

Cancer Patients' Perspectives and Experiences of Chemotherapy-Induced Myelosuppression and Its Impact on Daily Life

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Purpose: To evaluate which side effects of chemotherapy are considered most burdensome by patients with cancer, identify which health care professionals pay most attention to symptoms associated with chemotherapy-induced myelosuppression (CIM) from the patient perspective, and capture the “patient voice” describing how CIM impacts their daily lives.

Participants and Methods: Online survey of participants with breast, lung, or colorectal cancer who had received chemotherapy within the past 12 months and experienced ≥ 1 episode of CIM in the past year. Participants were asked to answer close-ended questions and provide qualitative responses to: “In your own words, please describe how side effects from myelosuppression have impacted your life.”

Results: Among 301 survey participants, fatigue was the most frequently reported side effect of chemotherapy; 55% of participants rated fatigue as highly bothersome (9 or 10 on a 1–10 scale of “bothersomeness”). Participants rated symptoms associated with CIM, including fatigue, weakened immune system (infections), bleeding and/or bruising, and shortness of breath, as being as bothersome as other side effects of chemotherapy, including alopecia, neuropathy, and nausea/vomiting. Overall, 24–43% of participants thought that CIM and its symptoms had a negative impact on their daily lives, including their ability to complete tasks at home and work, and to socialize. Qualitative responses supported these findings; participants highlighted that CIM-related symptoms, particularly fatigue and fear of infections, affected their ability to be physically active, complete work, or continue meaningful relationships with friends and family.

Conclusion: Participants described a real-world impact of CIM that often isolates them from family and friends, and means that they are unable to work or perform tasks of daily living. Using measures that help patients to recognize and communicate the signs and symptoms of CIM might increase the likelihood of maintaining daily lives as close to normal as possible, during and after chemotherapy treatment.

Keywords: cancer, chemotherapy, myelosuppression, real world, quality of life, patient burden

Plain Language Summary

What Did This Study Look at?

- The study looked at people with breast, lung, or large bowel cancer whose chemotherapy treatment meant that they developed a condition called myelosuppression.
- Myelosuppression leads to people having fewer blood cells, and can make people tired, or increase their risk of infection or bleeding.

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Who Took Part in This Study?

- Overall, 301 people in the United States completed an online survey in which they were asked questions about how the side effects of myelosuppression affected their daily lives.
 - They had all received chemotherapy in the last year and had myelosuppression at least once during their treatment.

What Were the Results of the Study?

- The most common side effect of chemotherapy was a lack of energy or tiredness (fatigue). Most people described fatigue as being highly bothersome.
- People felt that symptoms of myelosuppression were as bothersome as other side effects of chemotherapy, like hair loss and feeling or being sick.
- Up to 4/10 people felt that myelosuppression stopped them from completing everyday tasks and taking part in social activities.
- Myelosuppression also stopped people from being physically active and affected their relationships with family and friends.

What Were the Main Conclusions Reported by the Researchers?

- People with myelosuppression often feel isolated from their family and friends and cannot carry out everyday tasks.
- Preparing people for the symptoms of myelosuppression might reduce its effects on their daily lives during and after chemotherapy.

Introduction

Cytotoxic chemotherapy, alone or in combination with immunotherapy, remains a standard of care for many solid tumors, including lung cancer,^{1,2} breast cancer,³ and colorectal cancer (CRC).⁴ However, common side effects such as nausea, vomiting, alopecia, neuropathy, rash, diarrhea, and constipation are a major problem for patients.⁵ In addition, chemotherapy-induced damage to the bone marrow can result in myelosuppression, a disorder characterized by neutropenia, lymphopenia, anemia, and thrombocytopenia.^{6–9} The burden of these toxicities on patients' cancer care and physical health can range from a relatively minor inconvenience, to more severe complications such as shortness of breath, fatigue, excessive bleeding, and an increased risk of life-threatening infections.^{5,10}

