

A longitudinal narrative study
exploring representations of identity
for young adults with cancer

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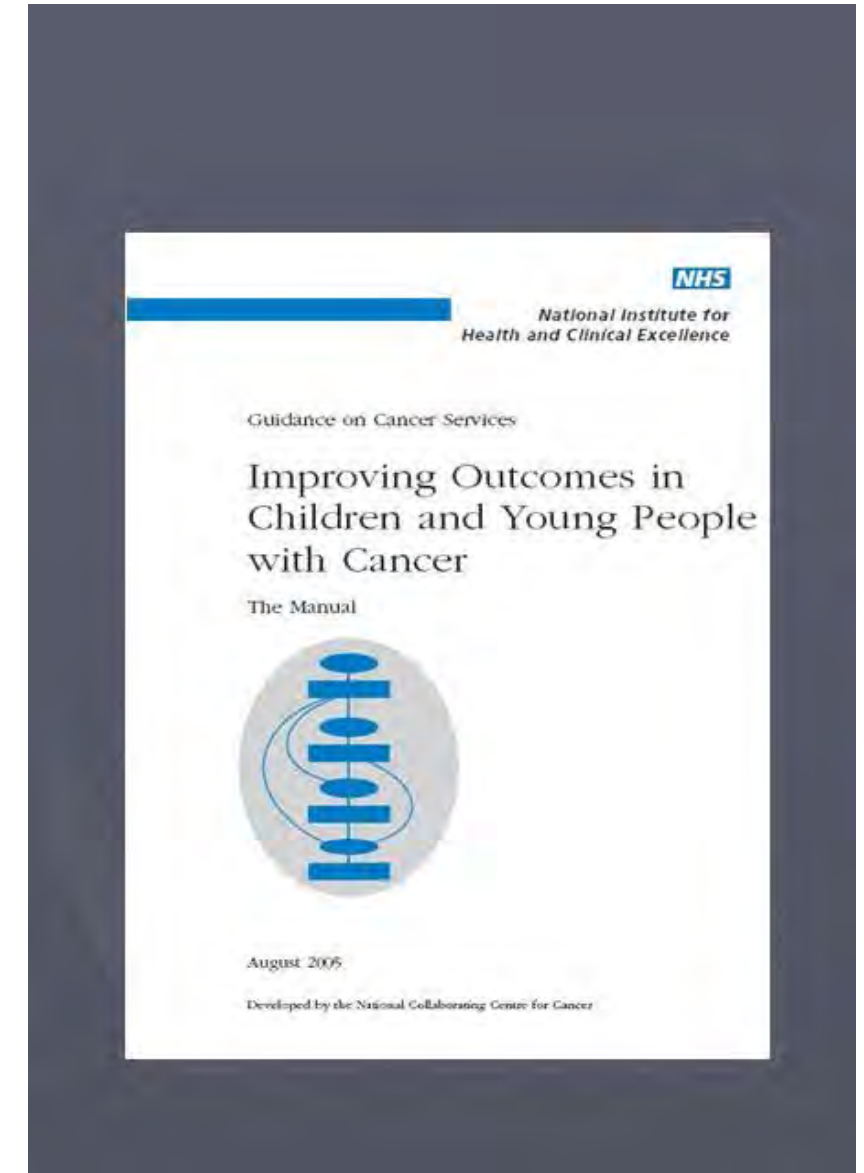
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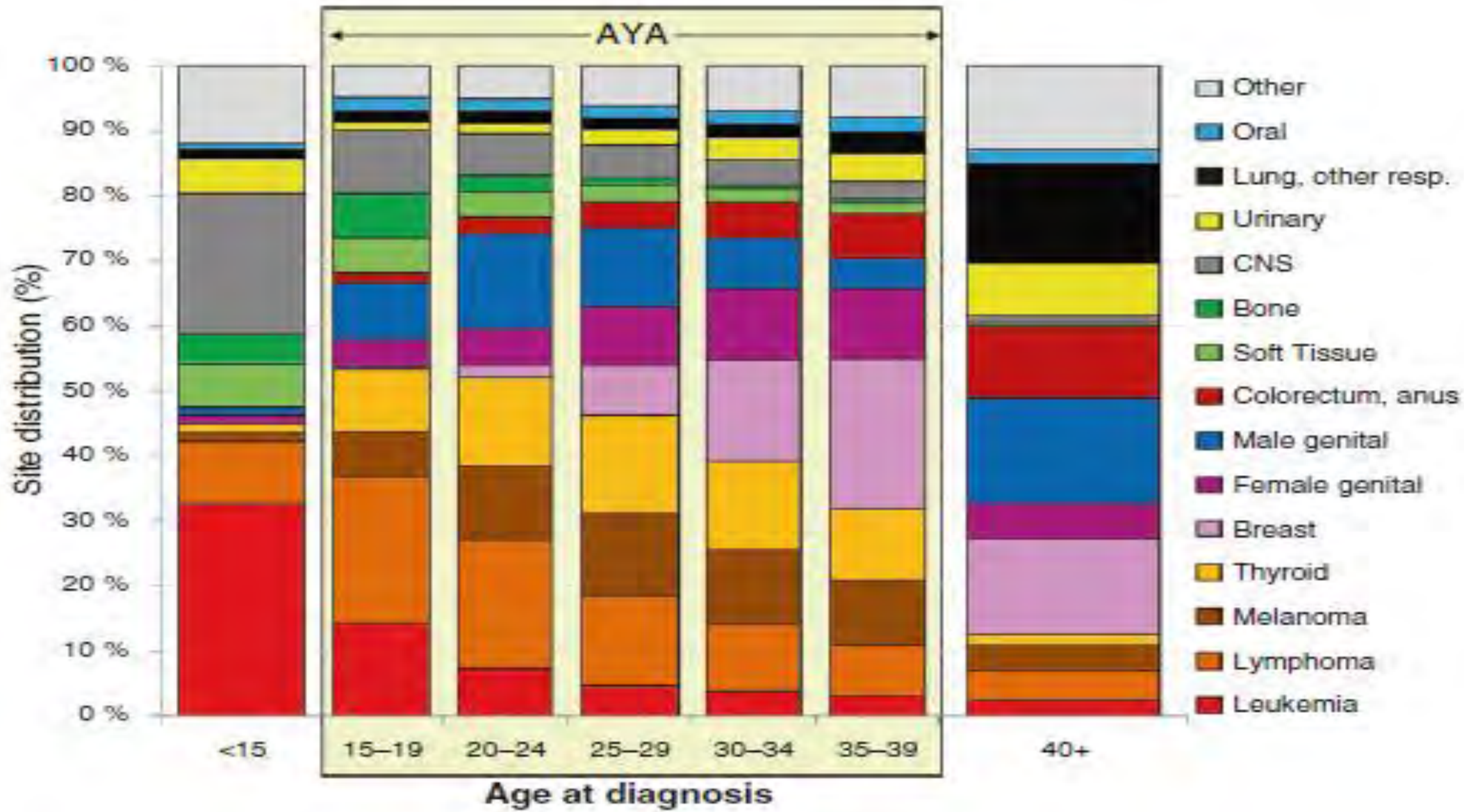
- To understand representations of identity for young adults with cancer aged between 16 and 30 years of age at diagnosis over one year from their diagnosis.
- **What are young adults' experiences over this time?**
- **How do these experiences impact on a sense of identity; sense of self; biography; and coping and recovery?**

