

'It just made it a million times worse'
**Cancer carers' needs and experiences of
support during the COVID-19 pandemic**

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Background

- Increasing cancer carer numbers (1.5 million in 2016)
- Only 1 in 10 referred for carers' needs assessments (Macmillan Cancer Support, 2016)
- COVID-19 exacerbated challenges for carers – the *'invisible workforce'* (Phillips et al., 2020)
- Experience at Penny Brohn UK – supporters accessing services dropped (25% to 7%)



Research Question

How has the COVID-19 pandemic impacted cancer carers' experiences of caring and accessing support?

- How has it impacted 'carer' role construction?
- How has it affected enablers and barriers to support?



Methodology

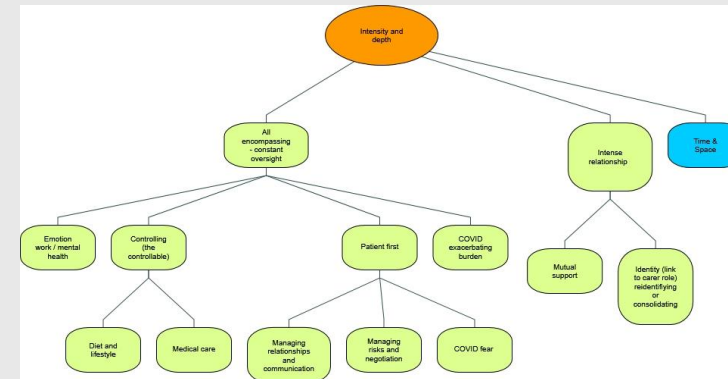
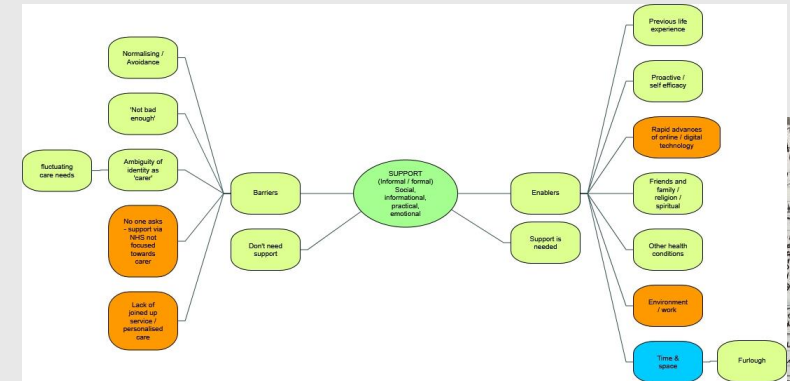
- In-depth, inductive qualitative approach
- Social constructionist position
- Ethical approval granted by the University of Bristol.
- Semi-structured interviews (via Zoom (10) and telephone (1))

- 11 participants
 - 4 men, 7 women
 - 3 non-spousal relationships
 - Wide range of cancer types and prognoses – 5 with advanced cancer, one at end of life.

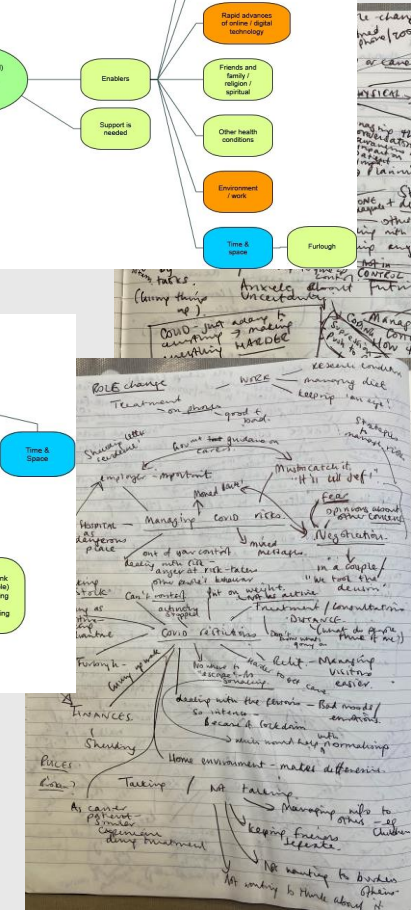


Analysis

- Interviews – average 70 minutes, June and July 2021.
- Data transcribed verbatim, anonymised and uploaded to Nvivo.
- Reflexive Thematic Analysis (Braun and Clarke, 2006, Braun and Clarke, 2021)
 - 6 phases (data familiarisation, data coding, initial theme generation, developing and reviewing themes, refining, defining and naming themes, writing up).
 - Research journal