Managing the consequences of chemotherapy-induced myelosuppression (CIM) can require chemotherapy dose reductions and/or delays that may limit therapeutic

efficacy and negatively affect patients' survival.^{8,11–15} In addition, serious hematologic toxicities often require hospitalization, blood cell transfusions, and the reactive use of hematopoietic growth factors (eg, granulocyte colony-stimulating factor and erythropoiesis-stimulating agents), which are lineage specific (ie, to neutrophils, red blood cells, or platelets) and associated with their own side effects^{8,9,15–21} and additional costs.²² Currently, there are no specific treatments available that can prevent the myelosuppressive effects of chemotherapy across more than one blood cell lineage.²¹

In addition to the physical, emotional, and economic burden of CIM and its side effects, studies have suggested that symptoms of fatigue, infections, and bleeding may also impact patients' quality of life (QoL), social relationships, and ability to perform daily tasks.^{23–28} For example, when 100 patients were asked to rank the physical and non-physical side effects of chemotherapy, "affects my family or partner" was rated as the most severe side effect. Alopecia and fatigue were ranked second and third, respectively, and effects on work or home responsibilities, social activities, and loss of interest in sex were ranked fourth, fifth, and sixth, respectively.²⁷ Additionally, a small qualitative survey of 34 patients who developed grade 4 neutropenia during the first cycle of chemotherapy reported interference in daily routine, negative emotion, and a sense of isolation and reduced self-worth, alongside the physical impact of fatigue.²⁴ These studies, though limited in size, suggest that CIM has a broader real-world burden on patients' lives beyond the physical side effects.

The purpose of the current online survey was to capture the perceptions, experiences, and challenges reported by patients with CIM during treatment for breast cancer, lung cancer, or CRC. Findings from this survey detailing patients' perspectives on the management of CIM in routine clinical practice have been previously reported.¹⁰ Here, we present patients' perspectives on how the side effects from CIM have impacted their global health and QoL, including qualitative responses describing their ability to work or perform tasks inside the home, undertake daily activities, and socialize with others.

Materials and Methods

Study Objectives and Format

In this study, an online survey of oncology patients in the US was used to achieve the following objectives: (1)

identify the side effects of chemotherapy perceived to be most burdensome by patients; (2) gain insights into which member of the care team paid most attention to symptoms associated with CIM; and (3) capture the “patient voice” describing how CIM and its symptoms has impacted their lives. As previously published, additional objectives were to understand what treatments were administered for CIM, what challenges patients encountered in receiving these treatments, and how often CIM resulted in chemotherapy dose modifications.¹⁰

The study was conducted between November 11, 2019 and December 8, 2019. The study was performed in accordance with the Declaration of Helsinki, and electronic consent was obtained from all participants prior to study entry. All participants were informed about the purpose of the survey. The study was reviewed by the Sterling Institutional Review Board (IRB) and granted exemption status according to Department of Health and Human Services research criteria, indicating that full IRB review was not required.

Study Population

Male and female participants aged ≥ 18 years who were living with breast cancer, lung cancer, or CRC were identified from an online opt-in patient panel in the US; this panel includes patients with a wide range of health conditions, including cancer. The target sample size was 300 survey participants, with a target ratio of 4:3:3 for breast cancer, lung cancer, and CRC, respectively. Participants were included if they had received chemotherapy and had experienced ≥ 1 episode of CIM in the past 12 months that resulted in the following: requirement of a blood transfusion; requirement of granulocyte colony-stimulating factor or granulocyte macrophage colony-stimulating factor; requirement of a platelet transfusion; a serious infection such as pneumonia or sepsis after chemotherapy treatment; requirement of erythropoiesis-stimulating agents to increase red blood cell count; or diagnosis of myelosuppression but with no treatment intervention.

Survey Questions

The survey was constructed based on the goals and objectives established for this research and a review of relevant published literature, and the draft questions were reviewed for design and scientific content. The survey included 12 questions to screen participants and capture information on demographics. Seven close-ended, multiple-choice, dichotomous (yes/no), and categorical questions (using Likert-type scales) were included to identify symptoms and treatments

received, and to assess the impact of CIM on daily living. In addition, participants were asked to provide qualitative responses to the following single open-ended question: “In your own words, please describe how side effects from myelosuppression have impacted your life.” To aid patient understanding before responses were given, lay definitions of the following common terms were provided upon cursor selection: anemia (“fewer red blood cells, which sometimes causes you to be tired”); lymphocytes (“types of white blood cells that work to fight illness and disease”); lymphopenia (“fewer lymphocytes, which sometimes increases your risk of infection”); myelosuppression (“a decrease in bone marrow activity that results in the reduced production of blood cells. Myelosuppression is a common side effect of chemotherapy”); neutropenia (“fewer white blood cells, which sometimes increases your risk of infection”); platelets (“tiny blood cells that help your body form clots to stop bleeding”); and thrombocytopenia (“fewer platelets, which sometimes increases your risk of bleeding”).

