

Patient Reported Outcomes in cancer, impact of Age and Carer role demands associated with Treatment (PROACT): The 'lucky' construct



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Background

Quality of survival is a growing area of research within oncology but measuring this concept can be difficult.

With more patients receiving help from people close to them, quality of survival extends to these informal caregivers.

The data presented here are drawn from the initial development stage of 2 scales measuring the impact of cancer on both patients (pts) and their informal caregivers (cgs) as part of the PROACT study.

A theme emerged of both groups describing themselves as 'lucky'. This was often done in comparison to 'other' people.

Aims

The PROACT study aims to develop 2 scales measuring the impact of cancer for both pts and cgs

There are 3 phases of the PROACT study. Here we focus on the first stage of interviews and the emergence of a 'lucky' theme

Phase 1

- Systematic reviews for current patient and caregiver PROs ^{1,2}

Phase 2

- Qualitative interviews for item development and refinement

Phase 3

- Early validation study using scales developed in Phase 2

Methods

- Semi-structured interviews conducted with pts with advanced disease and their nominated, informal, cgs
- Interviews conducted in pt and cg homes, both at the same time but in separate areas
- Interviewers used topic guides to start discussion (i.e. finances, family, work) but breadth and depth was dictated by each participant

Analysis

- Interviews were transcribed verbatim
- Two researchers reviewed the transcripts and a thematic framework was developed through open coding

Demographics

There were 3 tumour groups included with the dyads made up by:

Tumour Group

- 9 Melanoma
- 9 Gynae
- 6 Lung

Dyad Relationship

- Partners (N=15)
- Parents/Children (N=5)
- Siblings (N=2)

Findings

During the interviews, many pts and cgs expressed their experiences in terms of being 'lucky'

There were 3 main areas where this characterisation was made –

- General positioning of being 'lucky'
- Disease specifics
- Finances

In contrast, a few pts and cgs very much felt that their situation was unfair and unjust

Findings Cont'd

General Outlook

Some pts and cgs contrasted their cancer experiences with their life in general, describing how they had been 'lucky' up to that point:

"I've got nothing to look back and feel sorry for myself. If I died tomorrow, I've had more happiness in my life than a lot of people have had in a hundred years you know? So I've got nothing to feel sorry for myself for, so I just think I'm such a lucky person that what is there to feel miserable about." (P4001)

"I mean we're very lucky and I don't ever lose sight of that, very lucky. So this nonsense with - and that's how I see it now, that's how I describe it - this nonsense with his health is just a nuisance really but I'm quite determined it won't win. Not if I can help it." (C1006)

Other participants focused on unexpected benefits borne from their experiences:

"It is amazing how you feel, even about nature and am I going to see the daffodils grow, which I thought last year when it came back at Christmas, and yes there were the daffs, will I see the roses, yes. It's just amazing, whereas before you wouldn't really think about it, and it's just tiny things like that." (P1005)

"But I think at the end of it I'll look back on it and I'll be like thank god for it. I'll be like thank god that happened because it has made me stronger and it has made me more knowledgeable and more understanding." (C3005)

Downward social comparisons were apparent in pts and cgs who described themselves as 'lucky' in terms of the disease or their financial standing

These comparisons were not made to specific people but generic groups

'Luck' in relation to Disease

Pts and cgs described themselves as 'lucky' if they felt they were diagnosed promptly, had received good care or experienced fewer symptoms of disease/treatment than they expected

"We go to the (hospital) and you only have to look around the room and you just think you're not too badly off here. It's not too bad." (P1014)

"...sometimes it feels depressing and then P1011 would go for chemotherapy and you'd see somebody in a far worse boat than yourself, and then you think, well actually today I feel really positive, because you think, look I'm being so miserable about our situation and somebody else might have come out of...they just might be at a different stage or they just might have had some worse luck." (C1011)

Findings Cont'd

'Luck' in relation to Finances

Financially, pts and cgs described themselves as lucky based on:

- The availability of savings
- Retirement funds
- A work balance allowing them to maintain an income and attend appointments/treatments
- Having insurance policies in place to protect their finances

"So I've been really blessed with a lot of people who've given me time and a lot of help. So financially, at this moment in time, I'm okay. I'm very lucky because I'm sure that there are a lot of people who are not." (P3001)

"Well I'm not working. So yeah, obviously I'm losing money there so yeah a little, well, quite a lot, yeah. But I was in a lucky position so it's not, it's achievable at least in my eyes." (C1003)

Contrasting sentiments of 'luck'

Some pts and cgs acknowledged that their 'luck' may not last, others the unfairness of it all

"It worries, well it doesn't worry me, it upsets me when I think about the future and I think well I'm not going to see him grow up and do things and what have you." (P3001)

"I do feel aggrieved. You know, you get the syndrome 'why us?' Now there are thousands, tens of thousands of people with cancer. I mean what is it, one in four or something? Something like that. Something like that, maybe a greater proportion but it's huge [...] Clearly nobody deserves it but she really didn't deserve it, but that's life." (C1005)

Summary and Conclusions

- Pts and cgs often described their experiences through a lens of feeling 'lucky'
- The perception of 'luck' could be characterised by positive life experiences or by drawing comparisons to groups of 'other' unnamed people
- This is an application of cognitive reappraisal; the reassessment of the present situation and its emotional cadence to view events positively
- Review of any differences between individuals who naturally make social comparisons in an oncology setting could add to our understanding of this coping strategy
- This research could potentially inform intervention strategies for pts and cgs which target the traits and behaviours needed to assess a situation more positively

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References

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