CANCER RECOVERY NARRATIVES PRE AND PERI COVID: A MIXED METHODS COMPARATIVE ANALYSIS

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Abstract

This study is the first of its kind to compare narratives from cancer survivors collected at the end of treatment both before the pandemic began (2017-2019) and three years following (2023-2024). Data was collected through short narrative care interviews, designed to provide a supportive way for cancer survivors to process the experience of treatment and recovery, and find ways to effectively move forward in life. Preliminary quantitative findings indicate the potential effectiveness and acceptability of the narrative interview for supporting individuals at the end of cancer treatment, with notable increases in self-reported social well-being. Emergent qualitative thematic differences include frequent reports of medical delays and experiences of loneliness during treatment in the peri-COVID cohort, as well as indications that this group was more inclined to advocate for their healthcare needs, express skepticism toward the medical system, and speak more positively about interpersonal support from loved ones than the pre-COVID cohort.

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Introduction

Psychosocial Cancer Care

Cancer continues to be the leading cause of death in Canada with an estimated 2 in 5 individuals being diagnosed with this disease over their lifetime. Of those diagnosed, many do not recover; 1 in 4 cancer patients die as a result of this widespread illness (Brenner et al., 2022). It is therefore unsurprising that diagnosis and treatment of cancer can result in severe psychological distress and a significant increase in depression symptoms for many individuals (Clark et al., 2010). Symptoms of depression and distress during the cancer treatment period are well represented in the literature, with a clearly identified reciprocal relationship between fatigue, pain, and depression over the course of the treatment process (Jhamb et al., 2019; Thorton et al., 2010). Furthermore, psychological distress has been associated with poorer physical health outcomes for individuals with cancer (such as significant increases in inflammation) for individuals undergoing cancer treatment (Renna et al., 2020). Conversely, improved physical health and survival outcomes have been shown to be related to early psychosocial support in many cancer patients (Mirosevic et al., 2019).

While the majority of psychosocial treatments aim to alleviate symptoms of distress and provide support during the difficult process of cancer diagnosis and treatment, the period following the *conclusion* of treatment is known to be related to elevated distress and increased vulnerability for many individuals, and yet is less commonly a focus of psychosocial intervention (Bilodeau et al., 2022). This period, sometimes referred to as the "re-entry phase" (Mullan, 1984), is associated with a range of issues for individuals across demographics and cancer types, including practical concerns such as a reduction in ability to work and persistent side effects of treatment (e.g., sexual function concerns, chronic pain, and urinary/bowel issues), ongoing sleep disturbance, fatigue, and anxiety (Harrington et al., 2010; Ramsey et al., 2021). Many individuals

experience an increase in intolerance for uncertainty, cognitive difficulties (including problems with concentration, attention, planning, and memory), and cancer-related distress (such as hyperarousal, intrusive thoughts, and avoidance behaviours) up to a year following the completion of cancer treatment (Eisenberg et al., 2015).

The concept of cancer survivorship has become increasingly controversial since it was first introduced by Dr. Fitzhugh Mullen in 1985, with varying definitions of survivorship, and many individuals who have recovered from cancer rejecting the term "survivor" (Fitch, 2019; Mullan, 1984). Although the definition and terminology surrounding individuals at the end of cancer treatment may be in question, what is clear is that the number of Canadians who are alive five years after a cancer diagnosis has increased substantially over the past decades (Government of Canada, 2023). The average five-year survival rate of all cancers combined in the 1940s was approximately 25%; this number rose to 55% in the early 1990s, and is currently at 64%, with the most common cancers (breast, colon, prostate, and rectal) resulting in a 90% 5-year survival rate when diagnosed at stage 1 (Government of Canada, 2023). Canadian mental health services and oncology supportive care have struggled to keep pace with these increases in survivorship, with significant inconsistencies in available care (rural areas in particular suffer from minimal access to psychosocial support) and a lack of patient knowledge of support offerings even when resources are available (Romkey-Sinasac et al., 2021). While evidence-based therapeutic interventions (such as Acceptance and Commitment Therapy and Cognitive Behavioural Therapy) have been shown to be effective in treating a range of cancer-related issues (Lewson et al., 2021; Mirosevic et al., 2019), the growing number of patients transitioning out of active treatment each year makes access to programs such as these difficult (as they typically consist of a minimum of 8 weeks of treatment), and wait times for Canadian, government funded therapy

can range from several weeks to up to one year (Moroz et al., 2020). As a result, there is a need for time-limited, cost-effective psychosocial support for individuals at this vulnerable and important transition point.

The COVID-19 Pandemic

While the pandemic created instability and significant change across a variety of societal domains worldwide, perhaps the most negatively impacted was healthcare. During the first year of the COVID-19 pandemic, Ontario hospitals experienced a 20.7% reduction in overall cancer care services, and a 40% reduction in general diagnostic testing for all forms of cancer (Walker et al., 2022). As a result, patients have experienced delays in diagnosis and necessary surgeries, as well as in receiving adjuvant treatments (e.g., radiation, chemotherapy), creating a substantial and ongoing backlog which has yet to be fully addressed (Lofters et al., 2023; Walker et al., 2022). These delays are associated with poorer treatment outcomes, increases in psychosocial distress (including fears of cancer progression), and increased levels of anxiety and depression (Chen et al., 2020; Neal et al., 2015; Üzar-Özçetin & Öcalan, 2022). For individuals who underwent cancer treatment during the height of the pandemic, additional worries surrounding contracting COVID while in treatment, the secondary effects of cancer treatment increasing the risk of COVID infection, and negative health outcomes due to past COVID infection, were reported (Yan et al., 2023).

Despite the universal increase in psychosocial distress during the pandemic, there is a dearth of literature that specifically examines patient experiences of cancer care at that time. Preliminary qualitative findings suggest that repetitive cancer and COVID-19 related ruminations may have been more common in cancer patients during the height of the pandemic, alongside more positive narratives related to overcoming the pandemic in much the same way

that they overcame their cancer (Üzar-Özçetin & Öcalan, 2022). Moreover, the ways in which pandemic-related stressors on the health care system may have influenced cancer recovery during the post-treatment period are not well understood, particularly during the peri-COVID era following the most intensive social restrictions (lockdowns, social distancing) (Bilodeau et al., 2022). In general, the lingering effects of the pandemic have been shown to relate to a deterioration in the mental health of many individuals by creating social challenges and disrupting routines, as well as through job loss and financial hardship (Lin et al., 2024). While some of the lasting psychosocial effects of the pandemic are already understood (including increased rates of substance use, depression, anxiety, and fear of contamination) (Balakrishnan et al., 2022; Erbiçer et al., 2021; Salari et al., 2020), the subtler impacts, such as shifts in interpersonal relationships and increases in medically focused social media information sharing, have not been well studied (Dubey et al., 2020). Such 'traces' of COVID-19 could have wide reaching implications for psychosocial support across mental health contexts, particularly for individuals recovering from highly stressful health related life events such as a cancer diagnosis.

Narrative Care

Human beings are meaning-making creatures. The question of why a significant life event has occurred is a critical one for most of us, as we seek to find meaning in the way in which the events of our lives unfold. In the case of uncontrollable and unpredictable adverse life events, such as a cancer diagnosis, the answer as to why something has occurred is generally not forthcoming, and thus we tend to find our own answers to these questions through the construction of narratives. Narratives are the ways in which we organize our experiences and imbue them with meaning, and they are transmitted on both individual and cultural levels (Bruner, 1991). Rather than following empirical or logical avenues of truth, narratives need only

achieve what Bruner describes as narrative "verisimilitude" – a kind of truth which is guided by convention, and "narrative necessity" - the fixing of purpose to actions, experiences, and uncontrolled events within an individual's life (Bruner, 1991; Westlund, 2011). Narrative is also used even more fundamentally to help answer some of the deepest philosophical questions we are faced with such as, "Who am I?" "How did I end up like this?" and "What will happen to me?" These questions tend to emerge in adolescence and early adulthood and require narrative answers as part of adult identity formation (Erikson, 1950; McAdams, 1988). This narrative identity forms slowly over time, is continuous across the lifespan, occurs in the context of the individual's social and cultural position in groups, and is regularly edited, reinterpreted, disrupted, and processed, gradually developing into a broad and integrative story of one's life (McAdams & McLean, 2013). One's storied identity becomes particularly salient in the context of dealing with suffering, as studies have shown that resolving negative events through positive narratives is related to increased levels of wellbeing and happiness – a happy or meaningful ending to a sad story (King & Hicks, 2007; Lilgendahl & McAdams, 2011).

In the decades following the publication of Rita Charon's (2001) seminal paper on narrative medicine, more attention has been paid to the patient's experience of medical treatment and how practitioners can better meet the emotional and psychosocial needs of the individuals they treat, with narratives being an important part of the medical effort to be more holistic and patient centered (Carlick & Biley, 2004). An important component of this effort is the concept of narrative care - the belief that the stories which individuals tell about themselves, others, and the wider social community are highly significant not only to individual meaning making, but also in the psychosocial health of individuals and groups (Baldwin, 2015). Narrative care as a practice entails respectful and open listening to a part or version of the story of another's life, with the

intention of increasing their experience of meaning, personal empowerment, insight, and ultimately emotional and/or spiritual healing (Baldwin, 2015). Narrative care is experiential, meaning making, idiosyncratic, relational (in that it involves at a minimum both a speaker and a listener), unstable (as personal narratives can be, and frequently are, modified over time), and can be understood as a way to facilitate change within individuals (Baldwin, 2015). These concepts are core components of narrative therapeutic approaches, in which stories guide how individuals view their lives in a variety of ways including expression of personal agency (that is, the ability to recognize one's own input into situations, regardless of the outcome), externalization of problems (allowing individuals to change their relationship to their difficulties rather than identifying with them directly), and the development of preferred stories (experiential involvement in a story in order to develop richness and meaning) (Combs & Freedman, 2012). While narrative therapy shows promising results in the treatment of PTSD, eating disorders, anxiety and depression related to drug use, and depression in cancer patients, narrative approaches to treatment tend to be as resource intensive as other therapeutic modalities (Conti et al., 2022; Robjant et al., 2019; Rodríguez Vega et al., 2014; Shakeri et al., 2020). Narrative *care* in the context of medical treatment, on the other hand, may be of particular value as this approach can be employed throughout the treatment process in time limited ways by all members of the patient's treatment team, including medical doctors, nurses, support staff, or other health care professionals (Charon, 2001). The experience of agency which comes with robust narrative accounts, facilitated through narrative care, may have substantial utility in both medical and psychotherapeutic applications (McAdams & McLean, 2013).

A pilot study at the Sunnybrook Odette Cancer Centre that began in 2017 applied this concept of a brief approach to the provision of narrative care through a single-session narrative

informed interview for individuals following the conclusion of their cancer treatment (Ianakieva, 2021). The narrative care interview (NCI) was administered at the post-treatment, re-entry time point specifically to address the vulnerable period of increased distress which often accompanies patients' transition from intensive medical care to resumption of 'normal' life (Bilodeau et al., 2022; Harrington et al., 2010; Ramsey et al., 2021). The intervention gave participants an opportunity to both reflect on their experiences of diagnosis, treatment, and recovery as well as look to their future and consider what their life following cancer may look like. This study included both quantitative and qualitative measures to better understand the needs and experiences of patients at this vulnerable timepoint. The findings demonstrated early support for the utility and benefit of the intervention, with the majority of participants self-reporting the value of participating in the interview, and a notable increase in ratings of social well-being at the post NCI timepoint (Ianakieva, 2021). Qualitative analyses identified several themes across participants' narratives which spoke to concepts of woundedness and healing, refining and solidifying identity, and maximizing one's time going forward (Ianakieva, 2021). Overall, this study provided preliminary evidence for the potential value of a brief, narrative informed intervention to support individuals at the end of cancer treatment.

The Current Study

With the aim of understanding the pandemic's unique effects on cancer survivorship, the current study compared narrative accounts collected prior to the pandemic from 2017 to 2019 (Ianakieva, 2021), with those collected from individuals who completed treatment three years following the start of the pandemic, in 2023-2024 (i.e., during the peri-COVID period). This study sought to elucidate the unique effects of the pandemic and provide qualitative insight into the issues survivors may be struggling with as a result. As these interviews were completed after

the most severe COVID-19 restrictions were lifted, a central goal of this study was to investigate the differences between these two groups related to possible effects of the pandemic on cancer treatment and recovery.

The primary objective of the study was to compare the personal experiences of individuals at the post-treatment juncture of cancer recovery at pre-COVID and peri-COVID timepoints. A secondary objective was to further test the NCI intervention. Increasing the sample size between the two timepoints allowed for more rigorous effectiveness testing of the intervention – to the extent possible without a control arm. The research questions were as follows:

(1) How has COVID affected patient experiences of the diagnosis and treatment of cancer?

(2) How do patient experiences of cancer care at present (i.e., since COVID) differ from patient experiences prior to COVID?

(3) Do patients benefit from the opportunity to participate in a narrative care interview after completing treatment, and what do they gain from their participation in the narrative care interview?

Methods

Participants

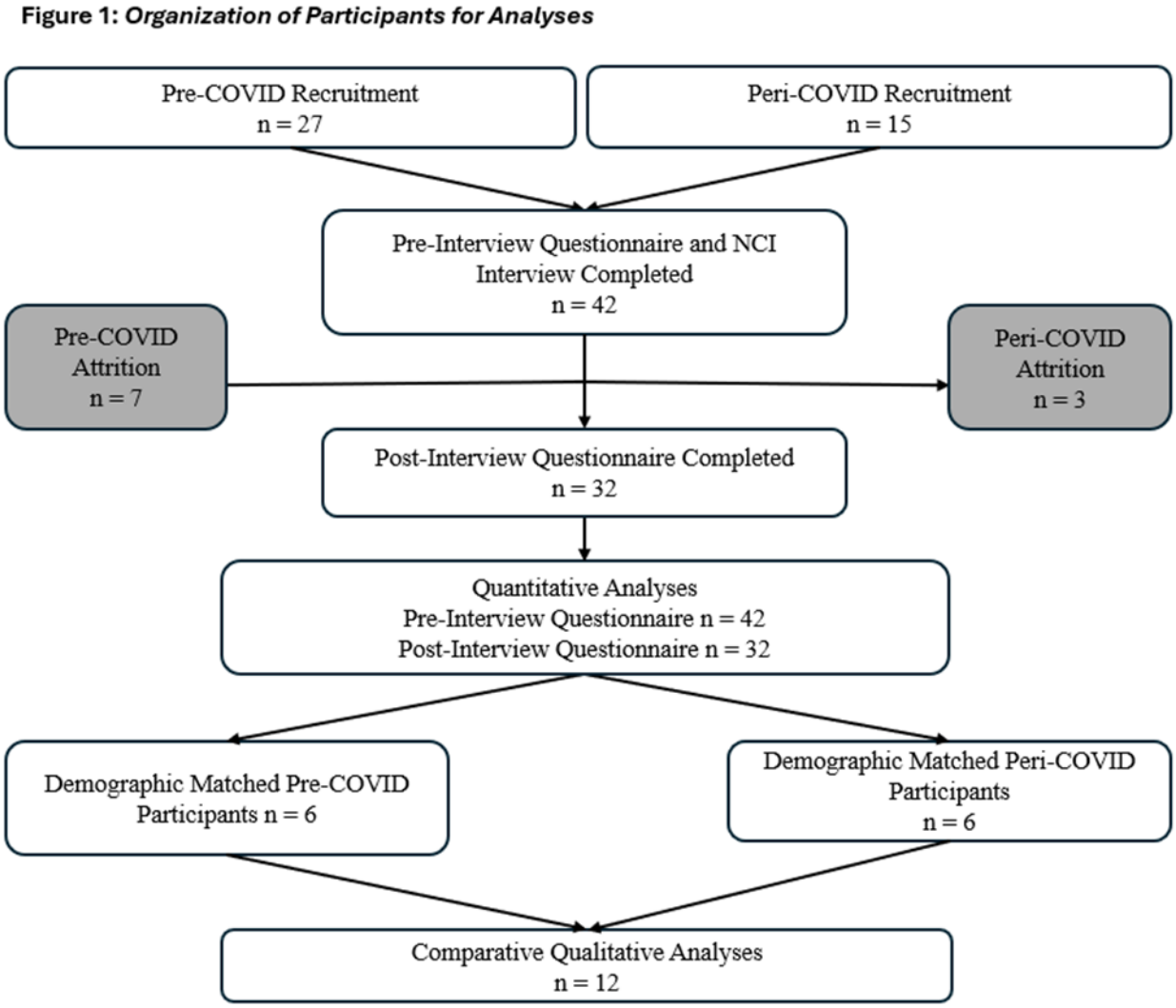
Participants from both the pre- and peri-COVID samples were patients with a non-metastatic cancer diagnosis who had completed all primary treatments through the Odette Cancer Centre (OCC) at Sunnybrook Health Sciences Centre. The pre-COVID group included 27 participants, while the peri-COVID group included 15. Eligibility criteria for participants included the following: 1) a diagnosis of a primary cancer (non-metastatic); 2) completion of all primary treatments, including surgery, chemotherapy, and/or radiation therapy within the past two years of participation in the study; 3) not attending ongoing psychotherapy/counselling while participating in the study; and 4) ability to read, write, and converse in English.

