Charities’ use of Twitter: exploring social support for women living with and beyond breast cancer

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Charities’ use of Twitter: Exploring social support for women living with and beyond breast cancer.

Twitter is one social media platform that enables those experiencing breast cancer to access support from others. This study explores how cancer charities provide support to women living with and beyond breast cancer (LWBBC) through their Twitter feeds. 772 tweets from seven purposively sampled cancer charities were used to explore Twitter posts made relating to social support. Two questions were posed: (1) what type of support is positioned by cancer charities on Twitter for women LWBBC and (2) what themes emerge from tweet content pertaining to support for women LWBBC?

Using a peer reviewed typology of ‘social support’ (Rui, Chen & Damiano, 2013), a deductive content analysis was utilised to identify informational, instrumental or emotional social support tweets (n= 199). Over half (56%) of tweets offered informational support; 27% provided or sought instrumental support; and 18% related to emotional support. Interestingly, 74.3% (n = 573) of tweets were not related to providing or seeking social support. An inductive qualitative thematic analysis of the 199 tweets identified the focus (i.e. themes) of support. Three themes, were identified: (1) raising awareness (2) focusing on the future and (3) sharing stories. Cancer charities predominantly use Twitter to signpost women to informational resources and to seek instrumental support to meet charitable objectives. As the number of women LWBBC continues to increase, this study provides valuable insight into how charities represent themselves on Twitter in relation to the social support needs of women LWBBC.

Keywords: Breast cancer; tweets; social support; charities; living with and beyond; Twitter.

Introduction

The number of women living with and beyond breast cancer (LWBBC) in the United Kingdom (UK) is increasing due to earlier diagnosis, improvements in treatments and an ageing population (Maddams et al., 2009; Maddams, Utley, & Møller, 2012). For many,
LWBBC is about managing chronic illness on an ongoing basis (Maher & Fenlon, 2010; McCorkle et al., 2011). Women can experience a range of ongoing effects and unmet needs related to physical, emotional, social or spiritual concerns (Harrison, Young, Price, Butow, & Solomon, 2009) including pain, fatigue, fear of recurrence, lymphedema and financial and work related issues (Aaronson et al., 2014; Burg et al., 2015; Cheng, Wong, & Koh, 2015; Fiszer, Dolbeault, Sultan, & Brédart, 2014; Foster, Wright, Hill, Hopkinson, & Roffe, 2008; Park & Hwang, 2012). With growing numbers of women LWBBC, there has been increasing focus towards encouraging ‘self-management’ of day to day problems occurring because of chronic health conditions (Foster & Fenlon, 2011; McCorkle et al., 2011).

At the same time, charities are being encouraged to take a greater role in eHealth (Hunt, Koteyko & Gunter, 2015). Medical health charities play a significant role in advancing health provision and providing welfare, support care, education and information to support patient communities (All Party Parliamentary Group on Global Health, 2015). More recently, the ‘Stronger Charities for a Stronger Society’ report acknowledges the opportunities social media presents for charities to gain ‘relevance and reach, in a world where many people expected to run their lives digitally’ (House of Lords, 2017, p.75).

Ream, Blows, Scanlon, & Richardson (2009) posit that cancer charities play an important role in supporting individuals LWBBC, with relationship building considered a key aim of social media use (Phethean, Tiropnias, & Harris, 2015a). The integration of social media use into everyday life, provides opportunities for charities to engage with those LWBBC 24/7 supporting self-care and self-management behaviours across the whole cancer trajectory. However, there is an absence of research into the types of supportive communications that are disseminated by charities using social media to meet the needs of women LWBBC. Indeed, it has been argued that healthcare policies generally in the UK fail to consider the
role of social media in “mediating ongoing support and self-management for patients with long term conditions” (Hunt et al., 2015, p.1).

Twitter is one social media platform that offers the opportunity to study online interactions between charities and their ‘followers’. Twitter is an important channel for communicating about cancer (Lyles, López, Pasick, & Sarkar, 2013) with Twitter networks providing psychological and educational support for cancer patients (Attai et al., 2015; Sugawara et al., 2012). Twitter plays a significant role in supporting “online ‘wired’ cancer patients” (Sugawara et al., 2012, p.1) with women sharing details of their symptoms, diagnosis and treatments of breast cancer (Tsuya, Sugawara, Tanaka, & Narimatsu, 2014). The establishment and use of a global breast cancer chat using the hashtag #bcsm (breast cancer social media) by patient advocates (Attai et al., 2015) suggests an active, engaged online community of women LWBBC. Whilst social media has changed the pattern of health-related behaviour (Himelboim & Han, 2013) and there is evidence of significant interactions between women LWBBC on Twitter, little remains known about charities approach to using Twitter to provide social support online.

