Widening Access to Online Health Education for Lung Cancer: A Feasibility Study

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ABSTRACT

Having lung cancer is associated with accessibility issues because people afflicted with lung cancer tend to be older and less familiar with technology, and have low education levels and low health literacy. Fear, embarrassment and stigmatization also play a role. This makes it difficult for people to access the information they need to understand and manage their illness, particularly in the time before the diagnosis. We can mitigate these disadvantages and bridge the accessibility gap by ensuring people at risk for lung cancer are informed about symptoms and when to seek medical advice. The Web is uniquely placed to fulfill this role. We therefore developed an online lung cancer symptom appraisal tool tailored towards people with low education levels and health literacy and based on psychological theory to target barriers like fear and embarrassment. At present we are conducting a feasibility study to assess whether it is possible to reach the high risk population and encourage early help-seeking. So far, 97 users have participated, 97.9% of which report symptoms and risk factors that indicate they should seek medical help. 34% report education levels below school leaving qualification. Our tool led to a significantly higher intention to seek medical help than the same information without theory-based components ($p = 0.01$). Our initial analyses suggest this is a suitable approach to widening health education to excluded groups.

Keywords: Health education; patient empowerment; online health information; lung cancer; symptom appraisal; feasibility

1. INTRODUCTION

Having lung cancer is associated with accessibility issues because people afflicted with lung cancer tend to be older and less familiar with technology, and have low education levels and low health literacy [13]. Older adults employ different search and retrieval strategies than younger adults and thus may have greater difficulty in performing health-related information searches [9]. Furthermore, people with low education and health literacy levels are less likely to engage with health services and lay health information sources [5]. Additionally, psychological barriers such as fear of cancer and embarrassment due to stigmatization often prevent individuals from seeking assistance for their illness [4]. Thus, people with lung cancer tend to be disadvantaged as they experience difficulty in identifying and assessing information needed to understand and manage their disease. This is particularly important in the time prior

to diagnosis, as appropriate health education about symptoms is lacking among those at high risk, and affected individuals often delay seeking medical help for a prolonged time [4].

Due to the vagueness and ambiguity of symptoms, people with lung cancer struggle to access relevant information prior to being diagnosed [4]. In addition, awareness for lung cancer symptoms is lower than for other cancer types, particularly among people with lower socio-economic status [12], and lung cancer is under-represented in the media [7]. This indicates that more needs to be done to promote education about lung cancer, and to ensure vulnerable individuals like those with low socio-economic status can access relevant information.

The Web provides a unique opportunity to reach this target population. The Web has become a primary source of lay health information and could thus be an important tool in promoting health education and facilitating access to health information for vulnerable, excluded groups. Many people in search of health information value the Web because it can deliver specific content, while also offering a large range of information that is often verified by professional bodies [6].

Web-based lung cancer information needs to be improved to ensure it is easily accessible and intelligible to the high risk group. One shortcoming of current online lung cancer information is that it is often static, lacking interactivity and personalization, which are linked to higher potential impact on decisions and behavior [8]. Moreover, current websites do not usually address psychosocial barriers to help-seeking such as beliefs, attitudes, fear and denial.

To address these barriers to information access, we developed a tool ('When2Go') which provides information on symptoms of lung cancer and when to seek medical help, tailored to the needs of older users with low health literacy. This tool provides personalized, theory-driven information to users. Personalization involves presenting specific symptoms and risk factor information to users based on their responses to an initial survey. The theory-driven components are based on the Theory of Planned Behavior [1], which has been successfully used in the field of education and technology adoption [11]. It explains intention to carry out a behavior (e.g. seeking help for symptoms) in terms of beliefs, norms and perceived control over the behavior. The theory-based components target psychological constructs related to help-seeking, such as fear. This constitutes a novel approach to online health education by combining medical content with psychological theory using a technical approach.

At present we are conducting a study to determine the feasibility of testing this tool in an online experimental trial. We aim to determine whether it is possible to reach vulnerable, excluded individuals, i.e. those in the high risk population for lung cancer who are older and reticent about engaging with health services and technology. We also aim to examine whether accessibility is improved by providing personalized, theory-based information.

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2. METHODS

After giving informed consent, participants are randomized to four possible experimental conditions (Figure 1). The conditions comprise three different versions of our tool to test the differential effects of information personalization and theory-driven content. The fourth ‘usual care’ (UC) condition was included to assess how our tool compared to existing websites about lung cancer. It was based on the ‘Lung cancer signs and symptoms’ page within the website of the Roy Castle Lung Cancer Foundation (www.roycastle.org).

