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Harnessing Social Media to Develop Conceptual Domains of Quality of Life for Adolescents With Advanced Cancer

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ABSTRACT

Background: Many adolescents will not survive their cancer diagnosis and will live with advanced cancer (cancer i.e. difficult to cure). Due to the advancement of cancer therapies, many adolescents will live with advanced cancer for long periods of time. Enhancing QoL is a well-established goal of their clinical oncology and palliative care however, there has been little research to conceptualize QoL in ways meaningful to them. There has also been a lack of QoL research focused on the inclusion of their voices and experiences into QoL construct development.

Objectives: The aim of this study was to develop proposed conceptual domains of QoL relevant to adolescents with advanced cancer.

Methods: This study was a qualitative study grounded in Interpretive Description. We used social media content created by adolescents living with advanced cancer to inform the development of QoL domains. Adolescents are increasingly using social media to share their experiences and we believed social media would facilitate access to rich data.

Results: 235 social media posts recorded by 14 adolescents were included in the analysis. This analysis generated domains relevant to the QoL of adolescents with advanced cancer: (1) Perceived Health, (2) The Lived Body, (3) Emotional Wellbeing, (4) Normalcy, (5) Purpose and Direction and (6) Re-Orientation.

Conclusions: The QoL of adolescents with advanced cancer is poorly understood. This research has generated unique conceptual domains of QoL relevant to this population of adolescents. These concepts will inform the future development of a patient-reported outcome measure (PROM) that can measure their QoL.

1 | Background

Due to the increase in the incidence of certain cancers for adolescents [1] and slower improvements in their cancer survival compared to other populations [2], many adolescents will live with advanced cancer. Advanced cancer is defined by the National Cancer Institute as cancer that is unlikely to be cured but can often be controlled [3] and novel therapies have facilitated greater numbers of adolescents to live with disease control for

an extended period [4]. Quality of life (QoL) is often a component of clinical care following a cancer diagnosis, but it is a focus of care when cancer becomes advanced [5, 6]. As adolescents are living longer with advanced cancer, attention to their QoL within oncology and palliative care services is a pressing consideration.

Adolescents are a unique oncology population with distinct needs resulting from the intersection of their physical and

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psychosocial development with a diagnosis of a serious illness. This intersection creates psychosocial vulnerabilities that have been acknowledged as different from those of children and adults diagnosed with cancer [7, 8]. When treatment is not successful and their cancer is advanced, these vulnerabilities can become exacerbated. Adolescents with advanced cancer experience heightened distress and grief [9] and have significantly higher rates of anxiety and depression than younger and older age groups [10]. They have a variety of unmet needs [14] and experience significant impact to their psychosocial development [9]. They are also a patient population with identified knowledge gaps when their cancer becomes advanced [11].

This study uses social media created by adolescents with advanced cancer. Adolescents are the biggest users of social media and TikTok is the fastest growing social media platform they use [12]. Social media platforms have been identified as significant digital health resources for adolescents [13] and a systematic review found that TikTok is being used for disseminating adolescent public and mental health information [12]. Increasingly, adolescents are using social media to share personal health narratives [13]. Recent research has focused on adolescents' use of social media regarding their mental health. A study examining user-generated content and engagement by adolescents regarding mental health found that personal experiences were the most prevalent content posted [14]. Adolescents have also used social media posts to increase awareness of mental health and to provide information to destigmatize symptoms [15]. Adolescents with cancer also report using social media following a cancer diagnosis [16] and the use of social media facilitated our ability to access the narratives of adolescents with advanced cancer.

