



Writing cancer

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Abstract

Purpose Novels and autopathographies that employ cancer as a central theme offer a wealth of opportunities for researching the way patients with cancer make sense of their illness and its treatment. Such literatures can also inform clinical care, because they can support patients in living with their illness. The use of novels and autopathographies for research and care in persons with cancer fits within the framework of ‘Health Humanities’, the interdisciplinary field where medicine and social science meet. This paper presents a concise overview of novels and autopathographies that explore cancer as their theme.

Methods Literature searches were conducted using PubMed, major scientific journals of medicine and clinical oncology, and databases in the Health Humanities. Searches focused on novels and autopathographies where cancer is the central theme, which are available in English, and which can be considered to represent ‘high literature’.

Results Twenty-nine books were identified. The majority of the books were written originally in English, and breast cancer and lung cancer were the most frequently discussed types of cancer. The core themes identified were giving meaning to illness; coping with medical treatment; and the psychological and social consequences of illness.

Conclusion Novels and autopathographies about cancer represent an innovative base for research on living with cancer and offer rich data on how people make sense of cancer and its medical treatment. Clinical implications of this review pertain to interventions based on bibliotherapy and expressive writing. Novels and autopathographies are just part of the Health Humanities context: a wide range of art genres may prove helpful in improving the quality of life of persons with cancer.

Keywords Art · Bibliotherapy · Expressive writing · Health humanities · Novels · Patient-reported outcomes

Introduction

Cancer is tragic. The diagnosis ‘cancer’ initiates a set of usually invasive further diagnostic procedures and therapeutic activities. The illness ‘cancer’ elicits a tsunami of behavioral, psychological, and social consequences, for the person afflicted and for his or her social environment. The tragedy of cancer impacts also the professionals—physicians, nurses, psychologists, and others—who provide their care. Acknowledging the gains made in medical management of cancer, the disease cancer still elicits very major psychosocial problems in the patients afflicted. Major journals in the area of oncology focus on living with cancer (e.g., *Psycho-oncology*, *Supportive Care in Cancer*) or provide a small but stable niche in which the subject can be explored (e.g., *JAMA Oncology*

[“Cancer Care Chronicles”], *Lancet Oncology* [“Cancer and Society”], and *Journal of Clinical Oncology* [“Art of Oncology”]). Often profound and heartrending, the contents of such venues attest to the tragedy for all those involved.

Medical care aims to reduce and alleviate the tragedy of cancer, with methods that are usually designated as ‘biomedical’: namely, chemotherapy, radiotherapy, and surgery. However, the reduction and alleviation of suffering will remain incomplete without additional ingenuity. The concept of ‘biopsychosocial care’ comes into focus here. In oncology research and clinical care, concepts such as quality of life, patient-reported outcomes, value-based health care, coping, self-management, sexuality, cognitive-behavioral therapy, and palliative care have all reached establishment status over the past decades, due to the increasingly strong voice of persons with cancer who emphasize the importance of diagnosing and managing their illness’s psychological and social consequences. Given the support of medical professionals and their professional organizations for this development, the tragedy of cancer is increasingly being approached within a biopsychosocial context [1–3].

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‘*Medical Humanities*’ is a term that offers a critical scientific context for research and clinical work in this area. Medical Humanities can be defined as ‘the interdisciplinary field of humanities (literature, philosophy, ethics, history and religion), social science (anthropology, cultural studies, psychology, sociology), and the arts (literature, theater, film, multimedia and visual arts) and their application to healthcare education and practice’ (www.medhum.med.nyu.edu). Given the increasing contribution of non-medical professionals to this field, a newer term—‘*Health Humanities*’—has recently been presented as a more modern and relevant label [4, 5]. A major contributor to the Health Humanities, Arthur W. Frank, uses the metaphors of ‘giving patients voice lessons’ [6, 7] and ‘encouraging the formation of a narrative’ [8]—both operationalizations of Health Humanities on the patient’s level.

In addition to scientific journals that focus explicitly and exclusively on Health/Medical Humanities (e.g., *Journal of Medical Humanities*; *Medical Humanities*; *Hektoen International*), medical journals regularly devote attention to Health Humanities topics. Examples include *Annals of Internal Medicine* [‘On being a doctor’]; *British Journal of Psychiatry* [‘Psychiatry in literature, novels’]; *Chest* [‘Pectoriloquy’]; *CMAJ* [‘Humanities’]; *JAMA* [‘Art in Medicine’]; *Journal of Clinical Oncology* [‘Art of Oncology’]; *Läkartidningen* [Swedish Journal of Medicine; ‘Kultur’]; and *Medisch Contact* [Dutch Journal of Medicine; ‘Boeken en films’]. In the German language, von Engelhardt provides an invaluable stream of papers and books on Literature and Medicine [9]. In French, Hoerni focusses on Literature and Medicine in oncology [10]. In Dutch, the journal *Medische Oncologie* publishes the column ‘Healing words’, which reviews novels and poems about living with cancer.