What is cancer in young adulthood

- In the UK -13 or 15 years to 24
- Europe and Australia range of 16 to 29 or 30 year olds
- US often up to 40

- There are 350,000 diagnoses of cancer in the 15-29 age range in the world (Barr, 2011)





Relative Incidence of the Most Frequent Types of Cancer by age. (Ries *et al.*, 2017 p. 14)

Why the study

- A recurring question raised by clinicians, why a cut off at the age of 24 for young adulthood and age appropriate cancer care?
- 2010 little research evidence
- 2017 Few qualitative studies over the age of 24; no published prospective qualitative studies

What is young adulthood?

- ‘Project of self’, with the task being one of inventing adulthood. There are many different routes. Located firmly within individual and social contexts. (Henderson *et al.*, 2007)
- Quest for identity to distinguish oneself from others and explore notions of ‘who am I, also who am I not’ (Briggs, 2008 p 11).
- A period of liminality



Theoretical underpinnings

- The central part of identity is - a 'constant questioning and reconstruction of the self ' (Giddens, 1991, p.2).
- For Ricoeur (1991), self is understood as unfolding through episodes which both express and constitute the self, over time and through narrative and self-interpretation
- Thus identity is situated in narrative

Setting, sample

- Principal Treatment Centre for the care of Teenagers and Young Adults with Cancer
- Sample 16-30 years old
- Bone cancer, leukaemia or lymphoma
- High incidence, high degree of treatment intensity, differences in the length of treatments and expected treatment outcomes
- *Ethical approval REC Reference 12/LO/0183*

Recruiting the sample

- Recruitment April 2012 and December 2012
- Total population sampling

Total number of eligible patients	59
Number not approached by gatekeepers	13
Information given but researcher not able to follow up	3
Declined at time of initial contact	14
Declined after time for considering	4
Researcher stopped following up after time	6
Numbers consented	18

Methods: Free association interviews

- Three points in time. 4 to 12 weeks after diagnosis, 6 months and 12 months
- A joint construction of narrative and meaning (Mischler, 1986).
- Participant-led, free association with the guidance of interview probes (Hollway and Jefferson, 2000).

Methods: Visual

- Medium through which to express feelings, ideas and a sense of self; capturing the past and different contexts beyond the researcher participant interactions; a window into everyday life



Methods: Self reflective researcher data

- Free associative writing
- Context, body language, emotions, images, thoughts, informal conversations, research process reflections
- Monthly debriefing from a psychotherapist; monthly psychosocial research group meetings at the Tavistock
- Contained spaces for reflexivity

The ethical foundation for this study was through 'being with' the participant, in an ethic of caring (Tschudin, 2003) and an ethic of relating (Dewing, 2002) within each interaction

Interview 1.

2 months from diagnosis

Initial discussion about taking photographs



Follow up phone call/text message/visit

Photo diary period 1.

Phone call/ visit/ transfer of photographs to researcher



Interview 2.

About 6 months from diagnosis



Follow phone call/text message/visit

Photo diary period 2.

Phone call/ visit / transfer of photographs to researcher



Interview 3.

12 months from diagnosis



Phone call / text/Visit

Follow up visit face to face to hello when next in if appropriate

Data collected

18 participants

14 male, 4 female

41 interviews

Average 69 minutes

Photographs

5 participants

3 interviews

8 participants

2 interviews

6 participants

1 interview

4 participants

Analysis

- Narratives of the individual over time and narratives of community (Thomson and Holland, 2003).
- Diachronic- longitudinal and individual holistic case
- These were then, brought into conversation with each other.
- Visual not analysed in isolation

Reading each transcript/, set of field notes, memoing, coding key themes and categories

Data summaries for each of the participant's stories, using all the data sources.

Synthesized all the data in each case - **overall thematic map** and longitudinal table.

5 Longitudinal case stories

Memoing, mapping and constant comparison - **higher order themes across all data sets**

Development of higher order conceptual framework

Martin

Career as identity
Private/ public face
Career as treadmill
Stepping of the treadmill
Reflection and evaluation
Life as meaning Integrating
identity

Patient/ professional
Patient as experience
Professional as experience
Knowing the script
Actors/ cues
Empathy
Treatment and quality of life
Ethics compassion
Dealing with the end of life

Social world
Partner- relationship
Family and friends
Support
Independence and isolation
Communication and social
media
Private/ public
Achieving milestones

Coping/ meaning
Self and others
Blocking/boxing
Imagery
Lack of emotion
Intellect as a defence
Managing emotions in
others
The medical lense