Procedure

This study was reviewed and approved by both the Sunnybrook Health Sciences Centre (project ID# 2434) and the York University research ethics boards prior to beginning participant recruitment. A purposive sampling strategy (Campbell et al., 2020) was employed to recruit participants from the Odette Cancer Centre at Sunnybrook Health Sciences Centre with the goal of collecting a heterogenous sample of participants representing varied ages, gender, and cancer diagnoses. Recruitment strategies for both samples followed the same procedure but were conducted by different researchers (Iana Ianakieva for the pre-COVID sample and Lucas Norton for the peri-COVID sample; see Ianakieva (2021) for details on the pre-COVID dataset). Quantitative analyses were performed on the full dataset of participants, while comparative qualitative analyses were performed on a selected subset of six participants from the peri-COVID group who were then matched with six participants from the pre-COVID group based on gender, age, and cancer diagnosis (n = 12). See Figure 1 for a flowchart of this organization procedure. Ahead of planned recruitment dates (between 2017-219 for the pre-COVID cohort

and 2023-2024 for the peri-COVID cohort), the radiation therapy team was informed of which patients would be approached by the research assistants. Patients meeting the study's eligibility criteria and within the final week of treatment were identified using Sunnybrook Hospital's Mosaic software, an integrated operational workflow and medical records platform. Once identified, research assistants approached potential participants on site while waiting for their appointments using a prepared script. Those who expressed interest in the study were given a brochure with more information and were asked to provide their contact information (see recruitment script in Appendix A and flier in Appendix B).

Figure 1: ***Organization of Participants for Quantitative and Qualitative Analyses***



Patients who expressed interest were subsequently contacted via phone by the research coordinator, who provided additional details about the study, answered questions, and administered a brief screening questionnaire to ensure eligibility (a script for the telephone screening questionnaire is provided in Appendix C). Individuals who were found to be ineligible, or decided they did not wish to participate in the study, were given information about resources for psychosocial support available through the community or the Odette Cancer Centre's Patient and Family Support program, when it was deemed that they might benefit. Following the

screening procedure, eligible and interested participants had a narrative care interview date scheduled approximately two weeks later. Participants were informed that they would be completing a pre- and post-interview questionnaire package which would take up to 30 minutes to complete, and the NCI would be approximately 90 minutes in length.

There were three timepoints of note for participants once recruited into the study: 1) completion of the pre-interview questionnaire package, called Time 1; 2) participation in the interview itself, called Time 2; and 3) completion of the post-interview questionnaire package, called Time 3. The average time between Time 1 and Time 2 was one to two weeks, as was the average time between Time 2 and Time 3 - meaning that questionnaires were completed approximately one week before and one week after the NCI itself. Both pre-interview and post-interview questionnaires were administered via the secure ISO 27001 certified online platform Qualtrics. The pre-interview questionnaire at Time 1 included the confidentiality agreement, which participants were required to review and indicate their consent, before proceeding with completing the questionnaire package which was comprised of demographics questions, and four quantitative scales (described in detail below). The post-interview questionnaire included the same four quantitative scales as well as a treatment satisfaction questionnaire designed specifically for this study with 14 open-ended questions. See Appendix E for a full list of measures used at each timepoint, and Appendix F for quantitative measures and the treatment satisfaction questionnaire. All 42 participants completed the pre-interview questionnaire and the NCI. Seven participants in the pre-COVID sample and three in the peri-COVID sample left the study after Time 2 and did not complete the post-interview questionnaire. The full sample which quantitative methods were performed on was therefore n = 42 (pre-interview) and n = 32 (post-interview).

The NCI consisted of a series of questions based on appreciative inquiry principles (Cooperrider & Whitney, 2005) designed to help participants to consolidate their experiences of cancer and promote the generation of new ideas and possibilities for action/positive change. This intervention guides participants through a self-generated narrative of their cancer journey, with questions about diagnosis ("Can you say a little bit about how you came to be diagnosed with cancer?"), how they coped with their illness ("What helped with your coping? What made it difficult or more challenging?"), reflections on changes resulting from their experience with cancer ("What is the most pronounced difference for you – between now and before you were diagnosed with cancer?"), personal meaning making ("Did you come to any new insights through this experience?"), and orientation toward the future ("Is there anything that you have learned over the course of your illness that you would like to take with you?"). In order to test the NCI as an intervention, the NCI questions were held constant between the two time points – that is, no additional questions related to COVID-19 were added for the peri-COVID sub-sample. Likewise, participants were not directed or otherwise led to discuss pandemic specific experiences by the interviewer or the structure of the NCI. A full version of the NCI can be found in Appendix D.

All interviews were conducted through a PHIPA compliant Zoom platform, and although audio and video were recorded, only audio files were retained for transcription purposes. With respect to the peri-COVID sample, nine interviews were conducted by the first author (Lucas Norton), five were conducted by a fellow graduate student research assistant (David Olsen), and one was conducted by the first author's supervisor (Karen Fergus). All interviews were subsequently transcribed verbatim by research assistants. All pre- and post- interview questionnaire packages, demographics questionnaires, and interview transcripts were

anonymized and identified only by participant identification numbers. A document linking the participant identification numbers to the data and audio-recordings was stored only on-site at Sunnybrook Hospital and paper documents used during the recruitment process were shredded following the transfer of participant information to the hospital computer.

Measures

The battery of online questionnaires was selected to assess both psychosocial and physical functioning and well-being before and after the NCI. The first item administered to participants at Time 1 was the brief demographics questionnaire. Following this, selected measures examined positive and negative affect, well-being (physical, functional, and social), self-efficacy in coping with cancer, and perceived personal meaning. These items were administered in both the pre- and post-treatment questionnaire package at Time 1 and Time 3 in the following order: (1) Positive and Negative Affect Schedule Short Form (PANAS-SF) (Watson et al., 1988), (2) Functional Assessment of Cancer Therapy (FACT-G) (Cella et al., 1993), (3) Cancer Behavior Inventory-Brief Version (CBI-B) (Heitzmann et al., 2011; Merluzzi et al., 2001).

Affect

Overall affect was measured using the PANAS (Watson et al., 1988), two 10-item scales which measure positive and negative affect respectively. This five point scale (which ranges from 1 = “very slightly or not at all” to 5 = “extremely”) rates the extent and intensity of experienced emotions within the past two weeks. The emotions cover a substantial range, including “alert,” “determined,” “afraid,” and “hostile.” Total scores for both subscales range from 10 to 50 points, with a higher score on either scale indicating higher levels of either positive or negative affect. The PANAS is a validated measure of affect and mood with a strong test-retest reliability and

internal consistency and high construct validity (congruence coefficient > 0.85), and has been shown by researchers to have good psychometric properties (Terraciano et al., 2003; Watson et al., 1988). The Cronbach's alphas from the current sample were as follows: pre-positive affect: 0.89, post-positive affect: 0.87, pre-negative affect: 0.82, post-negative affect: 0.87.

Quality of Life

Quality of Life was captured with the FACT-G, a popular measure of well-being and life satisfaction in the context of cancer recovery (Cella et al., 1993). All four subscales, physical, social/family, emotional, and functional were administered, with each subscale consisting of seven items, however the emotional subscale was not included in this analysis because this data was not collected in the pre-COVID study. Scales have participants rate their well-being from zero ("not at all" to four "very much") with total subscale scores ranging from zero to 28; higher values on the physical subscale indicates lower quality of life in the physical domain, while higher values on the social/family, emotional, and functional subscales indicate higher quality of life in their respective domains. Sample items include "I lack energy" (physical), "I get support from my friends" (social), and "I am able to enjoy life" (functional). The FACT-G has been found to have good psychometric properties with a test-retest coefficient of .92, strong convergent and discriminant validity, and very high internal consistency (Cella et al., 1993). The Cronbach's alphas for the current sample (pre- and post-interview) were as follows: pre-physical: 0.81, post-physical: 0.82, pre-social/family: 0.83, post-social/family: 0.83, pre-functional: 0.87, post-functional: 0.88.

Self-Efficacy in Coping with Cancer

Self-efficacy in coping with cancer was measured using the 12 item brief form of the Cancer Behavior Inventory (CBI-B), adapted from the revised version of Merluzzi (2001) 33

item questionnaire. The CBI-B utilizes a 9-point scale (with 1 = “not at all confident” and 9 = “totally confident”) on questions about how effective respondents feel in coping with their cancer recovery. Items include “maintaining a positive attitude,” “expressing feelings about cancer,” and actively participating in care decisions”. The CBI-B has been found to be a reliable and valid measure of self-efficacy in coping with cancer, with a test-retest coefficient of .82 - .92 over a 3-7 day interval and strong internal consistency (Heitzmann et al., 2011). The Cronbach’s alphas in the current sample were .91 for the pre-interview sample and .84 for the post-interview.

Sample Demographics

The demographic information questionnaire was presented at the start of the pre-interview questionnaire immediately following completion of the consent form. This questionnaire collected information on age, ethnicity, highest level of education, employment status, relationship status, socioeconomic status, number of children, cancer diagnosis, and treatment history. The demographic questionnaire is provided in Appendix G.

Treatment Satisfaction Questionnaire

Eleven of the 15-items on the Treatment Satisfaction Questionnaire were identical to the questions included in the pre-COVID study and included all the same quantitative and open-ended qualitative questions, plus four additional questions which were not included in the original study (Ianakieva, 2021). Quantitative questions included items such as “The interview gave me more perspective on my experience with cancer (1 = “strongly disagree” to 5 = “strongly agree”), and open-ended qualitative questions included items such as “Are there any questions (or parts from the interview) that stayed with you?” Of the four questions which were added in the peri-COVID interview, two asked participants directly about their experiences with COVID-19 and what their experience of the end of treatment was like; as these two questions

were relevant to the research question of the current study, they were included in the analysis, while the remaining two questions were not.

Analysis

Quantitative Data Analysis

All quantitative analyses were conducted on the combined pre- and peri-COVID datasets (pre-interview questionnaire n = 42, post-interview questionnaire n = 32) in order to examine the effectiveness of the NCI[1]. Descriptive statistics were first obtained, including means and standard deviations of all variables of interest. With the goal of addressing the third objective of the current study (assessment of intervention effectiveness), analyses were designed to detect any significant differences between variables before and after the NCI; two-tailed paired sample t-tests were utilized to identify these potential differences. Before analyses were performed, all data were examined to ensure that assumptions for t-tests were met, including homogeneity of variance and normality of data distribution. Data which met these assumptions were examined using a t-tailed paired sample t-test, while data which did not meet assumptions were examined using a Wilcoxon Signed-Rank Test. The hypotheses of these tests were as follows:

H_0: $\mu d = 0$

These is no difference between the variable in question (positive/negative affect, quality of life, self-efficacy in coping with cancer, and perceived personal meaning) between the pre- (Time 1) and post- (Time 2) interview timepoints.

H_1: $\mu d \neq 0$

[1] Note: The peri-COVID sample was not tested independently from the pre-COVID sample as the pre-interview group consisted of 15 responses (and the post-interview group consisted of 12); as such, paired samples t-tests would have extremely low power and any significant findings would be very difficult to distinguish from chance, resulting in a high rate of both Type I and Type II errors (Serdar et al., 2021).

There is a difference between pre- (Time 1) and post- (Time 2) interview time points for the variable in question.

An alpha of .05 was used for all significance tests, and higher order significance (i.e. .01 or .005) was also noted. Spearman correlations for non-normal data between all listed variables were also examined. Means for multiple choice questions on the Treatment Satisfaction Questionnaire were also obtained to assess acceptability of the NCI to participants. All analyses were conducted using R software.

Qualitative Data Extraction Rule

The qualitative analyses were aimed at uncovering any potential experiential differences between the pre-COVID and peri-COVID sub-samples of individuals following a course of primary cancer treatment. As this study examined differences resulting from the COVID-19 pandemic specifically - any kind of interface with the healthcare system, as well as any relevant experiences with personal health decisions (including wellbeing and illness-related choices), were the focus of this analysis. Given not all of the interview text was considered relevant to our research questions, a data extraction rule (DER) was created. The DER delineates the sections of the transcripts which were relevant to the experience of receiving treatment for cancer - the various facets of which could later be compared and contrasted between the two historically distinct sub-samples.

For the purposes of this analysis, interfacing with the healthcare system is defined as any cancer-related or COVID-related content (i.e., thoughts, feelings, actions, incidents, experiences) involving contact between the individual (or a close other - friend/family member) and healthcare providers of any kind (doctors, nurses, administration, reception, security, and support), healthcare treatments (including side effects), or infrastructural components of the

healthcare system (such as parking, commuting services, financial barriers, self-check-in kiosks, support documents, telehealth services, and waiting areas/times). This definition further includes any perceived failures or elements which may be lacking within the healthcare system. Personal health decisions are defined as content pertaining to behavioural changes or choices influenced by the physical or mental health of the individual (or a close other – i.e., friend/family member) in the context of their cancer and/or COVID-19. This includes content concerning the management of physical illness, psychosocial health, concerns about health, self-management of health (e.g., dietary changes, exercise, engagement with alternative medicine, substance use – i.e., in reference to coping or self-medicating), and indirect effects of personal health issues (e.g., isolation due to illness, delays in seeking treatment due to fears of COVID, support offered by others as a result of illness, changes in activities resulting from illness, and beliefs and attitudes which lead to a decision or change). While this definition is focused on behavioural changes and choices, stated *intentions* to change in the future, and/or *goals* related to physical and psychosocial health are also included. The purpose of the personal health decisions component of the DER is to capture the impact of COVID on various aspects of recovery (e.g., social support, exercise, self-care, engagement with alternative medicine and holistic care) which may be separate from the health care system but may still be related to the effects of the pandemic on individual wellbeing. Furthermore, this same component of the DER is specific to behavioural changes to ensure that the analysis remains focused on the impacts of the pandemic as opposed to more introspective content, such as existential concerns and fears of recurrence which are common to this population (Luigjes-Huizer et al., 2022; Walsh et al., 2024).

Qualitative Methodology

Based on the assumption that there is a reality or phenomenon that exists independent of individual participant perspective which might account for differences in participant experiences at the post-treatment juncture (namely, between individuals treated before and after the COVID-19 pandemic), we chose to adopt a realist ontological orientation. This approach assumes that the analysis, in some meaningful ways, "holds up a mirror to reflect the real world" (Willig, 2012, p. 8). However, epistemologically speaking, we recognize that the mirror which reflects our research question does not do so directly. Participants from varying backgrounds and social locations have differing experiences of, and offer diverse windows into, the phenomenon under investigation. For this reason, the textual data subject to analysis ultimately reflects a spectrum of perspectives and requires a critical interpretation. This 'critical realist' approach to analysis (as opposed to a naïve realist approach which assumes a direct relationship between the data being interpreted and reality) both recognizes the need for interpretation required to understand and articulate the subjective experiences of participants, while also approaching analysis with the assumption that there is an underlying reality which can be apprehended (Willig, 2012). This approach is also well suited to situations where participant experience may contain meaning which the participants themselves are not aware of (Willig, 2012), such as the more subtle impacts of a global pandemic on personal experiences of cancer recovery.

