



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

EUonQoL

Quality of Life in Oncology: measuring what matters for cancer
patients and survivors in Europe

Deliverable number: 5.2

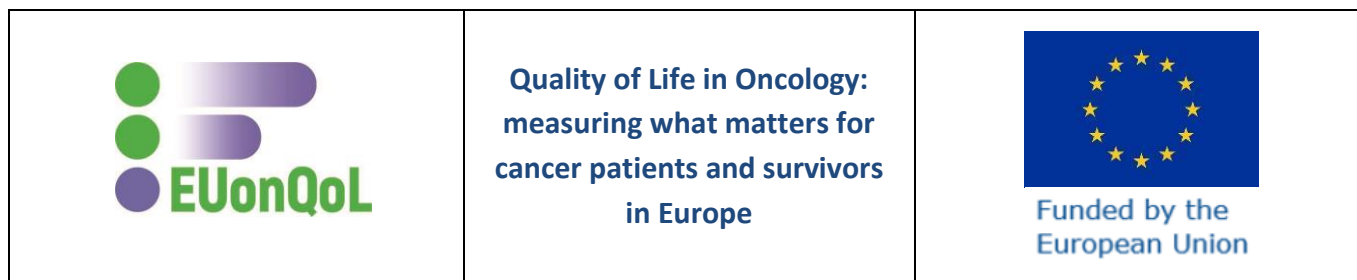
Deliverable title: Report on cultural/social/psychological factors

Deliverable type	Document, report
Deliverable responsible partner	IEO and SporeData
Authors	IEO: Diana Sala, Chiara Marzorati, Viktorya Voskanyan, Roberto Grasso, Gabriella Pravettoni Co-researchers: Carina Dantas, Laura Pinnavaia: SporeData: Ricardo Pietrobon, Aline Machiavelli, Mirtha Valencia, Rafael Woloski
Contractual date of delivery	Month: April 2024 Month 16
Actual date of delivery	Month: April 2024 Month 16
Dissemination level	Public
Status of deliverable	Final version

Grant Agreement information table

Grant Agreement number	101096362
Project acronym	EUonQoL
Project title	Quality of Life in Oncology: measuring what matters for cancer patients and survivors in Europe
Start date	1 January 2023
Duration	48 months

“This project has received funding from the European Union’s Horizon Europe Research and Innovation Programme under Grant Agreement No 101096362”.



Preface

This report is written as a product of the project “Quality of Life in Oncology: measuring what matters for cancer patients and survivors in Europe (EUonQoL)”. This project is funded by the European Union.

The authors from IEO team and Sporedata team would like to thank the EUonQoL Executive Committee for providing us with input on the tasks, roles, and responsibilities that co-researchers have been involved in.

Furthermore, both teams would like to thank co-researchers (Carina Dantas and Laura Pinnavaia) for their involvement and input addressed during the entire process to reach the aims of WP5 Tasks.

The authors would like finally to thank NIVEL (Netherlands Institute for Health Services Research) for the collaboration within Work Package 5 of the EUonQoL project and along the collaboration with co-researchers.

Diana Sala (IEO)

Chiara Marzorati (IEO)

Viktorya Voskanyan (IEO)

Roberto Grasso (IEO)

Gabriella Pravettoni (IEO)

Ricardo Pietrobon (SporeData)

Aline Machiavelli (SporeData)

Mirtha Valencia (SporeData)

Rafael Woloski (SporeData)



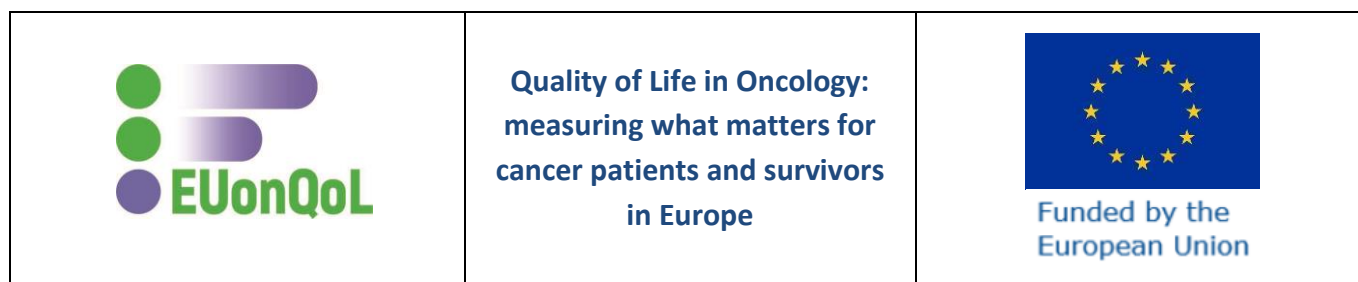
Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



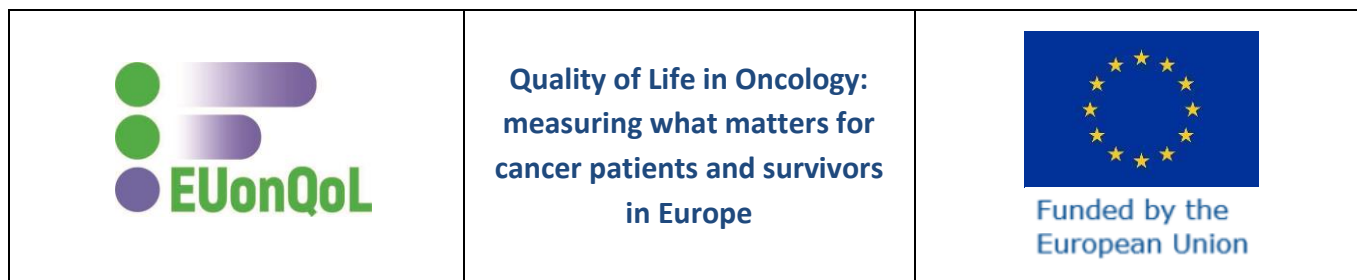
Funded by the
European Union

Summary

Preface.....	2
1. Introduction	5
1.1. The EUonQoL project.....	5
1.1.1. Population: Active treatment, Survivors, Palliative Care.....	6
1.2. Aim of the Report	7
2. URs of quantitative studies.....	8
2.1. Literature research	8
2.2. Selection process and methodology.....	8
2.2.1. Inclusion and exclusion criteria.....	8
2.2.2. Literature search and data selection.....	9
2.2.3. Data Synthesis	9
2.2.4. Quality assessment.....	9
2.2.5. Results.....	10
3. Meta-meta-analysis of qualitative studies	13
3.1. Literature research	13
3.2. Methodology and selection process	14
3.2.1. Inclusion and exclusion criteria.....	14
3.2.2. Literature search and data selection.....	14
3.2.3. Data synthesis.....	14
3.2.4. Quality assessment.....	15
4. Sentiment analysis	23
4.1. Methodology of NLP process and text analysis	24
4.1.2. Analysis of Tweet Content.....	25
4.1.3. Challenges in Data Collection	26
5. Conclusions.....	27
6. Appendix	29
6.1. List of search strings	29
6.1.1. Search strings for Scopus	29
6.1.2. Search strings for Embase	32



6.1.3.	Search strings for PubMed	34
6.1.4.	Search strings used for PsycInfo	37
6.2.	Table Active treatment	39
6.2.1.	Table 2 - Characteristics of the included studies	39
6.2.2.	Table 3 - Characteristics of the included studies	57
6.3.	Table Survivors	72
6.3.1.	Table 4 - Characteristics of the included studies	72
6.3.2.	Table 5 - Characteristics of the included studies	82
6.4.	Table End of Life and Palliative Care.....	88
6.4.1.	Table 6 - Characteristics of the included studies	88
6.4.2.	Table 7 - Characteristics of the included studies	92
7.	References.....	96



1. Introduction

The first part of the present report will provide an overview of the EUonQoL project within which this report is produced. Additionally, it will introduce and outline the objectives and contents of the present report. Subsequently, the next paragraphs will present and delineate methodologies followed to reach the aim of task 5.1 and the material used to keep track of it. Conclusions are presented in the final part of the report.

This WP is part of an EU funded project entitled “EUonQoL-Quality of Life in Oncology: measuring what matters for cancer patients and survivors in Europe” (grant agreement n° 101096362). The overall project aims to develop, pilot and validate the European Oncology Quality of Life toolkit (EUonQoL-Kit), a patient co-researcher driven, unified system for the assessment of quality of life (QoL) based on the evaluations and preferences of cancer patients (ongoing treatment, palliative care) and survivors. The EUonQoL-Kit has been developed from the patient perspective, administered digitally, and will be available in all 27 European Union (EU) languages and in the languages of the associated countries.



1.1. The EUonQoL project

Cancer is the second cause of death and the first cause of suffering for patients and caregivers in Europe, as well as it has an enormous financial impact on health services and individuals. There were 2.7 million new cases of cancer and 1.3 million deaths in 2020, which is expected to increase with about 25% by 2035. Additionally, there is an unacceptable variability in terms of access to innovation, quality of care, and outcomes (including QoL), within and between countries in Europe. QoL can be interpreted as satisfaction and happiness measured, as the achievement of aspirations and/or the realization of individual expectations. The burden of cancer and cancer treatment on QoL is well-recognized. Nonetheless, the implementation of QoL assessment in routine oncology practice is not yet part of the standard of care. In the same way, health care systems and cancer control programs do not take into consideration QoL measures when developing clinical, societal, and healthcare policymaking systems.

Emerging needs related to new cancer treatments along with societal developments require a revision of traditional QoL assessment tools, most of which have been developed a few decades ago and are not available in all official and non-official European languages.

Available questionnaires are often “static”, thus presenting the same set of questions/items to all patients, without any difference. A recent innovation in the assessment of HRQoL (Health-Related Quality of Life) in cancer care is the development of the Computer-Adaptive Testing (CAT). CAT allows a more precise assessment of HRQoL, with systems presenting subsequent questions based on answers of the previous ones, ultimately adapting the questions to the health state of the individual patient. In addition, most existing HRQoL tools were developed to be filled out with paper and pencil. CAT tools will in turn allow for more dynamic instruments, suitable for a personalized patient’s experience of data collection. The overall project process wants to ensure that the EUonQoL-Kit and its future development would be a unified, standard European QoL assessment system. For the aforementioned reasons, significant focus was directed towards the translation process, in order to ensure a consistently high standard of translated materials and to cover both linguistic and cultural diversity across Europe.

In Table 1 all WPs involved in the project are presented.

	Quality of Life in Oncology: measuring what matters for cancer patients and survivors in Europe	 Funded by the European Union
---	--	--

Work Package	WP Title
WP1	Ethics
WP2	Involvement of stakeholders and patients
WP3	Review of existing HRQoL databases, measures and item libraries
WP4	Development of the EUonQoL-Kit
WP5	Cross-cultural determinants of the QoL and linguistic and cultural adaptation of EUonQoL-Kit
WP6	Digital tools for data collection
WP7	EUonQoL-Kit Pilot Survey
WP8	Implementation
WP9	Dissemination
WP10	Project Management/Coordination

Table 1 Work packages of the EUonQoL EU project

To gain a better understanding of the process utilized in the EUonQoL project, refer to Figure 1, which depicts the flow diagram illustrating the involved Work Packages and their connections.

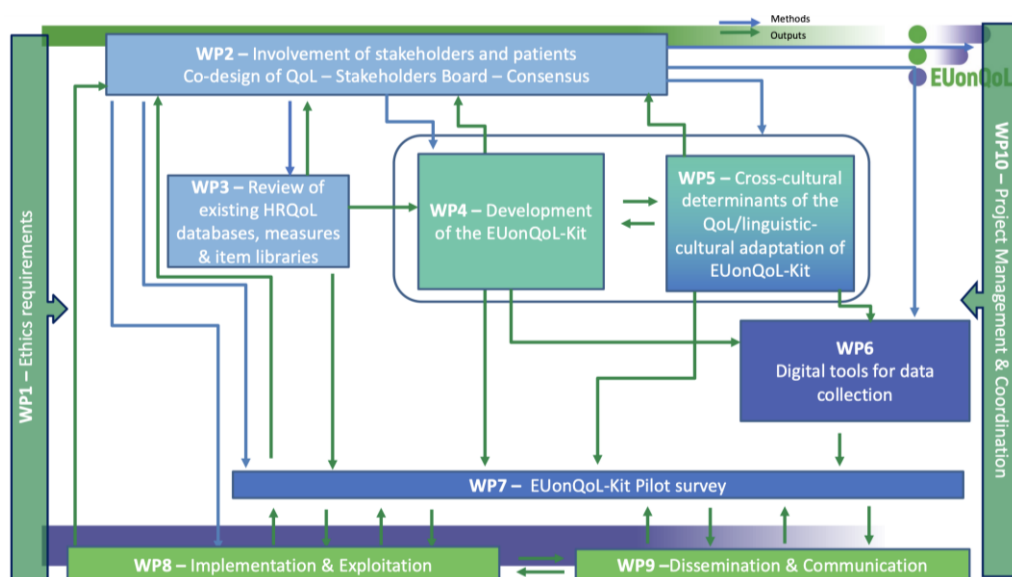




Figure 1 Flow diagram of project

1.1.1. Population: Active treatment, Survivors, Palliative Care

The aim of the EUonQoL-Kit is to reflect the spectrum of patients diagnosed with cancer. The questionnaires will be administered and validated in three different cancer groups: active treatment, survivors, and palliative care. The definitions outlined within the project might not be exhaustive of the whole cancer patient population, but they are essential to validate the tool and to be able to distinguish three different patient groups with relative precision. As agreed with the EUonQoL Consortium, the target population groups are defined throughout all stages of this study as:

	<p style="text-align: center;">Quality of Life in Oncology: measuring what matters for cancer patients and survivors in Europe</p>	 <p style="text-align: center;">Funded by the European Union</p>
---	---	---

Group A. Active Treatment:

i. curative treatment - undergoing or recently completed curative treatment for early-stage cancers.

Examples: - Early stage 1-2 breast cancer during or up to 3 months following radiotherapy, surgery or systemic treatments.

ii. non-curative treatment for advanced/metastatic cancers, including disease controlling/life prolonging tumour-directed treatment (e.g. patients with metastatic disease receiving chemotherapy, immunotherapy or targeted agents).

Examples: - *Metastatic breast cancer on 1st line palliative chemotherapy;* - *Lung cancer on immunotherapy.*

Group B. Survivors:

i. At least one year off active treatment (but can be on long-term adjuvant hormonal therapy) and being disease-free without evidence of active cancer.

Examples: - *ER/PR+ breast cancer treated with surgery, adjuvant radiotherapy and on 10 years of hormonal treatment.*

Group C. Palliative Care: Patients with advanced cancers who meet at least one of the following criteria:

i. Patients with projected prognosis ≤ 70 or ECOG ≤ 2 .

ii. Patients referred to a specialist palliative care team for symptom control.

iii. Patients may be receiving non-curative treatment purely for symptom control (including palliative radiotherapy and/or systemic treatment).

Examples: - *Patients with castrate-resistant prostate cancer, progressed through systemic treatment options referred for radiotherapy for bone pain;* - *Metastatic breast cancer patient on 5th line systemic treatment.*

1.2.Aim of the Report

This report refers to Task 5.1 conducted within the Work Package 5.

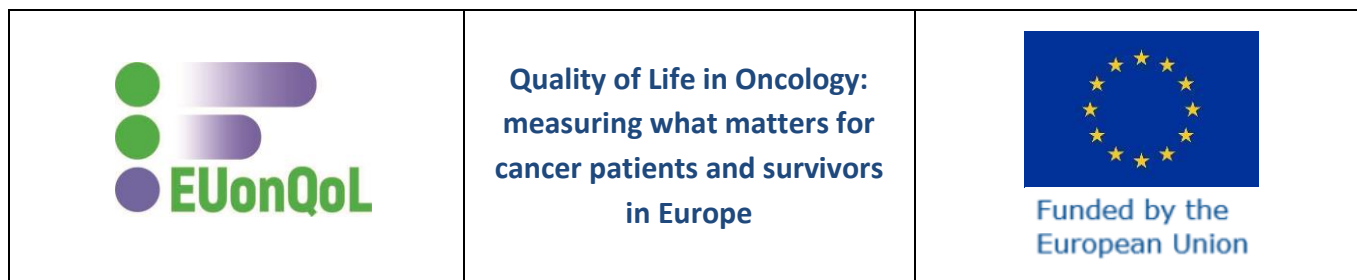
The aim of T5.1 is to define a set of key clinical, cultural, sociodemographic and psychosocial factors associated with QoL.

The obtained results would enrich the findings reported in WP3 and WP4 and highlight potential differences with the domains included in the EUonQoL-Kit; they would also be used to define factors to be collected in the CRF (Case Report Form) developed within the WP7 Pilot Survey.

To reach this aim, WP5 performed three quantitative studies (three Umbrella Reviews), a qualitative study (meta-meta-analysis) and a sentiment analysis (Natural Language Process, NLP) that will be separately described in the following paragraphs.

Finally, to ensure that all the aspects were correctly addressed, all data collected were discussed among all the partners and co-researchers involved in this WP.

At the end of the process, a group of experts, including co-researchers, reviewed the obtained results, to identify any discrepancies and reach consensus.



2. URs of quantitative studies

The European Institute of Oncology IRCCS (Leader of the WP5) performed three Umbrella Reviews (URs) to identify quantitative research studies investigating psychosocial factors associated with QoL in patients with active treatments, in palliative care, and survivors, respectively.

Due to the great number of systematic reviews already available on this topic, the IEO team decided to conduct an UR, with the aim of summarizing the results of multiple systematic reviews. Indeed, the UR is considered one of the highest levels of evidence currently available and is aimed at conducting a narrative compilation of evidence from multiple systematic reviews and meta-analysis into one document with text, tables, and graphics. It is designed to provide a summary of existing research syntheses related to a given topic or question.

All the URs were conducted following the guidelines from Joanna Briggs Institute (JBI) (Aromataris et al., 2015) and registered in the International Prospective Register of Systematic Reviews with the following PROSPERO protocol numbers:

- CRD42023413899: UR on patients undergoing active treatments;
- CRD42023415288: UR on cancer survivors;
- CRD42023413281: UR on patients in palliative care.

2.1.Literature research

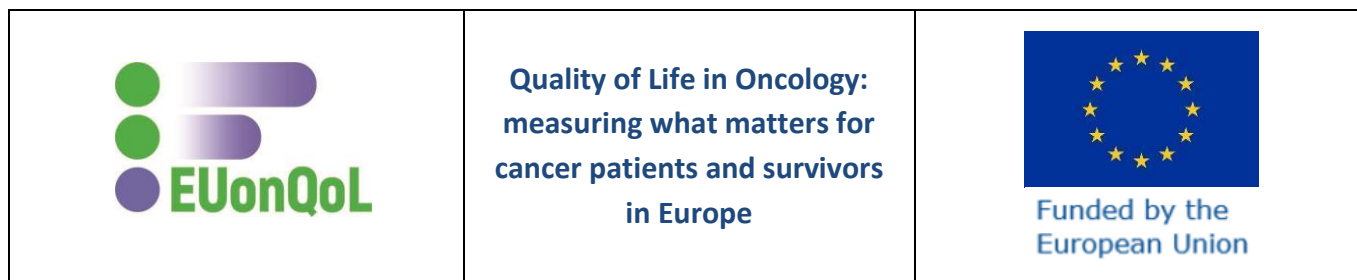
A search strategy was built and adapted for each UR depending on patients' group. A research librarian was involved and created different search strings for the following four electronic scientific databases: PubMed, Embase, Scopus and PsycInfo. These search strings were optimized with a combination of several search terms divided into the following topics: Cancer, Quality of Life, Factors, Psychosocial, Impact, and adapted for each patients group. Specific search strings developed for each database are presented in Appendix.

2.2.Selection process and methodology

2.2.1. Inclusion and exclusion criteria

For the present URs clear exclusion and inclusion criteria were established to avoid biases that may impact the quality of the research. Hence, the research was limited to (a) systematic reviews, (b) without geographical restrictions, (c) conducted from 1st January 2012 to January 2023 (the research was limited to this year because the field of cancer care is rapidly changing), (d) including adult cancer patients (>18 years), (e) active treatment, or survivors or in palliative care and (f) investigating the relationship between QoL and psychosocial factors. These eligibility criteria were established according to the research question (PICO questions; P: adult cancer patients; I: not applicable; C: not applicable; O: factors affecting QoL).

The exclusion criteria for the present UR included (a) non-psychosocial factors associated with QoL (e.g. economic, cultural, pharmacological outcomes), (b) non-adult or non-cancer patients (e.g., adolescents, population with other diseases aside from cancer, caregivers, children, etc).



2.2.2. Literature search and data selection

Starting from this search strategy, two researchers started the preliminary screening independently (reading titles and abstracts) using Rayyan (Ouzzani et al., 2016) to import results. Rayyan is an online Software, which allows the use of the “blinded” mode for reviewing papers. Duplicates from different electronic databases were removed automatically by Rayyan. Any disagreements concerning the eligibility of studies were resolved by the third researcher through group discussion and full-text review.

All reviews potentially eligible for inclusion were retrieved for full-text screening based on the inclusion and exclusion criteria. Any doubts regarding final inclusion were solved through consensus. Additionally, the reference lists of all included articles were screened to identify other relevant articles not detected in the automated search. Grey literature was not taken into consideration.

