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WRITING BY YOUNG PEOPLE WITH CANCER: INTEGRATIVE LITERATURE REVIEW

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Abstract: This integrative literature review article analyzes national and international scientific publications that addressed the writing of young people aged between 12 and 29 years old with cancer. The search covered the Virtual Health Library, Web of Science; SCOPUS (Elsevier); CINAHL and PsycINFO (APA) and after applying selection criteria, 18 studies were reached. The topics covered were categorized into two topics: “Writing and expression of emotions in the face of loss and imminence of death” and “Writing and sociality”, highlighting the writings in virtual space (blogs). We conclude that the writing brings evidence of personal, social, existential and contextual representations that mark the experience of young people with cancer and, despite the shyness of publications in the age group from 12 to 29 years old, there is potential to make visible the procedural, relational and contextualized character of expanded care, democratic, sensitive, personalized and situated.

Keywords: Cancer; Young; Expressive writing; blog.

INTRODUCTION

Writing as a dimension of the human condition¹ constitutes an important form of expression of knowledge, culture, democracy, information and art. Even if it is not a faithful portrait of a life, the word on paper is a ghost that affects with its appearance, but it never guarantees more than a quasi-perception of what they apparently deliver to us². It allows telling and recreating the story itself, which, in the case of cancer illness in youth, can be marked by the turbulent paths of this experience.

Thus, the writing that we focus on is the one whose author made everything he wrote about life and death a rubric of himself, an autobiographical trace, which refers to a name, a life, the shrewdness of a

lived experience³. That is why it is necessary to observe the marks of life that pulsate in the text⁴, referring to experience as “what happens to us, not everything that happens to us, but what touches us, affects us” [...] requiring a reflective attitude “a relationship with something that is experienced that is proven” (p. 18; 26)⁵.

Cancer in adolescents and young adults corresponds to 6% of all cases diagnosed in the world⁶ and its occurrence at this stage of life has consequences for biopsychosocial and existential projects⁷. In addition to talking about human pain, writing during cancer illness portrays social and ethical norms that influence the perception, meanings and senses of pain, body, health and disease that are socio-historically constructed⁸.

Thus, such writings can subsidize the provision of that care not enclosed in technique, but expanded, sensitive, personalized, situated, that is, as “an activity of the species itself that includes everything we can do to maintain, continue and repair our world so that we can live in it as best we can” (p.287)⁹.

In view of the above, this review proposed to describe and analyze national and international scientific publications that addressed the writing of young people aged between 12 and 29 years old with cancer.

METHODOLOGY

We adopted the integrative review following six steps: elaboration of the guiding question; search and selection of primary studies; data collect; critical analysis of studies; discussion of results; review presentation¹⁰.

For the guiding question, it was guided by the PICo strategy (Population, Phenomenon of interest, Context)¹¹, with a lowercase ‘o’ because it is more sensitive to qualitative scientific evidence¹². Thus, P refers to the Adolescent/Young person; I to Writing, Co

to cancer and the guiding question was: how are national and international scientific publications on the writing of young people between 12 and 29 years old suffering from cancer characterized, in terms of their form and focused themes?

The databases consulted in the period from 8/23/2021 to 9/10/2021 are relevant for the health area and interfaces and started from two comprehensive portals, namely: Virtual Health Library (BVS) and Capes Periodicals, without delimitation of the period.

From the initial search, titles and abstracts were read, applying the criteria of exclusion of texts with: a) the production of vlogs; b) the writing of family members of the person with cancer; c) writing about cancer prevention d) lexical decisions and eye movements in reading; e) non-cancer blogs; f) therapeutic interventions not related to writing; g) the

clinical perspective; h) absence of the age group of the participants or, exclusively, below 12 or above 29 years old; and i) written after the curing of the cancer. It ended up with 18 texts that met the objective of the review, whose selection flow is represented in Figure 1, guided by the PRISMA-ScR flowchart¹³.

After reading, in full, the 18 texts included were analyzed, organized and presented below in two topics as results.