Qualitative Data Analysis

Transcribed interview content was analyzed using reflexive thematic analysis, a qualitative research approach first described in Gerald Holton's 1973 book *"Thematic Origins of Scientific Thought; Kepler to Einstein"* in which he introduces the concept of inductive identification of 'themata' alongside deductive reasoning (Holton, 1973); however, the current study's reflexive thematic analysis approach was modeled more directly off the seminal Braun &

Clarke article, *"Using Thematic Analysis in Psychology"*, and explicitly incorporated the reflexive approach described in their 2019 work *"Reflecting on Reflexive Thematic Analysis"* (Braun & Clarke, 2006, 2019). Reflexive thematic analysis identifies themes and patterns in data through either an inductive (bottom up) approach, which seeks to code data without fitting it into a predetermined framework, or a deductive (top-down/theoretical) approach, which focuses primarily on the researcher's analytic interest and research questions (Braun & Clarke, 2006, 2019). The current study made use of both deductive and inductive elements during the qualitative analysis. By way of a primarily deductive theoretical approach, analysis of the data was filtered through the above-described data extraction rule in order to capture cancer related health and healthcare content relevant to the research question – the impact of the COVID-19 pandemic on cancer care and cancer recovery. One important consideration during this process was "keyness" of themes – how well a theme captures ideas in relationship to the research question (Braun & Clarke, 2006, 2019). For this reason, the parameters of the data extraction boundaries were kept broad enough to capture as many of these pandemic-related health and healthcare differences as possible while still remaining focused on the core research questions surrounding the impact of the pandemic on cancer recovery (Braun & Clarke, 2006, 2019). These relevant portions of the transcripts were then analyzed inductively to better understand the landscape of health and healthcare pre- and peri-COVID. During this process, emergent themes were organized using an iterative, open categorizing method in order to better test and refine them (Rennie et al., 1988). Making use of an inductive approach to analysis while maintaining a critical realist epistemology was relevant to the goals of this study in order to both remain focused on the pandemic related research questions, as well as to capture the contextual and uniquely individual components of participant content. As it was also considered important to

represent the intended meaning of participants in the context they were presented, category generation was kept descriptive; the names of categories were developed using minimal inference in order to reflect participant's intended meaning as closely as possible and, in some cases, by making direct use of the very language that participants shared (Rennie et al., 1988).

In order to discern qualitative differences between the pre- and peri-COVID samples, 12 transcripts were selected for analysis (six pre- and six peri-COVID). In keeping with a critical-realist epistemology, biases, expectations and presuppositions pertaining to the research objectives were tracked through written documentation (i.e., memoing) and through continuous discussion of the emergent themes among team members over the course of the research process (Glaser, 1968; D. L. Rennie et al., 1988; B. G. Strauss Anselm, 2017). The analysis was iterative throughout, with new data informing changes in previously assigned meaning units and concepts until no new theoretical insights emerged and adequate theoretical coverage was achieved (Weed, 2009). This constant comparison process continued until theoretical saturation occurred, ensuring that the concepts generated fit the phenomenon they are meant to represent (Charmaz, 2014; Weed, 2009). This process was also used to ensure the themes emerging from the data were both relevant and 'worked,' by way of producing logical explanations in the context of the research questions (Weed, 2009).

Statement of Reflexivity. As part of assuming a critical realist stance for the purpose of qualitative analyses, it's important to recognize that the act of interpretation is intrinsically reflexive and culture-bound, and researcher influence on participant meaning is inevitable (Rennie, 1998). The author of this paper takes a humanistic approach to qualitative research, informed by his experience with person-centered approaches to psychotherapy and clinical psychology. A primary goal in the qualitative analysis of the current study was to ensure that

intended meaning of participant ideas was captured by listening to the audio of transcribed interviews, empathizing with the experiences of participant situations, and listening to the full context in which participant statements were made. The author also examined and tracked his own social and cultural biases, as well as his relative lack of personal experience in cancer treatment, through self-reflection, memoing, and discussion with the research team (Glaser, 1968; B. G. Strauss Anselm, 2017) with the underlying goal of generating themes and codes that reflect the intended meaning behind participant statements as closely as possible. During the data collection and interviewing process, the author created memos of several personal assumptions and biases he became aware of. First, the author expected that the peri-COVID cohort would share more experiences of problems with access to healthcare services due to limitations caused by the pandemic. Specifically, he expected to see delays in care and diagnoses, as well as difficulty accessing services. Second, due to the prevalence of misinformation and criticism of medicine in the media (particularly vaccine hesitancy), the author expected to see themes of reduced trust in medicine as well as increased interest in alternative medicines (such as homeopathy) in the peri-COVID cohort. Finally, the author lived alone during the COVID-19 pandemic and had personal experiences of loneliness and distress during that period, as well as difficulty staying connected with loved ones. He was therefore more likely to be biased when looking for themes of loneliness, distress, and disconnecting from important others in the peri-COVID group during the coding process.

As per Braun and Clarke (2006), the following six steps were taken to guide the practical aspects of the reflexive thematic analysis: (1) The authors familiarized themselves with the data, reading transcriptions, listening to audio recordings, and making memos regarding initial ideas. (2) Codes were generated by demarcating individual meaning units and assigning appropriate

descriptive labels to them. Meaning units are defined as the constitution of parts generated by the researcher through the process of identifying a transition between meaningful ideas in participant narratives (Giorgi, 2012); meaning units are intrinsically arbitrary, carry no theoretical weight, and will vary depending on the researcher who generates them (Giorgi, 2012). In order to balance the investigation of themes in the pre- and peri-COVID samples and compare them as directly as possible, participants were matched into six pairs based on demographic and medical characteristics (age, gender, and cancer diagnosis). These pairs were selected concurrently from the pre- and peri-COVID groups with the intention of matching participants as closely as possible on these demographic characteristics. While the first author was aware of which transcripts he was selecting from the peri-COVID group (having conducted the interviews himself), he was blind to the matched pre-COVID transcripts, having not reviewed them prior to the matching process. The first author then coded three transcripts from the peri-COVID sample, followed by three from the pre-COVID sample, and repeated this process a second time to fully code all 12 transcripts. During this process, codes which were developed in later transcripts were retroactively scanned for and coded in previous transcripts to ensure they were correctly captured as part of the constant comparison process. Codes were also modified when deemed appropriate as the sampled data expanded so as to capture the full intention of the constituent meaning units within a given code. When the final transcript was coded, very few new codes were emerging, with 86 codes in total, approximately at the average point of saturation for qualitative coding in a sample of this size (Lowe et al., 2018). Theoretical saturation was assumed to be met once review of the later, additional transcripts did not lead to the generation of unique codes or insights (Charmaz, 2014). Within this dataset, saturation appeared to have been achieved by the 11th transcript. (3) Higher order themes were identified by collating the identified codes into

related groups – six major themes were initially generated. (4) Themes were reviewed carefully by comparing the various labeled codes inside them as well as coded extracts; during this process, 13 subclusters were identified within the themes which had been created, and a thematic map of the analysis was generated based on this structure. (5) Themes and subclusters of codes were clearly defined and named, and an overarching 'reading' of the analysis was performed. (6) Fine tuning of the analysis occurred during the write-up itself which included refining the definitions of themes and integrating compelling textual extracts in the form of verbatim quotes to serve as representations of specific themes. The presentation of the results was reviewed to ensure they related directly back to the research questions – that is, potential differences in the pre- and peri-COVID samples in relation to the effects of the pandemic on the individual and the healthcare system.

While written transcripts were the primary source of coding for this analysis, audio recordings of each session were retained and referred to throughout the process to ensure a clear understanding of participant meaning in the appropriate context and to avoid overly literal interpretations of qualitative content, as well as to ensure as much latent meaning as possible was captured (Braun & Clarke, 2006, 2019). All qualitative data was managed and coded using NVivo software. Memos and thematic organization were managed with Microsoft Excel spreadsheet software.

Results

Participant Demographics

In total, 42 participants completed the pre-interview questionnaire and participated in the Narrative Care Interview (NCI). Of those 42, 32 participants completed the post-interview questionnaire. Half of the participants in the study were male and half were female (50% female; 50% male). The majority of participants self-identified ethnicity was White (74%). Most participants had received a post-secondary degree or higher (78%) and were married (76%) at the time of data collection. The mean participant age was 63.57 (SD = 12.69) with the youngest participant being 38, and the oldest 86. Most participants had been diagnosed with stage 0, I, or II (76%) non-metastatic cancer, with breast (38%) and prostate (36%) making up the majority of cancer locations. The average time elapsed between the conclusion of treatment and participation in the NCI was 10.28 weeks (SD = 11.23), with 89% of participants having completed their treatment within three months of the NCI. While the pre- and peri-COVID samples are demographically similar, there are some notable differences between them. First, mean length of relationship was longer in the pre-COVID sample (36.74 years compared to 24.56 years in the peri-COVID group). Second, a proportionately greater number of participants in the peri-COVID sample lived alone (two out of 27 in the pre-COVID sample compared with three out of fifteen in the peri-COVID sample). Finally, participants in the peri-COVID sample had greater homogeneity in cancer diagnoses, with all but one being breast or prostate, while the pre-COVID sample had seven additional diagnoses beyond breast and prostate. A summary of all demographic data is provided in Tables 1 and 2.

Table 1 - ***Participant Demographic Characteristics***

(Total n = 42, pre-COVID n = 27, peri-COVID n = 15)

Variable		Total Mean(Range)	Pre Mean	Peri Mean	SD(Total)
Age		63.57 (38-86)	62.78	65	12.69
Length of Relationship (Years)		27.43 (3-57)	36.74	24.56	14.61
Variable		**n (Total)**	**n (Pre)**	**n (Peri)**	**% (Total)**
Gender					
	Female	21	12	9	50.00
	Male	21	15	6	50.00
	Other (Please Specify)	0	0	0	0
Self-Identified Ethnic Background					
	African	1	1	0	2.38
	Afro-Caribbean	1	1	0	2.83
	Asian	3	2	1	7.14
	Eurasian	1	0	1	2.38
	Indigenous	1	1	0	2.38
	Jewish	1	0	1	2.38
	Slavic	1	0	1	2.38
	South Asian	2	2	2	4.76
	White	31	20	11	73.81
Birth Country					
	Canada	25	19	6	59.52
	Other	17	8	9	40.48
First Language					
	English	30	19	11	71.43
	Other	12	8	4	28.57
Employment Status					
	Employed	16	11	5	38.10
	Stay at Home Parent	4	3	1	9.52
	Retired	19	11	8	45.24
	Semi-Retired	3	2	1	7.14
Highest Education Level					
	Grade 9	2	2	0	4.76
	High School	7	5	2	16.67
	College	7	5	2	16.67
	University	20	12	8	47.62
	Post-Graduate Diploma	1	1	0	2.38
	Graduate Degree	5	2	3	11.90
Marital Status					
	Divorced	1	1	0	2.38
	Married/Common Law	32	20	12	76.19
	Single	9	6	3	21.43

Children					
	No	7	6	1	16.67
	Yes	35	21	14	83.33
Self-Identified Living Situation					
	Alone	5	2	3	11.90
	With Parents	2	2	0	4.76
	With Partner	19	11	8	45.24
	With Partner and Children	13	8	5	30.95
	With Partner and Parent	1	1	0	2.38
	With Roommate	2	2	0	4.76
Income					
	No Response	5	4	1	11.90
	$0-9,999	3	3	0	7.14
	$10,000-25,000	2	1	1	4.76
	$25,000-50,000	8	7	1	19.05
	$50,000-75,000	6	3	3	14.29
	$75,000-100,000	9	4	5	21.43
	$100,000+	9	5	4	21.43

Table 2 - ***Medical Demographic Characteristics (n=45)***

Variable		Mean (Total)	Mean (Pre)	Mean (Peri)	SD (Total)
Weeks Since Treatment Completed		10.28			11.23
Variable		n (Total)	n (Pre)	n (Peri)	% (Total)
Type of Cancer					
	Anal	1	1	0	2.38
	Breast	16	8	8	38.10
	Cervical	1	0	1	2.38
	Colorectal	1	1	0	2.38
	HPV-Related	1	1	0	2.38
	Lymphoma	1	1	0	2.38
	Prostate	15	9	6	35.71
	Rectal	3	3	0	7.14
	Skin	2	2	0	4.76
	Urologic	1	1	0	2.38
Cancer Stage					
	0	1	1	0	2.38
	1	16	9	7	38.10
	2	13	8	5	30.95
	3	7	4	3	16.67

	Not Aware	1	1	0	2.38
	No Response	4	4	0	9.52
Chemotherapy					
	No	24	16	8	57.14
	Yes	18	11	7	42.26
Radiation					
	No	1	1	0	2.38
	Yes	41	26	15	97.62
Surgery					
	No	20	15	5	47.62
	Yes	22	12	10	52.38
Other Treatment					
	No	24	17	7	57.14
	Yes	15	7	8	35.71
	No Response	3	3	0	7.14
Chemotherapy + Radiation		6	6	0	14.29
Chemotherapy + Radiation + Surgery		11	4	7	26.19
Surgery + Chemotherapy		2	0	2	4.76
Surgery + Radiation		11	8	3	26.19
Other Medical Condition					
	No	26	17	9	61.90
	Yes	13	7	6	30.95
	No Response	3	0	3	7.14
Mental Health Diagnosis					
	No	36	22	14	85.71
	Yes	4	3	1	9.52
	No Response	2	2	0	4.76

Effectiveness of the Intervention

Means, standard deviations, and correlations between all variables of interest are reported in Table 3. All variables met homogeneity of variance assumptions, and the pre- and post-Positive Affect subscales, the pre- and post- FACT-F subscales, as well as the Post NCI CBI scale were normally distributed; all other scales were found to be non-normally distributed. A Fligner-Killeen test determined that the variances of the non-normal data in each pre-post pair were equal. Due to the non-normal distribution of most variables, a Spearman's Rho ($\boldsymbol{\rho}$) calculation was used to examine correlations; note that these relationships are monotonic (as

opposed to linear), and significant correlations indicate that as one variable tends to increase, the other tends to increase (or decrease for negative correlations). Although several significant correlations were found ($p < 0.05$), 12 variables were all examined for correlations simultaneously, and the strength of these correlations were at most moderate; it is therefore unlikely that these correlations represent meaningful findings.

Paired t-tests (for normal data) and Wilcoxon Signed-Rank Tests (for non-normal data) were used to examine all pre- and post- variables of interest for significant differences in mean scores. The alternate hypotheses (that a significant difference/improvement would be found) for all variables of interest were not supported, except for one. A Wilcoxon Signed-Rank Test for non-normal data revealed a significant difference between the pre- and post- timepoints for the FACT-G Social Well-Being subscale ($n = 32$, $V = 102.5$, $p = 0.007$) with a small effect size ($d = 0.12$). The mean pre-interview score of the FACT-G Social Wellbeing subscale was 20.33 ($SD = 4.98$), and the mean post-interview score was 20.88 ($SD = 4.53$). Post hoc testing using the Bonferroni correction to account for multiple comparisons revealed that this finding remains significant even after correction and is unlikely to be due to a Type 1 Error (adjusted $p = 0.042$).

While no significant results were found for changes in positive or negative affect (PANAS) in these analyses, it is notable that average affect scores for this sample (Positive Affect = 33.19, Negative Affect = 16.80) were somewhat more positive than non-clinical population averages prior to the COVID-19 pandemic (Positive Affect = 31.31, Negative Affect = 16.00) and much more positive than average scores found during the pandemic between March 2020 to July 2021 (Positive Affect = 27.2, Negative Affect = 19) (Crawford & Henry, 2004; Li et al., 2024). In the case of positive affect, the current sample is a full standard deviation higher than the COVID population, representing a significantly higher score in the current sample.

Table 3 – ***Means, Standard Deviations, and Correlations (Spearman's ρ) of Variables of Interest***

Variable	Mean (SD)	1	2	3	4	5	6	7	8	9	10	11	12
1. Pos-Aff-Pre	32.79 (6.98)	1											
2. Pos-Aff-Post	33.59 (6.15)	**0.63***	1										
3. Neg-Aff-Pre	17.00 (6.04)	**-0.34***	-0.34	1									
4. Neg Aff-Post	16.61 (5.26)	**-0.36***	-0.26	**0.58***	1								
5. FACT-G-P-Pre	5.62 (4.44)	-0.26	-0.31	**0.55***	**0.41***	1							
6. FACT-G-P-Post	5.56 (4.66)	-0.22	**-0.36***	**0.36***	0.26	**0.72***	1						
7. FACT-G-S-Pre	20.33 (4.98)	**0.41***	0.30	-0.15	0	-0.13	-0.09	1					
8. FACT-G-S-Post	20.88 (4.53)	0.31	**0.37***	-0.17	-0.13	-0.04	-0.11	**0.89***	1				
9. FACT-G-F-Pre	18.52 (5.64)	**0.47***	**0.40***	**-0.56***	-0.23	**-0.52***	**-0.48***	**0.57***	0.32	1			
10. FACT-G-F-Post	17.88 (5.67)	**0.59***	**0.56***	**-0.50***	**-0.46***	**-0.49***	-0.42	**0.42***	**0.45***	**0.56***	1		
11. CBI-Pre	7.17 (1.35)	**0.55***	**0.53***	**-0.38***	-0.24	**-0.37***	**-0.36***	**0.48***	**0.47***	**0.55***	**0.60***	1	
12. CBI-Post	7.4 (0.96)	0.12	0.20	**-0.47***	-0.21	-0.23	-0.10	**0.39**	**0.44***	0.32	**0.42***	**0.56***	1

Note: *p < 0.05, Pos-Aff = Positive Affect; Neg-Aff = Negative Affect, FACT-G = Functional Assessment of Cancer Therapy – General (-P = Physical, -S = Social, -F = Functional); CBI = Cancer Behaviour Inventory Scale.

