



# Exploring Frailty in Older Adults with Cancer: Journey Mapping a Patient-reported Outcome Measure

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## Article

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## Abstract

Frailty in older adults with cancer is complex, evolving, and often overlooked in care. This qualitative study explored how frailty is experienced and reported using patient-reported outcome measures (PROMs) and visualized over time through journey maps. Eleven participants (65+) completed the Comprehensive Frailty Assessment Instrument (CFAI) and semi-structured interviews. Individual journey maps combined CFAI scores with personal narratives to track changes in physical, mental, and social aspects of frailty over time. While PROMs showed variability in frailty severity, narratives revealed discrepancies, such as low frailty scores despite significant treatment-related challenges. Fatigue, emotional distress, and isolation were common during treatment, with lasting impacts post-treatment. Findings suggest PROMs alone may not fully capture lived experience. Integrating narrative dialogue provides a more person-centred approach to frailty assessment and care planning.

## Résumé

La fragilité chez les personnes âgées atteintes de cancer est complexe, évolutive et parfois négligée dans les soins. Cette étude qualitative a exploré comment la fragilité est vécue et rapportée à l'aide de mesures des résultats rapportés par les patients (patient-reported outcome measures – PROM), et visualisée au fil du temps à l'aide de cartes de parcours. Onze participants (âgés de 65 ans et plus) ont répondu au questionnaire de l'outil d'évaluation globale de la fragilité (Comprehensive Frailty Assessment Instrument – CFAI) et participé à des entrevues semi-structurées. Les cartes de parcours individuelles ont combiné les scores du CFAI avec les récits personnels pour suivre l'évolution des aspects physiques, mentaux et sociaux de la fragilité au fil du temps. Alors que les PROM ont montré des degrés variables de gravité de la fragilité, les récits personnels ont révélé des écarts, tels que de faibles scores de fragilité malgré d'importants défis liés aux traitements. La fatigue, la détresse émotionnelle et l'isolement étaient courants pendant le traitement, et leurs effets étaient durables par la suite. Les résultats indiquent que les PROM ne peuvent à elles seules pleinement cerner l'expérience vécue. L'intégration du dialogue narratif offre une approche plus centrée sur la personne de l'évaluation de la fragilité et de la planification des soins.

## Introduction

Frailty is a major concern for older adults with cancer, as it increases vulnerability to adverse outcomes associated with treatment such as chemotherapy toxicity, surgical complications, and mortality (Fletcher et al., 2022; Handforth et al., 2015). Traditionally, frailty has been conceptualized as a clinical syndrome characterized by diminished physiological reserve and resilience, often assessed using physical indicators like unintentional weight loss, exhaustion, and slowness (Fried et al., 2001). While this physical phenotype model remains widely used, it may overlook the broader psychosocial aspects that shape patients' lived experiences. A more holistic perspective frames frailty as a multidimensional condition encompassing physical, mental, and social domains (Muszalik et al., 2021; Sobhani et al., 2021). Additional conceptualizations of frailty, such as the deficit accumulation model (Rockwood and Mitnitski, 2007) and the biopsychosocial model (Gobbens et al., 2010), provide more comprehensive frameworks that account for how cumulative health deficits interact with emotional and social well-being. These models are

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particularly relevant in oncology, where treatment intensity must be balanced with quality of life considerations (Crowder et al., 2022; Ethun et al., 2017).

Despite these broader conceptualizations of frailty, most frailty assessments continue to rely on clinician-reported or performance-based measures (Panhwar et al., 2019), which may not fully reflect how patients perceive their own health. Patient-reported outcome measures (PROMs), such as the Comprehensive Frailty Assessment Instrument (CFAI), offer a valuable complement by allowing older adults to directly report on their symptoms such as fatigue, emotional distress, and social isolation (de Vries et al., 2011; Murugappan et al., 2023). PROM-based assessments can enhance person-centred care by facilitating shared decision making and improving communication between patients and clinicians (Licqurish et al., 2019; van Egdom et al., 2019). However, when interpreted in isolation, PROM scores risk overlooking the contextual nuances of individual experiences (Kwon et al., 2019). In a systematic review of qualitative studies, Campbell et al. (2022) found that PROMs can unintentionally inhibit patient-clinician interaction, misrepresent patients' issues, and omit clinically meaningful context for nuanced care planning. For example, two patients may have identical CFAI scores yet face vastly different challenges based on their coping strategies, social supports, or life goals, which can only be understood through meaningful clinical dialogue. To highlight these complexities, this study integrated PROMs with journey mapping, a service design method that visualizes patients' care trajectories, health care interactions, and emotional experiences over time (Gibbons, 2018). Journey mapping situates PROM scores within patients' personal narratives, helping to explain the 'why' behind the numbers. Emerging evidence suggests that combining PROMs with qualitative methods can reveal emotional, social, and structural barriers that would otherwise remain hidden (Campbell et al., 2022; Kwon et al., 2024; McCarthy et al., 2016; Zomerdijsk and Voss, 2010). By incorporating PROMs within journey maps, patient-clinician interactions can move beyond static scores towards a more contextualized understanding of frailty from the patients' perspective. This integration allows for deeper insights into patient priorities, helps avoid misrepresentation, identifies care gaps, and supports more individualized, person-centred conversations about frailty and care planning (Greenhalgh et al., 2018; McCarthy et al., 2016; Zomerdijsk and Voss, 2010). This study examined how integrating PROM-based frailty scores with patient narratives through journey mapping can enhance the relevance, interpretability, and person-centredness of frailty assessments for older adults with cancer.