Social support is an umbrella term for the link between social relationships and health and wellbeing (Goldsmith and Albrecht, 2011). A wide body of literature has explored this construct and is associated with better adjustment to breast cancer (Bloom, Stewart, Johnston, Banks, & Fobair, 2001; Boinon et al., 2014; Chou, Stewart, Wild, & Bloom, 2010; Drageset, Lindstrom, Giske, & Underlid, 2012; Falagas et al., 2007; Fong, Scarapicchia, McDonough, Wrosch, & Sabiston, 2016; (Kroenke, Kubzansky, Schernhammer, Holmes, & Kawachi, 2006). Social support is theorized as having two constructs: structural support and functional support (Bloom et al., 2001; Helgeson, 2003). Structural support relates to networks of social
relationships. Functional support relates to the resources available from these networks and have been further sub-divided into informational, instrumental and emotional support (Drageset, Lindstrøm, Giske, & Underlid, 2015; Helgeson, 2003; Suwankhong & Liamputtong, 2015). Informational support refers to knowledge provision relevant to the situation the individual is encountering (Bloom et al., 2001). Instrumental support refers to concrete support such as financial assistance; help with childcare or transportation to medical appointments. Emotional support refers to having someone to listen, to sympathise, to provide reassurance, and to make one feel valued and cared for (Helgeson, 2003).

Social media sites such as Twitter and Facebook offer women different opportunities to gain social support to meet individual needs (Wright, Sparks, & O'Hair, 2013). To date, social support related communication online between individuals has been the major focus of attention (Rains, Peterson, & Wright, 2015) and the role of health organisations in providing social support has been largely ignored (Rui, Chen, & Damiano, 2013). To begin to fill this gap, this study concentrates on how UK based charities collectively represent themselves on Twitter through considering tweets using a social support lens. Firstly, it explores the communication mix of informational, instrumental and emotional support messages relevant to women LWBBC by asking: what type of social support is positioned by cancer charities on Twitter for women LWBBC? Classifying and quantifying the content in relation to the ‘type’ of social support provided would initially afford a better understanding of the data (Chen, 2014). To then deepen our understanding of what the key support topics positioned by charities are, we ask a second research question: what themes emerge from tweet content pertaining to support for women LWBBC?

**Methods**

**Design**
A two-phase approach was adopted. Firstly, content analysis (Elo & Kyngäs, 2008) quantified tweets in relation to type of support (informational, instrumental or emotional). Then, analysis based on thematic analysis methodology (Braun & Clarke, 2006) was used to identify, analyse and report patterns in the data. The combination of these approaches has previously been used in health-related Twitter research (Jamieson-Powell, Linehan, Daley, Garbutt, & Lawson, 2015).

**Sampling**

From an initial 495 cancer charities identified using the The Charity Trends® search tool, via the Charities Aid Foundation (CAF) website, 7 charities met the sampling criteria. Charities had to i) have submitted a Charity Commission return for 2012 or later\(^1\) ii) be a Twitter ‘power account’ defined as having over 500 followers (Sugawara et al., 2012; Chretien, Azar, & Kind, 2011), iii) have a UK wide remit identified on their Twitter profile, iv) have broad interests in the prevention, diagnosis, treatment and LWBBC and v) were actively using Twitter by posting at least once a week (Hughes & Palen, 2009). On April 23\(^{rd}\) 2015, the seven UK charities had an average of 85,341 followers, ranging from 7,920 to 216,000. All tweets posted (n=3089), including retweets and @mentions were collected from a ‘constructed month’, consisting of four weeks from a three-month period in late 2014/early 2015. Developing a randomly constructed week for sampling is recognised as a reliable method for sampling media content (Artwick, 2013; Luke, Caburney, & Cohen, 2011) and ‘constructed months’ have previously been used with retrospective tweet data (Armstrong & Gao, 2010, Artwick, 2013; Himelboim & Han, 2013). Previous studies of Twitter have employed a selective sampling procedure to enable a manageable corpus for qualitative analysis. We drew on the approach used by Jamieson-Powell et al., (2015). They selected every 25th tweet of an initial corpus resulting in the use of 749 tweets for thematic analysis. As we began with a smaller corpus of tweets than Jamieson-Powell et al., (2015), we selected every 4th tweet from the original 3089 resulting in 772 tweets for analysis.