Acceptability and Treatment Satisfaction

The Treatment Satisfaction Questionnaire was completed by 32 participants and indicated that participants generally had a positive perception of the NCI. When asked if they had found the interview to be helpful, 30 participants (93.75%) indicated that they had, while the remaining 2 participants (6.25%) indicated it was unhelpful. When asked if there was "something specific that they took away from the interview" experience, 20 replied yes (63.5%) and 12 replied no (37.5%). Participants were also asked whether the interview had given them more perspective on their experience with cancer on a 5-point scale (from 1 = "strongly disagree" to 5 = "strongly agree"); the average score from their responses was 3.94 (SD = 2.12). When asked if the interview had highlighted important insights or learnings in relation to their experience with cancer the average score obtained from participants was 3.88 (SD = 1.41). Participants were further questioned as to whether some parts of the interview had been challenging or hard for them, with an average response of 2.47 (SD = 2.12) obtained. When asked if the interview had opened 'old wounds' or been upsetting in some ways, the average score was found to be 2.03 (SD = 0.71). When asked if they were considering doing something differently or trying something new as a result of taking part in the interview, six participants said yes (18.75%) and 26 said no (81.25%). In terms of the length of the interview, two participants indicated that it had been too long (6.25%), while the other 30 (93.75%) responded that it had been just the right length. Finally, when asked if, based on their own experience, all patients should have an opportunity to participate in a post-treatment interview should they wish to do so, the average response on a scale from 1 (strongly disagree) to 5 (strongly agree) was 3.91 (SD = 1.41).

Peri-COVID Open-Ended Question Responses

Two questions relevant to the current study were introduced in the Peri-COVID group in order to gather additional information on patient experiences of the conclusion of cancer treatment and the impact of the pandemic on their experience of living with cancer. Twelve of the 15 participants in the peri-COVID group completed the post NCI questionnaire and responded to these questions. The first question asked participants to describe any ways in which the pandemic may have impacted their cancer treatment and recovery. Of the 11 participants who responded to the question, five (41.67%) stated that COVID-19 had no effect on their cancer treatment process, two participants (16.67%) felt that they had experienced significant delays in detection and/or treatment of their cancer, and four participants (33.33%) felt the pandemic reduced their ability to be supported by important others during treatment (with one of these participants (8.33%) describing feelings of vulnerability to illness as the reason for reduced social support, and another (8.33%) citing isolation from his family due to his decision not to be vaccinated). The second question asked participants what concerns they had while transitioning out of cancer care. Two participants (16.67%) described physical symptoms (pain, nausea, weakness, side effects of medications), three participants (25%) felt they were alone while exiting treatment and wished there had been additional resources (such as counselling services) offered to them, one participant (8.33%) felt stress while waiting for their next follow-up appointment, one participant (8.33%) was on a waitlist for Wellspring programs and felt it was a long wait, one participant (8.33%) felt confused about which doctor was now responsible for them, and three participants (25%) chose not to respond. One participant (8.33%) also shared an experience of contacting/attempting to register in a smoking cessation program twice during treatment but was never followed up with; the same participant also described significant anxiety regarding the possibility of her cancer returning.

Qualitative Comparison of Pre- and Peri-COVID Narratives

The reflexive thematic analysis resulted in the generation of 86 individual codes based on 12 participant interviews, six in the pre-COVID and six in the peri-COVID groups. Pre- and peri-COVID participants were matched in pairs based on demographic data (age, gender, and cancer diagnosis) to increase the similarity of experiences across groups (Table 4).

Table 4 – ***Matched Participant Demographics***

Pre-COVID				Peri-COVID			
ID#	Age	Gender	Diagnosis	ID#	Age	Gender	Diagnosis
27	74	F	Breast	37	79	F	Breast
25	75	M	Prostate	39	73	M	Prostate
2	67	F	Breast	45	67	F	Breast
28	86	M	Prostate	36	83	M	Prostate
20	48	F	Breast	40	49	F	Breast
21	68	M	Prostate	43	69	M	Prostate

Codes which were thematically related were collapsed into six top-level thematic categories, each with zero to three subthemes. See Table 5 for the organization of the themes and related subthemes.

Table 5 – ***Organization of Themes and Subthemes***

Main Theme	Subtheme
1) Understanding the Disease and the Cure	
2) Responsibility for Healthcare	a) Taking Health into One's Own Hands b) The System is Responsible for our Health c) Hesitation and Confusion
3) Seeking the 'Care' in Healthcare	a) Unsupported in the System
	b) Well Cared For c) Accessing Supplementary Support
4) System Functionality	a) Functioning as Expected b) Breakdowns and Delays
5) Sharing and Caring	a) Nudging me Back to Health b) Disconnecting from Others
6) Roads to Recovery	a) Experiences of Treatment b) Reactions to Treatment

Top level themes are described briefly here, with subcategories (as well as specific examples of patient experiences which exemplify them) explained in detail below. (1) 'Understanding the Disease and the Cure' covers all experiences of seeking or avoiding information in order to better understand and/or deal with cancer diagnosis, treatment, and recovery. (2) 'Responsibility for Healthcare' includes any experiences which touch on who is responsible for patient healthcare and recovery. This theme includes patients taking personal responsibility for their own health, expressing feelings that the system should be responsible for

keeping them healthy, and experiences of uncertainty in where responsibility or control lies in the context of remaining healthy. (3) 'Seeking the 'Care' in Healthcare' covers patient expressions of desire for supplementary support and resources which are offered by the healthcare system or team during the treatment process, including positive supportive experiences, perceived failures in system support, and interest/disinterest in accessing available support. (4) 'System Functionality' encompasses experiences of the healthcare system functioning as expected or failing to do so. This includes critiques of system structures or thoughts on how the system could be improved. (5) 'Sharing and Caring' covers all experiences of interpersonal social support both to and from the patient, as well as descriptions of issues which impede or facilitate such support. (6) 'Roads to Recovery' includes all descriptions of dealing with treatment and recovery as well as how these experiences have impacted the patient's life. Explicit experiences of the healthcare system are covered by this theme but are more experiential rather than functional or support based.

A complete list of codes and definitions are listed in Appendix H. The number of participants from the pre- and peri-COVID groups who endorsed codes in each category and subtheme was directly compared to capture the emergent differences between these two time periods. There was overlap in many codes and themes between the pre- and peri-COVID groups as many experiences of healthcare in relation to treatment for cancer are common across these time periods. As the research aims of this study focused on possible differences due to the pandemic, the qualitative results presented below focus primarily on these differences while also making note of the most ubiquitous commonalities. All findings reported here should be considered preliminary regarding potential differences between these two cohorts. Note that subthemes are represented within the text body in italics.

(1) Understanding the Disease and the Cure

Many participants described experiences of seeking cancer related information with the goal of better understanding and dealing with their illness. Between the pre- and peri-COVID groups, some of these experiences were very similar; the majority of participants in both the pre- (n = 6) and peri-COVID (n = 5) groups shared descriptions of doctors giving opinions on, and making specific recommendations regarding their treatment, with little notable difference between the two groups. Beyond these basic descriptions, some differences between the two groups emerged in the context of desire for knowledge of cancer and healthcare procedures, with the peri-COVID group sharing more of these experiences than the pre-COVID group. Every participant in the peri-COVID group (n = 6) expressed an interest in learning more about their cancer independently from the healthcare system, often focusing on individual research or learning from knowledgeable friends or family, while less than half of the pre-COVID group shared this desire (n = 2). One participant in the peri-COVID group stated:

> "I was the type of person who'd be online doing research, checking this, checking that, checking stats, reports, reading what I could to try and see if I could get…one step ahead of the doctor and how they were going to be talking to me about certain things…basically first-hand knowledge, whether it's accurate or not. I was always researching, right?" (peri-COVID, Female, 49 years old)

Participants in the peri-COVID group were also more inclined to describe conversations with medical staff in which they discussed details of treatment (such as risks, or side effects), after which the patient made their own choices about their healthcare decisions (pre-COVID n = 0, peri-COVID n = 3). Likewise, a feeling that basic information was not always provided when it should be by medical staff (peri-COVID n = 2) appeared in the peri-COVID group but was not

present in the pre-COVID group; in one participant these experiences were accompanied by a desire not to be caught by surprise:

> "If there's anything I can't stand in medicine, it's being caught with a surprise. You know, I don't care how awful things can be. If there is a possibility that one thing could occur even if it's not likely, at least tell me about it. So, if it does happen, I'm not caught off guard… 'It was expected.' I had that told to me afterwards. 'We expected that.' If there is something, you tell me." (peri-COVID, Male, 83 years old)

For another participant, feeling uninformed by the medical team was related to an experience of vulnerability:

> "What are you going to do? What's your name? You know, like it's, they don't think about it, I guess, because they do it every day. But you come in there in a totally strange situation... you feel extremely vulnerable physically and emotionally. And so, I said, who are you, what are you going to do? Please explain it to me like I'm in kindergarten." (peri-COVID, Female, 79 years old)

Two participants in the pre-COVID group (and none in the peri-COVID group) expressed the opposite feelings describing a concern that learning too much about cancer outcomes, treatments, or statistics would cause him additional anxiety rather than alleviating fears, with one participant saying:

> "I would read about uh side effects and that sort of thing and I think if you do enough reading…longevity rates and survival rates…like statistics…that did not help me [laughter]… I came to the conclusion that maybe I was better off not knowing everything." (Pre-COVID, Male, 68 years old)

Overall, peri-COVID participants expressed more interest in learning about cancer, understanding their treatments, and receiving clear communication from medical staff which could be used to inform treatment decisions. One participant in the peri-COVID group talked more broadly about knowledge and healthcare, expressing annoyance with those who are suspicious of medicine and doctors: “I've always been a great supporter of medical treatment. I don't doubt medicine, and yes, I don't think it's perfect. But I'm not one to be suspicious…of doctors. That kind of stuff really just irritates me when I hear some people.” (Peri-COVID, Male, 83 years old)

(2) Responsibility for Healthcare

The subtheme *Taking Health into One’s Own Hands* covers all participant descriptions of personal actions, narratives, and ideas which place them in control of their own health. Many codes in this subtheme saw significant overlap between the pre- and peri-COVID cohorts: one participant in each group expressed interest in alternative medicine, three participants in each group described feelings of failure to care for themself through exercise, healthy eating, etc., and almost all participants had a focus on becoming healthy following the conclusion of cancer treatment (pre-COVID n=5, peri-COVID n=6). These ideas were represented nearly equally in both groups, with little qualitative differences between responses.

Despite many similarities in this subtheme, there were two areas of notable difference. Five participants in the peri-COVID group (and no participants in the pre-COVID group) shared experiences of certainty in which treatments they wanted or did not want (surgery, chemotherapy, etc.); four of these five participants described telling their doctors and healthcare providers exactly which treatments they were interested in – as one participant stated:

> "I understand the biomechanics of radiation and, and cell death and PSA [prostate specific antigen] results…it's not a mystery to me. I'm not sitting there wondering if the doctor told me the truth when I don't like his answer, I challenge him, and we agree on the truth. They offer me something I don't want; I quite knowledgeably reject it. They offered me a hormone therapy just as a sort of blanket coverage in case there's something out there. And I said, no, I'm not interested." (Peri-COVID, Male, 69 years old)

Two participants in the peri-COVID group also shared feelings of being pressured by others to maintain an attitude of "getting over it," even though this was a struggle for them. A 49-year-old woman in the peri-COVID group said that "no matter how many times people will tell you 'you're gonna be fine,' 'you're gonna get through this,' when you're actually going through the treatments, the treatments medically can impact your emotions, right?" Participants in the peri-COVID cohort were the only ones to express strong opinions about the types of treatment they wished to undergo, making this surety about medical decisions the primary difference between the two cohorts in this subtheme.

The subtheme *The System is Responsible for our Health* covers statements which place the healthcare system in control of patient health, or public health more broadly. There was similarity in this subtheme both in the idea that healthcare should be left to the doctors (pre-COVID n=1, peri-COVID n=2), and in the idea that the healthcare system has a responsibility to inform and care for patients proactively (pre-COVID n=1, peri-COVID n=1); one participant in the pre-COVID group stated:

> "There should be educated by doctors, by family doctors. To pay attention. When you have a little problem, a little prostate enlargement. A family doctor or a urologist. They

> should pay more attention, you know. So don't let your patient go without an inspection every six months right." (Pre-COVID, Male, 75 years old)

Differences in this subcategory were found in two distinct areas, with only peri-COVID participants endorsing them. Three participants in the peri-COVID group shared discussions of plans to continue to engage in regular cancer testing to avoid recurrence in the future, with one man saying:

> "Now, my life uh, my life, numbers are gonna change my life. That's the way it goes, right? Because now, I have to go check my numbers with the prostate doctors. But if my regular doctor says they were good, you know what? What can I do? Nothing." (Peri-COVID, Male, 73 years old)

Similarly, three participants in the peri-COVID group (and none in the pre-COVID) expressed a desire for more holistic or alternative medical practices in the context the healthcare system (as opposed to engaging with these practices independently):

> "I also would have liked…for somebody to have a different, maybe more holistic approach as an add-on. I would not have said I'm not going to have the surgery. And I did not say I'm not going to have radiation. But I've been again, reading a lot since and looked at alternatives, just an add on, you know, vitamins, um, different tests that that weren't done…There's nothing ever available in Canada. I don't understand it." (Peri-COVID, Female, 79 years old)

The *Hesitation and Confusion* subtheme covers descriptions of fear, confusion, or helplessness, as well as decision paralysis, in the context of participants trying to remain healthy or become healthy again. Two participants in both the pre- and peri-COVID groups expressed feelings of uncertainty about whether personal lifestyle changes they made would improve their

health or have any real impact on the likelihood of cancer recurrence. Similarly, one participant in the pre-COVID and two in the per-COVID group described information overload, or the inability to identify which health advice (foods to eat, exercise levels, etc.) is truly helpful. However, there was a qualitative difference in how these ideas were expressed between pre- and peri-COVID participants in this area. A pre-COVID participant (86-year-old woman) described some confusion but settled on her and her husband "cut[ting] down on our meat consumption and…cook[ing] fish instead of steak, or chicken instead of a pork chop. You know…stuff like that," while a peri-COVID participant stated more emphatically:

> "You know, now I'm just to a point where maybe I'm looking too much in YouTube. Oh, you can't do this, you cannot do this, you cannot do that. I'm going crazy, you know. They say about wine. My family grew up on wine, glass of wine every day and now wine is no good for you. And, you know, I don't give a shit. I'm gonna drink my glass of wine, what happens, you know. And one YouTube says this is good for you, and another YouTube says that's not good for you. They're screwing you up." (Peri-COVID, Male, 73 years old)

A similar kind of frustration with (and resistance to) making health changes, such as changing to a healthier diet was present in the peri-COVID group but not the pre-COVID group (pre-COVID n=0, peri-COVID n=2). A 67-year-old woman in the peri-COVID group said "You know, cause like I'm not going to go out and start eating organic and all that shit, you know? That's not me. And go vegetarian and I try to eat a lot more vegetables and blah blah blah, and I have people telling me you should never eat this and that cause it's bad for this and that and it's like, eh…".

A final difference was noted between the two groups in fears of contracting illnesses (including but not limited to COVID-19) during the treatment and recovery process. This included descriptions of self-isolation due to these fears, as well as feelings that one should be very careful or take precautions surrounding potential infections. While fears from both groups entailed concerns about being immune-compromised during treatment, all three peri-COVID participants cited the pandemic as a reason for exhibiting extra caution. One participant in the pre-COVID group and three in the peri-COVID group expressed concerns such as these. A 67-year-old female peri-COVID participant shared, "So, the hardest part for me, that fear, like being vulnerable to anything, especially in COVID times and not being able to be around people and do my social things."

3) Seeking the 'Care' in Healthcare

The *Unsupported in the System* subtheme covers negative experiences participants had in the healthcare system during their cancer treatment, both feelings that that they were not cared for appropriately or situations in which more compassionate care would have been helpful. Participants in both the pre- and peri-COVID groups (pre-COVID n=3, peri-COVID n=3) described experiences of hospital and healthcare staff being rude, dismissive, cold, or dehumanizing. Descriptions of stress during normative, expected waiting times (as opposed to medical delays) for appointments, results, and surgery dates were similarly reported across the pre-COVID (n=3) and peri-COVID (n=2) groups; participants in both groups described similar experiences of waiting related stress. As well, complaints that the healthcare system was unable to accommodate patient needs appeared in both the pre-COVID group (n=2) and peri-COVID group (n=1), with issues relating primarily to lack of consistency in appointment times and inability to access care at patient preferred locations.

