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Web psychosocial surveys in cancer survivorship – a methodological note

Abstract

Purpose: The number of internet surveys is increasing and there is a need to examine critically their value in psychosocial cancer care research. This study explored the use of an online method of recruiting and surveying people affected by cancer.

Methods and sample: An online survey was designed to measure the health status and service needs of adult cancer survivors and caregivers.

Key results: The online survey received 491 page visits; only 5% of visitors (13 survivors and 14 cancer caregivers) completed the online questionnaire. The average age of survivors and caregivers was 43- and 42-years, respectively. The majority of survivor and caregiver online respondents were female (23/27; 85%) and had been affected by cancer between 1-3 years previously (16/27; 59%).

Conclusions: Our online research did not appear to be an effective method for recruiting and surveying the psychosocial health of cancer survivors. This study identified potential pitfalls and obstacles of online cancer care surveys particularly in relation to the age of cancer survivors, access to the internet and the need to ensure surveys are easily and immediately accessible. Future internet surveys should pay particular attention to the need to advertise and improve survey access via targeted and tailored techniques.

Keywords: Cancer, cancer survivors, online survey, web surveys, methods

Introduction

Internet usage has increased exponentially within the past 20 years and approximately 10% (606 million) of the world's population are online (Eysenbach, 2003). In 2011, 19 million (77%) UK households had internet access with the majority of users accessing the internet more than once a month (ONS, 2012). A slightly higher proportion of men (86%) use the internet compared to women (81%), with young people (16-24 years) contributing to the largest proportion of users (Eysenbach 2003).

The internet appears to play a major role in daily life in western society and it is one of the most frequently accessed sources of health information (Williamson & Hocken, 2011). Approximately, 72% of internet users have recently searched for health information, with women more likely than men to go online and seek health information (Fox & Duggan, 2013). In addition, many people access support from online disease-specific 'communities' (Nabisan, 2011). In 2005, the term 'cancer' had an estimated 82 million hits using the search engine Google (Cooper, Mallon, Leadbetter, Pollack & Peipins, 2005). Patients and caregivers use the internet as a key source of information throughout the disease pathway with 60% accessing the internet at diagnosis, 71% during treatment and 56% following treatment (Van de Poll-Franse & Eenbergen 2008). The internet is continually expanding and its technological capabilities are increasing and it has the potential to make a significant impact on cancer care research (Holmes, 2009).

One of the major challenges faced by cancer care researchers is poor patient response rates. Various techniques (Nakash et al; 2006) have been trialled such as follow-up phone calls from General Medical Practitioners and providing free pens for questionnaire completion (Santin, Mills, Treanor & Donnelly, 2012). As response rates to postal surveys are poor and technology use is rising the number of online surveys is rapidly increasing (Buchanan & Hvizdak, 2009). The time and costs of data collection may be reduced by 78% by using the internet (Ashley et al., 2011). It may also have advantages in terms of reducing embarrassment or social awkwardness that may be associated with other methods of data collection (Ziebland et al., 2004). Published guidelines exist about how to conduct good quality online research (Eysenbach & Wyatt 2002; Eysenbach, 2004). For example, the potential for sample bias and the self-selection of participants should be taken into account. The online researcher must also overcome a number

of technical issues such as duplicate responses and the security or privacy of online responses (Eysenbach, 2004). The use of the internet to recruit cancer survivors, conduct surveys and improve response rates would appear to merit consideration.

Methods

The online survey was advertised to attract adult cancer survivors (who had completed their treatment and who were not in receipt of palliative care) and also adult caregivers. The study was approved by the National Research Ethics Committee (ORECNI).