Response Analysis

For all close-ended responses, data were aggregated to ensure anonymity, and key findings were summarized using descriptive statistics. Multivariable logistic regression models were used to examine the relationship between the impact of myelosuppression (minor, moderate, or major) and age, fatigue, weakened immune system, and easy bleeding/bruising. Crude and age-adjusted odds ratios (ORs) and corresponding 95% confidence intervals (95% CI) were calculated. Logistic regression analyses were performed using SAS software version 9.4 (SAS Inc., Cary, NC). Qualitative responses to the single open-ended survey question were compiled and coded into themes by three independent analysts. The analysts reviewed all responses to identify up to a maximum of ten common themes, after which, two of the analysts manually coded the responses against the common set of themes; the third analyst applied ATLAS.ti software (ATLAS.ti Scientific Software Development GmbH, Berlin, Germany) to thematically code the responses. Responses could be coded under more than one key theme. Only responses for which all three analysts agreed on the final thematic coding (92% of responses) are reported here.

Results

Patient Characteristics

As previously reported, the full survey was completed by 301 participants.¹⁰ Most of the participants were <60 years

of age (80%), and over half were female (60%) and in full- or part-time employment (60%). Just over half of the participants (51%) were living with breast cancer, 33% had lung cancer, and 16% had CRC; approximately three-quarters of participants had been diagnosed with cancer within the previous 3 years. Anemia (61%) and neutropenia (59%) were the most commonly self-reported manifestations of CIM, followed by lymphopenia (37%) and thrombocytopenia (34%). Self-reported comorbidities included diabetes (30%), depression (28%), and hypertension (23%).

Side Effects of Chemotherapy

Fatigue was the most frequently reported side effect of chemotherapy (reported by 72% of participants), with 55% of participants rating it as highly bothersome (9 or 10, on a 1–10 scale of “bothersomeness”, where 1 was “not at all bothersome” and 10 was “extremely bothersome”). Patient-reported symptoms associated with CIM, including fatigue, a weakened immune system (infections), bleeding and/or bruising, and shortness of breath, were considered to be as bothersome as other common side effects of chemotherapy, including hair loss, nausea/vomiting, and neuropathy (Table 1).

Overall, more than half of the participants (57%) reported that, among health care providers (HCPs),

oncologists paid the most attention to and/or helped to treat the side effects; this was followed by nurses (28%), physician assistants (PAs; 18%), and other HCPs (3%). A similar pattern was observed across the individual symptoms associated with CIM; for symptoms of fatigue, weakened immune system, bleeding and/or bruising, and shortness of breath, 62%, 64%, 66%, and 62% of participants reported that oncologists paid the most attention to and/or helped treat the respective symptoms (Table 1).

Impact of CIM and Its Side Effects on QoL

When rating overall impact on a scale of 1–5, 24–43% of participants felt that the side effects of CIM had a significant impact (scale 5) on various aspects of daily living (Figure 1). Over one-third (36%) of participants felt that CIM had significantly impacted their ability to complete daily tasks within the home (eg, cleaning, cooking, chores), 43% reported a significant impact on work inside or outside the home, 31% felt that opportunities to socialize were significantly impacted, 27% felt that CIM had significantly impacted their relationships with their children and extended family, and 29% felt it had significantly impacted relationships with their spouse, partner, or significant other.