## Methods

This qualitative descriptive study (Bradshaw et al., 2017), grounded in an interpretivist paradigm (Kwon et al., 2019), employed semi-structured interviews and journey mapping to explore older adults' experiences of frailty during and after cancer treatment. This paradigm assumes that knowledge is co-constructed through participant-researcher dialogue, making it well-suited for understanding how individuals make meaning of frailty in the context of their lived experience. Journey mapping was used both as a method of integrating qualitative interviews and PROMs and served as a visual analytic tool. Drawing on patient-oriented design, journey maps represented each participant's frailty trajectory across key phases of their cancer journey (e.g. treatment and post-treatment). Each map incorporated CFAI scores alongside their emotional

responses and care experiences, enabling comparison between patient narratives and PROM responses. This approach supported a more nuanced, person-centred assessment of frailty that extended beyond numerical scores to include clinically meaningful context.

## Frailty-specific PROM: comprehensive frailty assessment instrument

The CFAI is a multidimensional PROM designed to assess self-reported frailty severity across four domains: physical, psychological (comprised of mood disorders and emotional loneliness subdomains), social (comprised of social loneliness and social support network subdomains), and environmental (De Witte, Gobbens, De Donder, Dury, Buffel, Schols, et al., 2013). This study specifically utilized the physical domain, the mood disorder subdomain of the psychological domain, and the social loneliness subdomain of the social domain based on clinical and patient partner input. Each domain includes specific items rated on Likert-type scales, with higher scores reflecting higher frailty. Domain scores were summed and classified as low, moderate, and high frailty (see Table 1).

The psychological and social subdomains were relabelled 'mental' and 'social' domains, respectively, to enhance clarity for participants. The CFAI was selected over other frailty PROMs due to its comprehensiveness, reliability (Cronbach's alpha >0.70), and its alignment with both physical and psychosocial dimensions of frailty (De Witte, Gobbens, De Donder, Dury, Buffel, Schols, et al., 2013; De Witte, Gobbens, De Donder, Dury, Buffel, Verté, et al., 2013). To adapt the CFAI for this study, participants completed retrospective self-assessments for both treatment and post-treatment periods. This approach, informed by qualitative evaluation practices (Patton, 2014), enabled exploration of perceived changes in frailty over time.

## Recruitment and sampling

Participants were recruited by convenience sampling through community organizations across Canada from May to June 2023. Eligible participants were (a) diagnosed with cancer at or after 65 years of age, (b) had completed or were undergoing cancer treatment, and (c) resided in Canada. To capture a range of recovery experiences, no strict limit was imposed on the time since treatment. Participants self-identified when their post-treatment phase began, recognizing that this period may vary based on symptoms, follow-up care, and individual perceptions of recovery. However, participants were not asked specifically when their post-treatment phase ended. Ethnicity data were not collected, a decision made in consultation with patient partners to prioritize interview depth over demographic profiling.

## Patient involvement and ethics

To ensure respectful framing of frailty within the context of cancer, two older patient partners with lived cancer experiences collaborated with the research team, actively participating in research team meetings and contributing to the study design. Patient partners assisted in refining the language for the recruitment poster and the interview guide to avoid inadvertent ageist language associated with frailty.

Research ethics approval was provided by the University of British Columbia Behavioural Research Ethics Board. All participants provided informed consent and received a \$50 grocery gift card as an honorarium. This study is reported in accordance with the consolidated criteria for reporting of qualitative research (COREQ; see supplementary file) guideline (Tong et al., 2007).

**Table 1.** Comprehensive frailty assessment instrument item and scoring summary

Domain	Item	Response scale	Scoring threshold
Physical limitations	Carrying shopping bags	0 = not at all, 1 = ≤3 months, 2 = >3 months	Low: 0–2, moderate: 3–5, high: 6–8
	Walking up a hill or stairs		
	Bending or lifting		
	Going for a walk		
Mental (mood disorder)	Feeling unhappy and depressed	0 = not at all, 1 = not more than usual, 2 = more than usual, 3 = considerably more than usual	Low: 0–4, moderate: 5–9, high: 10–15
	Losing self-confidence		
	Feeling life is meaningless		
	Feeling tired of everything		
	Feeling tense or anxious		
Social (social loneliness)	There are enough people whom I can rely on when I am in trouble	0 = completely agree to 4 = completely disagree	Low: 0–3, moderate: 4–7, high: 8–12
	I know many people whom I can totally trust		
	There are enough people with whom I feel a bond		

### Data collection procedures

Retrospective interviews, approximately 60 minutes in length, were conducted virtually via Zoom by three trained qualitative researchers (JY, JW, CW). Each interview began with an open-ended question inviting participants to share background information they were comfortable disclosing, along with demographic details (e.g. age, cancer diagnosis, treatment history). For those who received multiple cancer treatments, additional questions explored the sequence and timing of each treatment. This was followed by questions to understand the participants' cancer journey, focussing on the treatment and post-treatment phases. For the treatment phase, participants were asked what it was like, their thoughts during treatment, and what they were feeling during treatment. Participants then completed items from the CFAI, covering physical, psychological, and social domains (De Witte et al., 2013). If participants received multiple treatments, they were asked to reflect on one specific treatment when responding to the CFAI items. They were also prompted to explain why they chose each response, share any limitations or concerns they experienced at the time, and reflect on conversations they would like to have had with their health care provider. The same process was repeated for the post-treatment phase. Participants were first asked to describe their experiences adjusting to life after treatment; then, they completed the CFAI with post-treatment reflections and elaborated on their responses. The interviews concluded with questions about participants' perceptions of frailty (e.g. what comes to mind when you think of the word frailty) (see [supplementary file](#) interview guide). All interviews were audio recorded and transcribed verbatim in preparation for data analysis.

