Quality of Life of Patients with Advanced Cancer in Treatment: Review and Qualitative Synthesis

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Qualidade de Vida de Pacientes com Câncer Avançado em Tratamento: Revisão e Síntese Qualitativa

Calidad de Vida de los Pacientes con Cáncer Avanzado en Tratamiento: Revisión con Síntesis Cualitativa

Cristiano de Assis Pereira Hansen[1]; Carlos Roberto de Oliveira Nunes[2]; Tatiane Aparecida Simas Fernandes[3]

ABSTRACT

Introduction: Global cancer incidence has increased and many patients live for a long time with a metastatic disease when it is important to discuss the quality of life during treatment. **Objective:** To conduct a qualitative literature review to describe what are the main factors affecting the quality of life of patients with advanced cancer in oncological treatment highlighting the most relevant findings in the perspective of the patients. **Method:** Nine articles that form the *corpus* of analysis have been selected. The methodological approach was Bardin´s content analysis through code frequency, co-occurrence and contingent analysis, eventually leading to a final thematic synthesis. **Results:** Eleven themes and fifteen sub-themes addressing the main theme were found: possibility of becoming a family burden. The theme least related to the others, possibly indicating a complementary dimension, was keeping hope. **Conclusion:** Qualitative synthesis concluded that concerns regarding family support network appear to significantly influence the quality of life of patients with advanced cancer under treatment.

Key words: Quality of Life; Neoplasm Metastasis; Qualitative Research; Indicators of Quality of Life.

RESUMO

Introdução: A incidência global de câncer tem aumentado e muitos pacientes convivem por muito tempo com a doença em cenário metastático, no qual – a par de considerações sobre quanto tempo têm de vida – torna-se relevante discutir qualidade de vida durante o tratamento. **Objetivo:** Construir uma revisão da literatura qualitativa, com vistas a descrever fatores intervenientes sobre a qualidade de vida dos pacientes com câncer avançado em tratamento, destacando os achados mais relevantes na perspectiva dos sujeitos. **Método:** Foram selecionados nove artigos que constituíram o *corpus* de análise. A metodologia empregada foi a análise de conteúdo de Bardin, por meio da análise de frequência dos códigos, análise de co-ocorrência e análise contingencial, culminando com uma síntese temática. **Resultados:** Foram encontrados 11 temas e 15 subtemas que abordam o tema principal: expectativa de ser um fardo familiar. O tema com menor relação com os outros, possivelmente indicando uma dimensão complementar aos demais, foi: manter a esperança. **Conclusão:** A síntese qualitativa indicou que preocupações com a rede de suporte familiar parecem influenciar de modo importante a qualidade de vida de pacientes com câncer avançado em tratamento.

Palavras-chave: Qualidade de Vida; Metástase Neoplásica; Pesquisa Qualitativa; Indicadores de Qualidade de Vida.

RESUMEN

Introducción: La incidencia mundial de cáncer ha aumentado y muchos pacientes viven un tiempo considerable con la enfermedad después del diagnóstico, incluso en un escenario de caso avanzado con enfermedad metastásica. En este sentido, la reflexión ética sobre la calidad –no solo sobre la cantidad de vida– es de suma consideración. **Objetivo:** Se realizó una revisión cualitativa de la literatura, con el objetivo de describir cuáles son los principales factores que afectan la calidad de vida en pacientes con cáncer avanzado en tratamiento oncológico y se intentó describir cuáles son los principales hallazgos de este, desde una perspectiva de los sujetos. **Método:** Se seleccionaron nueve artículos que constituyen el corpus de análisis. Nuestro enfoque metodológico fue el análisis de contenido de Bardin, principalmente la frecuencia de códigos, la coocorrencia y el análisis contingente, culminando con una síntesis temática. **Resultados:** Se encontraron once temas y quince subtemas, orbitando en torno al tema principal: la perspectiva de ser una carga familiar. El tema menos relacionado con los otros, posiblemente indicando una dimensión complementaria a los demás, fue: mantener la esperanza. **Conclusión:** La síntesis cualitativa ha demostrado que la preocupación por la red de apoyo familiar parece influir significativamente en la calidad de vida de los pacientes con cáncer avanzado en tratamiento.

Palabras clave: Calidad de Vida; Metástasis de la Neoplasia; Investigación Cualitativa; Indicadores de Calidad de Vida.