Despite adolescents living longer with advanced cancer and the relevance of QoL to their care, QoL has been poorly conceptualized for them. QoL has been broadly defined by the World Health Organization as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns," [17, p. 1403] but what specifically accounts for QoL for adolescents with advanced cancer has not been adequately explored [5]. Previous studies have highlighted extant challenges in conceptualizing and measuring QoL for adolescents with advanced cancer when using existing QoL instruments [18, 19]. A systematic review examining the measurement and feasibility properties of QoL instruments used with children and adolescents with advanced disease determined that there was no valid instrument for use with this population. Authors also identified a lack of consistency between domains of QoL underlying different instruments [18]. A few studies have sought to develop domains of QoL relevant to adolescents with advanced cancer [5, 20, 21]. However, none generated domains that were developed specifically from the voices and lived experiences of adolescents with advanced cancer. These studies suggest that there is a lack of adolescents' perspectives integrated within existing QoL conceptualization and measurement and little research describing what adolescents themselves identify as important to their QoL when living with advanced cancer.

Measuring QoL for people with advanced disease is increasingly being done with patient-reported outcome measures (PROMs)

[22]. PROMs are validated questionnaires designed to capture patients' subjective perspectives on the impact of illness on their wellbeing [23]. In line with international guidelines of PROM development [24], there is broad agreement that development of a PROM should proceed from valid underlying concepts [25]. To ensure that information obtained from PROMs are clinically useful, a PROM must be conceptually grounded in the experiences and perspectives of the patient group to whom the PROM will be applied [24]. Developing valid concepts underpinning a PROM thereby relies on the inclusion of patient experiences to create concepts derived from their perspectives that will be meaningful and relevant to a specific patient population. The overall goal of this research is to develop a validated QoL PROM for use with adolescents with advanced cancer. There is not a QoL PROM developed for use specifically with them [26] and improving QoL for this population is hindered without a valid QoL instrument. Therefore, as the initial phase of this work, the aim of this current study was to develop proposed conceptual domains of QoL relevant to adolescents with advanced cancer. This will inform the development of a future conceptual framework that will underpin a new valid PROM.

2 | Methods

Institutional ethics review board approval was obtained from the University of Toronto Health Sciences Research Ethics Board (REB) (Protocol #: 44,009).

2.1 | Sample

We used convenience sampling to identify pre-existing data from social media posts. Eligible content included both text and video posts: (1) created by adolescents aged 13 to 19, (2) referenced having advanced cancer (i.e., terminal cancer, recurrence, palliative cancer, or identified having cancer difficult to cure), (3) available in English, and (4) publicly accessible. Social media posts were excluded if they were created by others about the life of an adolescent. All authors of social content that met the above criteria were included in the sample.

2.2 | Data Collection

Data were collected from February 1 to May 15, 2023 and included social media platforms were additionally searched until July, 2024. Search strings (e.g., adolescent + terminal cancer; teenager + recurrence) were used to identify posts within the following social media platforms: TikTok, Facebook, Instagram, YouTube, Blogger, Blogspot, and Reddit. These platforms were suggested by our adolescent and young adult (AYA) research advisory group accompanying this research. Potentially relevant posts were examined according to the established eligibility criteria. If an identified post met inclusion criteria, all individual posts created by the author were read. Screened posts rarely mentioned QoL directly, so we referred to the WHO definition of QoL [17, p. 1403] to guide determination of their eligibility for inclusion. All posts that included adolescents' comments and perspectives related to their goals, expectations, standards and

concerns, within the context of advanced cancer, were included, anonymized, and transcribed verbatim. Audio and textual data were extracted and recorded initially on a Microsoft Word document and then copied into NVivo 12 for analysis. Data collection ended when the topics in the data were being repeated and the data was sufficiently rich. We acknowledge that there might be more variation represented by a much larger sample size but the quality of the data collected supported our decision to end data collection at 14 participants.