**Ethical considerations**

\(^1\) Typically, the most up to date cancer charity sector financial information published online at the time of data collection were annual returns made for 2012,
Data was taken from an online space considered ‘public’ (Anderson & Clarke, 2017; British Psychological Society, 2009; Chae, 2015; Zimmer & Proferes, 2014) with tweets being public by default (Twitter, 2016). As such, it is deemed that no specific consent for use was necessary, positioning the ‘information’ or ‘tweet’ as ‘the subject under investigation’ rather than the individual tweeter. Arguably, cancer charities operate within this space with ‘no perception and/or expectation of privacy’ (British Psychological Society, 2013, p. 7). Nevertheless, data has been anonymised by replacing identifiable material in tweets with closed parentheses [] and identities anonymised using ‘@ []’ in line with BPS guidelines for Internet-mediated research (2013).

Coding

In Excel, a deductive content analysis was carried out on the 772 tweets. The typology previously used by Rui, Chen & Damiano (2013) to analyse social support tweets posted by health organisations was adopted (Table 1).

[Take Table 1: Insert here]

Tweets were classified as ‘related to social support’ or ‘not related to social support’. If ‘social support’ tweets were: i) relevant to the experiences of LWBBC ii) related to informational, instrumental or emotional support, in line with the Rui et al.’s (2013) ‘social support typology’; and iv) were original tweets, retweets or directed to a specific @username, they were included in the final dataset.

Following this we examined the content across all social support tweets using an approach based on thematic analysis methodology (Braun & Clarke, 2006) in order to gain a sense of the topics or themes that charities tweeted about in relation to LWBBC. We saw the outcomes of these analysis processes as being complementary yet distinct. This methodology was employed for a more detailed and nuanced analysis of the data (Braun & Clarke, 2006; Vaismoradi, Turunen & Bondas, 2013) around social support on Twitter. By exploring themes ‘emerging’ from charities’ tweets, it is possible to explore which ‘support’ topics charities make, knowingly or not, salient. For the thematic analysis, the dataset of ‘social support’ tweets was considered as a whole (n=199), rather than analysed by ‘type’ (informational, instrumental, emotional). Free comments were initially made against each tweet to reflect the focus of the tweet. Then, each tweet was given an initial descriptor or
code such as ‘resource availability’ or ‘reduce your risk’. Finally, all codes were considered in relation to identifying salient ‘master’ themes and ‘sub themes’ (Braun & Clarke, 2006). The development of themes and subthemes was an iterative process, with re-evaluations of theme/subtheme headings taking place through discussion with all authors as analysis continued, including during the writing-up process.

**Analysis**

The results of the deductive content analysis to identify tweets pertaining to social support are reported followed by a breakdown by ‘type’ of support – Instrumental, Informational or Emotional. The key themes identified through thematic analysis are provided together with an overview of the type and frequency of social support expressed in relation to each theme.

**Deductive content analysis of tweets**

An unexpected finding was the high proportion of tweets not specifically related to women’s experiences of LWBBC. Nearly three quarters of tweets (n=573) related to charities communication with other stakeholders and aspects of their organisational interests, for example:

‘We’re excited to be working with @ []. There are still places left for its half iron man event, # [] http://t.co/ [] Feb [], 2015’

This is a noteworthy finding as it indicates Twitter use to primarily engage with wider audiences. As analyzing these tweets would not address the research questions, they were excluded from the dataset and no further analysis undertaken. Using the coding criteria (Table 1), 25.7% of tweets (n=199) were identified as relating to social support and LWBBC. 111 (56%) tweets related to informational support; 52 (27%) to instrumental and 36 (18%) to emotional support. In relation to social support provision to women LWBBC, the findings from this study suggest charities position themselves on Twitter as information providers primarily.