However, several clearer differences emerged between the two groups, particularly in the areas of mistrust in healthcare systems and feelings of loneliness during treatment. Four participants in the peri-COVID group (and none in the pre-COVID) expressed a lack of trust in healthcare related structures and systems, which included suspicion of financial incentives overshadowing the provision of healthcare. One 67-year-old woman said "I recently had large lipomas on my inner elbows MRIed, and they wouldn't MRI them the same day because then OHIP doesn't get paid twice. So, they made me do it a week apart." Another man, speaking about the Canadian Cancer Society, stated:

> "I don't like the Cancer Society…I cannot stand various charities, that get your name off the list in the hospital and start asking for money. I'll never give to the Cancer Society for that alone. And they're not just preying on people, but they're also deliberately building this fear. Cancer is not that dangerous. Yes, it can be horrible. My mother died of cancer. my father died of cancer…but it isn't necessarily so." (Peri-COVID, Male, 83 years old)

Loneliness was also a more common theme which arose in the peri-COVID group, with four peri-COVID participants (and no pre-COVID participants) describing a lack of social contact during cancer treatment. In some cases, this was explicitly a result of the pandemic:

> "It was COVID, and although you're not asking about that, that was the most significant impact…. For those of us that from [the] beginning didn't buy the mainstream narrative there was extreme isolation. Extreme social isolation to the people who didn't go along with the narrative, including my entire family. So, for a couple of years, they all knew that I was a kook. And was a dangerous infectious kook. I shouldn't come to any family events because I would kill them all." (Peri-COVID, Male, 69)

Another participant felt that the isolation of cancer treatment was in some ways similar to the isolation experienced during the pandemic:

> "Coming out of COVID, we had just started getting a bit of our real lives back…I mean, everything shut down for me personally after [cancer treatment began]. I was working [again] and suddenly my life revolved around doctor's appointments." (Peri-COVID, Female, 67 years old)

The same female participant was also the only one to describe fears of going to the hospital unaccompanied, as she had known friends and family who had experiences of being painfully alone during the height of the pandemic:

> "You know, when during the throes of COVID, we knew people who died alone in the hospital and had to have bypasses alone in the hospital…they were people, friends. And my nieces had babies during COVID. Someone we knew was dropped off to have bypass surgery…I couldn't imagine. (Peri-COVID, Female, 67 years old)

Overall, peri-COVID participants appeared to be more cautious about placing their trust in health care systems, and described more feelings of loneliness, or fears of loneliness, throughout the cancer treatment process.

Well Cared For, in contrast, includes all expressions of satisfaction with the ways in which participants were taken care of by the healthcare system, both medically and through good patient centered care. All participants (pre-COVID n=6, peri-COVID n=6) described hospital and healthcare staff as providing compassionate care (i.e., being friendly, kind, helpful, and/or sociable) which made the experience more pleasant. Similarly, the majority of participants in both groups (pre-COVID n=5, peri-COVID n=4) expressed gratitude for having access to the resources which led them to being treated successfully; this included the Canadian healthcare

system itself, financial advantages, or social support which guided them toward cancer treatments. While there were not notable differences in the style of responses between the two groups in this subtheme, the following quote represents both these ideas clearly: “Yeah, well I always knew it was a good healthcare system, but I had to depend on it these last few months [more] than I had in my whole lifetime. And everybody has been so pleasant and lovely, caring.” (Pre-COVID, Female, 74 years old)

The subtheme *Accessing Supplementary Support* includes any descriptions of making use of, attempting to use, or not feeling the need to use supplementary support such as mental health care services, psychoeducational materials, or brochures outlining resources. Some overlap was observed between the groups: two participants in both the pre-and peri-COVID groups expressed participation in, or an intention to participate in, cancer related support groups, exercise classes, nutrition courses, or cancer specific mental health support. Similarly, two participants in the pre-COVID group and one in the peri-COVID described reaching out to a healthcare organization and finding themselves unable to get in contact or find support.

The most notable difference which emerged in the comparison was supplementary support being available and known about by the participant, but not needed. Five participants in the pre-COVID group (and one in the peri-COVID group) described having had this experience. For example, a 74-year-old woman in the pre-COVID group said, “I mean they kept offering these resources, but to be honest I didn’t feel I needed them.” Another 48-year-old woman in the pre-COVID group echoed this sentiment, saying “You could see it all nutrition support…I knew it was there if I needed it, but I didn’t feel like I need[ed] it… so yeah so I know it was here, but I didn't utilize [it] I have to say.” In contrast to this experience, two participants in the peri-COVID group (and none in the pre-COVID group) described patient support information being nearby or

available, but not realizing they had access to these resources or becoming aware of them until much later. One participant shared:

> "Nobody put a pamphlet…in my hands to say there's a center where you can maybe get some help, talk to a nutritionist to talk to a psychologist, talk to a social worker. I didn't know anything about it…eventually when I felt more comfortable, I noticed a wall with all the pamphlets and I thought, why did I not notice that before? Why didn't anyone come around and put a pamphlet in my hand?" (Peri-COVID, Female, 79 years old)

This same participant was also the only one to express a feeling of lost support following the conclusion of cancer treatment:

> "And what I also feel is that you are left hanging on your own when the treatment is over. I saw the radiation, radiologist, he said well, you know, everything looks fine, I'll see you in a year or something like that and that's it." (Peri-COVID, Female, 79 years old)

In addition to the experiences of simply not knowing about support offerings, more participants in the peri-COVID group described feeling isolated, alone, or vulnerable during medical treatment procedures (pre-COVID n=1, peri-COVID n=3). One participant stated:

> "The chemotherapy, the radiation, there would be times where I would just start crying. For one reason or another and it would just, it would just be like a momentary lapse, I would say, maybe is like 10 min or so and I'd be like, okay, what am I doing? Why am I doing this? And it's just, you start to feel sorry for yourself." (Peri-COVID, Female, 49 years old)

Overall, the pre-COVID group appeared more likely to be aware of support but not require it, while the peri-COVID group expressed more concern over being uninformed about the availability of potential support resources.

System Functionality

Functioning as Expected covers descriptions of confidence in the healthcare system and experiences which indicate that the system is running well. More participants in the peri-COVID than the pre-COVID group expressed confidence in their treatment plan and a sense of security in the idea that they will make a full recovery (pre-COVID n=1, peri-COVID n=3). Similarly, four participants in the peri-COVID group (and none in the pre-COVID group) described their cancer treatment moving forward as expected, with no problems or major issues occurring. As one participant remarked, "[laughter] It was my normal life. I went there, did my radiation, went home…People kept asking me are you okay? I kept thinking to myself maybe [there] should be something wrong..." (peri-COVID, Male, 73 years old)

More participants in the pre-COVID group expressed feeling lucky to have detected the cancer, often because it was found during examination for an unrelated medical issue (pre-COVID n=5, peri-COVID n=2). A participant in the pre-COVID group shared:

> "I broke my knee very badly and I had to have knee surgery and I was on crutches for 6 weeks and towards the end of it, I saw a lump up here. It was just a big and it felt really soft… I had to go to my doctor for a prescription for compression stockings and I showed her the lump, and she was very concerned. So, anyway that's how it came about." (Pre-COVID, Female, 74 years old)

Breakdowns and Delays encompass problems in the system which interfere with typical care. These can be issues caused by the pandemic, or other factors described by patients which they feel are impeding system functionality, such as socioeconomic or structural barriers to care. Participants in both groups described experiences of their cancer, which was thought to be small or easily treatable initially, turn out to be more serious than expected and require more aggressive

treatment (pre-COVID n=2, peri-COVID n=3). Missed information, misdiagnosis, or other medical errors in judgement by doctors or other healthcare workers were also described by both groups (pre-COVID n=2, peri-COVID n=1).

A notable difference between the groups emerged when examining how quickly treatment was administered relative to how long participants expected it to be. Four participants in the peri-COVID group, and one participant in the pre-COVID group, described delays interfering with diagnosis and/or treatments of any kind. The single pre-COVID participant who described delays spoke about a biopsy machine breaking down just before an appointment as well as miscommunications between administrative staff interfering with treatment, while all the participants in the peri-COVID group felt that the pandemic was responsible for the delays they experienced. An 83-year-old male participant said "I think actually the pandemic was the big factor in somewhat slow responses. Can't prove that" and another explained:

> "It seems everything was kind of slow. It took a couple of weeks before I got an appointment. Then it took time…for them to get back, I had to do a biopsy. Then it took 2 weeks to get the biopsy results, which normally happens quicker apparently. Then it was 3 weeks before I saw the surgeon…then it took 5 weeks for the pathology report to come back. Now [my doctor] was quite annoyed about that, she said since COVID they don't have enough personnel. It should have come back within 2 weeks." (Peri-COVID, Female, 79 Female)

Conversely, more pre-COVID participants described the medical system moving more quickly and efficiently than they expected, addressing their cancer treatment without delay (pre-COVID n=4, peri-COVID n=2). One participant stated:

> "I can tell one thing; they were pretty fast with…the treatment. They really wanted to get you healed, cured and on your way out the door. That they do, they do rush. You know, you can sit in emerge for hours and hours, and they can put the cast on your leg. But this booboo, they do try to fix really fast." (Pre-COVID, Female, 67 years old)

A final difference in this subtheme was in the experience of costs and logistics involved in transportation to the hospital for appointments and treatments, including uber or taxi rides, public transit, or paying for parking at the hospital. All six participants in the peri-COVID group discussed some issues in this area, while only one participant in the pre-COVID group did so.

> "People said to me one day, why don't you take a taxi rather than the TTC…If I try to taxi to and from [hospital name] every day, that would have cost me $2,000. That's not considered medical expenses. Our whole system is built around the car. [And there's the] problem of possible incontinence. Um, holding the water, having to pee when you leave. Well, as it turns out…I learned where there were three stops on the way home, I needed them probably once or twice on that route." (Peri-COVID, Male, 83 years old)

The major difference which emerged in this subtheme was the speed of the healthcare system in testing and treatment; perceived as much faster by the pre-COVID group, and significantly slower (or delayed) by the peri-COVID. Difficulty with the costs associated with accessing treatment via transportation was also more frequently discussed in the peri-COVID group.

Sharing and Caring

Nudging me Back to Health covers experiences of positive social support from loved ones, including family, friends, and co-workers (as opposed to any interpersonal support received through the healthcare system). Every participant in both groups provided general descriptions of support coming from loved ones being helpful in dealing with their cancer recovery. Substantial

overlap between the pre- and peri-COVID groups was also found in a range of other support areas, including spiritual or religious support (pre-COVID n=2, peri-COVID n=2), sharing of the diagnosis with others (pre-COVID n=2, peri-COVID n=1), an intention or plan to offer support to future cancer patients (pre-COVID n=3, peri-COVID n=2), and finding support from other individuals who have experienced cancer personally (pre-COVID n=3, peri-COVID n=4). One participant shared the importance of support in her experience of recovery:

> "Well, my husband's been amazing. Like amazing, and my friends are…it gets me weepy [laughter] in a nice way because I just feel so grateful. I had a few moments when I was just…[crying] [when I was] just breaking down, I would call one friend in particular, I'd say 'talk me down' [laughter]. She would. She would." (Peri-COVID, Female, 67 years old)

Two minor differences emerged in this subtheme. First, two participants in the peri-COVID group (and none in the pre-COVID group) described the importance of getting out of the house, seeing others, and returning to their typical social activities following the end of treatment. Second, three participants in the peri-COVID group (and one in the pre-COVID group) talked about the ways in which social contact during treatment helped them feel as though they were living their life the way they did before cancer – feeling 'back to normal.' One participant put it thus:

> "It was great to be able to just be with other people, do normal things. And when I felt sort of alone, I did pick up the phone to good friends, and they would say, 'you're not sitting at home, we're gonna go for coffee, we're gonna go for a walk, we're gonna do this, we're gonna do that'." (Peri-COVID, Female, 79 years old.)

Disconnecting from Others represents circumstances, emotions, or ideas which interfere with, or prevent interpersonal support from being shared or received. This subtheme revealed broad overlap in codes between the pre- and peri-COVID groups. Participants from both groups shared similar experiences around loved ones exercising more control in the relationship than they had before the cancer diagnosis, including a level of control beyond what they were comfortable with (pre-COVID n=2, peri-COVID n=2). Both groups also included descriptions of friends or family feeling uncomfortable or more socially distant following diagnosis (pre-COVID n=1, peri-COVID n=2), concerns about burdening loved ones with responsibility in the context of cancer care (pre-COVID n=2, peri-COVID n=1), as well as having feelings of continued responsibility for dependent others despite finding themselves in the role of a patient (pre-COVID n=1, peri-COVID n=2). Peri-COVID participants described more experiences of protecting friends or family members by withholding information about their cancer diagnosis due to concerns that the reality of the situation would be difficult for them to handle (pre-COVID n=1, peri-COVID n=3). One participant in the peri-COVID group, a 79-year-old woman, said "I have not talked to my children 100% about everything I feel because I don't want them to carry that anxiety..."

A greater difference emerged in the context of a limited desire for social support, as well as feelings of inadequate support being provided by loved ones described by the pre-COVID group. Two participants in the pre-COVID group (and none in the peri-COVID group) discussed important others not being there for them when they needed support:

> "I was really surprised by this one friend, that she didn't put in more effort… it was disappointing. …I was really surprised, I still don't understand it. But you know that

> happens sometimes, people don't really live up to [your] expectations. Maybe she has a lot of stuff going on…I don't know." (Pre-COVID, Female, 74 years old)

Similarly, two members in the pre-COVID group (and none in the peri-COVID group) described the inability for others to understand their experience of cancer if they haven't been through it themselves:

> "You have to do it yourself. Other people can't help you because they don't have the empathy. They don't understand…so, you have to help yourself. Sometimes, friends or people, relatives, they ask you, what I'm trying to cut short to explain. Because they won't understand. They [are] ignorant. [You] know in a sense that they feel you, but they don't know the subject." (Pre-COVID, Male, 75 years old)."

The most notable difference between the two groups appeared through assertions of self-sufficiency in the pre-COVID group; four pre-COVID participants (and no peri-COVID participants) described not requiring much help from others and taking care of their own needs independently, as well as changing their relationships to others when they felt they were not being well supported. For example, one participant expressed, "People would say, 'can I do something?' Oh no, I've done it already. And they are trying to be nice. Which you know, they are. But it's still, I don't rely on anybody." (Pre-COVID, Female, 67 years old), and another stated, "I'm just less willing to…put up with certain things in other people that I used to put up with [laughter].I find I'm…[with] some people I'm just less willing to…waste a certain amount of time." (Pre-COVID, Male, 68 years old)

Broadly speaking, a sense of independence from (and occasionally criticism of) offered support was more frequently described by the pre-COVID cohort, while participants in the peri-

COVID group were somewhat more likely to avoid disclosing the details of their diagnosis to loved ones whom they wished to protect.

Roads to Recovery

The subtheme *Experiences of Treatment* covers direct patient descriptions of what the treatment or recovery process felt like for them including specific memories of treatment. Participants from both groups described common uncomfortable experiences during the course of cancer treatment, including feeling exhausted from the treatments they were receiving (pre-COVID n=4, peri-COVID n=3), displeasure with how much time medical appointments were taking up in their life (pre-COVID n=2, peri-COVID n=1), irritation with the seemingly endless number of scans needing to be taken (pre-COVID n=5, peri-COVID n=4), and fears of surgical procedures which cut or puncture the body (pre-COVID n=1, peri-COVID n=1). A greater number of participants in the pre-COVID group had experiences of acceptance or resignation regarding their diagnosis and treatment side effects (pre-COVID n=5, peri-COVID n=3), with a 75-year-old man in the pre-COVID group succinctly stating, “Accept things, I accept things. It's the key. It's the best medicine.”

Participants in the peri-COVID group appeared slightly more optimistic about their diagnosis and treatment outcomes, both in terms of feeling that their cancer was small or easily treatable (pre-COVID n=1, peri-COVID n=3), as well as describing their health as almost completely recovered following the end of treatment (pre-COVID n=3, peri-COVID n=5):

> “I climb hills, I exercise every morning. There's no impact. I mean, I get it up in the night to pee, which I didn't used to. So, I can live with that if I get up to pee and go back to sleep. It's not as if I've ruined my night. That's about it. There's no other symptom that I can even think of.” (Peri-COVID, Male, 69 years old)

Peri-COVID participants also described an urgency in completing cancer treatments as quickly as possible more frequently than pre-COVID participants did (pre-COVID n=1, peri-COVID n=3). A 67-year-old woman in the peri-COVID groups described her desire for a rapid double mastectomy, saying "I was very anxious to get those done, and when I saw the surgeon for the first time… I said I wanna chop them off. Let's just do it. And then we can do the chemo." Similarly, three peri-COVID participants and one pre-COVID participant described painful or unpleasant components of treatment as extreme but necessary:

> "It was right before you start the chemo and then you know when you've had the chemo, okay, they've killed bloody everything in there, including the healthy cells, then you got to do radiation. Then you're like, 'Okay, are we doing overkill now?' But you know that you want to do this because you want to make sure that they've killed every microscopic cell in there." (Peri-COVID, Female, 49 years old)

Overall, peri-COVID participants expressed more optimism about their treatment outcomes, as well as a desire to complete treatment quickly, while pre-COVID participants appeared more accepting of their cancer diagnosis.