2.3 | Data Analysis

This study was guided by ID which is an inductive qualitative methodology focusing on understanding contextual meaning of human experiences and aims to generate knowledge relevant to applied disciplines [27]. Guided by thematic analysis, ID supports the development of shared patterns and themes from the data and preserves exemplars as important sources of meaning [28]. Transcripts of the social media data were read and re-read multiple times by A.J. and initial impressions were recorded in a journal which began our audit trail. A.J. is an experienced clinician in pediatric palliative care and has expertise in qualitative methodologies. Data judged to qualify QoL were marked and discussions between A.J. and K.W. were ongoing at this initial analytic phase to clarify how QoL was represented in the data. Codes were developed to represent the initial data and the developed coding scheme was used to code all data iteratively. Transcripts were coded by A.J. and constant comparison was used to move back and forth between the social media posts and the codes. Codes were then grouped together thematically to form preliminary analytic categories and then analyzed and collapsed to develop our proposed conceptual domains and their corresponding themes. Throughout the analysis, regular meetings were held between A.J. and K.W. Preliminary analyses were also shared and discussed with our AYA research advisory

group. Trustworthiness of our results were supported by principles of auditability, fit, dependence and transferability [29] that we were mindful of throughout this study.

3 | Results

The analysis included 235 social media posts created by 14 adolescent authors. Details of the included social media data are listed in Table 1 and demographics of the authors are listed in Table 2. Analysis led to the identification of six conceptual domains: (1) Perceived health; (2) The lived body; (3) Emotional wellbeing; (4) Normalcy; (5) Purpose and direction, and (6) Re-orientation along with corresponding themes (Table 3).

3.1 | Perceived Health

Perceived health represents adolescents' appraisal of their current physical wellness and state of their cancer. Consideration and explanation of their cancer, and the physical changes they were experiencing resulting from cancer, were frequent topics of their narratives. Physical symptoms, and pain specifically, dominated their posts and appeared to occupy much of their daily attention. Confronted with physical symptoms and pain, they actively deliberated the meaning of these changes. Living with advanced cancer introduced the need to acutely monitor and interpret new symptoms more actively than they had at prior points in their cancer. When trying to understand the meaning of perceived changes to their health, many adolescents spoke from a liminal position of noticing these changes but also maintaining hope for their improvement or for a cure. Statements such as "things are not looking fantastic, but I will get through this" were frequently shared. Descriptions of health were coded into two themes for this domain: (1) Pain and physical symptoms and (2) Health stability. For many adolescents, pain and physical symptoms were often

TABLE 1 | Sampling of social media.

Adolescent social media author	Social media platform	Number of included social media posts	Length of total social media posts
1	TikTok	11	19.42 (mins.)
2	TikTok	13	41.22 (mins.)
3	TikTok	7	25.18 (mins.)
4	TikTok	5	14.22 (mins.)
5	TikTok	42	77.55 (mins.)
6	TikTok	5	13.22 (mins)
7	TikTok	64	109.13 (mins)
8	TikTok	27	42.56 (mins)
9	YouTube	22	55.04 (mins)
10	YouTube	1	28.24 (mins.)
11	YouTube	15	182.82 (mins.)
12	BlogSpot	16	8552 (words)
13	BlogSpot	6	2758 (words)
14	Reddit	1	1800 (words)
Total: 235			

TABLE 2 | Demographics of adolescent authors of social media data.

	<i>N</i> = 14	%
Country		
North America	4	28.6
Europe	5	35.7
Australia	2	14.3
Unknown	3	21.4
Sex [*]		
Female or Male	12	85.7
Unknown	2	14.3
Age		
13–16 years	3	21.4
17–19 years	8	57.1
Unknown (mentions adolescent)	3	21.4
Diagnosis		
Blood cancer (leukemia, lymphoma)	3	21.4
Brain tumor	4	28.6
Solid organ tumors	5	35.7
Unknown	2	14.3
Social media source		
TikTok	8	57.1
Youtube	3	21.4
Blogs	2	14.3
Reddit	1	7.1

^{*}Gender was not identified by the participants and was unable to be collected.

not well-controlled and they created significant impact to adolescents' wellbeing and daily life. The second theme of health stability represents adolescents' perception of stability of their cancer and current health as they experienced oscillating changes that were unpredictable, difficult to manage, and provoked interpretation.

