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Riding the melanoma rollercoaster: The experiences and support needs of melanoma patients and their carers

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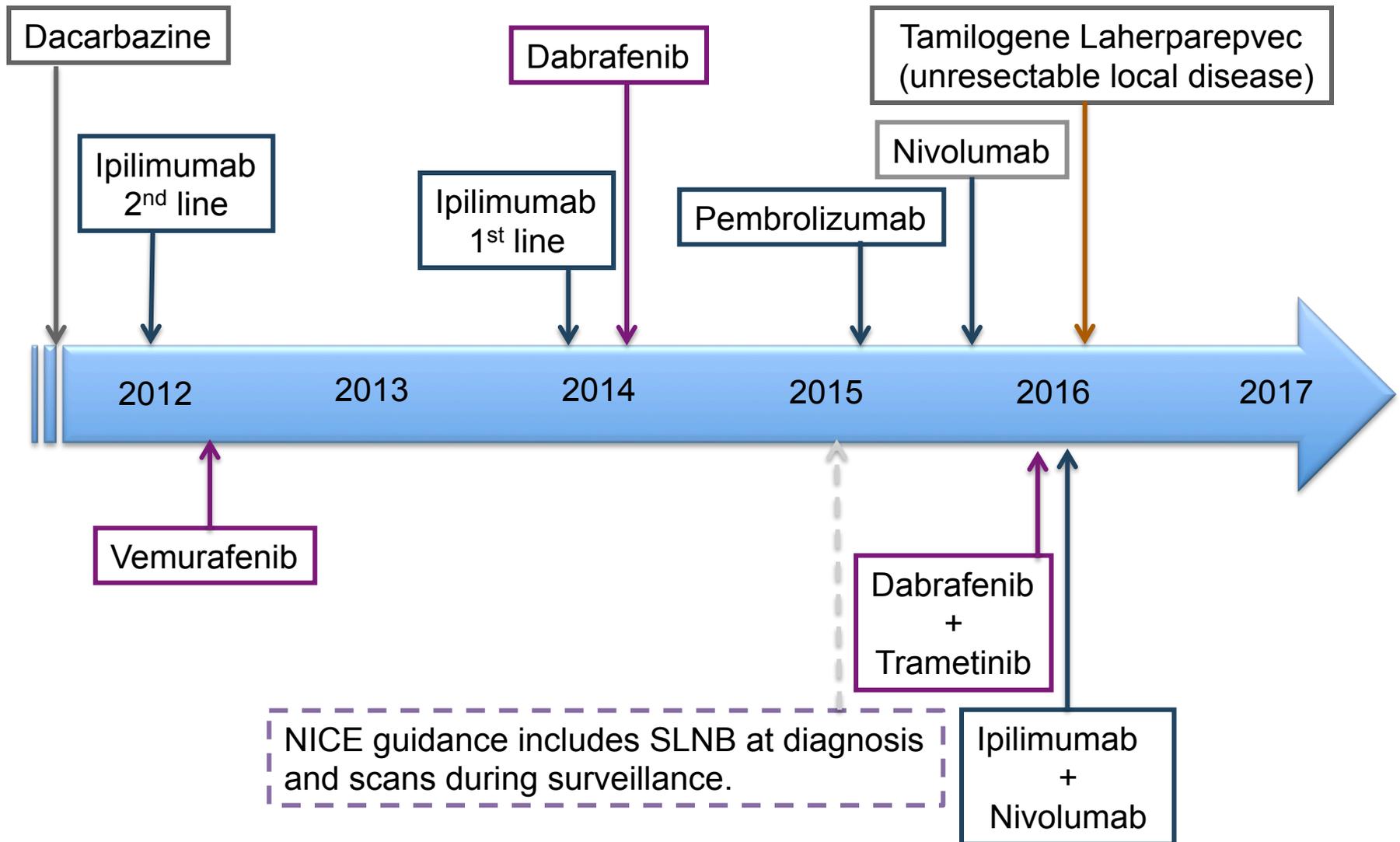
SHEFFIELD INNOVATION & RESEARCH
SIRON
IN ONCOLOGY NURSING

Background

- Increasing incidence. Four fold increase in the last 30 years
- More patients needing support
- Lack of evidence regarding support needs (NICE 2006)