The final subtheme, *Responses to Treatment,* covers the ways in which participants' behaviour, ideas, or perspective has changed over the process of treatment and recovery. Overlap between the pre- and peri-COVID groups in this subtheme was found in participant plans to return to normal life activities (such as work or hobbies) which had been stopped due to cancer treatments (pre-COVID n=5, peri-COVID n=5), major life changes resulting from the experience of cancer (including decisions to retire) (pre-COVID n=1, peri-COVID n=2), and feelings that the participant is now weaker than before the cancer diagnosis with lower energy levels that impact their ability to engage in normal activities (pre-COVID n=5, peri-COVID n=4).

Changes in approaches to personal appearance (such as wearing a wig during/after chemotherapy) (pre-COVID n=0, peri-COVID n=2), as well as self-care behaviours (pre-COVID n=2, peri-COVID n=4) appeared slightly more often in the peri-COVID group than in the pre-COVID group, with some references to the pandemic made in the context of these behaviours among peri-COVID participants. For example, one 79-year-old woman said "COVID, of course, didn't help anything about being much more of a slob at home. You know, tracksuit pants and the top and whatever." Later in the interview, the same woman added:

> "I've changed. You're gonna laugh at that if you have a mom, about my age or younger, I changed the way I dress. I've changed the way I wear makeup. I've changed…a lot of things like silly little things like that. I get out of bed now, dress in whichever way I want. It's been summer. I've donned a new wardrobe with linen dresses. I'm sure you don't care about that. But I mean, make sure I put on my lipstick, make sure, I do my hair, that kind of thing. It does make you feel better." (Peri-COVID, Female, 79 years old)

Peri-COVID participants were also somewhat more likely to describe complaining to others as being unhelpful in relation to dealing with their symptoms (pre-COVID n=0, peri-COVID n=2), and feeling disconnected from their work or other identity defining activities as a result of their illness (pre-COVID n=0, peri-COVID n=2). However, the most notable difference which emerged between the two groups in this subtheme was in descriptions of being stuck at home, unable to go out, travel, or otherwise engage in activities outside the home which they normally would, with two pre-COVID participants and all six peri-COVID participants expressing these feelings. For Peri-COVID participants, this appeared to be a result of both the pandemic and their diagnosis in combination. As one participant put it, "…before I was

travelling more, like I said COVID and this treatment stopped me and now you really have an urge for it." (Peri-COVID, Male, 73 years old). Another commented:

> "In [those] two years, like 2022, we were still not out of the pandemic. We were still following all the [COVID] protocols. We were still masking everywhere like that was kind of like the reality of what we were living in. Nothing was drastically different for me. It really wasn't. We were looking forward to vacations and getting rid of all this stuff, and 2024 we're still talking about it so… You know?" (Peri-COVID, Female, 49 years old)

Discussion

One of the aims of the current study was to investigate the effectiveness of the narrative care intervention (NCI) quantitatively. While self-reported acceptability of the NCI was high among participants, a significant difference in the objective measures before and after the interview was only detected in one subscale: the FACT-G Social/Family wellbeing subscale revealed significantly higher levels of social wellbeing reported following participation in the intervention. As several of the questions in the NCI orient participants toward the informal care they may have received over the course of their cancer journey, including "What helped with your coping (e.g. relationships, resources)" and "Did you learn anything new about your loved ones through your experience with cancer," it is possible that these conversations led participants to become more aware of, and experience feelings of gratitude toward, the interpersonal support which was provided by their loved ones in the days following the interview. Research has shown that expressions of gratitude increase the support offered by close others, and may serve as one of the mechanisms supporting the "find-remind-and-bind" theory of gratitude (Algoe, 2012; Williams & Bartlett, 2015). Simply making the value of social support more salient could increase the feeling of being loved by important others for participants, an effect which is known to impact a range of well-being outcomes in older adults (Kahana et al., 2021). Regardless, these findings should be interpreted conservatively, as only one of the FACT-G well-being scales showed this significant increase. In addition, the small effect size identified in this measure indicates that the intervention may have a very modest impact on social wellbeing. Further study of the effectiveness of the narrative care intervention on social well-being measures with a larger sample size and control arm would strengthen these findings. The qualitative findings in this study further support these quantitative results, as all 12 participants in the reflexive thematic analysis described experiences of positive social support and the value they placed on it during

the interview; indeed, the baseline code “Good to Have Support” was the most frequent code in the study, with 78 instances of this code appearing across all 12 qualitative transcripts.

Beyond the above results, it was also found that positive affect scores in the current sample were a full standard deviation higher than in the general population during the COVID-19 pandemic, a substantial difference in experiences of happiness and well-being. Considering previous findings show that the end of cancer treatment is a period associated with increased distress and anxiety(Bilodeau et al., 2022), what might explain this discrepancy? It is possible that a kind of self-selection bias occurred during the recruitment process, with patients who felt more ready to deal with their experiences and emotions being more willing to join the study, while those who were struggling may have felt unwilling or unable to participate, thus resulting in inflated positive affect scores for this population. As well, the current sample was collected later in the peri-COVID period (between 2023 and 2024) relative to when COVID-19 PANAS scores were obtained (between 2020 and 2021) (Li et al., 2024); if average positive and negative affect scores returned to baseline over this time, that may explain why the current sample is scoring much closer to the general population mean than to a sample taken in the ‘height’ of the pandemic (Crawford & Henry, 2004). Finally, most participants in the current sample completed questionnaires and were interviewed in the weeks immediately following the end of cancer treatment. Because many interviews were conducted so close to the end of treatment, these participants may have been in a “honeymoon” phase, the period of relative calm and reduced worry about recurrence or other cancer related issues which precedes a gradual increase in distress for many individuals (Garofalo et al., 2009). Future studies examining the effectiveness of post-treatment cancer interventions such as this would benefit from the recruitment of participants from several months to up to a year following the conclusion of treatment.

Two questions formed the basis of the qualitative component of the current study: What effect (if any) did the COVID-19 pandemic have on patient experiences of cancer recovery, and what differences exist between the experiences of these two cohorts? Note that all qualitative findings discussed here are very preliminary and do not represent definitive findings or causal relationships. They are presented here to stimulate further thinking and discussion about the ways that COVID-19 may have altered how individuals experience cancer's treatment and impacts over the shorter and longer terms. Unsurprisingly, many similar themes between pre- and peri-COVID patient experiences were identified. Participants in both groups felt weak following treatments, had positive and negative experiences of healthcare during treatment, listened to the advice of their physicians, were grateful for the love and support they received from friends and family, and described a focus on returning themselves to health. Of the differences which did emerge, some were more anticipated based on previous literature surrounding COVID-19 than others. The fact that many peri-COVID participants experienced delays in cancer care while pre-COVID participants felt their cancer was diagnosed and treated quickly is likely due to pandemic related delays and backlogs in the cancer care system, as well as reductions in staffing for hospitals (particularly nurse practitioners) (Tardif et al., 2022; Walker et al., 2022). This staffing shortage may also be related to the differences between pre- and peri-COVID participants' experiences of support resources, with most pre-COVID participants reporting feeling generally well-resourced (and in many cases not in need of support) and some peri-COVID participants feeling that while resources may have been available, they were never directed toward them. Staffing issues, as well as healthcare worker burnout resulting from the pandemic (Singh et al., 2022; Tardif et al., 2022), could have negatively impacted the tendency for hospital staff to recommend resources or advise the uptake

of additional support services to patients. Similarly, the higher number of pre-COVID participants feeling “lucky to have caught” the cancer early on may be related to more regular in person visits to general practitioners as well as more frequent screenings; primary care visits declined by 28% in the first year of the pandemic with office visits dropping by 79.1% (Glazier et al., 2021). In addition, significant reductions in early-stage cancer diagnoses were found throughout this same time period, not only due to lower rates of cancer screening (Lofters et al., 2023) but also likely due to minimizing in person doctor visits for non-COVID-19 related services (Heer et al., 2023). Likewise, concerns about vulnerability and exposure to illness were described more frequently in the peri-COVID group, a finding which stands to reason in the context of both general fear of illness resulting from the pandemic as well as exacerbation of symptoms of fears of contamination among those already prone to such concerns (Duong, 2021; Mertens et al., 2020). Finally, themes of loneliness were more prevalent in peri-COVID participants, both during medical treatments and in their lives more broadly. Loneliness due to social distancing was common during the pandemic, with one in three Canadians found to be experiencing severe loneliness over this time (Lin, 2023); these issues could help to explain the higher incidence of loneliness themes in the peri-COVID subgroup.

Beyond these findings, some less expected themes emerged as more common in one group than the other. Peri-COVID participants shared more experiences of attempting to learn more about their illness, felt more upset about perceptions of withheld medical information, planned to actively return for cancer testing in the future, and were less afraid to disagree with their physician or take a firm stance on which treatments they would prefer to receive or not receive. These findings stand in contrast to research that shows that older adults tend to seek less information and prefer to make fewer healthcare-related choices than younger adults

(Löckenhoff et al., 2016). During COVID-19, medicine and health issues were brought to the forefront of public awareness, prompting increased engagement with researching health topics than prior to the pandemic (Mach et al., 2021). While the participants in the current study were primarily older adults, the increased occurrence of health-related researching and decision-making occurring during the pandemic may be related to a shift in this documented cohort effect, such that even older adults may now be more oriented toward being informed and empowered to make their own healthcare decisions.

The pandemic appears to have impacted the Canadian public's trust in the healthcare system through negative perceptions of health mandate communications, implementation of restrictions, and government decision-making (Herati et al., 2023; Stolzenberg et al., 2023). This mistrust was partially reflected in the more frequently expressed themes of cynicism and skepticism toward healthcare organizations and structures in the peri-COVID sample. However, these themes did not appear to indicate a lack of trust in the cancer treatments peri-COVID participants were receiving; in fact, the peri-COVID group was more inclined to describe confidence in the treatments working for them and feeling the treatments went well. This finding could indicate that this skepticism is not about the effects of the treatment as much as it is a criticism of the ways in which the healthcare system functions. The peri-COVID group also expressed greater confusion and frustration about which health focused lifestyle regimens to follow (as well as outright rejection of some health-related advice), pointing to difficulties in parsing the large number of options in caring for one's personal health as well as the broader issue of information overload which is endemic to life in the information age. The pandemic brought a flood of health related information which had not been part of the public discourse prior; this included false news and conspiracy theories alongside research based medical

recommendations (Mach et al., 2021; Mohammed et al., 2022). This exposure to a glut of health-related advice (often of dubious value) may have increased the level of confusion individuals feel surrounding keeping themselves healthy, as well as increasing the likelihood of rejecting some advice outright.

One less obvious difference worth considering emerged in peri-COVID participants expressing greater concern about transportation to and from treatment, as well as parking costs while accessing medical care. Increases in social inequality (as well as health and wealth inequality) resulting from the pandemic have been well documented (Bambra et al., 2021; Marmot & Allen, 2020; Ventriglio et al., 2021), and many of these issues were highlighted in media coverage over the past several years. Some peri-COVID participants described concerns surrounding costs in transportation and parking personally, and others described that while they were able to pay for these costs themselves, they felt others who were less financially resourced than they were must be struggling. This difference may reflect a growing awareness of economic inequality issues and associated downstream health equality consequences since COVID. Additionally, the pandemic brought with it substantial changes in behavioural norms, including experiences of working from home and changes in expectations regarding shared public spaces (Aarts et al., 2021). Thus, another explanation for increased commentary on parking and transportation may reflect a shift in norms regarding the experience of needing to pay for parking and navigating the logistics of transportation for a cohort that had become more accustomed to staying home and therefore not incurring transportation expenses. For individuals who have shifted to fully working from home, or simply become more used to socially isolating and therefore not visiting public spaces with any frequency, suddenly finding oneself required to pay

for parking (approximately $25 for each treatment visit) could be experienced as a stark difference.

Finally, participants in the pre-COVID group described needing less interpersonal support from others during treatment and were more critical of the kinds of support they did receive, while the peri-COVID group expressed more concern about burdening others. It is possible that following the period of social isolation and separation from important others during the pandemic, gratitude for the receipt of support may be more pronounced for individuals. Furthermore, gratitude appears to mitigate loneliness and promote social bonds (Caputo, 2015); a greater focus on feeling grateful for connection and support, particularly during a distressing life event such as a cancer diagnosis, could have helped to reduce feelings of loneliness in cancer patients during the pandemic. In addition, it is noteworthy that more peri-COVID participants in this sample were concerned about emotionally burdening loved ones by sharing all the details of their diagnosis, with the majority of participants indicating hesitation to disclose and worrying specifically about the well-being of their children if they were saddled with too much distressing information. Considering the substantial increase in stressors during the pandemic, reflected by increased rates of depression and anxiety (particularly among adolescents and young adults) (Cloutier & Marshaall, 2021; Erbiçer et al., 2021; Salari et al., 2020; Wathelet et al., 2022), peri-COVID participants with adult children may have been aware that their children were already dealing with difficulties in their lives and thus may have been inclined to avoid sharing additional stressful information with their families. In the related pre-COVID study which examined some of the same measures as the current one, quantitative findings on the FACT-G Social/Family Wellbeing Subscale were found to be significant at a substantially lower significance threshold ($p < 0.05$) compared with the current study ($p < 0.005$) (Ianakieva, 2021).

This increased significance in quantitative findings may be reflective of the absence of criticism of social support in the peri-COVID group relative to the pre-COVID one reported above, further reinforcing the potential higher levels of gratitude for support in the former group. However, it is also possible that by increasing the sample size in the current study, sensitivity to the original finding was simply magnified, leading to this increased significance; further research on the NCI with a larger sample size could resolve this uncertainty.

Limitations

Although there is preliminary evidence based on participant feedback that the NCI is valuable (from a patient perspective), it is important to note that nearly one quarter (10/42) of participants did not complete the post-NCI questionnaire, limiting the validity of this feedback[2]. A larger sample size with lower attrition rates would be helpful in providing this evidence, as well as increase the power for the statistical analyses. A better understanding of the reasons for attrition rates in the sampled population may also be helpful in future recruitment of NCI participants. Likewise, the qualitative sample (six pre-COVID and six peri-COVID participants) is too small to draw definitive qualitative comparisons; it is not possible to determine whether the differences noted in this study are true differences or the result of individual differences in experience unrelated to the pandemic. That said, as the questions in the NCI were identical between both subgroups, participants were in no way led to discuss pandemic related experiences and were therefore unlikely to have been shaped by the interviewer or the interview process. Beyond this, the qualitative sample was limited to the most common cancer types in males and

[2] Of the three participants in the peri-COVID group who did not complete the post-NCI questionnaire, we have reason to believe that one participant may have passed away and another indicated being too distressed by the occurrence in Israel on October 7, 2023. One participant in the pre-COVID group stated that he chose not to complete the post-interview questionnaire as he felt it was focused on negative feelings which he did not want to engage with, and another failed to receive the post-treatment questionnaire package due to logistical issues. It is therefore likely that external factors, rather than concerns with the NCI itself, led to a lack of feedback from these participants.

females (prostate and breast, respectively) for matching purposes; a wider range of cancer types, as well as broader range of demographics (including diversification of ethnicity and socioeconomic status), would provide more external validity to the results. As a result, the findings presented in this study should only be considered in relation to individuals with breast and prostate cancers. It should also be noted that breast and prostate cancers are the highest funded and most researched cancer types for women and men respectively (Carter & Nguyen, 2012); while they are highly common forms of cancer, it is important to recognize the substantial range of cancer types which are not represented here and the differences in individual experiences which result from them. Future research in this area should include a greater range of diagnoses in the sample both to increase external validity, as well as to provide inclusive representation of the full range of cancer experiences. Finally, implicit bias on the part of the author may have impacted the outcome of the analysis, although this issue was mitigated in part by both awareness of possible biases (per the reflexivity statement in the Methods section), a continuous memoing process of author reflections, and a separation of the organization of themes from frequency of codes arising in the pre- or peri-COVID groups; although coding was performed in NVivo Software, the thematic structure was generated in an Excel spreadsheet, such that while the author was not blind to which transcript themes appeared in during the preliminary coding process, he was initially blind to which participants had contributed to each group (pre- and peri-COVID) during the clustering and organization of the codes.

