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REVIEW

Health-related quality of life domains relevant to people in Europe undergoing cancer treatment: a systematic review of qualitative research

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Abstract

Purpose To identify and synthesize evidence from European qualitative studies on cancer-related quality of life outcomes, needs, experiences, preferences, and concerns of people undergoing cancer treatment in the last decade.

Methods Systematic review (https://www.crd.york.ac.uk/PROSPERO, CRD42024575065) of European studies using qualitative methodology, assessing constructs related to HRQoL, and involving adults receiving cancer treatment. The search was performed in PubMed and Scopus from January 2013 to July 2024. Titles, abstracts, and full texts screening, data extraction and risk of bias assessment were conducted independently by two researchers. The main outcomes were the themes reported in each study. The thematic analysis was performed by organizing the themes of the studies into categories.

Results Out of 18,256 articles initially identified, 36 met the inclusion criteria: 21 with generic and 15 with specific objectives. Five categories encompassing 110 themes were identified from the generic studies: Psychological Function (n = 41), Clinical Management (n = 26), Symptoms and Physical Function (n = 18), Social Function (n = 16), and Life Disruption (n = 9). Eleven studies with specific objectives focused on clinical management with all their themes fitting within the categories identified in the generic studies.

Conclusions Results showed the predominance of psychological function and clinical management themes. Symptoms and physical function, social function, and life disruption maintained their importance within the classical HRQoL framework. The emergence of clinical management is consistent with the growing patient-centered care approach, suggesting the need to integrate this content into the evaluation of patients undergoing cancer treatment. Limitations: most European countries were not represented, and publication bias could hide traditional domains.

Keywords Quality of life · Cancer patients · Systematic review · Qualitative research

Plain English summary

Patients undergoing cancer treatment in Europe report many concerns that go beyond their physical symptoms. While traditional quality of life questionnaires often focus on symptoms and functioning, the 36 qualitative studies of our systematic review show that psychological well-being and experiences with the healthcare system are especially important to patients undergoing cancer treatment. The psychological well-being was the most mentioned aspect in

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the included studies, showing its key role from the patients' perspective. Patients also highlighted the need for clear and personalized communication, respectful and coordinated care, and being involved in treatment decisions. Our findings show the importance of expanding the content of health-related quality of life measuring tools to better reflect what matters most to patients receiving cancer treatment in Europe, helping health professionals and policymakers improve the support provided throughout the cancer process.

Introduction

The number of cancer diagnoses is expected to rise, with projections estimating an increase of 22.5% in Europe and 63.4% worldwide by 2045. In 2022, Europe accounted for 4.5 million new cases (22.4% of the world's cases) despite representing only 10% of the worldwide population [1].

Patient-reported outcome measures (PROMs) has been defined as "any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else" [2]. It is an umbrella term that covers different types of outcomes, such as symptoms, activity limitations, health status, health-related quality of life (HRQoL) and quality of life [3]. There is consistent evidence that the integration of PROMs into cancer care may improve overall survival and HRQoL [4–7]. People undergoing curative or life-prolonging cancer treatment face specific challenges, with symptoms and needs often fluctuating rapidly and treatment cycles significantly impairing their health-related quality of life (HRQoL) [8–11]. The integration of PROMs into cancer care enhances healthcare professionals' awareness and enables early identification and management of unmet needs during treatment [12, 13], resulting in improved HRQoL and clinical outcomes, reduced unplanned hospitalizations [14, 15], and, in some cases, increased survival [4, 6, 12, 16].

Despite this evidence, the monitoring of perceived symptoms and HRQoL remains underutilized in this population [17]. Advances in technology facilitate a broader implementation of HRQoL and other PROMs with a reduced administrative burden [18]. However, their limited adoption in routine oncologic care may stem from the content of the existing ones, which often either fail to fully reflect the evolving needs of this population or lack a clear applicability for clinical management and quality assessment [19, 20].

Moreover, the introduction of novel avenues for treatment—such as immunotherapy, targeted treatments, minimally invasive surgeries, and multimodal therapies—has transformed and further diversified the experiences of patients receiving cancer treatment [21] and the practical challenges they face [8, 22]. Frequent disruption of work and family life, accompanied by increased financial burdens, are some of the main practical challenges identified [23]. In this context, qualitative research has become essential for identifying emerging needs, concerns, and preferences among patients [24]. Incorporating such evidence from qualitative studies is crucial for the development of more relevant, patient-centered PROMs.

Despite the exponential rise in systematic reviews of qualitative studies in recent years, most published reviews are either tumor-specific or narrowly focused on specific aspects of the experiences of the cancer journey, such as one centered in studies of HRQoL in breast cancer patients [25], or another one on benefits and challenges of cancer peer support groups [26]. Nevertheless, none have addressed HRQoL constructs relevant to all patients undergoing cancer treatment. As a result, a comprehensive synthesis of qualitative research is still needed to identify HRQoL issues for this population.

The aim of this systematic review was to identify and synthesize evidence on cancer-related quality of life outcomes, needs, experiences, preferences, and concerns of people undergoing cancer treatment, from qualitative studies conducted in the last decade in European countries. This review presents one of the first steps of the 'Quality of Life in Oncology: measuring what matters to cancer patients and survivors in Europe' project [27–30], aimed at developing and validating a new questionnaire (EUonQoL-kit) to assess HRQoL in patients across the cancer care continuum in Europe. Although our final aim was to contribute to the development of a new HRQoL instrument, the focus of the systematic review was wider, to avoid the loss of relevant aspects due to the misuse of, and the confusion surrounding, concepts related to the term 'quality of life'. The synthesis of the qualitative evidence from this review, along with one focusing on people surviving cancer [31] and one on patients in need of palliative care [32], have contributed as sources of information for the selection of dimensions in the development process of the EUonQoL-kit. Lastly, this systematic review could also be of interest for the development of other HRQoL instruments designed specifically for people undergoing cancer treatment, particularly for identifying domains that are often underrepresented in traditional HRQoL conceptual models.

Methods

This study is a systematic review, presented in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (supplementary checklist) [33], with a registered protocol

(CRD42024575065; https://www.crd.york.ac.uk/PROSPERO).

Eligibility criteria

Studies were eligible if they employed qualitative methodologies, including mixed-method designs, and explored cancer-related quality of life outcomes, needs, preferences, concerns, or worries among persons undergoing cancer treatment. This included both curative treatments for early-stage cancers and non-curative tumor-directed therapies aimed at disease control or life prolongation in advanced or metastatic cases. Only peer-reviewed articles published in European languages were considered, with study populations drawn from the 27 European Union (EU) member states, the United Kingdom (UK), and 11 associated countries (full list of countries in supplementary Table 1).

Studies were excluded if they focused on children, adolescents, or young adults diagnosed with cancer at or below the age of 39 [34]; individuals surviving cancer or in need of palliative care; patients with multimorbidity; caregivers, partners or healthcare professionals; on tumor site-specific issues; or if data collection occurred exclusively before 2013, to capture the present situation of people undergoing cancer treatment after the introduction of relevant novel therapeutic procedures (i.e. immunotherapy, ambulatory administration of chemotherapy…) in the last decade that have changed their lived experiences.

Information sources

An initial search was carried out in the MEDLINE database via PubMed on March 6th, 2023. This search was later updated on July 8th, 2024, and expanded to include both MEDLINE and Scopus databases.

Search strategy

Supplementary Table 2 shows how the search strategy was structured into four main components: (1) population type, including individuals in any cancer care phase; (2) pathology, specifically neoplasms; (3) constructs of interest, such as quality of life or health status; and (4) terms addressing relevant issues such as preferences, concerns, or worries. In PubMed, both MeSH terms and free-text keywords were used to enhance sensitivity.

Several search strategies were evaluated to ensure that no qualitative studies were missed due to variations in terminology or indexing, and the final selection was based on comparing the sensitivity of two approaches to include well-known studies in the field: MeSH subheading–restricted search versus a wider strategy. The latter strategy was chosen because it produced 16% more references and higher capacity for including the relevant studies used for test.

