidence based practice?
■ How to improve access to quality palliative care?
■ How to influence the values of a health system to recognise, own and deliver palliative care….and the health systems itself?
MPCU model; ensuring quality

Research agenda

- support, develop, deliver and evaluate palliative care in a hospital setting and ensure its integration into the community

- 3 main strands;
  - 1. Patient needs and perspectives
  - 2. Staff needs and perspectives
  - 3. Frameworks and models of care
1: Patient needs and perspectives

MPCU needs assessment

- point prevalence study
- baseline for advocacy and planning
- 267 notes reviewed
  - 122 (45%) life-limiting illness
  - HIV/AIDS 73, cancer 21, renal failure 11, heart failure 8
- 3% known to PC service
- 78 interviews

Lewington, Namukwaya, Limoges, Leng and Harding
BMJ Support Palliat Care 2012;2:140-144
1: Patient needs and perspectives

Needs assessment

- development of standardised tool
- regular use of instruments
  - Africa APCA POS
- intervention study to measure impact
1: Patient needs and perspectives

- Information needs and sources of women with cancer of the cervix

“When you finish your radiotherapy do your sexual feelings return...will it destroy my marriage”

Abstract presented AORTIC, PCAU, APCA 2013
1: Patient needs and perspectives

- Collaboration with ICPCN and APCA
- Participation in development of paediatric POS
- Review of tools used for paediatric pain assessment

- Collaboration with University of Edinburgh
  - Two versus three steps of ladder
  - Need of heart failure patients
  - Development of nurse leaders
2: Staff needs and perspectives

- Attitudes and beliefs about morphine among health care staff
  
  “…the users tend to be physically and psychologically dependent, so they think they need the substance…. I haven’t seen it but it is something I have read about, it is well documented in motion pictures and is widely publicized”

- Prescribing audit

Abstracts presented APM 2012, IAPC 2014
2: Staff needs and perspectives

- Curriculum integration
  - “It (clinical attachment) has made a very big impact. My practice has changed, not only in Palliative Care, even the other illnesses. There’s more to caring for the person than just that (the disease). It feels more satisfying.” Postgraduate internal medicine

Abstracts presented IAPC 2011, 2014
2: Staff needs and perspectives

- training, mentorship and building capacity for research
- workshops
- support delivery of BSc module *introduction to research and research project* 2010-2015
- Advanced Research school Nov 12th to 23rd 2012
3. Frameworks for care

- Link nurse programme
  - 27 trained and given ongoing mentorship
  - Use of clinical protocols and modeling
  - Integrating and supporting PC skills
  - Evaluation includes activity, training impact, competencies achieved, improvement in patient outcomes

Abstracts on model and evaluation 2011-2014; with reviewers
3. Frameworks for care

MPCU model

- Patient categorised based on severity of needs (1-4)

- **Level 4**: Complex needs requiring referral and input from multiple members of the specialist PC team.

- **Level 3**: Complex needs requiring referral and input from one member of the specialist PC team.

- **Level 2**: Generalist needs can be met at ward level but health care workers need some additional training.

- **Level 1**: Generalist needs can be met at ward level by all health and social care workers (needs curriculum integration).

*Abstracts APCA, AORTIC, IAPC 2013-14, with reviewers*
3. Frameworks for care

2012: 95 patients, 425 visits
2013: 236 patients, 1173 visits

Support provided to patients by the volunteer service 2013
3. Frameworks for care

- Opioid consumption; proxy indicator for PC
3. Frameworks for care

• Integrate project (THET/DFID UK)
  • Strengthening and integrating PC into national health systems in 4 countries
• [http://integratepc.org/](http://integratepc.org/)
The Question....

• Getting the right question is as important as obtaining the answer to the question is the driving force behind the research.
Exercise

- Think about FINER and identify two research questions in areas that you are interested in studying or think are important for palliative care

- F – Feasible
- I – Interesting and important
- N – Novel
- E – Ethical
- R – Relevant
Way forward

• Build a culture of evidence based practise
  • build into strategic planning
  • embed coherent and integrated approach
  • allow evidence based practice to become routine.
  • offer incentives and career path

• Develop research agenda and priorities
  • use existing data sets
  • generate research questions
  • get started and be resilient
  • identify funding; should be costed but may not need large funding
Way forward

• Build capacity throughout your team
  • review needs
  • develop critical appraisal; journal clubs, problem solving
  • build specific skills eg qualitative methodology
  • consider research school / tailored training / advanced skills

• Form research collaborations and networks
  • consider areas such as basic science, sociology, anthropology, public health, multi-professional groups

• Encourage publication and present findings
Enjoy!