[1-3] Universidade de Blumenau (FURB). Blumenau (SC), Brasil.
[1] E-mail: cristianohansen@yahoo.com.br. Orcid iD: https://orcid.org/0000-0003-1456-9591
[2] E-mail: cnunes@furb.br. Orcid iD: https://orcid.org/0000-0001-6301-4053
[3] E-mail: tasfernandes@furb.br. Orcid iD: https://orcid.org/0009-0000-3381-7242
Corresponding author: Cristiano de Assis Pereira Hansen. Centro de Oncologia Unimed Blumenau. Rua Ingo Hering, 20, 7º andar – Centro. Blumenau (SC), Brasil. CEP 89010-205. E-mail: cristianohansen@yahoo.com.br

INTRODUCTION

The global incidence of cancer has increased over the last decades[1] with around 20 million new cases and ten million deaths in 2022, according to the International Agency for Research on Cancer (Iarc)[2]. The disease generates deaths and sequelae, causing great damage in terms of lost life years[2] and years lived with incapacity[1].

In specialized oncology care, an area of clinical oncology, some outcomes are usually analyzed in relation with cancer treatment, that is, tumoral response to treatment, duration of response, time rid of symptoms and time to tumoral recurrence, with those being called disease-related outcomes; in addition, some outcomes, called patient outcomes, are related to the benefit of therapy in terms of increasing survival and quality of life (QL). Health professionals tend to focus on disease-related outcomes, because even the current instruments to assess QL need to be improved[3].

Some instruments were developed with the aim of assessing health-related quality of life, with no consensus on the best instrument to be used in the context of clinical oncology[4]. The most used instruments include the short-form health survey (SF-36) and the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC-QLQ-C30)[5]. In clinical trials with new medication, the EuroQol 5 Dimensions (EQ-5D)[6] has been used the most. The first instrument specifically designed for oncology patients was Spitzer's QL-Index, from the 80s[7].

The analysis of different studies makes it possible to infer that the use of QL assessment instruments could be complemented by the patients' testimonies, including upon filling the forms, which allows the elaboration of new and more encompassing instruments[8].

QL is associated with survival of the sick[5,9,10], and thus, has been acquiring great relevancy from a theoretical and practical perspective in clinical oncology. With field research and quantitative perspective results, some variables seem to relate better with QL during cancer treatment, like gender and age of individuals, type of cancer and disease volume, time from advanced cancer diagnosis, among others[11,12].

A study from a French group[13] that used a qualitative approach showed that the side effects of the treatment are among the most mentioned themes by the patients, especially in a "negative" sense. On the other hand, some themes that emerge from the qualitative perspective regarding factors that favor, from the patients' perspective, a good QL during oncological therapy are: 1) having a support object (something the patients imbue with positive meaning and help them cope with the disease), that can be a relationship, an activity, a personal goal, or even an object or animal; 2) the perception that the treatment is working; 3) positive effects of relationships with friends, family or even doctors[13].

The research question is: what determines the quality of life of advanced cancer patients during treatment? What factors are associated with a better or worse quality of life during the disease treatment in the patients' perspective? And how are these multiple factors considered on a qualitative scale?

The objective of this study is to conduct a literature review on QL of patients with advanced cancer in outpatient clinic treatment, with the aim of describing intervening factors, highlighting the most relevant findings from the patients' perspective.

METHOD

Literature review with content analysis by Bardin, from qualitative data found in the selected articles, along the lines of a qualitative metasynthesis.

To answer the research question, a search strategy was elaborated around the following question: "What determines the quality of life of advanced cancer patients during treatment?"

This search was conducted in December 2023, in the PubMed and Scopus databases, with no language restriction, using the following keywords, Boolean indicators and filters: "qualitative" [title/abstract] AND "quality of life" [title] AND "cancer" [title] NOT (children OR childhood). A total of 262 articles were found on PubMed and 303 on Scopus.

Using the Mendeley reference manager, 211 duplicates were found, leaving 354 articles, among the original 565 found in both databases. From this list of articles, one of the authors (CAPH) performed a title/abstract reading to identify the context (patients with advanced cancer, in outpatient clinic treatment) and the aim of the study (QL), in addition to the qualitative research methodology; if those items were not contemplated, the article was excluded. In the end, 37 articles remained (Figure 1[14,15]).

A detailed read was performed to assess the scope and methodological quality using the mixed-method appraisal tool (MMAT)[14], with the cutoff point being at least three of five items in the MMAT tool. At this stage, the articles were analyzed by two independent reviewers who reached a consensus regarding the

