Quality of care: Distress, health care use and needs of women with breast cancer

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Cancer in full-colour: Use of a graphic novel to identify distress in women with breast cancer

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Abstract

The graphic novel *Cancer Vixen* about breast cancer was used as an example to examine whether reading of graphic novels may enhance insight in illness experiences. Content analysis showed that the graphic novel depicts the full range of distress, by portraying practical, social, emotional, religious/spiritual and physical problems. Findings were illustrated with descriptions from the book. The results indicate that – from a content perspective – this graphic novel may be of value in medical education and health psychology settings to teach students and patients about the human side of being ill.
Introduction

Medical education and health psychology are facing the era of multiliteracy. Thanks to new information technologies, people communicate through combinations of text, images, sound, gestures, and movements instead of mainly printed text only. An emerging product in these ‘New Times’ is the graphic novel, which combines prose and pictures in a comic-book narrative (c.f.).

As a narrative, the graphic novel can be placed within the humanistic, narrative perspective. According to this perspective, the process of storymaking is part of our daily thinking: we constantly create coherent storylines to organize the world around us. By doing so, we aim to gain further insight into our identities and experiences within the social context we live in. The manner in which we choose to convey our stories may differ, from for example oral communication to communication through visual art work and onstage performances. In the case of the graphic novel, the narrative is presented in print. Images and text are to be read together. This results in a multimodal experience that differs from either reading or seeing.

Compared to text novels, the combination of images and text in graphic novels facilitates identification with characters in the book. Also, this combination leads to better cognitive understanding due to simultaneous activation of visual image and text processing areas in the brain. Graphic novels appeal to children, teenagers and adults, as attested by a growing demand in shops, book clubs, and libraries. According to some people, there may even come a day that the graphic novel replaces the novel as the literary form of choice thanks to its visual allure and the shorter attention span required.

Graphic novels have the potential to be used in medical education and health psychology, just as literary novels and poems are used. It has been established that the more traditional forms of literature offer insight into the
‘human side of medicine’ – as opposed to objective, empirical ‘cold’ science\textsuperscript{18,19}. Use of novels, for example about suffering, physician-patient encounters, or coping with illness, may improve understanding of and ideas about patients’ health, illness and disease. Additionally, courses on literature and medicine may enhance medical students’ capacity for empathy\textsuperscript{20,21}, increase their observation, interpersonal and narrative skills\textsuperscript{20,22}, and stimulate reflection on personal values within clinical practice\textsuperscript{22-24}. Within health psychology, literature may be used to help patients cope with their own illness (e.g.,\textsuperscript{25}). Strategic adaptations of an existing novel have proven to positively influence patients’ health attitudes (e.g.,\textsuperscript{26}), opening the path for health psychologists to write fiction that influences health behaviours\textsuperscript{18} (see\textsuperscript{27-30} for examples of how other art forms are used in medical education or health and clinical psychology settings).

The use of graphic novels alongside novels and poems may be an original approach to educate medical students, patients or patients’ relatives and friends. Patients may feel more in control and less lonely if they read a graphic novel about the experiences of a fellow patient, and discuss arising questions with their physician\textsuperscript{17}. At least some patients are attracted to the visually oriented genre, as is apparent from the increasing demand for the genre, and postings on patient fora on the internet (e.g., breastcancercare.org.uk/forum; doc2doc.bmj.com/forums). In addition, for patients and patients’ relatives and friends who are less text-literate or more multi-literate oriented, graphic novels and other multimodal material may be their choice of preference\textsuperscript{9,31,32}.

There are a number of comics and graphic novels that were intentionally developed for health educational purposes. For example, in Brazil a series of comics was created to inform the general population and diabetic patients about diabetes and diabetes treatment regulations\textsuperscript{33} (see for other examples;\textsuperscript{34-37}).
A smaller number of studies provide examples of the use of existing graphic novels in medical education and health education of patients. With regard to the latter studies, we need more knowledge about the extent to which reading of graphic novels may enhance insight in illness experiences. More specifically, up to now we lack information about the types of patient experiences in which graphic novels may provide insight. Such knowledge allows tailored use of graphic novels to achieve specific educational goals.