### Data analysis and journey map development

Data analysis and development of the journey maps followed a systematic process. Initially, all transcripts were thoroughly read independently by three researchers (JY, MM, CW) to gain a comprehensive understanding of the participants' experiences. A data summary template was developed (see [supplementary file](#)) based on the interview structure to capture keywords and descriptions.

The template also incorporated an empathy map process used to capture the emotional aspects of participants' experiences by focusing on their thoughts and feelings during the treatment and post-treatment phases (Gray et al., 2010). The data summaries included participants' interview responses to the CFAI items, and the physical, mental, and social domain scores were calculated. Detailed data summaries were created for each interview. These summaries were then used to populate a journey map template (see [supplementary file](#)), ensuring a structured and coherent representation of each participant's experiences over time.

After the initial journey maps were developed, the researchers (JY, MM, CW) worked collaboratively to refine and condense the information while staying true to the interview data (e.g. using participants' words whenever possible). This iterative process went through multiple revisions and ultimately resulted in succinct journey maps representing participants' experiences. To visualize participants' frailty during treatment and post-treatment phases, their frailty assessment scores (i.e. CFAI scores) were included in the journey maps. This allowed us to understand patients' frailty alongside their reported experiences. Finally, an 'Opportunities to Discuss Frailty Throughout Care' section was added, which was developed from reviewing the data summaries, participants' responses to having conversations with their health care providers, and taking into consideration their overall cancer experiences. The larger research team, including a clinician investigator (CM), methodological expert (RS), and patient partners (LW, HH), reviewed and provided feedback on the journey maps. To ensure the validity and authenticity of the findings, member checking was conducted with the participants (Bradshaw et al., 2017). This rigorous process resulted in 11 journey maps, which were anonymized using pseudonyms to reflect the personal nature of the participants' experiences while protecting their privacy.

### Results

Out of the 20 initially interested individuals, 11 participated in this study. Reasons for non-participation included: not meeting the

**Table 2.** Participants' demographics and comprehensive frailty assessment instrument (CFAI) scores

Pseudonym	Sex	Age	Cancer	Treatment focus for CFAI items	Length of time since treatment ended	Treatment P/M/S scores	Post-treatment P/M/S scores	Frailty level
Karen	Female	72	Lung	Chemo	6 months	4/8/0	4/1/0	Moderate to low
Paul	Male	71	Prostate	Hormone	1 year	0/6.5/7	0/2/2.5	Moderate to low
Jack	Male	65	Prostate	Radiation	1 month	1/7/0	1/2/0	Low
Luke	Male	77	Prostate	Radiation	11 days	0/0/0	0/3/0	Low
Donna	Female	70	Breast	Chemo	2 years	3/8/5	0/6/5	Moderate
Linda	Female	67	Breast	Hormone	1 year	0/1/0	0/1/0	Low
Elizabeth	Female	67	Pancreatic	Surgery	4 years	8/5/0	4/2/1	Moderate
Genevieve	Female	69	Thyroid/tongue	Chemo	6 years	5/6/8	8/6/7	Moderate to high
Rick	Male	71	Lymphoma	Chemo	6 years	2/2/2	0/2/0	Low
Walter	Male	68	Colorectal	Chemo	8 years	7/5/0	8/6/4	Moderate to high
Susan	Female	79	Skin	Surgery	12 years	0/1/3	0/2/3	Low

Note: Decimal values indicate participant responses that fell between two adjacent Likert scale categories (e.g. between not more than usual and more than usual). Abbreviations: CFAI = comprehensive frailty assessment instrument; P = physical domain; M = mental domain; S = social domain.

eligibility criteria (diagnosed under 65 years,  $n = 5$ ), no response ( $n = 2$ ), self-withdrawal ( $n = 1$ ), and having received treatment more than 20 years prior ( $n = 1$ ). The final sample included six women and five men who were diagnosed with cancer between 65 and 79 years of age. Participants varied considerably in terms of cancer types, treatment modalities, and length of time since treatment ended. CFAI treatment and post-treatment scores categorized participants into four frailty levels: low ( $n = 5$ ), moderate to low ( $n = 2$ ), moderate ( $n = 2$ ), and moderate to high ( $n = 2$ ) (see Table 2).

Journey maps (see Appendix in online supplementary material) were developed to visually illustrate participants' intricate experiences, providing depth beyond what CFAI scores alone could capture. Rather than repeating detailed narratives, cross-case analyses are provided below, highlighting key themes within each frailty category.

### Low frailty

Participants categorized as having low frailty ( $n = 5$ ) generally reported minimal disruptions across physical, mental, and social domains on the CFAI. Physically, they remained independent in daily activities, and socially, they retained strong support networks. Mental health challenges were also minimal based on CFAI scoring. However, narrative analysis uncovered important nuances and clinically meaningful concerns not reflected in quantitative measures alone. In particular, side effects and emotional impacts from treatment emerged as key issues requiring attention beyond the CFAI's domain scores.