Subsequently, the research team organized three Excel© worksheets (one for each population group) containing included articles with the following categories: publication data (title, authors, year), study origin, study characteristics (number of studies included in each review, study design, year of publication of included articles, country of origin), aim of each review, participant details (total number, sociodemographic characteristics if mentioned), type of cancer diagnosis, and factors (psychological and social). The authors also gathered clinical factors identified in studies exploring psychosocial factors. For more details about the Excel© worksheet, see Appendix.

2.2.3. Data Synthesis

The selected reviews were reported using the guidelines for Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Page et al., 2021); Once the consensus of the reviewers was reached, these identified data were incorporated into the Excel© table.

2.2.4. Quality assessment

Two investigators independently evaluated the methodological quality of the included Systematic Reviews and Meta-analyses using the Assessment of Multiple Systematic Reviews 2 (AMSTAR2) (Shea et al., 2017) rating scale. Any discrepancies in ratings were resolved through discussion. This assessment tool consists of 16 items designed to assess the quality and bias of the selected studies. Each article received a score based on the number of positive, partially positive, and negative responses. A higher rate of positive responses indicated a lower risk of bias.

Researchers adhered to the AMSTAR 2 rating guidelines, but modifications were made for item 1 (“Did the research questions and inclusion criteria for the review include the components of PICO?”). For this item, the scoring approach was adjusted as follows: responses were categorized as “Yes,” “Partially yes,” or “Not.” A rating of “Yes” was assigned if the included Systematic Review (SR) had a clearly defined research question and explicitly described all components of PICO somewhere in the SR’s report. The rating “Partially yes” was used when the PICO questions were only partially described in the SR. For example, if the SR reported only the study population and outcome, the authors assigned a “Partially yes” rating instead of “Not”.

The main questions where most of the systematic reviews included in the URs failed regarded 1) the registration of the protocol, 2) the explanation of the selection of the study design, 3) the provision of the list of the excluded studies, and 4) the report on the sources of income of the included studies.



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

2.2.5. Results

The search in 4 electronic databases identified 2872 potentially relevant references for patients undergoing treatment, 506 references for survivors, and 256 for patients in palliative care, respectively. After the removal of the duplicates, 1952 SRs remained for title and abstract screening for patients undergoing treatment, 315 reviews for survivors, and 176 reviews for patients in palliative care. After the initial screening, 53 reviews were retrieved for full-text screening for patients undergoing treatment, 29 reviews for survivors, and 6 reviews for patients in palliative care. Full-text screening identified 18 SRs that met the inclusion criteria for patients undergoing treatment, 13 SRs for survivors, and 3 reviews for patients in palliative care.

Results of the **UR for patients ongoing treatment** show that QoL in this population group is associated with the following psychosocial factors: depression, coping/coping strategies (i.e. problem-solving and positive thinking), social support/functioning/interactions, anxiety, distress, faith/religiosity, optimism, resilience, unmet needs, body image, emotional focus/functioning, neuroticism, self-efficacy, spiritual well-being, avoidance, boredom, confidence about remaining cancer-free, empowerment, external/internal locus control, extraversion, family harmony status, fear of cancer recurrence, harm avoidance, helplessness, hope, illness perception, impaired mental health, mental fatigue, mental health, openness, personal control over the patients' own disease, personality type D, positive illness perception, positive mood, post-traumatic growth, post-traumatic stress disorder, psychological symptoms, psychological well-being, reduced motivation, sadness, satisfaction with esthetic outcome, self-regulation, sense of coherence, somatization, tolerant personality type, trait anxiety, healthier behavior, exercise, role limitations, and sense of self-efficacy (for a better understanding of the aforementioned results please refer to Figure 2). This study also identifies significant clinical factors documented in the SRs included. The following clinical factors result negatively associated with QoL in this patients' group: chemotherapy, tumor stage, symptoms, and presence of recurrence. Furthermore, some contradictory results are associated with the following clinical factors: comorbidities, epilepsy, hormone therapy, radiotherapy, and time since diagnosis; indeed, some reviews show a positive association with QoL and others a negative one. Interestingly, one study shows a positive association between immune therapy and QoL.



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

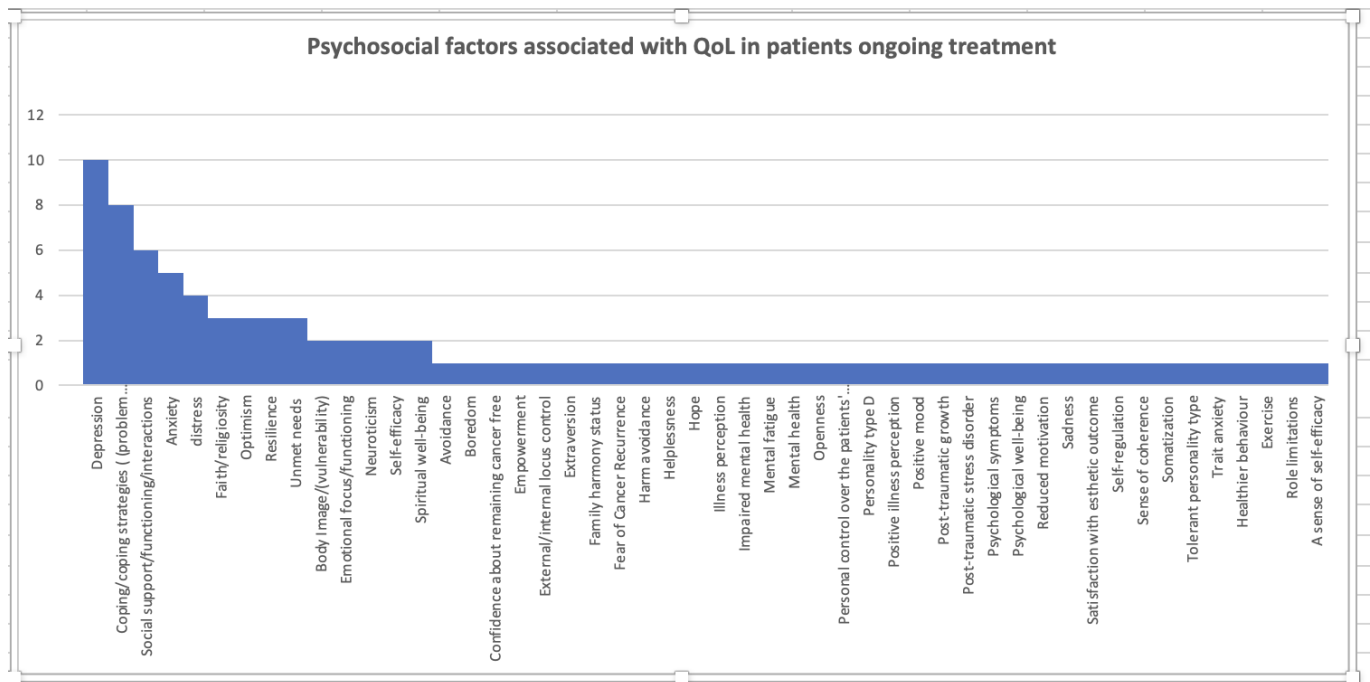


Figure 2 Psychosocial factors associated with QoL in patients in active treatment

For the survivors group, the factors associated with QoL found in the UR are the following: social support/interactions, coping/coping strategies, depression, stress/psychological distress, emotions/emotional well-being/emotional abilities/emotional growth, anxiety, fear of cancer recurrence, post-traumatic growth, body image distress/body image concerns, sense of coherence, neuroticism, spiritual growth/faith, meaning/peace, post-traumatic growth, post-traumatic stress disorder, resilience, well-being at the time of diagnosis, body image distress, optimism, negative cancer-threat appraisal, less benefit finding, denial, hostility, pessimism, hope, impaired sexual life, cancer-threat appraisal, repression defense, post-traumatic stress disorder (Please see Figure 3). While investigating psychosocial factors associated with QoL in cancer survivors, this UR also extracts some major clinical factors reported in the systematic reviews. Specifically, our findings demonstrate that comorbidities, adverse symptomology, cancer and treatment-related symptoms have been negatively associated with QoL. Contradictory results are highlighted regarding the association between QoL and tumor grade, tumor location, adjuvant therapy, and time after treatment. In addition to the findings mentioned above, there are also other clinical factors negatively impacting QoL: epilepsy/seizure burden, worse Tumor-Nodes-Metastasis (TNM), more extensive surgery, tumor recurrence, fatigue, and short-term surgical complications.



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

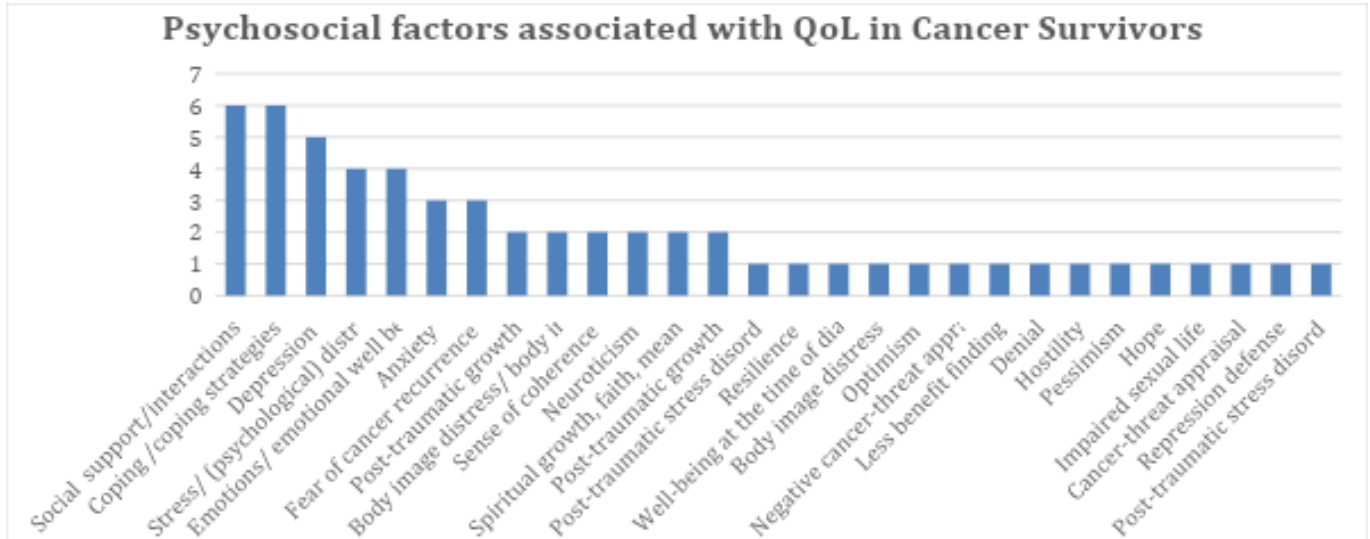


Figure 3 Psychosocial factors associated with QoL in cancer survivors

Results for **patients in palliative care** highlight the following psychosocial factors associated with QoL: depression and anxiety, spirituality/religiosity, diagnosis awareness, depression, feeling of coherence, intrusive thoughts, awareness of terminal disease, spirituality (faith and meaning/peace), and family function/support (Please see Figure 4). Two SRs also investigated the association between clinical variables on QoL. Specifically, undergoing medical treatment or symptom management strategies positively impact on QoL, while pain intensity, fatigue, effects of targeted treatments and severity of the disease negatively affect QoL.



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

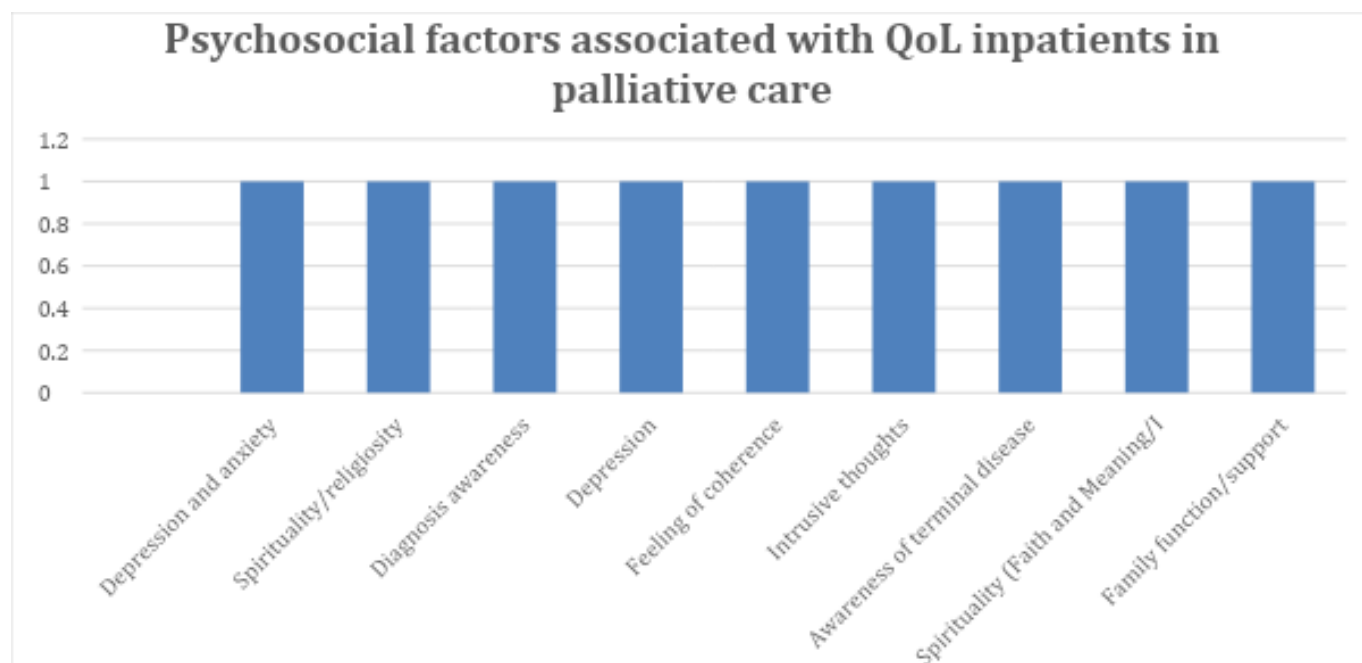


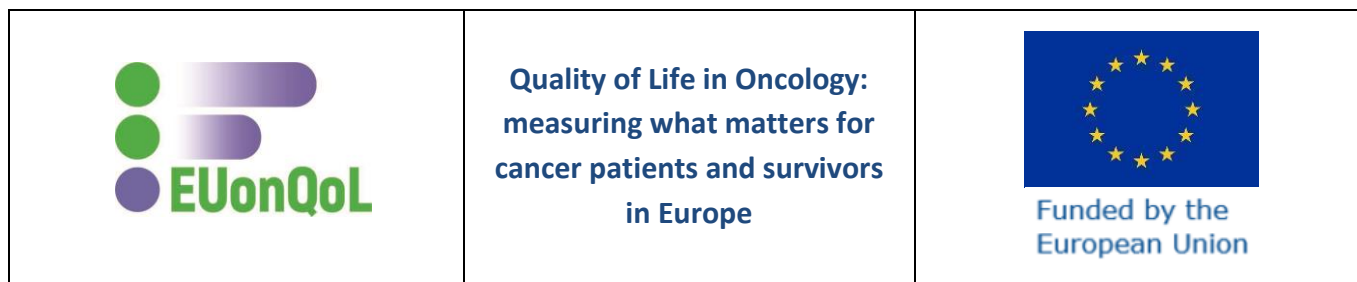
Figure 4 Psychosocial factors associated with QoL in patients in palliative care

3. Meta-meta-analysis of qualitative studies

The aim of the present review, conducted by Sporedata team, was to analyze the evidence of sociodemographic, cultural, clinical, and psychosocial variables that may impact the quality of life (QoL) in cancer patients and survivors. A Systematic Review (SR) of qualitative studies assessing cancer patients' QoL was performed, considering risk perception, lifestyle, environment, and early-life factors. Additionally, the studies were geocoded to verify any differences between Western and Eastern Europe. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Stewart et al., 2015) have been followed to ensure accurate and transparent article selection.

3.1.Literature research

To gather relevant data for a comprehensive SR, a rigorous and comprehensive search was conducted for studies focusing on QoL in cancer patients published between 2013 and 2022. Four major scientific electronic databases (PubMed, Scopus, EMBASE, and OVID) served as the basis for the search strategy. To streamline the selection process, specific search terms were used, tailored for systematic reviews or meta-reviews of qualitative studies evaluating the QoL in cancer patients. This strategy aimed to retrieve the most relevant studies in the field. The search strategy was carefully constructed as follows: (cancer OR tumor OR tumour OR neoplas* OR oncolog) AND ("meta-analysis" OR "systematic review") AND ("quality of life" OR "QOL") AND (experience OR interview* OR "emerging themes") AND ("qualitative studies"). This methodological approach facilitated exploring relevant scientific articles while focusing on our research objective.



3.2. Methodology and selection process

3.2.1. Inclusion and exclusion criteria

A strict set of criteria in the selection process was applied. The search strategy was limited to original researches published in five major European languages: English, Spanish, Italian, Portuguese, and French. Conference abstracts, editorials, and review articles were excluded to ensure research rigour and validity, as these publications may lack necessary detail or peer review. The inclusion criteria were limited to SRs or meta-reviews that examined the QoL in cancer patients using qualitative research methods. The aim was to gain a comprehensive understanding of the lived experiences of these individuals by analyzing the themes that emerged from the interviews. Interventional and cross-sectional studies were excluded from the selection process to maintain a robust methodology and clear focus. Through meticulously adhering to these selection criteria, the aim was to distil a rich and nuanced understanding of the QoL in cancer patients from a qualitative perspective.



3.2.2. Literature search and data selection

Data from qualitative studies were gathered in the selected SRs and meta-reviews. Qualitative studies that were published before 2013 and those that did not focus on cancer patients were excluded. For each qualitative study, the following labels were recorded: title, year of publication, themes that emerged from the interviews, patient group (active treatment, survivors, and end-of-life/palliative), and location data (geocoding). In cases where the articles did not include location information, the authors were contacted to request the countries from which the patients were recruited. It is important to mention that the scope of the analysis extended beyond studies focusing on a single patient group. Some research encompassed multiple groups, examining the interplay of psychosocial, risk perception, lifestyle, and environmental factors across different stages of the patient experience. Specifically, several studies provided insights into ongoing treatment and cancer survivorship, while others bridged the experiences of patients undergoing ongoing treatment with those in end-of-life care. To assess the risk of bias and study quality of the papers, the "Quality in Qualitative Evaluation: a Framework for Assessing Research Evidence (The Spencer Framework)" (Spencer et al., 2004) was followed. This framework was chosen for its holistic evaluation approach, which was crucial for ensuring the findings' credibility and relevance.

3.2.3. Data synthesis

Different factors related to cancer patients' QoL outcomes were analyzed, with a focus on emerging themes and their context within qualitative studies. This analysis examined the psychosocial dimension derived from previous umbrella reviews of quantitative studies. These studies assessed psychosocial factors in three subgroups of cancer patients, which included those receiving ongoing treatment, those in end-of-life or palliative care, and cancer survivors. The studies were submitted to PROSPERO under the registration numbers CRD42023413899, CRD42023413281, and CRD42023415288. This classification provided a solid foundation of psychosocial factors that guided the qualitative data analysis.

In addition to the psychosocial factors, other factors already published in the literature were examined, such as risk perception, lifestyle, environmental, and early life factors (Cárceles-Álvarez et al., 2020; Murphy et al., 2019; Parkin et al., 2011; Tilburt JC, et al., 2012; van Roekel et al., 2014). A table

	<p style="text-align: center;">Quality of Life in Oncology: measuring what matters for cancer patients and survivors in Europe</p>	 <p style="text-align: center;">Funded by the European Union</p>
---	---	---

listing each study was prepared. To facilitate the interpretation of the contextual themes, some statements were extracted from the original text and added to a column in this table for reference. Then, the respective factors were placed in the columns next to them. Utilizing the sets of factors related to the QoL as parameters ensured a comprehensive and meaningful analysis of the emerging themes from the qualitative studies.

3.2.4. Quality assessment

Exploratory analyses were used to gain comprehensive insights into the data. The objective was to explore the relationship between cancer patients' QoL and various contributing factors, including psychosocial, risk perception, lifestyle, environmental, and early life. An evaluation of how these relationships vary among different subgroups of cancer patients was also conducted. Bar plots were created to visually represent the distribution of QoL across three different subgroups of cancer patients.

In addition to analyzing the factors across patient groups, visual representations were also constructed to showcase the geographical distribution of the studies included in the analysis. A world map plot provided a global overview, indicating the number of studies per country, with varying shades of color denoting the count. A more detailed plot focused on the European Union, highlighting the studies per country within this region. Further, bar plots were created to compare the distribution of the studied factors between Eastern and Western European countries, illustrating the number of factors stratified by region and patient group.

3.2.5. Results

Twenty-two studies focused on examining cancer patients' QoL were identified. These studies were meta-analyses and systematic reviews that used qualitative research methods. The search covered the PubMed, EMBASE, OVID, and Scopus databases, resulting in 265 systematic reviews and meta-reviews. Of these, 145 duplicated studies were excluded. Upon reviewing the remaining 120 papers, 98 were excluded as they did not align with the criteria. Among these, 28 studies were unrelated to cancer, 42 focused on interventions, 11 did not involve patients, and 17 were not qualitative studies. Ultimately, 22 systematic reviews were considered eligible (Figure 5). Subsequently, from the 22 systematic reviews, 351 papers were selected.