Initial thematic maps



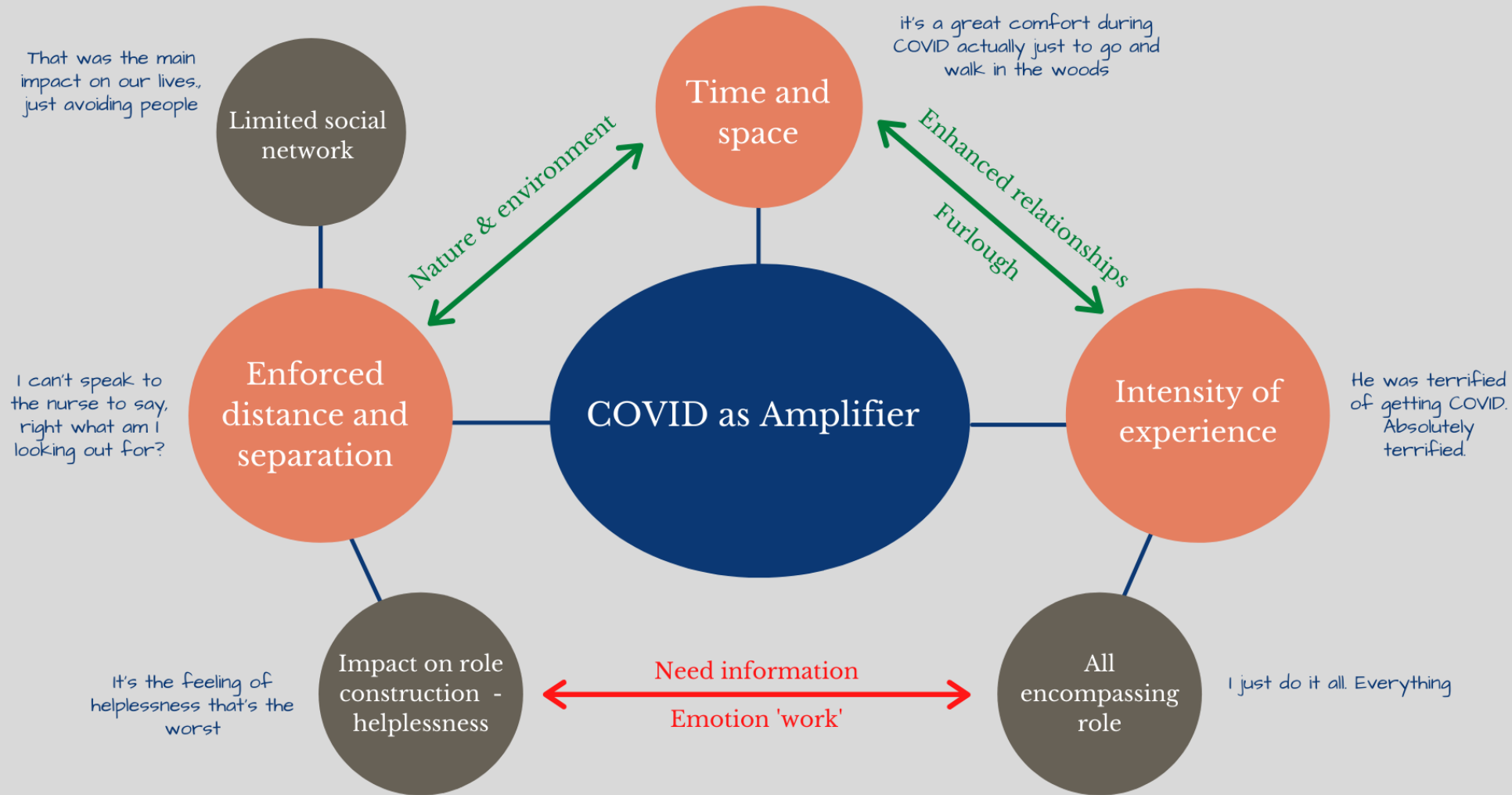
Journal extracts

● Theme

● Sub-theme

— Negative impact

— Positive impact



Enforced distance & separation

It was awful... I couldn't... couldn't go and see him. And then I think I picked him up the following week, which was equally horrible because... Obviously I couldn't go into the hospital to pick him up, so he was on the phone, ... and he sounded awful, he was in a lot of pain, (P11, 40-50s, female, spousal, advanced)