Content analysis of graphic novels is a new area of research. Therefore, as a first systematic exploration, the current study examined which illness experiences are depicted in a single graphic novel (see an example of a study that examines occurrence of illness perceptions in a traditional novel). For the current study we selected a graphic novel that addresses breast cancer, as this is the most frequently diagnosed cancer among women, and the leading cause of cancer death in women worldwide. We refer to the Method section for a description of the selected graphic novel, and a rationale why we chose to analyse this specific graphic novel.

Framework and objectives

The illness experiences in our selected graphic novel about breast cancer were identified by use of the concept of distress. Distress is defined as ‘a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment’. The multifactorial nature of distress made this concept particularly equipped to examine a wide range of illness experiences.

Our primary objective was to determine which illness experiences were portrayed in the graphic novel about breast cancer. As a secondary objective, we
wanted to illustrate the results by providing examples of the manner in which frequently depicted illness experiences were portrayed. Practically, teachers may use these examples as a starting point for class discussions about the graphic novel.

Given the framework of distress, the following research questions were addressed:

1. Which distress-related problems are portrayed in a contemporary graphic novel about breast cancer?
2. Which of these distress-related problems are most frequently portrayed, and what are examples of the manner in which these problems are portrayed?

Method

Database

Our graphic novel of choice was Cancer Vixen, a graphic memoir of a 43-year old fashionista and cartoonist in New York who discovers that she has early stage breast cancer. The graphic novel portrays the main character experiences during the disease trajectory, from diagnosis to the end of treatment.

The book shows how the main character receives surgery, chemo- and radiotherapy. She has encounters with a wide range of care providers, among whom a radiologist, an oncologist, a nutritionist, a nurse, a psychiatrist, a pseudo doctor, a priest and a rabbi. But the book shows us more than that. We see, for example, the main character’s anxiety as she is waiting for the diagnosis, her struggle with the side effects of the treatments, her anxiety and anger during the treatment phase, and her grief when she realizes that it will not be possible for her to have children due to her age in combination with the type of treatment received.
Coping with cancer is just one of the main character’s challenges. She is diagnosed three weeks before her wedding with a famous restaurateur. She has to deal with the problem that her health insurance has expired, and with the well-meant but sometimes confusing advice of her family and friends. In the meantime, she tries to keep up her normal work and social activities in Manhattan.

In the end, the main character gets married, and the insurance problem gets solved. She survives the breast cancer. Then she has to face a new type of anxiety, the fear of cancer recurrence. The main character indicates that the experience has changed her perspective on life and will keep influencing her spiritual and emotional development (see also 41,42).

We selected Cancer Vixen for this study because it is a well-known graphic novel, which has been translated into several languages (e.g., in Spanish, French (as ‘Cancer and the City’) and Dutch (as ‘Chemogirl’)). Also, it is the only full-colour graphic novel about breast cancer that we have been able to trace. The content of the graphic novel is praised for its effective use of combining prose and pictures in ways that text only could not 41 – which made it promising to examine as an example of the graphic novel. Furthermore, this graphic novel is praised for its attention for medical details and the social consequences of having cancer 41.

We learned from online accounts that there are breast cancer patients who like the book and recommend it to fellow patients (e.g. www.deamazones.nl/phpbbforum). There are also reports that Cancer Vixen is used in medical educational settings to teach students about the importance of proper physician–patient communication 43.

We would like to point out that Cancer Vixen did not only receive praise. Some reviewers have criticized the graphic novel for its ‘obsession with brand
names, skinniness, and the ins and outs of the celebrity media/culture’ 41: p.16), others for the intense use of colours and font sizes 44. It has also been postulated that some readers may find it hard to relate to the extraordinary lifestyle of the main character 41,45. However, reviewers seemed to agree that this graphic novel provides more than a shallow story, thanks to the personal and medical details provided.