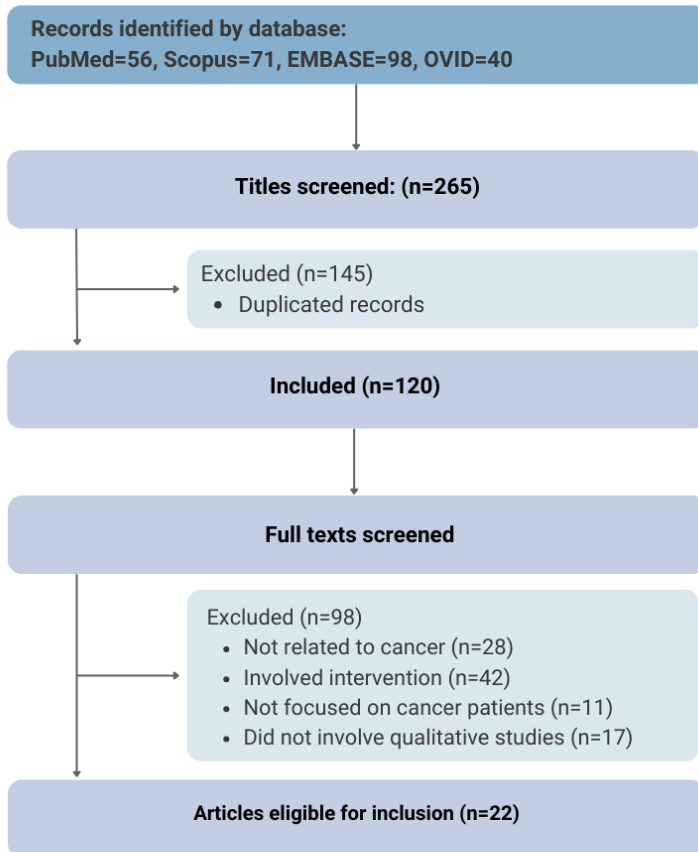


Figure 5 Flow diagram of the articles' selection process



**Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe**



Funded by the
European Union

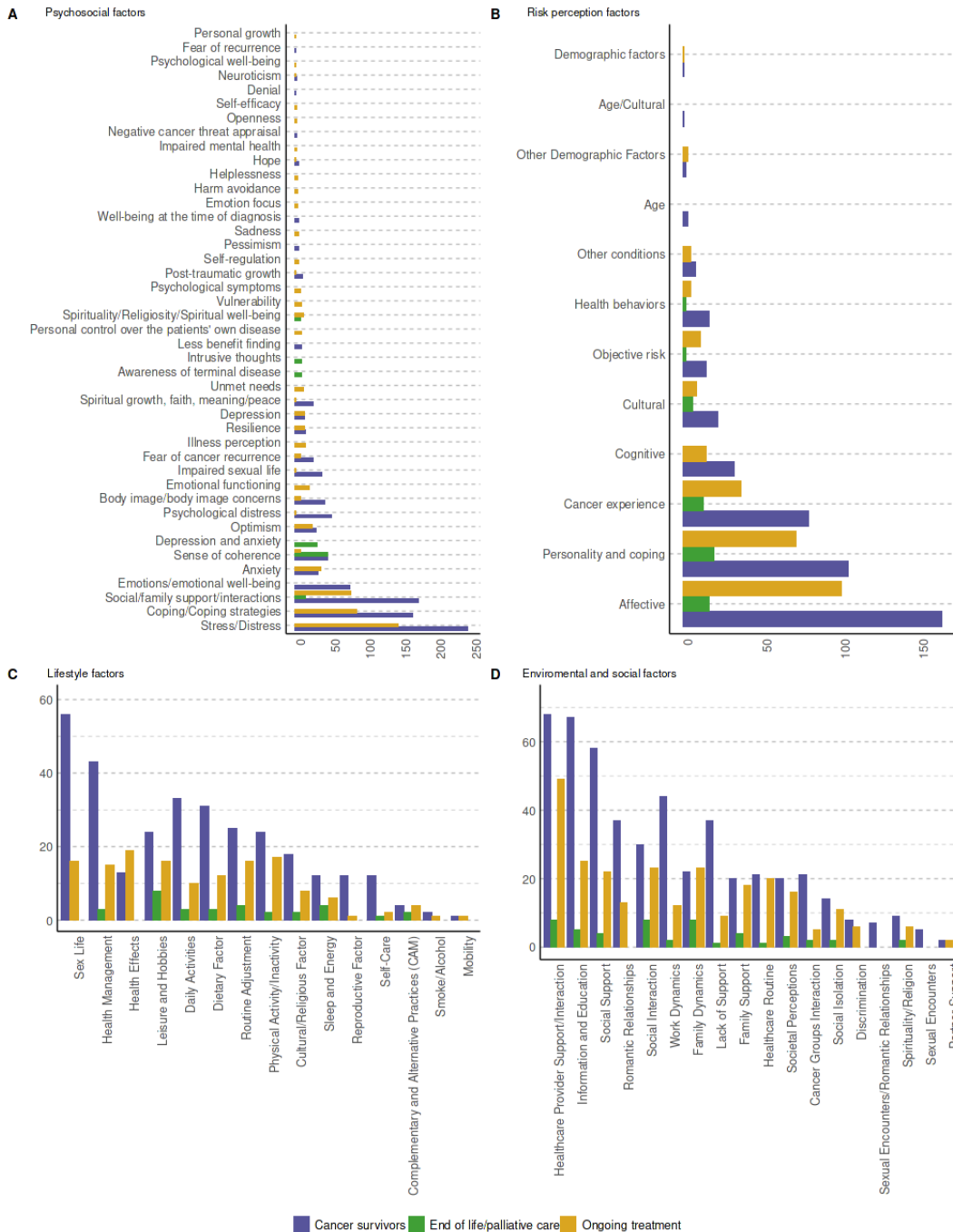
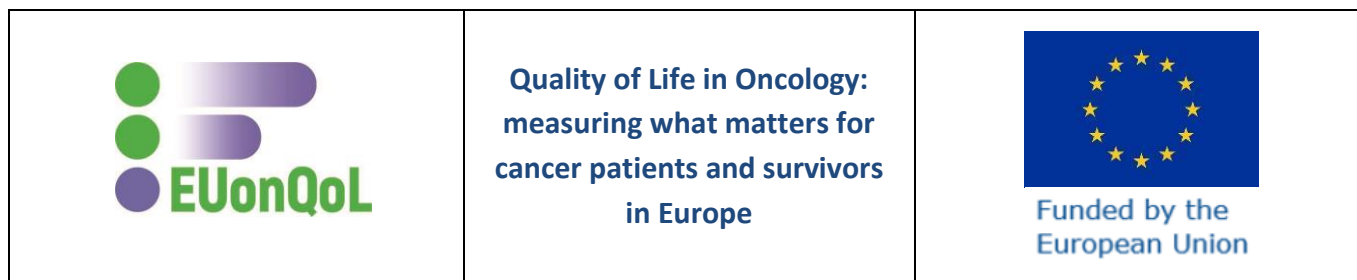


Figure 6 Frequency of psychosocial (A), risk perception (B), lifestyle (C), and environmental/social (D) factors in cancer survivors (blue bar), patients in palliative care (green bar), and those undergoing treatment (orange bar).

The bar chart in Figure 6 provides a detailed comparison of the frequency of psychosocial, risk perception, lifestyle, and environmental factors among three distinct patient groups: cancer survivors EUonQoL
Pag. 17 | 100



(represented by blue bars), individuals in end-of-life/palliative care (green bars), and those undergoing ongoing treatment (orange bars).

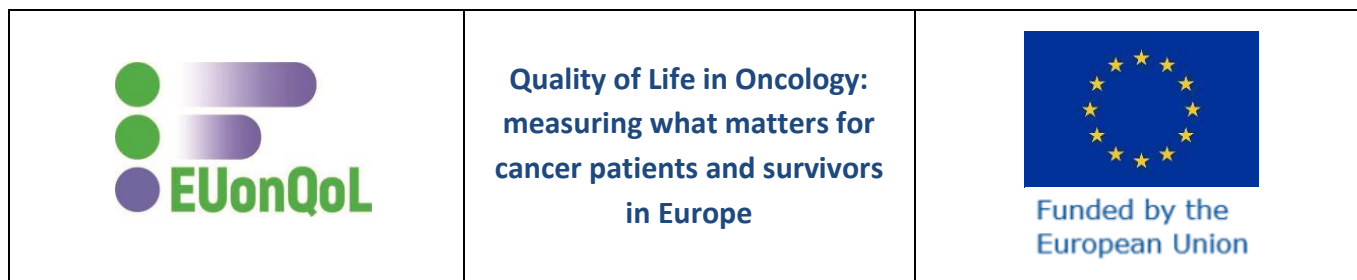
Among **psychosocial factors** depicted in Figure 6A, stress and distress were the most frequently reported for cancer survivors, with 246 occurrences highlighting the significant impact of stress on this group. Social and family support and interactions follow, with a count of 175, underscoring the importance of a strong support network. Close behind, coping strategies were identified 168 times, indicating the emphasis on adaptive mechanisms in managing the illness. Psychological distress is noted for its impact on cancer survivors, with 52 occurrences. A range of factors, including anxiety, sense of coherence, optimism, body image concerns, sexual life impairment, fear of cancer recurrence, resilience, and spiritual growth, fell within the 25 to 50 occurrence range, demonstrating a spectrum of psychosocial challenges. Other factors such as resilience, depression, benefit-finding, post-traumatic growth, pessimism, well-being at diagnosis, and hope are mentioned less frequently, each accounting for less than 25 occurrences.

For individuals in the end-of-life patient group, as illustrated by the green bars in Figure 6A, the sense of coherence emerged as the most prominent psychosocial factor, with the highest frequency of 46 occurrences. This reflects the importance of finding meaning and comprehensibility in their experiences at this stage of life. Depression and anxiety were also prevalent concerns, ranking as the second most common factor with 32 occurrences, indicating the psychological challenges that accompany terminal illness. Social and family support and interactions were the third most frequently cited factor (15 occurrences), underscoring the crucial role of supportive relationships in providing comfort and assistance to these patients. While less prominent, other factors such as awareness of terminal disease, intrusive thoughts (10 occurrences), and spirituality/religiosity/spiritual (8 occurrences) well-being were acknowledged, each contributing to the multifaceted psychosocial landscape of end-of-life care.

In the context of ongoing treatment, the bar chart in Figure 6A revealed that the most frequently reported psychosocial factors were stress and distress, with 147 occurrences. This underlines the considerable impact of stress on patients actively receiving treatment. Following stress and distress, coping strategies (88 occurrences) and social/family support and interactions (80 occurrences) stood out as the following most significant factors, indicating the importance of adaptive mechanisms and a reliable support network during treatment. Anxiety ranked as the third most prevalent factor for this group, with 37 occurrences reflecting the commonality of anxiety among patients in active treatment. The incidence of all other psychosocial factors was reported to be below 25 occurrences.

This systematic review evaluated three significant categories of **risk perception factors**: clinical, demographic, and psychosocial. Each category encompasses key aspects illustrated in Figure 6B, which details the frequency of occurrence in each patient group.

Our findings reveal that, among cancer survivors, the affective components of psychosocial factors—such as distress, anxiety, worry, intrusive thoughts, avoidance, and fear of cancer—emerged as the most influential in shaping risk perception, with 165 occurrences. Additionally, within the psychosocial domain, personality traits and coping mechanisms were identified as the second most influential factor in this group, accounting for 105 occurrences. In terms of clinical factors, both personal and familial cancer experiences significantly impacted risk perception among cancer survivors, with 80 instances noted. The cognitive aspect, encompassing beliefs about cancer's preventability, seriousness, and hereditary risks, also affected risk perception, with 33 occurrences in this group. Factors with fewer than 25 occurrences



included a psychosocial element related to cultural aspects (22 occurrences), mainly faith and spiritual coping, and clinical factors such as health behaviors (17 occurrences), objective risk assessment (15 occurrences), and other conditions like menopause status (8 occurrences). Demographic factors, including age, race/ethnicity, education, marital status, employment, and gender, also presented less than five occurrences.

Personality traits and coping mechanisms, part of psychosocial factors, were the most frequently identified aspects for patients in palliative care, with 20 occurrences. These include locus of control, monitoring, and punishment/reward sensitivity. Affective responses, another psychosocial component focusing on emotional reactions, were also prevalent, with 17 occurrences. Personal and family cancer experiences, a clinical factor, ranked third in significance for risk perception in end-of-life patients, with 13 instances. Other factors presented few occurrences, such as cultural aspects (6 occurrences), objective risks, and health behaviors, with two occurrences each.

Patients undergoing ongoing treatment exhibited a pattern of risk perception factors similar to that of cancer survivors. The four most prevalent aspects are:

1. Affective psychosocial factors, with 101 occurrences
2. Personality traits and coping mechanisms, also psychosocial, with 72 occurrences
3. Personal and familial cancer experiences, a clinical factor, with 37 occurrences
4. Cognitive factors, another psychosocial aspect, with 15 occurrences

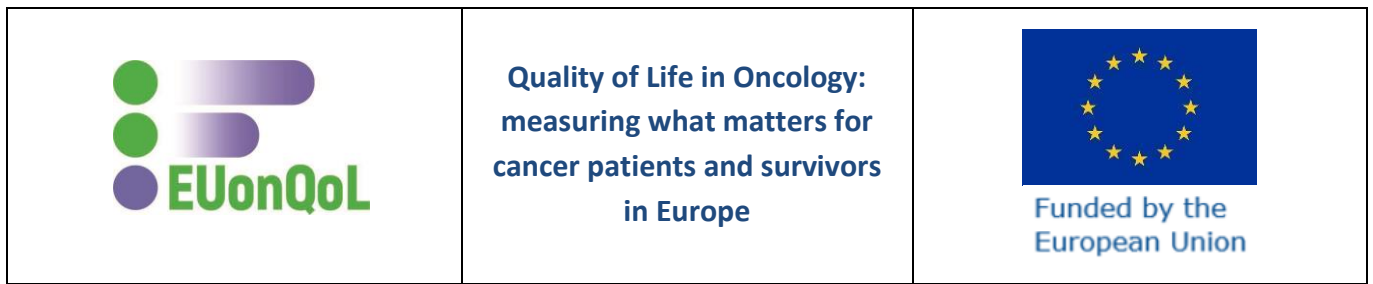
Less influential factors in this group included cultural aspects, objective risks (11 occurrences), health behaviors (5 occurrences), and demographic characteristics, accounting for fewer than five occurrences.

The bar chart “Lifestyle factors” in Figure 6C compares the frequency of various **lifestyle factors** among the three patient groups. These factors encompass physical activity, dietary habits, sleep quality, health and routine management, social interactions, substance use, religious and spiritual practices, and intimate life.

For cancer survivors, intimate life emerged as the most significant concern, with 56 recorded occurrences indicating the importance of relationships in this group's QoL. Health management followed with 43 occurrences and daily activities with 33. Other notable factors included dietary factors (31 occurrences), routine adjustment (25 occurrences), physical activity/inactivity and leisure/hobbies with 24 occurrences each, and cultural/religious practices with 18 occurrences. Sleep and energy, reproductive health, and self-care all featured similarly with 12 occurrences. Lifestyle factors with minimal impact, such as complementary and alternative medicine (CAM), smoking/alcohol consumption, and mobility issues, presented fewer than five occurrences.

In the end-of-life/palliative care group, leisure and hobbies appeared most frequently, with eight occurrences underscoring the value of enjoyment and personal interests during this life stage. All the other factors had less prevalence, with fewer than five occurrences.

Health effects were the most significant concern for patients undergoing ongoing treatment, with 19 occurrences. The second most prominent lifestyle factor was physical activity/inactivity, with 17 occurrences. The most relevant factors were leisure and hobbies, routine adjustment, and sex life, with 16 occurrences each. Similarly, health management (15 occurrences), dietary factors (12 occurrences), daily activities (10 occurrences), cultural/religious factors (8 occurrences), and sleep and energy (6





occurrences) were also frequent lifestyle factors. The other factors, CAM, self-care, smoking/alcohol, reproductive factors, and mobility, all presented less than five occurrences.

The bar chart “Environmental factors” in Figure 6D offers a comparative analysis of the frequency at which various **environmental and social factors** occur among the three groups of cancer patients. These factors encompass a range of elements, including healthcare provider interactions, information and education, social support, romantic relationships, social isolation, work dynamics, family support, lack of support, healthcare routines, social interactions, cancer group interactions, discrimination, spirituality and religion, sexual encounters, and partner support.

In the case of cancer survivors, interactions with healthcare providers were cited most frequently as the vital factor, with 68 instances underscoring the role played by medical staff in their care. Similarly, information and education were emphasized, with 67 mentions highlighting patients' need to be well-informed about their health and treatment. Social support and work dynamics were also significant factors, with 58 and 44 instances, respectively. Both romantic relationships and lack of support were manifested in 37 occurrences, and social interaction in 30 occurrences. Family dynamics, cancer group interaction, healthcare routine, and societal perception presented 20 to 22 occurrences. The other environmental factors, such as social isolation, sexual encounters, spirituality/religion, discrimination, and partner support, presented 14, 12, 9, 8, and 2 occurrences, respectively.

For end-of-life/palliative care patients, social interactions, family dynamics, and healthcare-provider interactions were the most noteworthy, each with eight instances, followed by information and education, with five occurrences. A diverse array of factors—including social support, work dynamics, lack of support, family support, healthcare routines, societal perceptions, cancer group interactions, social isolation, and spirituality and religion—registered less than five times.

Patients who were undergoing ongoing treatment showed a similar trend to cancer survivors, where interactions with healthcare providers were found to be the main factor in 49 cases. Information and education were the second most significant environmental factor in 25 instances. Family dynamics and social interactions were the third most frequent factor, with 23 occurrences, closely followed by social support, with 22 occurrences. Healthcare routine emerged as the fourth most frequent factor among patients undergoing ongoing treatment, with 20 occurrences. The following environmental factors were observed, and their frequency of occurrence was noted: family support (18), societal perception (16), romantic relationships (13), work dynamics (12), and social isolation (11). On the other hand, factors such as lack of support (9), discrimination (6), spirituality/religion (6), and cancer group interaction (5) were the least frequently occurring factors.

	<p style="text-align: center;">Quality of Life in Oncology: measuring what matters for cancer patients and survivors in Europe</p>	 <p style="text-align: center;">Funded by the European Union</p>
---	---	---

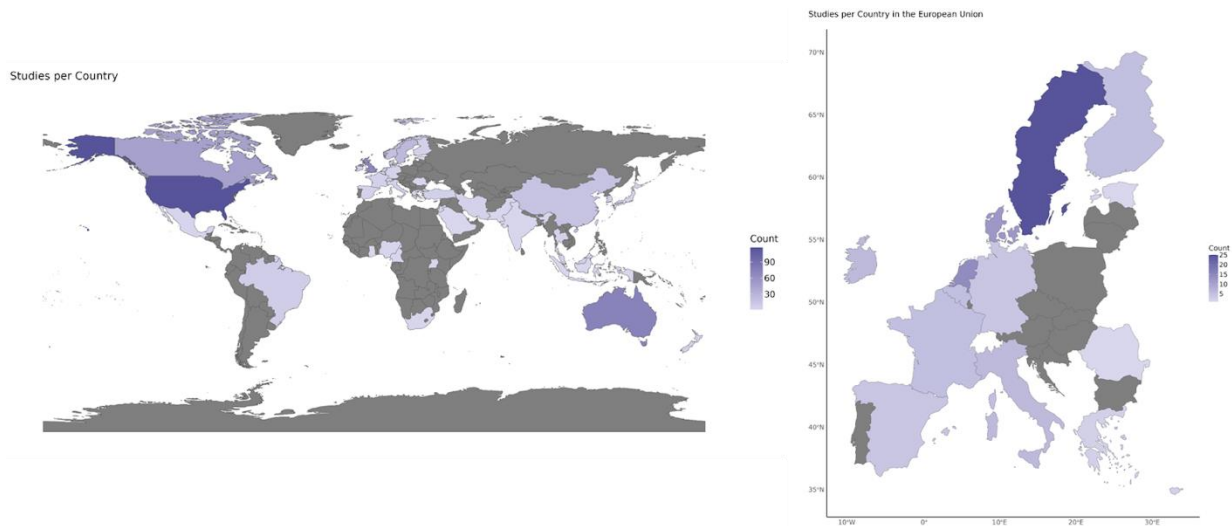


Figure 7 *Global and European distribution of studies by country*

Figure 7 consists of two **maps** presenting the **distribution of studies** included in the analysis. On the left, a world map titled "Studies per Country" uses varying shades of blue to indicate the number of studies conducted in each country globally. Darker shades of blue represent a higher count of studies, with a legend scaling from light blue (fewer studies) to dark blue (more studies). According to the data, the United States conducted the highest number of studies with 117, followed by Australia with 73, the United Kingdom with 68, Canada with 46, and Sweden with 25 studies. Norway, China, Netherlands, and Denmark had 19, 17, 14, and 12 studies respectively. The remaining countries had less than ten studies, with Brazil having 9, Israel 8, and Ireland, Italy, Korea, Malaysia, New Zealand, Singapore, Taiwan, and Turkey having six studies each. Belgium, Finland, France, Hong Kong, Iran, and Japan had five studies, while Germany, Spain, and Thailand had four. Jordan, Mexico, and Switzerland had three studies, while Cyprus, Greece, India, Nigeria, Palestine, Puerto Rico, South Africa, and Uganda had two. Finally, there was only one study in Barbados, Cameroon, Estonia, Ghana, Indonesia, Pakistan, Romania, Samoa, and Saudi Arabia.

