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INVOLVING HEALTHCARE PROFESSIONALS AND FAMILY CARERS IN SETTING RESEARCH PRIORITIES FOR END-OF-LIFE CARE IN GREATER MANCHESTER

Janet Diffin[1], Michael Spence[2], Rebecca Spencer[2], Peter Mellor[2], Gunn Grande[1]

[1.] Division of Nursing, Midwifery and Social Work, School of Health Sciences, University of Manchester, UK

[2.] NIHR Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Greater Manchester, UK

- Janet Diffin: Research Associate, The University of Manchester, Manchester, UK.

- Michael Spence: Programme Manager, NIHR Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Greater Manchester, Manchester, UK.

- Rebecca Spencer: Project Manager, NIHR Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Greater Manchester, Manchester, UK.

- Peter Mellor: Facilitator, NIHR Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Greater Manchester, Manchester, UK.

- Gunn Grande: Professor of Palliative Care, The University of Manchester, Manchester, UK.

Corresponding Author

Janet Diffin

Division of Nursing, Midwifery & Social Work

School of Health Sciences

Faculty of Biology, Medicine and Health

The University of Manchester

Oxford Road

Manchester M13 9PL

Email: janet.diffin@manchester.ac.uk

Phone: (+44) 161 3067817

ABSTRACT

It is important to ensure regional variances are considered when setting future end-of-life research priorities, given the differing demographics and service provision. This project sought to identify end-of-life research priorities within Greater Manchester (United Kingdom). Following an initial scoping exercise, six topics within the 10 national priorities outlined by The Palliative and end-of-life care Priority Setting Partnership were selected for exploration. A workshop involving 32 healthcare professionals and a consultation process with 26 family carers was conducted. Healthcare professionals and carers selected and discussed the topics important to them. The topics selected most frequently by both healthcare professionals and carers were 'Access to 24 hour care', 'Planning end-of-life care in advance' and 'Staff and carer education'. Healthcare professionals also developed research questions for their topics of choice which were refined to incorporate carers' views. These questions are an important starting point for future end-of-life research within Greater Manchester.

BACKGROUND

It is vital to focus on research that is most likely to bring benefits to local patients and their families within end-of-life (EoL) care. Within the UK, the Palliative and end-of-life care Priority Setting Partnership (PeolcPSP) worked with patients, carers, and health and social care professionals to identify and prioritise research questions to influence future end-of-life care research (PeolcPSP, 2015). This partnership identified ten topics for future EoL research (See Supplemental File 1 for a summary of the ten topics). However, it is also important to ensure that regional variances in population demographics and service provision are taken into account when setting future EoL research priorities. The All Ireland Institute of Hospice and Palliative Care (AIIHPC) have already adapted the priorities to Northern Ireland and the Republic of Ireland specifically (AIIHPC, 2015). However, variations in service provision within EoL care across different localities have also been reported within England (Personal Social Services Research Unit, 2015; Care Quality Commission 2016). The aim of this project was to identify EoL research priorities specific to Greater Manchester via a consultation process with both healthcare professionals (HCPs) and carers.

METHODS

Initial scoping by The National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care Greater Manchester (CLAHRC GM) with a wide range of HCPs from primary, community and secondary care about local EoL care services within Greater Manchester identified five main themes for future research in end-of-life care (CLAHRC GM, 2016). These themes overlapped with six of the national top ten priorities identified by PeolcPSP (Figure 1). These six local priority topics formed the basis of the consultation process carried out by CLAHRC GM with HCPs and carers.

[Insert Figure 1]

Consultation with healthcare professionals

HCPs from various care delivery settings and organisations within Greater Manchester were purposively selected and invited to attend a workshop facilitated by staff within CLAHRC GM. Prior to attendance, HCPs chose two topics from the six local priority topic areas and were allocated to facilitated discussion groups related to their chosen topics. Within these group discussions, HCPs discussed why their chosen topics were important to them and developed research questions that they felt would be important to address. Details of all discussions were recorded on flip charts and notes were transcribed.