As previously reported, 30% of participants agreed or strongly agreed that their oncologist did not understand

Table 1 Participant-Reported Frequency of Chemotherapy Side Effects and Their “Bothersomeness” and HCPs Who Paid Most Attention to the Side Effects

Side Effect	Reported Frequency, %	Bothersomeness ^a %	HCP That Paid Most Attention to or Helped Treat Specific Side Effects, n/N (%)			
			Oncologist	Nurse	Physician Assistant	Other
Fatigue ^b	72	55	135/217 (62)	49/217 (23)	31/217 (14)	2/217 (1)
Weakened immune system ^b	52	49	100/157 (64)	31/157 (20)	26/157 (17)	0
Hair loss	50	55	87/151 (58)	38/151 (25)	23/151 (15)	3/151 (2)
Nausea and/or vomiting	49	58	92/148 (62)	31/148 (21)	24/148 (16)	1/148 (<1)
Generalized pain	45	56	78/134 (58)	35/134 (26)	20/134 (15)	1/134 (1)
Diarrhea/constipation	40	51	75/125 (60)	21/125 (17)	23/125 (18)	2/125 (2)
Bleeding and/or bruising ^b	35	47	69/104 (66)	18/104 (17)	17/104 (16)	0
Neuropathy	34	54	60/102 (59)	21/102 (21)	19/102 (19)	2/102 (2)
Shortness of breath ^b	34	52	63/101 (62)	18/101 (18)	18/101 (18)	2/101 (2)
Mouth sores	25	56	39/76 (51)	19/76 (25)	16/76 (21)	2/76 (3)

Notes: ^aReported by participants as a 9 or 10 (“highly bothersome”) on a 1–10 scale of “bothersomeness.” ^bSide effects potentially associated with chemotherapy-induced myelosuppression.

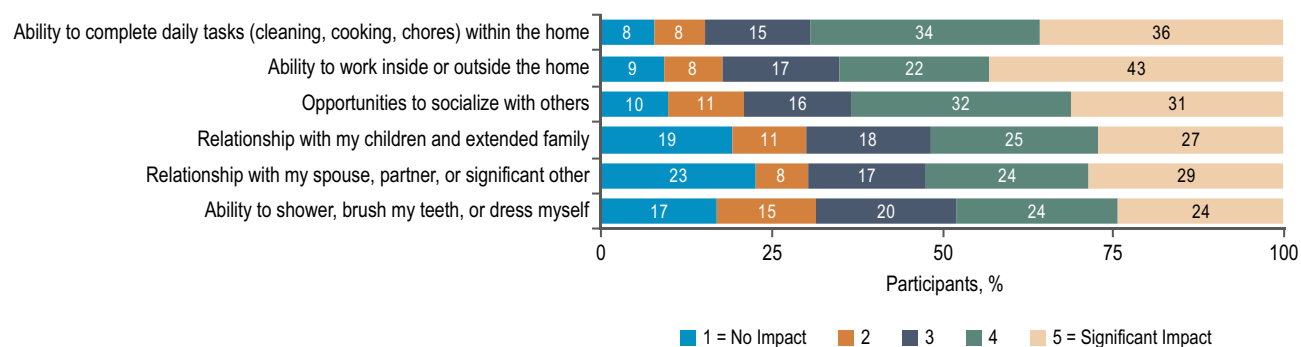


Figure 1 Participant-reported impact of the side effects of CIM on daily living.
Abbreviation: CIM, chemotherapy-induced myelosuppression.

their discomfort due to CIM, and 29% of participants felt that their side effects were not treated.¹⁰ Results were similar across the three tumor types, although when analyzed by sex, more male participants with breast cancer (62% [13/21]) than female participants with breast cancer strongly felt that their oncologist did not understand how uncomfortable they were, and 57% (12/21) agreed that their oncologist did not treat their side effects. In general, younger participants (aged <60 years) were more likely to agree that their oncologist did not understand or treat their side effects related to CIM, compared with those aged ≥60 years (Table 2). The difference between age groups was most apparent in participants with lung cancer or CRC.

Overall, the impact of CIM was reported to be higher among younger participants (OR 0.86 for patients aged ≥50 years vs those aged <50 years; Table 3). More participants with fatigue, who considered themselves to have a weakened immune system, or who noticed easy bruising/bleeding reported a major life impact compared with those without these side effects (OR >1 in all cases; Table 3).

Sub-analyses conducted across the three tumor types revealed that, among participants who felt that their oncologist did not understand how uncomfortable they were from side effects, or did not feel that their side effects

had been treated, many experienced a negative impact on their relationship with their partner. This appeared to be particularly pronounced in participants with lung cancer (Table 4). A similar pattern was seen with other measures of daily living, including: 1) relationship with children and extended family; 2) ability to complete daily tasks such as cleaning, cooking, or chores around the home; 3) ability to work inside or outside the home; 4) ability to shower, brush teeth, or dress self; and 5) opportunities to socialize with others (Table 4).