3.2 | The Lived Body

Although experiences of the lived body are related to perceptions of health, this domain is distinct from perceived health. This domain represents adolescents' subjective experiences living within bodies that are sick and changing significantly with advancing cancer. Adolescents provided rich descriptions of these changes often involving their legs, spine, bladder, head, and weight, with the implications for their daily life and independence. It was common for adolescents to describe a change in their body and the meaning of this change for them: "I have been virtually bed bound for months...you can't do anything except for being on your phone and read." Another adolescent noted "Right now I am feeling like a piece of meat that is getting injected, stabbed-it's just normal now." This domain has two themes: (1) Loss of bodily autonomy and (2) Unrecognizable body. Loss of bodily autonomy represents the loss of independence with their bodies introduced by changes from cancer and the meaning of this

for adolescents. Many adolescents had to actively adapt in order to re-gain some independence when physically engaging with the world (e.g. wheelchair, time in bed, always being with a parent). The second theme, the unrecognizable body, refers to inhibiting bodies that are no longer known to them. Many adolescents described changes to their bodies as ones that made their bodies unfamiliar to them. Their bodies felt "different" and "strange" as they adjusted to physical changes. Descriptions of not recognizing their body were often followed with negative appraisals of the body: "I hate the way I look."

3.3 | Emotional Wellbeing

Having advanced cancer introduced strong emotions for many adolescents that were rawer than experienced at other times in their cancer treatment. Experienced emotions, and how adolescents managed them, are represented in this domain. This domain has two themes: (1) Intense emotions and (2) Coping with intense emotions. Many adolescents described their emotions with intensity. In particular, they discussed anger: "I am just feeling very, very angry at the world and I am questioning everything at the moment" and distress: "I believe I have a post-trauma experience from cancer; you are on a roller-coaster through treatment and you don't have time to think about stuff but once that roller-coaster slows down a bit, all you do is think... and it's really distressing." Most adolescents described acute emotions that fluctuated at different times and that were not directly connected to a specific medical event or change. Times of more heightened stress (e.g. hospital scans) were felt with strong emotions and so were days where there was not a specific event or change in their health. The second theme represents how adolescents lived with their emotions. In describing their emotions, adolescents frequently discussed their efforts to balance intense emotions while living life. The ability to manage their emotions fluctuated and many discussed feeling emotionally overwhelmed.

3.3.1 | Normalcy

Advanced cancer introduced significant life disruptions and many adolescents discussed desiring a feeling of normalcy and a "normal life." Adolescents offered statements such as, "I just want to live a normal teenage life." Many discussed wanting a normal life while comparing their current life to the life they knew prior to their cancer diagnosis. This comparison of present life to past life was described frequently by adolescents. This domain has two themes: (1) Re-establishing plans and (2) Participating in age-typical activities. Key to acquiring a feeling of normalcy for many adolescents was to re-establish planning for their life. Cancer interrupted the plans they made for their daily life and future and the return to some of this planning facilitated more normalcy. The second theme represents the hope to return to participating in activities believed to be typical ones for their age and development. These activities and experiences were those they would be engaging in if they were not living with advanced cancer and acted as significant markers of normalcy (e.g. driving, vacations, attending school).

TABLE 3 | Proposed domains and themes of QoL for adolescents with advanced cancer.

