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Understanding the emotional impact of bowel cancer on younger patients: A mixed-methods study of online narratives written by Australian young patients

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ABSTRACT

Background: The incidence of bowel cancer in young people is rising globally. In response, many patients share their cancer journeys online to raise awareness. **Aim:** This study explores personal narratives of young bowel cancer patients and examines how cancer shaped their emotions. **Method:** We conducted a convergent mixed-methods study of narratives from Bowel Cancer Australia's Never2Young webpage (N=48; age range: 21–48 years). Sentiment analysis quantified emotion distributions and valence across pre-diagnosis, diagnosis, and post-diagnosis. Thematic analysis was used to interpret these patterns. **Results:** Fear, sadness, and trust were most common. Overall sentiment was slightly positive. Women contributed longer narratives and showed marginally more negative valence than men. Temporal tokens were salient. Qualitative findings connected peaks in fear and sadness to uncertainty, age-related dismissal, and long waits for colonoscopy. Clearer information, family involvement, and self-care accompanied later increases in trust. Together, findings identify time (e.g., waiting for investigation) as a central mechanism linking care processes to emotion. **Discussion:** Emotional trajectories were phase-specific, with fear and sadness highest before diagnosis and trust increasing afterwards, often alongside persisting negative affect. **Conclusion:** Results of sentiment and thematic analysis of emotions reflect early delays/uncertainty and later clarity and support in young bowel cancer patients.

KEYWORDS

Bowel cancer, emotions, sentiment analysis, sentiments, thematic analysis, young cancer patients.

BIOGRAPHIES

Dr Vanda Nissen is a health researcher with a multidisciplinary background in psychology, communication and linguistics. Her research interests include health communication, psycho-oncology, multilingualism in health, Indigenous health and health inequities. She has a particular focus on uncertainty in healthcare and how it shapes patient experiences and outcomes. Vanda uses qualitative and mixed-methods approaches in her research.

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Maja M. Olsson is a healthcare researcher with a clinical nursing background and international experience across Europe, Australia, and Asia. Her research spans a broad range of areas including health systems, health economics, chronic conditions, wound care, digital health education, quality of life, and palliative care, often through collaborative and interdisciplinary studies. She values research grounded in clinical practice and aims to support meaningful improvements in healthcare delivery and patient outcomes.

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Dr Kate Kalmaz (nee Zhaunerchyk) is a researcher whose work centres on the development and implementation of robust quantitative research designs. With a doctoral background from the University of Queensland Business School, she brings a multi-disciplinary perspective to statistical and data-driven inquiry. Her expertise lies in refining research frameworks and ensuring methodological integrity across diverse fields of study.

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Dr Renata F. Meuter (D.Phil., Oxon) is an Adjunct Professor at the Queensland University of Technology, Brisbane, Australia. Her research uses experimental (laboratory-based and quantitative) as well as qualitative approaches and mixed-method designs to understand language processing in multilingual/cultural individuals, and their communication in real world settings (such as during health consultations).

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Introduction

Bowel cancer is the third most commonly diagnosed cancer worldwide, accounting for over 1.9 million new cases and more than 900,000 deaths each year, and representing the second leading cause of cancer-related mortality (Bray et al., 2024). The incidence of bowel cancer in people younger than 50 is increasing worldwide, including Australia (Karuppannan et al., 2020; Olivo & Ratnayake, 2019; Waddell et al., 2023). Between 2000 and 2024, in Australia, the incidence of early-onset bowel cancer increased markedly among people aged 20–49, while rates declined among those aged 50 and older (Cancer Australia, 2025).Yet, until recently, Australia's National Bowel Cancer Screening Program invited only those aged 50-74.

Younger adults with bowel cancer face distinctive challenges. It is not uncommon that younger persons with bowel cancer are initially misdiagnosed and, at times, even dismissed by healthcare professionals as being too young to have this type of cancer (Araujo et al., 2020). Being diagnosed with bowel cancer as a younger person often provokes strong emotional reactions that may include distress, shock, fear that cancer may spread, and fear of complications and of having to deal with physical symptoms (Abelson et al., 2018). Compared with older patients, younger individuals experience unique emotional concerns because they are more likely to face advanced disease at diagnosis, disruptions to education or career development, concerns about fertility and family planning, and strain on intimate and social relationships (Ng et al., 2020; Vetter et al., 2022). These challenges are compounded by financial toxicity and a sense of being isolated from peers who are not facing serious illness at this stage of life (Vetter et al., 2022; Lee et al., 2025). Despite an increase in cases among younger patients (Waddell et al., 2023), little is known about the emotional landscape of younger adults' first-person narratives, how these emotions vary across the care pathway (pre-diagnosis, diagnosis, post-treatment), or how patterns differ by gender. Addressing this gap can clarify where communication breaks down and how clinicians' responses might be strengthened.

Narratives in digital health communication

The desire to access and to provide mutual support, and to increase the awareness of cancer in younger people, encourages online networking in this particular patient group (Araujo et al., 2020; Keim-Malpass et al., 2013; McCosker & Darcy, 2013; Namkoong et al., 2017). Blogging and sharing personal disease journeys online are increasingly common and provide insights into what to expect during the course of illness. These narratives, publicly available online, provide valuable data for understanding of the emotional impact of cancer on young people (Keim-Malpass et al., 2013; McCosker & Darcy, 2013). Sharing stories can also provide social and emotional support, with studies showing that empathic online messages improve psychological outcomes, including depression management (Bender et al., 2011; Han et al., 2019; Zhong et al., 2022).

Illness narratives[1], defined as autobiographical stories about experiences with illness and its consequences, are important for health communication because they illuminate how patients cope and what they need from care (Lucius-Hoene et al., 2018; Manning et al., 2017; Hinton et al., 2018). Narratives can persuade, educate, or elicit empathy (Lucius-Hoene et al., 2018), especially when listeners identify with the protagonist and are transported into the story world (Neil et al., 2019). Identification involves cognitive and affective alignment with the protagonist, and transportation deepens emotional engagement - processes that shape attitudes and behaviour (Ooms et al., 2019). In clinical encounters, emotions expressed in a patient's story influence professional responses: sadness, for example, is more likely than fear or anger to trigger empathy, although empathic reactions are often brief and quickly redirected to biomedical tasks (Sheldon et al., 2008; Kennifer et al., 2008; Pollak et al., 2007). Taken together, this evidence indicates that the extent to which health professionals identify with patient narratives influences their engagement and communicative behaviour. Accordingly, examining the emotional contours of bowel cancer narratives is integral to understanding clinician responses and to designing communication strategies that support compassionate, effective care.

A better understanding of patients' emotions may be especially important for younger patients with bowel cancer, for whom delays with doctor referrals mean the delayed diagnosis of bowel cancer (Taggarshe et al., 2013), potentially decreasing their survival chances. Narratives from this group can help health professionals to better understand their needs, including a more nuanced understanding of the emotional reality of female and male patients with bowel cancer. Research suggests that female cancer patients are more likely to express at least one negative emotion when treated by a female oncologist, creating opportunities for empathic responses (Pollak et al., 2007). While most patients experience understandable distress following a cancer diagnosis (Chambers et al., 2014), research indicates that women in online support groups express more negative emotions, particularly anger and sadness, whereas men are more likely to seek information than emotional support (Lieberman & Goldstein, 2006). Similarly, in studies of cancer narratives, nearly all women used emotional language, compared to around one quarter of men, who did not use any emotional expressions at all (Salander & Hamberg, 2005). The above findings highlight the importance of exploring how emotions are expressed and interpreted in online narratives of young patients affected by bowel cancer.

