



A Qualitative Content Analysis of Breast Cancer Narratives Hosted Through the Medium of Social Media

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Authors' contributions

This work was carried out in collaboration between all authors. Each author contributed equally to this work. Authors MAC, TC and NMF were involved in manuscript preparation. Authors MOM and EAL were involved in data analysis. All authors contributed to manuscript editing. All authors read and approved the final manuscript.

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ABSTRACT

Aims: Social media and networking host a significant amount of breast cancer related information. Breast cancer accounts for the largest number of new internet postings amongst the top four cancers. The objective of this study was to apply qualitative content analysis to the most highly rated breast cancer narratives hosted on youtube and identify the common themes.

Study Design: Qualitative content analysis of youtube video blogs.

Methodology: Data for analysis were extracted from youtube. The search terms used were "breast cancer survivor" and "breast cancer stories". All clips were transcribed in their entirety. Data were analysed subsequently.

Results: The overarching theme apparent from transcript analysis was that of 'the experience of fighting cancer'. Five categories, namely, (1) 'first finding out', (2) coping strategies, (3) 'living with

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uncertainty', (4) 'reaching out and giving back' and (5) 'learning lessons' were identified as key issues for participants in fighting cancer.

Conclusion: Participating in blogs generates important peer and social support. Many patients wanted to 'reach out and give back', an endeavour contributing to satisfaction among breast cancer survivors in peer support programmes and an enormous resource to potential survivorship programmes.

Keywords: Breast cancer; oncology; social media; survivorship; social support; support groups.

ABBREVIATIONS

HCP: Healthcare Professional; SM: Social Media.

1. INTRODUCTION

The internet is rapidly becoming patients preferred source of cancer related information, with over 10,000 medically related websites in existence in 2002 [1]. Yahoo!Health, the most popular health website, has 21,500,000 unique users per month [2]. Quinn et al. [3] have previously demonstrated that the combined total searches of just the top 4 four cancers (breast, lung, prostate and colorectal) account for the 12th most overall searched topic on the internet. The same authors demonstrated that of these, searches for information on breast cancer were the most common of all the cancers studied at 44.1%, representing a threefold increase between the years 2008-2010. Over a one month period in 2011, 368,000 searches using the words 'breast cancer' were conducted using the google.co.uk search engine [4]. As of November 2013, Internet searches using the term "breast cancer" return over 207 million results, double the yield of an identical internet search in 2012 [5].

Social media has been defined as "a group of Internet-based applications.....that allow the creation and exchange of user-generated content" [6]. According to a 2013 report, YouTube is the third most popular social media website with a 25% market share, ranking behind Facebook on 51% and Google+ with 26% [7]. The total time spent on social media in the U.S. across PCs and mobile devices increased 37% to 121 billion minutes in July 2012, compared to 88 billion in July 2011 [8]. YouTube is a video sharing website and form of social media created in 2005. The company, now owned by Google, was featured on the cover of Fortune magazine, boasting over one billion unique users per month and growth of over 50% in the first half of 2013 [9]. An estimated 100 minutes of video are uploaded every minute on the site with

individuals responsible for the majority of content [10].

Social media and networking hosts a significant amount of breast cancer related information, with breast cancer accounting for the largest number of new internet postings amongst the top four cancers (24.6%) [3]. Health video blogs, or vlogs, have become a popular method for people to express themselves. Personal, experiential stories feature strongly in these, amounting to a total of 27.8% of all new postings. Evidence suggests that sharing personal stories with others is helpful in generating peer, social and emotional support [11]. The most important aspect of sharing stories seems to be the connection with others, which can serve as self-therapy [12].

The objective of this study was to apply qualitative content analysis to the most commonly accessed breast cancer narratives hosted on YouTube and identify the common themes found within these personal stories, in order to explore the motivations driving people to upload their personal stories.