On the right side is a map called "Studies per Country in the European Union," which provides a detailed view of the distribution of studies within Europe. The map uses a color scheme to differentiate the counts, with darker shades indicating more studies. The top five countries in the European Union with the most studies were the United Kingdom (68), Sweden (25), Norway (19), Netherlands (14), and Denmark (12). The other 13 countries had less than ten studies.

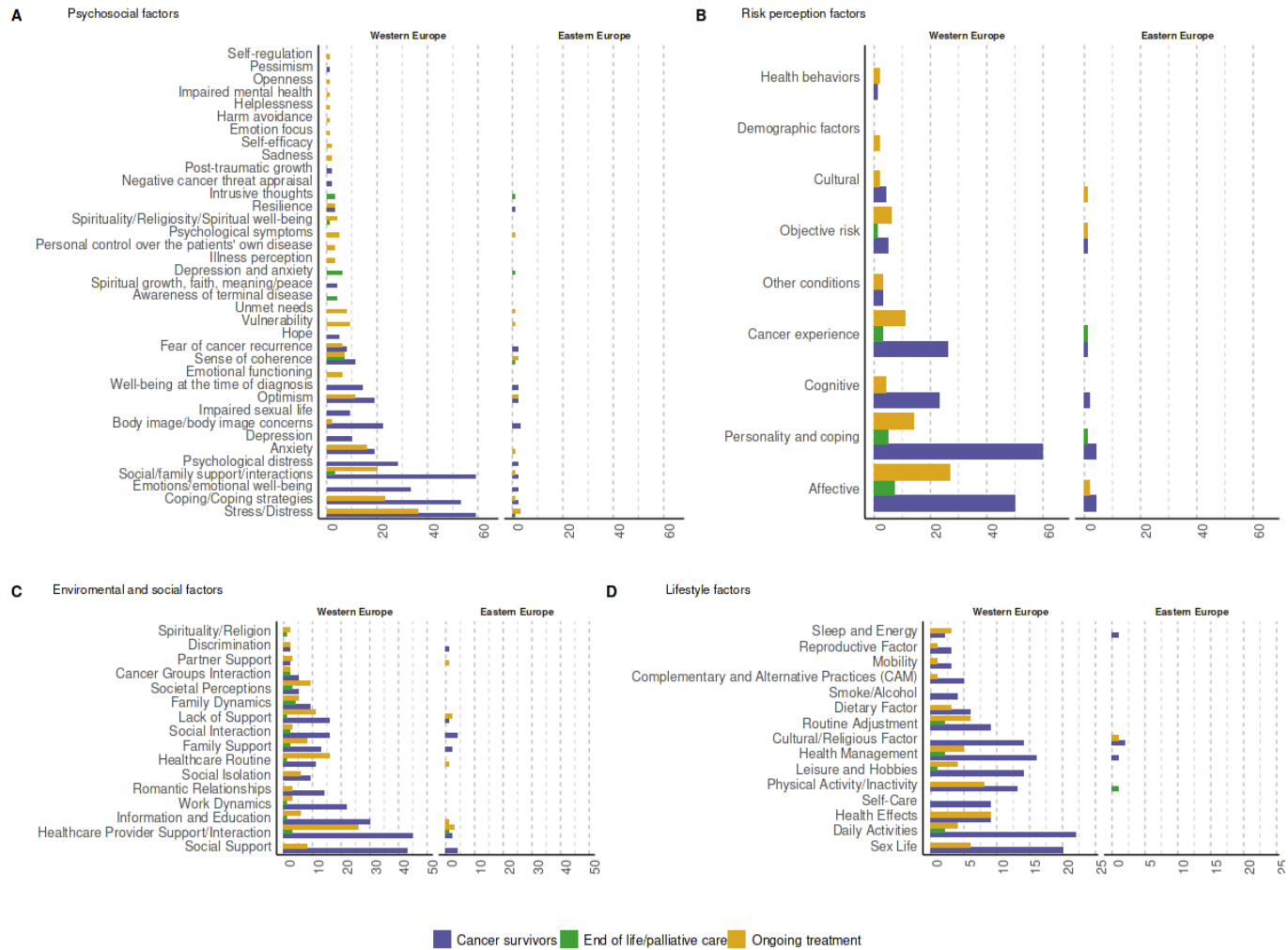
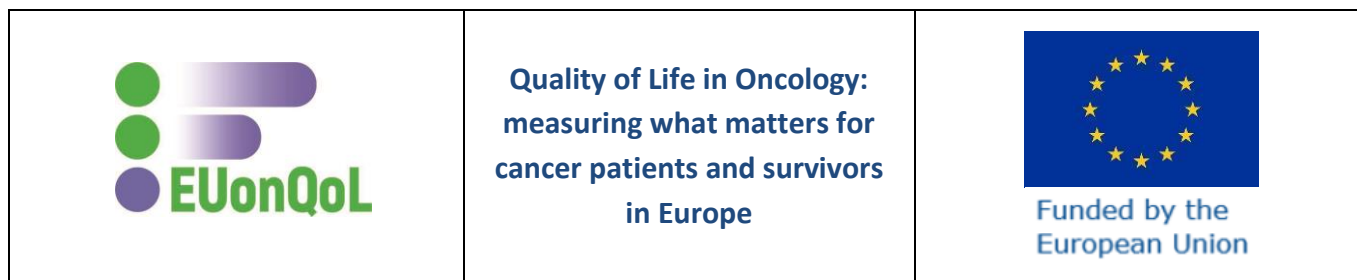


Figure 8 Distribution of psychosocial (A), risk perception (B), environmental (C), and lifestyle (D) factors in Western and Eastern European countries.

Figure 8 illustrates the distribution of psychosocial, risk perception, environmental, and lifestyle factors among Western and Eastern European cancer patients. The graph includes three patient groups: cancer survivors (blue bar), those in end-of-life/palliative care (green bar), and those undergoing treatment (orange bar).

Concerning psychosocial factors shown in Figure 8A, the occurrences of various categories were much lower in Eastern Europe than in Western Europe. In Eastern Europe, body image concerns among cancer survivors (3 occurrences) and stress/distress during ongoing treatment (3 occurrences) were the most frequent. On the other hand, Western Europe showed a much higher frequency of factors, particularly coping strategies in cancer survivors (53 occurrences) and stress/distress both in cancer survivors and during ongoing treatment (59 occurrences each). In Western Europe, anxiety, body image concerns, and social/family support were also significantly more frequent compared to Eastern Europe.



The risk perception factors among cancer patients in Western and Eastern Europe show distinct patterns, as shown in Figure 8B. In Eastern Europe, lower occurrences were noted, with the affective personality and coping categories being the most common among cancer survivors, each with four occurrences. On the other hand, Western Europe reported higher instances across all categories, with personality and coping being the most common among cancer survivors, with 60 occurrences. Other categories, such as cancer experience, cognitive, and affective, also showed notably higher occurrences in Western Europe for both cancer survivors and those in active treatment.

For environmental and social factors in Western and Eastern European countries (Figure 8C), healthcare provider support/interaction for cancer survivors was the most frequent category (45 occurrences), followed by social support for cancer survivors (43 occurrences) and information and education for cancer survivors (30 occurrences). On the other hand, Eastern Europe had much fewer occurrences, with social interaction and social support for cancer survivors being the most noted (4 occurrences each). Furthermore, there were significant differences between the two regions in other categories, such as family support, healthcare routine, work dynamics, and lack of support.

Regarding lifestyle factors, as shown in Figure 8D, Eastern Europe reported minimal occurrences, with only one mention each of cultural/religious factors for cancer survivors, physical activity/inactivity during end-of-life/palliative care, health management, and sleep and energy for cancer survivors. On the other hand, Western Europe showed a higher frequency of various lifestyle factors. The most commonly reported factor was daily activities for cancer survivors, which was mentioned 22 times, followed by sex life for cancer survivors with 20 mentions. Health management and leisure and hobbies, both for cancer survivors, were reported 16 and 14 times, respectively. Physical activity/inactivity for cancer survivors was also notable, with 13 mentions.

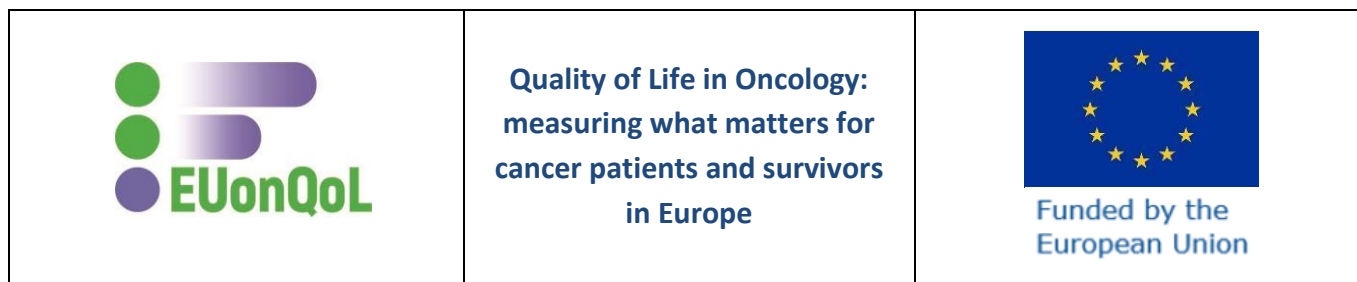
4. Sentiment analysis

In recent years, the analysis of social media content has become increasingly relevant in health informatics, offering insights into patient experiences and perceptions (Banaye Yazdipour et al., 2022; Khan et al., 2022; Sugawara et al., 2012).

Cancer, being a critical public health issue worldwide, has been the subject of extensive research in various fields, including psychology, oncology, and patient care. The quality of life for cancer patients is a multifaceted concept, encompassing physical, psychological, and social well-being (Bender et al., 2021). Social media platforms like Twitter have become instrumental in providing a space for patients to share their experiences, concerns, and support networks, thus offering a rich source of data for understanding these aspects (de Ruyter et al., 1993).

The utilization of sentiment analysis in healthcare research has seen significant growth, with studies demonstrating its effectiveness in capturing patient experiences and perceptions from online platforms. This approach enables the extraction of both quantitative and qualitative insights, providing a deeper understanding of the factors impacting the quality of life of cancer patients (Clark et al., 2018).

In Italy, where healthcare systems and patient experiences may differ from other regions, it is crucial to analyze and understand the sentiments of cancer patients within this specific context (De Rosis et al.,



2020). Therefore, this study aimed to identify the overall "mood" behind the text among cancer patients concerning the quality of life expressed in social media posts in Italy. To achieve this objective, one million tweets were collected from Italy, posted between 2014 and 2022, using a Twitter Academic application programming interface. Our focus was to analyze tweets written by individuals who were personally affected by cancer.



4.1. Methodology of NLP process and text analysis

The data collection process for Sentiment Analysis involved the extraction of datasets from the public tweets streaming via the Twitter API. Specifically, the Twar2 tool was utilized on the PowerShell to extract one million tweets from Italy, spanning the period between May 26, 2014, and December 29, 2022. Further data collection was limited by the loss of access to the Twitter API in February 2023. To prepare the extracted data for analysis, the output file, which was initially in JSON format, was processed and transformed. This was accomplished by flattening the JSON file and converting it into a comma-separated values (CSV) file format. All subsequent analyses on the processed CSV file were performed using Python and R, widely used programming languages for data analysis and visualization. Adopting these steps ensured that the data was cleaned and structured in a way that made it suitable for sentiment analysis, thereby increasing the accuracy and reliability of the results.

In order to preprocess data for sentiment analysis, first a large set of tweets was filtered based on language, selecting those written in Italian (377,048 tweets) and English (289,677 tweets). To further refine the analysis, the SpaCy's regular expressions (regex) were used to filter tweets related to cancer. SpaCy is a powerful tool that is built around NLP (Natural Language Processing) tools. By using the regex functions of SpaCy, it is possible to create better patterns that can take linguistic context into account. For the cancer-related tweets, terms such as "cancer", "cancro", "carcinoma", "tumor", and "neoplasia" were used as filters, resulting in a total of 718 tweets. Those 588 tweets were written in Italian, and 130 were written in English.

To ensure that only tweets written by individuals who were personally affected by this condition were analyzed, the OpenAI's text-davinci-003 model was used to filter tweets written in the first person for cancer. To validate the effectiveness of this approach, a sample of tweets previously classified in the first-person category by OpenAI was also manually inspected. Tweets about personal experiences regarding cancer were also manually identified. This additional step helped ensure that the analyzed tweets were more likely to provide firsthand accounts and perspectives, which can be particularly valuable for sentiment analysis. However, both using OpenAI's model and after the manual validation, no tweet written in the first person or related to personal experiences was identified. Consequently, the sentiment analysis was not concluded.

To better understand the data collected, the tweets were divided into two categories based on the language they were written in - English and Italian. Then, a series of graphical analyses was conducted to gain insights. First, word cloud visualizations were performed for each language to determine the main themes of the tweets. Next, all cancer-related tweets were classified into four groups: Political, Family-Related, News or Research-Related, and Other. The Other category included tweets related to horoscopes, insults to people or things outside of a political context, celebrities or famous people

	<p style="text-align: center;">Quality of Life in Oncology: measuring what matters for cancer patients and survivors in Europe</p>	 <p style="text-align: center;">Funded by the European Union</p>
---	---	---

diagnosed with cancer or dying from it, calls for donations, and marches against cancer, among others. Using this classification, treemap visualizations were created to illustrate the distribution and proportion of each category within the dataset.

4.1.1. Results

Separate Word Cloud plots for Italian and English tweets about cancer were prepared (Figure 9). The two-word cloud plots illustrate the most frequently occurring words in social media discussions about cancer, one for Italian (a) and English (b).

The Italian **word cloud** features "cancro" (cancer in Italian) as the central term, with "prevenzione" (prevention), "ricerca" (research), "pazienti" (patients), and "grazie" (thank you) being prominently displayed. Words like "seno" (breast), "prostata" (prostate), and "tumori" (tumors) indicate the types of cancer being discussed. The term "immunoterapia" (immunotherapy) suggests conversations around specific treatments. Similar to the English word cloud, this one also reflects a blend of medical terms, treatment types, and personal aspects of the cancer experience (Figure 9a).

In the English language **word cloud**, the central and most prominent term is "cancer," surrounded by other significant words such as "breast," "fight," "love," "treatment," and "research." The presence of words like "donate," "support," and "cure" suggests a focus on treatment, recovery, and possibly fundraising or awareness campaigns. The inclusion of "mom," "friend," and "family" indicates personal connections to the disease, hinting at discussions centered on patient experiences and support networks (Figure 9b).

a)



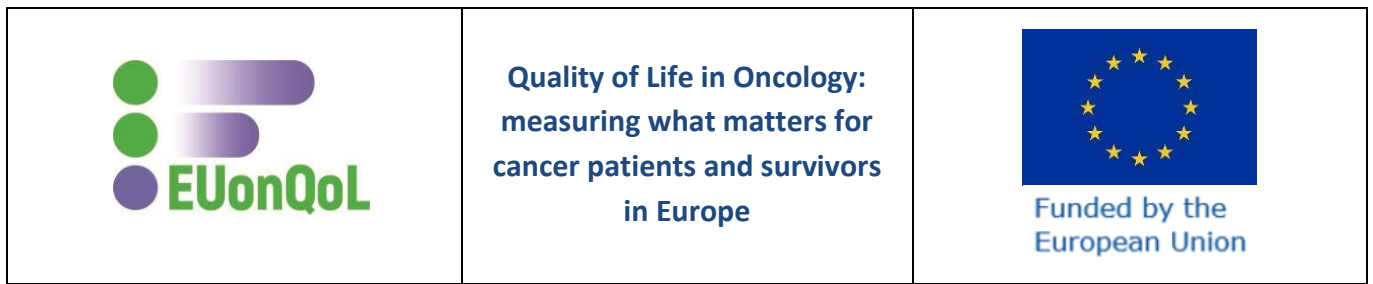
b)



Figure 9 Word cloud plots showing the most frequent words used in Italian (a) and in English (b)

4.1.2. Analysis of Tweet Content

When parsing through the tweets related to cancer, it was noted that most of the tweets containing the words selected for the analysis were either using it in a manner not related to cancer, usually politically charged (e.g. "il cancro della democrazia italiana"), using it to convey news, factoid or research ("Ministero Salute ritira nuovi colori per tatuaggi, rischio cancro!", "Malasanità a Sesto San Giovanni Tribunale di Monza condanna medico per intervento errato per un tumore allo stomaco non esistente.", "Novel



Sequencing Approach Seeks to Detect Cancer Genomic Alterations”), or not related to a personal experience, but rather about family or friends that suffer from cancer (“Io lo odio il cancro. Mi sta portando via i nonni, mi ha quasi portato via la mamma e spazza via vite ogni giorno”) (Figure 10).

For tweets in Italian, "News or Research" forms the largest category with 283 tweets, illustrating a significant interest in the scientific and informational aspects of cancer within the Italian-speaking community. "Other" includes 254 tweets and encompasses a broad array of topics such as horoscopes, celebrities or well-known figures battling or succumbing to cancer, appeals for charitable contributions, among others. "Politics" is represented with 41 tweets, suggesting a level of discourse on cancer in relation to political issues. "Cancer Related To Family" appears to be the smallest category with 8 tweets, indicating fewer tweets written in Italian explicitly referencing family connections to cancer (Figure 10a).

For tweets written in English, the largest segment is labeled "Other," with 72 tweets, suggesting a diverse range of discussions outside the specified categories. "News Or Research" is represented with 35 tweets, indicating a substantial engagement with content on cancer research and news updates. "Cancer Related to Family" contains 14 tweets, which could reflect stories related to family members' experiences with cancer. The smallest category, "Politics," with 9 tweets, indicates some discussion on cancer within a political context (Figure 10b).

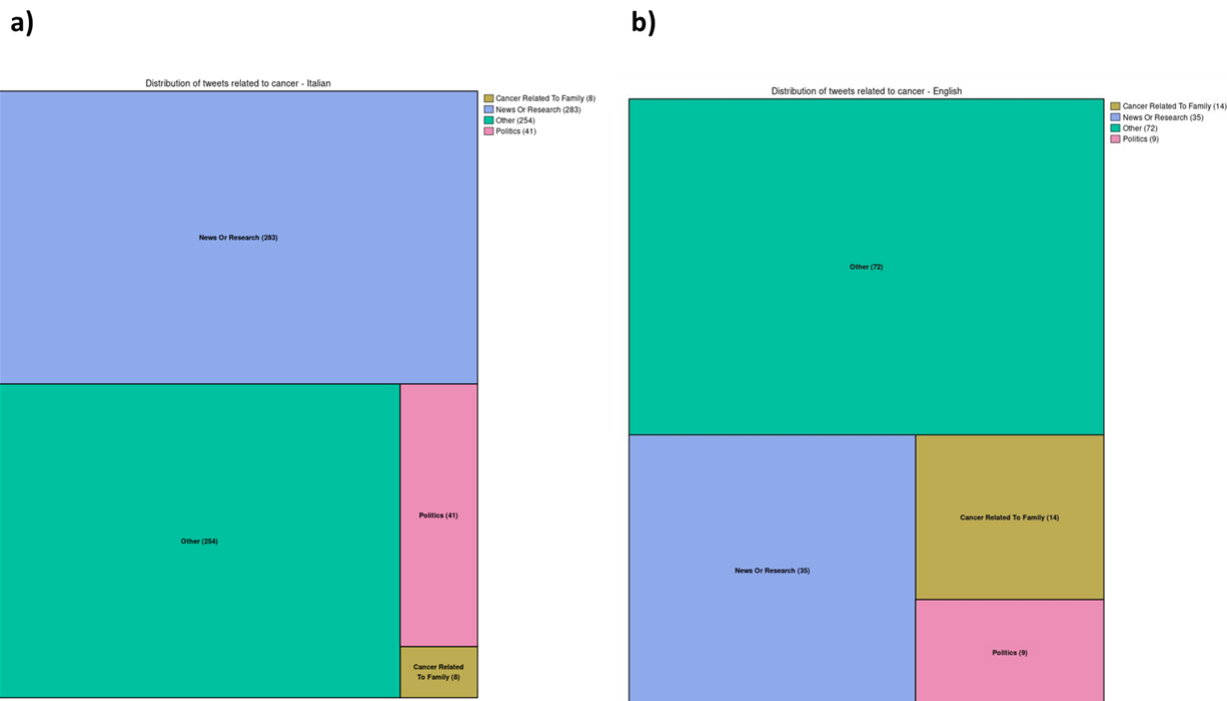
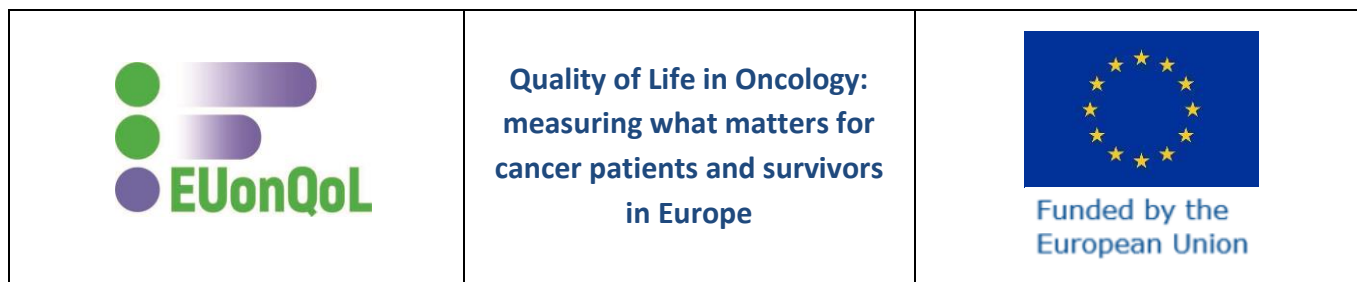


Figure 10 Distribution of tweets related to cancer in Italian (a) and in English (b)

4.1.3. Challenges in Data Collection



The primary challenge faced was the sheer volume of tweets in comparison to the size of our sample. Considering the global production of approximately 6,000 tweets per second, our dataset might have been too small to capture a representative sample of Italian tweets about cancer. Initially, a modest sample was selected to assess the feasibility of the study, with plans to gather more data subsequently. However, access to the Twitter's API was discontinued in February 2023, which posed a significant limitation.