Therefore, this study aims to explore the emotional experiences of younger adults' lived experiences with bowel cancer as shared in their online illness narratives, to understand how these emotions shift across the care pathway and differ between genders, and to inform more empathetic and effective clinician–patient communication.

Methods

Approach

Illness narratives published online are valuable sources of patient-reported data, offering insights into how individuals make sense of illness and treatment. Using illness narratives for research naturally raises several methodological considerations, including ethical integrity, being aware that more digitally literate or motivated individuals may be over-represented, and carefully reflecting on the reliability and validity. In this study, the specific characteristics of the empirical material have shaped the analysis and interpretation of the findings.

Unlike interactive blogs or social media platforms, the narratives analysed here are drawn from an organisational platform where patients submit a single story without opportunities for dialogue, commentary, or ongoing interaction. Narratives published on the Never2Young webpage (Bowel Cancer Australia, n.d.) are submitted directly by patients to Bowel Cancer Australia. They are then made publicly available following organisational review and consent procedures.

Additionally, noninteractive narratives typically include the patient journey over time (Lamprell et al., 2025), which could influence both style and emotional expression. To address these challenges, we adopted a mixed-methods approach. By combining sentiment analysis with thematic analysis, we were able to capture both the contextual richness of patient narratives and the systematic patterns of emotional expression that emerge across a larger dataset.

Sentiment analysis

Social networking has emerged as a powerful platform for individuals to express their emotions to the world (Nandwani & Verma, 2021), and with the growing use of online platforms, people increasingly share their emotional experiences through online narratives. To comprehend human psychology, this data must be processed as rapidly as it is generated, which can be accomplished through sentiment analysis (Nandwani & Verma, 2021). Sentiment analysis enables a systematic exploration of the polarity and intensity of emotions embedded in written stories, enabling the identification of patterns that might not be evident through qualitative interpretation alone.

Sentiment analysis has become a widely used tool in health communication research. Clark et al. (2018) analysed emotions on Twitter, while Cabling et al. (2018) examined emotions and opinions in a breast cancer online support group users, finding that more active users were significantly more positive than less active ones. Similarly, Pérez-Pérez et al. (2019) used sentiment analysis to examine tweets from the bowel disease community, identifying bowel diseases and symptoms were the categories with the highest number of mentions in negative tweets. Liu (2020) defines emotion as “a mental state that arises spontaneously rather than through conscious effort and is often accompanied by physiological changes” (p. 36). Examples of emotions include “joy”, “anger”, and “surprise”. However, the term ‘sentiment’ is used to express the polarity of emotion, such as positive, negative, or neutral.

Thematic analysis

While sentiment analysis reveals important patterns in emotional expression, it does not allow the examination of the emotions. To understand the broader context, such as delays in diagnosis, interactions with health professionals, and coping after treatment, thematic analysis was used to interpret meaning, identify recurring themes, and situate emotional expressions within patients’ lived experiences. Unlike other qualitative methods, thematic analysis is not bound to a particular theoretical framework and is well positioned to report patients’ experiences and reality (Braun and Clarke, 2013). This flexibility makes it an appropriate complement to the more structured lens of sentiment analysis.

By combining these two methods, this study offers a more comprehensive understanding of the narratives of younger bowel cancer patients than either approach could achieve independently. The mixed-method design integrates the systematic insights of sentiment analysis with the contextual depth of thematic analysis. Using this framework, the study analysed online narratives shared by younger bowel cancer patients on Bowel Cancer Australia's website. The analysis focused on three key areas: the dominant sentiments and emotions expressed in these narratives, gender differences in emotional expression between male and female narrators, and the lived experiences of patients across pre-diagnosis, diagnosis, and post-diagnosis phases.

Ethics

The study was approved by the Queensland University of Technology Human Ethics Research Committee (No. 4161). Patients gave consent to Bowel Cancer Australia to publish their stories on its website, and Bowel Cancer Australia granted permission to use the published data for this study.

Data collection

The data were extracted from narratives published on from Bowel Cancer Australia's website (Bowel Cancer Australia, n.d.). Bowel Cancer Australia, a national charity, offers a platform for cancer patients and their families to share their experiences. For this study, all narratives available as of the 15th of March 2021 on the Never2Young webpage (dedicated to patients under the age of 50)[2] were retrieved (n = 61). Because the focus was on an exploration of the emotions of younger bowel cancer patients as expressed by them personally, narratives about deceased patients written by their relatives were excluded (n = 13). Of the remaining 48 narratives, most were written by women (62.5%). The narrators' ages ranged from 21 to 48 (women=[25, 48]; men = [21, 46]).

Data cleaning and sentiment analysis

Special characters were manually replaced with apostrophes (e.g., wasnÕt was corrected to wasn't). Next, the narratives were imported into the text mining package "tm" in R (Theußl et al., 2012). The resulting text corpus was cleaned by removing extra spaces, numbers, punctuation, and stop words, and all text was converted to lowercase. The text was then stemmed using Porter's stemming algorithm (Willett, 2006)[3]. A term-document matrix was constructed to enable the quantitative analysis of the terms (n = 75) presented in the word cloud. The sentiment analysis was carried out in R, using the package SentimentR based on the Opinion Lexicon by Hu and Liu (2004). Manual checks revealed inconsistencies and misinterpretations of the corpus text in terms of the sentiment orientation of sentences. These errors arose because, firstly, Hu and Liu (2004) and Liu (2020) used a lexicon-based algorithm for aspect-level sentiment classification, which enables the determination of the sentiment orientation of the whole sentence (positive or negative), potentially generating errors for longer sentences. Secondly, there were some context-related issues that arose because the same word, depending on the context in which it is used, may express different sentiments. There is currently no computer-based method for distinguishing context-dependent sentiments (Liu, 2020). For example, in the following sentence "I will end by expressing my gratitude for the Bowel Cancer Australia website and many other online forums in the Bowel cancer space", a negative sentiment was detected because of the words 'bowel cancer', however the sentiment of this sentence is clearly positive; the words 'bowel cancer' are associated with "gratitude" and with the name of the organization and online forums supporting those with the disease. Hence, sentiment value may change depending on context. In a disturbing example, Saif (2017) noted that most existing sentiment analysis methods fail to detect the negative sentiment of the tweet "#Syria. Execution continues with smile!:(#ISIS" (p.92) because of the positive word "smile".

Given the potential for errors and to ensure that no misleading or erroneous sentiments were assigned, a manual revision and corrections were undertaken by two of the authors (V.N. and M.M.O.). Annotations were made independently by reading sentences in every story line by line and showed a high agreement between the authors. The goal was to interpret the underlying meaning and the emotions expressed, and to identify positive or negative sentiments related to the context. Positive (+1) or negative (-1) values were assigned to each word collocation expressing an emotion. The word collocations (positive collocations, n = 52; negative collocations, n = 37) were then added to the Hu and Liu's (2004) lexicon. The sentiment was computed by summing the emotional valence scores of each word collocation, with -1 being the negative emotion and +1 being the positive emotion. Emotional valence is a quantitative indicator of affective/emotional state (Mammen et al., 2019).