Domain	Themes	Examples of participants' voices
Perceived health	Pain and physical symptoms	<p>"I came in to hospital crying in so much pain- I told them that you have to help me because I can't carry on I am in so much pain."</p> <p>"I have been having symptoms that are getting worse- my eye is getting bigger, the roof of my mouth is numb, I have a headache. This is the part of cancer that people don't see- the waiting and the symptoms and the frustration of it all."</p>
	Health stability	<p>"Every day I wake up and open my eyes and hope that I will see an improvement or positive change and that's what's killing me. But hopefully, there will be some small improvement soon."</p> <p>"Living with cancer is like living on a knife-edge... in a split second it can go wrong."</p>
The lived body	Loss of bodily autonomy	<p>"So now I have a catheter I have to take with me everywhere I am... my permanent best friend. I can't pee myself anymore- it's just another thing that has been taken out of my control."</p> <p>"I basically have to get somebody to do everything for me now and it really does suck because I was a really independent person before this happened."</p> <p>"I feel really alien and I feel really ugly and I just want my life back."</p> <p>"I can't do this, I feel like I can't deal with this because it's all too much. Even though I am 18, I feel like an elderly person in a young person's body- I feel rubbish all the time- glasses, hearing aids, medication, the stick to walk, this problem with my eye, trouble walking."</p>
	Unrecognizable body	
Emotional wellbeing	Intense emotions	<p>"I have never felt this low."</p> <p>"I wasn't in a good place mentally; it was a dark time and I wasn't happy."</p>
	Coping with intense emotions	<p>"This morning I just woke up and just wept- I can't really see the point anymore. I Am finding it very hard to cope just because every day, day in and day out, it's the same crap- every hour, every minute that passes, feels hours long."</p> <p>"I am not ok and everything is awful. I Am going away on the weekend to see some family and I hope that takes my mind off things. So I am still doing stuff and normal things and getting out and about which is really positive, it's just everything is a bit harder at the moment."</p>
Normalcy	Re-establishing plans	<p>"I shouldn't really have this. I Just felt like a rug has been pulled out from under me. I Had this whole life planned out for me- what I was going to do, how I was going to do it, what was going to happen... and then this one bit of news and plans out of the window."</p> <p>"I was watching all my friends moving on with their lives and they are all moving forward and I stuck here standing still."</p>
	Participating in age-typical activities	<p>"And I just want to feel normal- I just want to be an 18 year old girl who goes out, and has fun, and does things that teenagers do- go to festivals, go on holidays, and I can't at the moment."</p> <p>"I watch my friends going to school, parties, clubs, and living their lives while I am lying here trying not to die."</p>
Purpose and direction	Accomplishing something of meaning	<p>"Cancer is something that needs to be brought to the forefront, brought to awareness... we need to find a cure. I Know that there's not a cure for every type of cancer but this just can't keep happening to people."</p> <p>"I need to spread awareness of adolescent cancer any way I can."</p>
	Creating meaningful moments	<p>"I am scared as hell about what is going to happen to me... but I know that I need to enjoy every moment I have on this earth because I know</p>

(Continues)

TABLE 3 | (Continued)

Domain	Themes	Examples of participants' voices
Re-orientation		what it's like to go through hell and I don't like to be sick and tired and stuck to a hospital bed."
		"I just want to do things that bring me joy before I pass."
		"It's terminal- I should make my peace with that but it's hard"
		"I wish there was something that could be done but there isn't; the best thing that you all can do is pray for me."

Abbreviation: QoL, quality of life.

3.3.2 | Purpose and Direction

Advanced cancer challenged the meaning many adolescents held about their life. Like the interpretations they were doing with their bodily changes, they also actively interpreted what was important to them. This domain represents their consideration of purpose and direction for their life with advanced cancer and includes two themes: (1) Accomplishing something of meaning and (2) Creating meaningful moments. The first theme represents adolescents' desire to accomplish something meaningful that would affect the lives of others. Adolescents described specifically wanting to impact others' cancer experiences and this provided a sense of purpose as they transferred their cancer knowledge and experiences to others with cancer. Many articulated their disbelief about the lack of public awareness of adolescent cancer and sharing their experiences was a way to demystify cancer for this age-group. They offered statements such as wanting to "shine a light on what terminal patients go through." The second theme represents the desire to create meaningful moments for themselves which also offered direction while living with advanced cancer. Many perceived information about their advancing cancer as an important invitation to engage in new experiences and in activities they enjoy. One adolescent shared, "For once, I am not going to listen to what everybody is telling me to do. I am going to enjoy my life and enjoy doing things in my life with the time I have left. I just want to enjoy my life." A focus on living meaningful and enjoyable moments was a strong contrast to treatment and focusing only on cancer.