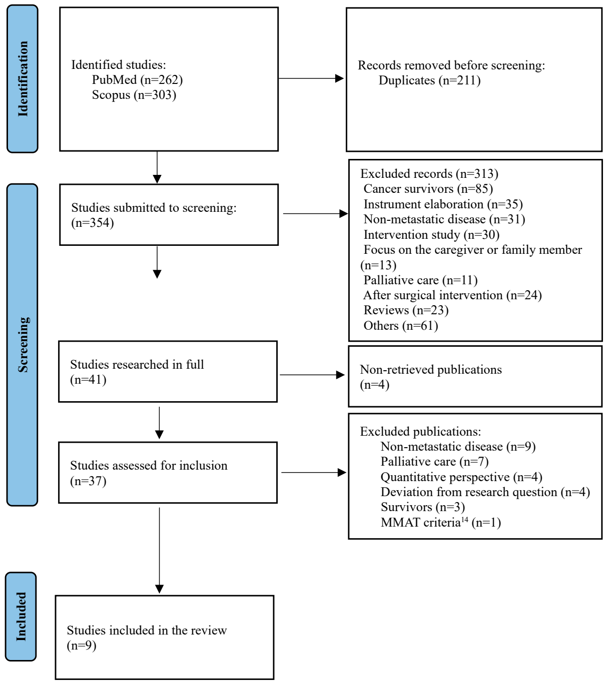

Figure 1. Flowchart of studies selected
Source: Adapted from PRISMA[15].
Caption: MMAT = mixed methods appraisal tool[14].

selection of articles that compose the current review (Chart 1). To become eligible, the study needed to have a clear research question, and the collected data should be able to answer this question. In addition, the collected qualitative data should allow the assessment of intervening factors on patients' QL, in line with the primary objective of this review.

The methodological path followed the PRISMA[15] checklist (Figure 1). The qualitative synthesis was performed from the qualitative data extracted from the nine articles included through Bardin's[16], content analysis, including all the participants transcriptions (analysis corpus). A frequency analysis was conducted, along with an analysis of code relations (co-occurrences and contingencies), following a thematic synthesis.

To establish validity and reliability parameters to the investigation, the validity concept that guides this research is based on the "extent to which conclusions derived from the data provide an accurate description of what occurred or a correct explanation of what occurred and why", according to Harding[17]. Moreover, another important concept is the one of reflexivity, according to Olmos-Veja[18]: "set of collaborative, multifaceted and ongoing practices in which researchers criticize, analyze and evaluate how their subjectivity and context influence research processes". These concepts permeated the discussion between the research team, during and after codification, analysis and thematic synthesis, as recommended by other authors regarding qualitative studies[19].

Regarding reliability, one of the researchers (CAPH), 60 days after the initial codification was performed, having been randomly selected one of the context units by the research team (Berterö[20] et al.'s article), reapplied the codes, obtaining Cohen kappa of 0.89; in addition, another researcher (TASF) who did not take part in the first stage of the study, with no instruction aside from the code book, codified the same context unit, obtaining a Cohen kappa of 0.55 initially, and then, after a brief orientation regarding the main codes and themes of the review, obtained a kappa of 0.88 (indicating an almost perfect concordance).

RESULTS

The qualitative data were extracted with the aim of gathering detailed information on the participants, country, study objective, methodology employed and results (Chart 1)[21-28].

A total of 34 codes were found in the nine reviewed articles (Chart 2). Combining the codes of three articles[21,24,28], 31 codes were found in a total of 34 in the review, that is, over 90% of the codes came from only a third of the reviewed articles.

The most expressed code was the feeling of being a burden on the family, occurring in eight of the nine reviewed articles (Figure 2).

Co-occurrences analysis

The most co-expressed codes are shown in the following excerpts.

Codes 16, 5 and 1 in two articles[21,25] show that the loss of autonomy is connected to cancer fatigue and compromised functionality.

"My body is weak. Sometimes I can't get up, wash up, brush my teeth… sometimes my little one helps me in the bathroom" (translated from Lee et al.[25]).

Codes 6, 8, 12 and 14 with certain density in one article[21] showed that keeping away bad thoughts helps reduce cancer stigma, in an attempt to keep normality in the lives of friends.

> I try to be like others and be with them. I don't want to be alone, and I feel pity for myself. I have to move on. It makes it easier. If I'm lonely and start thinking of things, it doesn't help anything. It's better to be out there and live life like everybody else, or at least try to live like everybody else (translated from Luoma and Hakamies-Blomqvist[21]).