We used a dictionary of sentiments and emotions from the Syuzhet package in R (Jockers, 2015) and the NRC Word Emotion Association Lexicon (EmoLex) dictionary (Mohammad & Turney, 2013) to calculate the 8 emotions' scores from the Plutchik's wheel of emotions (sadness, trust, anger, fear, joy, anticipation, disgust, and surprise) and their corresponding valence, as well as positive and negative sentiments. Some emotions can only be associated with one emotional valence (for example, joy is always associated with positive valence). In contrast, other emotions may be associated with differing valence (some kinds of surprises are associated with positive valence, while others are associated with negative valence). Consequently, emotion classification can benefit from using valence features (Mohammad, 2016).

Thematic analysis

Data was analysed using reflexive thematic analysis. We followed Braun and Clarke six-step process (Braun & Clarke, 2022), which provides a theoretically flexible approach to analysing qualitative data. These six steps include: (1) familiarisation with the data; generation of initial codes; (3) searching for themes; (4) reviewing themes; (5) defining and naming themes, and (6) producing the report. One of the authors (V.N.) familiarised themselves with the data. Second, they systematically coded the data (Braun & Clarke, 2022) from an inductive perspective and identified both semantic and latent meanings. The second author (N.K.) provided feedback on an early subset of this coding (e.g., ensuring consistency and suggesting alternative codes) before V.N.

completed full coding. Next, V.N. developed initial themes from the codes (Phase 3). The authors then met to discuss the proposed themes (e.g., theme distinctiveness, relevance to the research questions, link to the quantitative findings) after which V.N. revised the themes (Phases 4 and 5). In the final phase, the authors collaboratively reviewed and refined the themes and produced the report.

The analysis was conducted from a critical realist perspective, which asserts that while reality exists (e.g., psychological concepts such as beliefs and emotions are real), our comprehension of it is influenced by the research context, as well as the interpretations and subjectivity of the researchers (Braun & Clarke, 2022). The analysis was performed by the first author (V.N.) who has a PhD in Psychology and extensive experience in qualitative health research and the second author (N.K.), who has extensive experience in qualitative health research.

Results

The total aggregated word count of the narratives was 19,941 (mean word count/narrative = 894). In addition to writing most of the narratives, women also wrote longer narratives (mean word count/narrative = 951) and, overall, accounted for 66% of the total word count across all narratives (n = 13,194). Men not only contributed fewer narratives (n = 18), their narratives were also shorter (mean word count/narrative = 798). The men's narratives accounted for 34% of the total word count (n = 6,747).

Quantitative findings

Most dominant words across the stories

As shown in Figure 1, high-frequency terms cluster around three domains: cancer-specific (cancer and bowel), clinical care (doctor, surgery), and time markers (day, week, and time). Words signalling experience and recovery are also among high-frequency terms (feel and back). Cancer was the top term for both women (n = 218) and men (n = 97), but the second-ranked term differed - bowel for women (n = 152) and day for men (n = 78). We treat high-frequency function verbs such as 'get' as non-substantive for interpretation; emphasis is placed on clinical and temporal tokens (doctor, surgery; day, week, time).

For the purposes of this analysis, it is important to note that all narratives followed chronological order: time before receiving bowel cancer diagnosis, diagnosis, treatment, and post-treatment period. Personal illness narratives often rely on temporal ordering, and frequent references to days, weeks, or months may therefore reflect conventions for this type of narratives. In this study, we do not interpret temporal salience as a direct proxy for diagnostic delay. Rather, its significance emerges through alignment with the thematic analysis, where narrators explicitly describe long waits for colonoscopy, repeated presentations, and extended periods of uncertainty.

Figure 1. *The 10 most frequently used words in the bowel cancer stories.*

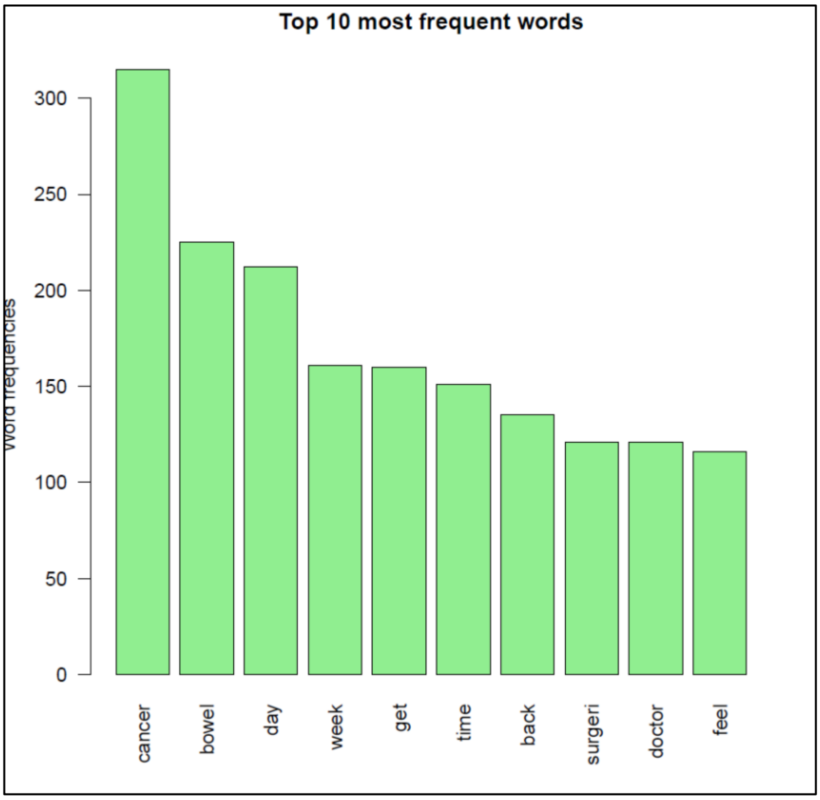
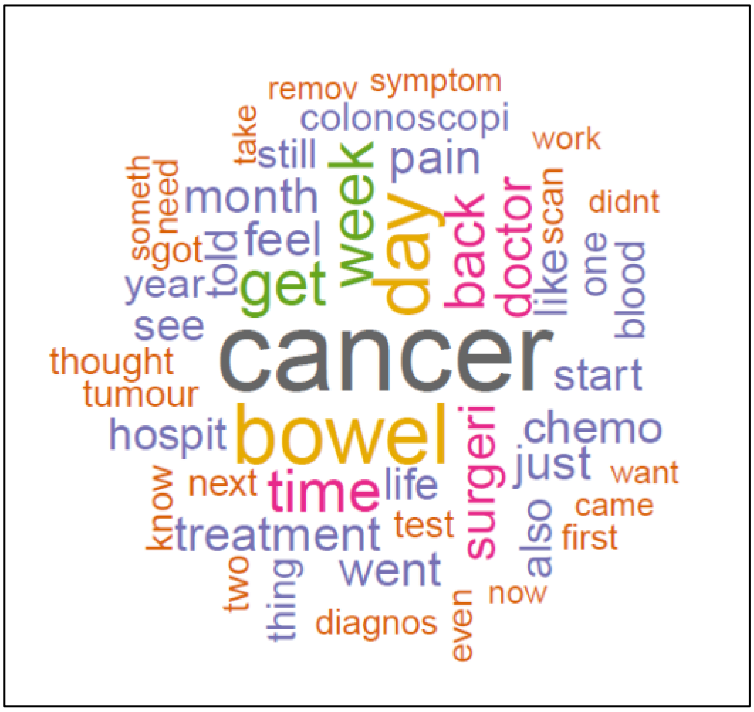


Figure 2, the word cloud, complements Figure 1 by providing a visual overview of the broader vocabulary: in the word cloud, a larger font size indicates higher frequency. Beyond the top ten, frequently used terms relate to the existence and progression of bowel cancer, its investigation and treatment, and clinical context (for example, symptom, chemo, blood, diagnosis, scan, treatment, colonoscopy, surgery, remove, hospital, and doctor).

