

Understanding The Experience of Patients With Early-Stage Cancers: A Targeted Qualitative Literature Review

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Background

- Qualitative research within a target population provides a rich and in-depth understanding of the patient experience. Such information is critical to support identification of relevant measurement concepts and selection of appropriate clinical outcome assessments (COAs) with sufficient evidence of content validity in the context of use for clinical studies (e.g., to evaluate treatment efficacy and support regulatory and Health Technology Assessments).¹⁻⁵
- The experience of patients with cancer varies depending on stage of disease and treatment received. Health-related quality of life (HRQoL) is expected to be better in patients with early-stage cancer compared with those with advanced disease.⁶⁻⁸
- There is a need to better understand the patient experience (i.e., disease- and treatment-related symptoms, HRQoL impacts) of early-stage cancer to inform patient-focused drug development for novel treatments targeting early-stage cancers.

Objective

- To synthesize existing qualitative literature describing the experience of patients with early-stage breast, endometrial, head and neck, bladder, melanoma, non-small cell lung cancer (NSCLC) and renal cell carcinoma (RCC) cancers and develop a conceptual model of the patient experience in these populations.

Methods

Searches

- A targeted literature search was conducted in OVID SP[®] (MEDLINE[®], Embase[®], PsycINFO) on October 10th 2023. Searches were limited to English language and to human subjects, and used relevant disease terms and/or methodological terms as key words and Medical Subject Headings. The literature search in breast cancer was limited to articles from the previous 10 years due to the extent of the literature available. Searches in the other cancer types were not limited by date. Review of the bibliographies of included articles and a supplementary Google Scholar search were also conducted to identify any additional articles.

Selection of studies

- Abstracts were considered eligible for full-text review based on the criteria in **Table 1**. Eligible abstracts were reviewed according to pre-defined ranking criteria based on study methodology (i.e. prioritization of qualitative or mixed-methods study designs) to inform the final selection of full-text articles to review.

Table 1. Eligibility criteria used in abstract screening

Inclusion criteria
Include if the source:
<ul style="list-style-type: none"> Includes adults (≥18 years of age), of any race or gender. Includes patients diagnosed at early stage (i.e. in general, stages I to III, excluding metastatic cancer or unresectable stages I-III, unless otherwise specified below) with at least one of the following cancers: <ul style="list-style-type: none"> Breast cancer Endometrial cancer (any histology – stages I to IVA) Head and neck cancer (stages I-IVA, including locally advanced) Bladder cancer (muscle invasive and non-muscle invasive) Melanoma NSCLC (squamous and non-squamous), including: <ul style="list-style-type: none"> Surgically treated early-stage patients with stage Ib-IIIa NSCLC (AJCC V7), corresponding to stage II, IIIA and resectable IIIB (T3-4N2) NSCLC (AJCC V8) Renal cell carcinoma (Stage I-IV; T1-T4, N0/M0). References or describes the patient experience of early-stage cancer in at least one of the 7 tumor types of interest (e.g., signs, symptoms and impacts of the disease, as reported directly by the patient). Qualitative, mixed-methods, or quantitative observational studies that explore or report the patient experience in at least one of the 7 tumor types of interest.
Exclusion criteria
<ul style="list-style-type: none"> Exclude if the source: <ul style="list-style-type: none"> Includes patients with metastatic or unresectable stages I-III cancers (unless specified otherwise in the inclusion criteria). Includes any cancer types other than those specified in the inclusion criteria. Reports information by anyone other than the patient (e.g., clinician or caregiver) and/or the information does not describe the patient experience of at least one of the seven early-stage tumor types of interest. Is not published in English.

Conclusions

- Findings from this review demonstrate the significant burden of diagnosis with and treatment for early-stage cancers, particularly in terms of fatigue, pain, and psychological well-being. This review supports the assessment of these concepts using patient-reported outcome measures in future clinical studies that inform early-stage cancer drug development and evaluation.
- Further qualitative research may help identify the most salient and clinically relevant concepts given the diverse range of concepts identified. Further qualitative research may also serve to generate data in populations where qualitative evidence in early-stage populations is currently lacking (i.e., RCC) or minimal (e.g., melanoma, NSCLC and bladder cancers).

References

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Acknowledgments

- Funding for this research was provided by Merck Sharp & Dohme LLC, a subsidiary of Merck & Co., Inc., Rahway, NJ, USA.

Results

Key findings

- N=48 eligible articles were selected for review (see QR code for full reference list). **Table 2** summarises the number of articles identified per cancer type.