For example, Luke, a 77-year-old single man, exemplified how low frailty scores may obscure important challenges. His interview took place 10 days after completing radiation treatment. Despite reporting no physical limitations (0/8) and maintaining strong social ties (0/12), treatment-related side effects such as urinary incontinence and constipation confined him to his home, disrupting social routines and diminishing his quality of life. While his mental domain score remained 0/15 during treatment, he

described feeling 'horrible', confused about his prognosis, and disillusioned with counselling. This dissonance between CFAI scores and the contextualized lived experience highlights the importance of narrative elaboration for understanding frailty more holistically and avoiding misrepresentation. At the time of the interview, Luke's CFAI physical score remained 0/8, though he reported persisting fatigue and a reduced ability to engage in physical and social activities. His mental domain score increased to 3/15, reflecting growing emotional strain from inactivity and uncertainty around his cancer status. Social scores remained unchanged, but his actual participation in social activities declined due to ongoing physical discomfort.

Luke's case illustrates how narrative mapping reveals the dynamic, intersecting impacts of treatment-related side effects on mental and social well-being, even in those categorized as 'low frailty'. Integrating journey mapping into frailty assessment enabled the identification of unmet patient needs, such as post-treatment recovery guidance, peer support opportunities, and more transparent communication about prognosis. This approach demonstrates that PROM scores may not fully reflect the complexity of patient experiences unless interpreted within the context of a clinical conversation. Moreover, even those with low frailty scores benefit from tailored, person-centred interventions when PROMs are integrated with other forms of data, such as clinician assessment.

### Moderate-to-low frailty

Participants with moderate-to-low frailty ( $n = 2$ ) presented moderate impairments across physical, mental, and social domain scores during treatment, with post-treatment improvements reflected in declining CFAI scores. While their overall recovery trajectories were positive, interview narratives revealed ongoing challenges, particularly in managing fatigue, emotional uncertainty, and information needs, highlighting the complexity masked by aggregated scores. The complexity of patient experiences of frailty can be better interpreted within a larger context.



Karen, a 72-year-old woman diagnosed with lung cancer exemplified this profile. Living in a rural community with her husband, Karen underwent a rigorous course of chemotherapy, radiation, and immunotherapy. During treatment, her CFAI physical domain score was 4/8, reflecting her need for help with most daily activities due to extreme fatigue. However, interview data contextualized this score further: Karen reported severe side effects, including difficulty in swallowing and a lack of appetite, which contributed to her functional decline. These side effects were not fully captured in the physical domain score but had a compounding effect on her overall energy and autonomy. Karen's mental domain score during treatment (8/15) highlighted notable emotional distress. She described feeling persistently unhappy and overwhelmed, driven by the unpredictability of her illness and the stress of undergoing treatment while unwell. A critical factor that emerged was a lack of information as Karen was unsure what to expect from treatment and found this uncertainty highly anxiety-inducing. Notably, despite these difficulties, her social domain score was 0/12, reflecting strong family and community support, which appeared to buffer the impact of treatment stress. By the post-treatment phase, Karen reported gradual physical improvement, although her recovery was slower than anticipated. Her physical domain score remained unchanged at 4/8, reflecting residual fatigue. Mentally, her score dropped to 1/15, indicating emotional recovery, although she continued to experience scan and test-related anxiety and a generalized sense of unease about recurrence. Her social connections remained stable (0/12), though she expressed interest in joining a local cancer support group, signalling a potential unmet need for peer-based emotional support.

Karen's case illustrates how even moderate levels of frailty may require significant support for recovery. Her experience underscores the value of integrating narrative data through patient-clinician conversations to uncover patient priorities not fully represented by PROMs such as the need for anticipatory guidance about recovery timelines, strategies to manage side effects like dysphagia, and psychosocial interventions to ease anxiety. Journey mapping thus highlights what may be missing from standardized frailty assessments by accounting for the clinical context, illustrating individualized recovery goals and persistent vulnerabilities in the survivorship phase.

### *Moderate frailty*

Participants with moderate frailty ( $n = 2$ ) experienced compounded challenges across physical, mental, and social domains, both during and after treatment. While their CFAI scores indicated moderate impairments, journey mapping revealed ongoing struggles with pain, mental distress, and social disconnections, highlighting a need for more responsive, individualized treatment and post-treatment support.

Donna, a 70-year-old woman diagnosed with stage 2b triple-negative breast cancer, underwent intensive treatment during the COVID-19 pandemic, including chemotherapy, a bilateral mastectomy, and radiation. Her physical domain score of 3/8 during treatment reflected moderate frailty, but interview narratives captured the breadth of her experience more vividly. Donna described debilitating fatigue, difficulty in eating, and a range of severe side effects that disrupted her ability to complete daily tasks. Her experiences were compounded by chronic conditions like arthritis and osteoporosis, which further hindered her functional capacity and compounded treatment side effects. Mentally, Donna's score of 8/15 during treatment captured significant psychological strain.