32 HCPs took part in the consultation; 44% (14/32) were clinicians, 40% (13/32) were senior managers and 16% (5/32) were managers in a quality improvement, practice development or research role. A wide range of clinicians were involved, including palliative care consultants, GPs, nurses and EoL care facilitators. Managers were generally directors or leads for services such as palliative care, community EoL care, nursing home services or the complex discharge service.

Consultation with carers

Carers from seven local carer groups within Greater Manchester that had experience of, and an interest in EoL care were invited to be part of the consultation process. A range of methods were used including informal workshops facilitated by two members of CLAHRC GM staff at each carer organisation, and one-to-one telephone and face to face interviews conducted by a CLAHRC GM facilitator. Carers selected which of the six topics they wanted to discuss including why that topic was important to them. Unlike the HCPs who were limited to two choices, there was no restriction on the number of topics that carers could select. The discussions (where consent was gained) were recorded and subsequently transcribed verbatim, with key points recorded on flipchart paper. All the information from the audio recordings, flip chart notes, and completed data collection forms was organised under the six main topic areas.

26 carers took part in the consultation process. Table 1 presents the demographic information. The majority were previous carers (58%, 15/26). In addition, 54% (14/26) had been in a caring role for two or more different people, with an average time period of 12.5 years (ranged from 8 weeks to 69 years). The majority (55%; 14/26) were carers for older adults between 65-84 years old.

[insert Table 1]

RESULTS

Topics of shared importance

The three topics selected most frequently for discussion by HCPs were: Planning end-of-life care in advance, Access to 24 hour care, and Knowledge and education (Figure 2). Four out of the six topics were selected most frequently by local carers: Knowledge and education, Access to 24 hour care, Consistent/continuity of care, and Planning end-of-life care in advance (Figure 3).

Overall, there were 3 shared topics of highest priority for both HCPs and carers:

1) Access to 24 hour care

2) Planning end-of-life care in advance

3) Staff and carer education

[Insert Figure 2]

[Insert Figure 3]

Themes emerging across topic areas

Three common themes emerged from the discussions with both HCPs and carers which spanned

across all six topics areas:

1. The need for improved communication with patients and carers, and between different

   services and/or agencies.

2. The need for equal access to care across different diagnosis groups, socio-economic status

   and geographical location.

3. The management of both the patient and carers, and HCPs expectations in relation to their

   involvement in various aspects of care.

Refining research questions

Research questions were developed by HCPs in relation to each topic during the workshop. Carers'

views on why each topic was important to them were used by the project team to help refine these

questions and to ensure that their views were represented. Table 2 displays the research questions

developed for the 3 shared topics of highest priority for both HCPs and carers. Table 3 displays the

research questions for the three remaining topic areas.

[Insert Table 2]

[Insert Table 3]

CONCLUSIONS

The overall aim of this project was to identify the local EoL research priorities for Greater Manchester via a consultation process with both HCPs and carers. All six topics selected for inclusion in this consultation process were relevant for HCPs and carers, which validates the national findings. Three topics in particular had shared importance for both HCPs and carers; 'Access to 24 hour care', 'Planning end-of-life care in advance' and 'Staff and carer education'. However, moving forward, any one of the research questions developed for each of the six topics could be used as a starting point for future EoL research. Whilst further work is required to further define these relatively broad questions and to ascertain if the current literature may indeed already sufficiently address some of the questions, they provide an excellent starting point for future EoL research within both the clinical and academic communities of Greater Manchester.