Chart 1. Characteristics of the included studies and methodological quality

Author	Country	Participants	Research objective	Method	Results	MMAT score
Luoma M; Hakamies-Blomqvist, 2004[21]	Finland	Twenty-five women with advanced breast cancer, under chemotherapy treatment, aged between 18 and 70 years old	Investigate factors that affect QL and are not perceived by a quantitative assessment instrument (EORTC QLQ C30)	Purposive sampling until theoretical saturation is achieved (reached with 18 participants) within a clinical trial. Semi-structured interviews were subjected to phenomenological analysis. The AtlasTi software was used.	The treatment is capable of negatively influencing QL (due to side effects) and sometimes positively (with oncological pain relief or regained capacity to do good things). Being able to work helped the QL of some patients, as well as support from friends and family. Learning to live day-to-day had a positive effect.	5
Janssens et al., 2021[22]	Belgium and Italy	Twenty-four patients in treatment for lung cancer, average age of 62 years-old	Investigate how patients with advanced lung cancer perceive their QL and what they consider most important in its determination	Purposive sampling of patients submitted to focus groups with transcribed interviews for thematic analysis. The NVivo software was used	Three themes were found: physical aspects, psychological aspects and social aspects. Changes in physical appearance, nausea, fatigue, sensory changes and risk of infections affected QL. Loss of autonomy, freedom and independence affected QL. Social interaction is capable to keep QL and communication with health professionals can be negative	5
Lee Mortensen et al., 2018[23]	Denmark	Eighteen women with metastatic breast cancer aged between 41 and 72 years old	Exploring QL of Danish women with metastatic breast cancer and a possible relationship with their support needs.	Purposive sampling in multiple oncological centers of the country was explored through focus groups, with transcription of sessions and thematic analysis through constructive approach. The NVivo software was used	Two themes were explored: impact of metastatic cancer on QL and treatment and need for support. Symptoms or effects on the physical sphere compromised QL, highlighting fatigue. Continuing working or establishing goals helped QL. Emotional issues like depression and anxiety had an impact on QL. On the subject of need for support, exams cause anxiety and reduce the time available in the day-to-day. Social assistance and timely psychological support were other needs	4
Berterö et al., 2008[20]	Sweden	Twenty-three patients with advanced lung cancer under treatment, 12 men, average age of 63 years-old	Describe how people with advanced cancer diagnosis experienced the impact of the disease on their life situation and QL	Purposive sampling and qualitative interviews guided by the phenomenology approach	Six themes were found and one great general theme that aimed at capturing the general essence of the study object (QL): live with the usual	5
Ginter A.C, 2020[24]	USA	Nine young women (up to 40 years old) with metastatic breast cancer	Understand the life experience of young women with metastatic breast cancer, particularly the essence of their QL	Purposive sampling and recruitment in cascade motion with semistructured interviews guided by phenomenological approach and life course theory that guided the thematic analysis	Five themes were found: "this should not be happening right now", "how do I tell the others", "benefits of keeping the mind busy", "contemplating the future" and "living instead of surviving"	5

Continue...

Chart 1. Continuation

Author	Country	Participants	Research objective	Method	Results	MMAT score
Lee et al., 2016[25]	Singapore	Forty-six patients with advanced cancer, similar proportion of men and women, average age 59 years-old and breast cancer (19), colorectal (7) and lung (6), mainly	Identify QL domains exploring the subjective experience of what constitutes a good QL to the participants	Purposive sampling in two reference locations in Singapore Interviews and focus groups were conducted, subjected to thematic analysis The NVivo software was used	Twenty-two themes were found, grouped in six domains: "pain and suffering", "social health", "mental health", "spiritual health", "financial well-being" and "physical health"	5
CharalambousA; Kouta C, 2016[26]	Cyprus	Fifteen men with advanced prostate cancer under chemotherapy treatment	Explore cancer-related fatigue and its impact on the overall QL of patients	Purposive sampling in two outpatient oncology services of public hospitals in Cyprus, up to theoretical saturation. Open question interviews were conducted, object of the thematic analysis	Three themes were found: "dependency on others", "loss of decision-making power" and "disruption of daily life"	5
Rowland et al., 2014[27]	United Kingdom	Nine patients with advanced lung cancer, mostly men (6), average age of 66 years-old	Explore the perception of patients on their QL, considering their view on smoking	Purposive sampling with maximum variation strategy, in which semistructured interviews were conducted until theoretical saturation. A thematic analysis was conducted from an interpretive and phenomenological approach	Five themes were found: "effects of the disease on QL", "family support", "coping strategies", "medical support" and "smoking". Helped QL: adaptation, family support, open communication between the couple, hobbies or interests, in addition to focusing on the future. Affected QL: physical limitations, cancer stigma causing feeling of isolation and family concern	5
Parra-Morales et al., 2021[28]	Colombia	Seven men with advanced prostate cancer under treatment, average age of 60 years-old	Describe the perception of patients regarding changes in their QL since the diagnosis and during treatment	Purposive sampling, maximum variation of types with patients from the public or private systems, with a history of 1.5 to 4.5 years since the diagnosis, submitted to different treatments. Semistructured phone interviews were conducted and submitted to thematic analysis according to Braun & Clarke	Nine categories were found (five at first, reported in the literature review, and four new). Affected QL: urinary symptoms (mostly urinary obstruction), sexual dysfunction, hormonal changes (mostly hot flashes), pain/fatigue/nausea, changes in disposition and mental health (mostly negative emotions about the diagnosis), functional limitations (preventing the practice of sports, for example), health system issues (access limitations). Helped QL: incorporating personal practices (new lifestyle, spirituality/religiosity and positive attitude) and social support (from family and, mostly, medical assistance)	5

Captions: MMAT = Mixed Methods Appraisal Tool; QL = Quality of life; EORTC-QLQ-C30 = European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30.