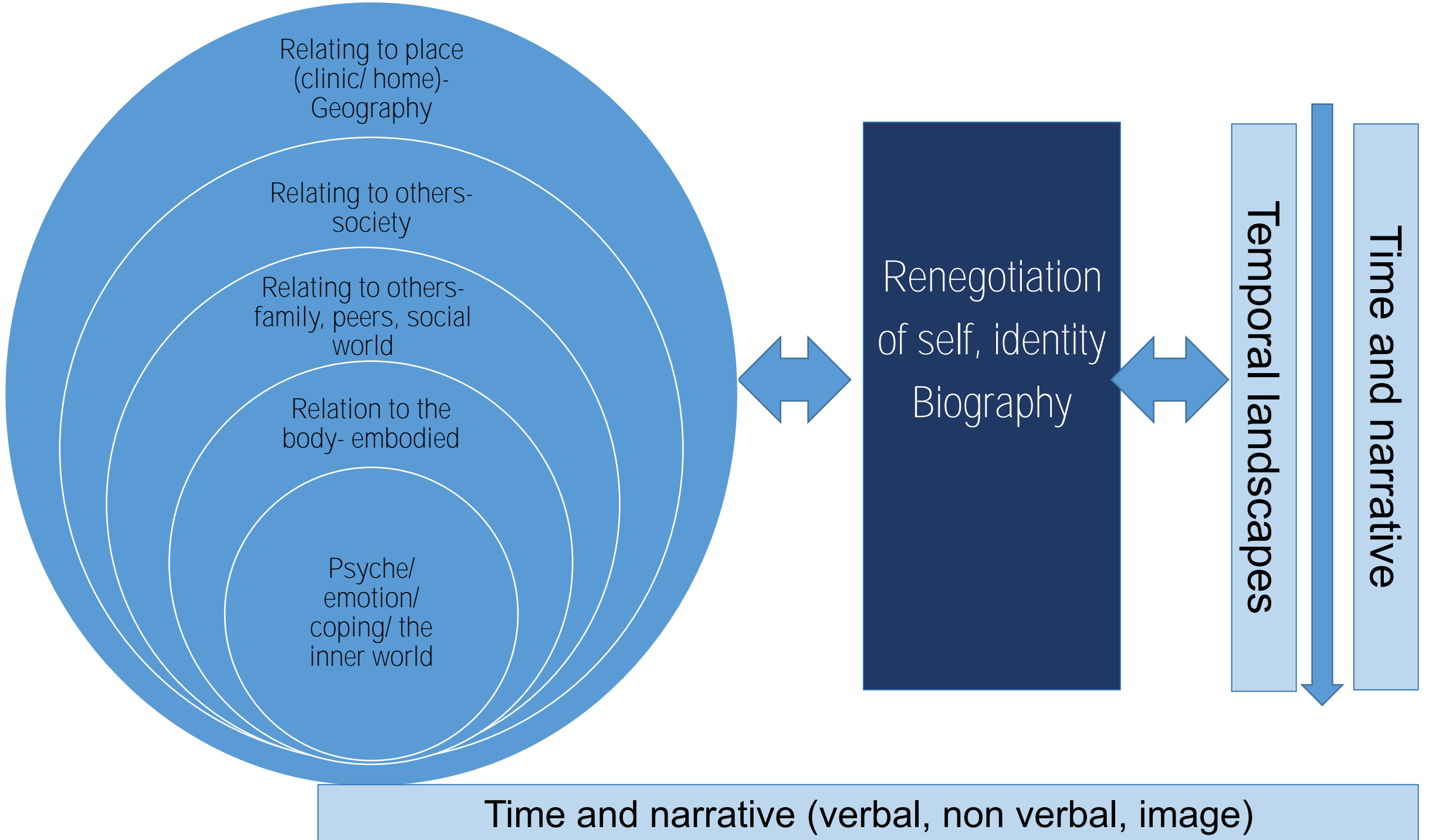
Cancer as narrative
Cancer as identity
Cancer as society
Donor and the gift
Cancer in everyday life



Trajectory
First symptoms to diagnosis
Diagnosis
Professional / patient
knowing
The script
Treatment and Time
Life after treatment
Managing fears of recurrence
Fear and mortality

Treatment experience
Understanding the body
Experiencing the unknown
Neutropenia
Impact of fatigue
Fatigue- emotion and coping
Link to social, independence,
Imagery and sense of place
Place of care
Safety and comfort

NARRATIVE/ STORY TELLING



- Two dominant temporal threads
 - the cancer and treatment trajectory,
 - biography of young adulthood
- Interweaving of narrative self and identity, young adult development and the nature of cancer.