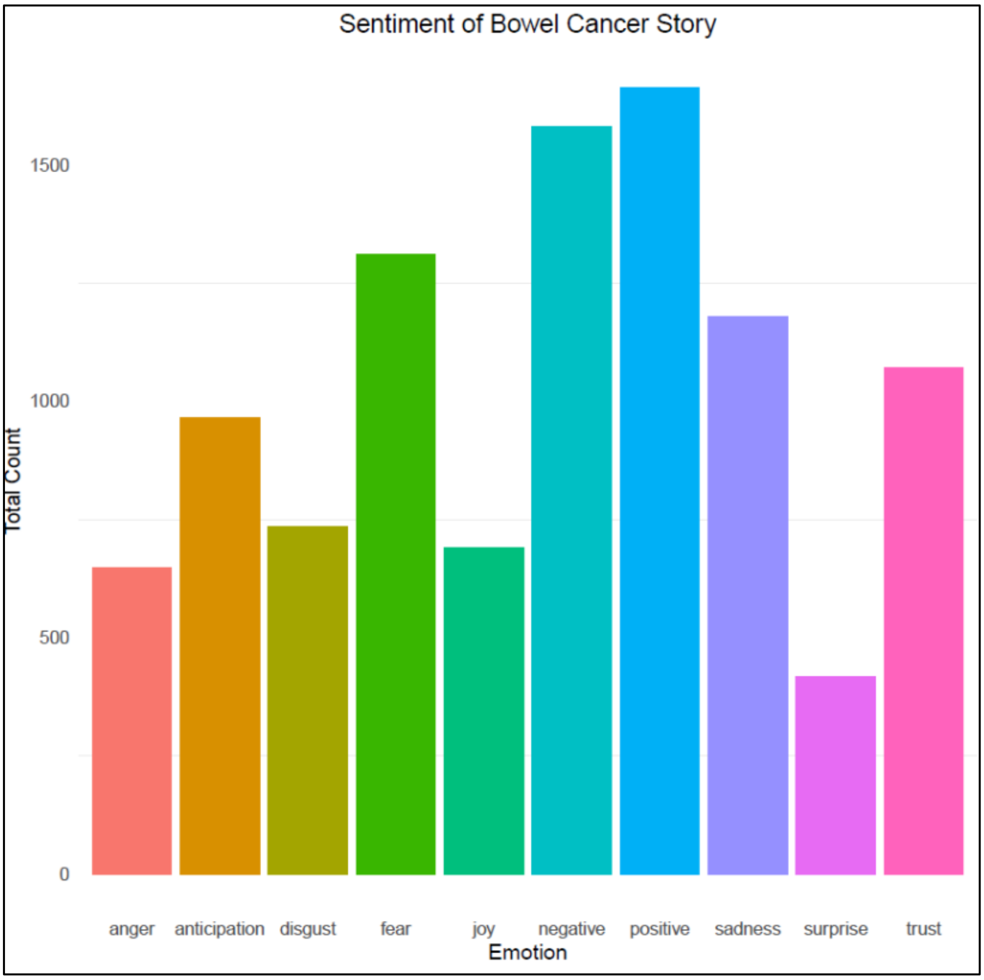
Figure 2. *Word cloud based on the most dominant words in the bowel cancer stories.*



Results of emotion distribution in bowel cancer stories

As shown in Figure 3, the patients' narratives included both general sentiment scores and specific emotion scores related to bowel cancer. Positive and negative sentiment represent the overall valence of the narratives, while the eight emotions capture more fine-grained categories within each polarity. For example, "fear" and "sadness" typically contribute to negative sentiment, while "joy" and "trust" contribute to positive sentiment. In the analysed narratives, overall sentiment leaned slightly positive (positive sentiment =1,663 vs. negative sentiment = 1,580). Among the specific emotions: "fear" (n=1,310), "sadness" (n=1,180), and "trust" (n=1,070) - were the most common ones, while "anger" (n=648) and "surprise" (n=417) were the least frequent ones.

Figure 3. *Emotion and sentiment scores in the bowel cancer stories for both genders.*



There was a difference in the emotion and sentiment scores in the narratives written by women and men. Figure 4 shows the emotion and sentiment scores in the stories written by women. In terms of overall sentiment, female-written narratives were only marginally more negative. Specifically, negative sentiment marginally prevailed over positive and equalled 50.1% (total count = 1087), while positive sentiment accounts for 49.9%. Within this overall valence, the most frequently expressed emotions were "fear" (n= 906), "sadness" (n=816), and "trust" (n=717). Although negative-valence emotions such as "fear" and "sadness" were common, they were closely followed by the positive-valence emotion of "trust". "Anger" (n = 211) and "surprise" (n = 135), were the least frequent emotions in the male narratives. This pattern was consistent with the narratives written by women ("anger", n = 437 and "surprise", n = 282).