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Table 1: Carer demographic information

Carer Demographics	N	%
Carer role		
Current carer only	2	8
Previous carer	15	58
Current carer and a previous carer	9	34
Age		
35-44	2	8
45-54	3	11
55-64	5	19
65-74	6	23
75-84	9	35
85-94	1	4
Ethnicity		
White	26	100
Religious background		
Christian	21	82
Jewish	2	7
No religion	3	11

Table 2: Refinement of research questions for the three shared topics of highest priority for HCPs and carers

ACCESS TO 24 HR CARE AND SUPPORT	PLANNING END-OF-LIFE CARE IN ADVANCE	STAFF AND CARER EDUCATION
1. What does effective and appropriate 24 hour care look like: - **For carers?** - **For professionals?** - **Across all settings?** 2. What resources are required to deliver 24 hour care? - What is the specialist/generalist mix required? 3. How does the need for 24hr care vary: by disease diagnosis? - by demographic/socio-economic factors? - By locality? - 4. Does the Electronic Palliative Care Co-ordination Systems (EPaCCs) impact on any variations identified? 5. What are the barriers to delivering 24 hour care across different disease groups at different points in the end-of-life pathway and how can these be overcome? 6. Can comparable locality specific service models be identified in order to generate evidence of effectiveness of 24 hour care?	1. How are ACP discussions held with patients and carers? **2. How can ACP discussions and decisions be communicated effectively between healthcare providers in different settings?** - How effective is EPaCCs* in communicating and sharing ACP to a variety of HCPs across different services/settings? 3. What resources are needed to provide general nurses with the skills to have ACP discussions? **4. What are carers' and patients' views and understanding of ACP?** - **Who do they feel should be initiating ACP conversations?** - **Do they feel ACP discussions are effective?** - **When is the most appropriate time to have ACP discussions?** - **Is ACP the most applicable name?**	**1. What are the education and training support needs of carers across the end-of-life care trajectory?** 2. What further training is required for HCPs working within end-of-life care? 3. What is the most effective way of engaging staff in further training/education?

± Questions in bold highlight inclusion of carers' views

*EPaCCs: Electronic Palliative Care Co-ordination Systems

Table 3: Refinement of research questions for the three remaining topic areas

CONSISTENCY/CONTINUITY OF CARE	CARE AT HOME	EQUAL ACCESS FOR ALL
1. What are the benefits of key workers in end-of-life care? - **What tasks and activities does this role require?** - **What skills are required by the professional who takes on this role?** **2. Do carers believe they have received consistent care?** - **How could this have been improved?** **3. What happens to patients with various diagnoses at the point of discharge from specialist centres?** - **How can continuity of care be promoted at the point of discharge?** **4. What does 'good' continuity of care look like from service, professional and patient/carer perspectives?** - **Can continuity of care be measured in end-of-life?** - **How can this be benchmarked to best support best practice?** 5. How can care planning documentation be standardised across services and organisations to promote continuity? **6. How can communication be improved across various agencies and services in order to promote continuity of care and what would enable this?**	1. How does the quality of Advance Care Planning affect the effectiveness of care at home? 2. What are the differences in the provision of care at home across different localities within GM? - How can this best be investigated? - Is a service evaluation required? 3. Do community specialist services improve the quality of care at home and how could this best be measured? - Are there differences between cancer and more chronic conditions? **4. What are carers' and patients' views on what effective care at home is?**	1. What can and should be measured in terms of equal access to care? 2. How can the Care Quality Commission (CQC) gold standard of end-of-life care be achieved and what data should be collected to evidence this? - What enables certain areas in GM to achieve the gold standard of care? **3. How can equal choice for all best be achieved?** - **What should be the minimum level of care offered to all patients?** - **What can patients and carers expect in terms of end-of-life care? (E.g. maximum wait times to access to services such as hospice care?)** - **How can a personalised care approach be developed which takes account of patient and carer preferences, including cultural and spiritual needs?**