Although the abovementioned search encompassed the full cancer care continuum as part of the EUonQoL project, the present report focuses specifically on individuals undergoing cancer treatment, given the distinct nature of their experiences compared to those of patients surviving cancer [31] or in need of palliative care [32].

Selection process

The screening process was managed using Covidence™ software (www.covidence.org). Each title and abstract was reviewed independently by two out of six researchers (CAF, CLB, OG, MF, LRC, MT), and discrepancies were resolved through discussion, with the involvement of a third reviewer.

Data collection process

Full-text review and data extraction were independently conducted by two out of eight reviewers (CAF, CLB, OG, YP, LRC, MT, OPC, PNS) for each article, using a customized extraction form developed specifically for this review. To ensure accuracy and completeness, a third researcher reviewed and validated the data extracted and resolved discrepancies.

Data items

The extracted data encompassed three main categories: study characteristics (author, aim, design, country and year of data collection, recruitment strategy, theoretical approach, and qualitative methodology); sample characteristics (tumor location, size, age, sex and stage of treatment); and reporting information (qualitative research guidelines followed, data saturation, and themes, subthemes, and verbatims). For mixed methods studies, only the information of the qualitative part was extracted for the analysis.

Study risk of bias

The risk of bias in the included studies was assessed using the Specialist Unit for Review Evidence Qualitative Studies Critical Appraisal (SURE) checklist [35]. This tool comprises 10 items, each rated as ‘Yes’, ‘No’, or ‘Can’t tell’. The same researchers who performed data extraction conducted this appraisal. Studies receiving a ‘No’ rating on three or more items were categorized as being of ‘poor quality’, acknowledging that the SURE checklist does not provide an overall score.

Outcomes

The primary outcomes of this review were the themes and subthemes identified in the included studies (along with specific verbatims when relevant), which were extracted literally from the source articles to preserve the original meaning and minimize interpretive bias.

Synthesis methods

The synthesis was based on Wilson and Cleary's original conceptual model of health-related quality of life (HRQoL) [36] and the Ferrans et al. 2005 revision [37], one of the most widely accepted frameworks in this field [38], since it also guided the development of the EUonQoL-kit. A thematic analysis was conducted by a team of researchers in two sequential phases: first, a deductive phase to organize the extracted themes and subthemes within the predefined domains of the Wilson and Cleary framework; and second, an inductive phase to identify emergent subcategories arising from the data coded in the original studies without trying to fit into any preexisting frame, following an iterative process until consensus was achieved [39]. In both phases, triangulation of the analysis was performed by 4 researchers—a physician, a biologist, an exercise physiologist, and a pharmacist—who had no experience in treating patients with cancer. Therefore, their preconceptions were shaped mainly by the literature review, and rather than attempting to set aside these preconceptions, the team explicitly acknowledged them by comparing the results of our systematic review with the Wilson and Cleary framework and critically engaged with them to enrich the interpretative process. The procedural rigor applied —including the triangulation by researchers with diverse health sciences backgrounds and qualitative methods knowledge and the interdisciplinary research team's reflexivity—ensures the findings' validity, and reliability.

Reporting bias assessment

To address potential reporting bias, a sensitivity analysis was intended by repeating the synthesis using only studies considered to be of good quality (with fewer than three SURE items rated as 'No'). To minimize the overrepresentation of narrowly focused studies in the overall synthesis, the primary analysis was restricted to studies with a generic objective on cancer-related outcomes, and secondary analyses were performed on studies with specific objectives. We defined studies with a generic objective as those that explored broad experiences, needs, preferences, concerns, or quality-of-life issues among people undergoing cancer treatment, without focusing on a single predefined construct. In contrast, studies with a specific objective were defined as those targeting a particular construct or topic (such as psychological distress or spiritual well-being).

Results

Study selection

A total of 18,256 articles were identified across PubMed and Scopus. Detailed information of the study selection process is described in the PRISMA flowchart (Fig. 1). After screening titles and abstracts, a complete full-text review of 1,207 manuscripts was carried out. The most frequent reasons for exclusion of studies at this phase were: not in the list of countries included (29.5%), not including a qualitative study design (17.8%), children, adolescents and young adults (14.4%), data collected prior to 2013 (14%), and not including outcomes of interest (10%). Finally, 36 qualitative studies on people undergoing cancer treatment fulfilled the inclusion criteria, 32 of which were purely qualitative and 4 were mixed-methods studies combining qualitative data with surveys: 3 with HRQoL questionnaires and one with importance ratings.

Study characteristics

A summary of the studies' characteristics is shown in Table 1. The countries in which more studies had been conducted were the UK (n = 10), Denmark (n = 8), the Netherlands (n = 6) and Sweden (n = 5). The data collection method most often used was semi-structured interviews (n = 25), and the most frequent samples were patients with various tumor locations (n = 11), hematological (n = 8) and prostate neoplasms (n = 5). Women represented 28–74% of the sample in 30 non-gender related cancer studies. Treatment stage was curative in 13 studies, non-curative treatments for advanced or metastatic cancers in 12 studies, active surveillance in 3 studies, and various stages of treatment in 8. A substantial portion of the studies aimed to explore cancer-related outcomes, experiences, needs, concerns, preferences and quality of life of people in treatment through generic objectives (n = 21) [40–60], but 15 studies focused on specific objectives: 11 on clinical management [61–71]; 2 on psychological distress [72, 73], 1 on working situation [74], and 1 on pain [75].

Risk of bias in studies

Supplementary Table 4 shows the detailed completion of the SURE checklist [35]. All 36 studies discussed ethical issues, made an appropriate choice of the qualitative methodology,