To expand the dataset, the possibility of gathering data from other popular social media platforms was explored, such as Facebook, Instagram, and Reddit. However, this endeavor was met with limited success. Facebook and Instagram, both part of the Meta platform, have stringent restrictions on accessing public content. According to the documentation provided by Facebook for developers (<https://developers.facebook.com/docs/features-reference/page-public-content-access>), public content access is limited. In fact, to fetch such data, one would need to be an app developer engaged in providing services such as competitive benchmark analysis.

Reddit, on the other hand, offers an API that allows for the extraction of all public posts and comments from any public subreddit. Nevertheless, the platform is primarily structured around English as the main language of communication. This presents a challenge for this study, which is focused on Italian-speaking users. While there are subreddits dedicated to discussions about cancer, such as r/cancer and r/cancerfamilysupport, they are predominantly populated by English-speaking users from around the globe. This language barrier significantly hinders the ability to analyze sentiment among Italian speakers and underscores the necessity for a more nuanced approach to data collection in future research endeavors.

To minimize these limitations in future research, an exploration of alternative data sources such as forums, blogs, and news websites popular among Italian speakers can provide a more comprehensive view of public sentiment. These sources often have less restrictive data access policies compared to major social media platforms.

5. Conclusions

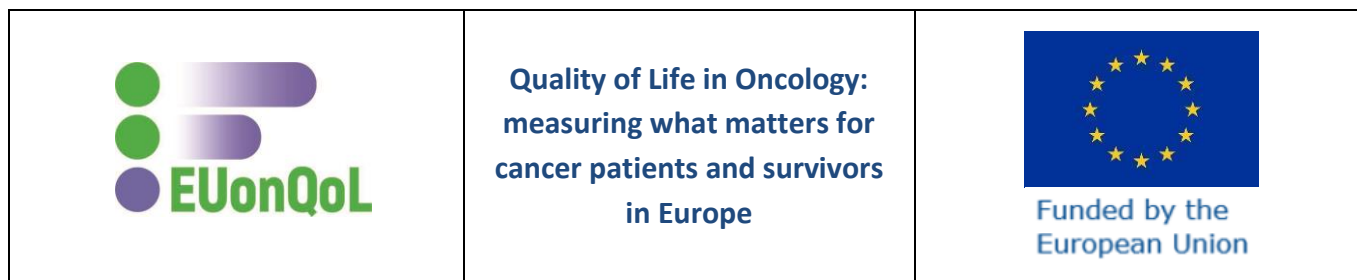
The aim of the present report is to identify and summarize a range of clinical, cultural, sociodemographic, and psychosocial factors associated with QoL. Obtained results will contribute to highlighting factors affecting QoL among adult cancer patients in different phases of the cancer pathway. The results will also allow for the identification of differences between contributions from WP3 and WP4 aimed to identify domains covered by the EUonQoL-Kit. Additionally, the aforementioned domains, will serve as the basis for determining factors to be included in the CRF developed as part of the WP7 Pilot Survey. Indeed, the overlapping themes between domains of QoL identified by WP4 and factors associated with QoL in 3 URs are the following:

Physical domain (i.e. symptoms, impact of treatment, body image)

Social health (i.e. self-efficacy, ability to cope)

Psychological well-being (i.e. anxiety, depression, sadness, psychological distress, stress, fear of recurrence, spirituality, meaning)

Overall health (overall QoL)



Findings retrieved from the 3 URs show that in all cancer groups **anxiety and depression** were the main **psychological factors** negatively affecting QoL in cancer patients in treatment, survivors and patients in palliative care, while **social support** is the main social factor positively affecting QoL. Also, **coping/coping strategy** was another prominent factor positively impacting QoL in active treatment group and in survivors.

For qualitative studies, psychosocial factors like stress and distress, coping strategies, and family support were the most prevalent across cancer survivors and those undergoing treatment. For palliative care patients, a sense of coherence, depression, and anxiety were the most relevant factors. Other important factors, from the risk perception category, such as affective responses, personality traits, coping mechanisms, and personal or family cancer experiences, were significant across all patient groups. Lifestyle factors, such as physical activity, dietary habits, health management, and intimate life, varied across the patient groups. For instance, intimate life was a major concern for cancer survivors, while leisure and hobbies were highlighted in the palliative care group. Environmental and social factors like interactions with healthcare providers, information and education, social support, and work dynamics were key, with cancer survivors emphasizing the importance of healthcare provider interactions and information.

Regarding the use of social media to analyze Italian cancer patients' sentiments, the extraction of insights about these patients' quality of life posed some challenges, mainly due to the loss of Twitter API access and limitations in content access from platforms like Facebook, Instagram, and Reddit. The study results revealed that Italian-language tweets mostly referred to news and research when mentioning cancer, showing less focus on political and family matters compared to the more topic-diverse English-language tweets. The findings point out the cultural and linguistic differences in online cancer-related discussions and the study's shortcomings in accurately representing Italian-speaking cancer patients' experiences. It suggests future research should aim for broader data collection and improved methods to more effectively understand and support cancer patients' needs.

One of the final aims of the present report was to define a set of factors that could be used in the CRF, for all three population groups of patients, during the Pilot phase of the EUonQoL Project.

The identified factors included in the CRF for the 3 population groups, extrapolated from key individual, clinical, psychosocial, and cultural factors identified by WP5 are the following:

Sociodemographic data, including country of birth, place of residence, living situation, total number of members in your household, number of children in your household aged under 18, keeping up with household bills in the last year, and "Do you identify as a person with disability or other chronic condition?". Furthermore, there is a specific theme for both the active treatment group of patients and end-of-life/palliative care patients (support needed to interpret items) and some themes specific for the survivors' group of patients (ECOG performance status, comorbidities, currently undergoing pharmacological treatment for physical symptoms other than pain, involuntary weight loss in the last 6 months, follow-up frequency, support needed to interpret items).



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

6. Appendix

6.1. List of search strings

6.1.1. Search strings for Scopus

Active Treatment:

(INDEXTERMS (neoplasms) OR TITLE-ABS-KEY (cancer*) OR TITLE-ABS-KEY (tumor*) OR TITLE-ABS-KEY (tumour*) OR TITLE-ABS-KEY (malignanc*) OR TITLE-ABS-KEY (neoplasm*) OR TITLE-ABS-KEY (carcinoma*) OR TITLE-ABS-KEY (oncolog*))

AND (INDEXTERMS ("Quality of Life") OR TITLE-ABS-KEY ("Quality of life") OR TITLE-ABS-KEY ("Health Related Quality Of Life") OR TITLE-ABS-KEY (hrqol) OR TITLE-ABS-KEY (qol))

AND (TITLE-ABS-KEY (factor*) OR TITLE-ABS-KEY (indicator*) OR TITLE-ABS-KEY (characteristic*) OR TITLE-ABS-KEY (predictor*) OR TITLE-ABS-KEY (determinant*))

AND (INDEXTERMS (psychology) OR TITLE-ABS-KEY (psycho*) OR TITLE-ABS-KEY (social) OR TITLE-ABS-KEY (individual) OR TITLE-ABS-KEY (personal) OR TITLE-ABS-KEY ("Psychological Side Effect") OR TITLE-ABS-KEY ("Psychosocial Factor") OR TITLE-ABS-KEY ("Factor, Psychosocial") OR TITLE-ABS-KEY ("Psychological Factors") OR TITLE-ABS-KEY ("Factor, Psychological") OR TITLE-ABS-KEY (affect) OR TITLE-ABS-KEY (effect) OR TITLE-ABS-KEY (related) OR TITLE-ABS-KEY (impact) OR TITLE-ABS-KEY ("side effect")) AND (INDEXTERMS (radiotherapy) OR INDEXTERMS (therapy) OR TITLE-ABS-KEY (treatment) OR TITLE-ABS-KEY ("active treatment") OR TITLE-ABS-KEY (chemotherapy) OR TITLE-ABS-KEY (radiotherapy) OR TITLE-ABS-KEY (endocrine) OR TITLE-ABS-KEY (adjuvant) OR TITLE-ABS-KEY (therapy) OR TITLE-ABS-KEY (therapeutic) OR TITLE-ABS-KEY ("neo-adjuvant") OR TITLE-ABS-KEY (neoadjuvant))

AND ((KEY ({systematic review}) OR TITLE ({systematic review})))



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



AND DOCTYPE ("Re")) AND LANGUAGE (english)

AND PUBYEAR > 2012

AND PUBYEAR < 2023

Survivor:

(INDEXTERMS(Neoplasms) OR TITLE-ABS-KEY(cancer*) OR TITLE-ABS-KEY(tumor*) OR TITLE-ABS-KEY(tumour*) OR TITLE-ABS-KEY(malignanc*) OR TITLE-ABS-KEY(neoplasm*) OR TITLE-ABS-KEY(carcinoma*) OR TITLE-ABS-KEY(Oncolog*))

AND (INDEXTERMS("Quality of Life") OR TITLE-ABS-KEY("Quality of life") OR TITLE-ABS-KEY("Health Related Quality Of Life") OR TITLE-ABS-KEY(HRQOL) OR TITLE-ABS-KEY(QOL))

AND (TITLE-ABS-KEY(Factor*) OR TITLE-ABS-KEY(indicator*) OR TITLE-ABS-KEY(Characteristic*) OR TITLE-ABS-KEY(predictor*) OR TITLE-ABS-KEY(determinant*))

AND (INDEXTERMS(Psychology) OR TITLE-ABS-KEY(psycho*) OR TITLE-ABS-KEY(social) OR TITLE-ABS-KEY(individual) OR TITLE-ABS-KEY(personal) OR TITLE-ABS-KEY("Psychological Side Effect") OR TITLE-ABS-KEY("Psychosocial Factor") OR TITLE-ABS-KEY("Factor, Psychosocial") OR TITLE-ABS-KEY("Psychological Factors") OR TITLE-ABS-KEY("Factor, Psychological") OR TITLE-ABS-KEY(affect) OR TITLE-ABS-KEY(effect) OR TITLE-ABS-KEY(related) OR TITLE-ABS-KEY(impact) OR TITLE-ABS-KEY("side effect"))

AND (INDEXTERMS("Cancer Survivor") OR INDEXTERMS(Survivors) OR TITLE-ABS-KEY("Cancer Survivor") OR TITLE-ABS-KEY("Survivors, Cancer") OR TITLE-ABS-KEY("Cancer Survivorship") OR TITLE-ABS-KEY("Survivorship, Cancer") OR TITLE-ABS-KEY("Long Term Cancer Survivor") OR TITLE-ABS-KEY("Cancer Survivor, Long-Term") OR TITLE-ABS-KEY(Survivor) OR TITLE-ABS-KEY("Long Term Survivor") OR TITLE-ABS-KEY("Survivor, Long-Term") OR TITLE-ABS-KEY(survivorship))



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



AND ((KEY({systematic review}) OR TITLE({systematic review})) AND DOCTYPE("Re"))

AND LANGUAGE(english)

End of life and Palliative Care:

(INDEXTERMS(Neoplasms) OR TITLE-ABS-KEY(cancer*) OR TITLE-ABS-KEY(tumor*) OR TITLE-ABS-KEY(tumour*) OR TITLE-ABS-KEY(malignanc*) OR TITLE-ABS-KEY(neoplasm*) OR TITLE-ABS-KEY(carcinoma*) OR TITLE-ABS-KEY(Oncolog*))

AND (INDEXTERMS("Quality of Life") OR TITLE-ABS-KEY("Quality of life") OR TITLE-ABS-KEY("Health Related Quality Of Life") OR TITLE-ABS-KEY(HRQOL) OR TITLE-ABS-KEY(QOL))

AND (TITLE-ABS-KEY(Factor*) OR TITLE-ABS-KEY(indicator*) OR TITLE-ABS-KEY(Characteristic*) OR TITLE-ABS-KEY(predictor*) OR TITLE-ABS-KEY(determinant*))

AND (INDEXTERMS(Psychology) OR TITLE-ABS-KEY(psycho*) OR TITLE-ABS-KEY(social) OR TITLE-ABS-KEY(individual) OR TITLE-ABS-KEY(personal) OR TITLE-ABS-KEY("Psychological Side Effect") OR TITLE-ABS-KEY("Psychosocial Factor") OR TITLE-ABS-KEY("Factor, Psychosocial") OR TITLE-ABS-KEY("Psychological Factors") OR TITLE-ABS-KEY("Factor, Psychological") OR TITLE-ABS-KEY(affect) OR TITLE-ABS-KEY(effect) OR TITLE-ABS-KEY(related) OR TITLE-ABS-KEY(impact) OR TITLE-ABS-KEY("side effect"))

AND (INDEXTERMS("Terminal Care") OR INDEXTERMS("Hospice Care") OR INDEXTERMS("Palliative Care") OR TITLE-ABS-KEY("Care, Palliative") OR TITLE-ABS-KEY("Palliative Treatment") OR TITLE-ABS-KEY("Therapy, Palliative") OR TITLE-ABS-KEY("Palliative Therapy") OR TITLE-ABS-KEY("Palliative Supportive Care") OR TITLE-ABS-KEY("Supportive Care, Palliative") OR TITLE-ABS-KEY("Care, Hospice") OR TITLE-ABS-KEY("Care, Terminal") OR TITLE-ABS-KEY("End of Life Care") OR TITLE-ABS-KEY("Care, End-Of-Life") OR TITLE-ABS-KEY("end of life") OR TITLE-ABS-KEY(palliative) OR TITLE-ABS-KEY(hospice))



AND ((KEY({systematic review}) OR TITLE({systematic review})) AND DOCTYPE("Re"))

AND LANGUAGE(english)

6.1.2. Search strings for Embase

Active Treatment:

('neoplasm'/exp OR cancer*:ti,ab,kw OR tumor*:ti,ab,kw OR tumour*:ti,ab,kw OR malignanc*:ti,ab,kw OR neoplasm*:ti,ab,kw OR carcinoma*:ti,ab,kw OR Oncolog*:ti,ab,kw)

AND ('quality of life'/exp OR 'Quality of life':ti,ab,kw OR 'Health-Related Quality Of Life':ti,ab,kw OR 'Health Related Quality Of Life':ti,ab,kw OR HRQOL:ti,ab,kw OR QOL:ti,ab,kw OR 'Life quality':ti,ab,kw)

AND (factor*:ti,ab,kw OR indicator*:ti,ab,kw OR characteristic*:ti,ab,kw OR predictor*:ti,ab,kw OR determinant*:ti,ab,kw)

AND ('psychology'/exp OR psycho*:ti,ab,kw OR social:ti,ab,kw OR individual:ti,ab,kw OR personal:ti,ab,kw OR 'Psychological Side Effect':ti,ab,kw OR 'Psychological Side Effects':ti,ab,kw OR 'Psychosocial Factors':ti,ab,kw OR 'Factor, Psychosocial':ti,ab,kw OR 'Factors, Psychosocial':ti,ab,kw OR 'Psychosocial Factor':ti,ab,kw OR 'Psychological Factors':ti,ab,kw OR 'Factor, Psychological':ti,ab,kw OR 'Psychological Factor':ti,ab,kw OR 'Factors, Psychological':ti,ab,kw OR affect:ti,ab,kw OR effect:ti,ab,kw OR related:ti,ab,kw OR impact:ti,ab,kw OR 'side effect*':ti,ab,kw)

AND ('neoplasm'/exp/dm_dt,dm_rt,dm_su,dm_th OR treatment:ti,ab,kw OR "active treatment":ti,ab,kw OR chemotherapy:ti,ab,kw OR radiotherapy:ti,ab,kw OR endocrine:ti,ab,kw OR adjuvant:ti,ab,kw OR therapy:ti,ab,kw OR therapeutic:ti,ab,kw OR ("neo-adjuvant":ti,ab,kw OR neoadjuvant:ti,ab,kw OR "neo adjuvant":ti,ab,kw))

AND ("systematic review":pt OR 'systematic review'/mj OR 'systematic review':ti,ab,kw) NOT ('animal'/exp NOT 'human'/exp) AND (2013:py OR 2014:py OR 2015:py OR 2016:py OR 2017:py OR 2018:py OR 2019:py OR 2020:py OR 2021:py OR 2022:py)



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Survivor:

('neoplasm'/exp OR cancer*:ti,ab,kw OR tumor*:ti,ab,kw OR tumour*:ti,ab,kw OR malignanc*:ti,ab,kw OR neoplasm*:ti,ab,kw OR carcinoma*:ti,ab,kw OR Oncolog*:ti,ab,kw)

AND ('quality of life'/exp OR 'Quality of life':ti,ab,kw OR 'Health-Related Quality Of Life':ti,ab,kw OR 'Health Related Quality Of Life':ti,ab,kw OR HRQOL:ti,ab,kw OR QOL:ti,ab,kw OR 'Life quality':ti,ab,kw)

AND (factor*:ti,ab,kw OR indicator*:ti,ab,kw OR characteristic*:ti,ab,kw OR predictor*:ti,ab,kw OR determinant*:ti,ab,kw)

AND ('psychology'/exp OR psycho*:ti,ab,kw OR social:ti,ab,kw OR individual:ti,ab,kw OR personal:ti,ab,kw OR 'Psychological Side Effect':ti,ab,kw OR 'Psychological Side Effects':ti,ab,kw OR 'Psychosocial Factors':ti,ab,kw OR 'Factor, Psychosocial':ti,ab,kw OR 'Factors, Psychosocial':ti,ab,kw OR 'Psychosocial Factor':ti,ab,kw OR 'Psychological Factors':ti,ab,kw OR 'Factor, Psychological':ti,ab,kw OR 'Psychological Factor':ti,ab,kw OR 'Factors, Psychological':ti,ab,kw OR affect:ti,ab,kw OR effect:ti,ab,kw OR related:ti,ab,kw OR impact:ti,ab,kw OR 'side effect*':ti,ab,kw)

AND ('cancer survivor'/exp OR 'survivor'/exp OR "Cancer Survivor":ti,ab,kw OR "Survivors, Cancer":ti,ab,kw OR "Cancer Survivorship":ti,ab,kw OR "Survivorship, Cancer":ti,ab,kw OR "Long-Term Cancer Survivors":ti,ab,kw OR "Cancer Survivor, Long-Term":ti,ab,kw OR "Long Term Cancer Survivor*":ti,ab,kw OR Survivor:ti,ab,kw OR "Long-Term Survivors":ti,ab,kw OR "Long Term Survivors":ti,ab,kw OR "Long-Term Survivor":ti,ab,kw OR "Survivor, Long-Term":ti,ab,kw OR "Survivors, Long-Term":ti,ab,kw OR survivorship:ti,ab,kw)

AND ("systematic review":pt OR 'systematic review'/mj OR 'systematic review':ti,ab,kw) NOT ('animal'/exp NOT 'human'/exp) AND [2013-2022]/py

End of life and Palliative Care:

('neoplasm'/exp OR cancer*:ti,ab,kw OR tumor*:ti,ab,kw OR tumour*:ti,ab,kw OR malignanc*:ti,ab,kw OR neoplasm*:ti,ab,kw OR carcinoma*:ti,ab,kw OR Oncolog*:ti,ab,kw)



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

AND ('quality of life'/exp OR 'Quality of life':ti,ab,kw OR 'Health-Related Quality Of Life':ti,ab,kw OR 'Health Related Quality Of Life':ti,ab,kw OR HRQOL:ti,ab,kw OR QOL:ti,ab,kw OR 'Life quality':ti,ab,kw)

AND (factor*:ti,ab,kw OR indicator*:ti,ab,kw OR characteristic*:ti,ab,kw OR predictor*:ti,ab,kw OR determinant*:ti,ab,kw)

AND ('psychology'/exp OR psycho*:ti,ab,kw OR social:ti,ab,kw OR individual:ti,ab,kw OR personal:ti,ab,kw OR 'Psychological Side Effect':ti,ab,kw OR 'Psychological Side Effects':ti,ab,kw OR 'Psychosocial Factors':ti,ab,kw OR 'Factor, Psychosocial':ti,ab,kw OR 'Factors, Psychosocial':ti,ab,kw OR 'Psychosocial Factor':ti,ab,kw OR 'Psychological Factors':ti,ab,kw OR 'Factor, Psychological':ti,ab,kw OR 'Psychological Factor':ti,ab,kw OR 'Factors, Psychological':ti,ab,kw OR affect:ti,ab,kw OR effect:ti,ab,kw OR related:ti,ab,kw OR impact:ti,ab,kw OR 'side effect*':ti,ab,kw)

