The haemato-oncology patient experience of the process of palliative care in the last year of life: A Constructivist grounded theory study

***Karen Campbell* [1], *Fiona Harris* [2], *Kath Stoddart* [2]**
[1] Macmillan Cancer Support
[2] University of Stirling

Abbreviated abstract:

This study reconceptualises the incurable haemato-oncology pathway as a '*Suspended and silent status passage'* with the inevitable outcome of death rather than a possibility of cure. The two core categories '*facing death'* and '*talking about death'* describes the length of time, which is suspended, that the patients face death; where overtime discussions around dying and future care needs are silenced. The findings also illustrate that palliative care service provision should be based upon episodic critical episodes of care allowing responsive process of care.

Related publications:

Corbin, J. & Strauss, A. (1985). Managing chronic illness at home: Three lines of work. *Qualitative Sociology*, 8(3), pp.224-247.
Glaser, B.G. & Strauss. A.L (1971). *Status Passage*. Taylor & Francis.

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kcampbell@macmillan.org.uk

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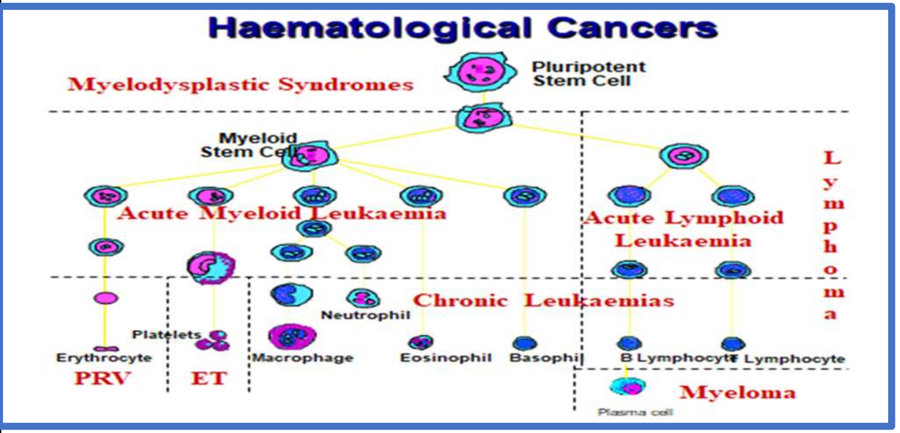
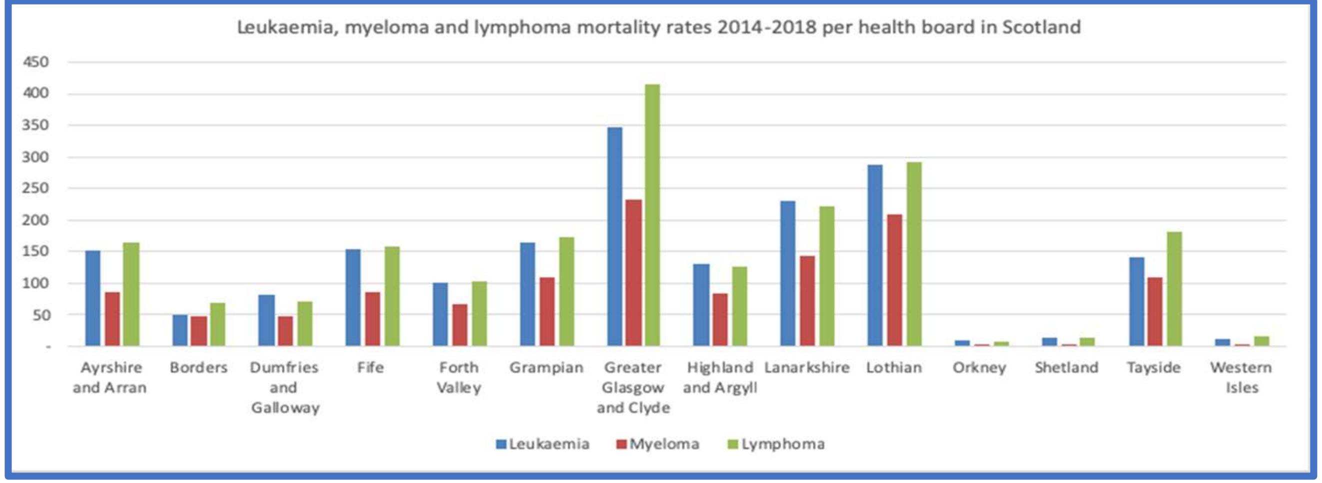
Previous work, challenge, and approach