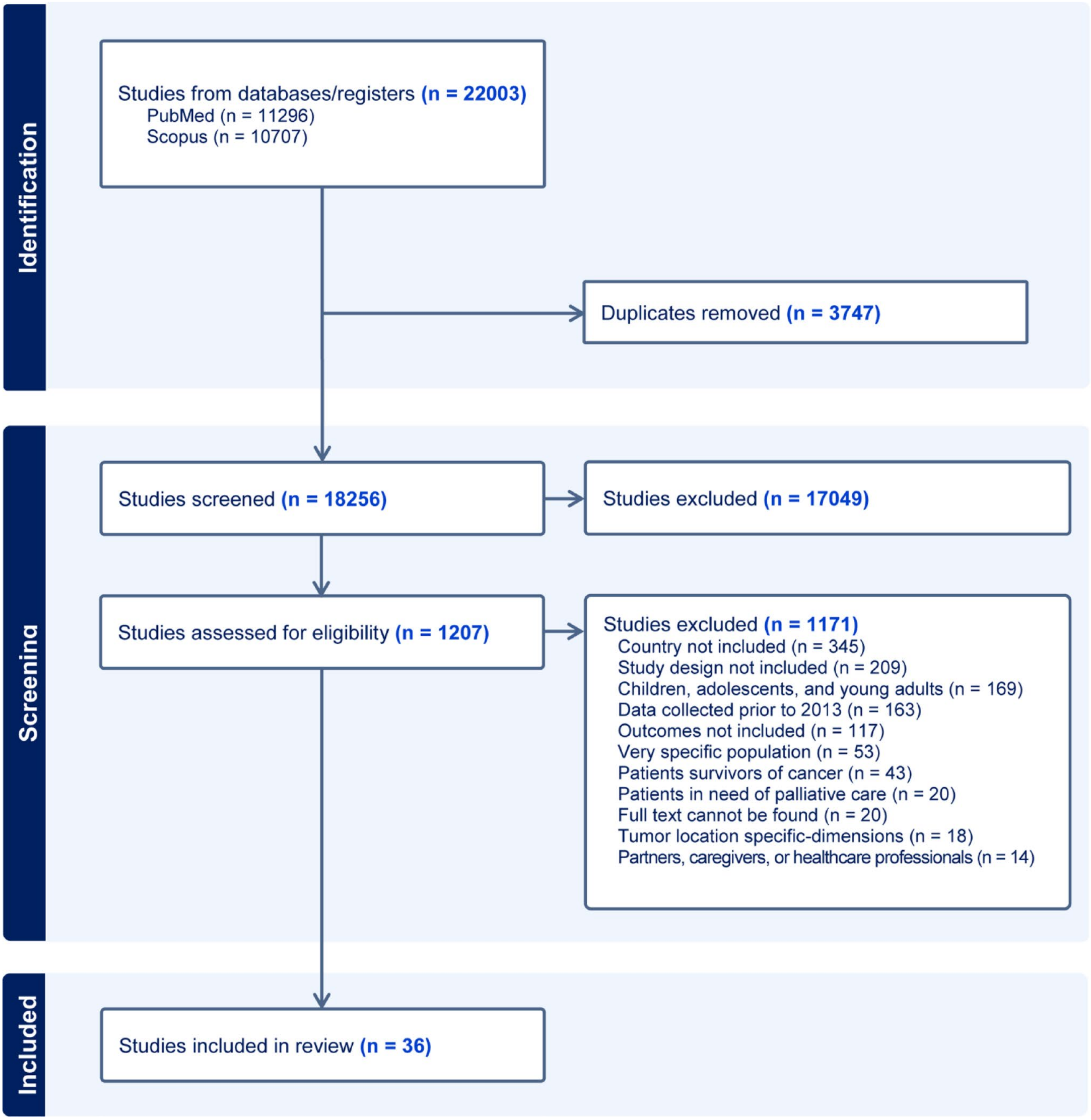

Fig. 1 Selection process overview – PRISMA flow-chart

and properly described and justified the analysis and interpretation process. More than 90% of the studies addressed a clearly focused question or hypothesis, presented credible findings, reported whether they had any conflict of interest, correctly identified the study's limitations, and clearly described their method of data collection. Sampling strategy was specified by 72.2% of studies, whereas the relationship between the researcher and the participant was reported in 33.3% of them. Only one study, focusing on how to help young people with cancer regarding their care needs, was assessed as 'poor quality' [40]. The sensitivity analysis was not performed because none of the themes from this study made up a significant part of any subcategory of the primary thematic analysis.

Results of individual studies

Table 2 shows the characteristics and themes identified in the studies with a generic objective, and supplementary Table 3 shows the information for those with a construct-specific

Table 1 Characteristics of the included studies

	Number of studies
Total	36
Country	
United Kingdom	10
Denmark	8
Netherlands	6
Sweden	5
Portugal	1
Italy	1
Ireland	1
Norway	1
Multiple countries	3
Year of publication	
2013–2016	4
2017–2020	11
2021–2024	21
Qualitative approach	
Semi-structured interviews	25
In-depth interviews	4
Focus groups	2
Semi-structured interviews and focus groups	2
Narrative medicine	1
Narrative analysis of relevant blogs	1
Photo-interviewing	1
Tumor location	
Multiple locations	11
Hematological	8
Prostate	5
Colorectal	2
Lung	2
Other locations	8
*Gender (% of women)**	
< 25%	0
25–49%	10
50–74%	12
≥ 75	7
Not specified	1
Treatment stages	
Curative treatment for early-stage cancers	13
Non-curative treatment for advanced/metastatic cancers	12
Active surveillance	2
Various stages of treatment	8
Focus	
General	21
Clinical management	11
Pain	1
Work	1
Psychological aspects	2

*Excluding gender-dependent tumors

objective. The 21 qualitative studies with a generic objective were mostly published in 2021–2024, with sample sizes ranging from 3 to 158 participants, and the number of themes was 90, ranging from 2 to 9 in each study. Supplementary Table 3 details the 67 themes emerging from studies with a specific objective, their sample sizes ranging from 7 to 48: 52 themes from studies focusing on clinical management, 7 from the studies on psychological distress, 4 from the study centered on the working situation and 4 from the one exploring pain.

Results of synthesis: primary thematic analysis of studies with generic objectives

Figure 2 integrates the findings of the thematic analysis within the conceptual model proposed by Wilson and Cleary [36], in which HRQoL is conceptualized as a multidimensional construct encompassing five interconnected components: Biological Function, Symptom Status, Functional Status, General Health Perceptions, and Overall Quality of Life. Alongside these 5 components, the Characteristics of the Individual and Environment are placed in parallel above and below the main line.

The 5 categories identified in the analysis of the 21 studies with a generic objective are visually representeds in rounded shadowed boxes, mapped onto the corresponding components of the framework. Symptoms & Physical Function' corresponds to Symptom Status, 'Psychological Function' and 'Social Function' primarily align with the component of Functional Status, and 'Life Disruption' corresponds to General Health Perceptions. Finally, the emerging 'Clinical Management' category was conceptually distinct from the main line of components of the original model and is therefore represented outside of it, aligned with the component Characteristics of the Environment. Table 3 presents the detailed thematic synthesis, with the 110 themes, subthemes or verbatims aggregated into the five overarching categories.

Psychological function

This category included the largest number of themes (41 out of 110), with 37 grouped under 3 subcategories: 'Coping with cancer and the new reality', 'Worries and fears related to treatment and controls' and 'Fearing and expecting death'. Only 2 themes in 'Shock of diagnosis', and 1 in 'Reminders' subcategories.

A1. 'Coping with cancer and the new reality' includes 20 themes describing how individuals prepared for treatment, adjusted to physical and mental changes, recognized emotional impact, regained abilities and embraced new opportunities, with several coping strategies:

> "A new project, new ideas, new beginnings… Before I had cancer, I would have said, 'Oh no, get someone

Table 2 Characteristics and results of included studies with generic objectives

Study (Author, Year, Country)	Methods (qualitative approach, data collection)	Participants (sample size, age, % women, treatment stage, tumor location)	Aim of study	Themes identified (as reported in the study)
Alander 2021 [40]Sweden	Phenomenology Narrative analysis of relevant blogs	n = 8 Range: 20–29 yrs 100% women Curative stage Does not specify	To explore the lived experience of young adults diagnosed with cancer and to increase our understanding of how to help them with their caring needs	-Interactions with Healthcare Personnel -Cancer Voyager
Almeida 2024 [41]Portugal	Phenomenology Semi-structured interviews	n = 7 Range: 22–78 yrs 57% women Curative stage Sarcoma	To enhance the understanding of the QoL challenges of Portuguese sarcoma patients, particularly by merging objective outcomes with their lived experiences	-Interrupted life – the impact of being diagnosed with sarcoma -Learning to live with sarcoma -Need for individualized care
Balmer 2015 [42]UK	Symbolic interactionism Photo-interviewing	n = 30 Range: 22–82 yrs 77% women Non-curative stage Multiple locations	To explore the experiences of living after cancer for people diagnosed with a poor prognostic cancer and contextualise it within the social and cultural representation of cancer in contemporary UK society	-A new normal -Looking towards the future -Reminders -A greater appreciation -The involvement of friends and family
Doveson 2020[43]Sweden	Does not specify Semi-structured interviews	n = 16 Mean: 72 yrs 0% women Non-curative stage Prostate	To explore the perspectives of men when facing life-prolonging treatment of metastatic Castration Resistant Prostate Cancer	-Considering treatment when the remainder of life is at stake -Preparing for the life-prolonging treatment after deciding to go through with it -Considering the prospect of the current life-prolonging treatment not being successful -Reflecting on death and dying in the light of a life-limiting illness
Eymech 2022[44]UK	Phenomenology Semi-structured interviews	n = 13 Mean: 66 yrs; Range: 57–74 yrs 0% women Active Surveillance Prostate	To qualitatively explore the experiences of patients with prostate cancer undergoing active surveillance and describe the effect this has on their wellbeing	-Mental wellbeing -Social wellbeing -Physical wellbeing
Giesinger 2018 [45]Spain, Poland, UK, Austria, the Netherlands, Italy	Does not specify Semi-structured interviews	n = 83 Mean: 60.3 yrs 49% women Various stages Multiple locations	To investigate what makes a symptom or functional impairment clinically important, that is, relevant for a patient to discuss with a health care professional	-Problem limits everyday life or daily functioning -Problem causes other problems -Emotional impact of the problem -Duration/frequency -Not normal/unexpected/change from normal -Help or treatment is needed -Emotional impact on family or partner
Graffigna 2017 [46]Italy	Narrative inquiry approach Narrative medicine	n = 158 Does not specify Does not specify Non-curative stage Myeloid leukaemia	Gain a deeper understanding of how patients suffering from chronic myeloid leukaemia cope with their illness	-Chronic myeloid leukaemia illness burden -The chronic myeloid leukaemia illness journey: from deep darkness to renewed hope
Jakobsson 2017 [47] Sweden	Phenomenology In-depth interviews	n = 10 Mean: 70.5 yrs 70% women Curative stage Colorectal	To describe the lived experience of recovery during the first 6 months after colorectal cancer surgery	-Physical powerlessness -Difficulties with food intake -Altered bowel function -Dependency on others