I mean, we were ... we became prisoners of our house, we really didn't go anywhere. (P9, 50-60s, female, spousal, advanced)

That was the main impact on our lives, just avoiding people

Limited social network

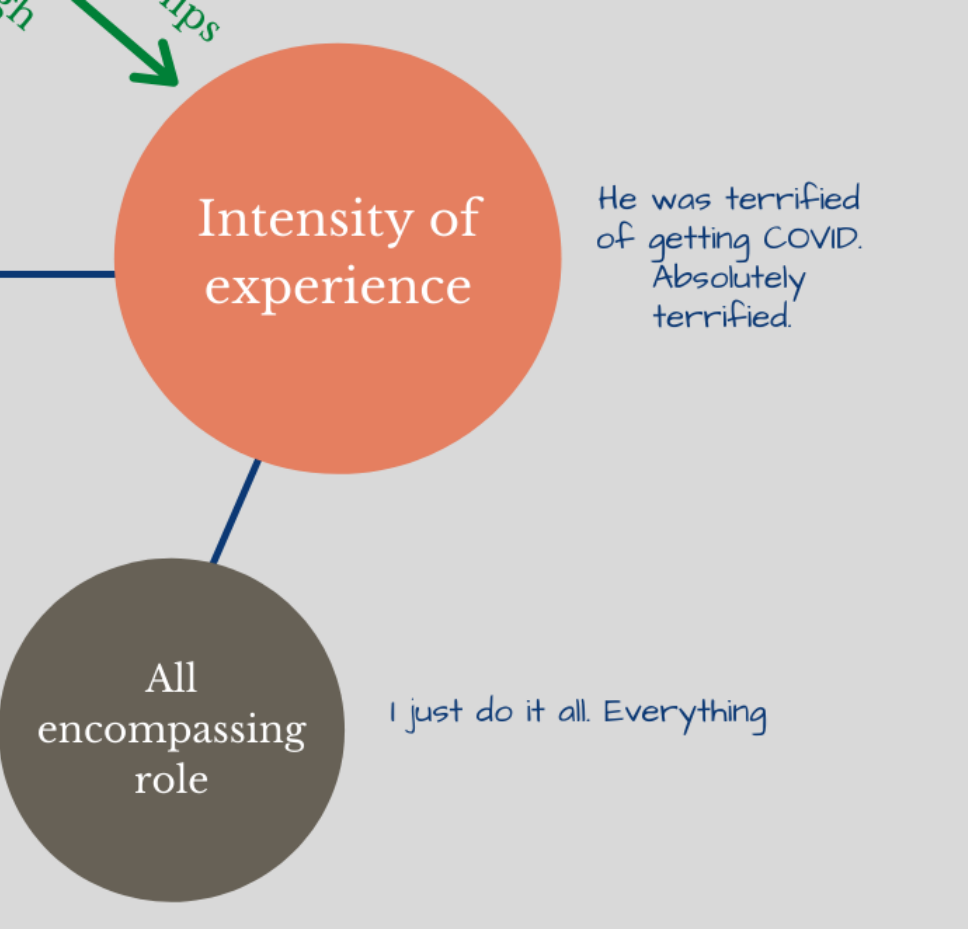
Nature & environment

I can't speak to the nurse to say, right what am I looking out for?

Enforced distance and separation

It's the feeling of helplessness that's the worst

Impact on role construction - helplessness



Intensity of experience

I stayed in with [her]. I largely kept her company. I feel almost guilty, going out and doing things, leaving her on her own. (P8, 60s-70s, male, spousal, advanced)