New treatments for melanoma



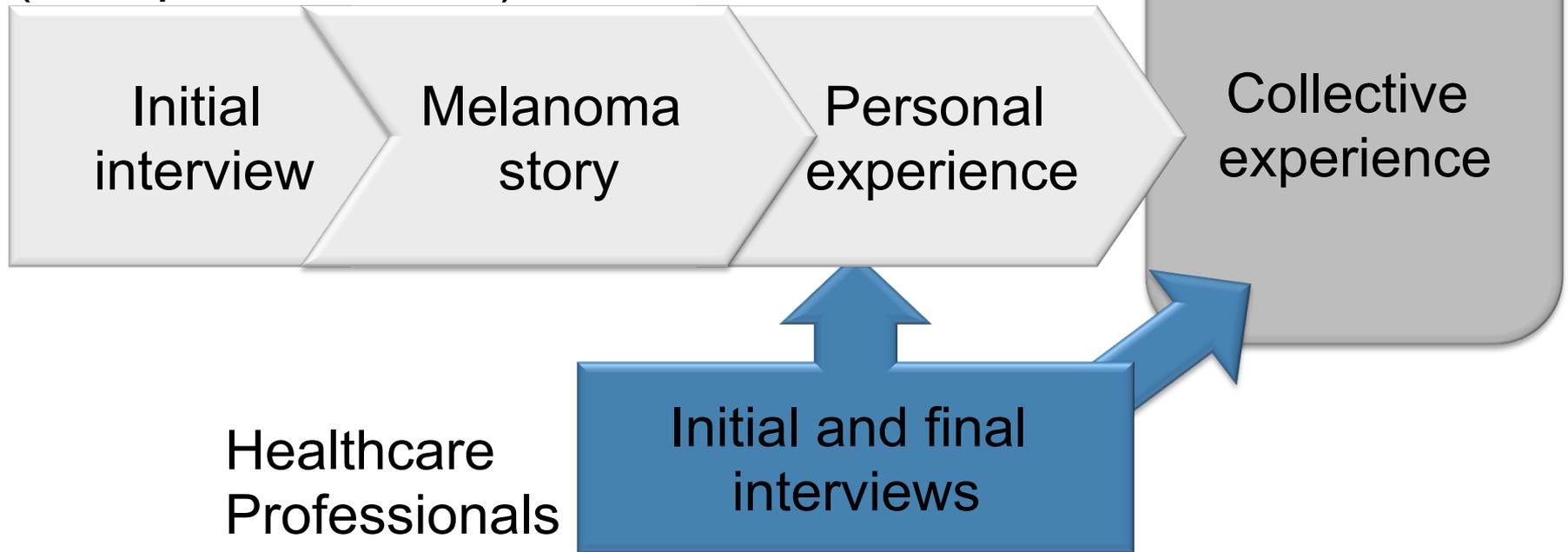
Research Aims

To explore the changing experiences and support needs of patients with melanoma and their carers throughout the disease pathway

Can we improve the patient experience?

Constructivist Grounded Theory

Patients & nominated carers
(in-depth interviews)