Table 2 (continued)

Study (Author, Year, Country)	Methods (qualitative approach, data collection)	Participants (sample size, age, % women, treatment stage, tumor location)	Aim of study	Themes identified (as reported in the study)
Jepsen 2016 [48]Denmark	Phenomenology Semi-structured interviews	n = 26 Mean: 56,7 yrs; Range: 26–74 yrs 50% women Curative stage Acute leukaemia	To elucidate how patients with acute leukaemia experience the different conditions of the inpatient and outpatient settings and how they reflect on these transitions in order to create meaning in and keep up everyday life	-Everyday activities -Privacy -Social relations -Patient involvement in care
Lee Mortensen 2018 [49] Denmark	Does not specify Focus groups	n = 18 Mean: 57.2 yrs; Range: 41–72 yrs 100% women Non-curative stage Breast	To explore in depth the HRQoL of Danish metastatic breast cancer patients of all ages and how this might be related to their support needs	-Quality of life impact of metastatic breast cancer -Treatment and support needs
Matheson 2021 [50]UK	Phenomenology Semi-structured interviews	n = 24 Mean: 66.3 yrs; Range: 46–77 yrs 0% women Non-curative stage Prostate	To explore the experiences of all interviewees living with stage IV hormone-responsive prostate cancer, drawn from the total sample of interviewed men. To explore the influences on their perceived QoL and to highlight how support services could be optimized, as few interventions have addressed the needs of this growing population of men	-Connectedness to others -Engagement in meaningful activities -Adjustment strategies -Having resources to self-manage -Managing uncertainties -Support, communication, and information from health professionals
Nielsen 2021[51]Sweden	Does not specify Semi-structured interviews	n = 60 Mean: 68.3 yrs 28% women Curative stage Oesophageal	To examine the advice that patients who had oesophageal cancer surgery would like to share to future patients, based on their lived experiences	-Health promoting advice -Acknowledging the new situation -Advise on embracing support from others
Osborne 2014[52]UK	Does not specify Semi-structured interviews and focus groups	n = 51 Median: 64 yrs; Range: 41–81 yrs 41% women Curative stage Multiple myeloma	To (1) explore the issues important to QoL from the perspective of people with multiple myeloma, and (2) explore the views of patients and clinical staff on existing QoL questionnaires and their use in clinical practice	-Biological Status -Treatment Factors -Symptom Status -Activity & Participation -Emotional Status -Support Factors -Expectations -Adaptation & Coping -Spirituality
Petri 2015 [53]Denmark	Phenomenology Open qualitative interviews	n = 3 Range: 65–72 yrs 33% women Curative stage Lung	To explore and describe the essential meaning of lived experiences of the phenomenon: Everyday life during curative radiotherapy in patients with non-small-cell lung cancer	-Radiotherapy as a life priority -A struggle for acceptance of an altered everyday life -Interpersonal relationships for better or worse -Meeting the health care system
Schölvinck 2019[54]the Netherlands	Grounded Theory Semi-structured interviews and focus groups	n = 33 Mean: 60 yrs 53% women Various stages Haematological	To identify and prioritise everyday problems and research needs of haematological cancer patients and people who have undergone a stem cell transplantation	-Diagnosis and treatment of haematological cancer -Physical problems -Psychosocial problems -Problems in/around healthcare system -Societal problems -Anxiety for the future and a diminished quality of life

Table 2 (continued)

Study (Author, Year, Country)	Methods (qualitative approach, data collection)	Participants (sample size, age, % women, treatment stage, tumor location)	Aim of study	Themes identified (as reported in the study)
Sonsby 2023 [55]Denmark	Phenomenology Semi-structured interviews	n = 14 Median: 73 yrs; IQR: 65–80 yrs 36% women Curative stage Haematological	To explore whether patients with multiple myeloma change their construct of HRQOL while undergoing treatment to six months thereafter	-Insecurity -Coping
Stewart 2023 [56]Ireland	Phenomenology Semi-structured interviews	n = 10 Range: 59–84 yrs 30% women Active surveillance Bladder	To investigate the lived experience of non-muscle invasive bladder cancer patients attending surveillance cystoscopy	-Being Diagnosed and Treated for NMIBC -Grappling with the Illness -"I Don't Treat It as a Problem. I Treat It as an Issue"
Van Dongen 2022 [57] the Nehterlands	Does not specify Semi-structured interviews	n = 14 Mean age 55,5 86% women Various stages Multiple locations	To explore (1) the challenges and controversies patients experience in managing vaginal, vulvar, penile or anal cancer; their unmet needs; and how this affects their psychosocial functioning and (2) the gaps health care professionals experience in providing psychosocial support and potential improvements in care	-Recognisable symptoms, but unfamiliar diagnosis -Double hit has severe impact on psychosocial functioning -Personal and tailored information is important but not guaranteed -All-encompassing care to improve psychosocial functioning and QoL
van Overveld 2018 [58] the Netherlands	Does not specify Semi-structured interviews	n = 12 Mean: 59.5 yrs; Range: 50–67 yrs 50% women Various stages Head & Neck	To identify all possible needs and preferences of Dutch patients with head & neck cancer in integrated care to obtain tools to make current integrated head & neck cancer care more patient-centered	-Respect for patient-centred values -Coordination and integration of care -Information, communication, and education -Physical comfort -Emotional support and alleviation of fear and anxiety -Involvement of family and friends -Transition and continuity of care -Access to care
Zanotto 2023 [59] UK	Phenomenology Semi-structured interviews	n = 12 Mean: 42 yrs; Range: 29–54 yrs 83% women Various stages Brain	To gain an in-depth understanding of the lived experience of adjustment to living with a brain tumor	-Making Sense of the Diagnosis -Seeking Empowerment -Feeling Appreciative -Taking Charge of Coping -Learning to Accept -Negotiating a New Normality
Zwanenburg 2024 [60] the Netherlands	Does not specify Semi-structured interviews	n = 17 Mean: 56.4 yrs 65% women Non-curative stage Multiple locations	To gain a deeper understanding of long-term responders lived experiences with obtaining a long-term response to immunotherapy or targeted therapy	-Twilight zone: Neither feeling like a patient nor feeling healthy -Living with uncertainty: Going back and forth between hope and despair -Struggling to adapt to a life with cancer