AND ('terminal care'/exp OR 'palliative therapy'/exp OR "Care, Palliative":ti,ab,kw OR "Palliative Treatment*":ti,ab,kw OR "Therapy, Palliative":ti,ab,kw OR "Palliative Therapy":ti,ab,kw OR "Palliative Supportive Care":ti,ab,kw OR "Supportive Care, Palliative":ti,ab,kw OR "Care, Hospice":ti,ab,kw OR "Care, Terminal":ti,ab,kw OR "End of Life Care":ti,ab,kw OR "End-Of-Life Care*":ti,ab,kw OR "Care, End-Of-Life":ti,ab,kw OR "end of life":ti,ab,kw OR palliative:ti,ab,kw OR hospice:ti,ab,kw)

AND ("systematic review":pt OR 'systematic review'/mj OR 'systematic review':ti,ab,kw) NOT ('animal'/exp NOT 'human'/exp) AND [2013-2022]/py

6.1.3. Search strings for PubMed

Active Treatment:

("Neoplasms"[MeSH Terms] OR cancer*[tw] OR tumor*[tw] OR tumour* [tw] OR malignanc*[tw] OR neoplasm*[tw] OR carcinoma*[tw] OR Oncolog*[tw])

AND ("Quality of Life/psychology"[Mesh] OR "Quality of Life"[Mesh] OR "Quality of life"[tw] OR "Health-Related Quality Of Life"[tw] OR "Health Related Quality Of Life"[tw] OR HRQOL[tw] OR QOL[tw])

AND (Factor*[tw] OR indicator*[tw] OR Characteristic*[tw] OR predictor*[tw] OR determinant*[tw])



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



AND ("psychology" [Subheading] OR "Psychology"[Mesh] OR "Neoplasms/psychology"[Mesh] OR psycho*[tw] OR social[tw] OR individual[tw] OR personal[tw] OR "Psychological Side Effect"[tw] OR "Psychological Side Effects"[tw] OR "Psychosocial Factors"[tw] OR "Factor, Psychosocial"[tw] OR "Factors, Psychosocial"[tw] OR "Psychosocial Factor"[tw] OR "Psychological Factors"[tw] OR "Factor, Psychological"[tw] OR "Psychological Factor"[tw] "Factors, Psychological"[tw] OR affect[tw] OR effect[tw] OR related[tw] OR impact[tw] OR "side effect*" [tw])

AND ("Neoplasms/diet therapy"[Mesh] OR "Neoplasms/drug therapy"[Mesh] OR "Neoplasms/radiotherapy"[Mesh] OR "Neoplasms/surgery"[Mesh] OR "Neoplasms/therapy"[Mesh] OR "Neoplasms/pathology"[Mesh] OR treatment[tw] OR "active treatment"[tw] OR chemotherapy[tw] OR radiotherapy[tw] OR endocrine[tw] OR adjuvant[tw] OR therapy[tw] OR therapeutic[tw] OR (neo-adjuvant[tw] OR neoadjuvant[tw] OR neo adjuvant[tw]))

AND (systematic review[pt] OR "systematic review"[tw]) AND (2013/01/01:2022/12/31[Date - Publication] AND "english"[Language] NOT ("animals"[MeSH Terms] NOT "humans"[MeSH Terms]))

Survivor:

("Neoplasms"[MeSH Terms] OR cancer*[tw] OR tumor*[tw] OR tumour* [tw] OR malignanc*[tw] OR neoplasm*[tw] OR carcinoma*[tw] OR Oncolog*[tw])

AND ("Quality of Life/psychology"[Mesh] OR "Quality of Life"[Mesh] OR "Quality of life"[tw] OR "Health-Related Quality Of Life"[tw] OR "Health Related Quality Of Life"[tw] OR HRQOL[tw] OR QOL[tw])

AND (Factor*[tw] OR indicator*[tw] OR Characteristic*[tw] OR predictor*[tw] OR determinant*[tw])

AND ("psychology" [Subheading] OR "Psychology"[Mesh] OR "Neoplasms/psychology"[Mesh] OR psycho*[tw] OR social[tw] OR individual[tw] OR personal[tw] OR "Psychological Side Effect"[tw] OR "Psychological Side Effects"[tw] OR "Psychosocial Factors"[tw] OR "Factor, Psychosocial"[tw] OR "Factors, Psychosocial"[tw] OR "Psychosocial Factor"[tw] OR "Psychological Factors"[tw] OR "Factor, Psychological"[tw] OR "Psychological Factor"[tw] "Factors, Psychological"[tw] OR affect[tw] OR effect[tw] OR related[tw] OR impact[tw] OR "side effect*" [tw])



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



AND ("Cancer Survivors"[Mesh] OR "Survivors"[Mesh] OR "Cancer Survivor"[tw] OR "Survivors, Cancer"[tw] OR "Survivors of Childhood Cancer"[tw] OR "Childhood Cancer Survivor*"[tw] OR "Cancer Survivorship"[tw] OR "Survivorship, Cancer"[tw] OR "Long-Term Cancer Survivors"[tw] OR "Cancer Survivor, Long-Term"[tw] OR "Long Term Cancer Survivor*"[tw] OR "Survivors"[Mesh] OR Survivor[tw] OR "Long-Term Survivors"[tw] OR "Long Term Survivors"[tw] OR "Long-Term Survivor"[tw] OR "Survivor, Long-Term"[tw] OR "Survivors, Long-Term"[tw] OR survivorship[tw])

AND (systematic review[pt] OR "systematic review"[tw]) AND (2013/01/01:2022/12/31[Date - Publication] AND "english"[Language] NOT ("animals"[MeSH Terms] NOT "humans"[MeSH Terms]))

End of life and Palliative Care:

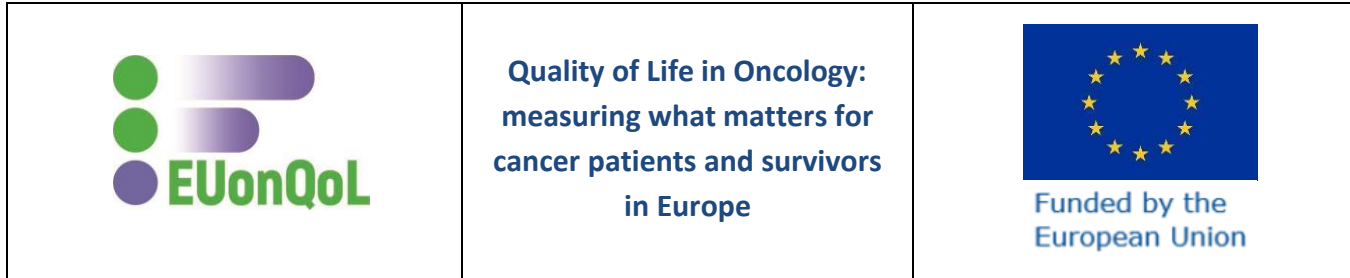
("Neoplasms"[MeSH Terms] OR cancer*[tw] OR tumor*[tw] OR tumour* [tw] OR malignanc*[tw] OR neoplasm*[tw] OR carcinoma*[tw] OR Oncolog*[tw])

AND ("Quality of Life/psychology"[Mesh] OR "Quality of Life"[Mesh] OR "Quality of life"[tw] OR "Health-Related Quality Of Life"[tw] OR "Health Related Quality Of Life"[tw] OR HRQOL[tw] OR QOL[tw])

AND (Factor*[tw] OR indicator*[tw] OR Characteristic*[tw] OR predictor*[tw] OR determinant*[tw])

AND ("psychology" [Subheading] OR "Psychology"[Mesh] OR psycho*[tw] OR social[tw] OR individual[tw] OR personal[tw] OR "Psychological Side Effect"[tw] OR "Psychological Side Effects"[tw] OR "Psychosocial Factors"[tw] OR "Factor, Psychosocial"[tw] OR "Factors, Psychosocial"[tw] OR "Psychosocial Factor"[tw] OR "Psychological Factors"[tw] OR "Factor, Psychological"[tw] OR "Psychological Factor"[tw] OR "Factors, Psychological"[tw] OR affect[tw] OR effect[tw] OR related[tw] OR impact[tw] OR "side effect*"[tw])

AND ("Terminal Care/psychology"[Mesh] OR "Hospice Care/psychology"[Mesh] OR "Palliative Care/psychology"[Mesh] OR "Care, Palliative"[tw] OR "Palliative Treatment*"[tw] OR "Therapy, Palliative"[tw] OR "Palliative Therapy"[tw] OR "Palliative Supportive Care"[tw] OR "Supportive Care, Palliative"[tw] OR "Care, Hospice"[tw] OR "Care, Terminal"[tw] OR "End of Life Care"[tw] OR "End-Of-Life Care*"[tw] OR "Care, End-Of-Life"[tw] OR "end of life"[tw] OR palliative[tw] OR hospice[tw])



AND (systematic review[pt] OR "systematic review"[tw]) AND (1990/01/01:2022/12/31[Date - Publication] AND "english"[Language] NOT ("animals"[MeSH Terms] NOT "humans"[MeSH Terms]))

6.1.4. Search strings used for PsycInfo

Active Treatment:

(exp Neoplasms/ OR cancer*.ti,ab,id. OR tumor*.ti,ab,id. OR tumour*.ti,ab,id. OR malignanc*.ti,ab,id. OR neoplasm*.ti,ab,id. OR carcinoma*.ti,ab,id. OR Oncolog*.ti,ab,id.)

AND (exp "Quality of Life"/ OR "Quality of life".ti,ab,id. OR "Health-Related Quality Of Life".ti,ab,id. OR "Health Related Quality Of Life".ti,ab,id. OR HRQOL.ti,ab,id. OR QOL.ti,ab,id.)

AND (Factor*.ti,ab,id. OR indicator*.ti,ab,id. OR Characteristic*.ti,ab,id. OR predictor*.ti,ab,id. OR determinant*.ti,ab,id.)

AND (exp Psychology/ OR psycho*.ti,ab,id. OR social.ti,ab,id. OR individual.ti,ab,id. OR personal.ti,ab,id. OR "Psychological Side Effect".ti,ab,id. OR "Psychological Side Effects".ti,ab,id. OR "Psychosocial Factors".ti,ab,id. OR "Factor, Psychosocial".ti,ab,id. OR "Factors, Psychosocial".ti,ab,id. OR "Psychosocial Factor".ti,ab,id. OR "Psychological Factors".ti,ab,id. OR "Factor, Psychological".ti,ab,id. OR "Psychological Factor "Factors, Psychological"".ti,ab,id. OR affect.ti,ab,id. OR effect.ti,ab,id. OR related.ti,ab,id. OR impact.ti,ab,id. OR "side effect*".ti,ab,id.)

AND (exp "Antineoplastic Drugs"/ OR exp surgery/ OR exp Treatment/ OR exp pathology/ OR treatment.ti,ab,id. OR "active treatment".ti,ab,id. OR chemotherapy.ti,ab,id. OR radiotherapy.ti,ab,id. OR endocrine.ti,ab,id. OR adjuvant.ti,ab,id. OR therapy.ti,ab,id. OR therapeutic.ti,ab,id. OR (neo-adjuvant.ti,ab,id. OR neoadjuvant.ti,ab,id. OR "neo adjuvant".ti,ab,id.))

AND ("systematic review".dt. OR "systematic review".pt. OR "systematic review".ti,ab,id.)



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Survivor:

(exp Neoplasms/ OR cancer*.ti,ab,id. OR tumor*.ti,ab,id. OR tumour*.ti,ab,id. OR malignanc*.ti,ab,id. OR neoplasm*.ti,ab,id. OR carcinoma*.ti,ab,id. OR Oncolog*.ti,ab,id.)

AND (exp "Quality of Life"/ OR "Quality of life".ti,ab,id. OR "Health-Related Quality Of Life".ti,ab,id. OR "Health Related Quality Of Life".ti,ab,id. OR HRQOL.ti,ab,id. OR QOL.ti,ab,id.)

AND (Factor*.ti,ab,id. OR indicator*.ti,ab,id. OR Characteristic*.ti,ab,id. OR predictor*.ti,ab,id. OR determinant*.ti,ab,id.)

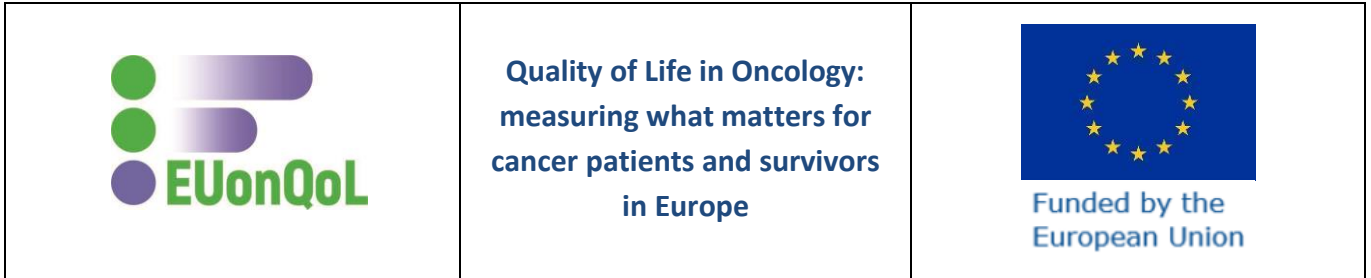
AND (exp Psychology/ OR psycho*.ti,ab,id. OR social.ti,ab,id. OR individual.ti,ab,id. OR personal.ti,ab,id. OR "Psychological Side Effect".ti,ab,id. OR "Psychological Side Effects".ti,ab,id. OR "Psychosocial Factors".ti,ab,id. OR "Factor, Psychosocial".ti,ab,id. OR "Factors, Psychosocial".ti,ab,id. OR "Psychosocial Factor".ti,ab,id. OR "Psychological Factors".ti,ab,id. OR "Factor, Psychological".ti,ab,id. OR "Psychological Factor "Factors, Psychological"".ti,ab,id. OR affect.ti,ab,id. OR effect.ti,ab,id. OR related.ti,ab,id. OR impact.ti,ab,id. OR "side effect*".ti,ab,id.)

AND (exp Survivors/ OR "Cancer Survivor".ti,ab,id. OR "Survivors, Cancer".ti,ab,id. OR "Cancer Survivorship".ti,ab,id. OR "Survivorship, Cancer".ti,ab,id. OR "Long-Term Cancer Survivors".ti,ab,id. OR "Cancer Survivor, Long-Term".ti,ab,id. OR "Long Term Cancer Survivor*".ti,ab,id. OR Survivor.ti,ab,id. OR "Long-Term Survivors".ti,ab,id. OR "Long Term Survivors".ti,ab,id. OR "Long-Term Survivor".ti,ab,id. OR "Survivor, Long-Term".ti,ab,id. OR "Survivors, Long-Term".ti,ab,id. OR survivorship.ti,ab,id.)

AND ("systematic review".dt. OR "systematic review".pt. OR "systematic review".ti,ab,id.)

End of life and Palliative Care:

(exp Neoplasms/ OR cancer*.ti,ab,id. OR tumor*.ti,ab,id. OR tumour*.ti,ab,id. OR malignanc*.ti,ab,id. OR neoplasm*.ti,ab,id. OR carcinoma*.ti,ab,id. OR Oncolog*.ti,ab,id.)



AND (exp "Quality of Life"/ OR "Quality of life".ti,ab,id. OR "Health-Related Quality Of Life".ti,ab,id. OR "Health Related Quality Of Life".ti,ab,id. OR HRQOL.ti,ab,id. OR QOL.ti,ab,id.)

AND (Factor*.ti,ab,id. OR indicator*.ti,ab,id. OR Characteristic*.ti,ab,id. OR predictor*.ti,ab,id. OR determinant*.ti,ab,id.)

AND (exp Psychology/ OR psycho*.ti,ab,id. OR social.ti,ab,id. OR individual.ti,ab,id. OR personal.ti,ab,id. OR "Psychological Side Effect".ti,ab,id. OR "Psychological Side Effects".ti,ab,id. OR "Psychosocial Factors".ti,ab,id. OR "Factor, Psychosocial".ti,ab,id. OR "Factors, Psychosocial".ti,ab,id. OR "Psychosocial Factor".ti,ab,id. OR "Psychological Factors".ti,ab,id. OR "Factor, Psychological".ti,ab,id. OR "Psychological Factor "Factors, Psychological"".ti,ab,id. OR affect.ti,ab,id. OR effect.ti,ab,id. OR related.ti,ab,id. OR impact.ti,ab,id. OR "side effect*".ti,ab,id.)

AND (exp "Terminal Cancer"/ OR exp Hospice/ OR exp "Palliative Care"/ OR "Care, Palliative".ti,ab,id. OR "Palliative Treatment*".ti,ab,id. OR "Therapy, Palliative".ti,ab,id. OR "Palliative Therapy".ti,ab,id. OR "Palliative Supportive Care".ti,ab,id. OR "Supportive Care, Palliative".ti,ab,id. OR "Care, Hospice".ti,ab,id. OR "Care, Terminal".ti,ab,id. OR "End of Life Care".ti,ab,id. OR "End-Of-Life Care*".ti,ab,id. OR "Care, End-Of-Life".ti,ab,id. OR "end of life".ti,ab,id. OR palliative.ti,ab,id. OR hospice.ti,ab,id.)

AND ("systematic review".dt. OR "systematic review".pt. OR "systematic review".ti,ab,id.)

6.2. Table Active treatment

6.2.1. Table 2 - Characteristics of the included studies

Year of publication	Study origin	Study design	Objectives/aim of the research	Studies included				Participants	Cancer Group		



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

Landry, V., et al. 2022	Canada	Systematic review	to identify relevant studies reporting on patients' HrQoL following total or near-total thyroidectomy (TT) or hemithyroidectomy (HT) with regard to postoperative HrQoL providing peer-reviewed information to clinicians that may be integrated into the shared treatment decision-making process with their patients.	25	16 cross-sectional, 4 cohort studies, 5 mixed methods or qualitative studies	2003-2022	Asia (n=9), Europe (n=8), America (n=6), Africa (n=1), Oceania (n=1)	54571	NA	DTC (differentiated thyroid carcinoma) patients	54571



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

Zou, H., et al. 2022	China	Systematic review	to analyze current evidence about economic and humanistic impact of Hepatocellular Carcinoma in gretaer China	27	2 retrospective cohort studies, 1 retrospective case-control study, 11 cross-sectional, 11 prospective cohort studies, 1 interrupted time series, 1 case-control study	before April 2021	Asia (27)	20861	>18 years	hepatocellular carcinoma	20861
									chinese patients		
Baba, M. A., et al. 2021	Morocco	Systematic review	to determine the exact neurocognitive status andQoL in patients with glioblastoma	13	13 cross-sectional observational studies	2009-2020	Italy (n=9), France (n=2), Egypt (n=1),	617	>18 years	Glioblastoma	617
									Min-max: 19-85		



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

			in the mediterranean region and the different predictive factors responsible for their deterioration				Turkish (n=1)				
El Haidari, R., et al. 2020	France	Systematic review	to identify the factors associated with HRQoL in the countries of the Middle East	33	28 cross-sectional, 3 case control, 2 longitudinal	2004-2018	Iran (n=15), Turkey (n=9), Saudi Arabia (n=3), Jordan (n=2), Lebanon (n=1), Kuwait (n=1), Bahrain (n=1), Yemen (n=1)	9323	middle east countries	Breast cancer	9323
									Age range: 25-60		



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

			patients' overall well-being		cohort studies, population-based studies		(n=1), Germany (n=4), Iran (n=2), Israel (n=1), Japan (n=1), Korea (n=18), Portugal (n=1), Sweden (n=3), Taiwan (n=1), Turkey (n=1), United Kingdom (n=4), Vietnam (n=1)				
Wintraecken, V. M., et al. 2022	Netherlands	Systematic review	to examine the relationship between	12	6 cohort studies, 6 cross-	2004-2020	China (n=1), Germany	2729	≥18 years	Breast cancer	2729



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

			personality and QoL in women with non-metastatic breast cancer		sectional studies		(n=1), Italy (n=1), Netherlands (n=1), Serbia (n=1), USA (n=7)				
Sihvola, S., et al. 2021	Finland	systematic review	to explore resilience and its related factors in adult cancer patients	11	9 cross-sectional, 2 intervention (RCT)	2014-2021	Brazil (n=2), China (n=5), Israel (n=3), Turkey (n=1)	1553	≥ 18 years mean age: 59 years range age: 18-87 941: male; 623: female	colorectal cancer	1553
Razdan, S. N., et al. 2016	New York, USA	Systematic review	(1) identify studies describing health-related quality of life (HRQOL) in patients following BPM (Bilateral Prophylactic	22	18 Case Series, 4 Prospective Cohort	1995-2014	Canada (n=3), Netherlands (n=3), Norway (n=1), Sweden (n=8), Turkey (n=1), UK	2046	women	Breast	2046



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

			Mastectomy) with or without reconstruction ; (2) assess the effect of BPM with or without reconstruction on HRQOL; and (3) identify predictors of HRQOL post-BPM				(n=1), USA (n=5)				
James, C., et al. 2022	London	Systematic review	To 1) Identify the prevalence, severity and progression of Fear of Cancer Recurrence (FCR) and Prostate-Specific Antigen (PSA) anxiety symptoms in	32	18 longitudinal studies, 14 a cross-sectional studies	2003-2021	Europe (n=13), North America (n=11), Australia (n=6), Asia (n=2)	9953	males	prostate cancer	9953