Implications, Future Directions and Conclusion

Findings from this study could be used to aid in the development of improved narrative-based post cancer treatment interventions which give individuals at the end of treatment an opportunity to consolidate their experiences in dialogue with a trained listener. Sensitivity to

differences which may have emerged as a result of the COVID-19 pandemic could be of value in this process. In addition, the knowledge that peri-COVID cancer survivors may be more critical of healthcare organizations, as well as experience more confusion around appropriate healthy behaviours, could have utility for therapists working specifically in psychosocial oncology. While no definitive conclusions can be drawn from the qualitative results of this study, there is preliminary evidence to suggest that patients in the peri-COVID period are a little different from those in the pre-COVID period: more agential, more skeptical of medicine, and more sensitive to the interpersonal support they receive from close others. Future research could continue to investigate these findings by increasing the sample size in the matched participants in order to determine if the current findings hold.

The current study provided insight into potential experiential differences between individuals completing cancer treatment before and during the COVID-19 pandemic. Overall, the study's findings indicated both the potential benefits of an opportunity to share one's narrative following cancer treatment, as well as some subtle differences between cancer patients before and following the occurrence of COVID-19, differences which could have implications both on the ways in which patients prefer to receive medical care, as well as how to best offer psychosocial support to cancer survivors in post-pandemic world.

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Appendices

Appendix A

Recruitment Script

My name is _____ and I am a research assistant at the Patient and Family Support Program. I was wondering if I could have a minute of your time to talk to you about a research project that you might be of interest to you.

If yes*: Great. Our project gives patients who have completed treatment a chance to have a supportive conversation with one of the staff members from our Patient and Family Support Program about their treatment experiences. We are also evaluating this program so there would be some questionnaires to complete before and after the interview. Is this something you might be interested in?*

If yes: *Great. Do you mind if I give your name, email, and telephone number to the program coordinator so he can provide you with more detailed information about the study?*

- ➔ Write down email and telephone number on ballot
- ➔ Give flier
- ➔ Let them know they will receive a follow-up call/email to set up a date and time for the interview

If maybe: *I can give you a flier with more information and the research coordinator's contact information. You can call or email if you have any questions or decide that you might want to participate.*

- ➔ Give study flier

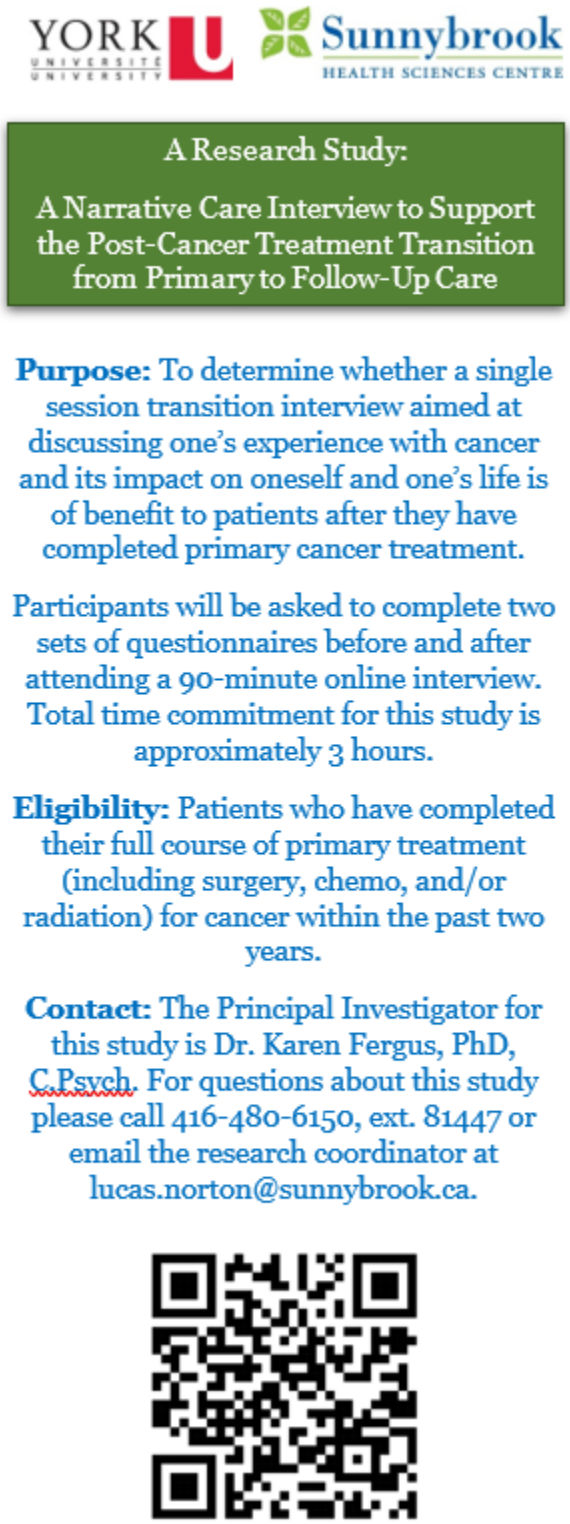
Basic info to know:

- "The interview includes questions about your experience with being diagnosed, going through treatment, and looking forward toward life beyond cancer"
- Benefits:
    - Might benefit you to have someone listen to your experience and potentially help you process it
    - Can help us evaluate the interview and make it better so that it can help others in the future
- The two pre-post treatment questionnaires take approximately 30 minutes to complete
- The questionnaires and interview are both conducted online
- Study is being done to evaluate this end-of-treatment program, which is why they're asked to complete questionnaires before the interview and two weeks after the interview
- Eligibility criteria (if asked):
    - Primary cancer (non-metastatic)

Completed all primary treatments (radiation, chemo, surgery) in the past 2 years

Appendix B

Narrative Care Study Informational Flier



Appendix C

Telephone Screening Script

Screened By: _____ Eligible? Yes/No If No, reason: _____
Date of Screen: _____

Participant Name: _____
Email: _____
Phone: _____

Mailing Address:

_____
_____
_____

Thank you for taking the time to speak with me today. During this time, I would like to tell you a bit more about the study and ask you some questions to make sure it's a good fit for you. If you have any questions, please feel free to ask at any time. In this study, we will be evaluating a one-session intervention that is meant to support patients in the time shortly after being discharged from treatment for primary cancer. If you agree to participate, in addition to attending an interview at Sunnybrook that will be about 90 minutes long, you would be asked to fill out a series of questionnaires at home about things like your mood and quality of life, before and after the interview. You can fill out these questionnaires online, or on paper if you do not have access to a computer or internet. The interview will have questions about your experience during and after treatment, and how it has impacted your life. Does this still sound like something you might be interested in? **Yes/No**

So first I would like to ask whether you attend any counselling or psychotherapy at this time? **Yes/No**

If Yes: *It is great that you have been able to find support and someone to talk to during this difficult time. However, because part of this study involves evaluating an intervention that is designed to do this as well, we are unable to include you. If we did, we would not know whether to attribute any changes to the intervention or to counselling/therapy. Do you have any questions about that?*

If No: *Okay, next I would like to know some details about your cancer treatment:*

type of cancer: _____

Exclusion: Patients with metastatic disease.

*type of treatment:*_____
completed treatment: **Yes/No**

*date of last treatment:*_____

Exclusion: Individuals who have not completed all of their primary treatment (chemotherapy, radiation and/or surgery) within the past one to three months.

And lastly, do you have any difficulty with written English? **Yes/No**

If eligibility criteria not met: *Thank you for answering those questions. Unfortunately, you do not meet the eligibility criteria for the study.* **Explain why and thank individual for their time.**

If eligibility criteria met: *Thank you very much for providing that information. It looks like you meet all of the eligibility criteria for the study. Are you interested in participating in the study? Okay, so the next step is for me to send you a consent form that will explain the study in more detail, as well as your rights as a participant. It's important to note that you can withdraw from the study at any point and that this will not have any effect on your current or future health care or treatments. If you would still like to participate, please sign this consent form and mail it back using the included envelope.*

In about a week from today, I will follow up by email to make sure that you have received the consent form and that you have signed and returned it. If you have, I will then email you a link to the online survey which I will ask you to complete before coming in to Sunnybrook for the interview. If you have not received the form or had a chance to send it back to me, I will ask you to email me once you do so that I can send you the link to the survey.

Do you have any questions about anything? If not, we can now set up a time for the interview, about three weeks from now to make sure you have enough time to receive the consent form and complete the online survey. **Set up date/time for interview.**

Date of interview: _____

If you have any questions or have to cancel/change the time or date of the interview, you can call me at 416-480-6150, ext. 90504 or email me at lucas.norton@sunnybrook.ca.

Appendix D

Narrative Care Interview Script

Illness period:

- Can you say a little bit about how you came to be diagnosed with cancer?
- What was going on in your life at the time?
- What types of treatments did you receive?
- What was the most challenging thing for you about having cancer? Going through the treatment?
- How did you cope with your illness?
- What helped with your coping (e.g., relationships, resources?) What made it difficult or more challenging?
- In hindsight, is there anything that you might have done differently?

Post treatment reflection:

- How are you feeling now that your primary treatments (surgery, chemotherapy and/or radiation) are over?
- What is the most pronounced difference for you - between now and before you were diagnosed with cancer?
- How would you say that having cancer has changed *your life* (if at all)? *Yourself*? Your most important relationships?
- What do you see as your main challenge right now?

New learning/meaning-making:

- Is there anything that could have been done to make your experience better/easier to cope with?
- Did you learn anything new about yourself through your experience with cancer? About your loved ones?
- Did you come to any new insights through this experience?

Orienting toward the future:

- How do you see yourself moving forward?
- Is there anything that you have learned over the course of your illness that you would like to take with you/apply to your life as you move forward?
- Is there anything I didn't ask about, or that you feel is important for me to know about your experience that you would like to mention?

Appendix E

List of Study Materials and Questionnaires

Time 0: Telephone Screening

Time 1: Pre-Interview Questionnaire Package

1. Demographics Questionnaire
2. Positive and Negative Affect Schedule (PANAS)
3. Functional Assessment of Cancer Therapy – General (FACT-G); Physical, Social/Family, and Function Well-Being Subscales
4. Cancer Behavior Inventory (CBI)

Time 2: Narrative Care Interview (NCI)

Time 3: Post-Interview Questionnaire Package

1. Positive and Negative Affect Schedule (PANAS)
2. Functional Assessment of Cancer Therapy – General (FACT-G); Physical, Social/Family, and Function Well-Being Subscales
3. Cancer Behavior Inventory (CBI)
4. Treatment Satisfaction Questionnaire

Appendix F

Pre- and Post- Interview Measures

Positive and Negative Affect Schedule (PANAS-SF)

Indicate the extent you have felt this way over the past week.		Very slightly or not at all	A little	Moderately	Quite a bit	Extremely
PANAS 1	Interested	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PANAS 2	Distressed	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PANAS 3	Excited	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PANAS 4	Upset	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PANAS 5	Strong	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PANAS 6	Guilty	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PANAS 7	Scared	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PANAS 8	Hostile	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PANAS 9	Enthusiastic	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PANAS 10	Proud	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PANAS 11	Irritable	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PANAS 12	Alert	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PANAS 13	Ashamed	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PANAS 14	Inspired	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PANAS 15	Nervous	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PANAS 16	Determined	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PANAS 17	Attentive	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PANAS 18	Jittery	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PANAS 19	Active	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PANAS 20	Afraid	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

FACT-G (Version 4)

Below is a list of statements that other people with your illness have said are important. **Please circle or mark one number per line to indicate your response as it applies to the past 7 days.**

	PHYSICAL WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GP1	I have a lack of energy	0	1	2	3	4
GP2	I have nausea	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
GP4	I have pain	0	1	2	3	4
GP5	I am bothered by side effects of treatment	0	1	2	3	4
GP6	I feel ill	0	1	2	3	4
GP7	I am forced to spend time in bed	0	1	2	3	4

	SOCIAL/FAMILY WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GS1	I feel close to my friends	0	1	2	3	4
GS2	I get emotional support from my family	0	1	2	3	4
GS3	I get support from my friends	0	1	2	3	4
GS4	My family has accepted my illness	0	1	2	3	4
GS5	I am satisfied with family communication about my illness	0	1	2	3	4
GS6	I feel close to my partner (or the person who is my main support)	0	1	2	3	4
Q1	*Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box* ☐ *and go to the next section.*					
GS7	I am satisfied with my sex life	0	1	2	3	4

	FUNCTIONAL WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
GF1	I am able to work (include work at home)	0	1	2	3	4
GF2	My work (include work at home) is fulfilling	0	1	2	3	4
GF3	I am able to enjoy life	0	1	2	3	4
GF4	I have accepted my illness	0	1	2	3	4
GF5	I am sleeping well	0	1	2	3	4
GF6	I am enjoying the things I usually do for fun	0	1	2	3	4
GF7	I am content with the quality of my life right now	0	1	2	3	4

CANCER BEHAVIOR INVENTORY (CBI-B V1.0-12)

This survey contains many things that a person might do during and after cancer treatment. We are interested in how confident you are that you can do those things. Be sure your ratings are about your confidence even if you have not done it in the past. So, your ratings are about your confidence that you can do these things now or in the near future.

Please read each item. Then rate that item on how confident you are that you can do that behavior. Circle a number on the scale. If you circle a "9" you are totally confident that you can do that behavior. If you circle a "1" you are not at all confident that you can do that behavior. Numbers in the middle mean that you are somewhat confident that you can do that behavior. Be sure your ratings reflect your confidence even if you have not done it in the past.

Please rate all items. If you are not sure about an item please rate it as best you can.

1.	**Maintaining independence**	NOT AT ALL CONFIDENT				MODERATELY CONFIDENT			TOTALLY CONFIDENT
		1	2	3	4	5	6	7	8	9
2.	**Maintaining a positive attitude**	NOT AT ALL CONFIDENT				MODERATELY CONFIDENT			TOTALLY CONFIDENT
		1	2	3	4	5	6	7	8	9
3.	**Maintaining a sense of humor**	NOT AT ALL CONFIDENT				MODERATELY CONFIDENT			TOTALLY CONFIDENT
		1	2	3	4	5	6	7	8	9
4.	**Expressing negative feelings about cancer**	NOT AT ALL CONFIDENT				MODERATELY CONFIDENT			TOTALLY CONFIDENT
		1	2	3	4	5	6	7	8	9
5.	**Maintaining activities (work, home, hobbies, social)**	NOT AT ALL CONFIDENT				MODERATELY CONFIDENT			TOTALLY CONFIDENT
		1	2	3	4	5	6	7	8	9
6.	**Remaining relaxed throughout treatments and not allowing scary thoughts to upset me**	NOT AT ALL CONFIDENT				MODERATELY CONFIDENT			TOTALLY CONFIDENT
		1	2	3	4	5	6	7	8	9
7.	**Actively participating in treatment decisions**	NOT AT ALL CONFIDENT				MODERATELY CONFIDENT			TOTALLY CONFIDENT
		1	2	3	4	5	6	7	8	9

8.	**Asking physicians questions**	NOT AT ALL CONFIDENT	1	2	3	4	5	6	7	8	9	TOTALLY CONFIDENT
9.	**Seeking consolation (support)**	NOT AT ALL CONFIDENT	1	2	3	4	5	6	7	8	9	TOTALLY CONFIDENT
10.	**Sharing feelings of concern**	NOT AT ALL CONFIDENT	1	2	3	4	5	6	7	8	9	TOTALLY CONFIDENT
11.	**Managing nausea and vomiting**	NOT AT ALL CONFIDENT	1	2	3	4	5	6	7	8	9	TOTALLY CONFIDENT
12.	**Coping with physical changes**	NOT AT ALL CONFIDENT	1	2	3	4	5	6	7	8	9	TOTALLY CONFIDENT

Treatment Satisfaction Survey

1.

I found the interview to be:

Helpful

Unhelpful

How so?

2.

Was there something specific that you took away from the interview?

Yes (please describe)

No

3.

The interview gave me more perspective on my experience with cancer

Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

Please elaborate:

4.

The interview highlighted important insights or learnings in relation to my experience with cancer

Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

Please elaborate:

5.

There were some parts of the interview that I found challenging or hard:

Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

If so, please elaborate:

6.

The interview opened up 'old wounds' and that was upsetting:

Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

If so, please elaborate:

7.

Are there any questions (or parts from the interview) that stayed with you?

Yes (please indicate what stayed with you and why)

No

8.

Are you considering doing something differently or trying something new as a result of the interview?

Yes (please elaborate)

No

9.

The duration of the interview was:

- Too long
- Just the right length
- Too short

10.

Based on my experience, I think that all patients should have an opportunity to do a post-treatment transition interview should they wish:

Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

11.