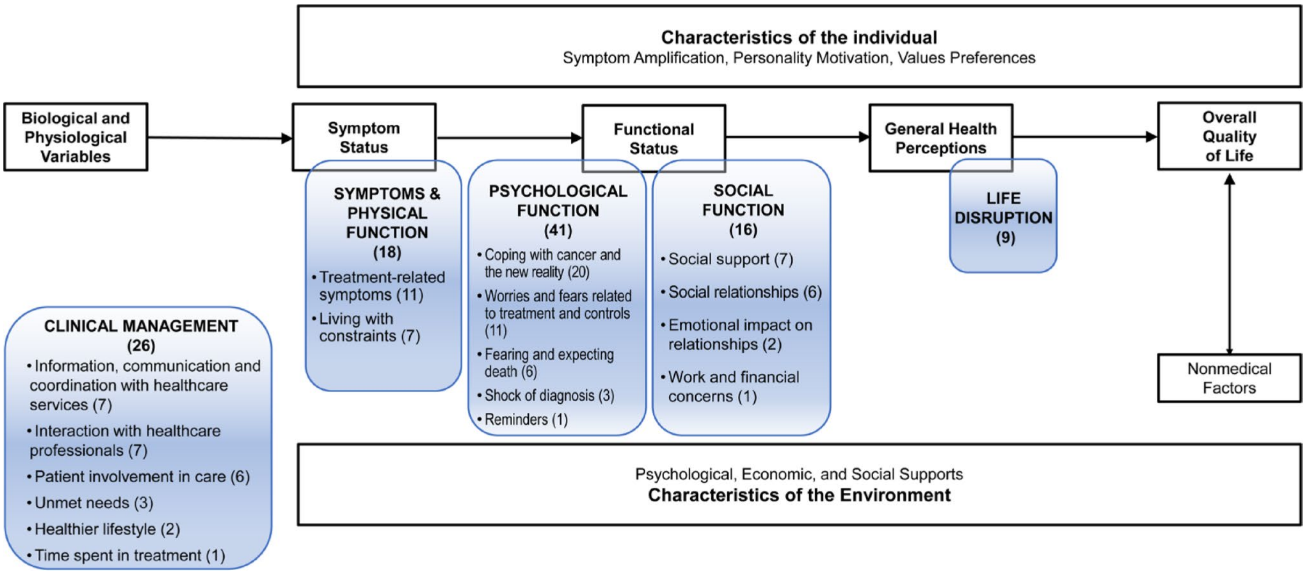

Fig. 2 Overview of the results of the primary thematic analysis of qualitative studies with a generic objective within the Wilson and Cleary HRQoL framework [36]. Clear boxes show the framework developed by Wilson and Cleary [36]. Colored boxes show the categories and subcategories that emerged from the primary thematic analysis (number of themes/subthemes identified in the studies)

> else to [refurbish the boat]'… but I said, 'OK, yes, why not? I'll do it.'" [42]

A2. **'**Worries and fears related to treatment and controls' includes 11 themes describing emotional responses to treatment and monitoring, as well as feelings of uncertainty about the future and of anxiety related to test results. Participants reported ongoing fear, emotional disequilibrium around diagnosis and follow-up, and an emotional strain linked to less common or stigmatized cancer types. One participant explained:

> "If causing me too much worry, it would eventually push me into mentioning it, whether it was pain or struggling mood-wise." [45]

A3. 'Fearing and expecting death' includes 6 themes regarding the sudden change in life expectations, the consideration of unsuccessful life-prolonging treatment, the never-ending uncertainty of disease progression, and the thoughts of leaving their families and the burden they will have to carry.

Clinical management

This category included 26 themes grouped mainly into three subcategories: 'Information, communication and coordination with healthcare services'; 'Interaction with healthcare professionals'; and 'Patient involvement in care'.

B1. The 7 themes in 'Information, communication and coordination with healthcare services' described the need for clear, timely, personalized communication, having clarity in care processes, and discussing persistent symptoms with professionals, as reported by a participant:

> "I think I should discuss the symptoms with the doctors when these symptoms have lasted for some days and do not disappear." [45]

B2. 'Interaction with healthcare professionals' includes 7 themes focusing on the quality of interactions, limited time for individualized attention, and the importance of privacy. Participants described both supportive and alienating encounters:

> "The nursing staff does not have the time necessary to listen properly to the patients, allow them to vent, and for the person to say whatever they need." [41]

B3. 'Patient involvement in care' themes described how patients engaged in their care, making treatment decisions based on prognosis, adapting behavior according to medical advice, and seeking empowerment through information. One participant reflected:

> "Sometimes you have to decide within 4 h for the rest of your life! [regarding a fertility-saving surgical procedure]" [54]

Symptoms & physical function

C1. The 11 themes in 'Treatment-related symptoms' described a range of physical symptoms attributed to cancer

Table 3 Themes and subthemes (or verbatims) distributed into categories of studies with generic objectives

A. PSYCHOLOGICAL FUNCTION (41 themes)	
A1. Coping with cancer and the new reality (20 themes)	
*Cancer Voyager [40]	Life in limbo and finding hope
Learning to live with sarcoma [41]	"It affected me… Before I was a more active person, I moved more, and now I feel more trapped"
Looking towards the future [42]	"I also remember the first time that I got up the stairs because it felt like such a huge achievement, and I quite often think now as I go up and down stairs, you know, I remember when I couldn't go up and down these, so that's great."
A greater appreciation [42]	"A new project, new ideas, new beginnings, and the fact that it's sort of new avenues opening up and new chances and opportunities that didn't really exist before—and the courage to go and do them … Before I had cancer, I would have said, 'Oh no, get someone else to [refurbish the boat]' … but I said, 'OK, yes, why not? I'll do it.'"
Preparing for the life-prolonging treatment after deciding to go through with it [43]	"I probably won't… do as much work now when going through the chemotherapy because the body, it needs to be … be as stable as possible. That's the most important thing of all"
*Mental wellbeing [44]	Recognition of the Impact
Chronic myeloid leukaemia illness burden [46]	Chronic myeloid leukemia: the "fight"; The promise of recovery
*The chronic myeloid leukaemia illness journey: from deep darkness to renewed hope [46]	The "hope"
*Quality of life impact of metastatic breast cancer [49]	Psychological; Strategies to cope with MBC
Adjustment strategies [50]	Planning ahead; Reappraisal of masculinity and sexuality
Acknowledging the new situation [51]	An optimistic approach; To persevere
Adaptation & Coping [52]	"Myeloma you can't cure. It's there to stay, that's it, so I accept it. It's when you don't accept it you get problems. But I accepted it and take it."
Spirituality [52]	"I just think it's my faith that restores everything, restores my hope, my ability to do what I used to do"
Coping [55]	Adjusting expectations to abilities; Expanding social networks; Exploring a meaningful life
"I Don't Treat It as a Problem. I Treat It as an Issue" [56]	Managing burden and isolation; Reappraising the label and response; Keeping emotions at bay
Feeling Appreciative [59]	Gratitude towards healthcare; Appreciation for small things
Taking Charge of Coping [59]	Developing personal strategies; Emotional regulation
Learning to Accept [59]	Coming to terms with uncertainty; Adjusting expectations
*Psychosocial problems [54]	"I was naive to be thinking, in a few years I'll be my old self again."
Grappling with the Illness[56]	"He said, "No, we're going to get rid of that. Now there's nothing to worry about." And he kept saying that — he must have said it about three times — and I believed him."
A2. Worries and fears related to treatment and controls (11 themes)	
*Cancer Voyager [40]	Physical and mental changes due to cancer treatment; Ongoing fear
*Mental wellbeing [44]	Emotional Diagnostic Disequilibrium; Unsettling Monitoring Cycle; Future Problem
Emotional impact of the problem [45]	"If causing me too much worry, it would eventually push me into mentioning it, whether it was pain or struggling mood-wise."
*The chronic myeloid leukaemia illness journey: from deep darkness to renewed hope [46]	The shock; The anxious alert; The depressive acceptance
*Treatment and support needs [49]	Worries related to treatment and controls
Managing uncertainties [50]	Adapting to uncertainty; Concerns about PSA testing
Emotional Status [52]	Low mood, frustration and anger, bodily violation
*Treatment Factors [52]	Chemotherapy, hickman line, steroids
Insecurity [55]	Concerns about having a meaningful life; Concerns about dealing with everyday limitations
Double hit has severe impact on psychosocial functioning [57]	Most patients were struggling with their feelings about the existing taboo on those body parts frequently associated with sexual activity and their cancer being located in that intimate area. […] it would have been less complicated if they were diagnosed with a common cancer, since these are well known and more accepted in society
Living with uncertainty: Going back and forth between hope and despair [60]	Fear of progression; Hope despite uncertainty; Scan-related anxiety
A3. Fearing and expecting death (6 themes)	
Expectations [52]	"It is the emotional side… saying goodbye…. you don't want that, yeah, not at forty-nine… you want to live on another twenty years at least… Too much to do, too much to see… see the grandchildren grow up"

Table 3 (continued)