Chart 2. List of codes identified in the analyzed articles included in the review

1. Compromised functionality	8. Keeping away bad thoughts	15. Social isolation	22. Health services interaction helps	29. Thinking of a meaning for life
2. Negative effects of the treatment	9. Support from work colleagues	16. Loss of autonomy	23. Adaptation	30. Spirituality
3. Positive effects of the treatment	10. Enjoy life	17. Preserved functionality	24. Not having financial concerns	31. Expressing the experience of cancer
4. Oncological pain	11. Family	18. Doubts about the future	25. Having financial concerns	32. Lack of a normal life
5. Fatigue	12. Keeping normality	19. Keeping hopes up	26. Learning or experimenting new things	33. Smoking
6. Cancer stigma	13. Lack of hope	20. Feeling of being a burden on the family	27. Keeping the mind busy	34. Taking care of their health
7. Accomplishing small things	14. Support from friends	21. Health services interaction impairs	28. Having a goal	

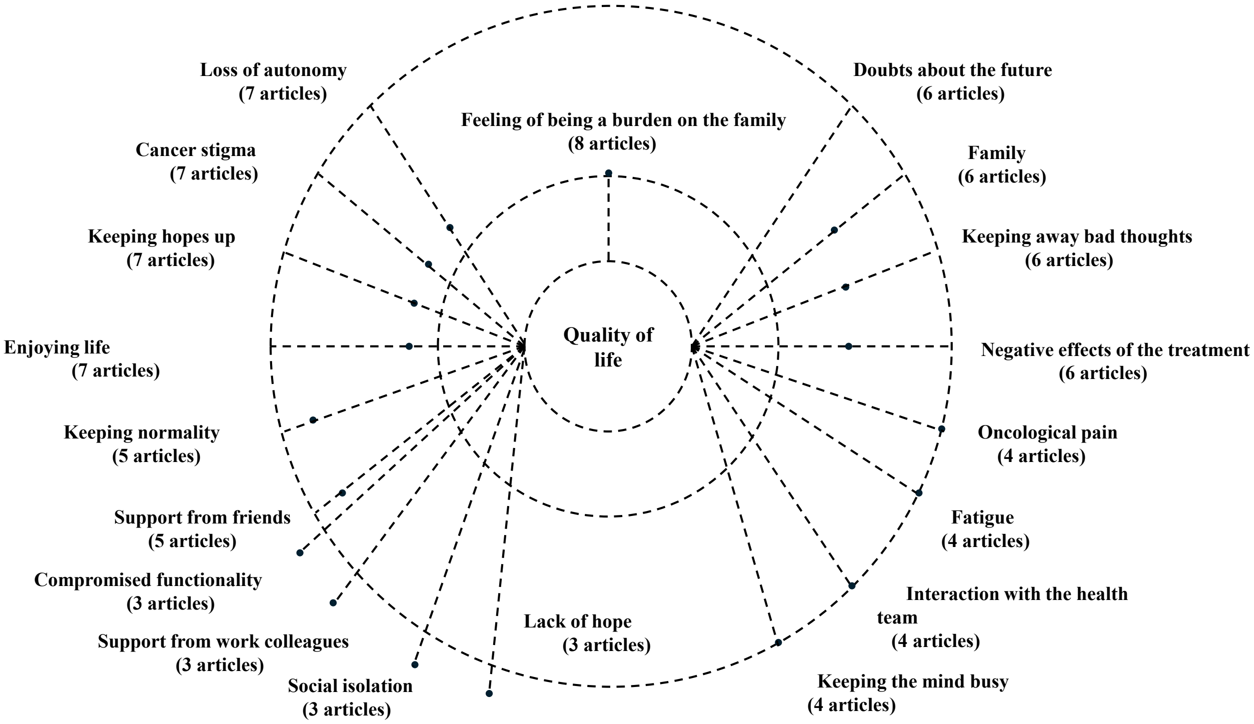

Figure 2. Frequency analysis with the most expressed codes by number of articles

Codes 18 and 20 in two articles[21,27] showed that the feeling of being a burden on the family permeates part of the doubts about the future.

"But I worry, if something happens to me, how they will deal with it. I worry about the pressure I put on my wife every time" (translated from Rowland et al.[27]).

Codes 8 and 27 in two articles[21,23] showed that enjoying life can be achieved, even with a tendency for loss of autonomy by the disease, especially keeping the mind busy, and thus, keeping away bad thoughts connected to the disease stigma.