RESULTS AND DISCUSSIONS

GENERAL CHARACTERISTICS OF PUBLICATIONS

As for the year of publication, the 18 selected articles were concentrated in the period 2004-2020, with greater frequency in the last five years (11 articles), as shown in Table 1.

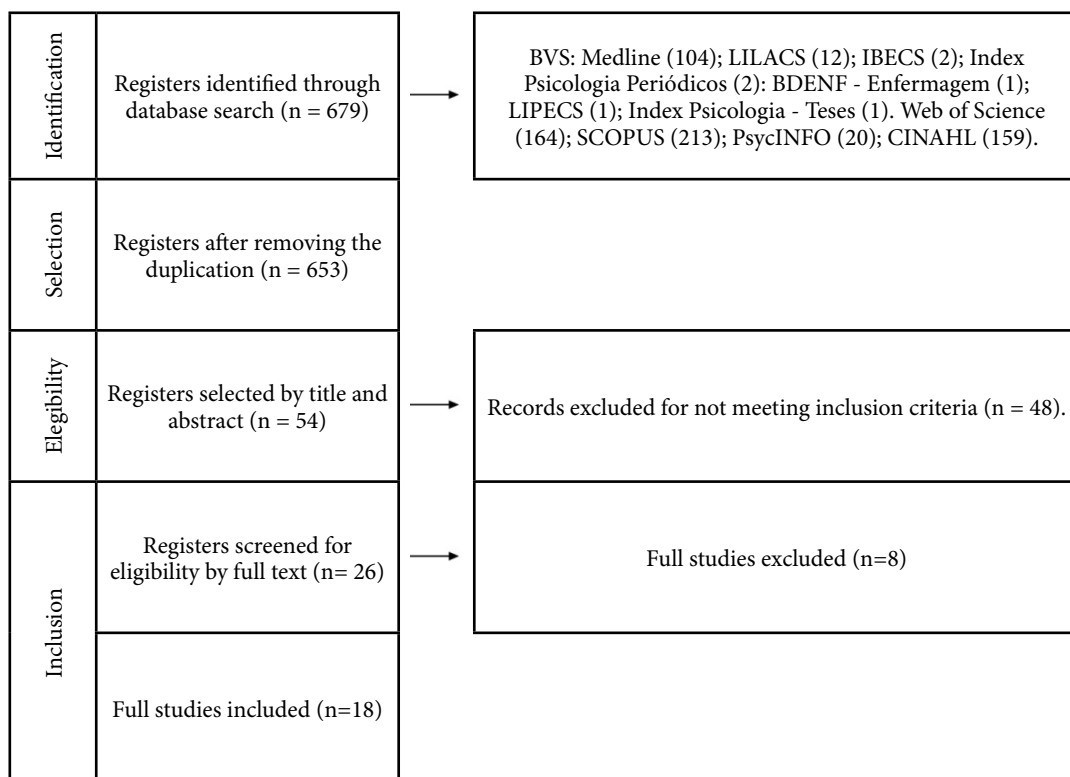


Figure 1- Flow of the publication selection process, according to PRISMA-ScR.

Year	2004	2008	2012	2013	2014	2015	2016	2017	2018	2019	2020
Number of publications	01	01	02	01	01	02	04	02	02	01	01
Total	18										

Table 1 – Distribution of texts by year of publication.

Source: Own elaboration (2022).

The greater number of publications in the last five years may be related to the evidence of beneficial effects on the health of sick people who exercised writing, motivating new studies¹⁴; increase in blogs written by young people with severe illness¹⁵ (nine articles found).

Regarding the area of knowledge, Nursing predominated (10 articles), which has the largest number of workers in the health sector and has care as the main object of training. Subsequently, they were distributed in the areas of medicine (three articles), Communication (two articles), Psychology (two articles) and one without information.