**Procedure**

The first two authors (DL and AB) individually read *Cancer Vixen*, and identified every occurrence of a distress-related problem along the way by use of a standardized list. More information about this list is provided in the next paragraph.

For every occurrence of a distress-related problem, the type of problem was registered, along with the page number and a short description to be able to retrace the findings. If the same problem was portrayed in a continuous sequence of images, this would count as one occurrence. If the same problem was portrayed in a non-continuous sequence of images, i.e., if a problem was described twice in two different settings, this would count as two occurrences. To support reliability, the two authors discussed their findings together. Disagreements about the occurrence or non-occurrence of problems were resolved through discussion/negotiated consensus.

The first author calculated how many times each problem occurred. Problems that occurred at least once, were identified (research question 1). Subsequently, the first author selected the five distress-related problems that were most frequently portrayed – the choice to select five problems was arbitrary. Examples were sought to illustrate how these five problems were depicted in the graphic novel (research question 2).
Measure

Distress-related problems in the graphic novel were identified through close-reading of the graphic novel, guided by the Dutch version of the Problem List\textsuperscript{40,46}. The Problem List is a questionnaire that often accompanies the Distress Thermometer, a screening instrument to detect cancer patients’ level of distress (reference for both questionnaires: \textsuperscript{40}). For the current study, only the Problem List was relevant.

The Dutch version of the Problem List identifies 47 distress-related problems across five life domains: the practical, family/social, emotional, religious/spiritual, and physical domain (answer categories for presence of problems: yes/no; no quantifications required). Thus, the Problem List represents a comprehensive range of problems that a cancer patient may encounter during the disease trajectory. In addition, the Problem List contains an open-ended text field to register other, additional problems. There is a final question in the Problem List, in which a patient is asked whether he or she would like to talk about his/her problems. This final question was not relevant within the scope of this paper.

The National Comprehensive Cancer Network in the United States recommends use of the Distress Thermometer and Problem List to assess the level of distress, and the occurrence of distress-related problems\textsuperscript{40}. The questionnaires have been validated in the Netherlands\textsuperscript{46}. With regard to the Problem List, validity of the Dutch version has been ensured by involving the following focus groups: medical specialists, oncology nurses, social workers, psychologists, pastoral counsellors, physical therapists, dieticians, and representatives from patient associations. Based on their recommendations, the original 35-item questionnaire was adapted to a Dutch version with 47 items (Figure 1). The total questionnaire has good internal consistency ($\alpha = 90$; we refer to\textsuperscript{46} for more information).
**Problem List**

Please indicate by checking yes or no if any of the following has been a problem for you in the past week (including today). Be sure to check YES or NO for each.

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Practical problems</th>
<th>Yes</th>
<th>No</th>
<th>Physical problems</th>
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<tbody>
<tr>
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<td>child care</td>
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<td>Family / social problems</td>
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<td>dealing with partner</td>
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<td>dealing with children</td>
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<td>nose dry/congested</td>
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<td></td>
<td></td>
<td>dealing with friends/family</td>
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<td>pain</td>
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<td>Emotional problems</td>
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<td>keep emotions under control</td>
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<td>nausea</td>
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<td>memory</td>
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<td>speech/talking</td>
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<td>self-confidence</td>
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<td>depression</td>
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<td>tingling in hands/feet</td>
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<td>tension/nervousness</td>
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<td>loneliness</td>
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<td>daily activities</td>
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<td>concentration</td>
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<td>fatigue</td>
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<td>feelings of guilt</td>
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<td>out of shape/condition</td>
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<td>loss of control</td>
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<td>muscle strength</td>
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<td>Religious/spiritual concerns</td>
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<td>meaning of life</td>
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<td></td>
<td>trust in God / religion</td>
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Would you like to talk with someone about your problems? Yes / Maybe / No
Results

Identification of distress-related problems

The content analysis showed that each of the five life domains from the Problem List was represented in Cancer Vixen. In total, twenty-two of the 47 predefined distress-related problems were portrayed, as indicated below:

- **Practical problems** – insurance problems, problems with work/school/study;
- **Family/social problems**: problems that involve dealing with a partner, problems that involve dealing with family/friends;
- **Emotional problems** – experiencing intrusions, problems with self-confidence, experiencing fears, experiencing depression, experiencing tension or nervousness, experiencing loneliness, concentration problems, experiencing guilt;
- **Religious problems** – doubts about the meaning of life, problems that relate to one’s trust in God/faith;
- **Physical problems** – having diarrhea, experiencing nausea, experiencing pain, experiencing dizziness or nausea, occurrence of weight change, experiencing fatigue, problems with physical fitness and condition, and problems with muscle strength.

