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What prevents advance care planning in Haematology?

A multi-perspectival Interpretative Phenomenological Analysis (IPA)

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Research Question

- What do doctors and nurses identify as the barriers and facilitators to Advance Care Planning (ACP) for adult patients with haematological malignancies?

Haematological Malignancies

- Account for 7% of all cancers
- 5th most common cancer in the UK
- Mortality risks vary
  - 5yr survival rates for Acute Myeloid Leukaemia (AML) as low as 8%
  - Survival of Hodgkin's Lymphoma estimated 75%
  - Likely higher as cause of death often different e.g. infection

(NICE, 2016)

End of Life Care in malignant haematology

- Meta-analysis: Hospital death twice as likely for Haematology cancer patients as it was for other cancers (OR 2.25; 95% CI, 2.07-2.44) (Howell et al, 2010).

- 68% of deaths related to haematological cancers occurred in hospital, compared to 47% of non-haematological cancers (NCIN, 2011).

- Meta-analysis: compared to other cancers, half as likely to receive specialist palliative care or hospice services (Risk Ratio 0.46; 95% CI 0.42–0.50) (Dixon et al., 2016) .

- Associated with aggressive EOL treatment in multivariate analysis (OR 6.6, 95% CI 4.1–10.7, $p<0.001$)(Hui et al. 2014)

ACP in haematology

- Howell et al. (2017) patients with haematological malignancies without documented PPD discussions were significantly more likely to have died in hospital when compared to those with such discussions (84% vs. 62%, $p \leq 0.0001$).

- Odejide et al. (2016) sample of 345 haematologists
  - 55.9% report EOLC discussions occur 'too late'
  - tertiary centres significantly more likely to report late discussions than those in community centres (64.9% vs. 48.7%, p=0.003).

Why do ACP?

- Dying in hospital associated with significantly lower-quality care than other settings (ONS, 2016)

- Secondary analysis of VOICES (Dixon et al., 2016)
- Documented PPD had the largest effect on overall quality of care when compared to other factors.
- Patients who were engaged in ACP were twice as likely to receive care reported as ‘outstanding’ or ‘excellent’ (Odds Ratio (OR) 2.27; 99% CI 2.04 to 2.53).

- Estimated daily cost of EOLC in the community at £145, compared to £425 in hospital (Marie Curie Cancer Care, 2012).
- £280 differential across 230653 total hospital deaths (ONS, 2017) amounts to approximately £64.5million per day

Existing evidence

- Research examining doctors' and nurses' perceptions of ACP in haematology is limited. No published UK studies.

- Literature review: 9 studies (2 qualitative methods and 5 quantitative, 2 mixed methods)

- Thematic synthesis: (evidence inconsistent)
- Patient characteristics e.g. Age (older more likely)
- Disease & treatment characteristics (may be related to prognosis)
- Psychological factors & attitudes e.g. 'ignorance is bliss' coping methods (less likely)
- Organisational factors: 'working within the culture of cure', documentation etc