**Thematic analysis of tweets**

Following discussion and review between all authors, three main themes were identified across the social support tweets: (1) raising awareness (2) focusing on the future and (3)
sharing stories. Just over half (50.7%) of the tweets related to ‘raising awareness’; 28.6% of tweets were ‘focused on the future’; and 20.6% of tweets involved ‘sharing stories’. For each theme, several sub-themes were identified.

[Insert Table 2: here].

**Theme 1: Raising awareness**

Just over 50% (n=101) of all tweets in the sample related in some way to raising awareness. Tweets related to 1) signposting (n=44) 2) breast cancer risk factors (n=17) and 3) asking for help (n=40)

(1) **Signposting:** Informational support is acknowledged as a critical platform of social support for women LWBBC (Atkins, 2015). Nearly 44% of tweets were informational, seeking to signpost women LWBBC to multiple other support mechanisms including web services; telephone helplines and location based support groups. For women LWBBC, charities’ tweets can suggest limits to the support resources available which may conflict with the 24/7 experiences of LWBBC. For instance, if one to one support is preferred, helplines are available during office hours

*Our free and confidential helpline is open today till 5pm if you need to talk:* [ ]

*Feb [ ], 2015*

Tweets demonstrated commitment to piloting alternative forms of online interaction such as virtual chat rooms. Women were signposted to accessing these through web links. Whilst these potentially aim to satisfy informational and emotional needs, this support is moved away from Twitter where an active and engaged breast cancer community exists (Attai et al., 2015).

A limited number of tweets specifically sought to support women at different stages of their experiences of LWBBC. Tweets specifically focused on knowledge provision related to cancer diagnosis and chemotherapy:

*If you're starting chemo and are unsure about terms you're reading about, don't hesitate. Call us [ ] (Mon-Fri, 9-8). Jan [ ], 2015.*

There was surprisingly limited communication within this sample relating to other aspects of LWBBC and could suggest that at this time charities did not consider Twitter to be a
A number of tweets focused on signposting women to face to face support through: detailing sites of care provision; location based support group or workshop activities; or to the physical provision of care by a health professional. When individual Twitter users directly communicated with charities in relation to their own experiences of perceived poor care, careful management of the interaction to a more personalised and less public environment (email) offered support in seeking to resolve specific issues.

@ [ ] @ [ ] please email us with name of your [ ] nurse, where you live & contact details, then we can look into it for you Jan [ ], 2015.

The apparent range of support mechanisms suggests charities do perceive support provision as a significant role for them. What is markedly absent however is the use of dialogic (i.e. conversational) communication on Twitter to support at an individual level. This suggests that Twitter may be considered an inappropriate space for the provision of emotional support by charities. Conversations are either held offline (by telephone or through support groups) or interaction which commences through Web 2.0 (e.g. through accessing a tweet) is moved through a web link to continue in online bounded spaces (chat rooms and online communities). Indeed, Scanlon (2013) notes that Breast Cancer Care framed the use of social media platforms as an information service used to signpost patients to “written, online and telephone information and support services” (p. 16). This needs exploring further, particularly considering that tweet chats held weekly by #bcsm demonstrate an appetite to communicate, share experiences and gain support in a public space. Further research should explore whether women LWBBC expect or want charities to offer emotional support via Twitter.

Employment of one-way communication strategies concentrating on information provision is commonly reported in empirical studies of not for profit organisations (Waters & Jamal, 2011; Lovejoy, Waters, & Saxton, 2012; Greenburg & MacAulay, 2009). This was found in
relation to tweets posted during Breast Cancer Awareness Month (Thackeray, Burton, Giraud-Carrier, Rollins, & Draper, 2013) and in a content analysis of Facebook pages and Twitter accounts of the 20 top US breast cancer charities (Fussell Sisco, & McCorkindale, 2013). Fussell Sisco and McCorkindale (2013) concluded that charities need to go further in their communication strategies and engage in dialogic communication with their followers. Given the potential benefits of social media to support women’s self-management and self-care (Hunt et al., 2015), further research to understand the attitudes of, and roles seen for, charities to engage in public conversations on Twitter to support women LWBBC would be a useful next step.

(2) Breast cancer risk factors: All tweets coded within this theme (n=17) were informational, focusing both on understanding ‘risk’ and taking measures to reduce risk. Most tweets were posted by the breast cancer charities. In terms of awareness, tweets reflected the importance of early detection and the risks and benefits of breast screening. Risk was reflected in content addressing genetic susceptibility and lifestyle choices related to obesity and use of e-cigarettes.