Themes in Qualitative Responses

From the responses to the single open-ended survey question, “In your own words, please describe how side effects from myelosuppression have impacted your life,” eight themes were identified, defined, and agreed by the three independent analysts; these were: physical functioning; activities of daily living; work; sleep/rest; emotions; social/family; worry/concern about health; and global health/QoL. Of the 301 responses, 97 (32%) did not fall into one of the eight identified themes and were excluded; these included responses that described a side effect of chemotherapy not associated with CIM, were considered ambiguous, or were not

Table 2 Association Between Participants' Age and Tumor Type, and Their Oncologist's Understanding or Treatment of Side Effects of Chemotherapy

Tumor Type	Breast Cancer		Lung Cancer		Colorectal Cancer	
Age Group, Years	<60 (n=134)	≥60 (n=19)	<60 (n=75)	≥60 (n=25)	<60 (n=32)	≥60 (n=16)
Oncologist did not understand how uncomfortable participant was from side effects (ranked 4 or 5), n (%)	47 (35)	4 (21)	26 (35)	2 (8)	11 (34)	1 (6)
Oncologist did not treat side effects (ranked 4 or 5), n (%)	39 (29)	5 (26)	27 (36)	2 (8)	12 (38)	2 (13)

Table 3 Association Between Selected Side Effects and Perceived Impact of Myelosuppression

	Patients, n	Minor Impact, n (%)	Moderate Impact, n (%)	Major Impact, n (%)	Crude OR (95% CI) ^a	Age-Adjusted OR (95% CI) ^a
Age						
< 50 years	191	15 (8)	98 (51)	78 (41)	0.86	
≥ 50 years	110	21 (19)	48 (44)	41 (37)	(0.53, 1.39)	
Fatigue						
Yes	217	13 (6)	108 (50)	96 (44)	2.10	2.16
No	84	23 (27)	38 (45)	23 (27)	(1.22, 3.65)	(1.24, 3.76)
Weakened immune system						
Yes	157	7 (5)	69 (44)	81 (52)	2.97	2.98
No	144	29 (20)	77 (54)	38 (26)	(1.83, 4.83)	(1.83, 4.83)
Easy bruising/bleeding						
Yes	104	5 (5)	47 (45)	52 (50)	1.94	1.93
No	197	31 (16)	99 (50)	67 (34)	(1.20, 3.15)	(1.18, 3.14)

Notes: ^aORs represent the odds of myelosuppression having a major impact (vs minor or moderate) for participants aged ≥ 50 years compared with those aged <50 years, and for participants with fatigue, a weakened immune system or easy bruising/bleeding (Yes) compared with participants without those symptoms (No).

Abbreviations: CI, confidence interval; OR, odds ratio.

applicable to the impact of CIM on patients' lives. The definitions and number of relevant responses assigned to each theme are provided in Table 5. Illustrative patient comments on the consequences of CIM and its side effects are summarized in Figure 2. Qualitative responses closely mirrored results from the descriptive analysis of close-ended responses outlined above. Participants highlighted that CIM and its symptoms, particularly fatigue, significantly impacted their ability to remain physically active, complete regular work, and even accomplish the most routine daily tasks such as cleaning, cooking, and taking a shower. In addition, participants reported that fatigue and fear of infections left them feeling irritated, isolated, and fearful of the future, unable to socialize, or that they could not continue meaningful relationships with their friends and family.

Discussion

Few studies have been conducted to understand patients' perspectives on the burden of CIM and its symptoms on their daily lives, including which side effects patients consider to be most bothersome, or likely to affect their personal relationships, ability to socialize, or ability to work or undertake activities inside or outside the home. In addition, the relationship between the patient and HCP most closely helping them to manage and treat their

symptoms of CIM, and the impact of this relationship on patients' QoL, remains largely unexplored.