Regarding the places of production, there is diversity with a concentration in North America, specifically in the United States of America (nine texts), with the others distributed in Europe (four articles), Oceania (three articles) and Asia (one article). It was in the North American context, in the 1980, that James Pennebaker developed the Expressive Writing Paradigm¹⁶, advocating that inhibiting feelings about traumatic events requires great effort on the body and accumulation of stress, compromising the immune system and causing disease, but writing for 15 to 30 minutes for three to five days about these traumas helps to understand them contributing to better health. Through their studies, Pennebaker et al. presented evidence of positive health outcomes^{17,18} and may have influenced the interest and

development of research and publications on writing and health.

Regarding the age group of the participants, the texts are distributed as follows: six were, specifically, with people aged between 12 and 29 years and 12 texts that covered other age groups that include and extrapolate this limit: nine to 16 years; 20 to 39 years old; 15 to 34 years old; 18 to 30 years old; 23 to 34 years old; 25 to 34 years old; 27 to 70 years; 18 to 75 years old; and 25 to 84 years. We chose to include these texts because they cover the age group of interest (12 to 29 years old) and because of the relevance of the studies to the proposed objective. It is noteworthy that most of the selected texts originate in the USA, which defines as cancer in youth that occurring between 15 and 39 years old¹⁹.

As for the sex of study participants, the female was unanimous in the 18 publications. Not exclusively, the masculine appeared together with the feminine in 11 articles^{20,21,22,23,24,25,26,27,28,29,30} following the trend of other studies related to males and difficulty expressing emotions^{29,31}, but that writing can help.

The types of writing were grouped into two categories: 1) creative writing (poetry, writing and comics), 2) expressive writing and narratives in cyberspace (blog) that appeared as a data source in 12 of the analyzed publications, possibly driven by the internet 2.0, diffusion of social media and the cheapening of digital technologies

that favored the dissemination and sharing of contents of everyday intimacy³².

Among the texts there are analyzes of posthumous material: five blogs (from 15 to 17 years old and three from 25 to 39 years old) and poetry (28 years old)^{15,33,34}. The handling of personal digital collection refers to discussions about Digital Heritage as goods, with and without economic valuation³⁵, that has been raising broad reflections, debates and the need for legislation that regulates its destiny³⁶, including the deceased person's wishes and impacts to their image³⁷.

As for the themes, we identified the central focuses of the publications that were categorized and organized into two sub-items, as follows.

WRITING AND EXPRESSION OF EMOTIONS IN THE FACE OF LOSS AND IMMINENCE OF DEATH

We found publications in which writing was an outlet for emotions^{21,23,27,28,30,38,39} such as creative writing (in comics) and blogs, enabling young people to communicate aspects of their experience by talking about their dreams, projects, fears, concerns and uncertainties regarding the future^{22,29,34}, in addition to enabling a greater understanding of the illness, helping to deal with and reduce symptoms of anxiety during hospitalization for the treatment of cancer^{21,26, 27,40}.

Another set of texts highlights the remarkable losses and the concrete proximity of death from the experience of becoming ill with cancer^{24,25,41,42} as an inexorable outcome in the face of the exhaustion of therapeutic possibilities. A sense of urgency can be glimpsed in the writings to complete and resize life projects, since the finite time that runs out is precious, and must be lived to the fullest and intensely^{24,25,42}.

Notably, the plasticity of projects treated by Gilberto Velho through the concept of

metamorphosis, embeds reflexivity and a certain negotiation in comparison with a field of possibilities⁴³ the case, ascribed by the illness with greater appreciation of the quality of time. He adds to Viktor Frankl⁴⁴ when he states that the human being has interior freedom that makes it possible, even in conditions of great suffering, to develop the ability to reconfigure his life and assume an alternative attitude in the face of given conditions. Similarly, comparing blog posts from terminally ill patients with cancer or amyotrophic lateral sclerosis with those from healthy people, a study found that the narratives of the sick had less negative content regarding the proximity of death⁴⁵.

As an autobiographical project, the sick person who writes about his condition records details of the processes that influence subjectivity when finding a place to tell about his suffering, so that writing gives clues and indications of who the author is and the transformations in the face of illness⁸, marking the experience. However, writings go through filters in which the author decides (always provisionally) what is or is not important to share, being able to review and change decisions and reports according to the reinterpretations undertaken in the midst of the contextual dynamics of the moment and in comparison with personal projects.