Figure 4. *Emotion and sentiment scores among females.*

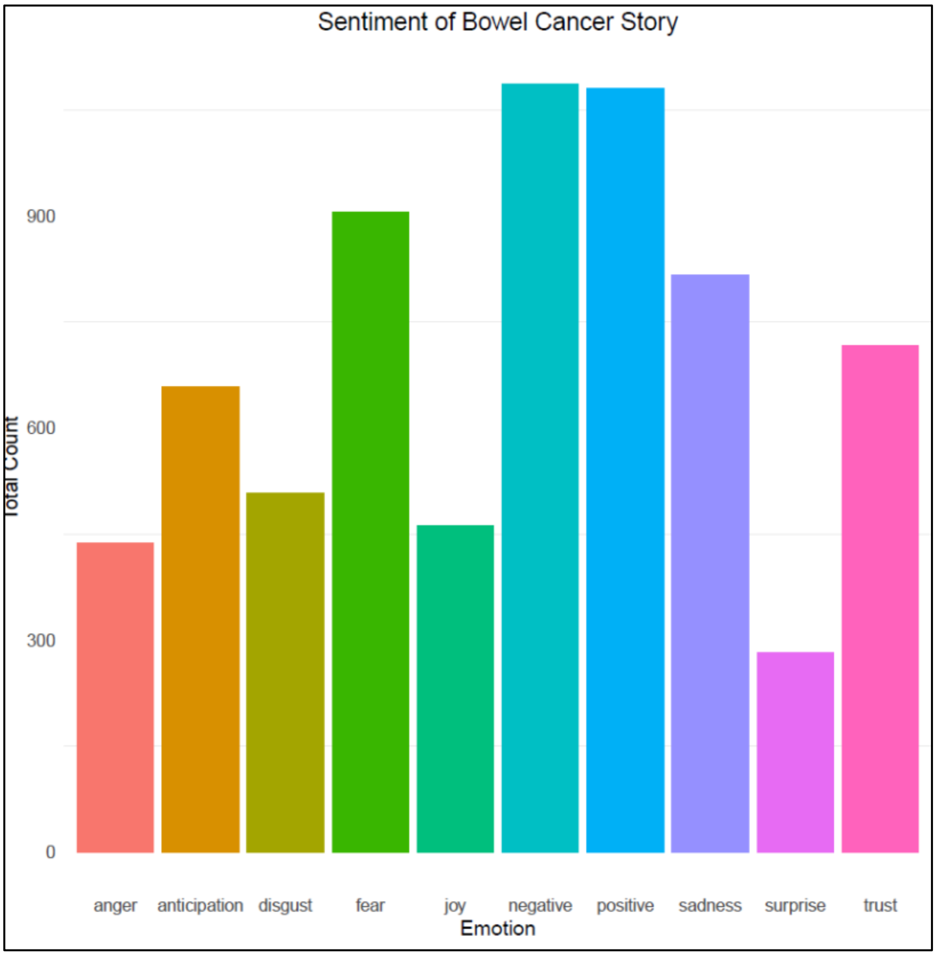
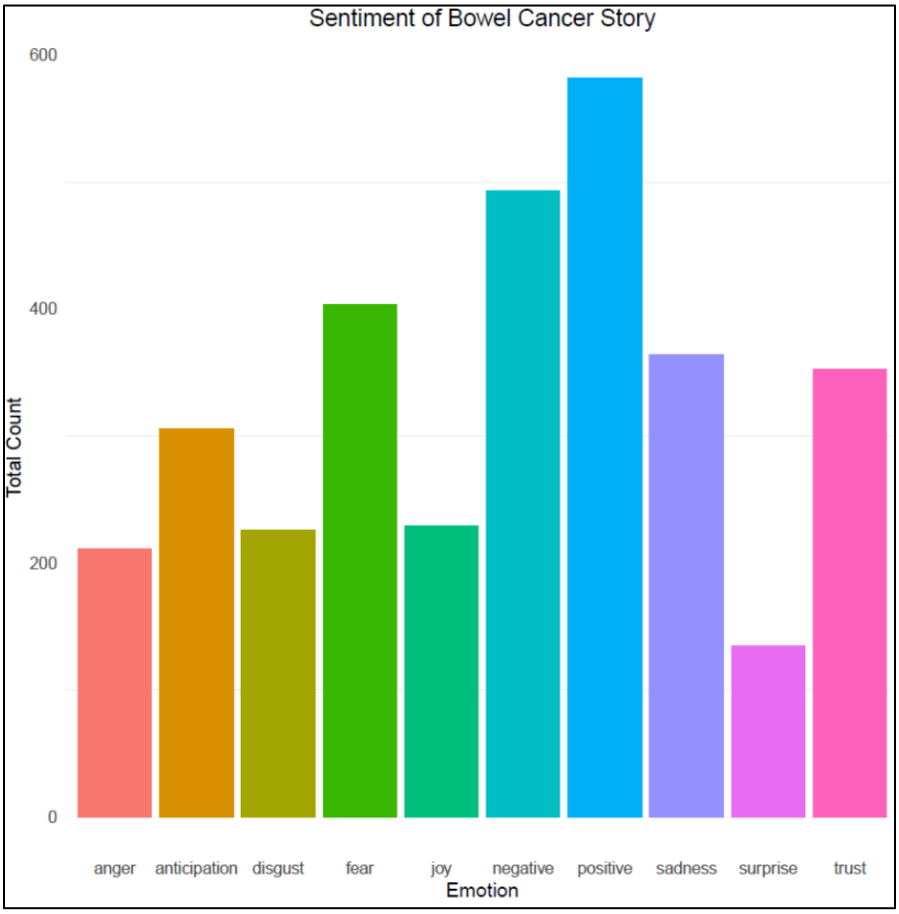


Figure 5 shows emotion and sentiment scores in the stories written by men. Unlike in the female-written stories, the proportion of "positive" sentiment in the male-written narratives is dominant and equals 54% (total count = 582). "Negative" sentiment accounts for 46% of the sentiment score (total count = 493). Just like in the female narratives, the top three emotions that prevail in male narratives are "fear" (n = 404), "sadness" (n = 364), and "trust" (n = 354).

Figure 5. *Emotion and sentiment scores among males.*

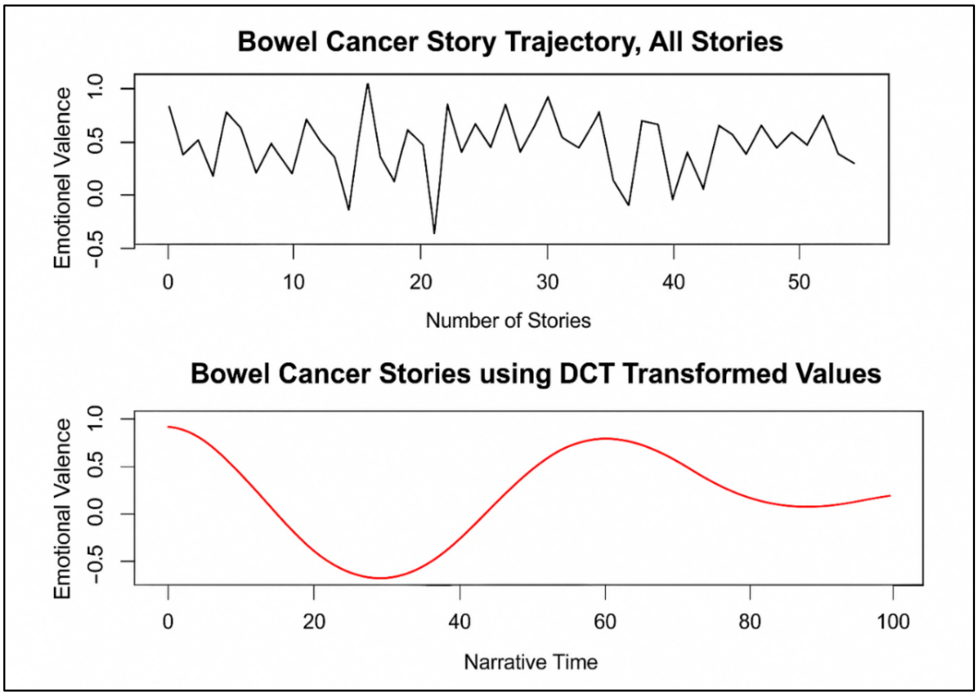


The overall distribution of the emotional sentiments among genders is relatively similar. While women expressed more than double the count for the emotion sentiments compared to men, such as “fear”, “sadness”, and “trust”, they also contributed nearly twice as many words compared to men (1.95 times; women=13,194 words; men=6,747 words).

