Understanding complex need in palliative care: the perceptions of professionals across 3 settings

Sarah Johnston¹, Catherine Winstanley¹, Jamie Morrish², Anne Finucane³, Juliet Spiller³, Emma Carduff⁴

¹University of Edinburgh, ²University of Aberdeen, ³Marie Curie Hospice, Edinburgh, ⁴Marie Curie Hospice, Glasgow.

Introduction

- Specialist palliative care (SPC) is for patients with ‘complex’ needs but these needs are not well defined.
- Clarity is necessary to meet the needs of patients and their families in all settings, at all times.

Aim

To explore professionals’ perspectives of patient complexity in PC across 3 healthcare settings.

Methods

Figure 1: Triangulating 3 qualitative studies.

Qualitative

Primary Care
- 11 participants
- Semi-structured, telephone interviews
- Thematic analysis

Acute Medical Unit
- 13 participants
- Semi-structured, face-to-face interviews
- Grounded theory and thematic analysis

Specialist Palliative Care
- 10 participants
- Semi-structured, face-to-face interviews
- Thematic analysis

Triangulation of Three Studies

Workshop
Diagrammatic mapping to extract core themes

Results

Figure 2: Diagrammatic representation of core themes and those specific to each setting.

Figure 2:

- Specialist Palliative Care
  - Spiritual care
  - Patient communication
  - Inappropriate referrals

- Core Themes
  - Interaction
  - Social factors
  - Therapeutic intervention
  - Setting
  - Prognostication
  - Communication

- “Generalists”
  - Identification
  - Inexperience
  - Skills
  - Training
  - Support
  - Time constraints

- Acute Medical Unit
  - Inappropriate referrals

- Inappropriate referrals

“...the trickiest patients are patients who’ve got a real disease and real problems that are causing symptoms but when their symptoms are...when there is a big psychological element to their symptoms. That’s when it becomes really tricky.” (Doctor, SPC)

“Families are just exhausted and at breaking point and aren’t really able to support the patient anymore.” (Nurse, AMU)

“We were prognosticating them wrong, we were trying our best but it took someone who specializes in dying to see more clearly...” (GP)

“The difficulty is knowing whether it is something that they will want to talk about or not, because you don’t want to be in that situation where you force them into that conversation that they’re not wanting to have and are not ready to have...” (GP)

Implications

1. EDUCATION and TRAINING
   - There is a role for SPC to support “generalists”, at all levels through education.
   - Ensure confidence building and reduce ‘perceived complexity’.

2. COMMUNICATION and CO-ORDINATION
   - Requires a holistic approach within and between generalist and specialist teams.

3. EARLIER IDENTIFICATION
   - Could improve the management of complex needs.
   - Integrated approach to help guide patients to the most appropriate palliative care setting and avoid “setting-related” complex needs.

Conclusion

- Complexity is inherent patient complexity in one or more dimensions of care, and perceived complexity.
- Both necessitate reaction and intervention to increase generalist confidence and skill in providing multidimensional palliative care.