A. PSYCHOLOGICAL FUNCTION (41 themes)	
Considering the prospect of the current life-prolonging treatment not being successful [43]	"For some, it [the treatment] just works for a couple of months but for some it can apparently work for … longer than for others. And I must hope … and believe that I'm in that category at least. No … but of course, if it comes to it … then I will have to … undergo radiotherapy or … chemotherapy and so on"
Reflecting on death and dying in the light of a life-limiting illness [43]	"No, I can't say I do [think about death]. It's on and off, off and on. But no, not a lot. In some weird way I keep it at a distance. But sure it comes to mind sometimes …"
*Psychosocial problems [54]	"For my spouse, it [untimely death] will be a financial burden, I think, […] She will have to continue on her own. The children will miss their dad. They are a little older […] but still, losing your father at that age is terrible"
Diagnosis and treatment of haematological cancer [54]	"It feels like you're never really cured, it can return any moment. Do I have a year, or ten years to live? That uncertainty is hanging above my head."
Anxiety for the future and a diminished quality of life [54]	"For me, I'm worried to die in a really ugly way"
A4. Shock of diagnosis (3 themes)	
*Quality of life impact of metastatic breast cancer [49]	Reactions to diagnosis
Making Sense of the Diagnosis [59]	Shock and disbelief; Lengthy diagnosis process
Interrupted life – the impact of being diagnosed with sarcoma [41]	"For me it was a big blow to my life, it was a big blow"; "I was so unhappy when I heard about the diagnosis, I had depression for two years"
A5. Reminders (1 theme)	
Reminders [42]	"I didn't want cancer to define me as a person—that was something I went through—but I think without realizing it, it does a bit."
B. CLINICAL MANAGEMENT (26 themes)	
B1. Information, communicationcoordinationwith healthcare services (7 themes)	
Duration/frequency [45]	"I think I should discuss the symptoms with the doctors when these symptoms have lasted for some days and do not disappear."
Support, communication, and information from health professionals [50]	Positive experiences with care; Need for more psychological support
Personal and tailored information is important but not guaranteed [57]	Most patients stated the necessity of clear information about the disease, treatment, residual symptoms and available psychosocial care. The received information partly depended on the type of hospital where they were treated. While information was frequently not sufficient in a regional hospital, most patients treated in a CoE did not share this experience. Patients often assumed that HCPs working in a Center of Expertise have more knowledge about these rare cancers than HCPs working in a regional hospital
Coordination and integration of care [58]	Clarity about healthcare process; Personalised involvement of allied health professionals; Availability of a contact person; Involvement of oncology nurse and peers as personal experts; Personalised involvement of peers; Personalised diagnostic phase; Home care for both patient and partner
Information, communication, and education [58]	Communication, information and education meets requirements; Training of health professionals; Personalised communication, information and education; Stimulation of perseverance of patients; Patients want to contribute to improvement in health care; Training of professionals in the home care; Transparent health care
Transition and continuity of care [58]	Good transfer from health professionals in the hospital to health professionals in the home situation; Involvement of GP in aftercare for optimal transfer; Cooperation of allied health professionals and hospital for optimal transfer
*Problems in/around healthcare system [54]	"It's tough, but in the medical world we are all just a number"
B2. Interaction with healthcare professionals (7 themes)	
Interactions with Healthcare Personnel [40]	Perceptions of information received from healthcare personnel; Alienating versus supporting encounters
Need for individualized care [41]	"The nursing staff does not have the time necessary to listen properly to the patients, allow them to vent, and for the person to say whatever they need. There should be someone with more time for conversation or more prepared to understand what's going on"

Table 3 (continued)

B. CLINICAL MANAGEMENT (26 themes)	
Privacy [48]	"Completely depending on my wellbeing – If I was feeling good I got a requisition and we took our meals at the patient hotel. My husband and I did that a few times when we got visit here [at the hospital]. And then privacy was ensured because over there you just found a corner where you could sit and hang for hours if you wanted. We did that some times. It was a way to get some privacy. But it was only possible in the periods when I felt good; otherwise I simply didn't have the strength for it."
Meeting the health care system [53]	"I felt safe, I felt very comfortable in the relationship... and several of them [radiation therapists] also had a spark of humor."
All-encompassing care to improve psychosocial functioning and QoL [57]	Patients were divided in their answers about whether they needed psychosocial care. While some patients did not feel the need to discuss their feelings with a psychologist or a sexologist, the majority did. However, they did not always know where to go for psychosocial care
Physical comfort [58]	Involvement of allied health professionals for physical support; Solutions for limitations of medical devices
Emotional support and alleviation of fear and anxiety [58]	Personalized psychological support for emotional problems; Attention to the impact of HNC and its treatment; Personalized involvement of peers for emotional support; Emotional support of GP in aftercare
B3. Patient involvement in care (6 themes)	
Considering treatment when the remainder of life is at stake [43]	"In no way have I imagined that I will all of a sudden be completely cured. But … that … well, that I can … keep going and feel well a little longer than I would otherwise have done [without treatment]."
*Chronic myeloid leukemia illness burden [46]	Patients' ambivalent connection to their drug
Patient involvement in care [48]	"Well, you don't go home and start eating honey or blue cheese as you usually do. You don't go out gardening and you don't start helping out with the reconstruction of the bathroom your brother is doing upstairs. […] So in a way, they [the special precautions] have influenced my behavior – but it's been – interfering with manageable areas."
Respect for patient-centered values [58]	Personalized care regarding patient values; Assertiveness relevant in personal health care; Emotional support towards inability to speak; Hospital facilities; Doctor-patient relationship; Disease physically demanding as a single
Seeking Empowerment [59]	Gaining control through information; Making treatment decisions
* Problems in/around healthcare system [54]	"Sometimes you have to decide within 4 h for the rest of your life! [regarding a fertility-saving surgical procedure]"
B4. Unmet needs (3 themes)	
Help or treatment is needed [45]	"I have been depressed for a period of time and I wanted to talk to my doctor on this topic. Maybe he could give me some medication for this low mood."
*Treatment and support needs [49]	Treatment needs; Socio-economical clarification; Psychological counselling; Information needs
Access to care [58]	Delay due to GP, dentist, general hospital, and the patients themselves; Short waiting times in hospital and before operation; Waiting time necessary for recovery between two treatments
B5. Healthier lifestyle (2 themes)	
*Physical wellbeing [44]	Healthier Lifestyle
Health promoting advice [51]	The importance of physical activity; A changed eating pattern; Preparing for a life after cancer
B6. Time spent in treatment (1 theme)	
*Treatment and support needs [49]	Minimizing time spend on treatment
C. SYMPTOMS & PHYSICAL FUNCTION (18 themes)	
C1. Treatment-related symptoms (11 themes)	
*A new normal [42]	"A battery is the fatigue … the fatigue has hit me hard … more so than anything else because that affects everything that you do and what you can manage to do in a day."
*Physical wellbeing [44]	Symptomatic Overshadowing
Physical powerlessness [47]	(…) they experienced great physical powerlessness: taking even a few steps required a great deal of effort. Powerlessness was accompanied by sensations of dizziness and reduced body control, which initially induced a need for support from the nursing staff or physiotherapist in combination with different walking aids in order to dare to mobilize. […] Most participants experienced substantial powerlessness during the first month after surgery. However, at the 1-month interview, they could sense that they were regaining strength, a transformation they sometimes regarded as rapid
Difficulties with food intake [47]	"It wasn't tasty. Not tasty at all. …You just didn't feel hungry. …It is like you have a lump here in the stomach saying 'stop'. And sometimes even a feeling of nausea. …I drank, I did. And I got those dietary supplements, and I tried to eat a little of what I felt was eatable… I complemented with other things that perhaps weren't so nutritious."