> It really pleases me the support plan in which the job agency doesn't have to follow me around every instant… Because I try to live my life each day, without the disease taking over all the space,

> and it's a bummer when the social worker has to occupy your time asking how you are doing. So, you have to sit there and think 'God, yes, I really feel weird and there's all these stuffs I can't do'. The option to keep health insurance (with a flexible job in this case), instead of receiving an invalid pension, is really good (translated from Lee Mortensen et al.[23]).

The codes are usually expressed in terms of number of articles where they show up and with which code they relate the most: 5, 6, 8, 12, 16, 21.

Code 20 (feeling of being a burden) is related to: 4, 5, 8, 11, 16, 18, and 25. This happens in five articles[21,24-27].

The feeling of being a burden on the family is related to oncological pain and fatigue, loss of autonomy and doubts about the future, in addition to financial concerns, and is sometimes sparked by the very own family life. It can be alleviated by keeping away bad thoughts regarding doubts about the future.

Code 6 (cancer stigma) is related to: 2, 4, 5, 8, 12, 14, 15, 16, 18, 27, 31 and 32. This happens in four articles[21,24,26,27].

Cancer stigma threatens the maintenance of a normal life, and can be alleviated by living life normally, especially when keeping away bad thoughts, being in the presence of friends, and thus, keeping the mind busy; this stigma causes doubts about the future, but even when aggravated by loss of autonomy generated by the disease, QL can be improved by trying to express the cancer experience to others. Still, in the presence of the negative effects of treatment and fatigue, the cancer stigma ends up causing social isolation due to the incapacity of living a normal life.

Code 16 (loss of autonomy) is related to: 1, 4, 5, 6, 7, 8, 10, 12, 17, 27, 31 and 32. This happens in six articles[21,22,24-27].

The loss of autonomy is precipitated by the loss of functionality and perceived as loss of normal life, partially compensated when the patient is able to accomplish small things. In some cases, even with the functionality preserved, the person may have their autonomy restricted (driving, for instance). By maintaining their jobs (even if part-time), it is possible to avoid losing autonomy, which appears as a threat to enjoying life (especially if it becomes hard to keep the mind busy to clear bad thoughts). Although it happens alongside the cancer stigma, QL can be improved by expressing the experience of living with cancer to others.

Code 8 (keep away bad thoughts) is related to: 4, 6, 7, 9, 10, 12, 14, 16, 18, 20, 24 and 27. This happens in three articles[20,21,23].

To keep bad thoughts away, plainly, it helps to be able to accomplish small things. However, sometimes, this can be even more complicated and — even in the presence of friends — it's necessary to suppress the cancer stigma; in a different scenario, to keep one's mind busy (by watching a movie, for instance) they need to not be in pain to be able to keep the bad thoughts away and maintain QL. Keeping away bad thoughts is related to the expectation of experiencing oncological pain or feeling like a burden on the family and is associated to having doubts about the future. Again, the support of work colleagues helps to keep the mind busy and keep bad thoughts away, which also helps to live a normal life.

Code 12 (normality) is related to: 4, 6, 7, 8, 10, 14, 16, 18, 27 and 31. This happens in five articles[20,22-24,28].

Living a normal life helps to avoid the stigma of an incurable disease. It seems to help emotionally, alleviating the weight of the disease stigma, by expressing to others that it is possible to live a normal life, even with some loss of autonomy imposed by the treatment. Living a normal life helps to keep away bad thoughts. Trying to live a normal life, in the presence of friends, is important to keep away bad thoughts connected to the disease stigma. Living normally also represents enjoying life and accomplishing small things helps keep this perception, but sometimes the doubts about the future make it harder to keep away bad thoughts.

Code 5 (fatigue) is related to: 2, 4, 6, 7, 8, 10, 12, 14, 16, 18, 27 and 31. This happens in two articles[21,25].

Fatigue is a limiting symptom and occurs, at times, along with oncological pain. It is also associated with the loss of functionality and, even when trying to accomplish small things, fatigue ends up generating loss of autonomy. Fatigue, by generating loss of functionality, results in the loss of a normal life. In addition, it interferes with attempts to enjoy life and, thus, keeping the mind busy. It is sometimes perceived as a negative effect of the treatment, causing loss of normal life and social isolation, due to the disease stigma. Sometimes, even in the presence of family, fatigue can cause the feeling of being a burden.

Contingency analysis

Frequently expressed themes in terms of number of articles, but that present little relation with the others: 2, 10, 11, 14, 18, and 19. Those codes may indicate dimensions complementary to the others, especially code 19 (keeping hopes up), since, in contingency analysis, it appears disconnected to the more frequent codes: 5, 6, 8, 12, 16, and 20.

Code 10 (enjoying life) is related to: 5, 8, 12, 23, 27, and 29. This happens in five articles[21,23,25,26,28]. It is not related to the codes: 6, 16 and 20.