Table 2. Articles identified per cancer type

Cancer type	Articles (N=48)
Breast	23
Endometrial	7
Head and neck	6
Bladder	5
Melanoma	4
NSCLC	3
RCC	0

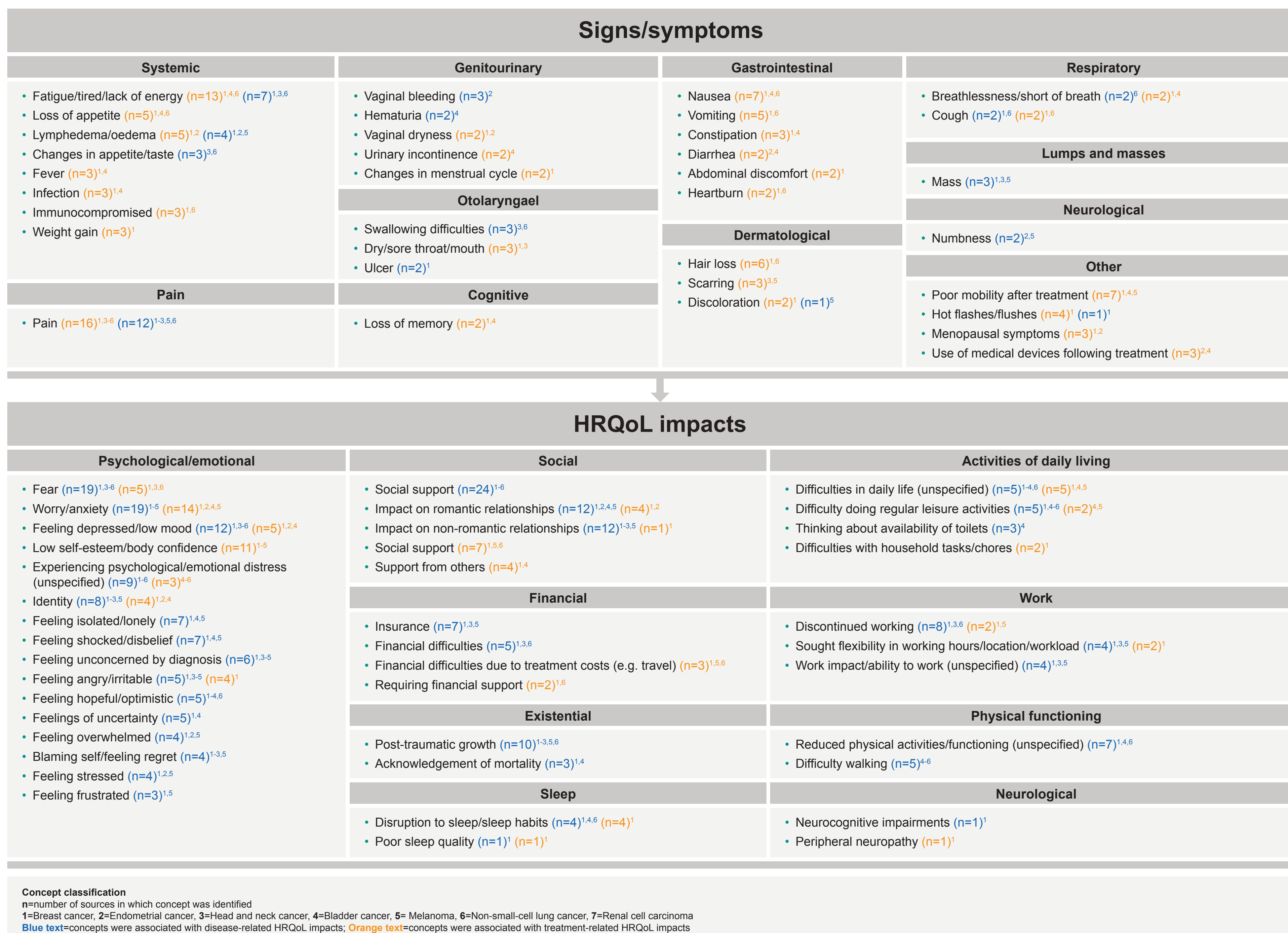
Signs/symptoms of early-stage cancers

- A total of 40 disease-related signs/symptoms and 25 treatment-related symptoms were identified across the included articles, some of which were identified as both disease- and treatment-related.
- Pain and fatigue were the most commonly reported disease- and treatment-related symptoms across the cancer types (breast, endometrial, head and neck, bladder, melanoma and NSCLC cancers); see **Table 3** for supporting quotes.
- Otherwise, signs and symptoms reported by early-stage cancer patients generally corresponded with the specific cancer and/or treatment site or type of treatment received. For instance, respiratory symptoms in NSCLC (e.g. breathlessness/short of breath and cough), otolaryngeal symptoms in head and neck cancer (e.g., swallowing difficulties), dermatological symptoms in melanoma (e.g. dry/scaly skin, skin discoloration) and genitourinary symptoms in endometrial and bladder cancers (e.g. haematuria and vaginal bleeding).
- Frequently reported treatment-related symptoms included urological symptoms following bladder cancer treatments (e.g. urinary incontinence), lymphoedema as a common complication of surgery and radiotherapy, and hair loss, vomiting and nausea as common side effects of chemotherapy.

HRQoL impacts

- A total of 52 disease-related HRQoL impacts and 25 treatment-related HRQoL impacts were identified across the articles, some of which were identified as both disease- and treatment-related.
- Psychological impacts were most frequently reported across cancers, primarily worry/anxiety, fear of recurrence, of their diagnosis, of dying, low mood/depression and low self-esteem due to treatment effects; see **Table 3** for supporting quotes. Other reported impacts included impacts on social life (e.g., impact on relationships), difficulties with activities of daily living, physical functioning (e.g., reduced physical activity) and impacts on finances and work (e.g., discontinued working).

Figure 1. Conceptual model of the most frequently reported disease- and treatment-related signs, symptoms and impacts in early-stage cancer



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Development of a conceptual model

- A conceptual model was developed following data extraction and review of all patient-reported concepts relevant to disease- and treatment-related signs/symptoms and HRQoL impacts of early-stage cancer according to the article content (see **Figure 1**).