2. MATERIALS AND METHODS

Data for analysis were extracted from YouTube. The search terms used were "breast cancer survivor" and "breast cancer stories". All videos were in the English language. The following data were recorded: the selected videos title, URL, length, view number, viewer rating on the day of extraction, author of the video and the YouTube categorisation of the video. Videos with the primary purpose of entertainment, advertisement, news broadcast, public service announcement, live speech, artistic expression or those that were highly scripted or elicited by someone other than a patient were excluded. The videos transcribed are attached in Table 1. Institutional ethical

approval was not obtained as it was not deemed within the remit of the board. This is primarily because the content used here is considered publically available published material, and therefore does not meet the standard definition of private material. Consent is not considered necessary for publically available data.

All clips were transcribed in their entirety. Data were analysed using qualitative content analysis, which focuses on analysis of what the text says (manifest content) and "interpretation of the underlying meaning" (latent content) of the text [13]. Initially, all of the You-Tube clips were transcribed and read through several times to get a sense of "the whole". Meaning units were then extracted from each clip and inserted into a table. These meaning units were then condensed and labelled as "codes". Subsequently codes were subsumed into sub-categories and further collapsed into categories revealing the "manifest content" of the data. These categories were reviewed and discussed by two of the authors who were in agreement with the issues emerging. Finally, the underlying meaning (latent content) of the categories was formulated into one over-arching theme. In order to assist with the writing up process each category was colour coded. Meaning units, codes and sub-categories were then colour coded according to their specific category [14]. To ensure trustworthiness of the findings a number of practices were performed. Explicit description of methodological considerations and the extensive use of interview transcripts by way of representative quotations were detailed to establish dependability of the study process and credibility of findings.

3. RESULTS AND DISCUSSION

Nineteen video-clip uploads underwent content analyses. Of the 19 participants, 9 were cancer free at the time of video upload, 5 were on treatment and 5 women acknowledged that their prognosis was terminal. A number of reasons were given by participants for posting their video on You-Tube, the key ones being to: provide support and advice to other women in similar situations; raise awareness of different aspects of breast cancer ranging from screening to cancer organisations and to simply tell their cancer story. The overarching theme apparent from transcript analysis was that of 'The experience of fighting cancer'. Five categories, namely, (1) 'First finding out', (2) Coping Strategies: 'Doing what you have to do' (3) Living with uncertainty, (4) Reaching out and giving

back and (5) Learning lessons were identified as key issues for participants in fighting cancer. Verbatim quotations are used to illustrate each category's derivation, which led to the elucidation of the overarching theme.

3.1 'First Finding Out'

3.1.1 Diagnosis moment

Women described the moment of diagnosis in detail. One woman mentioned that she remembered the "*exact moment*" another referred to "*that day*". Some women almost knew what the diagnosis was going to be: "*right then I knew*", another alluding to knowing "*from the moment I hung up the phone*". This period was seen as the "*hardest part*".

3.1.2 Immediate emotional response

On hearing of their cancer diagnosis, the immediate emotional response was devastating for some women as one woman commented:

"To have to hear the 'C' word once was devastating enough" and "getting that diagnosis was very devastating"

Another woman described it as:

"Hectic and overwhelming when you find out first, the bottom is falling out of your life".

Fear was evident in some of the clips. One woman described being "terrified while another was "*In shock*" saying "*I told myself I don't want to die*".

One woman described an array of contrasting emotional reactions in herself and her husband:

"How floored we were, I would cry, he would cry, I remember most of all how we laughed – strange bitter dark humour".

3.1.3 Diagnosis denial

Denial emerged in some narratives:

"Pretending that everything was normal"

Another reasoned:

"It can't be breast cancer" adding that she was "young" and at the "prime of life.....it can't be cancer".