She reported persistent depression, distress from brain fog, and a loss of control. Standard mental health supports, such as phone-based counselling, did not meet her needs, and she expressed frustration at the lack of individualized support. She felt these services failed to address her unique situation as an older adult navigating both cancer and the broader disruptions caused by the pandemic. Socially, Donna's domain score of 5/12 reflected a decline in her usual support networks. Although her husband was a consistent caregiver, other social connections weakened due to COVID-19 restrictions. She expressed feeling let down by the medical system and described having to independently seek out services, adding an emotional and cognitive burden during an already vulnerable time. In the post-treatment period, Donna's physical domain score decreased to 0/8, signaling a return to independence. However, the interview revealed that ongoing pain (not lack of strength) remained a major barrier to daily functioning. Her recovery was not linear; lingering symptoms and comorbidities continued to affect her social life and routine activities. Mentally, she continued to report issues with sleep, mood, and cognitive clarity, with a slightly improved but still elevated mental score (6/15). She emphasized the need for integrated mental health support that considers her entire life context, including aging, pain, and social role changes. Her social score remained unchanged (5/12), and she described the continued erosion of friendships and support groups. The loss of connection with her cancer community, exacerbated by public health restrictions, left her feeling isolated and emotionally adrift.

Donna's journey illustrates that moderate frailty is not a static condition but a fluid, context-dependent experience shaped by medical, psychological, and social factors. While PROMs such as the CFAI tracked some improvements post-treatment, journey mapping revealed persistent unmet needs and the limitations of standardized tools in capturing fluctuating symptoms and shifting priorities over time. Her case suggests actionable strategies, including anticipatory guidance for survivorship, dietary and pain management support, and enhanced access to personalized mental health care. Journey mapping uncovered these insights and supported the need for patient-clinician interaction to interpret the scores within the clinical context, thereby enabling a more comprehensive and person-centred approach to frailty during both treatment and post-treatment.

### *Moderate-to-high frailty*

Participants in the moderate-to-high frailty group ( $n = 2$ ) experienced substantial and persistent challenges across physical, mental, and social domains. Their CFAI scores reflected increased frailty, but the contextual narratives revealed deeper layers of vulnerability shaped by overlapping medical, psychosocial, and economic stressors. These cases illustrate how frailty, when compounded by external circumstances, can substantially limit recovery and re-engagement with daily life.

Genevieve, a 69-year-old woman diagnosed with thyroid and tongue cancer, underwent an intensive treatment regimen of radiation, chemotherapy, and surgery. During treatment, her primary focus was survival. Her physical domain score of 5/8 captured her functional decline, but her interview revealed additional complexities. Severe fatigue, nausea, and swallowing difficulties necessitated the use of a feeding tube and left her unable to perform daily activities independently. She described having 'no strength or energy', and required continuous support with basic tasks. Mentally, Genevieve reported a loss of self-confidence and persistent

emotional distress related to her inability to care for herself. Her CFAI mental domain score was 6/15 during treatment. She found psychiatric support helpful but still struggled with depressive symptoms. Socially, her usual sources of support were disrupted as her husband was recovering from heart surgery, and although her sister assumed the role of primary caregiver, Genevieve felt isolated and misunderstood. Her social domain score of 8/12 reflected this disruption and limited sense of connection. Post-treatment, the interplay between frailty and unmet recovery needs became more pronounced. Genevieve reported anxiety about returning to work, which proved difficult due to persistent brain fog and a weakened voice – key barriers given her work involved training and public speaking. Her CFAI physical score worsened (8/8), reflecting significant deconditioning, weight loss, and ongoing dependence on others for instrumental tasks. She also continued to struggle with mental health (6/15), expressing concern about long-term side effects and the unpredictability of her recovery. Socially, although her husband resumed a supportive role, Genevieve's score remained elevated at 7/12. She expressed a continued sense of isolation, which she attributed partly to ongoing swallowing difficulties that limited her participation in social activities. Her case demonstrates how specific symptoms (e.g. dysphagia) can create cascading effects across frailty domains, reinforcing disengagement and distress.

Narrative analysis of Genevieve's journey map highlighted several gaps in care and possible misrepresentation of patient issues. Beyond symptom management, she would have benefited from an interdisciplinary recovery plan that included swallowing assessments, rehabilitation support (e.g. occupational and physical therapy or referrals to certified exercise physiologists and community-based frailty-informed exercise programs), and social work input for workplace reintegration. Ongoing attention to mental health, tailored support groups, and caregiver-specific resources were also identified as key needs. Importantly, Genevieve's case illustrates that the CFAI scores may not fully reflect the complexity of patient experiences within a given context, potentially overlooking the cumulative effects of intersecting physical limitations, psychosocial strain, and structural barriers.

## Discussion

This study aimed to enhance our understanding of how patient-reported frailty assessment scores can inform more personalized and context-specific care for older adults with cancer. A key insight aligns with Campbell *et al.*'s (2022) systematic review, which emphasized both the benefits and limitations of using PROMs in clinical practice. While PROMs, such as the CFAI, can improve patient involvement and care quality, they can have significant limitations when interpreted without accompanying clinical conversations. Specifically, PROM scores alone may risk misrepresenting patient experiences and overlook essential contextual nuances (Campbell *et al.*, 2022; Kwon *et al.*, 2022). Building upon this existing knowledge, our study integrated frailty-specific PROMs with journey mapping to contextualize standardized assessments through detailed patient narratives. Journey maps visually represented CFAI scores within emotionally and socially meaningful contexts, highlighting nuanced aspects of patient experiences, such as long-term treatment effects, mental health concerns, and social isolation, that standardized scores alone cannot fully capture. The integration of PROMs and journey mapping directly addresses the limitations highlighted in prior research and provides clinicians with actionable, person-centred insights.