Emotional valence

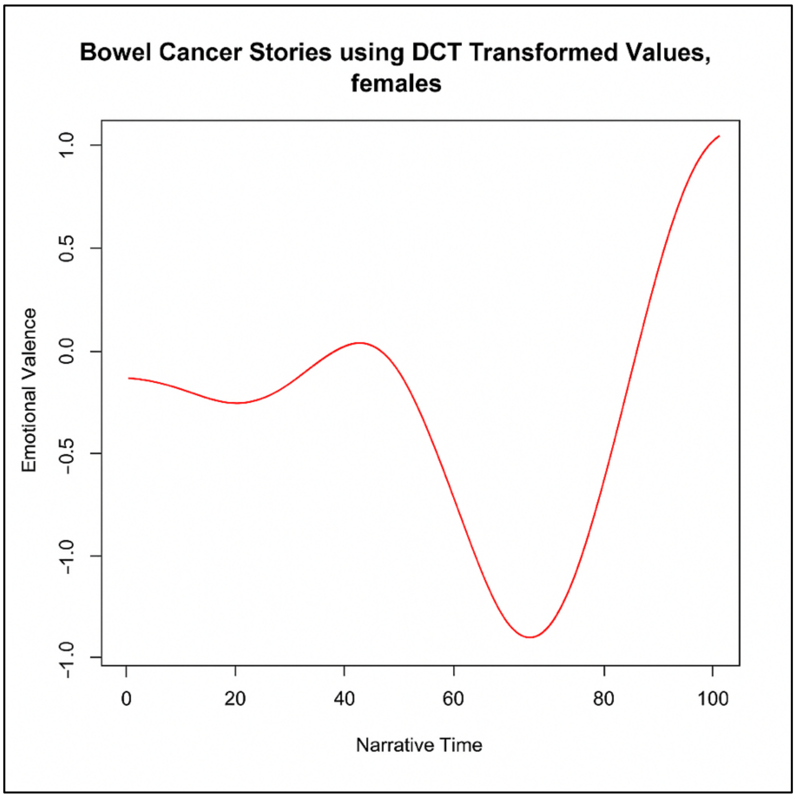
In the narratives, emotional valence shifted between positive and negative emotions, both across different stories and within individual narratives. This means that a single account could contain negative emotions such as fear or sadness alongside positive expressions of trust or gratitude, reflecting the emotionally complex nature of these stories. These fluctuations can be seen in the simple plot and the discrete cosine transformation (DCT), where the x-axis represents the number of narratives, and the y-axis shows the emotional valence (see Figure 6). This duality highlights the need to interpret sentiment scores together with thematic analysis.

Figure 6. *Emotional valence for all bowel cancer stories.*



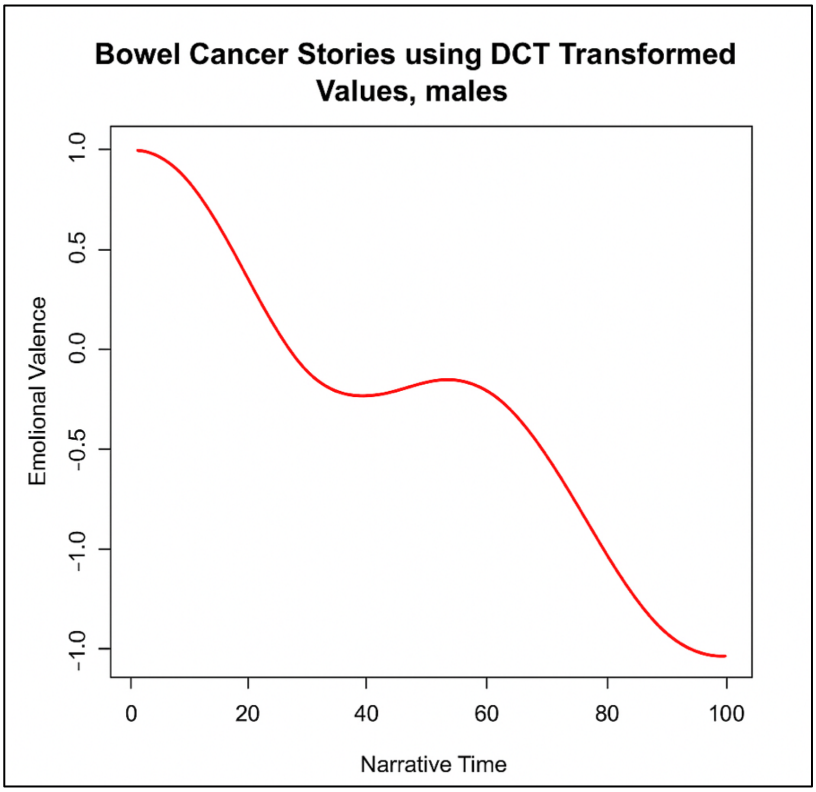
Emotional valence curves showed that the women's narratives were much more volatile with more pronounced oscillations between negative and positive valence (see Figure 7). First narrative segments (i.e., up to the story midpoint) showed overall neutrality, with marginal dips into negative effect, corresponding to the provision of the narrative`s context and to initial accounts of symptom appraisal, dismissal, and uncertainty. After the midpoint, we observe a stark shift in emotional valence with a pronounced, rapid negative drop followed by a strong rebound into positive valence. This pattern suggests that female participants articulated a wider emotional range and were more likely to integrate distress with expressions of trust, gratitude, or meaning-making as the narrative progressed.

Figure 7. *Emotional valence - females.*



In contrast, emotional valence in the men’s narratives had a pronounced downward direction (i.e., moving from positive to negative emotion). As shown in Figure 8, the males` stories tend to begin with a positive effect that gradually fades to a neutral point around the middle of the narrative. In contrast, the second half of the stories is dominated by a negative valence that persists throughout. This suggests a tendency toward delayed or restrained emotional expression, with fewer narrative shifts toward positive reframing or resolution. Figures 7 and 8 highlight not differences in disease trajectory, but variations in how emotional experience is sequenced, expressed, and resolved within illness narratives among female and male young bowel cancer patients.

Figure 8. *Emotional valence – males.*



Qualitative findings

The data analysis identified two overarching themes: (1) Uncertainty of bowel cancer and emotional impact and (2) Embracing self-care. An overview of the subthemes, with relevant quotes, is presented below.

Uncertainty of bowel cancer and emotional impact

The first theme highlights challenges faced by patients before and after the bowel cancer diagnosis due to medical uncertainty and barriers to healthcare access. During this time, the narrators experienced a range of different emotions, primarily characterised by negativity.

Being too young

Many young patients affected by bowel cancer felt that something was not right prior to their diagnosis; however, they ignored some concerning symptoms because they thought they were too young to have cancer. Some general practitioners (GPs) also ignored some of the symptoms and/or family history of bowel cancer and reassured patients that they were too young to have this type of cancer. Many narrators had multiple appointments with their doctors or presented to the emergency department with persistent symptoms before being diagnosed with bowel cancer. Age bias was one of the barriers to timely access to healthcare.

> I noticed I was bloating, and I became quite flatulent. I continued to follow up with my GP over a 6-month period and his diagnosis was IBS. I heeded his advice but still found no relief. My symptoms were getting worse and I was living on pain relief daily. My father had been diagnosed with bowel cancer two years earlier. My GP was aware of his diagnosis and treatment but when I asked about whether I should have some surveillance he didn't think it was necessary. I was getting desperate. The pain was ruling every second of every day. Again, I asked for a referral to a GI and finally he believed it might be worth looking into. (Female patient, no.14)

Long waiting times for colonoscopy

The subtheme of long waiting times for colonoscopy is interconnected with the subtheme of being too young to have bowel cancer. Several narrators reported experiencing long waiting times for colonoscopy procedures in public hospitals. For example, one patient had to wait 8 months. Another patient was advised that they would need to wait several months, even though their GP had requested that the colonoscopy be performed within 30 days. For some patients, this delay, along with the uncertainty of diagnosis, has potentially resulted in being diagnosed with a more advanced stage of bowel cancer or even incurable cancer. Correspondingly, valence plots show dips into negative area around pre-diagnosis episodes and waiting periods (Figures 6–8), underscoring the emotional cost of delay captured in these accounts. Reassuringly, all narrators reported positive experiences with health professionals after diagnosis. This aligns with the quantitative data (Figures 3-5), which show rising “trust” even as “sadness” and “fear” persist, mirroring shifts toward relief, gratitude, and reliance on health professionals and family.