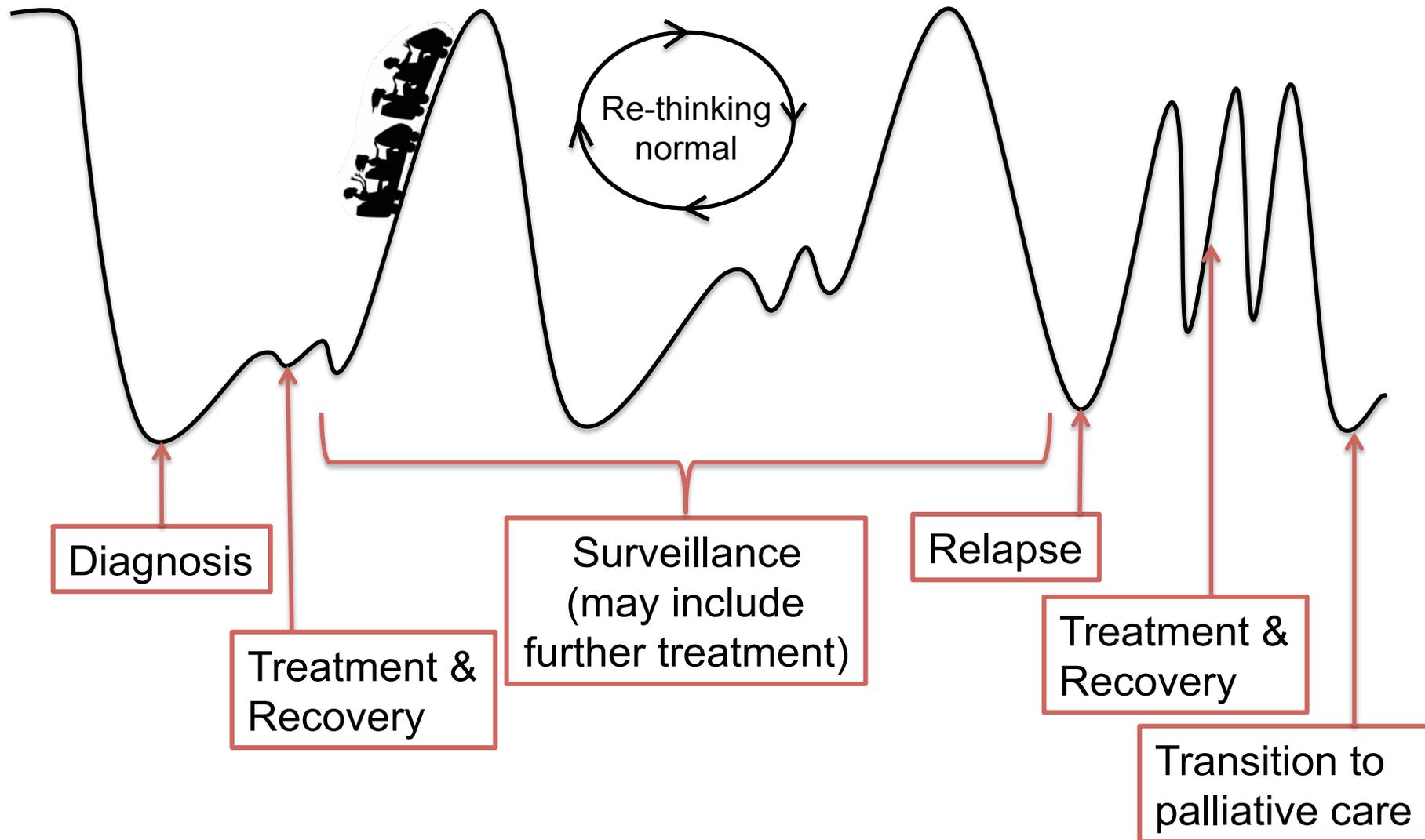
- Longitudinal, participant led, emergent design over 3 years