Participants in our study demonstrated varied frailty trajectories, reflecting the dynamic and multifaceted nature of frailty in oncology (Casals *et al.*, 2024). Some individuals experienced improvements post-treatment, while others continued to face persistent challenges such as fatigue, anxiety, and social withdrawal. These findings reinforce the importance of interpreting PROMs within meaningful clinical dialogues rather than as fixed indicators. For example, participants with low frailty scores frequently described significant impairments and unmet needs, highlighting discrepancies between numerical data and lived realities. Across all frailty groups, participants expressed needs that extended beyond their CFAI scores, including support for pain management, recovery expectations, and reconnecting socially post-treatment. These needs were particularly evident in narratives from participants classified within moderate and moderate-to-high frailty categories, who often faced intersecting barriers such as comorbidities, limited caregiver support, and economic constraints. Integrating PROM scores with journey mapping revealed that some physical domain items missed treatment-related side effects (e.g. dysphagia or arthritis-related pain) or mental health needs were obscured by minimal scores due to resilience or underreporting. These findings suggest that PROMs can be valuable conversation starters with an emphasis on the need for continuous patient–clinician interactions that meaningfully interpret and contextualize patient experiences (Skovlund *et al.*, 2020). In particular, clinicians should not rely solely on the scores but rather engage patients in conversations that unpack physical, mental, and social aspects of frailty. Such dialogue may open space to co-design interventions such as physical rehabilitation, tailored psychological support, and facilitated connections with peer or caregiver resources. To support clinicians to interpret and act on PROMs data, comprehensive education and practical skills training are essential (Stover *et al.*, 2021). Resources such as those provided by healthyqol.com (<https://www.healthyqol.com/resource-guide>) and recent 2025 symposia (<https://www.pathlms.com/isoqol/events/11999>) offer practical guidance to clinicians on incorporating PROMs into practice.

Ultimately, addressing frailty in older adults with cancer requires an integrated person-centred approach characterized by holistic and contextual patient–clinician interactions. Interventions should be framed in terms of resilience-building (e.g. supporting nutrition, managing fatigue and cognitive effects, and enhancing social engagement). Empowering patients through active participation in frailty assessments and ensuring tailored follow-up support based on their narratives can substantially promote recovery and improve overall quality of life. Journey mapping thus emerges as a valuable methodological tool not only for understanding frailty but also for designing care pathways that honour the complexity of aging and survivorship.

## Limitations

Several limitations must be considered when interpreting these findings. First, the study sample was recruited through community organizations and relied on virtual interviews conducted via Zoom. As such, participants were likely more digitally literate and socially connected than the broader population of older adults with cancer. This may have limited the representation of more isolated or underserved individuals, particularly those who face language barriers or are less comfortable with technology. Second, the sample was small and highly heterogeneous in terms of cancer types, age, frailty severity, and time since treatment completion. While this limits generalizability, it also allows for the exploration of diverse

experiences and challenges often overlooked in larger, more homogeneous samples. The use of journey mapping, in particular, facilitated the visualization of this diversity, highlighting patterns across and within frailty experiences. Third, the study did not capture participants' ethnic or cultural identities. As a result, the role of cultural background in shaping experiences of frailty, cancer, and support-seeking remains unexplored. Future studies should prioritize more inclusive recruitment strategies to reflect the diversity of older adult cancer survivors. Fourth, participants' narratives and responses to the CFAI were retrospective. This approach may have introduced bias or missed real-time variations in symptoms or experiences. Longitudinal studies capturing experiences at multiple time points could offer richer insights into how frailty evolves throughout cancer treatment and survivorship periods. Lastly, limitations in the CFAI tool itself should be acknowledged. The physical domain primarily assesses mobility and may not fully capture the broader range of physical symptoms encountered during cancer care, such as treatment-related side effects or chronic pain conditions. Complementary tools or modified PROMs may be needed to address this gap. Despite these limitations, this study offers meaningful contributions to frailty assessment and care planning among older adults with cancer. By integrating PROMs and journey mapping, it highlights the critical need for shared decision making and personalized, narrative-informed care. Future research should explore the implementation of frailty-specific PROMs in routine practice and invest in training clinicians to interpret and act on these data. Emphasis should also be placed on equity-oriented communication, co-creation of care strategies, and enhancing survivorship support systems tailored to patient context and preferences.

## Conclusion

This study demonstrates that journey mapping can meaningfully enhance the interpretation of frailty-related PROMs by contextualizing score changes within the lived experiences of older adults with cancer. While PROMs are valuable for amplifying the patient voice in care, they may not fully reflect the complexity of patient experiences unless interpreted within the context of a clinical conversation. Through journey mapping, we have illustrated how integrating patient narratives with PROMs can uncover important psychosocial challenges, particularly those that evolve post-treatment and may otherwise remain hidden. Frailty should be understood as a multidimensional, dynamic concept shaped not only by individual deficits but also by broader psychosocial and systemic influences. Integrating patient narratives with PROMs holds promise for enabling more responsive, person-centred care that aligns with the goals, needs, and lived realities of older adults navigating cancer and survivorship.

