Hope, loneliness, and cancer-related experiences among Canadians affected by Biliary Tract Cancers

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Background and Objectives

Hope & Loneliness:

- Hope associated with ↘ depression, distress, symptom burden, ↗ probability of survival & better coping.
- Loneliness (Social Isolation) associated with cancer progression, ↗ depression, ↗ anxiety, ↘ physical quality of life, ↘ survival.

(Cacioppo et al., Psychol Aging, 2010; Jaremka et al., Health Psychol, 2014; Lutgendorf et al., Am Psychol, 2015; Bower et al., JNCI Cancer Spectr, 2018; Feldman et al., Curr Opin Psychol, 2023)

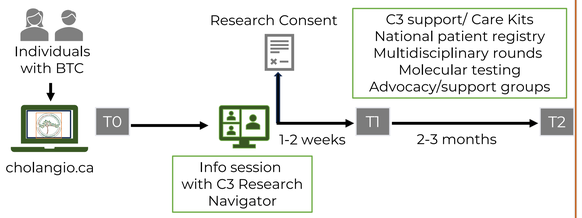
Knowledge gaps on hope and loneliness among individuals impacted by rare cancers, their lived experiences, and how to best support them.

The Canadian Cholangiocarcinoma Collaborative (C3)

C3 was founded to enhance patient access to research and care. This mixed-methods study aimed to document how participants' levels of hope & loneliness evolve over time while participating in C3's initiatives and to further understand patient and caregiver experiences with cancer care in Canada.

Methods

Sample: Patients/caregivers joining C3
Setting: Virtual across Canada
Design: Mixed-methods (quantitative/surveys, qualitative/focus groups)



e-measures at T0, T1, T2

Herth Hope Index (Herth, Sch Nurs Pract, 1991)
- 12 items, 4-point scale (Strongly Disagree → Strongly Agree), Score Range: 12-48 points. Higher scores = Higher Hope

UCLA Loneliness scale (Russel, J Pers Asses, 1996)
- 20 items, 4-point scale (Not at all → Often), Score Range: 20-80 points. Low Loneliness: 20-34 points; Moderate: 35-49 points; Moderately High: 50-64 points; High Loneliness: 65-80 points

Covariates: Medical/work/life changes/updates

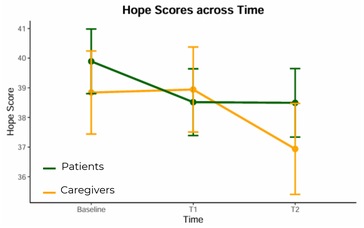
Data analysis: Linear mixed effect models/pairwise comparison

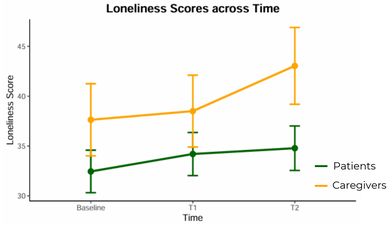
Focus groups (post T2)
- n = 14 (7 dyads)
- Virtual with audio/video recorded. Semi-structured interview guide.

Thematic analysis: Verbatim transcription, double coding, categorization, and theme generation (Braun & Clarks, Qual Res Psychol, 2006)