Methods

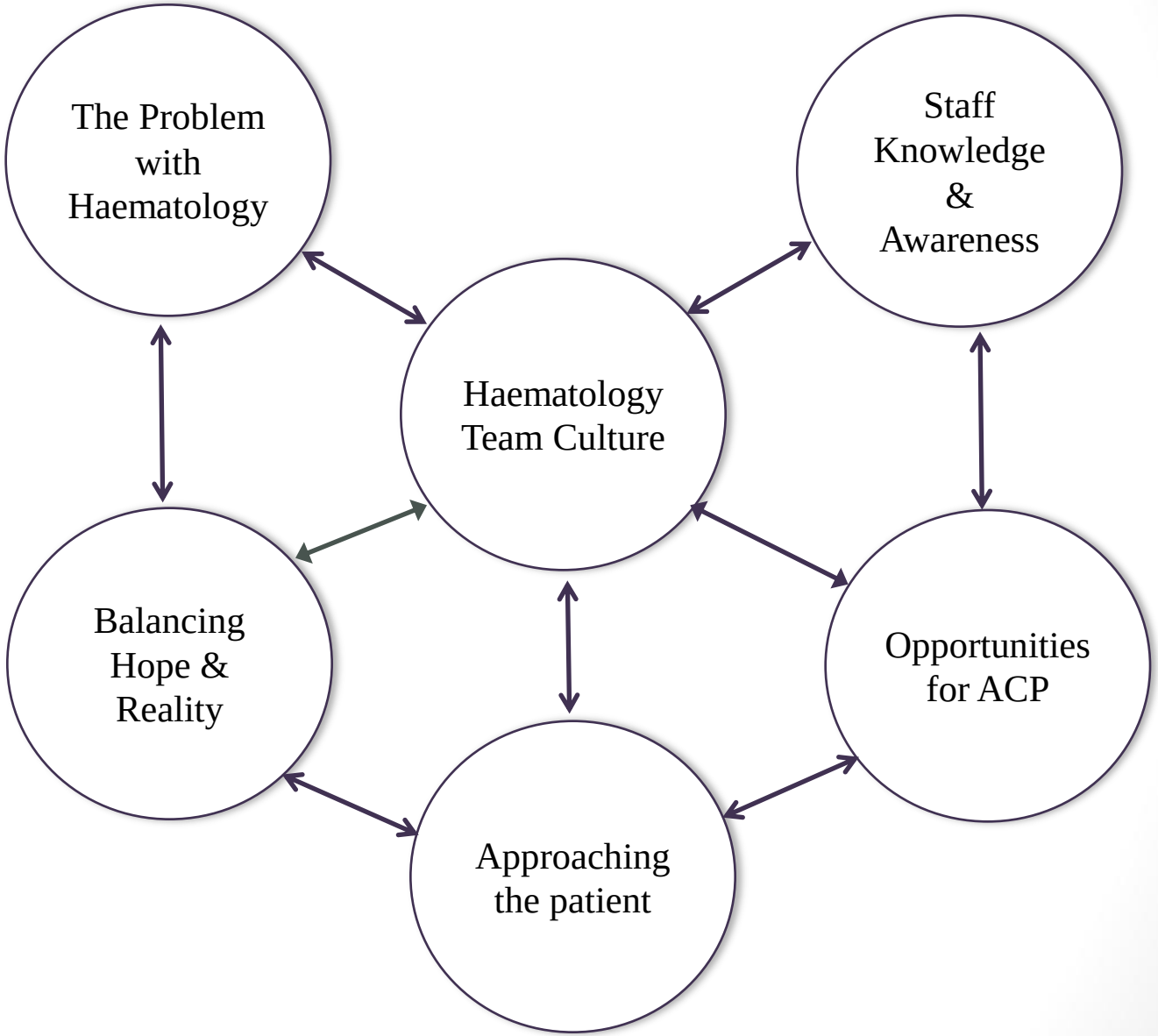
- 5 doctors and 5 nurses currently working in clinical haematology departments at two acute NHS Trust sites in the North West of England
- Purposive referral sampling via research nurse gatekeepers
- Semi-structured, one-to-one interviews.
  - Open questions about understanding of ACP, experiences of ACP, and perceived barriers or facilitators
- Demographic questionnaires.
- Interpretative Phenomenological Analysis (IPA)

Participants

Table 11: Summary of participant demographics	
Job Title	5 doctors: 2 Consultant Haematologists; 3 Specialty Training Registrars (STR) 5 nurses: 3 Clinical Nurse Specialists (CNS); 1 Charge Nurse (CN); 1 Staff Nurse (SN).
Gender	8 Female; 2 Male
Ethnic group	8 'White British/White Irish/White Other'; 1 'Asian/Asian British'; 1 'Other: Arabic'.
Highest level of education	1 Diploma; 4 Bachelor's degree; 1 Undergraduate Master's degree; 2 Postgraduate Master's; 2 Doctorate.