Population and Disease drivers:

- 40000 people diagnosed each year – 8 % cancer burden in UK
- Three main types Leukemia , Myeloma, Lymphoma
- Survival over 1 year :
    - Acute Leukemia < 10%
- Survival over 5 years :
    - Chronic Leukemia >89%; Myeloma < 50 %; B Cell Lymphoma <50%; Follicular Lymphoma >80%.

Policy Drivers:

British Haematology Society (2004, 2011); NICE Guidance (2003,2004,2016); Cancer Strategy (2016); Palliative care policy (2011, 2016) ; Cancer patient experience survey (2016, 2018); Realistic Medicine (2017); Personalised care (2019).

Key point to formulate research questions and method choice:

- Literature highlights the increasing opportunity to prolong life
- Referral main action in process of palliative care
- Referral is late due to identification of deterioration
- Dying in hospital increases if death occurs in the first three months for diagnosis
- Limited literature of how the process of palliative care is ‘lived or understood’ from a patient perspective.
- No literature on the experience of the referral process to palliative care services
- No broader conceptual frameworks of theory
- Patient voice is nonexistent
- No literature on those in last year as a category focused on survivorship models
- No robust evidence to base palliative care for this population

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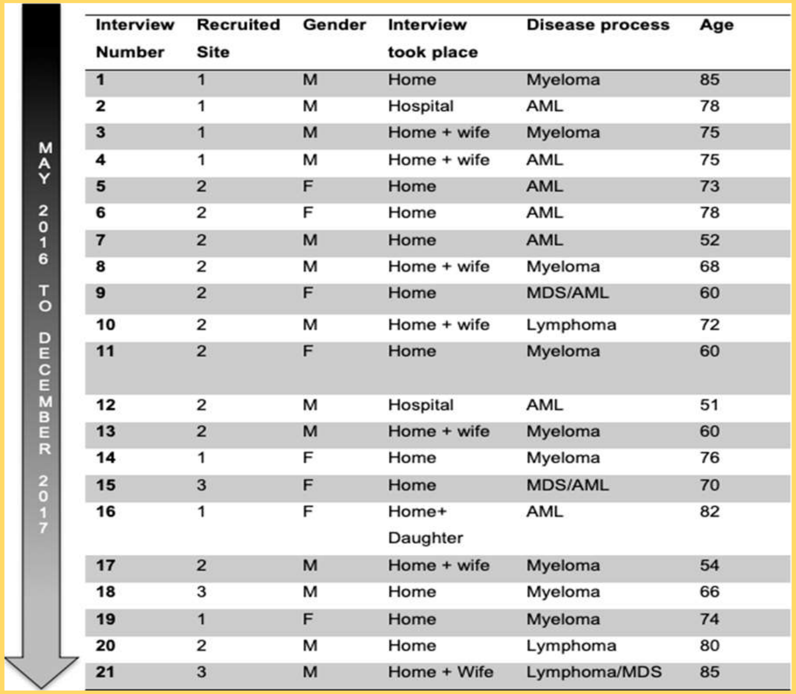
Techniques and Methods

Research Questions:

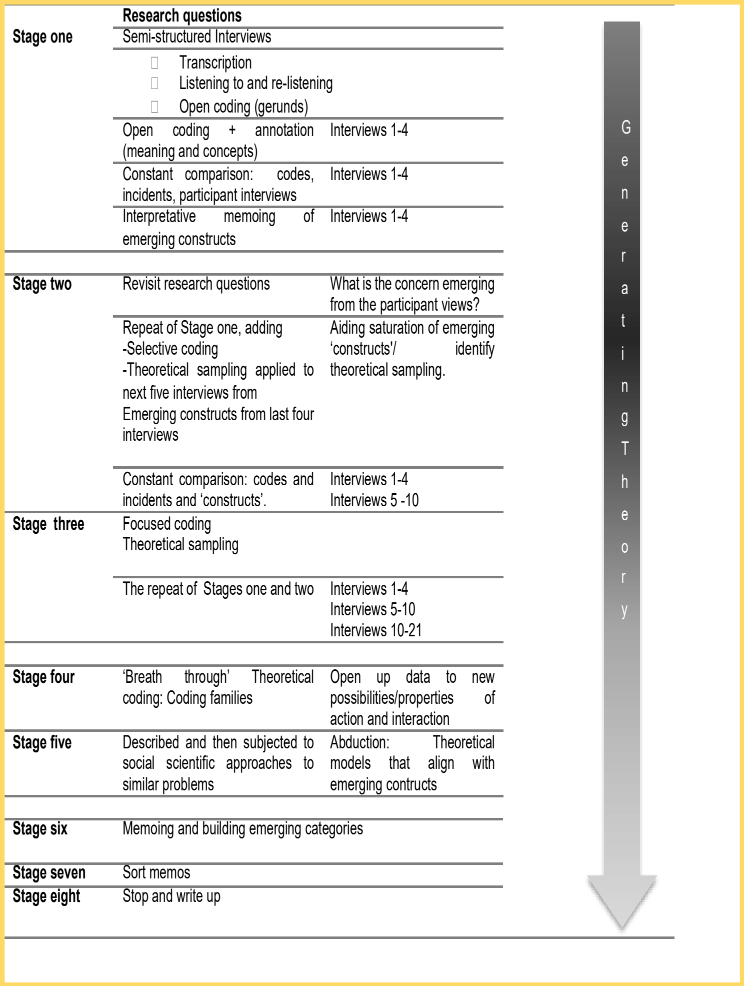
1. How do haemato-oncology patients experience the process of palliative care while in the last year of their life?
2. What are the patients' main concerns associated with the last year of life?
3. How do participants in the last year of life construct current and future palliative care needs ?

Methodology:

- Explorative – patient experience
- Grounded theory – Constructivist
- Philosophical stance – interpretative
- More than twenty semi-constructed interviews
- Principles of constant comparison, memoing and development of theory.
- Emerging rather than forcing the data into theory



Interview Number	Recruited Site	Gender	Interview took place	Disease process	Age
1	1	M	Home	Myeloma	85
2	1	M	Hospital	AML	78
3	1	M	Home + wife	Myeloma	75
4	1	M	Home + wife	AML	75
5	2	F	Home	AML	73
6	2	F	Home	AML	78
7	2	M	Home	AML	52
8	2	M	Home + wife	Myeloma	68
9	2	F	Home	MDS/AML	60
10	2	M	Home + wife	Lymphoma	72
11	2	F	Home	Myeloma	60
12	2	M	Hospital	AML	51
13	2	M	Home + wife	Myeloma	60
14	1	F	Home	Myeloma	76
15	3	F	Home	MDS/AML	70
16	1	F	Home+ Daughter	AML	82
17	2	M	Home + wife	Myeloma	54
18	3	M	Home	Myeloma	66
19	1	F	Home	Myeloma	74
20	2	M	Home	Lymphoma	80
21	3	M	Home + Wife	Lymphoma/MDS	85



	Research questions	
Stage one	Semi-structured Interviews	
	☐ Transcription ☐ Listening to and re-listening ☐ Open coding (gerunds)	
	Open coding + annotation (meaning and concepts)	Interviews 1-4
	Constant comparison: codes, incidents, participant interviews	Interviews 1-4
	Interpretative memoing of emerging constructs	Interviews 1-4
Stage two	Revisit research questions	What is the concern emerging from the participant views?
	Repeat of Stage one, adding -Selective coding -Theoretical sampling applied to next five interviews from Emerging constructs from last four interviews	Aiding saturation of emerging 'constructs'/ identify theoretical sampling.
	Constant comparison: codes and incidents and 'constructs'.	Interviews 1-4 Interviews 5 -10
Stage three	Focused coding Theoretical sampling	
	The repeat of Stages one and two	Interviews 1-4 Interviews 5-10 Interviews 10-21
Stage four	'Breath through' Theoretical coding: Coding families	Open up data to new possibilities/properties of action and interaction
Stage five	Described and then subjected to social scientific approaches to similar problems	Abduction: Theoretical models that align with emerging contructs
Stage six	Memoing and building emerging categories	
Stage seven	Sort memos	
Stage eight	Stop and write up	