Keeping normality helps enjoy life, as well as keeping away bad thoughts or coming up with a meaning for life; on the other hand, cancer fatigue impairs the ability to enjoy life and keep the mind busy. Adapting to the disease helps enjoying the time left to life.

Code 19 (keeping hopes up) is related to: 3, 13, 14, 22 and 30. This happens in five articles[21,23-25,28]. It is not related to the codes: 5, 6, 8, 12, 16, and 20.

Keeping hopes up is less hard with the support of friends and, in this sense, spirituality and interaction with the health team helps.

Code 2 (negative effects of the treatment) is related to: 4, 5, 6, 15, 23, and 32. This happens in two articles[26,28]. It is not related to the codes: 8, 12, 16, and 20.

Negative effects of the treatment, associated with the fatigue and loss of a normal life, are related to the cancer stigma, causing social isolation. The exacerbation of cancer pain is perceived as a negative effect of starting cancer treatment, and it is highlighted that a transcendental adaptation to certain effects of the treatment is possible (such as erectile dysfunction in prostate cancer).

Code 11 (family) is related to: 4, 5, 7, 16 and 20. This happens in four articles[21,25-27]. It is not related to the codes: 6, 8 and 12.

The ability of accomplishing small things, so important in maintaining QL, does not overshadow the role of families in the QL of patients. In a negative sense, the family can, in the face of cancer fatigue, highlight the feeling of being a burden. It's important to rely on the family considering oncological pain and the loss of autonomy the disease causes.

Code 18 (doubts about the future) is related to: 4, 6, 8, 12 and 20. This happens in four articles[21,22,24,27]. It is not related to the codes: 5 and 16.

Doubts about the future sometimes seem undissociated with the feeling of being a burden on the family. Keeping away bad thoughts connected to the feeling of being a burden on the family or in relation to oncological pain is affected by doubts about the future, especially considering the suspension of oncological treatment. In addition, these doubts pile up, even when the person lives within normality, when they remember the recurrence after a previous treatment, sometimes highlighting the disease stigma (of being incurable).

Code 14 (support of friends) is related to: 4, 6, 8, 12, 13, 14, 19 and 27. This happens in two articles[21,24]. It is not related to the codes: 5, 16 and 20.

The support of friends is important in the attempt to keep a normal life and keep bad thoughts away to reduce the cancer stigma. Moreover, this support can help keep hopes up. As long as they don't remember the disease stigma, keeping normality, and having friends around help keep away bad thoughts.

Thematic synthesis

The result of the thematic synthesis revealed 11 themes (in bold) and 15 sub-themes (Figure 3). The main ones will be discussed ahead.

DISCUSSION

The central theme of the qualitative synthesis in this review on the quality of life (QL) of patients with advanced cancer in outpatient clinic treatment involves the feeling of being a burden on the family.

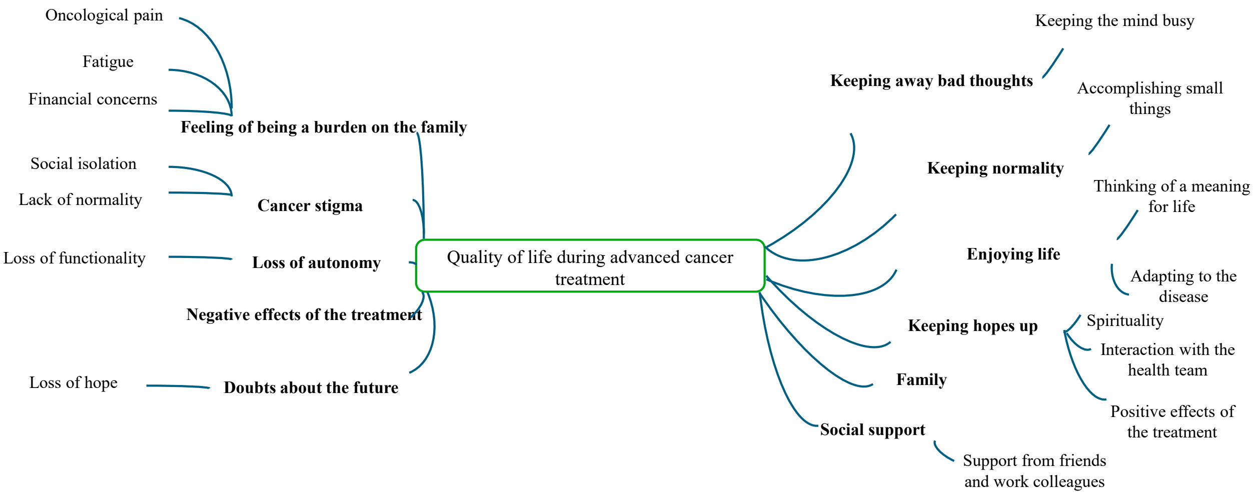

Figure 3. Qualitative synthesis of factors associated with patients' quality of life during advanced cancer treatment

This theme was initially described in terminal patients and in a setting of palliative care, in which the perception of being a burden is connected to the empathetic perception of patients regarding the impact caused in others due to the disease and their needs of care, associated with the feeling of guilt, suffering and responsibility[29]. However, this aspect of the life of cancer patients in treatment was described as an unusual finding of an inquiry conducted over two decades ago in a French hospital[30], where the researchers searched for adverse events of the oncological treatment and the most important finding was, in the patients' perspective, the impact caused in the family.