Table 3. Example quotes of early-stage cancer experiences

Signs/symptoms (number of articles that reported the concept)	Example quotes
Pain (n=27)	<p>"Every day I'm battling pain which has totally changed me. I loved the way I was raised, I loved the priorities, I loved working hard, I loved physical activity, I loved being out in the woods, I like hiking, I like going camping. And all of those things are being taken from me."⁹ (Cross-tumor: breast, head and neck and lung cancers)</p> <p>"I felt pain in my leg bones and bodily aches for three days after receiving each chemotherapy cycle."¹⁰ (Breast cancer)</p>
Fatigue (n=18)	<p>"Oh I was dead beat. Slept in the morning, slept in the afternoon, slept at night, I've never felt tired like it."¹¹ (NSCLC)</p> <p>"By the fourth treatment I had reached a state of complete exhaustion. Ah... I got up in the morning I remember, and I fell in the shower. I couldn't hold myself up any longer."¹² (Breast cancer)</p>
HRQoL impacts (number of articles that reported the concept)	
Worry/anxiety (n=27)	<p>"At the time [diagnosis] I was extremely worried, as one would be."¹³ (Bladder cancer)</p> <p>"After receiving chemotherapy, I was worried about a decreased white blood cell count and afraid of infections, so I need to be in a hygienic environment."¹⁰ (Breast cancer)</p>
Fear (n=18) e.g., fear of cancer recurrence, diagnosis and dying.	<p>"...I hope that the fear of recurrence will subside. Sometimes it feels like I can't get it off my mind, especially when I have aches and pains. I assume the worst, which is just ridiculous. Why do I have to assume the worst? Why can't I assume the best? I feel shell-shocked."¹⁴ (Breast cancer)</p> <p>"Fear, screaming. It's a word [cancer] you don't ever want to hear. That was my initial reaction. I was sure that, at the time, this is it, I'm dying, this is it. I was absolutely petrified and absolutely scared to death."¹⁵ (Melanoma)</p>
Low mood/depression (n=15)	<p>"... the phase of depression is quite hard."¹⁶ (NSCLC)</p> <p>"I felt sad every day, especially in the dead of night. I dare not cry in front of them, I knew they were sad too. I could only whimper under the blankets, sometimes all night."¹⁷ (Breast cancer)</p>
Low self-esteem/confidence due to treatment (n=12)	<p>"I have a lot of self-esteem problems associated with the treatments. The skin where they radiated does not feel the same and my mouth is dry all the time. I have to drink water all the time and the scar is noticeable don't you think?"¹⁸ (Head and neck cancer)</p>

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