We are also interested in understanding how you think the COVID-19 pandemic may have affected you during your diagnosis and treatment process, if at all. With this in mind, please describe the ways in which you believe COVID may have impacted your experience of cancer treatment and recovery:

12.

What has your experience of the conclusion of cancer treatment been like for you?

If applicable, please describe any challenges or concerns you've had during your transition out of cancer care:

Appendix G

Demographics Questionnaire

What is your age?

What is your date of birth? (month/year)

In what country were you born?

What is your first language?

How do you self-identify regarding your ethnicity?

- White/Caucasian
- Black, Afro-Caribbean, or African Canadian
- Latino or Hispanic Canadian
- Asian
- South Asian or East Indian
- Middle-Eastern
- Indigenous
- Other (please specify)

How do you self-identify regarding your gender?

- Female
- Male
- Other (specify)

What is your current relationship status?

Single

In an Intimate Relationship (please specify duration of relationship)

Married (please specify duration of marriage)

Common Law

Other (please specify)

Do you have children?

Yes

No

What is your current living situation?

- I live alone
- I live with a roommate(s)
- I live only with my partner
- I live with my partner and child/children
- I live with my partner and non-family members
- Other - please specify:

What is the highest level of education you have completed?
If currently enrolled please indicate the highest degree received.

- No formal schooling
- Primary school
- High-school
- College program
- University degree
- Graduate degree
- Other (please specify)

What is your annual income status?

- $0 - $9,999
- $10,000 - $25,000
- $25,000 - $50,000
- $50,000 - $75,000
- $75,000 - $100,000
- $100,000 +

What is your usual occupation?

- Currently working (please specify occupation)
- Semi-retired (please specify occupation)
- Retired (please specify former occupation)

Have you ever been diagnosed with a mental health condition?

- No
- Yes (please explain)

What type of cancer were you diagnosed with?

Please indicate month and year of diagnosis (__/____ e.g. 05/2015)

Please indicate the cancer stage at diagnosis:

- Stage 1
- Stage 2
- Stage 3

How long ago (in weeks) did you complete active treatment?

Did you undergo surgery during your cancer treatment?

Yes (please specify)

No

Did you undergo chemotherapy during your cancer treatment?

Yes

No

Did you undergo radiation therapy during your cancer treatment?

Yes

No

Did you undergo any other treatment for cancer?

Yes (please specify)

No

Have you ever had any other major medical conditions/concerns? Please list them here:

Appendix H

Themes, Subthemes, and Codes with Definitions

Theme / Subtheme	Code	Definition
1) Understanding the Disease and the Cure	**Experiences of seeking or avoiding information in order to better understand and/or deal with the cancer diagnosis, treatment, and recovery.**	
	Doctor's Prescription	Descriptions of doctors giving their opinion on treatment plans and making specific recommendations.
	Finding Out More	Seeking information from sources outside the healthcare system such as knowledgeable friends/family, books/literature, the internet, etc.
	Knowing Too Much	The feeling that learning too much about statistics, cancer outcomes, treatment approaches, etc. can causes additional anxiety rather than alleviating fears.
	Understanding the Odds	Descriptions of doctors/medical staff explaining details of treatment (including risks, side effects, etc.) but the patient ultimately makes their own choice about their healthcare decisions.
	Unshared Intentions	The experience of basic information not being shared by medical staff and a desire for better understanding each step of the process.
	Unfounded Mistrust in Medicine	Criticism of mistrust in doctors or the medical system. This ranges from irritation at people questioning their doctor's recommendations to rejection of anti-vaccination and anti-medical perspectives.
	Not Small to Me	Despite good prognosis, the reality of the intensity/invasiveness of the treatment makes one realize the seriousness of the disease
2) Responsibility for Healthcare	**Experiences which touch on who is responsible for the patient's healthcare and recovery. This could include patients taking personal responsibility for their health, feelings that the**	

	system is in control or responsible, as well as the intersection between these two ideas.	
a) Taking Health into One's Own Hands	**The patient describes their actions or ideas which place them in control of their own health.**	
	Failing to Care for Myself	The patient expresses disapointment in themselves or a desire to have done more to care for their own personal health in the context of initiating screening tests, treatment, or recovery.
	I Know What's Best for Me	Certainty from the patient in terms of which treatments they want or don't want - surgeries, chemotherapy, etc.
	Much Needed Rest	The patient takes time to themselves during recovery - resting, reading, relaxing as needed.
	The "Getting Over it" Attitude	Content pertaining to descriptions of coping strategies or management of distress while interfacing with the healthcare system.
	Change is Hard	Descriptions of difficulties in making changes oriented toward health, or frustration in the process of such changes.
	Stay Positive, Stay Healthy	An important part of maintaining health throughout treatment and recovery is having a positive attitude.
	Knowing How to Navigate and Self-Advocate	Descriptions of social factors (such as age, gender, language, culture, or education) interfering with access to care/support in the medical system. *changed from Not Everyone Can Advocate for Themselves
	Knew This Was Coming	The participant felt that a cancer diagnosis was likely before it occurred, possibly due to genetic history, proclivity to lymphoma, warnings from the healthcare system, or a self-held intuition.
	Speaking Up When it Matters	Speaking up for oneself and one's needs in the healthcare system, especially in the face of structural pressure not to. The patient uses their voice to draw a line in the sand or speak back critically to those in the system.

	Getting Healthy Again	Personal lifestyle changes aimed at improving health following cancer treatment.
	It Feels Good to Take Action	Descriptions of the improved wellbeing / positive affect / personal satisfaction with changes in lifestyle oriented toward health/mental health.
b) The System is Responsible for our Health	**Statements which place the healthcare system in control of patient health (or public health more broadly)**	
	Keep an Eye on It	Discussion of plans/intentions to continue to go in for cancer testing to avoid recurrence in the future.
	A More Holistic Approach	Desire for, or a focus on, alternative medical practices in the context of the medical system itself (as opposed to the patient seeking these independently).
	Leave it to the Doctor	When decision making, tests, scheduling, or other healthcare related issues are described as best left to the doctor's discretion.
	Responsibility to the Patients	The idea that the healthcare system is responsible for the wellbeing of the population - regular checkups, contact from the system, and educating patients is all the fundamental job of the system.
c) Hesitation and Confusion	**Descriptions of confusion, fear, or helplessness in the context of remaining healthy**	
	What IS Good for you...	Expressions of information overload or inability to distinguish which advice is correct/useful when it comes to healthy lifestyle, including foods to eat, exercise, etc.
	What Good Does it Do	Unsure of whether personal lifestyle changes (e.g., meditation) will improve health or have an impact on the likelihood of the occurrence/recurrence of cancer.
	Ridiculous Lifestyle Changes	Distain for, or disinterest in, making certain lifestyle changes (such as diet, reducing alcohol consumption, exercise, etc.) following cancer treatment.
	Doubly Vulnerable to Disease	Fear of contracting illnesses, such as COVID, during cancer treatment/recovery. Descriptions of self-isolation due to these fears, as well as

		feelings that one should be very careful or take precautions (even if not self-isolating) are covered by this code.
3) Seeking the 'Care' in Healthcare	**Patient experiences of, desire for, or lack and supplementary support/resources offered by the healthcare system.**	
a) Unsupported in the System	**The patient describes negative experiences in the healthcare system - either feeling that they were not cared for appropriately or situations in which more compassionate care would have been helpful.**	
	Dehumanizing Treatment	Descriptions of hospital/healthcare staff being unkind, rude, or unhelpful. Low empathy, impatience, dismissiveness, medicalization of the patient, and cold or dehumanizing behaviour are all included in this code.
	Issues Accommodating Patient Needs	The patient describes a lack of consistency or structure in their appointment organization, such as being moved between health care providers and feeling as though they aren't able to get their care centrally or an inability to have appointments at times which are accessible for them.
	Systems that Can't be Trusted	Mistrust in healthcare structures/systems such as the Cancer Society, or the pharmaceutical industry. This includes suspicion of ulterior motives, such as financial incentives.
	Unaccompanied and Alone	Descriptions of the patient's (self or others one knows) who had to go through treatment/surgery/procedures alone or without support of caregivers, friends or family because of COVID restrictions
	Lonely During Treatment	Loneliness and lack of social contact resulting from cancer treatment - this could come from feelings of illness, being busy with appointments, or fear of contact due to compromised immune system.
	Waiting is Stressful	Stress, anxiety, or discomfort resulting from waiting for results, appointments, surgeries, etc. This is distinct from delays - the waiting times are typical and expected.

b) Well Cared For	**Expressions of satisfaction with the way in which they were cared for, either medically or through good care.**	
	Compassionate Care	Descriptions of the hospital/healthcare staff in a positive light - being friendly, kind, helpful, and sociable; humanizing behaviour by the staff to make the experience of treatment more pleasant.
	Grateful for Good Care	The participant expresses gratitude for having access to the resources which led them to being treated successfully, whether through the healthcare system itself, financial advantages, or social support which guided them toward treatment.
c) Accessing Supplementary Support	**Any descriptions of accessing, attempting to access, or not needing to access supplementary support.**	
	Resources Available but Invisible	When patient information and patient support were nearby/available, but the patient wasn't told about them or aware of them (possibly until much later).
	Left Hanging After Treatment	The feeling of lack of support or lost support following the conclusion of cancer treatment.
	Available But Not Necessary	Supplementary support is available to and known about by the participant, but they feel they do not need or do not want that support.
	On My Own in the System	Experiences of aloneness and vulnerability during medical treatment. Regardless of the quality of medical care, ultimately, it's the participant who is dealing with cancer on their own
	Never Heard Back	Participants have reached out to a healthcare or healthcare adjacent organization and were unable to get in contact or find support.
	Seeking Supplementary Support	Participation in, or intention to participate in, cancer related support groups, exercise classes, nutrition courses, etc. as well as cancer specific mental health support.

4) System Functionality	**Experiences of the healthcare system functioning as expected or failing to do so, as well as critiques of system structures or thoughts on how the system might be improved.**	
a) Functioning as Expected	**Confidence in the healthcare system, and experiences which show the system functioning smoothly.**	
	Confidence in the Cure	The participant expresses confidence in their treatment plan and a sense of security in the idea that they will make a full recovery.
	Everything Working as it Should	Descriptions of cancer treatment going well and as expected. This includes "easy" treatment - no problems or issues occurring.
	Lucky We Caught It	When some aspect of the cancer was detected due to another medical issue being examined and the participant feels fortunate that it was found when it was.
b) Breakdowns and Delays	**Problems in the system which interfere with care. These can be issues caused by the pandemic, or issues which are described by patients as problematic for them personally.**	
	Delays, Delays, Delays	Delays of any kind which interfere with diagnosis or treatment, whether due to COVID, personal issues, or other reasons.
	Medical Mistakes	When a doctor or medical professional missed, misdiagnosed, or otherwise was perceived to have made an error in judgement in regard to the patient's cancer treatment.
	No Time Wasted	When the medical system moves quickly and efficiently without delay to address the cancer, whether through testing, surgery, or other treatments.
	Not as Innocent as we First Thought	The cancer, which had initially been thought to be small, simple, benign, or easily treatable, (by the participant or the medical team) turns out to be more serious and require more aggressive treatment.
	Paying Out of Pocket	Descriptions of medical costs being paid for by the patient as opposed to being covered by OHIP.
	The Cost of Getting There	When the costs and logistics involved in transportation to treatment are discussed, including public transit, Uber

		or taxi rides, and paying for parking at the hospital.
	Unexplained Side Effects	Descriptions of side effects which may or may not be related to cancer treatment that remain essentially unexplained by the medical system (or even the patient themself).
5) Sharing and Caring	**Experiences of interpersonal social support both directed to and from the patient, as well as descriptions of issues which impede or facilitate such support.**	
a) Nudging me Back to Health	**Positive support from loved ones - family, friends, and co-workers - as opposed to support from the medical system.**	
	Brings me "Back to Normal"	Social contact with others which helps the participant to feel as though they're living their life the way they did before cancer again.
	Spiritual Support	Social support provided by, or related to, religious or spiritual groups in the participant's life.
	Those Who Understand	Social support from others who have experience with cancer because they have also been through it.
	Sharing the Diagnosis with Others	Descriptions of telling others about the diagnosis, including family and friends, co-workers, or any others who the news is shared with.
	Reconnecting Again	Getting out of the house, seeing others again, and returning to social contact/activities at the end of treatment. This can include descriptions of COVID or non-COVID specific reconnecting.
	Good to Have Support	General support from others is mentioned but with little detail or context.
	Help for Those Who Come Next	Intention/plans/desire to help support future cancer patients.
b) Disconnecting from Others	**Circumstances, emotions, or ideas which interfere with or prevent interpersonal support.**	
	I'm Still Responsible for Them	Despite assuming the role of a patient themself, the participant is still responsible for caring for weaker, ill, or dependent others
	If You Haven't Had it, You Don't Understand	Only those who have personally experienced cancer can understand what

		it's like - sharing with supportive others, even well-meaning ones, who haven't had cancer doesn't allow them to understand the experience you've been through.
	I Don't Want to be a Burden	Avoiding burdening loved ones / co-workers with responsibility surrounding the patient's cancer care.
	Caring and Controlling	Social support from family or friends which also involves the supporter exercising more control than they would have before the cancer diagnosis, including control going beyond what the participant is comfortable with.
	Asserting Self-Sufficiency	The participant describes not needing much support or help from others and taking care of themselves and their own needs independently, as well as not being willing to put up with negative behaviours from close others.
	Loss of Intimacy and Sexuality	The patient describes losing sexual functioning or cancer resulting in a reduction or complete loss of sexual intimacy with their partner.
	Not Around When I Needed Them	Disapointment in others from whom support was expected but not provided.
	Too Personal to Talk About	Descriptions of self or others unwilling to share their experiences with cancer due to feelings of discomfort.
	They Won't Be Able to Handle It	Avoiding telling friends or family members about the cancer diagnosis due to concerns that they won't be able to handle the news, i.e., being protective of others, or softening/hiding cancer's effects
	They Don't Know What to Say	Description of friends or family who are somewhat uncomfortable or distant socially during/following cancer treatment, likely due to feeling unsure about how to talk to the patient about their experiences.
6) Roads to Recovery	**Descriptions of dealing with treatment and recovery and how these experiences impacted the patient's life. These include experiences of the healthcare system but are more experiential as opposed to functional or support based.**	

a) Experiences of Treatment	**Direct descriptions of treatment or recovery experiences**	
	Exhausted from Treatment	Feeling tired, weak, unwell, or fatigued during the treatment process.
	Almost Okay	The participant describes being almost completely better and feeling that their health has returned to the level it was at before cancer.
	Nothing to Worry About	The patient feels that the cancer is small, easily treated, or not a serious issue.
	Glad I Had it When I Did	Expressions of gratitude for having had cancer later in the pandemic, as opposed to at the height of it.
	It Is What It Is	A sense of acceptance/resignation in regard to diagnosis, treatment, and symptoms.
	Endless Appointments	Descriptions of a large portion of the patients time being taken up with medical appointments during cancer treatment, particularly when these appointments are interfering with other desired activities.
	COVID is Still Here	References to the continued impact COVID is having on our lives despite being generally perceived to be finished.
	Scans and More Scans	When tests are described as being repeated over and over again, or as though there is a feeling that there's just too many of them.
	Sliced and Punctured	Negative descriptions, as well as fears of, surgical and medical procedures which cut or puncture the body.
	Let's Get This Over With	Urgency in completing cancer treatment. A desire to have all the treatments over and done with, even if they are uncomfortable/painful.
	Kills Anything That Moves	When painful or nasty side effects are described in a flippant/matter-of-fact way, as part of the description of the treatment
b) Responses to Treatment	**Ways in which the participant's behaviour, ideas, or perspective changed over the process of treatment or recovery.**	

	Getting Back to My Life	Returning to activities (such as work or hobbies) which had been stopped due to cancer treatment/recovery.
	Major Life Changes	Cancer resulted directly in major life changes, such as permanently losing the ability to engage in an important activity or making the decision to retire.
	Not Caring about How I Look	Cancer/COVID related effects which cause the participant (or close loved ones) to worry less about how they look and do less to care for their appearance.
	There's No Point in Complaining	The patient describes not complaining about their symptoms or difficulties to others, or the futility of complaining about them.
	Weaker Than I Used to Be	Recovery has been difficult, and the participant is not feeling that their energy levels or overall health has returned to where it was before treatment.
	Losing My Identity	The participant feels disconnected from their work or other activities which help to define them as a person.
	Stuck at Home	The participant feels unable to go out, travel, or otherwise move around and do things that they would normally do.
	Taking Better Care	Changes in activities resulting from treatment which are not specifically health related, but are focused on self-care of the patient - appearance/clothing changes, cleaning or organizing the home, engaging in hobbies which bring joy, etc.