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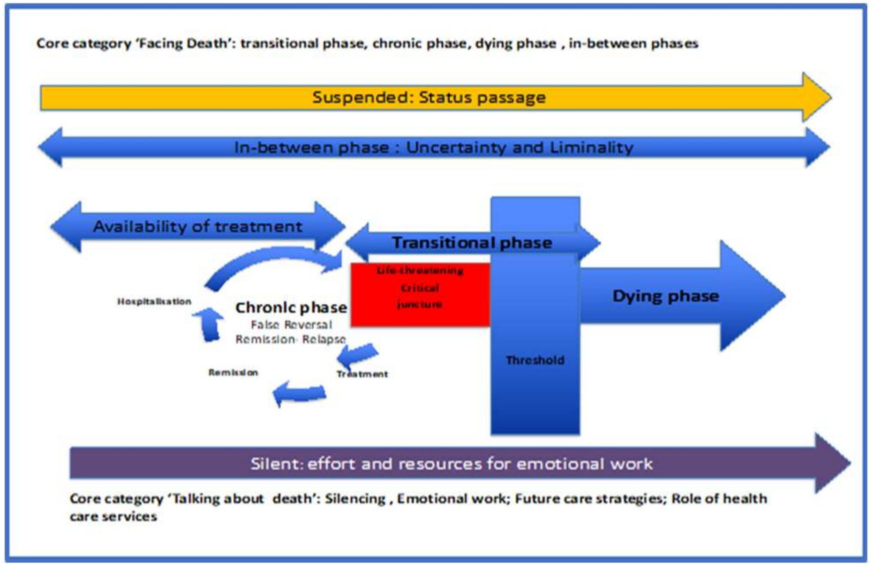
Results and Conclusions



Conclusion :

The findings have substantial implications for practice as they reconceptualise the incurable pathway as a 'status passage', with the inevitable outcome being death rather than the possibility of cure. As personalised care is central to the UK's health and social care integration agenda, it is a timely piece of work, illustrating that individuals diagnosed with an incurable haemato-oncology disease should be offered a holistic needs assessment which incorporates elements of palliative care and long-term remission. The findings also illustrate that palliative care service provision should be based upon critical episodes of care in combination with longer term follow up, allowing more flexibility and a responsive process of palliative care.

Suspended is underpinned when an individual is ***'facing death'*** differently in 4 phases:

The **chronic phase (**circular arrows), which is a cycle of false reversal/remission-relapse. Here, the availability of and response to the treatment can halt the disease process (suspend), but only for a time. The amount of this time is unpredictable, creating uncertainty and liminality, where 'facing death' is a regular feature of clinical visits and hospitalisation.

The **transitional phase** contains the critical juncture (red box), which is experienced as a life-threatening event of 'facing death'; here, living and dying are possible outcomes. At this juncture, if new treatment achieves a false reversal, the individual moves back to the chronic phase of the status passage (the circular arrows). If no treatment is available to extend life, the individual moves over a threshold (blue rectangle) towards the dying phase (blue arrow towards the right).

Once reached, the **dying phase** is also suspended in nature depending upon the progression of the disease, which determines the rate and pace of the trajectory.

The suspended nature leads to a pervasive uncertainty and liminal experience of being in an **in-between phases** over time (blue arrow moving left and right).

Silence is created when ***'talking about death*'**:

the energy and [in]dependence, effort and resources required by the illness over time (bottom blue arrow). To preserve energy over time, **emotion work** is reduced or avoided in order to protection self and others. This then impacts **communication work** within hospital consultations, at home, and ultimately in engaging in planning future care strategies. **Future care strategies** including choice of place of death was contingent upon the coping strategies of individuals and illness factors presented as Drive away, Deferring, Depending, Determined by disease and/or dependants, Designing.

Role of the Healthcare Professionals and palliative care :

The general practitioner was family-orientated and actively broke the silence by addressing anticipatory care needs and 'talking about death' during both the chronic and dying phases**.**

Hospital doctors, on the other hand, were linked to treatment, to maintaining false reversals, and to suspending the sentence of the incurable passage, which was not holistic in nature, but compassionate.

Clinical nurse specialists were associated with inpatient treatment supporting the chronic phase only.

Within this study, **palliative care services were minimally involved**, but when they were, they were associated with practical help and symptom control in both the chronic phase and the dying phase.

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