Table 3 (continued)

C. SYMPTOMS & PHYSICAL FUNCTION (18 themes)	
Altered bowel function [47]	"When I need to, I can go six, seven times, but I don't feel it until the very last moment… And it is like, they want me to come and visit at work. Well, I don't dare because I don't dare to get on a bus. If it starts like that in the morning, then I have to stay home because I don't know when it settles, so to speak. … It is the only thing that worries me."
*Quality of life impact of metastatic breast cancer [49]	Cognitive; Physical
Biological Status [52]	Bone lesions, fractures
*Treatment Factors [52]	Chemotherapy, hickman line, steroids
Recognizable symptoms, but unfamiliar diagnosis [57]	All patients stated that they recognized symptoms like itching, pain and/or loss of blood, before going to the general practitioner. However, they frequently linked these symptoms to more common diseases, e.g., hemorrhoids, since they were unfamiliar with and did not expect it to be cancer
*Cancer Voyager [40]	Physical and mental changes due to cancer treatment
*Physical problems [54]	"Around three pm, a blanket of fatigue covers me. […]. I simply can't do anything anymore, not even drive home from work."
C2. Living with constraints (7 themes)	
*A new normal [42]	"A battery is the fatigue … the fatigue has hit me hard … more so than anything else because that affects everything that you do and what you can manage to do in a day."
Problem limits everyday life or daily functioning [45]	"When I do not sleep well, I may feel tired during the day, and this may limit my daily activities."
*Chronic myeloid leukemia illness burden [46]	Daily life with the disease
Everyday activities [48]	"I actually do the same things as I used to, but I do them slower, and I may only manage half."
Engagement in meaningful activities [50]	Staying active; Feeling restricted due to symptoms
Activity & Participation [52]	Mobility, activities of daily living, sex and intimacy, work life
*Physical problems [54]	"After the transplantation I could not multitask anymore. Well, especially for a woman, that's a surprise! And it's hard, too."
D. SOCIAL FUNCTION (16 themes)	
D1. Social support (7 themes)	
The involvement of friends and family [42]	In all, 18 participants included at least one photograph of, or representing, friends or family members who had been supportive towards them and described their gratitude towards them
*Social wellbeing [44]	Importance of Social Support Network
Dependency on others [47]	…My husband had to cook and everything like that, and it was like I was just up to eat… But thereafter, I felt like I started to help a little by doing the dishes, and suddenly one day I was peeling potatoes… Then yesterday I did the most by myself
Having resources to self-manage [50]	Social support; Financial stability
Advise on embracing support from others [51]	To trust health care professionals; To receive support from family and friends
Support Factors [52]	Financial, housing
Involvement of family and friends [58]	Good carer makes allied health professionals and peers less relevant; Personalized involvement of family
D2. Social relationships (6 themes)	
Social relations [48]	"I'm there when they come home from school, right. I'm there for dinner. I'm there to say good night, when they need a bath and when they are doing homework and all those everyday stuff that you do as a family. That I'll say means a whole lot."
*Quality of life impact of metastatic breast cancer [49]	Social/relational QoL aspects of metastatic breast cancer
Connectedness to others [50]	Emotional closeness; Feeling inadequate in relationships
Interpersonal relationships for better or worse [53]	"I had no recurring person [family and friends]... they couldn't really keep up with me so I cheated; I said that I had eaten, but it was a lie."
*Psychosocial problems [54]	Related to changing social relationships, loneliness is fueled by societal problems, […], and by restrictions on being in large groups due to […] treatment
*Societal problems [54]	In addition to the stigma, participants face incomprehension as their disease is "invisible," while their physical constraints are not
D3. Emotional impact on relationships (2 themes)	
*Social wellbeing [44]	Concealment of Diagnosis
Emotional impact on family or partner [45]	"I would only discuss this if my family would be worried about this."
D4. Work and financial concerns (1 theme)	

Table 3 (continued)

D. SOCIAL FUNCTION (16 themes)	
*Societal problems [54]	“Well I do remember, the moment I received that call from the [employee insurance agency] to tell me I was unfit for work, yes that gave me some good cries”
E. LIFE DISRUPTION (9 themes)	
Problem causes other problems [45]	"If I feel my physical status limits my intimacy with my husband."
Not normal/unexpected/change from normal [45]	"As a consequence, I am tired during the day and I cannot work as I used to do before the disease."
Symptom Status [52]	Symptoms were commonly reported by participants as affecting QOL, although only by impacting on other issues (Emotional Status, Activity & Participation, Support Factors)
Radiotherapy as a life priority [53]	"Life is immediately put on hold … so a normal everyday life didn’t concern me because everything evolved around treatment and only completion of the treatment was important, so everything else didn’t matter."
A struggle for acceptance of an altered everyday life [53]	“Yes it has been tough, because I haven’t had the energy to do anything else than radiotherapy... those [other patients seen in the waiting area] who just come in, get the treatment and are off to work, it must be damn great.”
Being Diagnosed and Treated for NMIBC [56]	Experience of diagnosis; Bladder cancer as a physical entity
Negotiating a New Normality [59]	Adapting to changes in daily life; Work identity
Twilight zone: Neither feeling like a patient nor feeling healthy [60]	Shifting identity; Feeling misunderstood; Social perception of health status
Struggling to adapt to a life with cancer [60]	Loss of a carefree life; Difficulties making future plans; Changes in social and work life

*Themes categorized into more than one category or subcategory according to the content of the subthemes

or its treatment, such as fatigue, gastrointestinal issues, cognitive changes, and side effects from medication or medical devices. A participant expressed:

> “A battery is the fatigue … the fatigue has hit me hard … more so than anything else because that affects everything that you do and what you can manage to do in a day.” [42]

C2. The 7 themes in ‘Living with constraints’ highlighted limitations in daily activities participation due to physical symptoms or reduced energy causing the need to adapt routines:

> “I actually do the same things as I used to, but I do them slower, and I may only manage half.” [48]

Social function

This category included 16 themes grouped into 4 subcategories: ‘Social support’ (7 themes), ‘Social relationships’ (6 themes), ‘Emotional impact on relationships’ (2 themes), and ‘Work and financial concerns’ (1 theme).

D1. ‘Social support’ referred to the importance of networks of partners, family and friends, and their reliance on other people for their basic activities:

> “… without her [wife], it wouldn’t have been such an experience for me where I felt confident about going forward.” [44]

D2. ‘Social relationships’ emphasized the possibility to stay at home, to maintain the sense of normalcy, as well as the social engagement with fellow patients.

Life disruption

This category included 9 themes describing the sudden change in lifestyle, relationships, self-identity, mental health, and their social and work life, as well as their difficulties in adapting to these changes and the uncertainty of the prognosis:

> “When it seemed certain that I was going to die, it was super intense. Then it turned out that there’s therapy, which could make me live for another two or three years. That was very nice, yet also difficult, because it is also very uncertain.[…] It’s like death row without an execution date.” [60]

Results of synthesis: secondary thematic analysis of studies with specific objectives

The results of the thematic analysis from the 15 studies with specific objectives are shown in supplementary Tables 5–8. Supplementary Table 5 shows the thematic analysis for the 11 studies focused on clinical management, from which 41 themes emerged, mostly in the subcategories ‘Information, communication and coordination’ (14 themes) and ‘Unmet needs’ (15 themes), both subcategories present also in the primary thematic analysis. Interestingly, a new subcategory of ‘Individual emotional support’ emerged within the ‘Psychological function’ category. Supplementary Table 6 presents the results from studies centered on psychological aspects, in which 6 out of the 13 themes identified were classified under the category ‘Clinical management’, and 4 of the themes under ‘Social function’. The thematic analysis of the study focused on work, in supplementary Table 7, resulted in 3 out of the 4 themes classified under ‘Social function’. Supplementary Table 8 shows the thematic analysis from the single study focused on pain revealing 4 themes distributed among the categories of ‘Psychological function’, ‘Symptoms & physical function’, and ‘Social function’. Finally, the supplementary figure illustrates that the pattern of results of these secondary analyses is similar to the results obtained in the primary analysis.