Uncertainty of bowel cancer diagnosis and care

The subtheme of being too young was interconnected with the subtheme of medical uncertainty. Narrators reported a lot of uncertainty prior being diagnosed with bowel cancer. For some of the narrators, this uncertainty was caused by being previously diagnosed with another type of cancer or another serious disease. However, several narrators, otherwise healthy, experienced a range of alarming symptoms such as abdominal pain, vomitting, and bloating, which were overlooked by their GPs. Narrators often used emotionally charged words when describing their struggles with being diagnosed.

> I had been a busy few months and I kept putting off going to the doctor. Eventually after Christmas I went and got a referral for a colonoscopy. I booked in my colonoscopy and had to wait four weeks. A week before my colonoscopy I found out that I was pregnant with our third child. I called the endoscopy clinic and they told me unfortunately they were not able to give me the colonoscopy. I asked what I should do and they said to go see a Specialist. So, I booked an appointment with the recommended gastroenterologist. I had to wait six weeks to get in. When I went there, I was told it was likely to be haemorrhoids and to come back in six weeks if it hadn't stopped. I was unhappy about this and I went to several private gastroenterologists. All of them told me it was probably haemorrhoids or colitis and that they couldn't do anything for me while I was pregnant. Eventually a friend's brother who is a gastroenterologist took me seriously and got me in quickly for a flexible sigmoidoscopy. I went for that at 12 weeks pregnant. They were unable to go up too far and did not see anything. I left confused and frustrated. (Female patient, no.12).

Additionally, the narrators faced significant uncertainty after the diagnosis and treatment. The main concerns in both male and female participants included living with a colostomy bag, fears of cancer recurrence, and general concerns about the future. Importantly, participants were trying to reduce the burden of uncertainty and negativity by trying to find positive sides of their cancer experience.

> I tried to turn this negative around by naming the stoma 'Peter' and seeing it for what it is – a part of the fight against cancer. (Male patient, no.27).

Emotional impact

In addition to medical uncertainty, the narrators had some unmet needs which impacted their wellbeing. Specifically, some of the narrators reported experiencing financial strain. They expressed their frustration with the fact that for some categories of cancer patients there was no government support available.

> I found it unbelievable that since I had casual/freelance work at the time of the diagnosis I was not entitled to sick leave government payments (only available to people with permanent contracts) and had to go on unemployment benefits partaking in the unnecessary admin and stresses while I 'looked for work'. (Female patient, no.19).

Several narrators, especially females with younger children, were also worried about the future. For example, one of the narrators was concerned that she would not be able to see her daughter grow and attend her wedding. Overall, the bowel cancer diagnosis had an emotional toll on all the narrators. They reported experiencing the whole range of emotions, including fear, nervousness, shock, distress, and hope. Often, these emotions were interconnected, prompting several narrators to compare them to a roller coaster ride. This aligns with the dominance of “fear” and “sadness” in the sentiment analysis and the marginally more negative overall valence in women’s narratives (Figures 3–4), indicating that uncertainty is the principal driver of negative affect early in the journey.

> It has been a real roller coaster of a ride. (Female narrator, no 23).
>
> It has been a rollercoaster few months and I am still on the ride, but I am taking each day as it comes and remain confident and positive that I will be cured! (Male narrator, no.42).

Embracing self-care

Physical and psychological repercussions post-diagnosis were a significant focus in the majority of the narratives, revealing narrators’ struggles with emotional aftermath and anxiety. Nevertheless, young Australians affected by bowel cancer were trying to overcome these struggles by using different coping strategies, which helped with their physical and mental health.

Self-care: Physical health

While for many narrators, during treatment, their primary focus was on survival, after the treatment was finished, they had to deal with a daunting post-cancer reality. Many narrators reported that the cancer experience made them stronger and more resilient. One of the female patients noted that it has taught her “ the power of perspective”.

Self-care played an important role for all the narrators. Examples of physical self-care included having an active lifestyle, exercising, keeping a strict diet, and generally eating healthy. These strategies correspond to the positive elements in the sentiment profile, especially “trust”, and to local peaks in positive valence later in the narratives (Figures 3 and 6–8).

Self-care: Mental health

Physical health was often interconnected with mental health. Some narrators reported using psychological or counselling services which they found to be helpful to cope with the new reality, others started using spiritual practices such as religion and meditation. Other strategies included volunteering and socialising with family and friends. These reflections are consistent with trust appearing among the top emotions (Figures 3–5), often co-occurring with gratitude in post-treatment passages.

> And while I am not an overly religious person I chat to my local priest and sometimes sit in the church which gives me some solitude that is difficult to find living in the inner city. It has a little park with benches surrounded by lemon-scented gums that can be filled with rainbow lorikeets and other birds – I love the birds - they make me grateful that despite everything I am still here. (Male narrator no.27).
>
> I was told to stay active throughout the treatment cycle. As difficult as it was, I went for daily walks with my mum or with my husband or with my in-laws. I discovered meditation and used it as a step to sleep. (Female narrator no.47).

Discussion

Taken together, the quantitative and qualitative findings converge on a coherent story: “fear” and “sadness” cluster around pre-diagnosis uncertainty and delay; “trust” increases as diagnosis and treatment clarify next steps; and time is a salient axis across phases, echoed both in language use (day, week, time, and back) and in narrators’ descriptions of waiting. The qualitative subthemes explain why these distributional patterns arise, while the sentiment results show that they are not idiosyncratic to single cases.

Time emerged as a convergent theme across the patient stories. In the sentiment analysis, time-related words were highly frequent. Four of the top ten words were day, week, time, and back, with further time indicators in the word cloud (now, month, year, and timing). We note that all narratives were written in chronological order and the prominence of temporal markers may partly reflect this narrative structure.

Qualitative analysis clarified how time was experienced and perceived by participants who described long waits for colonoscopy and protracted diagnostic intervals. This was consistent with mixed-methods and qualitative studies reporting perceived barriers, referral challenges and delays for early-onset bowel cancer among younger adults in the UK, Australia and New Zealand, as well as GP-reported difficulties in recognising and expediting referrals (Lamprell et al., 2023; Owais et al., 2025). Together, these findings may indicate that time including waiting for investigation, progressing through pathways, and living with uncertainty,- operates both as a structural feature of care and as an affective driver in patients’ accounts.

Prior studies underscore how temporal experience shapes both emotions and care processes (Beddard et al., 2025; Hannum & Rubinstein, 2015). Hannum and Rubinstein (2015) show that patients construe time as elastic—compressed, suspended, or foreshortened—with meanings tied to illness trajectory and age, helping to explain younger adults' coexisting trust, sadness and fear as they move through care (Hannum & Rubinstein, 2015). The growing literature on "time toxicity" highlights the cumulative time burdens of appointments, late diagnosis, surgeries and recovery as a contributor to distress and decision-making - another pathway through which temporal pressures may sustain negative affect even as trust rebuilds post-diagnosis (Beddard et al., 2025; Pujadas Botey et al., 2024).