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## References

- Bradshaw, C., Atkinson, S., & Doody, O. (2017). Employing a qualitative description approach in health care research. *Global Qualitative Nursing Research*, 4, 2333393617742282. <https://doi.org/10.1177/2333393617742282>.
- Campbell, R., Ju, A., King, M. T., & Rutherford, C. (2022). Perceived benefits and limitations of using patient-reported outcome measures in clinical practice with individual patients: A systematic review of qualitative studies. *Quality of Life Research*, 31(6), 1597–1620. <https://doi.org/10.1007/s11136-021-03003-z>.
- Casals, C., Corral-Pérez, J., Ávila-Cabeza-de-Vaca, L., González-Mariscal, A., Carrión-Velasco, Y., Rodríguez-Martínez, M. C., Jiménez-Cebrián, A. M., & Vázquez-Sánchez, M. Á. (2024). Exploring the interplay of frailty, physical function, physical activity, nutritional status, and their association with quality of life and depressive symptoms in older adults with the frailty phenotype. *International Journal of Geriatric Psychiatry*, 39(3), e6078. <https://doi.org/10.1002/gps.6078>.
- Crowder, S. L., Hoogland, A. I., Small, B. J., Carpenter, K. M., Fischer, S. M., Li, D., Kinney, A. Y., Welniak, T. L., Brownstein, N., Reich, R. R., Hembree, T., Extermann, M., Kim, R., Afiat, T.-P., Berry, D. L., Turner, K., & Jim, H. S. L. (2022). Associations among frailty and quality of life in older patients with cancer treated with chemotherapy. *Journal of Geriatric Oncology*, 13(8), 1149–1155. <https://doi.org/10.1016/j.jgo.2022.08.010>.
- de Vries, N. M., Staal, J. B., van Ravensberg, C. D., Hobbelen, J. S. M., Olde Rikkert, M. G. M., & van der Sanden, M. W. G. (2011). Outcome instruments to measure frailty: A systematic review. *Ageing Research Reviews*, 10(1), 104–114. <https://doi.org/10.1016/j.arr.2010.09.001>.
- De Witte, N., Gobbens, R., De Donder, L., Dury, S., Buffel, T., Schols, J., & Verté, D. (2013). The comprehensive frailty assessment instrument: Development, validity and reliability. *Geriatric Nursing*, 34(4), 274–281. <https://doi.org/10.1016/j.gerinurse.2013.03.002>.
- De Witte, N., Gobbens, R., De Donder, L., Dury, S., Buffel, T., Verté, D., & Schols, J. M. G. A. (2013). Validation of the comprehensive frailty assessment instrument against the Tilburg frailty indicator. *European Geriatric Medicine*, 4(4), 248–254. <https://doi.org/10.1016/j.eurger.2013.03.001>.
- Ethun, C. G., Bilen, M. A., Jani, A. B., Maitel, S. K., Ogan, K., & Master, V. A. (2017). Frailty and cancer: Implications for oncology surgery, medical oncology, and radiation oncology. *CA: a Cancer Journal for Clinicians*, 67(5), 362–377. <https://doi.org/10.3322/caac.21406>.
- Fletcher, J. A., Fox, S. T., Reid, N., Hubbard, R. E., & Ladwa, R. (2022). The impact of frailty on health outcomes in older adults with lung cancer: A systematic review. *Cancer Treatment and Research Communications*, 33, 100652. <https://doi.org/10.1016/j.ctarc.2022.100652>.
- Fried, L. P., Tangen, C. M., Walston, J., Newman, A. B., Hirsch, C., Gottdiener, J., Seeman, T., Tracy, R., Kop, W. J., Burke, G., McBurnie, M. A., & Cardiovascular Health Study Collaborative Research Group. (2001). Frailty in older adults: Evidence for a phenotype. *The Journals of Gerontology. Series A, Biological Sciences and Medical Sciences*, 56(3), M146–M156. <https://doi.org/10.1093/gerona/56.3.m146>.
- Gibbons, S. (2018). *Journey mapping 101*. Nielsen Norman Group. <https://www.nngroup.com/articles/journey-mapping-101/>
- Gobbens, R. J. J., Luijckx, K. G., Wijnen-Sponselee, M. T., & Schols, J. M. G. A. (2010). Towards an integral conceptual model of frailty. *The Journal of Nutrition, Health & Aging*, 14(3), 175–181. <https://doi.org/10.1007/s12603-010-0045-6>.
- Gray, D., Brown, S., and Macanuso, J. (2010). *Gamestorming: A playbook for innovators, Rulebreakers, and changemakers*. O'Reilly. [https://www.amazon.com/gp/product/0596804172/ref=as\\_li\\_qf\\_sp\\_asin\\_il\\_tl?ie=UTF8&camp=1789&creative=9325&creativeASIN=0596804172&linkCode=as2&tag=gamestormingc-20](https://www.amazon.com/gp/product/0596804172/ref=as_li_qf_sp_asin_il_tl?ie=UTF8&camp=1789&creative=9325&creativeASIN=0596804172&linkCode=as2&tag=gamestormingc-20)
- Greenhalgh, J., Gooding, K., Gibbons, E., Dalkin, S., Wright, J., Valderas, J., & Black, N. (2018). How do patient reported outcome measures (PROMs) support clinician-patient communication and patient care? A realist synthesis. *Journal of Patient-Reported Outcomes*, 2, 42. <https://doi.org/10.1186/s41687-018-0061-6>.
- Handforth, C., Clegg, A., Young, C., Simpkins, S., Seymour, M. T., Selby, P. J., & Young, J. (2015). The prevalence and outcomes of frailty in older cancer patients: A systematic review. *Annals of Oncology*, 26(6), 1091–1101. <https://doi.org/10.1093/annonc/mdl540>.
- Kwon, J. Y., Moynihan, M., Wolff, A. C., Irlbacher, G., Joseph, A. L., Wilson, L., Horlock, H., Hung, L., Lambert, L. K., Lau, F., & Sawatzky, R. (2024). Using journey maps to understand patient-reported outcome measures in the cancer journey. *Canadian Oncology Nursing Journal*, 34(4), 443. <https://doi.org/10.5737/23688076344443>.
- Kwon, J.-Y., Russell, L., Coles, T., Klaassen, R. J., Schick-Makaroff, K., Sibley, K. M., Mitchell, S. A., & Sawatzky, R. (2022). Patient-reported outcomes