3.4 | Re-Orientation

Living with advanced cancer was dis-orienting and adolescents had to continuously re-orient themselves when symptoms changed or hospital visits increased. When symptoms were well-managed and they were able to participate fully in their life (e.g. seeing friends, returning to school), they were able to live life with cancer in the background. However, as symptoms became more acute, or new symptoms appeared, adolescents had to re-orient themselves to living with advancing disease and a potentially shortened life. Many lived these parallel experiences of cancer both in the foreground and background and had to actively adjust to their disease progression. Within this constant process of re-orientation, they often sought supports that facilitated their adjustment including seeking information and having conversations about their cancer. Although many adolescents had not considered their death prior to re-orienting to living with advanced cancer, they spoke pragmatically about their disease

and their understanding that they could no longer be cured. As one adolescent discussed, "I know one day I am going to die. I am not scared of dying because I have come to terms with what is going on in my life and I know one day it's going to happen."

4 | Discussion

In this study, we aimed to conceptualize QoL for adolescents with advanced cancer using social media posts. QoL has been poorly explored for this population and we developed six proposed conceptual domains of QoL relevant to adolescents with advanced cancer.

The QoL domains created from this study lays critical groundwork for the development of a valid QoL PROM for adolescents with advanced cancer. Domains of QoL have not been previously developed for adolescents with advanced cancer from their voices and experiences and our findings offer domains we propose to be meaningful to this population. PROM development should proceed from a valid conceptual framework to ensure that the information collected from a PROM is clinically meaningful [24, 25]. An absent or under-developed conceptual framework creates measurement challenges and impacts the validity and reliability of the PROM [25]. Therefore, developing conceptual domains informed by patients' experiences is a crucial initial step of PROM development. The next step of this research will be to validate these domains with adolescents with advanced cancer and then create a valid conceptual framework of QoL applicable to them.

Our findings complement three previous studies conducted to develop QoL domains for children and adolescents with advanced cancer [5, 20, 21]. Although domains created in these studies were neither developed exclusively for adolescents with advanced cancer, nor developed solely from their voices, there are similarities between some of these domains and ours. For example, "normalcy" was a shared domain between our study and a study by Hinkle et al. [5] whose sample included both adolescents and young adults. In both studies, normalcy aligns with the established acknowledgment that cancer disrupts typical adolescent development [7]. Preserving normalcy has been found to be an important way of coping with serious illness for AYAs and an essential component of quality end of life care [30]. In a recent study investigating normalcy for AYAs with advanced cancer, authors identify domains of normalcy and clinical recommendations for addressing normalcy with AYAs [31]. Our domain of emotional wellbeing was also resonant with domains of psychological wellbeing [20, 21] and psychosocial

wellbeing [5] identified in these previous studies. These findings support other research demonstrating that adolescents with cancer experience significant distress [32] and are at a higher risk of distress compared to both older adults treated for cancer and to peers not treated for cancer [33]. Our findings underscore the importance of attending to adolescents' emotional and psychosocial wellbeing throughout their oncology care. A notable difference between our study and prior research, is how the physical impact of advanced cancer is represented. Our study findings differentiated between "health" and the "lived body" to account for both pain and physical symptoms and the subjective experiences of living within a sick body. This distinction is different from the domains of physical wellbeing [5, 20] and physical comfort [21] identified by the three previous studies which represented physical symptoms, side-effects, and pain. In our research, adolescents spoke separately about the subjective experiences of illness and disease in the body from how their body was physically functioning. Their narratives reflected diverse ways adolescents lived with the physical experiences of cancer and the embodied nature of advanced cancer. Finally, other domains from our research, "purpose and direction" and "re-orientation" are novel domains that are distinct from previous research. Taken together, our findings contribute to developing a more fulsome understanding of domains of QoL important and meaningful to adolescents with advanced cancer. Future work could explore these domains as a trajectory of adolescents' QoL experiences when living with advanced cancer.