In line with other studies,^{7,24} fatigue was, by far, the most common side effect of chemotherapy reported by participants in the current survey. This was followed by participants considering themselves to have a weakened immune system. Interestingly, all of the symptoms associated with CIM (fatigue, a weakened immune system, bleeding and/or bruising, shortness of breath) were rated by participants to be as bothersome as other common side effects of chemotherapy, including hair loss, which is often reported in the literature to be among the most distressing side effects suffered by both sexes,^{29,30} neuropathy, which can persist for several months or even years after chemotherapy,³¹ and nausea/vomiting, which is among the most feared adverse events associated with chemotherapy.³² In their qualitative responses, participants repeatedly highlighted fatigue and the belief that their immune system was weakened as being a major burden on their daily lives. It follows that proactive and sustained measures aimed at preparing patients for fatigue may help them to manage this symptom more effectively and may increase the likelihood of maintaining daily lives as close to normal as possible, both during and after chemotherapy treatment.³³

A significant proportion of participants in the current study believed that CIM and its symptoms had a profound negative impact on their QoL, including their ability to

Table 4 Association Between Oncologist's Understanding and/or Treatment of Side Effects of Chemotherapy and Participant's Relationship with Partner and Other Measures of Daily Living

	Significant Impact (Ranked 5) on Relationship with Partner, n/n (%)			Significant Impact (Ranked 5) on Relationship with Children or Family, n/n (%)			Significant Impact (Ranked 5) on Ability to Complete Daily Tasks, n/n (%)			Significant Impact (Ranked 5) on Ability to Work Inside or Outside the Home, n/n (%)			Significant Impact (Ranked 5) on Ability to Shower, Brush Teeth, Dress, n/n (%)			Significant Impact (Ranked 5) on Ability to Socialize, n/n (%)		
	Breast	Lung	CRC	Breast	Lung	CRC	Breast	Lung	CRC	Breast	Lung	CRC	Breast	Lung	CRC	Breast	Lung	CRC
Oncologist understood how uncomfortable participant was from side effects (ranked 1)	21/63 (33)	4/45 (9)	3/23 (13)	17/63 (27)	4/45 (9)	4/23 (17)	27/63 (43)	14/45 (31)	5/23 (22)	36/63 (57)	17/45 (38)	8/23 (35)	17/63 (27)	5/45 (11)	3/23 (13)	24/63 (38)	8/45 (18)	6/23 (26)
Oncologist did not understand how uncomfortable participant was from side effects (ranked 5)	13/27 (48)	9/16 (56)	4/6 (67)	19/27 (70)	5/16 (31)	5/6 (83)	17/27 (63)	10/16 (63)	3/6 (50)	16/27 (59)	10/16 (63)	4/6 (67)	16/27 (59)	7/16 (44)	2/6 (33)	10/27 (37)	6/16 (38)	5/6 (83)
Oncologist treated side effects (ranked 1)	20/67 (30)	4/38 (11)	5/26 (19)	17/67 (25)	3/38 (8)	5/26 (19)	26/67 (39)	10/38 (26)	5/26 (19)	38/67 (57)	13/38 (34)	8/26 (31)	17/67 (25)	4/38 (11)	3/26 (12)	26/67 (39)	7/38 (18)	9/26 (35)
Oncologist did not treat side effects (ranked 5)	12/26 (46)	7/9 (78)	3/10 (30)	15/26 (58)	4/9 (44)	4/10 (40)	17/26 (65)	5/9 (56)	5/10 (50)	18/26 (69)	5/9 (56)	5/10 (50)	14/26 (55)	4/9 (44)	3/10 (30)	9/26 (35)	2/9 (22)	5/10 (50)

Abbreviation: CRC, colorectal cancer.

Table 5 Key Themes Identified from the Qualitative Responses to the Question, “In Your Own Words, Please Describe How Side Effects from Myelosuppression Have Impacted Your Life”^a