- Interview length: 16 to 78 minutes
- Transcripts: 2000 to 15000 words

Overview of themes



The Problem with Haematology:

- *ACP Shortcomings in Haematology - 'Everything's a rush'*
  - *"I think it's tiptoed around a lot until the last moment of their… like you know let's say last few weeks of their lives"* (Jessie, SN)

- *Prognostic uncertainty: Potentially rapid decline*
  - *"…for most of the haematology patient it is really difficult to know they can relapse out of the blue and er they can die in a few weeks if they don't respond to treatment"* (Michael, Consultant)

- *Focus on cure: 'Treatment to the bitter end'*
  - *"…of many medical jokes that exist it's one of the ones about haematologists it's why do you put..why do you put nails in a coffin? To keep haematologists out."* (Patrick, STR)

Haematology Team Culture:

- *Separation of Person and Disease*
  - *"OK it's a curative but you can see that your patient now is more frail more fragile he can't handle the chemotherapy very well and you think you need to start you know holding your weapons now and leave him alone"* (Olivia, STR)

- *Working Relationships*
  - *"…because I'm not in that wall so I really don't know. In my setting I can tell you it's the fear, because if I speak what have I got option to tell them, where do I stand if I speak about it?"* (Mae CN)

  - *"I just think sometimes it's…[sigh] you're just shoved back into a corner like your opinion doesn't matter"* (Jessie SN)

Haematology Team Culture:

- *Hierarchy of Haematology*
  - *"I always feel like it should be mine but I always feel like I need permission to do it."* (Rachel CNS)

  - *Personality*
  - *"It's our personality. It's our personality. It's nothing else. Some people are risk-takers and others are not. Some people erm think they care better by not letting the patient struggle. But er you know I… anyway… [participant shrugged] I obviously disagree with that [laughs]"* (Robyn Consultant)

  - *"…sometimes the consultants they're a bit more er….. a bit more haematology-ish [laughs] and a bit less good at looking at the patient as a whole er..are the ones that push it"* (Hazel STR)

Approaching the patient:

- *Rapport*
  - *"I think it all just boils down to having a good rapport with the patient erm..feeling trustworthy erm…being that point of contact throughout the journey erm…and knowing that the specialist nurse has got your best interests at heart."* (Eva CNS)

- *Healthcare Professional Emotional Regulation & Discomfort with dying*
  - *"it can be personally difficult" "…you get to know them really well and what makes them tick and then when it comes to that conversation it's quite tricky."* (Rachel CNS)

- *Protective factors*
  - *"…it's for both sides sometimes easier if somebody is older and they've had a quality of life"* (Robyn, Consultant)

Balancing Hope & Reality:

- *Conflict of treatment and ACP*
  - *"…it's difficult for the doctor to speak with about that I've got a miraculous drug that can keep everything under control but by the way you can die in 3 months it's very difficult to do."* (Michael, Consultant)

- *Managing Patient Psychology*
  - *"I don't know how you would cope without any kind of semblance of hope of success but I think it's important that people know that it doesn't always work"* (Patrick, STR)

- *Honesty & Informed Decisions*
  - *"..actually what people would want is for you to be honest with them and give them a bit more of a choice."* (Hazel, STR)

Opportunities for ACP:

- *Recognising & using opportunities*
  - *"…obviously one of the risks of it is death erm…and I think maybe then they could actually..when they discuss that side effect they could maybe go into it a little bit more then."* (Jessie, SN)

- *Creating opportunities*
  - *"…we could try and incorporate it into that because it's erm..it's a one-to-one erm discussion and we try and allow at least 50-60 minutes to go through it so that would be an opportunity"* (Eva CNS)

- *Normalising ACP*
  - *"…if everyone had these discussions with everyone then it's just a normal thing then isn't it I suppose um a little less taboo."* (Patrick STR)

Staff Awareness & Training:

- *Knowledge & Awareness*
  - *"…there probably could be things like that to make people more aware of what it is and how it fits into your job role and with your patient group"* (Rachel, CNS)

- *Training*
  - *"How does the opposite person will feel when I express..? Will I have that emotional control? Will I be able to console family as well as the patient? How much patient's going to take it on board?"* (Mae, CN)

  - *"…like leadership type of training where you could have the confidence to say to other members of the team what you kind of think should happen"* (Hazel, STR)