Participants

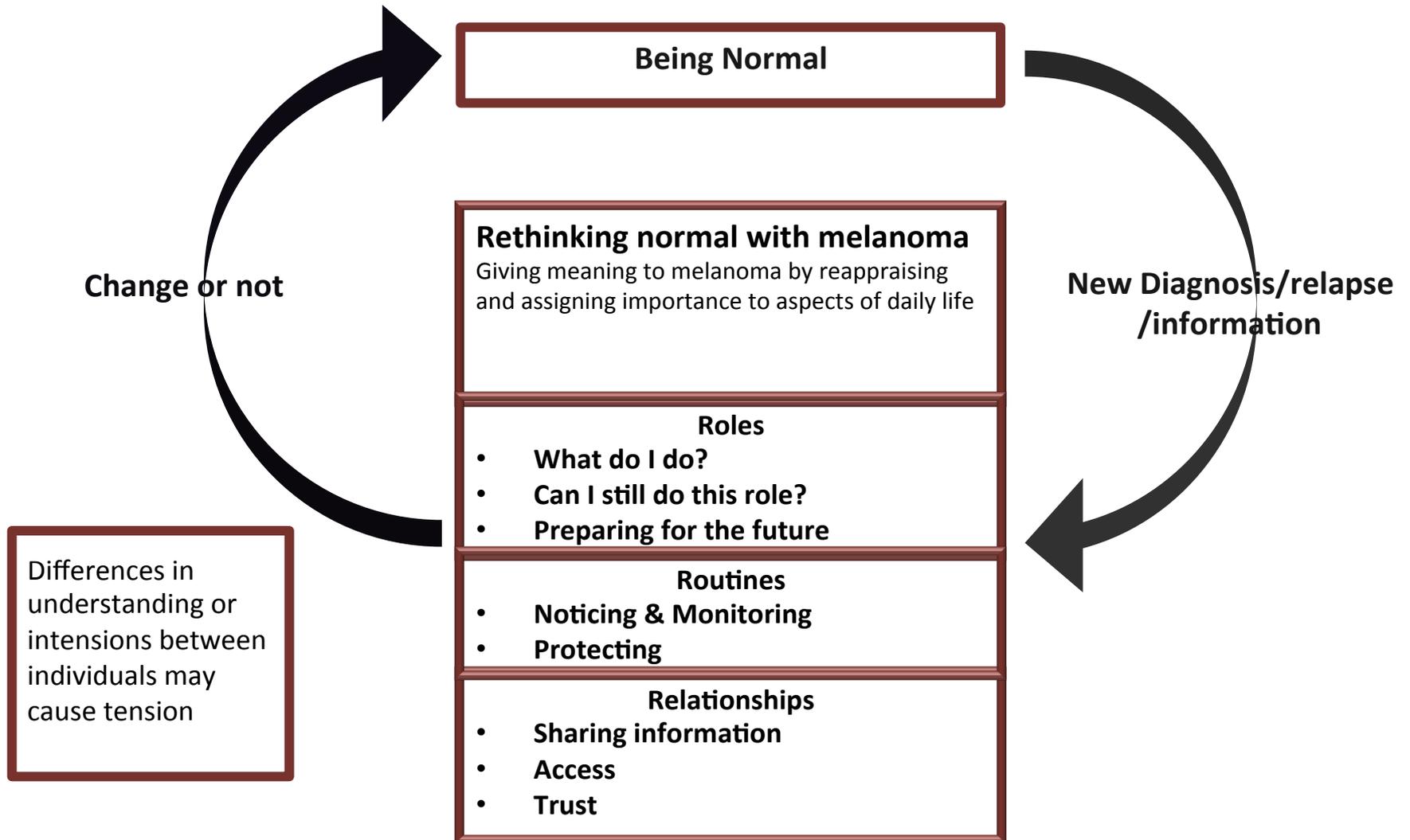
- 17 Patients
 - 1 relocated
 - 8 withdrew at disease progression
 - 8 completed
- 11 Healthcare Professionals
 - 7 Clinical Nurse Specialists
 - 1 Plastic Surgeon
 - 1 GP
 - 1 Macmillan Nurse
 - 1 Practice Nurse
- 12 Carers
 - 1 divorced
 - 2 continued after patient died
 - 9 continued while the patient participated

92 Interviews
3 Focus groups

Melanoma: Riding the rollercoaster



Melanoma: Riding the rollercoaster



*“It’s really strange that
one word can alter your life
and if you let it destroy it.”*

Tony, Patient

Roles

- May change temporarily or permanently
- Adjustments made to work, leisure & family roles
- Caring role most apparent during treatment & advanced disease

“I turned down a holiday in Spain. I’m going to Holland in September and the climate ‘s quite temperate there so should be alright.”

Matt, Patient

“I then felt guilty that I’d been at work for three days and that I’d not seen her and she’d been in pain and she’s not told me.”

Laura, Carer

“I’ve got three kids to look after. I’m just constantly tired and drained and finding it really hard. If I didn’t have my auntie here or my sister, they’ll help me bath them so that I don’t have to do a lot on my own at night.”

Sarah, Patient

Routines

- Monitoring treatment effects & symptoms
- Awareness of sun protection
- Anxiety reduced over time for some

“She doesn’t know that I know she’s feeling down. I’ve seen a change in her, especially the last month or so.”

Lyn, Carer

“I’ve kept my shirt on when I’ve been out in the sun, worn a hat and slip slap slop as they say.”

Phil, Patient

“Because I’m always looking. Everyday I look. It’s just from my perspective, I want to make sure that there’s nothing there.”

Fred, Patient

Relationships with Family & Friends

- Emotional & practical support
- Who to tell?
- Peer relationships

“People know not to ask me about it if my kids are there because I’ll just get upset and I don’t want them to see it. They don’t know my cancer’s come back.”