Discussion

The review of qualitative studies on outcomes, needs, experiences, preferences, concerns, and quality of life for people in Europe in active treatment for primary or metastatic cancer identified 36 studies that met the inclusion criteria from the 18,256 articles found in the literature search. The primary thematic analysis of 110 themes or subthemes from the 21 studies with a generic objective revealed that the majority aligned with Wilson and Cleary’s Symptoms and Functional Status domains (‘Symptoms and Physical Function’, ‘Psychological Function’, and ‘Social Function’ categories), while only the category ‘Life Disruption’ was classified in the general health perceptions domain. Interestingly, the ‘Clinical Management’ category arose as an important concern outside the original framework domains. Moreover, in the 15 studies with specific objectives, the most frequently explored subject was the experience with clinical management, addressed by 11 studies which generated 52 themes.

‘Psychological Function’ emerged as the most prominent category in the thematic analysis of the studies involving people undergoing active cancer treatment, appearing frequently across those with generic objectives and those with specific ones. After the initial shock of diagnosis, themes related to coping with cancer and adapting to the new reality were the most frequently identified, even more so than those concerning worries, distress and anxiety related to treatment and monitoring or fears about disease progression. These findings are consistent with systematic reviews showing that emotional adjustment and coping strategies have a great influence on the psychological wellbeing during cancer treatment [76, 77], as well as with other chronic conditions [78], whereas psychological distress—particularly related to treatment burden and persistent emotional challenges—is frequently also reported in this population [79].

The ‘Clinical Management’ category emerged importantly in this review, being the second most prevalent category of themes in studies with a generic objective. The contents of this category were aligned with the ‘Characteristics of the environment’ component, which has the role of influencing the components in the main line, from Biological Function to Overall Quality of Life. In addition, the 11 studies that aimed specifically to explore clinical management issues further underscored the relevance of this domain for stakeholders in the health care and research fields. The key themes identified are consistent with a previous systematic review synthesizing patients’ perspectives on supportive care, which found the need of communication with healthcare professionals and for high-quality, comprehensible and timely information about their illness and treatments [80]. Likewise, a review focusing on operationalizing patient-centered cancer care highlighted care coordination, shared decision-making, and information delivery as essential elements [81].

Similarly to the conclusions from the systematic review on people surviving cancer [31], these findings support that HRQoL instruments addressed to people undergoing cancer treatment should also cover how the needs and experiences lived in clinical management affect HRQoL. The predominance of this subject among qualitative studies is consistent with emergent patient-centered care approaches, but clinical experiences are often not covered in HRQoL instruments due to generally being considered covered by patient-reported experience measures (PREMs). The main difference between PROMs and PREMs is what the instrument aims to cover: a PREM aims to capture the experience of a patient with the care received, as perceived by the patient themself [82], that is ‘what happened’, whereas a PROM aims to know how experiences related to the disease and their treatment affect the patient’s outcomes. Therefore, the patient’s experience when undergoing cancer treatments can have an impact on their HRQoL, and its incorporation into PROMs aligns with patient-centered care.

‘Symptoms & physical function’ was the third category in number of themes arising from studies with generic objectives. Themes in this category were divided into two subcategories: symptoms derived from treatment and constraints of everyday activities due to the illness and its treatment. Both are usually well covered by traditional PROMs, such as the EORTC-QLQ-C30, the FACT-G and their tumor-specific modules [83, 84]. While the relative position of this category is consistent with the systematic review of people surviving cancer [31], the direction of its themes differs clearly, as cancer survivors intended on returning to their activities from before the disease and were dealing with the lingering physical and cognitive challenges post-treatment.

The’Social function’ category comprises a few themes about the impact of the disease on their relationships, work, and economic worries, though mainly the themes are related to the relationships with and support from family and close friends. Although social support originates externally to the individual, participants described it as an integral part of their lived experience during treatment, and it is the subcategory with the most themes in the ‘Social function’ category of the primary thematic analysis. There were also several social themes that emerged from studies focused on clinical management and psychological aspects. The ‘Work and financial concerns’ subcategory was more present in the secondary thematic analysis, given that one study was focused entirely on work. Work concerns also emerged as a particularly relevant aspect among people surviving cancer [31], including the working disability, the limitation of professional careers and the working relationships. This category highlights the importance for patients’ HRQoL of the relationship they have with the people they are closest to, depending on other people, and embracing the help from others.

The ‘Life disruption’ category emerged within the General Health Perceptions domain of the Wilson & Cleary framework, as also observed in the systematic review of people surviving cancer [31]. The themes included in this category comprise topics with negative connotations such as life interruption, the psychological impact of a changed identity, or the challenges of accepting their altered lifestyle.

The results of the systematic reviews of qualitative studies for each population in the cancer continuum [31, 32], a systematic review of existing PROMs [85], patient interviews, and a Delphi study [28] have been the sources for the development of the EUonQoL-kit. The information obtained from the above-mentioned studies, which were conducted in parallel, was combined into a master cross-tabulation, and reviewed in consensus meetings where each subdomain was rated for inclusion in the EUonQoL-kit, using the Nominal Group Technique (NGT) [86]. The purpose of using diverse sources of information and applying NGT was to ensure both the comprehensiveness and the practicability of the resulting EUonQoL-kit. For example, the inclusion of the subdomain ‘Physical Health – lack of energy’ was supported by the systematic review of qualitative studies on patients in active treatment, the systematic review of existing PROMs, and findings from the patient interviews and the Delphi consensus, resulting in a high NGT score, and thus being included in the item list.

Strengths and limitations

First, the studies meeting our inclusion criteria do not encompass all European countries. Published data were available from only 6 of the EU-27 and 2 associated countries. Consequently, the evidence synthesized in this review have a notable lack of information from people in central and eastern Europe. Secondly, publication bias may have caused an underrepresentation of studies reporting only traditional domains of HRQoL, as these topics might be perceived as less novel and thus less likely to be published in peer-reviewed journals. Third, the initial search was broad to maximize sensitivity, which implied a large number of references to screen and review, increasing the need for reviewers. However, the research team trained reviewers in the inclusion and exclusion criteria to avoid differences among them. The training was conducted always by the same researcher, and each article was reviewed, at least, by one of the first or last authors. Fourth, many of the included studies were designed to cover construct-specific objectives selected by researchers or health managers, rather than broadly exploring quality of life issues relevant to individuals undergoing cancer treatment. To minimize the risk of overemphasizing findings from these narrowly focused studies, our primary thematic analysis was based on results from studies with a general scope.

A strength of the present systematic review is that most of the studies included provide up-to-date information, with 58% published between 2021 and 2024, thereby reflecting the current experience of people undergoing cancer treatment nowadays. Furthermore, an ad-hoc exploration of the results of the main thematic analysis stratified by treatment stage was undertaken to elucidate if patients reported different unmet needs or concerns across the treatment timeline. All identified categories contained at least one theme originated from a study representing each treatment stage (curative, non-curative treatment, active surveillance, and various stages).

Lastly, nearly all studies were assessed as ‘good quality’, fulfilling at least 7 of the 10 SURE checklist criteria, and 11 studies meeting all 10 criteria. Considering these strengths, findings from this systematic review have a high value when selecting relevant content for the development of new PROMs for people undergoing cancer treatment.

Conclusions

Results of this systematic review clearly show the predominance of the psychological function and clinical management themes among patients undergoing curative and non-curative treatments in early or advanced stages of cancer. Anyhow, symptoms & physical function, social function and life disruption maintain their importance within the classical HRQoL framework. The emergence of clinical management is consistent with the growing patient-centered care approach, supporting the need to integrate this content into the evaluation of patients undergoing cancer treatment, taking specially into account clinical management needs, as they are usually not included in existing HRQoL instruments, and they are often considered part of patient-reported experience measures rather than outcomes. The findings from this review have contributed to the initial development steps of the EUonQoL-kit. Further qualitative research from central and eastern European countries is needed. In addition, the high relevance of psychological worries, fears and coping strategies highlights the importance to address the psychological wellbeing of cancer patients in clinical management, helping health professionals and policymakers improve the support provided throughout the cancer process.

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Declarations

Conflict of interest The authors declare no competing interests in this study, except for author GV who declares honoraria from Pfizer, Novartis, Eisai and Lilly; Consultancy fees from AstraZeneca, Roche, Novartis, Pfizer, Seagen, Eisai and Sanofi, and an institutional grant from Pfizer.

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