Quantitative Findings

	Patients N = 92	Caregivers N = 44
Age	Mean = 62 (Range 35-82)	Mean = 54 yrs (Range: 24-81)
Sex/Gender	51 males (54.9%), 41 females (45.1%)	8 males (18.2%), 36 females (81.8%)
Marital status	n = 77 (83.7%) married n = 84 (91.3%) have kids	n = 38 (86.4%) married n = 33 (76.7%) have kids
Work	n = 36 (39.1%) retired not due to health n = 18 (19.6%) disability/sick leave	n = 12 (23.3%) retired due to health n = 10 (14.6%) full time job
Education	n = 27 (29.3%) college n = 23 (27.5%) bachelor degree	n = 14 (31.8%) college n = 13 (29.5%) bachelor degree
Province	ON n = 29 (33%), BC n = 20 (22.7%), AB n = 17 (19.3%), QC n = 6 (6.8%), SK n = 9 (10.2%), MB n = 3 (3.4%), NB n = 2 (2.3%), NS n = 1 (1.1%), NL n = 1 (1.1%)	ON n = 12 (28.6%), BC n = 8 (19%), AB n = 9 (21.4%), QC n = 5 (11.9%), SK n = 3 (7.1%), MB n=0 (0.0%), NB n = 2 (4.8%), NS n = 1 (2.4%), NL n = 1 (2.4%)
Other	**BTC type:** Intrahepatic n = 30 (32.6%) Extrahepatic n = 10 (10.9%) Do not know n = 29 (31.5%) **Surgery for tumor removal** n = 27 (29.7%) **Receiving treatment** n = 62 (68.1%) **Year of diagnosis:** 2024/25 n = 61 (71.8%) 2022/23 n = 15 (17.6%)	**Relationship:** First degree relative n = 14 (31.8%), spouse/partner n = 30 (68.2%) **Role:** Emotional support n = 40 (33.1%), practical support cancer-related n = 39 (32.2%), management n = 40 (33.1%),





Patients	Caregivers
Main effect of time: $F(2, 150.77) = 4.39$; p = 0.014 • Significant ↘ in hope from baseline to T1 (p = 0.029) • No change in hope from T1 to T2	Main effect of time: $F(2, 67.84) = 5.38$; p = 0.007 • No change in hope from baseline to T1 • Significant ↘ in hope from T1 to T2 (p = 0.01)

Patients	Caregivers
Main effect of time: $F(2, 141.42) = 7.02$; p = 0.001 • Significant ↗ in loneliness from baseline to T1 (p = 0.016) • No change in loneliness from T1 to T2	Main effect of time: $F(2, 63.75) = 9.35$; p < 0.001 • No change in loneliness baseline to T1 • Significant ↗ in loneliness from T1 to T2 (p = 0.004)

- **Overall high hope and low to moderate loneliness levels across time**/ fluctuation rather than psychosocial deterioration
- High hope and low/moderate loneliness at baseline/ little room for an upward change: Ceiling effect
- No significant differences in hope and loneliness levels among those who engaged in C3 activities vs. those who did not.