After the story in [] about both men & women being able to inherit an altered BRCA gene. See our info here: http://t.co/Feb [ ], 2015

(3) Asking for help: Just over 39% of tweets related to charities seeking instrumental support. This indicates that Twitter is perceived as an important platform through which to achieve tangible support and resources. Tweets encouraged followers to be philanthropic through sharing, namely through the provision of personal images online, time and donations.

Share with us and @ [ ] #[ ] and [ ] will donate £5 to @[ ] and help us support those facing breast cancer. Feb 05, 2015

Had a #[ ] in 2014? Don’t forget to pay in your hard-earned donations & support those facing breast cancer: [ ] Feb [ ], 2015

The report ‘Stronger charities for a Stronger Society’ (2017) identifies digital fundraising and awareness raising of organisational activities through social media as significant digital
opportunities for charities. Research demonstrates some women LWBBC experience a need to ‘give back’ (Foley, 2015). Being involved in supporting charitable objectives through fundraising may provide positive benefits through a sense of mattering (Thoits, 2015). The extent to which women LWBBC find providing instrumental support to charities as a useful source of support however remains under-explored in the literature.

Theme 2: Focusing on the Future
Tweets in this theme focused on (1) promoting scientific and research advances; (2) building ‘political’ support and (3) projecting a future without cancer.

(1) Promoting research: Tweets in this subtheme (n=20) offer women support through the provision of information relating to ongoing research that is relevant to the experiences of LWBBC. Some tweets reflect cancer research generally and others specifically address developments in breast cancer research. The original tweets from charities focus on future benefits of research, concentrating on potential bio-medical advances and recent findings and future ‘life saving’ research

   'New drugs to tackle cancer cell weak spots could end 'scattergun' chemotherapy'
   | via @ [ ], 2015.

Tweets posted by charities concerning biomedical and health research advances reflect the key priorities described by the APPG (2015). Tweets signposting this research work to maintain and develop the public’s financial investment in biomedical research, achieved through taxation and charitable donations.

In contrast, retweets by charities focused on research already undertaken or currently being undertaken. They both celebrate and seek patients’ involvement in research. These may speak more closely to women’s own experiences through providing women new information on developments in breast cancer research disseminated via research conferences. In this sample of 20 tweets, 18 tweets and retweets were informational. Whilst some retweets point towards the involvement of those with breast cancer in research, tweets seeking patient’s engagement in research were less evident than those promoting biomedical research. deBronkart (2015) speaks of being on the verge of a new science of patient engagement – to understand and optimize the role of the patient (p.1). These tweets indicate a more ‘top down’ approach
being taken to involvement in research, which may exist in tension with deBronkart’s perspective of an informed patient/healthcare group eager to help shape the healthcare agenda.

(2) Building ‘political’ support: This sample of tweets was collected in Spring 2015 prior to the May General Election. Charities used the 2015 UK General Election to build political commitment to cancer care, through pressuring for broad manifesto commitments by the main political parties, evidenced by the ‘Timetochoose’ campaign (Macmillan.org.uk, 2015). By retweeting tweets which named individual politicians, and thanking politicians directly who tweet their support for charities’ pleas for cancer care to stay on the political agenda, the charities are both building ‘political’ support and reflecting ‘political’ support for this agenda:

RT @ [ ]: Here’s @ [UK politician] to [#] for World Cancer Day [#] http://t.co/ Feb (), 2015.

This democratization of politics through social media (Loader & Mercea, 2012; Papacharissi, 2010) enables charities to empower individuals to participate in moving the ‘political’ agenda forward in relation to cancer care.

Charities support those LWBBC through lobbying for improvements and taking a significant role in the strategic development of cancer services, including the formation in January 2015 of a new UK cancer taskforce (Cancer Research UK, 2015). However, related tweets emphasised roles and personalities rather than aims and objectives potentially missing opportunities to engage those LWBBC.