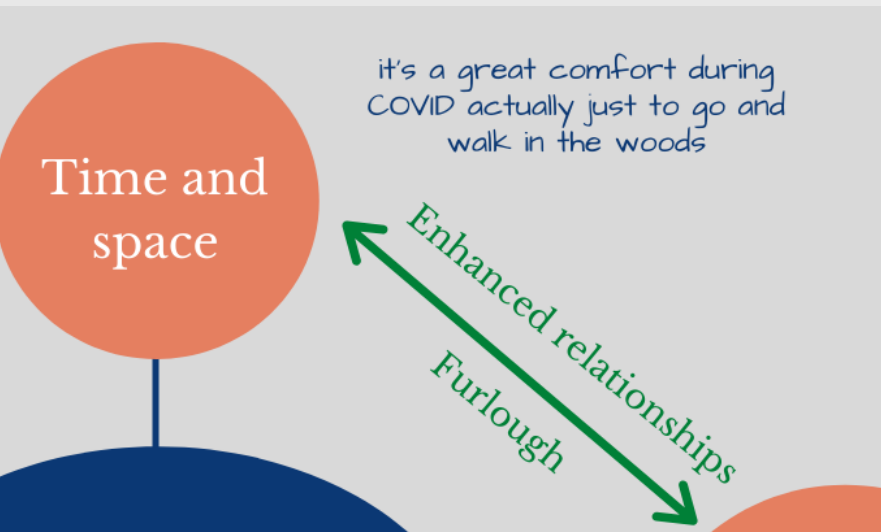
I'm just re-living it, it's horrible... oh it makes me feel sick... I'd go down with this all his meals. Sometimes he didn't want to eat, but I took down an evening meal. So I'd, you know, plate their dinner up, run down the road with his, come back, eat. Then I'd go back down, clear up for him... (P11, 40-50s, female, spousal, advanced)

Time and space

I think we were ... as I say, almost enjoying the peace and quiet.

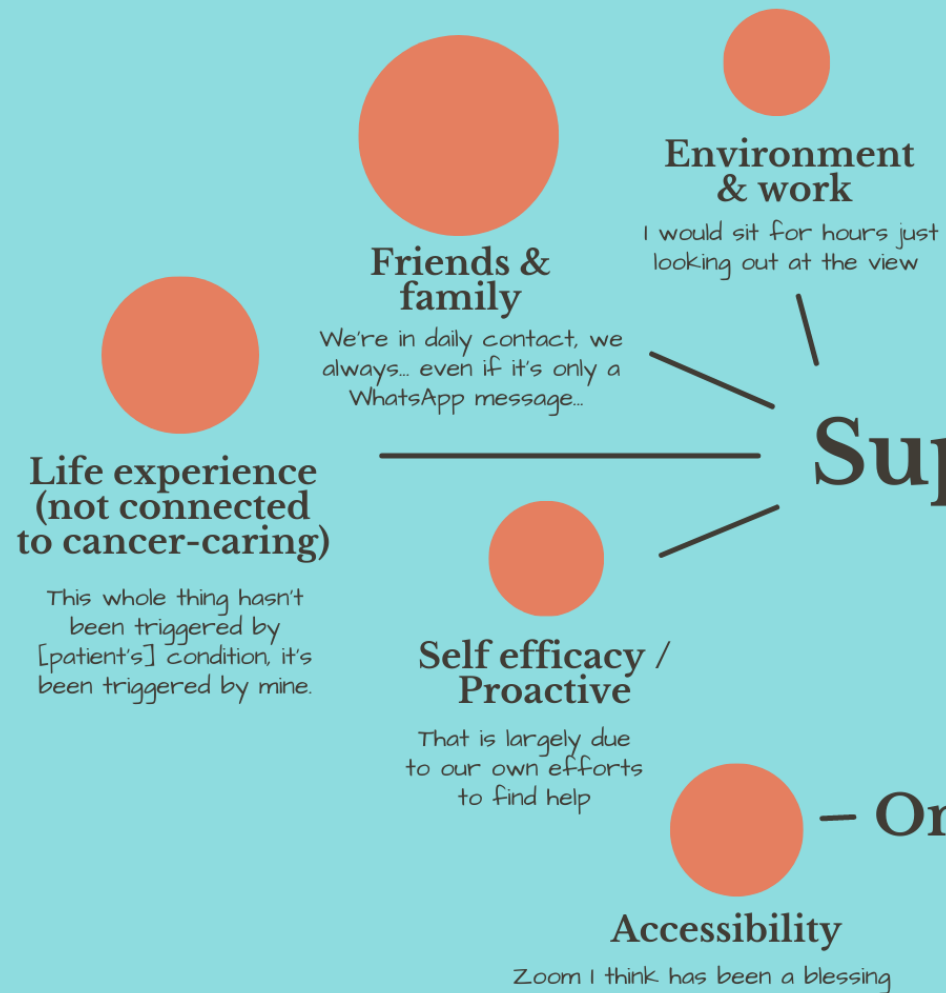
(P8, 60-70s, male, spousal, advanced)