The online questionnaire (which took approximately 30 minutes to complete) consisted of the following sections: socio-demographic questions (e.g. age, sex, employment); SF-36 health status questionnaire (Ware, Kosinski, & Keller, 1994); three items measuring health service use and satisfaction with services also used in the English Macmillan Health and Well-being Survey allowing comparability (Macmillan Cancer Support, 2008); an abbreviated and adapted version of Cancer Survivor Unmet Need (CaSUN) questionnaire (Hodgkinson, Butow & Hunt, 2007); and a single item self-reported late effects scale (Dische & Saunders 2003). An abbreviated version of the CaSUN was included to reduce the potential for participant burden. A scoping review of studies that used the CaSUN showed that cancer survivors regardless of cancer site had 7 common needs. Survivors indicated on the short version of the CaSUN if they experienced each need, whether the need was met or unmet and the severity of each need. Therefore standardised scoring was not affected.

A database and IT specialist and a Public Relations expert from Macmillan Cancer Support worked collaboratively with the researchers to develop the online survey. Participation in the survey required online registration after which the registrant was assigned a unique password which permitted access to, and completion of, the questionnaire. Only one completed questionnaire was permitted from each IP address. An alert was displayed to participants pointing them to relevant part of the survey when questions were skipped or unanswered.

A pilot study of the online survey was conducted with 5 cancer survivors and their primary caregivers in partnership with Northern Ireland Cancer Network and Macmillan Cancer Support. The pilot study was used to explore willingness to participate in an online survey and the

usability of the online survey. Pilot study participants were active volunteers in cancer charity organizations.

The finalised online survey went 'live' in November 2010 and ended in June 2011 via the Centre for Health Improvement (CHI), Queen's University Belfast website. In December 2010, the survey was advertised in local newspapers and from January- June 2011 it was advertised on the websites of all five Health and Social Care (provider) Trusts, Macmillan Cancer Support, Northern Ireland Cancer Network, Queen's University Belfast, local higher education colleges and on local caregiver and cancer charity websites. Posters advertising the online survey were sent to all Hospital Cancer Units, General Practice (primary care) surgeries and libraries in Northern Ireland. A poster pack was also sent to a random sample (N=100) of pharmacies. In February 2010, an advertisement appeared on the online accounts of all users who were registered as friends of Macmillan Cancer Support Facebook (approx. 300,000). Participants were required to click on a Macmillan questionnaire banner displayed on the website which opened a link to a joint Macmillan Cancer Support and Queens University web page; and then to click on the appropriate icon 'survivor' or 'caregiver'. Specific study and consent information was displayed to each group. Participants were requested to provide a user name, and email address upon which they received an email with log in details for completion of the questionnaire.

Results

In total, 350 people visited the online questionnaire advert via Facebook and 141 visited via adverts placed in newspapers and posters; only 13 survivors and 14 cancer caregivers completed the online questionnaire. The average age of survivors was 43 years and caregivers were 42 years. Responding survivors tended to be female (11/13) and were living 0-3 post diagnosis (8/13); and responding caregivers too were mainly females (12/14) providing care for survivors, 1-3 post diagnosis, for a range of different cancers (8/14).

Discussion

There was a very low participation rate despite the comprehensive and varied means of raising awareness about the survey among the cancer survivor population. A lack of incentives for participation may partly be responsible for the low participation rates. A meta-analysis of online

surveys suggests that offering incentives is beneficial in encouraging participation and retention (Goritz et al, 2006). Incentives in the form of online lotteries have been suggested to be beneficial in this respect (Doerfling et al, 2010). As this survey was funded and endorsed by Macmillan Cancer Support endorsements from other online cancer communities was not considered, there may be merit in considering this in future online surveys. The findings of this study highlight the complexities of internet research and the possibility that this method may not be transferrable to all patient groups. The lack of published research on internet surveys within cancer survivorship makes it difficult to make comparisons. A recent study however (Chou et al, 2011) suggested that cancer survivors use the internet less than the general population, this in part can be explained by social disparities in relation to age, education and ethnicity in the cancer survivor population (Chou et al, 2011).

Advertising on social network sites may not be an effective way to target the adult cancer population as only 18% of internet users aged 65 years+ use social networking sites (ONS, 2012) though it may be beneficial when trying to encourage research participation among a younger population. A recent survey has suggested that 71% of testicular cancer survivors are social media users, which would concur with the idea that social network sites may be useful to recruit younger cancer survivors. It should also be noted that Facebook is the most popular social network site with 67% of US internet users also using Facebook (Duggan & Brennan, 2012). The social network site twitter is also used by 16% of American internet users (Duggan & Brennan, 2012); perhaps advertising on twitter may have increased responses.