Clinical Implications

- Consider impact of hierarchical clinical team structure on ACP and explore ways to address this
- Examine existing strategies in order to optimise open, honest and patient-centred shared decision-making in relation to treatment options and ACP, and to ensure current clinical best practice guidelines are adhered to.
- Empowering sufficiently trained nurses to engage in ACP where appropriate, without ‘seeking permission’.
- Consider ACP training delivery and awareness promotion within organisations
  - for nurses and doctors across the hierarchy
  - addresses attitudes, collaborative working and holistic patient assessment
  - explore strategies for managing patient psychology and emphasising the role of ACP despite prognostic uncertainty.

Recommendations for future research

- Examine patient perceptions of ACP and shared decision-making in haematological malignancies.

- Explore feasibility, acceptability and effectiveness in practice of a prompt for professionals to trigger ACP early within routine care

References

- Dixon, J., King, D. & Knapp, M. (2016) Advance care planning in England: Is there an association with place of death? Secondary analysis of data from the National Survey of Bereaved People. *BMJ Supportive & Palliative Care*.
- Howell, D. A., Roman, E., Cox, H., Smith, A. G., Patmore, R., Garry, A. C. & Howard, M. R. (2010) Destined to die in hospital? Systematic review and meta-analysis of place of death in haematological malignancy. *BMC Palliat Care,* 9.
- Howell, D. A., Wang, H. I., Roman, E., Smith, A. G., Patmore, R., Johnson, M. J., Garry, A. & Howard, M. (2017) Preferred and actual place of death in haematological malignancy. *BMJ Supportive & Palliative Care,* 7(2)**,** 150.
- Hui, D., Didwaniya, N., Vidal, M., Shin, S. H., Chisholm, G., Roquemore, J. & Bruera, E. (2014) Quality of end-of-life care in patients with hematologic malignancies: a retrospective cohort study. *Cancer,* 120(10)**,** 1572-8.
- Marie Curie Cancer Care. (2012) Understanding the cost of end of life care in different settings. London: Marie Curie.
- National Cancer Intelligence Network [NCIN]. (2011) *Where do patients with blood cancers die? NCIN data briefing*. London: NCIN.
- National Institute for Health and Care Excellence [NICE]. (2016) Haematological cancers: improving outcomes. London: NICE.
- NIHR (2016) Accessed 28/09/17:https://www.nihr.ac.uk/funding-and-support/funding-for-training-and-career-development/training-programmes/nihr-hee-ica-programme/.

References contd.

- Odejide, O. O., Cronin, A. M., Condron, N., Earle, C. C., Wolfe, J. & Abel, G. A. (2016) Timeliness of end-of-life discussions for blood cancers: A national survey of hematologic oncologists. *JAMA Internal Medicine,* 176(2)**,** 263-265
- Office for National Statistics [ONS]. (2015) National Survey of Bereaved People (VOICES): England, 2015. Quality of care delivered in the last 3 months of life for adults who died in England. London?: Office for National Statistics.
- Office for National Statistics [ONS]. (2016) National Survey of Bereaved People (VOICES): England, 2015. Quality of care delivered in the last 3 months of life for adults who died in England. London: Office for National Statistics.
- Office for National Statistics [ONS]. (2017) Deaths by place of occurrence, England, deaths registered in rolling annual period 2010/11 Q4 - 2011/12 Q3 to 2015/16 Q4 - 2016/17 Q3. Hampshire: Office for National Statistics.
- Smith, J. A., Flowers, P. & Larkin, M. (2009) *Interpretative phenomenological analysis : theory, method and research*. Los Angeles, [Calif.]: Los Angeles, Calif. : SAGE.
- Travers, A. & Taylor, V. (2016) What are the barriers to initiating end-of-life conversations with patients in the last year of life? *International Journal of Palliative Nursing,* 22(9)**,** 454-462.
- Yardley, L. (2015) Demonstrating validity in qualitative psychology. *In:* Smith, J. A. (ed.) *Qualitative Psychology: A Practical Guide to Research Methods.* London: SAGE Publications.

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