Sarah, Patient

“Because we came home in complete silence, both of us... It’s as though you want to shut that door and it’ll go away.”

Carol, Carer

“Friends in all sorts of walks of life, just that little, how are you, and it does give you a boost.”

Tony, Patient M18

Relationships with HCPs

- Used as a resource
- Need to be accessible
- Valued for information & emotional support

“Just to ring up and you’re not afraid to ask her anything either.”

Helen, Patient

“It’s nice to have friends but sometimes you need a professional.”

Esther, Carer

“It’s just somebody to talk to, somebody to ask, is this right, is that right, or should we not panic over that, you know what I mean.”

Kate, Carer

Clinical Implications

- We know the important time points, particularly diagnosis
- Recognise the role & needs of carers
- Need to establish a therapeutic relationship
- HCPs need to be accessible
- How to facilitate peer support
- Further exploration of the experience of receiving novel treatments for melanoma

The experience of melanoma patients receiving novel therapies and their carers (OPAC Study)

Janine Smedley

Research Assistant

University of Sheffield



CANCER
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2011
THE AWARDS
AWARD WINNER
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Research Methods

- Constructivist Grounded Theory
- Participant led, emergent design
- Cross-sectional design, Interviews followed up with a single telephone call to clarify data
- Included patients & carers

- Patients were receiving targeted or immune therapies – no differences were found between the groups

Patient Goals

Throughout interviews it became clear that patients & carers hold two main goals and motivation:

1: Maintaining lifestyle

2: Maintaining treatment (and hope)

Balancing Treatment



Expectations

- Preconceptions of chemotherapy
- Came from family experience, TV, other people,
- Patients & carers refer to treatment as 'chemo' and HCPS observed in clinics doing the same
- Expected the wrong side effects
- Dismissed some side effects so did not seek support

Expectations of 'Chemo'

"I shouldn't like to think I was one of those that sat and couldn't do anything and the hair were dropping out, not that mine's got very far to drop, and feel nauseous all the time. So I'm just glad that's not happening."

P05

"In the village, how you might say somebody's got cancer and you see their hands going and you see their face going and, you know, so you sort of tend to think that that's kind of going to happen."

C04

"In the past when people had chemotherapy you hear about these horrendous side effects people have, you know. Well your sister-in-law, she was just flat refusing chemotherapy because the reputation had about side effects."

P04

Impact on lifestyle

- Aim to maintain normality & lessen impact on their lives
- May be able/willing to modify lifestyle to maintain treatment
- Living in a bubble
 - Continuous cycle of treatment (monitor for side effects & symptoms, wait for scan results)
 - Inability to plan (Day-to-day activities, Holidays, Carers afraid to leave patients)

Impact on lifestyle

“We feel as if we live in a three-week bubble. From one hospital appointment to the next and obviously one thing that we can't do is plan ahead like any holidays and it affects all that sort of thing.”

C04

“There are a lot of things we like doing together and most of that has sort of stopped hasn't it? And we always used to have friends round for something to eat and wed go round to their houses.”

C01

“It's like whenever I go anywhere, I don't have anything to eat until after I've been, or if I know that I'm going to leave here and I'm going to our house or my friends or whatever, somewhere in half an hour I know that I could be somewhere near a loo, I'll be fine. It usually takes about 25 minutes, half an hour, and everything seems to be going straight through me.”

P03

Emerging Issues

- Managing long term treatment
 - Adherence
 - Reporting side effects
 - Education
- Hope & Expectations
 - Short and medium term goals
 - Can treatment breaks to accommodate social needs be achieved?
 - Managing the unknown
- Introducing palliative care
 - Patients deteriorate quickly when treatment stops
 - Patients may be on treatment for weeks, months or years

Thank you

UNITI – Jo Bird

Supervisors

- Mike Nolan, Professor of Gerontological Nursing
- Sarah Danson, Professor/Honorary Consultant in Medical Oncology
- Kate Gerrish, Professor of Nursing Research

Advisory Panel

- John Rouse, Jacqui Gath & Dave Ardron, NTCRN Consumer Research Panel
- Claire Pendelbury & Marion Page, Skin Cancer Clinical Nurse Specialists

OPAC – Janine Smedley

Supervisors

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