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

			prostate cancer patients. 2) Evaluate the evidence for the association between patient, disease or treatment characteristics and FCR and PSA anxiety symptoms. 3) Assess the relationship between FCR and PSA anxiety and other psychological and quality of life outcomes and their impact on mental wellbeing.								
--	--	--	--	--	--	--	--	--	--	--	--



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

Rimmer, B., et al. 2022	England	Systematic review	aims to systematically identify quantitative studies assessing health-related quality of life in adult low-grade glioma patients.	29	13 cross-sectional studies, 9 longitudinal studies	2001 - 2021	Netherlands (n=3), USA (n=3), China (n=2), Italy (n=2), India (n=2), Japan (n=2), Norway (n=2), Australia (n=1), Finland (n=1), Germany (n=1), South Korea (n=1), Sweden (n=1), Turkey (n=1)	2093	Mean age range 35.8 - 49.5 years. Sex range 24-73% female.	Low-grade glioma	2093



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

Odeo, S. et al. 2020	Kenya	Systematic review	aims to determine the overall health-related quality of life and its associated among prostate cancer patients.	54	21 cross-sectional studies, 13 prospective Studies, 5 prospective cohort study, 4 prospective studies, 3 retrospective studies, 2 longitudinal prospective studies, 1 longitudinal, observational study, 1 multicente	2000 - 2020	N/A	7394	Most participants were from Europe and America, one few studies involved participants from Asia.	Prostate cancer	7394
----------------------	-------	-------------------	---	----	---	-------------	-----	------	--	-----------------	------



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

					r, prospectiv e, non- Interventi onal trial study, 1 Phase III, RCT, 1 prospectiv e longitudin al study, 1 cohort study, 1 longitudin al study						
Kang, D., et al. 2020	Korea	Systematic review	aims to evaluate studies assessing the health-related quality of life of hepatocellular carcinoma	45	23 cohort studies, 13 cross- sectional studies, 9 interventio n studies	2010 - 2018	China (n=11), USA (n=10), Taiwan (n=6), France (n=4), UK (n=2),	6988	Mean age 58.9 years.	Hepatocell ular carcinoma	6988



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

			patients from 2009 to 2018				Japan (n=5), Germany (n=2), Italy (n=2), Singapore (n=2), Hong Kong (n=1)				
Aizpurua-Perez, I., et al. 2020	Spain	Systematic review	aims to identify the biopsychosocial factors involved in the resilience of women with breast cancer and to integrate evidence on the interventions that can contribute to	39	30 cross-sectional studies, 8 intervention study, 1 longitudinal study	2011 - 2020	Asia (n = 16), Europe (n = 14), America (n = 8), Oceania (n = 1)	6189	Age range 18 - 90 years.	Breast cancer	6189



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

			significantly enhancing it.								
Sousa, H., et al. 2019	Portugal	Systematic review	aims to present a broader perspective of factors affecting quality of life after breast reconstruction in women with breast cancer.	44	31 retrospective cross-sectional studies, 12 prospective studies, 1 ambispective study	2000 - 2018	USA (n=8), UK (n=5), Canada & USA (n=4), The Netherlands (n=3), Sweden (n=3), Canada (n=2), Korea (n=2), Ireland (n=2), Germany (n=2), Spain (n=2), France (n=2), Australia (n=2), Turkey	16683	Mean age 50.9 years.	Breast cancer	16683



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

							(n=1), Poland (n=1), Norway (n=1), Italy (n=1), Denmark (n=1), Czech Republic (n=1), Brazil (n=1)				
Brandão, T., et al. 2017	Portugal	Systematic review	aims to analyze longitudinal studies that examine factors predicting psychological adjustment of women with breast cancer.	41	41 longitudinal studies	2000 - 2015	USA (n = 10), the Netherlands (n = 8), Australia (n=1), Canada(n =1), Denmark (n=1), France (n=1), Greece	9361 Sample size range 50- 763	Mean age 53.7 years.	Breast cancer	9361, 00



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

							(n=1), Hong Kong (n=3), Iran (n=2), Japan (n=1), Norway (n=1), Portugal (n=2), Spain (n=2), South Korea (n=1), Sweden (n=2), Taiwan (n=2), United Kingdom (n=2)				
Bai, M., et al. 2015	USA	Systematic review	aims to examine the literature for associations	36	32 cross- sectional studies, 4	1996 - 2014	USA (n=27), Jordan (n=2),	18948	N/A	All cancer types (8 studies targeted	18948



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

			between spiritual well-being and quality of life among adults diagnosed with cancer.		longitudinal studies		Australia (n=2), The Netherlands (n=1), Canada (n=1), Iran (n=1), Italy (n=1), Japan (n=1)			breast cancer, prostate or colorectal)	
								TOTAL 275.855			

6.2.2. Table 3 - Characteristics of the included studies

Year of publication	Factors			Association with QoL	Outcomes
	Psychological factors	Social factors	Clinical factors		
Ho, P. J., et al 2018			comorbidities with other diseases (e.g. hypertension, arthritis, diabetes)	Negative association ->HRQL	Comorbidities is associated with lower HRQL
			Tumour characteristics/stage	Negative association ->HRQL	Advanced stage disease is associated with lower HRQL
			chemotherapy	Negative association -> HRQL	chemotherapy is associated with lower HRQL



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

	lower social support			Negative association -> HRQL	lower social support is associated with lower HRQL
	unmet needs			Negative association -> HRQL NB: vedi sotto one study reported positive association -> QoL, one study reported negative association -> QoL	unmet needs are associated with lower HRQL
			Time since diagnosis	Positive association -> HRQL	time since diagnosis is associated with better HRQL
		healthier behaviour		Positive association -> HRQL	Healthier behaviour is associated with better HRQL
			type of surgery	one study reported positive association -> QoL, two studies reported negative association -> QoL	one study reported type of surgery is associated with better QoL, two studies reported type of surgery is associated with lower QoL
			radiotherapy	two studies reported positive association -> QoL, one study reported negative association -> QoL	two studies reported radiotherapy is associated with better QoL, one study reported radiotherapy is associated with lower
			hormone therapy	two studies reported positive association -> QoL, one study reported one	two studies reported hormone therapy is associated with better QoL, one study reported hormone



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

				negative association -> QoL	therapy is associated with lower QoL
	unmet needs			NB: one study reported positive association -> QoL, one study reported negative association -> QoL	one study reported unmet needs are associated with better QoL, one study reported unmet needs are associated with lower QoL
		Religion		Positive association - > HRQL	Presence of religion is associated with better HRQOL
			presence of recurrence	Negative association -> HRQL	presence of recurrence is associated with lower HRQOL
			chemotherapy	Negative association -> HRQL	Presence of chemotherapy is associated with lower HRQOL
			Immune therapy	Positive association - > HRQL	Immune therapy is associated with better QoL
		exercise		Positive association - > HRQL	Presence of exercise is associated with better HRQOL
	distress			Negative association ->HRQL	Symptom of distress is associated with poorer HRQOL
	Optimism			Positive association - > HRQL	optimism is associated with better HRQOL
	Positive mood			Positive association - > HRQL	Positive mood is associated with better HRQOL
	boredom			Negative association ->HRQL	higher levels of boredom are associated with poorer HRQOL



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

	internal locus of control			positive association - > QoL	internal locus of control is associated with better QoL
	external locus of control			negative association -> QoL	external lous of control is associated with ower QoL
	coping mode			Positive association - > HRQL	Active emotional coping is associated with better HRQOL
	empowerment			Positive association - > HRQL	presence of empowermwnt is associated with better HRQOL
	family harmony status			Positive association - > HRQL	good family harmony status is ssociated with better HRQOL
Nierop-van Baalen, C., et al. 2019	hope			positive association - > QoL	hope is associated with better QoL
Landry, V., et al. 2022	mental health			negative association -> QoL	Mental health is associated with lower QoL.
	mental fatigue			negative association -> QoL	Mental fatigue is associated with lower QoL.



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

	reduced motivation			negative association -> QoL	Reduced motivation is associated with lower QoL.
	distress			negative association -> QoL	Distress is associated with lower QoL.
	anxiety			negative association -> QoL	Anxiety is associated with lower QoL.
	depression			negative association -> QoL	Depression is associated with lower QoL.
	somatization			negative association -> QoL	Somatization is associated with lower QoL.
		Social functioning and interactions		negative association -> QoL	social functioning is associated with lower QoL.
		Role limitations		negative association -> QoL	Role limitations are associated with lower QoL.
Zou, H., et al. 2022			better liver functions (lower serum bilirubin levels, higher albumin levels, lower alkaline phosphate levels, better albumine to ALP ratios)	positive association - > QoL	better liver functions are associated with better QoL
			tumor stages	negative associated - > QoL	tumor stages are associated with lower QoL
			inflammatory states	negative associated - > QoL	inflammatory states are associated with lower QoL
			symptoms (pain, appetite loss)	negative associated - > QoL	severe symptoms are associated with lower QoL



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

	depression			negative associated - > QoL	depression is associated with lower QoL
	resilience			positive association - > QoL	psychological resilience is associated with better QoL
	positive illness perception			positive association - > QoL	positive illness perception is associated with better QoL
	coping			negative associated - > QoL	more emotion-oriented coping is associated with lower QoL
Baba, M. A., et al. 2021	coping strategies (problem solving and positive thinking)			positive association - > QoL	coping strategies (problem solving and positive thinking) are associated with better QoL
		social support		negative association -> QoL	social support is associated with lower QoL scores
	avoidance			positive association - > QoL	avoidance is associated with higher QoL score
	anxiety			negative association -> QoL	anxiety is associated with lower QoL
	depression			negative association -> QoL	depression is associated with lower QoL
El Haidari, R., et al. 2020			cancer stage	negative association -> QoL	
			presence of metastasis	negative association -> QoL	presence of metastasis is associated with lower QoL
			time since diagnosis	negative association -> QoL	Time since diagnosis is associated with lower QoL



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

			time since operation	negative association -> QoL	Time since operation is associated with lower QoL
			disease duration	negative association -> QoL	Disease duration is associated with lower QoL
			menopausal status	negative association -> QoL	mazzocco
			higher symptoms score	negative association -> QoL	Higher symptoms score are associated with lower QoL
			pain	negative association -> QoL	Pain is associated with lower QoL
			fatigue	negative association -> QoL	Fatigue is associated with lower QoL
			chemotherapy	negative association -> QoL	Chemotherapy is associated with lower QoL
			hormone therapy	positive association - > QoL	Hormone therapy is associated with better QoL
			early treatment	positive association - > QoL	Early treatment is associated with better QoL
			breast reconstruction surgery	positive association - > QoL	Breast reconstruction surgery is associated with better QoL
			radiotherapy	one study reported positive association - > QoL, one study reported negative association -> QoL	one study reported positive association -> QoL, one study reported negative association -> QoL
			complementary alternative medicine	positive association - > QoL	Complementary alternative medicine is associated with better QoL



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

religiosity			positive association - > QoL	Religiosity is associated with better QoL
spiritual well-being			positive association - > QoL	Spiritual well-being is associated with better QoL
depression			negative association - -> QoL	Depression is associated with lower QoL
anxiety			negative association - -> QoL	Anxiety is associated with lower QoL
psychological symptoms			negative association - -> QoL	Psychological symptoms are associated with lower QoL
emotional functioning			negative association - -> QoL	Emotional functioning is associated with lower QoL
helplessness			negative association - -> QoL	Helplessness is associated with lower QoL
coping			negative association - -> QoL	Coping is associated with lower QoL
unmet needs			positive association - > QoL	Unmet needs are associated with better QoL
self-efficacy			positive association - > QoL	Self-efficacy is associated with better QoL
self-regulation			positive association - > QoL	Self-regulation is associated with better QoL
sense of coherence			positive association - > QoL	Sense of coherence is associated with better QoL
emotion focus coping strategies			positive association - > QoL	Emotion focus coping strategies are associated with better QoL
	social support		positive association - > QoL	Social support is associated with better QoL



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

Rupp, S. K., et al. 2021			subtotal gastrectomy	positive association - > QoL	patients underwent to subtotal gastrectomy is associated with better QoL
			total gastrectomy	negative association -> QoL	underwent to total gastrectomy is associated with lower QoL
	personality type D			negative association -> QoL	Type D personality is associated with lower QoL
	tolerant personality type			positive association - > QoL	Tolerant personaity is associated with better QoL
			nanomedicine	positive association - > QoL	nanomedicine is associated with higher QoL
Wintraecken, V. M., et al. 2022	optimism			positive association - > QoL	optimism is associated with higher QoL
	self-efficacy			positive association - > QoL	self-efficacy is associated with higher QoL
	trait anxiety			negative association -> QoL	trait anxiety is associated with lower QoL
	extraversion			positive association - > QoL	extraversion is associated with higher QoL
Sihvola, S., et al. 2021	resilience			positive association - > QoL	resilience is associated with higher QoL



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

Razdan, S. N., et al. 2016	distress			Negative association -> QoL	Distress is associated with lower QoL After BPM
	Body Image (vulnerability)			Negative association -> QoL	Vulnerability is associated with lower QoL After BPM
James, C., et al. 2022	Fear of Cancer Recurrence			Negative association -> QoL	Higher FCR is associated with lower QoL
Rimmer, B., et al. 2022	Coping			Negative association -> QoL	Higher levels of avoidant coping are associated with lower QoL.
	Depression			Negative association -> QoL	Higher level of depression is associated with lower QoL
	Post-traumatic stress disorder			Negative association -> QoL	Post-traumatic stress disorder is associated with lower QoL.
	Post-traumatic growth			Positive association - > QoL	Post-traumatic growth is associated with better QoL.
			Time since diagnosis/treatment	Positive association - > QoL	Clinical: One- and three-years since treatment, is associated with better QoL
			Epilepsy/seizure burden	Negative association -> QoL	Epilepsy/seizure burden is associated with lower QoL
			Tumour grade	Positive association - > QoL	lower tumour grade is associated with better QoL



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

			Tumour-specific symptoms (e.g. cognitive limitations, seizures)	Negative association -> QoL	Tumour-specific symptoms is associated with lower QoL.
			Cancer-specific symptoms(e.g. fatigue, pain)	Negative association -> QoL	cancer-specific symptoms, are associated with lower QoL.
Odeo, S. et al. 2020			neoadjuvant hormonal therapy	Negative association -> QoL	Neoadjuvant hormonal therapy is associated with lower QoL.
			comorbidities	Negative association -> QoL	comorbidities are associated with lower QoL
			higher clinical stage	Negative association -> QoL	higher clinical stage is associated with lower QoL.
			greater cancer severity	Negative association -> QoL	greater cancer severity is associated with lower QoL
			Cancer stage	Positive association -> QoL	Early disease stage (1 & 2) is associated with better QoL.
	Depression			Negative association -> QoL	Depression is associated with lower QoL.
	impaired mental health			Negative association -> QoL	Impaired mental health are associated with lower QoL.
Kang, D., et al. 2020	distress			Negative association -> QoL	Distress is associated with lower QoL.
	sadness			Negative association -> QoL	sadness is associated with lower QoL



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

	depression			Negative association -> QoL	depression is associated with lower QoL
	illness perception			Positive association -> QoL	Illness perception is associated with higher QoL.
	personal control over the patients' own disease			Positive association -> QoL	Personal control over the patients' own disease is associated with higher QoL.
			transarterial chemoembolization	Negative association -> QoL	Transarterial chemoembolization is associated with lower QoL.
			hepatic resection	Negative association -> QoL	hepatic resection is associated with lower QoL.
			radio-frequency ablation	Negative association -> QoL	radio-frequency ablation is associated with lower QoL.
			TNM stage	Negative association -> QoL	Severe TNM stage is associated with lower QoL.
			Barcelona Clinic Liver Cancer tumor stage	Negative association -> QoL	Barcelona Clinic Liver Cancer tumor stage is associated with lower QoL.
		Social function		Negative association -> QoL	poor social function is associated with lower QoL
Aizpurua-Perez, I., et al. 2020	resilience		-	Positive association -> QoL	Resilience is associated with higher QoL
	coping strategies			Positive association -> QoL	Appropriate coping strategies is associated with higher QoL.
	anxiety			Negative association -> QoL	Anxiety is associated with lower QoL.



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

	depression			Negative association -> QoL	Depression is associated with lower QoL.
		Social support		Positive association - > QoL	Social support is associated with higher QoL.
Sousa, H., et al. 2019	Depression			Negative association -> QoL	Depression is associated with lower QoL
	Harm avoidance			Positive association - > QoL	Higher level of harm avoidance is associated with higher QoL.
	Neuroticism			Negative association -> QoL	Neuroticism is associated with lower QoL
	Openness			Negative association -> QoL	Openness is associated with lower QoL
	Satisfaction with esthetic outcome			Positive association - > QoL	Higher level of satisfaction with esthetic outcome are associated with higher QoL.
			Timing of reconstruction	Positive association - > QoL/ No association	Contradictory results are found concerning the association between time after reconstruction and QoL: 1) A study found QoL increased with time after reconstruction; 2) one study found no significant association between them.
			BR-related complications	Negative association -> QoL	BR-related complications are associated with lower QoL



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

			Fat grafting		Contradictory results are found concerning the association between fat grafting procedures and QoL: 1) A study found no significant associations; 2) one study reported that fat grafting is associated with psychosocial and sexual well-being.
			Chemotherapy	Negative association -> QoL	Chemotherapy is associated with lower QoL
			Body Mass Index (BMI)	Negative association -> QoL	BMI is associated with lower QoL
			Cancer stage	Negative association -> QoL	Cancer stage is associated with lower QoL
Brandão, T., et al. 2017			Chemotherapy	Negative association -> QoL	Chemotherapy is associated with lower QoL
			systematic adjuvant therapy (ie, chemotherapy, tamoxifen, or both)	Negative association -> QoL	Systematic adjuvant therapy is associated with lower QoL.
			advanced cancer stage	Negative association -> QoL/no association	Contradictory results are found concerning the association between advanced cancer stage and QoL: 1) three studies found that advanced cancer stage is associated with lower QoL; 2) two studies found no association between them.
			fatigue	Negative association -> QoL	Fatigue is associated with lower QoL.





Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

		Social support		Positive association - > QoL	Social support is associated with higher QoL
	Anxiety			Negative association -> QoL	Anxiety is associated with lower QoL
	depression			Negative association -> QoL	Depression is associated with lower QoL
	psychological well-being			Positive association - > QoL	Psychological well-being is associated with higher QoL
	optimism			Positive association - > QoL	Optimism is associated with higher QoL
	Neuroticism				
	a sense of self-efficacy, confidence about remaining cancer free (added from Cognitive and perceptual factors "Psychosocial variables were grouped into 6 categories " one of these groups os cognitive and perceptual factors) - added - new				
	Coping strategies			Positive association - > QoL	Coping strategies are associated with higher QoL

	<p align="center">Quality of Life in Oncology: measuring what matters for cancer patients and survivors in Europe</p>	 <p align="center">Funded by the European Union</p>
---	--	--

	body image			Positive association - > QoL / no association	Contradictory results are found concerning the correlation between body image and QoL: 1) 2 studies found that better body image and more satisfaction with appearance is associated with higher QoL; 2) 1 study found no association between body image and QoL.
Bai, M., et al. 2015	Spiritual well-being		-	Positive association - > QoL	Spiritual well-being is associated with higher QoL.
	Faith			Positive association - > QoL	Faith is associated with higher QoL.