Temporal landscapes: cancer

Critical moments

- *hearing the doctor say, 'This is what you've got,' you just sort of take it on board. . . .And then sort of had the three days' treatment, came home, didn't know what to do, didn't know how to eat, didn't know how to get up, didn't know how to lay down at first. You know, that's when I thought, 'Okay I understand now.'* Christopher, interview 1

Receiving news

- *“...panic attacks, getting quite anxious and like not sleeping very well heart was racing, I found it really scary. I thought I was losing my mind. I was just scared that I was going to get there and she was going to say, ‘The cancer is growing again and it’s spread’
Christopher, Interview 1.*

- *“hitting the wall, a marathon runner’s wall. ‘I said to mum I didn’t want to wake up, but not like I wanted to be dead. I wanted to just stay asleep and just sleep because I just didn’t see the point of waking up’”.*
- Simon Interview 2.

- Critical times for making sense of these moments, having a voice, renegotiating identity narrative.
- Time off treatment, getting home, side effect free: opportunity for identity negotiation, sense making, accomplishment of biographical opportunities.

Stopping treatment

- *“When I was on treatment, I didn’t want to think about it at all I just wanted to put the telly on and forget, you know, whereas now I’m sort of more – because I’m more relaxed, I’m more happy, to think about it think it’s all linked to feeling physically much better and stronger. I should just make the most of this time, however long it lasts”.*
- Christopher, Interview 2.
- Simon was having a week off treatment; had been told he could go swimming. He exclaimed:
- *“I’m sort of suddenly going, ‘let’s get some friends over, let’s go to town and have a beer, let’s go swimming.’ My latest thing is I’m buying a bouncy castle slide that I’m going to go into the pool in. I was thinking, ‘I’m not going to tell the doctors that I’m doing that, but it’s going to be great fun.’”*
- Simon, Interview 2.

Temporal landscapes -biography

- Themes relating to issues in the developmental stage, were broad and individually articulated
- ‘Clash’ the thrust for life of young adulthood with the sense of death/loss/ mourning that a cancer diagnosis brings.
- This can create a conflict at this age which may be harder to bear - for all concerned.

Loss and mourning

- These include body changes, hair loss, loss of relationships, loss of time, renegotiation of plans for the future, and career •



Jason negotiated amputation of his leg and the subsequent loss of his chosen career and the related identity.

“

Resignation and loss from unfulfilled goals

- *I wish I'd have done my Physics and the universe and something..” Paul, Interview 2*



- *“not the year I expected. I didn't expect to be in this position this time back then, because obviously I expected to be in a job and doing what they're doing [looking at the nurses]”.*
- *“it just seems a bit of a waste, it's seven years, it will be seven years wasted, you know.”*
- Andrew, Interview 2.

Thrust for life

- Those with shorter treatments seemed to have a developmental goal surge after the completion of treatment.
- Fast track lives, wasting no time
- Nick joked that it was: “*.I mean it was just an annoyance, a year a bit out of my career. I’ll never make partner by thirty now!*”



Participants with long treatments and an unlikeliness of cure still focused on developmental goals- future and present.



- *“It was like, ‘Damn, I’m going to have to put like a year of seeing my friends all with their new friends at uni, ‘But I’ve sort of, I’ve got caught up with everything around here, like the fundraising and I’ve just sort of busied myself. And it hasn’t been too bad”. I feel a lot braver than I was, my sister says, I’ve grown up almost overnight’*
- Simon Interview 2

Conclusions

- Biographical stage was fluid - services need reflexivity across age ranges and existing boundaries
- Constant inter relationship to the renegotiation of identity and adaption of biography through narrative and story-telling over time
- Juxtaposition of biographical stage and disease intensity
- Narrative as an intervention practice