While Health/Medical Humanities is a relative newcomer in the medical arena, its intellectual roots can be traced back to the theoretical bases of more mature fields, such as (medical) anthropology, (medical) sociology, (medical) psychology, and literary theory [11]. The art genres of novel, poem, film, painting, and music offer empirical material for scientific analysis and clinical applications in this domain. (The genres of dance, theatre, and sculpting seem not yet sufficiently present in medicine to allow the analysis of relevant empirical scholarship [12].) Given the empirical literature available, the present essay focuses on the genre of *writing* as a source of value for patients with cancer, as well as for their caregivers and health care providers [11].

The therapeutic use of *writing* in a passive way—such as by asking a person with cancer to read novels—is often referred to as ‘*bibliotherapy*’: the use of novels, autopathographies, or illness narratives to offer a means of make sense of, and coping with, their condition. In one particularly innovative study, bibliotherapy was explored in a sample of persons with chronic pain [13]. In this study,

participants in an experimental condition engaged in ‘*shared reading*’ in addition to standard cognitive-behavioural therapy. This involved them in group settings where they read relevant fiction and poetry aloud, helping them to become immersed in a live experience of pain and related sensations. Their experiences were then compared to those of participants in a control condition, who received standard cognitive-behavioural therapy on its own. Qualitative analyses indicated that ‘*shared reading*’ led to improvements in mood and pain levels over cognitive-behavioural therapy alone. Such ‘*shared reading*’ approaches are easily implemented in a wide range of contexts and have been studied in groups as diverse as women prisoners and persons with dementia [14, 15].

The therapeutic use of writing in a more active way—often based on ‘*expressive writing*’—requires the person with cancer to write their own texts describing their personal experiences, aiming to help them better recognize and understand their perceptions, feelings, and responses in relation to illness [16, 17]. ‘*Autopathography*’ is the written account by a patient of his/her coping with disease and its impact on daily life [18]. This biomedical term is increasingly being replaced by ‘*illness narrative*’, which emphasizes the patient’s subjective construction of their illness and its psychosocial concomitants [6, 19]. Table 1 summarizes the four systematic reviews of expressive writing and the two reviews of bibliotherapy.

Methods

Literature searches were conducted using PubMed, major scientific journals of medicine and clinical oncology, and databases in the Health Humanities. Searches focused on novels and autopathographies where cancer is the central theme, which are available in English, and which can be considered to represent ‘high literature’.

PubMed searches for variations of the terms ‘Novels and cancer’, ‘Bibliotherapy and cancer’, and ‘Expressive writing and cancer’ were used to identify relevant papers, along with corresponding searches of the database of New York University Langone Health (www.medhum.med.nyu.edu). German and French novels on cancer were drawn from Von Engelhardt and Hoerni, respectively, as well as from personal files relating to the literature on cancer novels [9, 10]. The focus of these searches was mainly on papers published since 2015.

Results

The provision of written information on how to cope with cancer has been explored in a number of studies. *Bibliotherapy* in a literal sense—‘the prescribing of books’—nowadays appears to have become focused on

Table 1 Summary of systematic reviews of expressive writing research in adults with cancer ($n = 4$) and empirical studies of bibliotherapy in adults with cancer ($n = 2$)

First author, ^{ref} year, country	N patients (min = minimum, max = maximum), diagnosis, N sessions	Design	N studies	Results
Kupeli [20] 2019, UK	Min $n = 24$, max $n = 86$, all cancer types, 4 sessions	Systematic review	4	Anxiety, depression, and fatigue ↓ Sleep quality: ↑
Merz [21] 2014, USA	Min $n = 30$, max $n = 507$, all cancer types, 1–4 sessions	Systematic review	13	Pain, ↓ QOL ↓
Zachariae [22] 2015, DK	Min $n = 30$, max $n = 507$, all cancer types, 1–4 sessions	Systematic review and meta-analysis	16	Moderate effects of social constraints: low emotional support, more benefits
Zhou [23] 2015, CHI	Min $n = 39$, max $n = 507$, all cancer types, 1–4 sessions	Systematic review and meta-analysis	11	
Korner [24] 2019, CAN	$n = 89$, all cancer types	RCT	1	Empowerment, QOL↑
Malibiran [25] 2018, USA	Not reported, all cancer types	‘Integrative literature review’, qualitative data analysis	6	All studies reported beneficial effects: reduced anxiety, depression, improved coping