In addition, we identified a number of other problems that could not be categorized with the Dutch version of the Problem List, namely experiencing anger, experiencing worries, having ‘medical menopausal’ problems such as night sweats and hot flashes, and experiencing numbness in the hand.

Top 5 of most frequently portrayed distress-related problems

The five distress-related problems most frequently portrayed in the graphic novel, were: experiencing fears (32 times portrayed), experiencing pain (15 times...
portrayed), having insurance problems (13 times portrayed), experiencing depression (11 times portrayed), and experiencing fatigue (11 times portrayed).

Below, we provide examples of each of these five problems, as illustrations of how distress-related problems are depicted in *Cancer Vixen*.

- **Fear** – Immediately after the main character receives the news of having breast cancer, we see her (as if she is) in space. She is being sucked away from earth with a large vacuum cleaner, into a black hole. Text boxes – the font sizes subsequently become larger – give us insight into the main character’s thoughts. She tells us that she is ‘alone’ and ‘afraid’.

- **Pain** – We zoom in on a part of the main character’s hand when she has her first chemotherapy session. We see the upper half of a needle; the other half has penetrated the skin. The only word is ‘gasp!’, to indicate the shock of the pain. The following, wordless, frame shows a close-up of the main character’s face. She is crying.

- **Insurance problems** – We see the main character telling her fiancé that her insurance has run out, immediately after telling him that she has breast cancer. There is a close-up of her face, full of anxiety, and a thought-balloon that tells us that the main character hopes her relationship will survive this double blow. A narrative text box provides us with the additional information that this disclosure felt like hours to the main character instead of the seconds it actually took.

- **Depression** – We see the main character feeling depressed after telling her friends about the diagnosis. She goes to bed and covers herself with the blankets for five hours (three pages). The picture-panels mainly show the main character’s bedroom, filled with a bed and in the bed, very small, the contours of her head and arms.
Fatigue – We see a full-page flow chart of the main character’s daily energy/fatigue levels between chemotherapy sessions. Little images in the flow chart show us the daily state the main character is in. She goes from feeling like superwoman (day 1), to lying in bed (day 10), to recovery to her normal energy level (day 21), after which the cycle starts over again.

Discussion

The current study showed that the full range of distress is depicted in the graphic novel Cancer Vixen (Marchetto, 2006; research question 1). The five problems that were most frequently portrayed, were experiencing fears, having insurance problems, experiencing pain, experiencing depression, and experiencing fatigue. We provided examples of the manner in which these problems are depicted (research question 2).

There are some studies, though still very few, that addressed the potential of the use of graphic novels in educational settings with medical students and patients. Those studies argued that graphic novels may provide insight into the subjective experience of being ill. Our study substantiates these assertions – with regard to one specific graphic novel. Of course, Cancer Vixen reflects the experiences of a single patient, who had early stage breast cancer, and who received care within the American health care system. It is important to keep in mind that the narrated experiences do not reflect the experiences of every breast cancer patient.

Our results depended on our choice to use distress and the most commonly reported distress-related problems as a framework. We would like to mention that we used the Problem List differently than the manner in which it is used in clinical practice. In practice, a patient consciously chooses which distress-related
experiences qualify as problems and which not, depending on the burden she experiences. In our study every occurrence of an item of the Problem List was listed as being a problem. Therefore, our results may show a far more extensive list of occurring problems than would be identified by a patient – which is acceptable given the objectives of the study.