Table 1. The top rated youtube videos

URL	Title	Length	Date posted	YouTube category	Views
http://www.youtube.com/watch?v=zyqwifZ7174	Kimberly's Story - The day I found out I had breast cancer - October 30, 2008	13:45	6/4/2011	Education	2,492
http://www.youtube.com/watch?v=cFF9pZeTOXk	Positively Pat's Breast Cancer Journey: A Story Of Survival	9:40	12/9/2010	People and blogs	4,359
http://www.youtube.com/watch?v=jSn_5qOylQY	Allyson's Story: Breast Cancer Awareness	4:26	14/1/2010	Entertainment	1,682
http://www.youtube.com/watch?v=HHWfJv8gOZY	Kim Malcolm tells her breast cancer story	10:42	14/12/2009	Non-profits and activism	1,796
http://www.youtube.com/watch?v=PcYNX_4GI_o	Breast Cancer Stories 2011 Amy Colthorp The Pink Cart, Breast Cancer Gifts	2:26	18/10/2011	People and blogs	374
http://www.youtube.com/watch?v=2dGHduelFu0	It Takes an Army - Sarah's Story - Stage 3 Breast Cancer Survivor	2:49	19/10/2011	People and blogs	725
http://www.youtube.com/watch?v=j6OCyaPBGcc	It Takes an Army - Melissa's Story - Breast Cancer Survivor	9:54	4/10/2011	Non-profits and activism	518
http://www.youtube.com/watch?v=E5U7LwV1jBU	The Day I Found Out I Had Breast Cancer - Laura's Story - May 11, 2009	9:42	21/4/2011	People and blogs	2,118
http://www.youtube.com/watch?v=-PxUaoLuqXU	My Story of Breast Cancer and Encouragement	12:03	23/9/2012	People and blogs	176
http://www.youtube.com/watch?v=INsurVEZJzs	The Day I Found Out (10/15/10): My Breast Cancer Story	14:43	8/4/2011	People and blogs	875
http://www.youtube.com/watch?v=Bgk2G6fkuNg	My breast cancer story	9:44	28/9/2012	People and blogs	31
http://www.youtube.com/watch?v=dWU1qq83bGg	It Takes an Army - Helena's Story - A Breast Cancer Caregiver	2:44	14/9/2011	Non-profits and activism	242
http://www.youtube.com/watch?v=qVKGuceRShk	My cancer story and im a breast cancer survivor	6:55	25/4/2012	People and blogs	37
http://www.youtube.com/watch?v=wsi7P_Le3uA	It Takes an Army of Women -Mary's Story - 21-Year Breast Cancer Survivor	6:23	17/9/2011	Non-profits and activism	245
http://www.youtube.com/watch?v=01J98Me1hoY	Live Legendary: Jen's Story	2:13	29/3/2013	Non-profits and activism	3,687
http://www.youtube.com/watch?v=vx-OXHfmDhA	Mailet's Story - Breast Cancer Survivor, Founder of IHadCancer	3:16	26/6/2011	People and blogs	490

URL	Title	Length	Date posted	YouTube category	Views
http://www.youtube.com/watch?v=F2elo_vp2s4	Breast cancer survivor	6:21	7/9/2008	Non-profits and activism	299
http://www.youtube.com/watch?v=48uC-KWGY-M	Breast cancer	2:58	7/10/2012	Non-profits and activism	9
http://www.youtube.com/watch?v=QSbbNGTAJe8	Coralee's Breast Cancer Story 2 of 3	6:15	18/2/2007	People and blogs	3,727

Another debated about whether she had found cancer:

"My first thought was this can't be happening, threads of hope I can hold onto, not the right time to check, finding things by mistake, wait two weeks, I dismissed it from my mind".

Narratives then moved onto the category of coping, a sense of women carrying on with life and *"Doing what you have to do"*.

3.2 Coping Strategies: "Doing what you have to do"

Coping strategies for living with cancer throughout the illness trajectory was a prominent issue raised by all participants. A number of sub-categories, were encompassed within this category and included; (a) Social support, (b) Professional support, (c) Spiritual support, (d) Understanding and information seeking, (e) Being in control, (f) Attitude and (g) Being 'normal'.

3.2.1 Social support

The majority of women acknowledged the absolute necessity of having family and friends support them through the cancer experience. This support predominantly centered around the sharing of emotions, fears and stories with their loved ones and gaining comfort, reassurance, strength and inspiration to carry on 'fighting' as evident in the following clips:

"After I was diagnosed with cancer my family had set up a caring bridge [internet] site, having that site was a lot easier to keep people who supported me, kept up to date on a daily basis and truthfully reading those messages from friends and family keeps my spirits up and it keeps me fighting".

"If I could give advice to anyone out there recently diagnosed I would say support is paramount, don't go through something like this alone, reach out to family, friends and organisations, they are there and willing to help".

"You need to surround yourself by those who love you, by those who inspire you, those who make you laugh...".