CAN, Canada; USA, United States of America; UK, United Kingdom; DK, Denmark; CHI, China; QOL, quality of life

eHealth information, where patients are digitally advised about giving meaning to cancer and ways to cope with the various phases of the illness trajectory. One literature review concludes that ‘patients with cancer benefit from bibliotherapy’ and that ‘stress reduction, relief of anxiety and depression, and effective coping are the most frequently patient-reported outcomes of bibliotherapy’ [25]. A recent randomized controlled trial assessing the efficacy of a self-administered bibliotherapy intervention for patients with cancer found that the degree of empowerment and quality of life increased, while distress decreased significantly [24, 26].

The empirical evidence for expressive writing has been the object of study in a fairly large number of (review) studies. One such systematic review concludes that there were ‘several main effects for expressive writing on sleep, pain, and general physical and psychological symptoms,’ although the authors acknowledged that there were methodological weaknesses in much of the relevant research [20, 21]. Expressive writing for caregivers of persons with cancer has also been examined, with a recent study concluding that it ‘can be a safe and cost-effective supportive intervention for caregivers of patients with cancer’ [22, 23, 27, 28].

The genre of graphic novels is a relatively new genre: ‘a form of visual storytelling that explores narratives of the body, health care, healing and disability’ (www.graphicmedicine.org) [29, 30]. At least one highly respected biomedical journal, the *Annals of Internal Medicine*, publishes summaries of graphic novels in each issue, to illustrate the potential utility and importance of graphic medicine. Such a genre of novel could provide a further bridge between empirical research in Health Humanities and clinical applications for persons with cancer, especially for younger patients.

Table 2 lists a number of novels, graphic novels, and illness narratives where cancer plays a more or less central role, illustrating the potential for wide-ranging bibliotherapy applications (in which patients might benefit from reading the publications listed) and resources for expressive writing interventions (as the illness narratives in particular seem to represent expressive writing by authors who themselves suffered cancer).

Teaching

A few decades ago, it became common for physicians—general practitioners, family physicians, and psychiatrists in particular—to suggest novels for their medical students to read. The feeling was that such novels would represent didactic material from which trainees could learn about ‘living with’ an illness. The assumption of these physicians, who quite often were associated with departments in medical schools, was that reading novels (about cancer) would improve the clinical and interpersonal skills of future clinicians. Studies that review this area provide a basis for some cautious optimism about this prediction [31].

At the same time, however, two Finnish authors who used *The Black Swan* by Thomas Mann in the hope of teaching their medical students about coping, quality of life, and living with cancer were shocked to find that the students instead became embroiled in figuring out the ‘correct’ diagnosis for the novel’s protagonist. Rather than reflect on her suffering and death due to ovarian cancer, they chose to focus on matters of ‘disease’ rather than ‘illness’ [32]. Such findings not only highlight the pitfalls of merely recommending texts to students but also provide insight into the possible themes that

Table 2 Novels, illness narratives, graphic novels, and poems regarding living with cancer: author, year of publication, title, nationality of author, and theme of publication