Theme	Description	Number of Responses Expressed per Theme ^b
Physical functioning	Impact on physical movement, physical activities, ability to be physically active, ability to do things, ability to exercise	13
Activities of daily living	Impact on ability to do/cope with daily activities, including hobbies, volunteer activities, housework, childcare, self-care (dressing, showering, toilet use), household chores (grocery shopping, cooking, cleaning)	26
Work	Impact on paid work, daily employment, career, going to school	22
Sleep/rest	Impact on sleep and rest patterns, ie, sleeping a lot, finding it hard to sleep through night, taking a lot of naps, resting a lot, spending a lot of time in bed	17
Emotions	Impact on emotions (depression, feeling down, fear, anxiety, irritability, stress), lack of self-confidence, upset at physical appearance	23
Social/family	Impact on relationships with friends and family, impact on engaging in social activities with others and family and on extracurricular activities (non-work) involving others and/or family. Impact on ability to leave house, to go out and enjoy life. Feelings of loneliness, increased isolation	37
Worry/concern about health	Worry about getting sick, worry about getting infections, worry about future health, worry about the need for extra precautions for infection or bleeding or bruising, extra health care appointments, worry about being a burden because of poor health	9
Global health/QoL	Impact on global health and QoL. General non-specific statements of health/QoL, eg, “it kept me from a lot of things I would rather be doing,” “my life has been impacted,” “I can’t do normal things,” “no energy ... to do what I used to be able to do” – overall dislike/lack of enjoyment of life/overall lifestyle (without detail)	36

Notes: ^aParticipant responses could be coded under more than one theme. ^bOnly responses where all three independent analysts agreed on the final thematic coding for each response are reported (92% of participants responses).

Abbreviation: QoL, quality of life.

complete daily tasks within the home and at work, and to socialize. In addition, approximately one-third of participants felt that CIM adversely impacted relationships with their partner, children, and wider family. These real-world patient perspectives mirror the findings of smaller studies^{23,24,27} and were supported by some of the qualitative comments provided in this study. Several participants verbalized issues with completing daily tasks, work, and maintaining relationships, as well as an overall feeling of anxiety and isolation. Notably, this survey was conducted prior to the start of the COVID-19 pandemic. Concerns about chemotherapy and cytopenia are likely to be even higher now, with many patients avoiding hospital appointments or consultations due to the fear of COVID-19 infection, or postponing chemotherapy despite the risk of disease progression. Since the feelings of anxiety and isolation noted in this survey are likely to have worsened during the pandemic, especially among patients living

alone, additional surveys to understand patient perspectives on the impact and management of CIM are warranted.

Relationships and communication between patients and HCPs are important for patients’ ability to cope with their illness, treatment, and/or side effects. In the current study, participants reported that the side effects they experienced during chemotherapy, including individual symptoms associated with CIM, were most frequently managed by an oncologist, as opposed to a nurse, PA, or other HCP. By contrast, many of the other common side effects of chemotherapy, including nausea/vomiting, neuropathy, and alopecia, are largely managed by nurses.^{5,34,35} Although oncologists and nurses are involved in the care of all patients, very few patients would have a PA as their primary care provider. Many oncology PAs see patients who are receiving active treatment in an outpatient setting, where PAs are primarily involved in history, physical



Figure 2 What oncology patients say about the burden of CIM and its side effects. Illustrative comments by each of the eight key themes are shown.
Abbreviation: CIM, chemotherapy-induced myelosuppression.

assessment, and planning; breaking bad news; patient education; and obtaining patient consent.³⁶ As oncologists have less time available to spend with patients compared with nurses, PAs, or other HCPs, increased awareness of,

and training in, the management of CIM among these other groups of HCPs could result in improved efficiency and patient care. Interestingly, the negative impact of CIM and its symptoms on partner relationships and other

measures of daily living were found to be exacerbated among participants who perceived that their oncologist did not understand how uncomfortable they were or did not treat their side effects. In a previous study of 990 patients with breast cancer, just under half reported that the information they received from doctors was unclear, and QoL scores for functioning, symptoms, body image, lifestyle, and other worries were all significantly worse when communication was perceived to be insufficient.³⁷ It is unknown if poorer communication leads to worse QoL or if patients who are unhappier are more likely to report problems; however, taken together, these data highlight the importance of patient–HCP communication, particularly in regard to improving patients’ understanding of potential side effects of CIM and their impact on QoL.