Practical support from friends and family featured to a lesser extent:

"...my girlfriends are my family, I have never in my entire life felt that the kind of love that I feel right now and I have always felt loved but this has been over the top".

3.2.2 Professional support

Brief mention was made by participants of the support they sought or received from professionals. One woman found support from contacting a breast cancer helpline:

".....most importantly she listened to my fears and my frustrations....I do not remember the lady's name but I will always, always remember that compassionate voice, helped me through one very dark night".

The supportive role of the healthcare team directly involved in treatment did not feature significantly. Where medical professionals were mentioned, they were often referred to as a source of information rather than support, as one woman commented:

"....there's basically strangers telling you this. It didn't occur to me that when I, if and when I found myself in that sort of situation, that how strong the urges to not believe the doctor. How much like the enemy they seem".

Conversely, another woman declared:

"I just love my oncologist, he's just wonderful".

The actual support and care that women received from healthcare professionals is not explicitly communicated within these transcripts.

3.2.3 Spiritual support

Finding support through spirituality was another strategy which helped some women cope positively with their cancer experience, as articulated in the following clips:

"When I'm with the church my whole friends and my moms friends the whole church they pray for me.....".

"..... my inspiration is my faith and my trust in God....I want to encourage you and give you a hope because it is not the end, the end of all this in God's hands".

"My spiritual connection is a huge part of my healing"

3.2.4 Understanding and information-seeking

Information seeking behavior was notable among these transcripts with improved understanding featuring prominently as a tool of empowerment. Knowledge was perceived as a 'weapon' or strategy to fight cancer:

"I've been on the Internet like crazy looking at other people's stories ...I need to find out why I definitely need to have chemo...."

"...you take the time to do your research, you take the time to understand whatever it is you're going to do...."

"I needed to get a second opinion, I needed to find a surgeon, an oncologist, I needed to do research to figure out my options ..."

3.2.5 Being in control

Many participants indicated that cancer had taken control over all aspects of their lives. These women did not want cancer to 'define them' and they strived to gain as much control as possible:

"So I found out, I've got the news, I cried for about an hour, stayed in bed for a while and then my sister and I hit the beach because that's what we were there to do, to have a good time and cancer was not going to take that away from me".

"I asked them [children] to cut my hair, we made moustaches out of it, we had fun. I wanted them to be part of being in control...I didn't want the cancer to have control of my hair falling out, I wanted the control...It was my decision not the chemotherapy or the cancer"

"....I knew then that I was going to be in control and I was going to be in charge. Not the other way round"

3.2.6 Attitude

Being positive and optimistic helped the majority through their cancer experience. Several adopted a determined mind-set to do what was necessary to 'beat' cancer.

"I want to be here for my children and I'm just gonna do what I have to do"

"I think the most important thing.....would be to have a positive attitude,Positive energy, positive outlook, positive attitude"

"I cope by being positive; I say the hell with cancer The love for my children keeps me positive and strong"

"It was a very difficult time for me but I just said you know what; we have to do it, let's just do it"

"I can do this, I can beat it"

3.2.7 Being 'normal'

Four participants found that being able to maintain a façade of normality allowed them to cope with their diagnosis and consequent treatments. For some this meant that their daily routine pre-diagnosis was maintained, while for others, appearing healthy was important:

"I pushed myself to doing the everyday things..... That's what helped me along....."

"I think I tried very hard to be a person that appeared not to be sick... wore a wig everywhere I went....., I just didn't want to be a sick person"

"I hate the idea of losing my hair and having people see what I'm going through rather than being able to hide behind a facade of everything being okay"

"Losing my hair and my strength were large hurdles for me..... The cancer could be seen on the outside now"

3.3 Living with Uncertainty

The unpredictable and uncertain nature of living with a breast cancer diagnosis was evident throughout.

One woman referred to the cancer as being "like the ticking bomb" and declared:

"I never know when my next visit to the doctor will be good news or bad news".

The random nature of cancer was highlighted by another woman who stated that being diagnosed with cancer was "just the luck of the draw".