The UK needs a new plan to tackle cancer, our [ ] will be leading a new taskforce to develop this, more here: http://t.co/ Jan (), 2015

One topic related to The Cancer Drug Fund (CDF) and proposals to end government funding for some breast cancer treatments. Original tweets provided informational support through linking to articles exploring relationships between key stakeholders and to discuss the wider issue of drugs funding


Some retweets offered a perspective from those working in the research community

Other retweets, however, presented a more emotive and polarizing account, prompting emergence of a more critical voice highlighting issues intersecting health politicization and medical consumerism (Sulik, 2011). These may support women through validating experiences.

RT @ [: ‘It is unacceptable that breast cancer patients could today be denied vital drugs due to cost’ @ ] in @ [media outlet] to... Jan (), 2015.

Previous studies have not, as far as we are aware, explored the role of social media in enabling women to affect the breast cancer ‘political’ agenda or the extent to which women feel engaged with and supported by the lobbying processes of cancer charities. Further research examining the online relationships between charities and those LWBBC would be useful to explore how perceived ‘political’ support impacts women’s experiences.

(3) Projecting a future without cancer:
This theme focuses attention on defeating cancer - on a world where cancer no longer exists. They present a view that a cancer free world is achievable given enough funds to support research. Instrumental support was sought through requesting text donations

# [ ] to bring forward the day when all cancers are cured. You can still donate £3 by texting [ ] to [ ]. http://t.co/ Feb (), 2015

or through using web based links


Some charities’ tweets include a problematic assumption that ‘we will beat cancer’ and use ‘battle’ language which can be both empowering and disempowering to those LWBBC (Semino et al., 2015). Potentially those charities utilising these discourses may be distancing themselves inadvertently from those LWBBC who are uncomfortable with ‘battle’ rhetoric. Women’s perspectives should be explored in relation to the discourses used for charitable fundraising online to understand if and how these impact their experiences. Similarly, exploring with charities the motivations for utilising the ‘battle’ rhetoric when some women LWBBC reject the war metaphor (Breast Cancer Care, 2016; Garrison, 2007) is an area for
further enquiry. Understanding the role of Twitter in achieving tangible support from followers is an area of enquiry that is still in its early stages (Livingston, 2009; Smitko, 2012). In an analysis of 24 non-profit US organisations, Saxton & Wang (2013), found social media fundraising was particularly successful for health-related causes which reflected the immediate needs or benefits to the general public (p. 863). In contrast, ‘slacktivism’ defined by Morozov (2009) as “feel good online activism that has zero political or social impact” is used as a pejorative term to describe online instrumental support, such as signing an epetition or liking a cause on Facebook for example. Currently, little is known about the benefits for charities from engaging in online hashtag campaigns or how these benefits translate into perceived or actual support for those LWBBC.

Theme 3: Sharing stories
This final theme consists of tweets which share a brief ‘story’ through celebrating others or through pointing to a personal narrative of breast cancer. The tweets captured within this theme provide more examples of emotional support than in the other themes combined. 55% of all emotional tweets (n=36) in the tweet sample (n=199) were identified as ‘celebrating others’.

(1) Celebrating others: This includes tweets celebrating those LWBBC; those who have died from breast cancer; and the work of charities. Instrumental tweets point to the relationship between celebrating others and fundraising. Tweets posted with the hashtag ‘#HeresTo’ were posted during December in the build up to Christmas. Followers were encouraged to

‘Share your #HeresTo moments and pictures with us, and text TOBEAT to [ ] to donate £3 http://t.co/ Dec [], 2014’.

Followers posted pictures as a celebration of those who had breast cancer or had died from breast cancer, whilst also contributing to a fundraising campaign. Those tweeting in response to the original tweet point to emotional support being gained from use of the hashtag campaign. These followers, happy to post publicly, used the #HeresTo and #Wewillunite hashtag campaigns to share their loss, through celebrating women who had died from breast cancer:

RT @ []: #HeresTo @username [] passed away [] 2014 to breast cancer after 6 mnths fight. My beautiful wife. Miss you so much. http: Dec [], 2014.
This candid, emotional expression demonstrates Papacharrisi’s (2010) characterisation of the Internet as both public and private sphere in which individuals participate publicly in ‘self-expression capabilities’ usually found in the private sphere. Retweets posted by charities demonstrate followers emotionally engaging in dialogic communication with charities

*RT @ [ ]: @ [ ] As someone currently fighting the disease, can I just say a MASSIVE thank you for all your wonderful work... Feb [ ], 2015*