Consistent with this temporal framing, our emotion analysis revealed that the emotion sentiments of "fear" and "sadness" were frequently voiced in the narratives of younger patients suffering from bowel cancer. Our qualitative findings showed, that prior to diagnosis, many narrators faced a lot of uncertainty, which caused feelings of fear and insecurity. This finding aligns with the findings of a recent qualitative study conducted in the Netherlands, which found that bowel cancer patients experienced primarily negative emotions during the process of receiving their diagnosis (van Driel et al., 2025). Similarly, an earlier study found that cancer patients experience interconnected emotions of fear and sadness as well as loneliness, shame, frustration, denial, and insecurity (Brandes et al., 2017).

In the quantitative part of our study, the emotion sentiments of fear and sadness were followed by the emotion of trust. A cancer diagnosis may shape a patient's perception of trust because of its life-threatening nature, causing cancer patients to experience a need to trust their doctors (Hillen et al., 2012). While results of the qualitative analysis revealed that some narrators experienced negative emotions towards the healthcare system during the diagnosis process, once the diagnosis was made, the narrators had mostly positive experiences with health professionals. The emotion of "trust" in the narratives may also be related to their trust in family and/or friends. Results of the thematic analysis revealed that the presence of family and friends was an essential part of a self-care process for many narrators.

Our findings revealed only marginal prevalence of a "negative" sentiment in narratives written by women (i.e., no specific sentiment dominance), while narratives written by men mostly conveyed a "positive" sentiment. In contrast, the qualitative analysis of the common themes did not reveal any differences between the narratives written by male and female patients. However, other research found significant gender differences in self-reported concerns of Swiss patients with inflammatory bowel diseases, with women being more concerned by symptoms, personal concerns such as intimacy, disease-related disabilities, and burden of going to medical consultations (Pittet et al., 2017). Further research should focus on gender differences in emotions experienced specifically by bowel cancer patients, considering that there is some evidence that the intensity of emotions may depend on the cancer type. For example, lung cancer patients had more negative emotions than other types of cancer (Niu et al., 2013), suggesting that bowel cancer patients' emotions can differ from emotions experienced by patients with other types of cancer.

It is imperative to acknowledge that cultural and gender conventions may shape the extent to which emotions are expressed. For example, men may have similar emotional needs to women but feel constrained in expressing them due to prevailing norms (Gough et al., 2021; Zakowski et al., 2003). While such considerations were beyond the scope of this study, future research could explore how cultural factors interact with gender in influencing emotional expression among bowel cancer patients.

Limitations

The study has some limitations. First, while Bowel Cancer Australia's website provides meaningful and insightful personal stories, drawing from a single platform may mean that only certain perspectives have been captured. As these narratives are written retrospectively and may be influenced by individual storytelling choices or the website's editorial process, they might reflect particular ways of making sense of one's experience rather than the full range of perspectives. It is therefore important to acknowledge that this sample reflects specific voices within the broader community of younger adults living with bowel cancer in Australia, rather than representing all experiences.

Second, the relatively small number of patients (n=61; 19,941 words) may limit the generalisability of our findings. Prior studies have successfully applied sentiment analysis to small health datasets. For example, sentiment analysis was applied to patient comments on ambulatory cancer care and interviews with health professionals (Golz et al., 2022; Vehviläinen-Julkunen et al., 2021).

Finally, although this is a mixed-methods study, the evidence comes from online narratives rather than observed clinical encounters. The communication practices we identify, therefore, need to be tested in real-world consultations before causal effects on trust, fear, or sadness can be inferred. Future research should validate these signals in interactive settings, link narrative phases to concrete timing milestones (for example, time to colonoscopy or first specialist review), and prospectively trial practice changes such as uncertainty scripts and timeline mapping.

Conclusion

This mixed-methods study shows that emotions in younger adults' bowel cancer narratives are patterned across the care pathway: fear and sadness concentrate before diagnosis. At the same time, trust increases after diagnosis, yet often coexists with persistent negative impacts. Qualitative analysis explains these trajectories through delays and uncertainty pre-diagnosis and clearer contact and support post-diagnosis, with family and self-care accompanying later positive turns.

Time emerged as a central mechanism linking care processes and emotion: waiting, pacing through investigations and treatment, and living with temporal uncertainty. Together, these insights should translate into practical actions for health professionals. These may include explicit validation and safety-netting before diagnosis, a timeline roadmap paired with emotionally safe communication that is sensitive to gender-patterned expression.

Declarations

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Author contributions

All authors contributed to the conceptualization of the project, its methodology, analysis, as well as the writing. RM provided project administration and supervision, and VN designed the project. VN, NK, and MMO were responsible for the introduction. VN and NK conducted thematic analysis. KK conducted sentiment analysis. VN was responsible for the original analyses and discussion/conclusion.

Conflict of interests

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Notes

1) In this study, we use the term “narratives” descriptively to refer to first-person accounts published by patients about their experiences with bowel cancer. We recognise that this differs from “narrative analysis” in the technical sense, which would examine the temporal organisation, tellership, identity work, and broader master narratives in illness stories. Our analytic strategy instead focuses on content and emotional expression across a large dataset, combining sentiment analysis and thematic analysis to address the research questions.
2) We focus on younger adults with bowel cancer, here defined as 21–48, aligning with the Never2Young stream of Bowel Cancer Australia to preserve the ecological validity of the source material; we acknowledge AYA definitions often cap at 39 and report age-banded descriptives accordingly.
3) Some examples of text-stemming transformations include the word *volume* being transformed to *volum*, and *colonoscopy* being transformed to *colonoscopi*.

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Appendix

Table 1. *Examples of how the 10 most dominant words were used in the bowel cancer stories.*

Word	Example
Cancer	*He was definite that **cancer** was virtually impossible. (Story 3, female)*
Bowel	*I thought it was just my quirky **bowel** which I had checked five years earlier after experiencing blood in my stools. (Story 26, male)*
Day	*The third **day** after chemo was when I began to feel quite ordinary, the chemo hit me like a freight train and I started to tick off most of the side effects from the booklet, including the ones above that seemed to contradict each other. (Story 8, male)*
Week	*I was diagnosed with colorectal cancer a **week** before Christmas 2018. (Story 28, female)*
Get	*Now I'm a couple months post chemo and I am working hard to **get** my body and mind back into shape. (Story 8, male)*
Time	*I was finally reunited with my baby after nine days and during my **time** in hospital she had been moved to another hospital. (Story 11, female)*
Back	*The results came **back**, and it was cancer. (Story 3, female)*
Surgery	*In Feb 2019, 6 weeks after my **surgery**, I began chemo which I would receive weekly through IV for 30 rounds. (Story 2, female)*
Doctor	*I vaguely remember the **doctor** coming to see me saying he was happy with the surgery and it went well. (Story 20, female)*
Feel	*My advice to everyone would be to not wait to seek medical advice, listen to your body and the symptoms you are experiencing and if your stomach just doesn't **feel** right ask for a colonoscopy! (Story 31, female)*

QUALITATIVE HEALTH COMMUNICATION

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