Our results also suggest that broader QoL, instead of health-related quality of life (HRQoL), is an important lens within which to understand QoL for adolescents with advanced cancer. Although QoL and HRQoL are often used indiscriminately [34], they do have subtle conceptual distinctions. QoL refers to the subjective elements of one's life [17]. It includes dimensions of life that someone deems meaningful and important to their life and wellbeing. In comparison, HRQoL focuses on the effects of a disease or illness on certain domains of one's life [34]. In our findings, adolescents did discuss the effects of living with advanced cancer on their physical and emotional health which is represented in our developed domains of "health" and "emotional wellbeing" respectively. However, other domains were not directly focused on health and instead, were meaningful dimensions of their life and wellbeing. The domain of purpose and direction for example impacted adolescents' wellbeing. The ability to engage in activities that contributed to something meaningful to others or facilitated meaning in their life was significant to their wellbeing and ultimately to their QoL. Other research has also suggested that HRQoL may be an ill-fitted construct for use with children and adolescents with advanced disease [18, 19]. This is an important distinction as HRQoL may not capture what is meaningful to adolescents with advanced cancer.

A significant strength of our study was the direct inclusion of adolescents' experiences and perspectives within the development of proposed domains of QoL. Adolescents with advanced cancer have been historically under-represented in research [35] and social media offered an innovative means to capture their voices. Adolescents living with advanced cancer are a small population, but our sample is in line with the sample size

suggested by ID [27] and the total lengths of their social media posts rivals the average length of research interviews conducted with adolescents [36]. Social media yielded particularly rich data and we were surprised at the vivid descriptions and details adolescents openly shared when discussing living with advanced cancer. There were no differences that we could detect in the tone and content between the included social media platforms.

4.1 | Study Limitations

Although the focus of this study was on developing domains of QoL, QoL was rarely articulated within adolescents' social media narratives. Therefore, we interpreted adolescents' comments as meaningful or relevant to their QoL. Although we undertook a rigorous approach to analysis, the next phase of this research will be to conduct interviews with adolescents with advanced cancer to explore the alignment of our proposed domains to their lived experiences. Another limitation of our research is our sample had limited diversity and our developed domains may not adequately account for adolescents' experiences. This also highlights the importance of a diverse sample within the next phase of this research. Finally, social media as the sole data source may not offer full representation of adolescents' experiences and there may be differences between adolescents who do post content online to adolescents who do not.

4.2 | Clinical Implications

This study is a step closer to the development of a valid QoL PROM for adolescents with advanced cancer that can be used in oncology and palliative care. The use of PROMs are recommended within clinical practice [37] and their use may narrow existing gaps in adolescents' care when cancer is advanced. Findings from this study can also inform patient-centred clinical care by guiding clinicians to focus on what matters to adolescents with advanced cancer. Our developed conceptual domains can support clinical conversations and decision-making between adolescents and health care providers by providing a conceptual structure to these conversations that are often focused on an adolescent's QoL [6].

5 | Conclusion

The QoL of adolescents is significantly impacted when living with advanced cancer. Despite the focus of QoL to their clinical care, little is known about their QoL and what contributes to it. This study proposes conceptual domains of QoL meaningful to adolescents with advanced cancer and supports the need for patient-centred QoL measurement for adolescents.

Author Contributions

Both authors contributed to the study conception and design. Data was collected and analyzed by A.J. Codes and domains were developed by A. J. and K.W. and analytic discussions between both occurred throughout

the research. The first draft of the manuscript was written by A.J., and both authors reviewed and approved the final manuscript.

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Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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