± **Questions in bold highlight inclusion of carers' views**

1. Staff and carer education   2. Planning end-of-life care in advance

3. Access to 24 hr care and support   4. Care at home

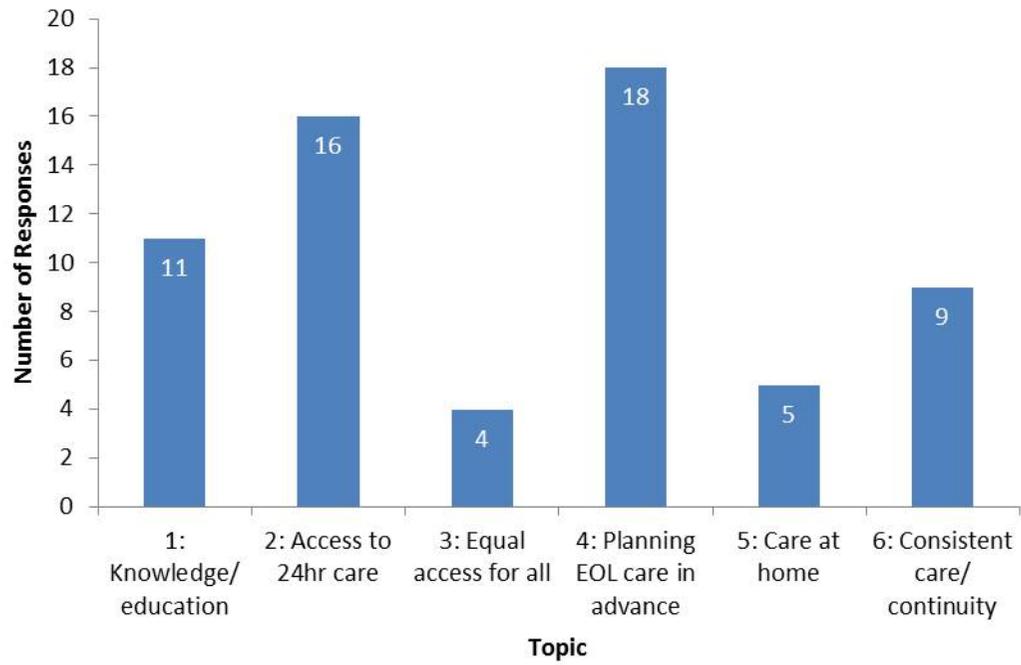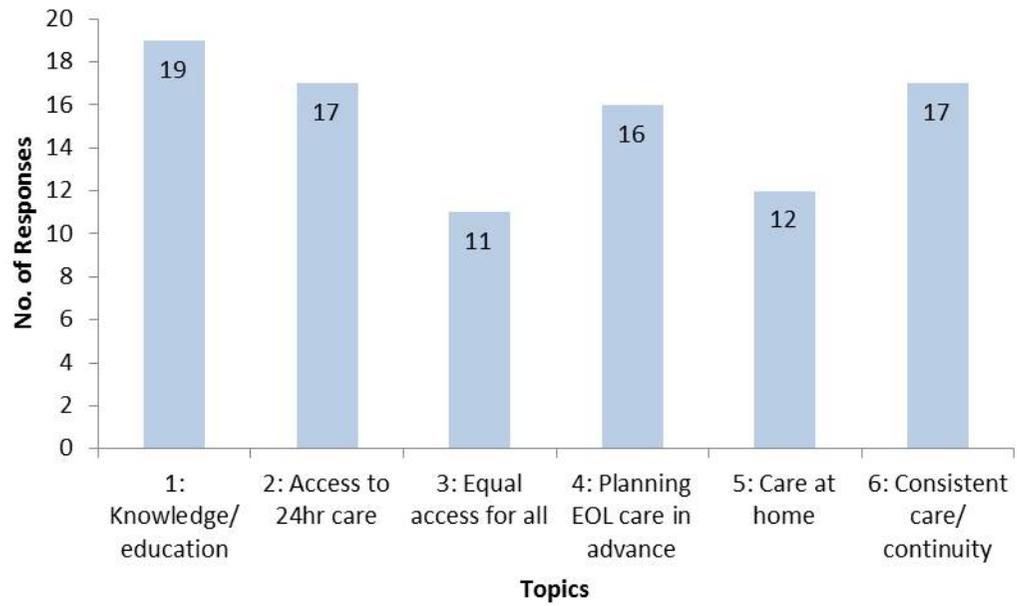5. Equitable access   6. Continuity of care

Figure 1

Figure 2

Figure 3