It was also emphasized by other authors[31,32] the central role of families in determining the QL of patients with advanced cancer. Family is a source of support, but also of concerns (financial, among others). In this qualitative synthesis, financial concerns constitute a sub-theme within the feeling of being a burden on the family.

The very loss of functionality as a consequence of cancer fatigue, that ends up compromising the autonomy of patients, causes pressure on the social support network, with the family being seen as not only emotional and physical support, but financial, since many patients can no longer work in that period. The financial-social impact of cancer has already been discussed by other authors of developing countries like Jansen van Rensburg et al.[33] in South Africa, but it seems to constitute a gap in the oncological research in Brazil. None of the articles included in the review was conducted by Brazilian authors.

Regarding the theme of the stigma, the etymology of the concept comes from the Greek "*stizein*", or mark, and refers to the fact that the patient is treated differently due to their disease, in comparison to other people, and to an individual inside experience of shame due to discrimination and lack of understanding of others[34]. Stigma is an apparent rupture with patients' normal lives, but it can be fought by trying to maintain normality, doing small things (usual activities from before the cancer was discovered).

A systematic review, including 4,161 women who survived breast cancer, showed some factors that relate to the stigma, among them: intrusive thoughts, ambivalence in expressing emotions, younger age, type of surgery (mastectomy instead of conservative breast surgery), full-time work and, finally, the perception of being a burden. On the other hand, there is a negative correlation between the stigma and QL, empathy of the health professional, education level and income of the patients, in addition to the social support received and adaptation to the situation[35].

It is interesting to note that adaptation to the disease situation and interaction with the health team constituted sub-themes, which favored or hindered the QL of the participants, while social support configured a theme in this qualitative synthesis, which demonstrates consistency between the findings of the current review and the quantitative study by Tang et al.[35]. From a quantitative perspective, this study involved thousands of women and came to similar conclusions to the present review, that, adding up the nine selected articles, included only 176 patients. It is worth highlighting the fact that a fraction of the articles (involving just 43 participants, by Luoma and Hakamies-Blomqvist[21], Ginter[24] and Parra-Morales et al.[28]) was able to saturate more than 90% of review codes, which relates to the concept of cultural competency mentioned by Romney et al.[36] and, possibly, a good rapport between researcher and participants, proving the robustness of qualitative research methodologies.

Code 8 used in the qualitative synthesis (keeping away bad thoughts) can be considered the counterpoint of the so-called "intrusive thoughts" described by Tang et al. In Bardin's co-occurrences analysis, it related to a variety of other codes, appearing as a pre-requisite to the other theme, enjoying life, and — in the perspective of some patients — helps reduce the disease stigma.

Finally, the theme "keeping hopes up", which constitutes a complementary dimension in the qualitative synthesis, can be exemplified in the speech "The day you lose hope, you start dying. I'm still not ready to give up my hope"[24]. This theme sparks deep bioethical reflections regarding the stance of health professionals, family members and society in the interaction with patients that struggle with advanced cancer treatment, in order not to reinforce the disease stigma — this social construct of the environment in which one lives, acts, thinks, relates and, sometimes, is the image of prejudice[37].

Regarding the limitations of the present review, it is necessary to mention that some studies may have inadvertently been excluded, based on the search strategy and filters used. However, for the goal of conducting a qualitative metasynthesis, within the review scope, it would be complicated to work with many qualitative data or coming from very heterogeneous samples.

CONCLUSION

The qualitative synthesis concluded that concerns regarding family support network appear to significantly influence the quality of life (QL) of patients with advanced cancer under treatment. Families are a source of affective support and often financial and are able to affect positively or negatively the QL of those people, allowing to infer that the QL of these patients is also a social construct that originates from the interaction between individual and the environment where they live and coexist. Other factors that seem decisive are the disease stigma and, additionally, the weight of hope regarding the instituted treatment.

CONTRIBUTIONS

All the authors have contributed to the study design, acquisition, analysis and interpretation of the data, wording, and critical review. They approved the final version for publication.

DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interest to declare.

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Associate-editor: Fernando Lopes Tavares de Lima. Orcid iD: https://orcid.org/0000-0002-8618-7608
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