In addition to mitigating negative emotional impacts and, consequently, the experience of living with cancer, the resource of writing, although restricted to literate people, is easy to apply, not costly, helps in freer expression, with lightness and beauty in the historical context. and symbolically, nefarious cancer^{29,41}.

WRITING AND SOCIALITY

In these texts, writing is a means of connecting people^{15,2,23,28,35,46} taking into

consideration, the significant disturbances in building and sustaining relationships, provided by the daily repercussions of illness and cancer treatment⁴⁶.

Interactions through blogs stand out, in the wake of the Nativos Digital 2.0 Generation, with important socialization in digital spaces where they share intimacies^{47,48} and other aspects of everyday experience (such as being chronically ill), favored by the supposed anonymity for people with difficulties expressing emotions face-to-face²².

In cyberspace the boundaries between public and private are blurred⁴⁹ even more, operating a game of exposure and concealment in the management of the image, identity, and the spectacularization of the personality⁴⁹ or lived condition may occur, molded to the intended audience. It is inherent to the virtual spaces of sociability the positive (likes) and negative (haters) manifestations protected by supposed invisibility. Likewise, the appeal to solidarity and assistance (receiving money from several friends to pay for a product, through virtual means), common in the case of afflictions and suffering (as in diseases), can mobilize collaboration, but also fraud with fake profiles. or misappropriated. In the blogs of young people with similar characteristics and conditions, their writings^{21,48}, they can function as sources of support (technical, affective, political, etc.), reduce isolation and form bonds and self-managed communities. This support refers to what Tronto⁹ (p. 288) addresses how to “take care of, care for” showing that care is not restricted to complex actions, it can be offered in the simplicity of a text that embraces the Other.

Such groupings can be formalized in associations of people with cancer, mediated by writing^{23,30,33,46}. This identification by biographies with common illness, for example, approximates the notion of

biosociality treated by Paul Rabinow⁵⁰ referring to groups gathered to talk about their experiences, share stories and traditions about issues of living with a given common biological or nosological condition.

Finally, there are humorous writings that invite readers to participate in comic stories, ironically inscribed in the outlines of the illness experience, full of difficulties and uncertainties⁴⁶. The expression of humor in laughter has a social function and the potential to soften the mechanical rigidity of society with rigid norms that repress the flexibility of life⁵¹. To laugh at a situation that normally requires seriousness, is an intellectual and not an emotional attitude, so we are able to transform dramas into comedies if we anesthetize emotion for a moment⁵¹. Nevertheless, the writings do not fail to show the difficulties of young people to obtain health care, palliative care and get a job after treatment⁴⁶. Finally, the use of humor in writing has the effect of deconstructing and disturbing the normalized senses and expectations about people with cancer, making it possible to share the experience from a different perspective.

CONCLUSIONS

Although with some incipience in the health area, the analyzed publications awaken to the importance of writing as a way for young people to star in their history and not be passive extras of an uncertain path and certain destination represented by the early death of cancer, and the reflections can extend to other illnesses, keeping the specifics.

Writing in virtual space can add political power by shifting illness to the public space, making visible the procedural, relational and contextualized character of care with the potential for engagement and activism for social rights. They pressure, thus calling

attention to the construction of democratic care, recognizing that the responsibility for providing it must be shared and assumed collectively⁵², in refusal to limit it to the private sphere by individualizing it or relegating it to the family.

The imminence of early death tinges the texts with uncertainties, fear and anxiety about the future²⁵ corroborating Norbert Elias⁴² for whom it is not death but the knowledge about its proximity that anguishes the human being. However, the consciousness of death may not immobilize, but encourage for agencies and resizing of the future and respective projects.

More than a means of expression, writing brings evidence of personal, social, existential and contextual representations that mark the paths of life, of falling ill and dying in youth, providing opportunities for health professionals (assistance, management) to approach the experience of falling ill due to cancer and shape sensitive care to better meet the needs of people⁵³, corroborating what Tronto says⁹ for whom, caring involves the willingness to recognize, first, the need for care.

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