6.3. Table Survivors

6.3.1. Table 4 - Characteristics of the included studies

			Studies included	Participants	Cancer Group
--	--	--	-------------------------	---------------------	---------------------



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

Author, Year of Publication	Study origin	Study design	Number of studies included	Type of studies included	Data range of included studies	Country of origin of included studies	Sample size (N)	Socio-demographic characteristics	Cancer type	Cancer stage	Time since diagnosis or treatment
Zainal et al., 2013	Malaysia	Systematic review	32	20 cross-sectional studies, 10 prospective studies, 1 case control study, 1 cohort study	1998 - 2012	USA (n=13), UK (n=4), Australia (n=2), Netherlands (n=2), Turkey (n=2), Norway (n=1), Japan (n=1), Germany (n=1), Brazil (n=1), China (n=1), Iran (n=1), Taiwan (n=1), Korea (n=1), Italy (n=1)	N=10,826 Median sample size 129. Sample size range 15 - 2208.	Mean age range 47 - 63. In the western studies the ethnic majority were Caucasians or white (median=80%, range: 30-100%), three-quarter of the subjects were married (median=73%, range=33-100%).	Breast cancer	0-II	1-98 months



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

Howard-Anderson et al., 2012	USA	Systematic review	28	15 cross-sectional studies, 8 longitudinal studies, 5 RCTs	1996 - 2010	N/A	Sample size range 144 - 657.	Women younger than 51 years. Mean age range 33 - 50.	Breast cancer	N/A	< 2 month - 13,2 years
Syrowatka et al., 2017	Canada	Systematic review	42	21 cohort studies, 20 cross-sectional studies, 1 retrospective chart review	2001 - 2016	USA (n=9), Taiwan(n=4), China(n=3), Korea (n=3), Sweden(n=3), Italy(n=2), Netherlands (n=2), England(n=1), Germany (n=1), Iran (n=1), Israel (n=1), France (n=1), Scotland (n=1)	N=20,216 . Sample size range 39 - 2595.	Mean age range 43.6 - 66.4. Age range 24 - 81.	Breast cancer	0-IV	1- 10 years



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

Rimmer et al., 2022	England	Systematic review	29	13 cross-sectional studies, 9 longitudinal studies	2001 - 2021	Netherlands (n=3), USA (n=3), China (n=2), Italy (n=2), India (n=2), Japan (n=2), Norway (n=2), Australia (n=1), Finland (n=1), Germany (n=1), South Korea (n=1), Sweden (n=1), Turkey (n=1)	N=2093. Sample size range 15-260.	Mean age range 35.8 - 49.5. Sex range 24-73% female.	Low-grade glioma	I-II	1-20 years
---------------------	---------	-------------------	----	--	-------------	--	-----------------------------------	--	------------------	------	------------



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

Wen et al., 2013	USA	Systematic review	26	10 qualitative studies, 10 quantitative studies, 5 mixed-method approach studies, 1 intervention study	1997 - 2013	N/A	N=7322. Sample size range 9-206.	Mean age range 33 - 75. Age range 29 - 91.	Breast cancer	0-IV	0 - 5 years
Aizpurua-Perez et al., 2020	Spain	Systematic review	39	30 cross-sectional studies, 8 intervention study, 1 longitudinal study	2011 - 2020	Asia (n = 16), Europe (n = 14), America (n = 8), Oceania (n = 1)	Sample size range 10-540.	Age range 18 - 90.	Breast cancer	I-IV	Mean 85 days - 4.9 years
Hamel et al., 2016	Belgium	Systematic review	10	7 cross-sectional studies, 1	2007 - 2015	N/A	N=4246. Sample size range 277 - 1320	The mean age 55.9. 54.9% female.	Melanoma cancer	N/A	Mean 1.2 - 9 years



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

				prospective study							
Bours et al., 2016	Netherlands	Systematic review	53	36 cross-sectional studies, 17 longitudinal studies	1994 - 2014	Netherlands (n=9), USA (n=20), Australia (7), Canada (n=3), UK (n=4), Greece (n=2), Germany (n=3), Turkey (n=1), France (n=1), Denmark (n=1), Japan (n=1), China (n=1)	N=36,336 . Sample size range 77 - 1966.	Mean age range 61-82.	Colorectal cancer	I-IV	2-12 years postdiagnosis



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

Dunne et al., 2016	Ireland	Systematic review	24	10 prospective studies, 9 cross-sectional studies	2004 - 2015	UK (n = 7), Norway (n = 2), USA (n = 2), Australia (n = 2), the Netherlands (n = 2), Germany (n = 1), China (n = 1), Poland (n = 1), Taiwan (n = 1)	N=2347. Sample size range 51 - 376.	Mean age 61. Age range 23–94. Sex 29% female.	Head and neck cancer	N/A	1 month -7 years
--------------------	---------	-------------------	----	---	-------------	---	-------------------------------------	---	----------------------	-----	------------------



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

J. Han et al., 2020	USA	Systematic review and meta-analysis	35	21 cross-sectional studies, 14 longitudinal, prospective studies	2008 -2019	UK (n=9), USA (n=9), Australia (n=8), China (n=3), Canada & Australia (n=2), Taiwan (n=1), Ireland (n=1), Netherlands (n=1), Portugal (n=1),	N=17,215	Mean age 63. Age range 50-70. The majority of participants (N=24 out of 35 studies) were male, 2 studies included only female participants.	Colorectal cancer	I-IV	< 11 years after diagnosis
Dahl et al., 2013	Denmark	Systematic review	57	N/A	1995 - 2012	Scandinavia, Austria, Australia, United States, Syria, Hawaii	N/A	N/A	gynecological cancer	N/A	N/A



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

Koch et al., 2012	Germany	Systematic review	17	N/A	2002 - 2010	USA(n=15), Germany (n=1), Norway(n=1), the Netherlands(1)	N=6352 Sample size range 92 - 1366.	Mean age range 44.8 - 75.9. Age range 29- 95. White/Caucasia n or African American in six studies, others had no restriction on race.	Breast cancer, head and neck, gynaecological , bladder, prostate, colorectal, leukaemia, non-Hodgkin's lymphoma, Wilms tumor, brain tumor, testicular	N/A	Mean 1.5 - 21.4 years
----------------------	---------	----------------------	----	-----	-------------	--	--	---	--	-----	--------------------------



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

Durosini et al., 2022	Italy	systematic review	33	23 cross-sectional studies, 1 longitudinal design study, 1 three-wave longitudinal study, 1 longitudinal study, 4 RCTs, 1 experimental study, 1 evidence-based interventions study, 1 cross-sectional and longitudinal study	2000 - 2020	N/A	N=6396.	N/A	Breast cancer	N/A	N/A
-----------------------	-------	-------------------	----	--	-------------	-----	---------	-----	---------------	-----	-----



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

6.3.2. Table 5 - Characteristics of the included studies

Author, Year of Publication	Study origin	Study design	Factors		Association with QoL
			Psychological factors	Social factors	
Zainal et al., 2013	Malaysia	Systematic review	Depression		Depression is associated with lower QoL.
Howard- Anderson et al., 2012	USA	Systematic review	Depression, stress, coping	Social support	Social and emotional support, coping are associated with better QoL. Depressions, stress are associated with lower QoL.
Syrowatka et al., 2017	Canada	Systematic review	Distress		Distress is associated with lower QoL.



**Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe**



Funded by the
European Union

Rimmer et al., 2022	England	Systematic review	coping, depression, post-traumatic stress disorder, post-traumatic growth		Post-traumatic stress disorder, higher levels of avoidant coping, higher level of depression are associated with lower QoL. Post-traumatic growth is associated with better QoL.
Wen et al., 2013	USA	Systematic review	Emotions, emotional well-being	Social support	Negative emotions are associated with lower HRQoL. Emotional well-being and social support are associated with higher QoL.



**Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe**



Funded by the
European Union

Aizpurua-Perez et al., 2020	Spain	Systematic review	Resilience, coping strategies, anxiety, depression	Social support	Resilience, appropriate coping strategies, social support are associated with higher QoL. Anxiety/depressive symptoms are associated with lower QoL.
Hamel et al., 2016	Belgium	Systematic review		Social interactions	Social interactions are associated with higher QoL.



**Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe**



Funded by the
European Union

Bours et al., 2016	Netherlands	Systematic review	Psychological distress, anxiety, depression, optimism, cancer-threat appraisal, a sense of coherence , repression defense, benefit- finding, posttraumatic growth, faith and meaning/peace, denial, hostility	Social support	Less perceived social support, psychological distress, anxiety, depression, lower optimism and negative cancer-threat appraisal , a weaker sense of coherence , more repression defense, less benefit finding, lower posttraumatic growth, less faith and meaning/peace, and less denial and more hostility are associated with lower HRQoL.
-----------------------	-------------	----------------------	---	----------------	---



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

Dunne et al., 2016	Ireland	Systematic review	Depression, anxiety, coping, fear of cancer recurrence, body image concerns, emotional and spiritual growth, neuroticism	Social support	Depression, anxiety, avoidance coping, fear of cancer recurrence, body image concerns, neuroticism are associated with lower QoL. Emotional and spiritual growth, perceptions and care received, satisfaction with social support are associated with higher QoL.
-----------------------	---------	----------------------	---	----------------	---





**Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe**



Funded by the
European Union

J. Han et al., 2020	USA	Systematic review and meta- analysis	Psychological distress, body image distress		Psychological distress, body image distress are associated with lower QoL.
Dahl et al., 2013	Denmark	Systematic review	Pessimism, fear of cancer recurrence, coping, neuroticism, sense of coherence, hope, well-being at the time of diagnosis, impaired sexual life		Hope, positive coping, high sense of coherence, positive coping, well-being at the time of diagnosis are associated with higher QoL. Pessimism, neuroticism, fear of cancer recurrence, impaired sexual life are associated with lower QoL.
Koch et al., 2012	Germany	Systematic review	Fear of cancer recurrence		Fear of cancer recurrence is significantly associated with lower QoL

	<p align="center">Quality of Life in Oncology: measuring what matters for cancer patients and survivors in Europe</p>	 <p align="center">Funded by the European Union</p>
---	--	--

Durosini et al., 2022	Italy	Systematic review	Emotional abilities (EA), coping strategies		Active coping/EA is associated with higher QoL. Passive coping/EA is negatively associated with lower QoL.
-----------------------	-------	-------------------	---	--	---

6.4. Table End of Life and Palliative Care

6.4.1. Table 6 - Characteristics of the included studies

Author & Year of publication	Study origin	Study design	Studies included	Participants	Cancer Group
------------------------------	--------------	--------------	------------------	--------------	--------------



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

			Number of studies included	Type of studies included	Years of published included articles	Country of origin of included studies	Number of patients in included articles	Range number of patients in included articles	Socio-demographic characteristics	Cancer type	
Gayatri et al. 2021	Indonesia	systematic review	55	36 cross-sectional, 15 cohort studies, 2 RCTs, and 2 quasi-experimental studies.	1999-2019	Asia (n = 40), Latin America and Caribbean region (n = 10), and Africa (n = 5)	11380	Range number of included pts: 15-1245	sex: varied among studies	all cancer types	4305
									Age range: 18-94	blood	25
										breast	640
										cervical cancer	224
										cervix	39
										colon and rectum	373
										digestive	5
										esophageal	105
										esophagus	62
										gallbladder	20
	gastric	123									
	gastrointestinal	228									
	genitourinary tract	24									



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

Flyum et al. 2021	Norway	systematic review and meta-analysis	11	5 prospective/longitudinal, 6 cross-sectional	2009-2020	Austria (n=1), Canada (n=1), Denmark and Sweden (n=1), Finland (n=3), Netherlands (n=1), Poland (n=2), South Korea (n=1), Turkey (n=1)	839	Range number of included pts: 35-1978	Age range: > 18	colon and rectum	839
									sex: varied among studies		



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

Bai et al. 2015	Georgia (USA)	systematic review	36	32 cross-sectional, 4 longitudinal	1996-2014	Australia (n=2), Canada (n=1), Japan (n=1), Jordan (n=2), Iran (n=1), Italy (n=1), Netherlands (n=1), United States (n=27)	170428	Range number of included pts: 45-8805	Age range:>18	all cancer types	169011
									breast	786	
									colorectal	258	
									prostate	373	
								sex: varied among studies			
							182647				

6.4.2. Table 7 - Characteristics of the included studies

Author & Year of publication	Factors	Association with QoL	Outcomes
------------------------------	---------	----------------------	----------



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

		Psychological factors	Social factors		
1	Gayatri et al. 2021			Negative association -> QoL	Higher pain intensity is associated with lower QoL
				Negative association -> QoL	Higher symptoms are associated with lower QoL
				Negative association -> QoL	Higher fatigue is associated with lower QoL
			family function/support	Positive association -> QoL	Higher family support is associated with better QoL
		Depression and anxiety		Negative association -> QoL	Higher depression and anxiety symptoms are associated with lower QoL
				Positive association -> QoL	Higher symptoms management therapy are associated with better QoL
		spirituality/religiosity		Positive association -> QoL	Spituality/religiosity is associated with better QoL
				Positive association -> QoL	Presence of treatments are associated with better QoL
		Diagnosis awareness		one study reported positive association -> QoL; three studies reported a negative association -> QoL	one study reported positive association -> QoL; three studies reported a negative association -> QoL



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

2	Flyum et al. 2021			Negative association -> HRQoL	more severe disease is associated with lower HRQoL
				Negative association -> HRQoL	effects of radiotherapy are associated with lower HRQoL
		depression		Negative association -> HRQoL	higher levels of depression are associated with lower HRQoL
				Positive association -> HRQoL	higher response to treatment is associated with better HRQoL



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

		feeling of coherence		Positive association -> HRQoL	higher feeling of coherence is associated with better HRQoL
				Positive association -> HRQoL	better performance status is associated with higher HRQoL
		intrusive thoughts		Negative association -> HRQoL	intrusive thoughts is associated with lower HRQoL
		awareness of terminal disease		Negative association -> HRQoL	awareness of terminal disease is associated with lower HRQoL
3	Bai et al. 2015	Spirituality (Faith and Meaning/Peace)		positive association -> QoL	higher overall spiritual well-being is associated with better QOL



Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

7. References

- Aromataris, E., Fernandez, R., Godfrey, C. M., Holly, C., Khalil, H., & Tungpunkom, P. (2015). Summarizing systematic reviews: Methodological development, conduct and reporting of an umbrella review approach. *International Journal of Evidence-Based Healthcare*, 13(3), 132–140. <https://doi.org/10.1097/XEB.0000000000000055>
- Banaye Yazdipour, A., Niakan Kalhori, S. R., Bostan, H., Masoorian, H., Ataee, E., & Sajjadi, H. (2022). Effect of social media interventions on the education and communication among patients with cancer: A systematic review protocol. *BMJ Open*, 12(11), e066550. <https://doi.org/10.1136/bmjopen-2022-066550>
- Bender, J. L., Hueniken, K., Eng, L., Brown, M. C., Kassirian, S., Geist, I., Balaratnam, K., Liang, M., Paulo, C. B., Geist, A., Rao, P., Magony, A., Smith, E. C., Xu, W., Liu, G., & Gupta, A. A. (2021). Internet and social media use in cancer patients: Association with distress and perceived benefits and limitations. *Supportive Care in Cancer: Official Journal of the Multinational Association of Supportive Care in Cancer*, 29(9), 5273–5281. <https://doi.org/10.1007/s00520-021-06077-0>
- Cárceles-Álvarez, A., Ortega-García, J. A., López-Hernández, F. A., Fuster-Soler, J. L., Sanz-Monllor, A., Ramis, R., & Claudio, L. (2020). Environment, lifestyle behavior and health-related quality of life in childhood and adolescent cancer survivors of extracranial malignancies. *Environmental Research*, 189, 109910. <https://doi.org/10.1016/j.envres.2020.109910>
- Clark, E. M., James, T., Jones, C. A., Alapati, A., Ukandu, P., Danforth, C. M., & Dodds, P. S. (2018). A Sentiment Analysis of Breast Cancer Treatment Experiences and Healthcare Perceptions Across Twitter (arXiv:1805.09959). arXiv. <https://doi.org/10.48550/arXiv.1805.09959>
- De Rosis, S., Cerasuolo, D., & Nuti, S. (2020). Using patient-reported measures to drive change in healthcare: The experience of the digital, continuous and systematic PREMs observatory in Italy. *BMC Health Services Research*, 20(1), 315. <https://doi.org/10.1186/s12913-020-05099-4>

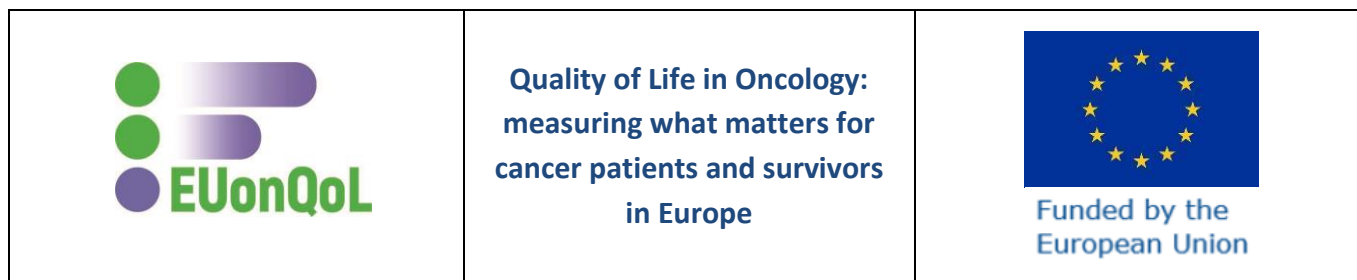


Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe



Funded by the
European Union

- de Ruiter, J. H., de Haes, J. C. J. M., & Tempelaar, R. (1993). Cancer patients and their network: The meaning of the social network and social interactions for quality of life. *Supportive Care in Cancer*, 1(3), 152–155. <https://doi.org/10.1007/BF00366062>
- Khan, M. I., Rahman, Z. U., Saleh, M. A., & Khan, S. U. Z. (2022). Social Media and Social Support: A Framework for Patient Satisfaction in Healthcare. *Informatics*, 9(1), Articolo 1. <https://doi.org/10.3390/informatics9010022>
- Murphy, N., Moreno, V., Hughes, D. J., Vodicka, L., Vodicka, P., Aglago, E. K., Gunter, M. J., & Jenab, M. (2019). Lifestyle and dietary environmental factors in colorectal cancer susceptibility. *Molecular Aspects of Medicine*, 69, 2–9. <https://doi.org/10.1016/j.mam.2019.06.005>
- Ouzzani, M., Hammady, H., Fedorowicz, Z., & Elmagarmid, A. (2016). Rayyan—A web and mobile app for systematic reviews. *Systematic Reviews*, 5(1), 210. <https://doi.org/10.1186/s13643-016-0384-4>
- Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., ... Moher, D. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *Systematic Reviews*, 10(1), 89. <https://doi.org/10.1186/s13643-021-01626-4>
- Parkin, D. M., Boyd, L., & Walker, L. C. (2011). 16. The fraction of cancer attributable to lifestyle and environmental factors in the UK in 2010. *British Journal of Cancer*, 105 Suppl 2(Suppl 2), S77-81. <https://doi.org/10.1038/bjc.2011.489>
- Shea, B. J., Reeves, B. C., Wells, G., Thuku, M., Hamel, C., Moran, J., Moher, D., Tugwell, P., Welch, V., Kristjansson, E., & Henry, D. A. (2017). AMSTAR 2: A critical appraisal tool for systematic reviews that include randomised or non-randomised studies of healthcare interventions, or both. *BMJ (Clinical Research Ed.)*, 358, j4008. <https://doi.org/10.1136/bmj.j4008>



Spencer, L., Ritchie, J., Lewis, J., & Dillon, L. (2004). *Quality in Qualitative Evaluation: A framework for assessing research evidence*.

Stewart, L. A., Clarke, M., Rovers, M., Riley, R. D., Simmonds, M., Stewart, G., Tierney, J. F., & PRISMA-IPD Development Group. (2015). Preferred Reporting Items for Systematic Review and Meta-Analyses of individual participant data: The PRISMA-IPD Statement. *JAMA*, *313*(16), 1657–1665. <https://doi.org/10.1001/jama.2015.3656>

Sugawara, Y., Narimatsu, H., Hozawa, A., Shao, L., Otani, K., & Fukao, A. (2012). Cancer patients on Twitter: A novel patient community on social media. *BMC Research Notes*, *5*(1), 699. <https://doi.org/10.1186/1756-0500-5-699>

Tilburt JC, et al. (2012). *Factors Influencing Cancer Risk Perception in High Risk Populations: A Systematic Review*. [https://www.google.com/search?q=Tilburt+JC%2C+James+KM%2C+Sinicrope+PS%2C+Eton+DT%2C+Costello+BA%2C+Carey+J%2C+et+al.+Factors+Influencing+Cancer+Risk+Perception+in+High+Risk+Populations%3A+A+Systematic+Review.+Hered+Cancer+Clin+Pract.+2011+May+19%3B9\(1\)%3A2.&rlz=1C1GCEB_enIT1003IT1004&oq=Tilburt+JC%2C+James+KM%2C+Sinicrope+PS%2C+Eton+DT%2C+Costello+BA%2C+Carey+J%2C+et+al.+Factors+Influencing+Cancer+Risk+Perception+in+High+Risk+Populations%3A+A+Systematic+Review.+Hered+Cancer+Clin+Pract.+2011+May+19%3B9\(1\)%3A2.&gs_lcrp=EgZjaHJvbWUyBggAEEUYOdIBBzQ3N2owajeoAgiwAgE&sourceid=chrome&ie=UTF-8](https://www.google.com/search?q=Tilburt+JC%2C+James+KM%2C+Sinicrope+PS%2C+Eton+DT%2C+Costello+BA%2C+Carey+J%2C+et+al.+Factors+Influencing+Cancer+Risk+Perception+in+High+Risk+Populations%3A+A+Systematic+Review.+Hered+Cancer+Clin+Pract.+2011+May+19%3B9(1)%3A2.&rlz=1C1GCEB_enIT1003IT1004&oq=Tilburt+JC%2C+James+KM%2C+Sinicrope+PS%2C+Eton+DT%2C+Costello+BA%2C+Carey+J%2C+et+al.+Factors+Influencing+Cancer+Risk+Perception+in+High+Risk+Populations%3A+A+Systematic+Review.+Hered+Cancer+Clin+Pract.+2011+May+19%3B9(1)%3A2.&gs_lcrp=EgZjaHJvbWUyBggAEEUYOdIBBzQ3N2owajeoAgiwAgE&sourceid=chrome&ie=UTF-8)

van Roekel, E. H., Bours, M. J. L., de Brouwer, C. P. M., Ten Napel, H., Sanduleanu, S., Beets, G. L., Kant, I. J., & Weijenberg, M. P. (2014). The applicability of the international classification of functioning, disability, and health to study lifestyle and quality of life of colorectal cancer survivors. *Cancer Epidemiology, Biomarkers & Prevention: A Publication of the American Association for*



**Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe**



**Funded by the
European Union**

Cancer Research, Cosponsored by the American Society of Preventive Oncology, 23(7), 1394–1405. <https://doi.org/10.1158/1055-9965.EPI-13-1144>



**Quality of Life in Oncology:
measuring what matters for
cancer patients and survivors
in Europe**



**Funded by the
European Union**

Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the European Commission. Neither the European Union nor the granting authority can be held responsible for them.