Qualitative Findings and Selected Quotes

1. The diagnosis as a crisis • Troublesome communication • Limited clinical expertise • Distress and life disruptions	✓ *"I was coming out of the anesthesia and that's when he told me" (Pt#4)* ✓ *"Our oncologist had never even heard of it. And we found that a bit weird" (Pt #3)* ✓ *"I was told 4 months with treatment and 20 without, I've spent the rest of the meeting counting in my head how long I would have if it were four months, and when did the four months begin?" (Pt#2)*
2. Uncertainty and the role of information • Multiple sources of information (online, C3, peers) • Variations in information-seeking patterns (intense, avoidant, need-based) • Emergence of knowledge	✓ *"I didn't find that the meeting with the oncologist was all that helpful. We probably found more information on Google" (Pt#7)* ✓ *"ChatGPT has been the biggest help when I can't get a hold of anybody"(Cg#6)* ✓ *"Everybody's different. It's good to have a gatekeeper. And I find that, I tend to just want to focus on the, the good point, good parts (Pt#6)* ✓ *"We are all, we're all advocates for cholangio now. We are actually educating, I mean no disrespect to the oncologist, but we are educating them" (Cg#2)*
3. Hope as an ongoing rollercoaster • Hope swept away at diagnosis, • Fluctuations over time with drivers and barriers	✓ *"I could tell that it was just such a shocking hit at the beginning, we weren't given any hope at all" (Cg#6)* ✓ *"I think, as we go further, as I last longer, the hope is always there. The hope is growing" (Pt #6)* ✓ *"My tumor hadn't grown, it's a reason for hope"(Pt#7)* ✓ *"It's a rollercoaster. You go through phases of hope and despair" (Cg#2)*
4. Managing a fragmented system with burden of self-advocacy • Delays • Provincial, cross-national, and cancer type inequities • Frustrations	✓ *"C3 website says very clearly like a note to the oncologist It's very important to get this test in immediately as soon as the diagnosis happens. Well, it was probably 3-4 months from the diagnosis before we got that in. And then of course it was another six weeks before we got the results. Delays were absolutely appalling and sometimes maybe negligent" (Cg#3)* ✓ *"It's been our experience that if you're stage 4, the cancer care doesn't care. All their resources go to people that they can cure. We've found that we've had to fight for every single bit of information or treatment" (Cg#7)* ✓ *"We're here kind of having to advocate for ourselves" (Pt#1)*
5. Unmet needs and reliance on informal support • Limited access to professional psychosocial support • Reliance on informal networks	✓ *"I have a good benefit plan, and I found myself a psychologist from the beginning. I did that on my own. It was not mentioned by anyone" (Pt#2)* ✓ *"I find those webinars and those focus groups just when we're all on as a community, that kind of settles me down. Just seeing the look on other people's faces, you can see the stress going off if someone gets a right answer, to hear somewhere else, you can just see the softness come into their shoulders. Then maybe that's psychosocial"(Cg#1)*
6. Patient-caregiver views of a hope-oriented system of care • C3's leading role in clinical education and knowledge dissemination • Care coordination • Integrated, equitable care and embedded psychosocial support	✓ *"What I think C3 could work on is an algorithm the compass all the information that C3 has gathered over the last two years on how the treatment protocols flow and what treatment options might be and what the sequence of events might be. That's a sort of algorithm that would be great for pathologists as well as newly diagnosed patients" (Cg#3)* ✓ *At C3, I would like you to be telling people that there is hope, the oncologist, so that you don't get told you've got between 4 and 20 months" (Pt #1)* ✓ *"We need to advocate powerfully for reducing and tightening up the timelines of testing and then getting into the treatment protocol and tightening those up so that the six-month, whatever delays just don't happen in this type of cancer" (Cg#2)*

Conclusions and Future Directions

- **C3 is a key source of hope, enhancing patient and caregiver experience through access to information, guidance, and peer support**
- **Hope is not static, emphasizing the need for ongoing support throughout the care journey**
- **Hope-informed communication, coordinated care, timely and equitable access to molecular testing and treatment, and integrated psychosocial support remain central priorities for a hope-oriented system of care**

Background

Hope and social connections play an important role in how people cope with cancer. Feeling hopeful is linked to less distress, better coping, and sometimes even longer survival. On the other hand, loneliness and social isolation can negatively affect mental health, quality of life, and possibly disease outcomes. However, for people living with rare cancers, we know very little about how hope and loneliness change over time or how they are experienced. The Canadian Cholangiocarcinoma Collaborative (C3) was created to improve care, support, and access to information and research for patients and caregivers. This study measures how hope and loneliness evolve over time and explores in depth patient and caregiver experiences.

Methods

Participants completed self-report measures (online) of hope and loneliness at T0 (when joining C3), T1 (post initial C3 information session), and T2 (2-3 months following C3 initiatives exposure). Some participants also took part in focus groups.

Results

Despite quantitative findings indicating decreases in hope and increases in loneliness from baseline to T1 among patients and from T1 to T2 among caregivers, overall levels of hope remained high and loneliness relatively low over time, suggesting fluctuation rather than psychosocial deterioration. The focus groups provided deeper insight into these findings. Participants described hope as a "rollercoaster", shaped by uncertainty, limited information, and challenges navigating fragmented care systems. Participants viewed C3 as a source of hope and support, providing reliable information, guidance on molecular testing and treatments, and opportunities to connect with others facing similar experiences.

Conclusion

This study highlights the importance of timely information, coordinated care, and ongoing psychosocial support for both patients and caregivers. It also shows how initiatives like C3 can help maintain hope and improve the overall cancer care experience, even in the face of uncertainty.

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