*RT @ [ ]: Very powerful video @username Wiping tears as so sad. Keep making those advances. Please. https://t.co/[ ] Feb [ ], 2015*

These tweets provide opportunities for charities to engage in dialogic communication with women LWBBC. However, limits on charitable resources may restrict this level of active engagement despite evidence that personalised communication improves well-being on Facebook (Burke & Kraut, 2016) and that the ‘reply’ evidences the greatest engagement on Twitter (Plethean et al., 2015a). Further investigation of whether charities’ personalised replies to followers’ tweets supports the psychological well-being of those posting would help determine what can be gained through greater dialogical engagement. This may particularly be beneficial for women with limited offline social support networks.

(2) Sharing self: This sub-theme emerges from charities retweeting posts and quoting personal tweets to share the experiences of women LWBBC. The sub-theme is therefore driven entirely by tweeters sharing personal narratives. The tweets hint at the empowering consequences of sharing personal stories in safe environments

*RT @ [ ]: Thank you to everyone in [ ] today. You are amazing ladies!! So wonderful to get such fantastic feedback. @ [ ] #s... Feb [ ]2, 2015*

However, the overall number of tweets in this sub-theme is surprisingly small (n=7), with the above tweet being posted in response to a specific charity’s breast cancer event. This, thereby is also promoting the event alongside sharing ‘individual experience’. This finding, together with the limited number of emotional support tweets within this sample, needs further exploration. These limited personal narratives, may indicate a reticence on the part of charities to engage in building dialogic communication with women’s comments about aspects of their experiences. An alternative explanation, that women LWBBC choose not to share their stories publicly with cancer charities, seems somewhat counter intuitive. Previous
research demonstrates that women are talking about diagnosis, symptoms and treatments relating to their breast cancer experiences on Twitter (Tsaya et al., 2014) and are engaged in Twitter chats moderated by other breast cancer ‘survivors’ in conjunction with clinical experts (Attai et a., 2015). However, potentially, women’s interactions are constrained by the key areas of interest they perceive charities as engaging in, as laid out in this paper, which they may consider not core to their own experiences. Understanding how women use social media to engage with charities in relation to their own experiences is an area which requires further study.

**Study limitations**

Methodologically, there are several issues to reflect upon. Less than 25% of the ‘constructed month’ tweet sample were related to ‘support’ (n=199). This limited sample restricts how representative we can claim these findings to be. Additionally, charities run different hashtag campaigns at different times of the year. In analysing content from a three-month period, the themes identified may well be dominated by topical concerns including ‘political priorities’ such as the 2015 General Election and proposed changes to the Cancer Drugs Fund. Analysing Twitter data longitudinally would deliver a wider understanding of how charities position ‘support’ over time. That said, it is acknowledged that charities may use different platforms for different purposes (Phethean et al., 2015b). This demonstrates the complexity of understanding social media use by examining use through a ‘one platform’ lens. Charities may select communicative strategies based on platform affordances (Merolli, Gray & Martin-Sanchez, 2013) and relationship building goals. For instance, Phua, Jin & Kim (2017) report Twitter as the most effective platform at increasing bridging social capital, as it affords development of wide networks of weak ties through the freedom to connect without a prior relationship. Charities therefore may focus their Twitter use primarily at gaining exposure and engagement with distance others. In contrast, Facebook users report higher bonding capital, that is a network that provides trust and support largely formed from offline relationships. Significantly however Phethean et al., (2015a) report a lack of clarity from UK charities on the success of relationship building strategies on Facebook in comparison to Twitter despite these differences in social capital. Within this study, questions have been raised regarding the potential role(s) of charities to those LWBBC and the importance of dialogic communication between them. How women LWBBC perceive the role of cancer and breast cancer charities in their lives is an underexplored area. Consequently, these questions need assessing further perhaps as part of a wider exploration of women’s use of social media to support unmet needs.
Conclusion