During our analysis of Cancer Vixen we came across four types of problems that could not be classified according to the pre-described categories of the Dutch version of the Problem List. That is not exceptional: the categories of the Problem List have not been designed to be exhaustive, hence the category ‘other problems’. Although the four types of problems were not pre-defined, they do fit within the scope of the Problem List’s five life domains: experiencing anger, and experiencing worries can be classified as emotional problems, and having ‘menopausal’ problems, and experiencing numbness in the hand can be classified as physical problems.

A limitation of this study is that our results depended on our interpretation of the study material. However, we believe that there is a firm foundation for our conclusion that the full range of distress is represented in Cancer Vixen. Firstly, the analyses in our study were independently performed by two authors, which increased the degree of reliability. Secondly, the identification of the occurrence of some problems was clear-cut thanks to the way that they were described by use of pictures, words, or a combination of both. Third, we hypothesize that portrayal of emotional problems in graphics – up to a certain degree – is derived from the manner in which we express universal basic emotions (e.g.,). Therefore, if someone would replicate our analysis, there would be a reasonable probability that he or she would identify the same emotions.

A second limitation is that we only analysed one graphic novel. We did not review the quality and complexity of Cancer Vixen in comparison to other graphic
novels. Therefore, without further research it is unclear to what extent the results may be extended to (auto)biographical, disease-related graphic novels in general. We would like to invite other researchers to conduct research in this emerging field.

Future studies with more and other graphic novels may investigate other psychological frameworks than distress, including frameworks that address concepts such as benefit-finding and positive experiences (e.g., relief). Furthermore, as indicated by Green and Myers (2010) 17, future research may examine with objective measures whether the aspired goals to influence students’ and patients’ knowledge, skills and/or attitude, are obtained. In line with the research questions of the current study, such studies may examine whether education by use of a graphic novel diminishes patients’ level of distress. Finally, we would like to suggest that future studies not only examine which illness experiences are portrayed, but also how they are portrayed. We know from previous research that comics and graphic novels are based on comic conventions, comparable to ‘grammar rules’ for texts (2 based on 48 and 49; see also 50). For example, a close-up shot in a comic may be used to portray strong emotions, while a long shot may be used to portray distance or feelings of loneliness. It would be interesting to explore whether such comic conventions are applied in graphic novels to portray patient experiences. More insight in the manner in which graphic novels are constructed, may be useful to develop effective graphic educational medical materials or interventions in the future.

Conclusions
The study showed that the graphic novel Cancer Vixen 1 depicts the full range of distress, by portraying practical, social, emotional, religious/spiritual and physical
distress-related problems. The results indicate that – from a content point of view – *Cancer Vixen* may be of value in medical education and health psychology settings to educate students, patients, and patients’ relatives and friends about the human side of having breast cancer. More in general, the study provides an example of how reading of a graphic novel may enhance insight in illness experiences.

Teachers in medical educational settings may ask students to read *Cancer Vixen* in preparation for a class discussion about distress-related problems. Examples of other topics or themes in *Cancer Vixen* that can be used as a starting point for discussions, are ways of coping and the influence of personality on ways of coping, perceived control, the significance of social support, the value of humour in medicine, and the importance of adequate physician-patient interaction (e.g., we repeatedly read in narrative text boxes that it is a bad sign if a doctor turns his back to a patient).

There are accounts of medical health care providers that would recommend *Cancer Vixen* to their patients 44 ([http://knopfdoubleday.com/book/107478/cancer-vixen/](http://knopfdoubleday.com/book/107478/cancer-vixen/)). Based on our study framework, there may be a place for *Cancer Vixen* to initiate and improve provider-patient communication about distress. For example, a breast cancer patient may be asked to read *Cancer Vixen* at home, after which the provider uses the graphic novel to provide information about the disease trajectory and discuss the images (i.e., distress-related problems) that the patient identifies with most. It has been suggested that, given the story line and the vivid use of colours, this graphic novel may be especially equipped to educate younger breast cancer patients 51.

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43. Connor JTH. Cancer, comics and canMEDS. CAME Newsletter 2010; 20: 7-12.