

Recipients' experience of Blood Stem Cell Transplants

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Support received from
Dawes Scholarship –IMVS-RAH
CNSA Glaxo-Wellcome Nurses Project Grant
Anti-Cancer Foundation of South Australia



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The Study

- Ethics approval from the institution and Flinders University South Australia
- Ethnographic Data collected on a transplant unit used to enhance understanding
- Recipients' and nurses' interview data transcribed and analysed using discourse analysis



The Study continued

■ The study

- 9 recipients of allo BSCT- for up to 1 yr or more post BSCT
- 16 nurses observed providing care
- 10 nursing handovers taped and transcribed
- Observed transplant and ward meetings over 1 year.
- Looked at ward documents such as clinical schedule IBMTR form,



An alternative view of BSCT



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An alternative view of BSCT



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More than Blood

Blood Lines Blood Ties	Blood Thirsty Blood Letting	Hot Blooded Cold Blooded
Blood Brothers Jewish, French	Blood Sport Blood Shed	Blood Boil Bad Blood
Half Blood Full Blood	Blood Cells Blood Test	Blood Clot Blood Bank
Red Blooded Blue Blood Bloodless	Blood Borne Blood sweat & tears	Give ones blood for ones country



A person to a patient in BSCT

- Relinquishing roles and power
- Insertion of central lines
- Admission to hospital
- The side room and isolation- contagion and clean
- Enculturation into the unit



Bloodlines and what else

- “They were good matches, Mary’s O-positive, and Helen and I are A-positive and I had {Helen’s}. Mary’s on the interchange bench” (Ian Day -1).
- “he may get some of his brother’s characteristics. He is a little quieter and that would be nice sometimes”
Bernard’s wife
- “I hope I’ve got a male donor cos you know I wouldn’t want to change-*{gesturing in an effeminate manner}*”
(David Day -3)



Bloodlines and what else

- “Comes tomorrow, yeah. It’s an unrelated, so I don’t know who or what....being an unrelated, they don’t tell you who or where or what- what from” (Francis Day -1)
- “the marrow that they’ve infused is supposed to take over. Not only does the marrow take over, but it’s also changing the blood” (Francis D+1)
- I’d read a bit about it and gone on the net. I found out about it they said it’s very anticlimactic, like they are telling you it’s **just** a transfusion, but then you just batten down the hatches.... You know it’s not you. But you’ve got to do it”. (Ian Day-1)



Identity deconstructed

- “I ‘m betwixt and between nothingness”
Ian on Day-1
- “I’m empty its up to grace of god and
medicine” Adam on Day -1
- Empty –David
- Harry couldn’t describe it the closest
was scared, fragile unsure



Infusing another's blood

They say its pretty simple... I've had plenty go through the drip and the blood cells will be the same but; It's just another drip but.... It's all the afters.

But it's not just another drip?

No. it's not just a drip it's the future
Adam D-1



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Embodied Changes

- So now the cells are in, with luck they will grow” (Francis Day 0)
- Same but different
- The Chimera
 - “doing well her chimerism was 98% myeloid and 67% T cell”



Loosing control

- Sore mouths, bruising, and IV drugs and fluids
- Shrinking spaces
 - “There was no outside. This was it”. Emma
- Loss of sense of time
 - What day are we?
 - It's Day 5and it's the fourth of July.
 - No I don't know what day it is?
 - What do you mean – Oh its Tuesday



The Body on the board

- “I wasn’t good yesterday...went to bed last night, and I feel better today. Hopefully they’re- those counts {nodding to board} that’s what I think” (Bernard Day +5)
- Emma refused to have the counts on a white board I don’t need reminding how bad they are
- Adam and Ian worried that they were slow to come up



Watching blood counts

Basically watch the telly when you've got nothing to do. And you're watching your counts, I've got a whiteboard on the front here, so they give you the counts, the blood count, your haemoglobin, platelets and white cells and neutrophils and that's the real excitement of the day 'cos you can see which way you're going -Francis



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Regaining some control

- Gradually doing more
 - Wanting time off IV's
 - Moving out of the room
 - Moving to oral medication
 - Huey's kitchen
 - Back to wearing clothes



Engraftment

- “Be happier when I get a bone marrow biopsy to make sure his bloody cells are in my body making more (Bernard Day+5)
- “When they start to go up, I’ll start feeling like myself again” (Francis Day+16)



Discharge Home

- Fear of outside and other people
- Coming in to outpatients till D+84
- Altered bodies
 - “fat Harry & thin Harry”
 - “never thought I wouldn’t have a beard”
Adam
 - Francis had curly hair
 - Emma forcing herself to eat



Freedom to come and go

- Controlled by the transplant schedule
- Routine of coming in
- Starting to drive again
- Freedom to interact socially
- Able to move back home to country

There isn't a next step

Then I got to the stage of concentrating on getting out of hospital, then it was having the day treatment and then it was counting the days to get to day eighty-four, then it was sort of the week before, planning to go home... And then it was starting new life again at home. And now you've got nothing to look forward to. Really haven't... There isn't a next step. (Adam Day +146; 1338-45).



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Bloody tired and...

“I’m 65, I’ve got a 65 year old blood inside me now, I’ve got to feel a bit –old.... I should be able to at least do a few things, do more than I’m doing and not feel so bloody tired and worn out (Adam Day +146 –at age 45yrs)

Francis wondered if “maybe the guy who gave me the bone marrow has got curly hair or something” (Francis 8 months post).



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Psychologically -Emotionally

- Depression
- Frustration
 - “Transplant was it, and then I could get back to normal haaa haaa”. Emma D+31
- Not sick and not well
 - “I look good but I don’t feel good” Adam D+146
- Focus on what they can’t do –Adam
- Scared will forget that alive is enough



Re-creating a Normal

- Getting a little bit sick
- Trusting themselves they were well.
- Resuming social roles



Relationships

- Adam “I’m not a husband”
- Harry-
 - steroid ‘rage’ on family, relationship failed
- Emma’s relationship failed
- Gary –planning second child
- Frances – unsure when if children may happen



Re-creating a Normal

- Had to take back their lives –
- Life back on track
 - Planning children – Gary
 - Looking for a house-Frances
- Missing Appointments
- Not counting time since the event
- “I’m cured, I’m not in remission”



Consent

- Medicine decides who is fit for BSCT
- Patients decide if they will undergo BSCT-
 - Sought second opinions/talk to partners.
 - only one way to go- Adam
 - I haven't got any choice-Bernard
 - This is my last chance-Francis
- Tissue typing sets on treadmill.
- Nurses confuse consent with understanding the transplant process?
 - Scared me ... you really did - Emma
 - Talk in failures not in success [too much of all the bad stuff]-Charles