This study seeks to gain an understanding of how charities represent themselves on Twitter through the lens of the social support needs of women LWBBC. Only seven cancer charities met all the inclusion criteria. This suggests that for smaller charities integrating social media use into day to day communication strategies may still be some way off. With 74.3% of tweets not being related to social support, charities demonstrate Twitter use to primarily connect with wider audiences. This is in line with the digital fundraising and awareness benefits digital technologies and social media are seen to provide for the charitable sector (House of Lords, 2017). Where social support is demonstrated in tweets, it is principally providing information (56%) or related to instrumental support (27%). The small number of tweets providing emotional support to women was an unexpected finding (18%). Consequently, Twitter may not be seen by this sector to be a platform to support emotional needs through the use of empathic, dialogic communication with those living post diagnosis and treatment. These findings are interesting given recent research which indicates that women have unmet and ongoing emotional, physical and psychosocial needs post treatment (Aaronson et al., 2014; Burg et al., 2015; Maher & McConnell, 2011) and share in Twitter conversations openly these needs and concerns (Tsuya et al., 2014). Understanding why charities signpost women towards other bounded environments to meet dialogic needs would be useful to understand. Women seek to utilise ‘weak ties’, which include charities, to gain appropriate emotional support which may be absent in other aspects of their lives (Wright et al., 2013) and seek emotional support through social networking sites (Lin, Zhang, & Li, 2016). The significance of these in mediating ongoing support and helping to support patient self-management remains an area for further inquiry. For women with limited social support, the feeling of connectedness with others through social media platforms may have positive psychosocial health implications which remain under-explored to date. Understanding whether psychosocial benefits can accrue from greater public dialogic engagement between cancer charities and women LWBBC is an area requiring further investigation.

References


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Phethean, C., Tiropanis, T., & Harris, L. (2015). Engaging with charities on Social Media: Comparing interaction on Facebook and Twitter. INSCI 2015, LNCS 9089, pp. 15–29, 2015. DOI: 10.1007/978-3-319-18609-2_2


http://dx.doi.org/10.1108/ajim-09-2013-0083
Table 1: Types of social support (based on Rui et al., 2013)

<table>
<thead>
<tr>
<th>Type of Support</th>
<th>Support orientation</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informational</td>
<td>Providing</td>
<td>A tweet provides followers information including medical or health related advice, guidance, news, or findings.</td>
</tr>
<tr>
<td></td>
<td>Seeking</td>
<td>A tweet asks followers for information including medical or health related advice, guidance, news or findings.</td>
</tr>
<tr>
<td>Instrumental</td>
<td>Providing</td>
<td>A tweet provides tangible aid such as resources.</td>
</tr>
<tr>
<td></td>
<td>Seeking</td>
<td>A tweet asks for tangible aid such as donations, materials, time etc.</td>
</tr>
<tr>
<td>Emotional</td>
<td>Providing</td>
<td>A tweet offers or provides encouragement, comfort, congratulations, praise, empathy, concerns or gratitude.</td>
</tr>
<tr>
<td></td>
<td>Seeking</td>
<td>A tweet asked for encouragement, comfort, congratulations, praise, empathy, concerns or gratitude.</td>
</tr>
</tbody>
</table>
Table 2: Themes and subthemes identified in ‘social support’ tweets posted by UK cancer and breast cancer charities.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Subtheme</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) Raising awareness</td>
<td>(1) Signposting</td>
<td>Tweets signpost women LWBBC from Twitter to alternative resources</td>
</tr>
<tr>
<td></td>
<td>(2) Raising awareness of ‘risk’</td>
<td>Tweets focus on understanding ‘risk’ and measures to reduce risk.</td>
</tr>
<tr>
<td></td>
<td>(3) Asking for help</td>
<td>Tweets ask those LWBBC for support</td>
</tr>
<tr>
<td>(2) Focusing on the future</td>
<td>(1) Promoting research</td>
<td>Tweets provide information relating to ongoing research relevant to the experiences of LWBBC</td>
</tr>
<tr>
<td></td>
<td>(2) Building ‘political’ support</td>
<td>Tweets predominantly relate to how charities lobby for continued focus on the needs of those LWBBC.</td>
</tr>
<tr>
<td></td>
<td>(3) A future without cancer</td>
<td>Tweets focus attention on defeating cancer.</td>
</tr>
<tr>
<td>(3) Sharing stories</td>
<td>(1) Celebrating others</td>
<td>Tweets celebrate those LWBBC; those who have died from breast cancer; and the work of charities.</td>
</tr>
<tr>
<td></td>
<td>(2) Sharing self</td>
<td>Tweets share the experiences of women LWBBC.</td>
</tr>
</tbody>
</table>