One woman hoped she "could live beyond this breast cancer and have a normal life". Furthermore, seeing women survive their cancer

was “empowering” as this “validated” what one woman too “was hoping for”. A sense of hope was apparent in the midst of uncertainty, as one woman referred to the time she was told about “being in remission” as hearing the words that she “so longed to hear”.

As women journeyed through their cancer experience, a sense of “reaching out and giving back” came through.

3.4 Reaching Out and Giving Back

One woman now “wanted to help other women who were newly diagnosed”, while another wanted to “help women see that healthy side of getting through this journey”.

On ‘giving back’ one woman reflected:

“but I knew that my skill set.....that this was something that I could do, a contribution that I could make to breast cancer”.

Reaching out to offer hope and encouragement was passionately narrated by one woman:

“I’m offering hope to you, that you can fight this and you too can be a long-term survivor. Everybody needs help and sometimes when you are in the middle of things, it does get dark and discouraging and it’s hard to remember that”.

Another encouraged others to:

“do something (e.g. volunteer).....to give some purpose to what you’ve been through”

3.5 Learning Lessons

As the narratives concluded, a strong sense of learning lessons emerged.

One woman surmised:

“What started out as the most devastating news of my life has turned out to be OK and I’ve even gained from the experience”.

This was reiterated by a woman who declared that her experience had made her “a lot stronger”.

In emphasising the positive outcomes of her cancer experience a woman contended:

“It’s all good; it’s happening for a reason, I just wish I knew what it was”.

Another concluded emphatically:

“I never see anything I can’t do, everything’s possible”, seeing herself as a “breast cancer survivor”.

3.6 Discussion

The internet is used by breast cancer patients to disseminate information regarding their diagnosis [12]. Once given a diagnosis of cancer, 71% patients search the internet for further information [15]. While clearly a source of receiving information, here we have examined the use of social media by patients as a means of providing information regarding breast cancer. This has been shown to be beneficial through the generation of peer and social supports [16]. In a study of comments posted to videos relating to inflammatory bowel disease, the majority contained informational support while a significant percentage contained messages of emotional and instrumental support [17]. Another study of cancer bloggers, revealed that users were more inclined to share personal experiences and emotional support than medical knowledge [18]. This is consistent with the findings in our study. Specifically the themes of ‘being in control’, despite ‘living with uncertainty’ were important to those publishing their stories. The concept of uncertainty was successfully addressed in a group of young American breast cancer survivors through interventions including listening to a scripted CD and receiving phone calls from nurse interventionists [19]. Uncertainty poses many challenges for women but it also helps some women to look at their lives from a fresh perspective [20]. Information gathering can become a strategy to reduce feelings of uncertainty and produce feelings of hope and being in control [21]. The theme of gaining empowerment through knowledge, a strong theme in our narratives, is a common one that has been raised among previous studies of breast cancer patients, as well as among other groups of patients [22,23].

It was revealing that in our cohort, patients saw health care professionals (HCPs) as ‘strangers’ who were sources of information, and instinctively the ‘enemy’, whereas it was family and friends who offered tangible social support. This is an important reminder of the key role

played by those who accompany our patients, an all too often sidelined presence.

Many women wanted to 'reach out and give back'. This may represent a way of making sense of what has happened to them. Previous studies have found a theme of wanting to give back within peer support groups [24]. This reaching out and giving back contributes to satisfaction and quality of life scores among breast cancer survivors who volunteer in peer support programmes [25]. Helping others, a prominent concept in peer support programmes, enabled mentors to "find meaning" in their own disease [26]. This desire to help and support others is an enormous resource to survivorship programmes.

4. CONCLUSION

The internet is not only a source for patients to receive information but also a platform that can be used to disseminate information on breast cancer. Women who are diagnosed with breast cancer tend to rely on friends and family as their initial confidantes rather than confiding in HCPs. The relationship with HCPs is one that needs to be developed throughout the cancer journey. The friends and family members who often accompany our patients are a crucial source of social support before, during and after a diagnosis of breast cancer, in contrast to the more transient role of the HCPs. In addition, the desire to reach out and give back is a powerful instinct amongst the community of patients with breast cancer. HCPs need to be cognisant of these findings in their efforts to support women throughout their breast cancer journey and beyond.

COMPETING INTERESTS

Authors have declared that no competing interests exist.

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