Regarding the findings of the current survey, it would be interesting to understand how patients’ perspectives on how the side effects from CIM impacted their global health and how QoL changed throughout the patient journey. For example: did the experience of chemotherapy match the patient’s expectations based on what he or she was told by his or her HCP; did the side effects improve, linger, or worsen after chemotherapy was completed; how much did the duration of side effects affect patients’ response and experience; and would the patient agree to chemotherapy again on the basis of their experience? It would also be interesting to survey the caregivers of patients receiving treatment with chemotherapy to gain a third-party perspective of the effects of CIM, both during and after chemotherapy. The setting in which patients receive chemotherapy may also impact how patients experience the unwanted side effects of chemotherapy, and their perception of the subsequent care that they receive. For example, compared with community-based cancer centers, there may be more resources available at an academic medical center (eg, more specialist oncologists, nurses, and pharmacists), which may affect how patients perceive the recognition and treatment of their side effects. In this regard, it would be useful to conduct further research that considers the patient burden of CIM and its consequences in community versus academic settings.

Notably, although most participants reported a relatively positive relationship with their oncologist in the present study, just under two-thirds of male patients with breast cancer felt that their oncologist did not understand how uncomfortable they were from their side effects, or felt that their side effects had not been treated by their

oncologist. This may reflect the broader ignorance and stigmatization reported by male patients with breast cancer³⁸ and/or the general reluctance of male patients to discuss health-related matters.³⁹ Similarly, the observation that younger patients were more likely to feel that their oncologist did not understand or treat their side effects may reflect several factors. For example, older patients, who have increasing comorbid conditions and progressive reduction of organ function, are less likely to tolerate chemotherapy and may therefore require more intervention from their HCP.⁴⁰ Secondly, there may be generational differences in how patients perceive the status of medical professionals, with older patients more likely than younger patients to defer to doctors’ authority.⁴¹ Additionally, there is evidence to suggest that younger patients have greater information needs that, if unmet by their HCP, can negatively impact QoL.⁴² These findings may explain, in part, why the overall impact of CIM was higher among participants aged <50 years than in those aged ≥50 years in the present survey. In addition, it is feasible that an inability to perform daily activities or continue employment may have more impact among younger participants, who may be more used to a higher level of physical and social interactions.

There are some limitations in the present study. Patients who were willing to participate in this study may have been more open to expressing their experiences about CIM and its symptoms compared with sicker patients; those who participated may have also been potentially more engaged and familiar with online discussion around the impact of CIM. However, one-third of qualitative responses from participants were not applicable to CIM, suggesting that some participants used the open-ended prompt to communicate other issues or experiences related to their disease or treatment. Indeed, some patients may have wanted an “ear” to vent to, particularly within the context of findings that their HCP did not fully understand their discomfort. Finally, as this was a descriptive survey, a formal statistical analysis plan was not pre-specified, which may limit the robustness and interpretation of the data collected. Replicating the findings with new data and in new settings would be important to ensure the reliability and validity of the current research approach. A key strength of using an online survey to collect patient perspectives is that participants may be less fearful of giving a “wrong” response to a question and, therefore, may be more willing to share experiences more representative

of their real lives. The additional use of qualitative responses provides important information on aspects of the patient burden of CIM that would not otherwise be captured in a closed-response questionnaire or by formal patient-reported outcome measures collected in a clinical trial setting.⁴³

Conclusion

Patients with cancer describe a real-world impact of CIM that often isolates them from family and friends, and prevents them from working or performing tasks of daily living. Improving communication between patients and oncologists, nurses, PAs, and other HCPs may result in more effective management of CIM-related symptoms and increase the likelihood of patients maintaining daily lives that are as close to normal as possible.

Abbreviations

CIM, chemotherapy-induced myelosuppression; CRC, colorectal cancer; HCP, health care provider; IRB, institutional review board; PA, physician assistant; QoL, quality of life; US, United States.

Data Sharing Statement

The datasets generated and/or analyzed during the current study are available from the corresponding author on reasonable request.

Ethics Approval and Informed Consent

The study was conducted in accordance with the Declaration of Helsinki, and electronic consent was obtained from all participants prior to study entry. All participants were informed about the purpose of the survey. The study was reviewed by the Sterling IRB and granted exemption status according to the Department of Health and Human Services research criteria, signifying that full IRB review was not required.

Consent for Publication

All named authors meet the International Committee of Medical Journal Editors criteria for authorship for this article, take responsibility for the integrity of the work as a whole, and have given their approval for this version to be published.

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