- measurement in radiation oncology: Interpretation of individual scores and change over time in clinical practice. *Current Oncology*, **29**(5), 3093–3103. <https://doi.org/10.3390/curroncol29050251>.
- Kwon, J. Y., Thorne, S., & Sawatzky, R. (2019). Interpretation and use of patient-reported outcome measures through a philosophical lens. *Quality of Life Research*, **28**(3), 629–636. <https://doi.org/10.1007/s11136-018-2051-9>.
- Licqurish, S. M., Cook, O. Y., Pattuwage, L. P., Saunders, C., Jefford, M., Koczwara, B., Johnson, C. E., & Emery, J. D. (2019). Tools to facilitate communication during physician-patient consultations in cancer care: An overview of systematic reviews. *CA: a Cancer Journal for Clinicians*, **69**(6), 497–520. <https://doi.org/10.3322/caac.21573>.
- McCarthy, S., O'Raghallaigh, P., Woodworth, S., Lim, Y. L., Kenny, L. C., & Adam, F. (2016). An integrated patient journey mapping tool for embedding quality in healthcare service reform. *Journal of Decision Systems*, **25**(Suppl. 1), 354–368. <https://doi.org/10.1080/12460125.2016.1187394>.
- Murugappan, M. N., King-Kallimanis, B. L., Bhatnagar, V., Kanapuru, B., Farley, J. F., Seifert, R. D., Stenehjem, D. D., Chen, T.-Y., Horodniceanu, E. G., & Kluetz, P. G. (2023). Measuring frailty using patient-reported outcomes (pro) data: A feasibility study in patients with multiple myeloma. *Quality of Life Research*, **32**(8), 2281–2292. <https://doi.org/10.1007/s11136-023-03390-5>.
- Muszalik, M., Kotarba, A., Borowiak, E., Puto, G., Cybulski, M., & Kędziora-Kornatowska, K. (2021). Socio-demographic, clinical and psychological profile of frailty patients living in the home environment and nursing homes: A cross-sectional study. *Frontiers in Psychiatry*, **12**. <https://doi.org/10.3389/fpsy.2021.736804>.
- Panhwar, Y. N., Naghdy, F., Naghdy, G., Stirling, D., & Potter, J. (2019). Assessment of frailty: A survey of quantitative and clinical methods. *BMC Biomedical Engineering*, **1**(1), 7. <https://doi.org/10.1186/s42490-019-0007-y>.
- Patton, M. Q. (2014). *Qualitative research and evaluation methods: Integrating theory and practice* (p. 532). Sage Publications, Inc.
- Rockwood, K., & Mitnitski, A. (2007). Frailty in relation to the accumulation of deficits. *The Journals of Gerontology. Series A, Biological Sciences and Medical Sciences*, **62**(7), 722–727. <https://doi.org/10.1093/gerona/62.7.722>.
- Skovlund, P. C., Ravn, S., Seibaek, L., Thaysen, H. V., Lomborg, K., & Nielsen, B. K. (2020). The development of PROMunication: A training-tool for clinicians using patient-reported outcomes to promote patient-centred communication in clinical cancer settings. *Journal of Patient-Reported Outcomes*, **4**(1), 10. <https://doi.org/10.1186/s41687-020-0174-6>.
- Sobhani, A., Fadayevatan, R., Sharifi, F., Kamrani, A. A., Ejtahed, H.-S., Hosseini, R. S., Mohamadi, S., Fadayevatan, A., & Mortazavi, S. (2021). The conceptual and practical definitions of frailty in older adults: A systematic review. *Journal of Diabetes and Metabolic Disorders*, **20**(2), 1975–2013. <https://doi.org/10.1007/s40200-021-00897-x>.
- Stover, A. M., Haverman, L., van Oers, H. A., Greenhalgh, J., Potter, C. M., & ISOQOL PROMs/PREMs in Clinical Practice Implementation Science Work Group (2021). Using an implementation science approach to implement and evaluate patient-reported outcome measures (PROM) initiatives in routine care settings. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation*, **30**(11), 3015–3033. <https://doi.org/10.1007/s11136-020-02564-9>.
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, **19**(6), 349–357. <https://doi.org/10.1093/intqhc/mzm042>.
- van Egdom, L. S. E., Oemrawsingh, A., Verweij, L. M., Lingsma, H. F., Koppert, L. B., Verhoef, C., Klazinga, N. S., & Hazelzet, J. A. (2019). Implementing patient-reported outcome measures in clinical breast cancer care: A systematic review. *Value in Health*, **22**(10), 1197–1226. <https://doi.org/10.1016/j.jval.2019.04.1927>.
- Zomerdiijk, L. G., & Voss, C. A. (2010). Service design for experience-centric services. *Journal of Service Research*, **13**(1), 67–82. <https://doi.org/10.1177/1094670509351960>.