The big advantage I had picking that middle bit, the lockdown, was not having to go to work and not even to think about work. (P4, 40-50s, male, spousal, treatable)



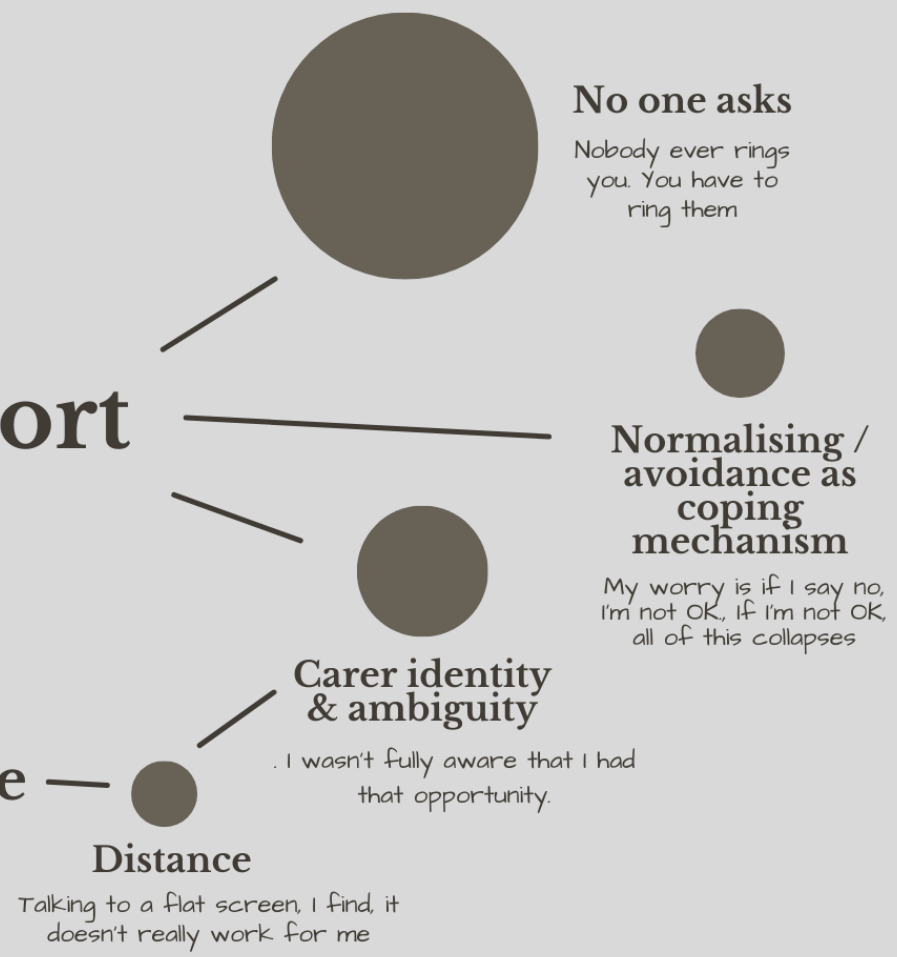
when I walk [the dog] in the morning... You know, ... you're outside, I could I put my headphones in ... and it's just... I loved it. I loved it. Got me through last year. (P11, 40-50s, female, spousal, advanced)

Enablers



Barriers

Support



Policy & practice implications

- Importance of actively engaging carers in treatment conversations.
- Pro-active engagement of healthcare professionals and local authorities in identifying carers' unmet support needs.
- Value of 'time' in nature and to make 'space' for their own wellbeing.
- Support preferences need to be recognised as multifaceted.
- Reliance on support network.



Conclusion and limitations

- In-depth, inductive approach – captured complexity of experiences
- COVID amplified negatives (information support restricted, practical burdens) and positives (enhanced relationships, time and space)
- Limitations
 - Sampling – supportive relationships
 - Penny Brohn UK and my role.
- Future study
 - non-spousal carers
 - Gender

Thank you!

Any questions?

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