Simone de Beauvoir, 1964	Une mort très douce (A very easy death)	French	Daughter's story of her mother dying
Anne Boyer, 2019	The undying	American	Illness narrative about living with breast cancer
Anatole Broyard, 1992	Intoxicated by my illness	American	Illness narrative about his living with prostate cancer
Raymond Carver, 1989	What the doctor said	American	Poem about coping with lung cancer
John Diamond, 1999	C - Because cowards get cancer too	English	Illness narrative about his living with head-neck cancer
Jenny Diski, 2016	In gratitude	English	Illness narrative about coping with her lung cancer
Margaret Edson, 1999	Wit	American	Novel/play about patient who dies due to ovarian carcinoma, and her struggles with MDs
Brian Fies, 2004	Mom's Cancer	American	Graphic novel by son of mother 's coping with her lung cancer
Arthur Frank, 2002	At the will of the body	Canadian	Illness narrative about his cancer
Élisabeth Gille, 1994	The crab at the back seat	French	Illness narrative about her life with lung cancer
Lars Gustafsson, 1981	Death of a beekeeper	Swedish	Novel about man living with dying of cancer
Christopher Hitchens, 2012	Mortality	English	Illness narrative about his life with esophageal carcinoma
Masuji Ibuse, 1965	Black rain	Japanese	Novel about living and dying with cancer due to radiation sickness
Paul Kalanithi, 2016	When breath becomes air	American	Illness narrative by an MD dying because of lung cancer
Frigyes Karinthy, 1936	A journey round my skull	Hungarian	Illness narrative about living with brain tumor
Sander Kollaard, 2015	Stage IV	Dutch	Interactions between man and wife about her lung cancer
Thomas Mann, 1952	The black swan	German	Novel about woman dying of ovarian cancer
Marisa Marchetto, 2006	Cancer vixen	American	Illness narrative in a graphic novel about breast cancer
Lieke Marsman, 2018	The next scan takes five minutes	Dutch	Illness narrative about young woman with cancer
Carson McCullers, 1961	Clock without hands	American	Novel about man dying because of leukemia
Robert Murphy, 1987	The body silent	American	Illness narrative about living with tumor in spinal cord
Gerhard Nijhof, 2018	Sickness work	Dutch	Researcher of illness faces cancer himself
Paget, 1993	A complex sorrow	American	Illness narrative and novel about coping with cancer
Philip Roth, 1991	Patrimony	American	Novel about son and his dying father
Aleksandr Solzhenitsyn, 1966	Cancer ward	Russian	Cancer in a Russian hospital
Susan Sontag, 1978	Illness as metaphor	American	Images of cancer in societies
Verena Stefan, 2007	Fremdschlaefer (Rough sleepers)	Swiss	Novel about refugees and their cancer careers
Leo Tolstoy, 1886	The death of Ivan Ilyich	Russian	Novel on sense making while ill due to cancer
John Updike, 2009	Endpoint	American	Lung cancer poem "Bronchoscopy"
Judith Vanistendael, 2013	When David lost his voice	Belgian	Graphic novel about a man dying because of larynx carcinoma
Fritz Zorn, 1982	Mars	Swiss	Novel/ illness narrative about living with head-neck cancer

a *discussion* of such texts could open up in a medical training context.

In the view of the present author, based on reflection and scrutiny of the empirical work on Health Humanities, two somewhat provocative and prescribing applications assert themselves: all medical students should read at least three novels given in Table 1; and no oncologist should be allowed to take care of persons with cancer without having read the novel *Cancer Ward*, by Aleksandr Solzhenitsyn. This book may be characterized as the novel that encompasses the biopsychosocial representation of all phases and aspects of cancer in humans, with ample (and moving) depictions of the implications of cancer for patients, health care providers, caregivers, and society at large.

Discussion

Ultimately, as with all areas of medicine, it is possible to conceive of an 'art' of oncology. This art of oncology supports a major domain of scientific research, as can be concluded from the empirical work presented above. Furthermore, this research to date has produced a wealth of clinically valuable implications. *Reading, writing, listening, and watching* are modalities that have yielded a rich tableau of scientific, intellectual, and clinically applicable accomplishments. Patients with cancer stand to derive benefit—in psychological and social terms—from reading and writing about cancer. Literature can help them in enduring invasive and painful medical procedures, while improving their quality of life.

Researchers have examined an increasing range of genres of art and their potential contribution to the well-being of patients with cancer. Examples include theatre, film, music, and painting. In a memorable study of patients with metastatic breast cancer, patients and health care providers were facilitated in transforming their experiences of illness and its management into short dramatic productions [33, 34]. The authors' book, 'Standing ovation', discusses the value of dramatic performance as a genre of art suitable for social science research in persons with cancer [35].

In recent years, a diverse range of art genres, and their application to persons with cancer, have been explored in empirical studies, for example music [36]; singing [37]; music therapy [38]; painting [39]; photography [40]; film [41]; and dance [42]; for reviews, see [43, 44].

A number of recent papers highlight the potentially major benefit even in terms of the survival in persons with cancer whose illness and symptoms are *monitored*; in other words, those whose narratives are acknowledged and recorded [45–47]. This prospect requires further study but does echo a significant theme of Health Humanities: bibliotherapy and expressive writing about cancer offers clinicians the opportunity not only to enrich their patients' lives but also to monitor their symptoms. Listening to a patient's story, to their illness narrative, helps persons with cancer to cope with their illness and its medical treatment—with potential positive effects on survival. Paying systematic and dedicated attention to *patient-reported outcomes* (PRO) may help health care providers in optimizing medical management for persons with cancer. Health Humanities is central to mitigating the tragedy of cancer and, for many, could be as important and meaningful as 'regular' medical treatment.

The selection and analysis of the novels selected must be considered a potential limitation of this paper: other authors select different novels. Nevertheless, the themes in virtually all novels (and 'autopathographies') with cancer as its core theme depict similar representations of living (and dying) with cancer.

Clinical implications pertain to suggestions about education for students of medicine and related professions. Incorporating 'health humanities' into their curriculum might translate into improvements in the quality of life for patients and their caregivers [48–50]. This might also impact the quality of life of health care professionals.

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