Advertising on discussion forums, in cancer centres and through cancer charities has been a successful mode of recruitment for internet surveys (Hodgson, 2004; Murray, 2004; Murray & Harrison 2004, Tschudin et al, 2010, Bender et al, 2012, Leonard et al, 2012). An online survey of chronic prostatitis patients that was advertised via a site-specific discussion forum received 180 respondents within a two month period (Alexander & Trissel, 1996); advertising via cancer advocacy groups yielded a sample of 473. Furthermore, cancer-specific internet mailing lists have been cited as a popular method of information and support-seeking for cancer survivors (Couper, 2000). Also, advertising surveys on popular search engines such as Google or Yahoo may increase accessibility and participation. Directly emailing cancer survivors may be beneficial in encouraging participation, as 1965 Breast cancer survivors participated in an online

survey within a two week period (Usher, Perz, & Gilbert 2012). Any future online surveys should consider obtaining email address from cancer organisations or medical records if appropriate. Contacting patients directly via email may help to simplify this process though emails may be misinterpreted as spam and deleted (Eysenbach & Wyatt 2002).

Approximately, 39% of UK households above the state pension age (65 years) have access to the internet compared to 79% of households below the state pension age (ONS, 2011). A significant proportion of the Northern Ireland population live rurally; internet connections and speeds have developed at a slower rate in these communities and they tend to have limited internet access compared to the urban centres because of these lack of or poor connections. Within rural areas there is little or no access to the internet via avenues such as internet cafes, or access at places such as a library as many rural towns do not have these facilities. Gaining access to the internet via mobile phones is also limited for cancer survivors who live rurally due to poor connections. It is unlikely however that a lack of mobile internet connection affected response as only approximately 8% of 65+ year olds in the UK use their mobile phones to access the internet (ONS, 2012).

It would appear that many survivors and caregivers did not have the skills or means to take part as the majority were above the state pension age (Maddams et al, 2009). Barriers to accessing health-related topics on the internet include physical access to the internet, motivation and lack of computer skills (Car, Lang, Colledge, Ung & Majeed, 2011). A combination of these factors may explain the poor uptake of this survey. Published guidelines for conducting effective email interviews suggest personal initiations, incentives and clear and concise information improves response rates (Couper, 2000).

Using the Centre of Health Improvement website as the 'home' for the survey may have reduced the potential for recruiting 'passers-by' as the general website was designed for university staff and not for patients or caregivers. A website that is visited frequently by patients and caregivers may be a more appropriate 'home' for online surveys, such as cancer specific forums (Hodges & Winstanley, 2012). Considering the total number of people who visited the site (491) compared to the number of people who completed a questionnaire (27), it seems reasonable to assume that barriers to participation occurred at this point. The process of obtaining 'permission' to log-in and to participate (as described above) may have been off-putting to prospective survey

participants. The process of participating online needs to be as simple and straightforward as possible and to allow respondents to move directly to questionnaire completion, this is evident in surveys which have had a high participation rate in a short period of time (Bunting et al, 2012). Limiting survey completion to one questionnaire per IP address may also have limited the potential for patients and caregivers in the same household to complete the survey. Future research should consider methods to ensure that the questionnaire is available to all family members whilst limiting the potential for multiple questionnaires completion by the same user.

In conclusion, online research does not appear to be an appropriate method of recruitment for people affected by cancer the majority of whom are elderly – at least not at this point in time. There are however, a number of important lessons to be learnt from this research particularly regarding where to situate online surveys and the need for immediate, easy and direct access to the survey. Web surveys may become a methodological option in the future as web use and the number of ‘silver surfers’ increases. Further research is required in order to develop sensitive, respectful and user-friendly online methods of capturing the experiences and views of cancer survivors and to test the validity and acceptability of these methods.

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