Figure 1. Study procedure. TP: Theory-based, personalized information; T: Theory-based information (not personalized); P: Personalized information (not theory-based); UC: usual care; comprises the information presented on typical lung cancer symptom websites.

We hypothesize that participants in the theory-driven, personalized condition (TP) will report higher intention to seek help for symptoms after being exposed to the information than participants in the theory-driven (T) or personalized (P) conditions:

1. $\text{Intention}_{\text{TP}} > \text{Intention}_{\text{P}}$
2. $\text{Intention}_{\text{TP}} > \text{Intention}_{\text{T}}$

We hypothesize that participants in the T and P condition will differ in their reported intention, but make no prediction regarding directionality:

3. $\text{Intention}_{\text{P}} \neq \text{Intention}_{\text{T}}$

The When2Go tool is online and can be viewed at www.when2go-study.co.uk. When2Go content is written in lay terms and straightforward language at grade 8 of the Flesch-Kincaid Reading level test, to ensure it is intelligible to users with low educational and health literacy levels. Moreover, adopting a user-centric approach, it was developed together with a patient and public engagement group to ensure content is acceptable to the target population. It was also tested extensively using Think Aloud methods in a usability study. In the tailored conditions (TP and P), the tool presents personalized content to users by using server side scripting to evaluate choices made by users and return content associated with the data they provided. To begin, users are asked whether they have experienced any symptoms related to lung cancer. If affirmed, users are asked for details regarding their symptoms, i.e. how long they have had them and their intensity. Users are also asked to provide their age and smoking status. When2Go then amalgamates this information into a recommendation on seeking medical help, based on UK clinical guidelines. For example, a user who reports being aged above 40, a smoker, and having any of the symptoms for more than 3 weeks would receive a recommendation to seek medical advice.

In the theory-based conditions (TP and T) the tool includes components based on the Theory of Planned Behavior, a psychological theory detailing how beliefs and attitudes impact on intention to perform a behavior [1]. This consisted of quotes from health professionals targeting specific beliefs and attitudes that, according to previous work [4], are central to help-seeking. For example, the quote below targets the belief that presenting symptoms to health services will waste health professionals’ time.

“Many people wait for a long time with symptoms because they don’t want to bother the doctors. But you need to see a doctor if your symptoms don’t go away after 3 weeks, if you’ve coughed up some blood, or if your symptoms are sudden or severe.” Fiona Blackhall, Consultant Medical Oncologist

Because the tool content is based on UK clinical guidelines, we exclude participants from other countries (based on self-reported geographic location). The tool was developed using the Python Flask framework, which is a micro-framework based on the Werkzeug WSGI toolkit and the Jinja2 template engine. The use of HTML templates enabled us to present different content to users based on which condition they were allocated during randomization. User data were stored server side in an SQL database using an object relational mapper and the Python SQL toolkit SQLAlchemy.

A questionnaire at the end of the intervention assesses demographic details (age, sex, ethnicity, education level), participants’ self-reported intention to seek help for their symptoms on a scale from 1 to 7, as well as behavioral attitudes and beliefs about help-seeking. Website usage is monitored using Google Analytics.

All statistical tests are carried out with $\alpha < 0.05$ and using the statistical software package IBM SPSS Statistics V.22. Chi square tests are used to test for significant differences between experimental groups on categorical measures, and Cramer’s V is computed as a measure of effect size. Mann Whitney U tests with Bonferroni correction are used for pairwise comparisons, using the correlation coefficient r to assess the effect size. Effect sizes are assessed according to Cohen’s [3] conventions: small: .10, medium: .30, large: .50. Intended recruitment for the feasibility study is 30 participants per arm [2].

Users are eligible to take part if they have any undiagnosed symptoms that could be related to lung cancer (even if they can also be related to other medical conditions), such as persistent coughing, breathlessness or hemoptysis. To attract users to our website and recruit participants, we used several strategies, including advertisement via mailing lists, social media, other websites, and Google Adwords. The Adwords campaign focuses geographically on the UK and uses the search terms ‘lung cancer’, ‘coughing up blood’, ‘chest pains’, ‘persistent cough’, as well as synonyms and related terms.

3. RESULTS AND DISCUSSION

3.1 Is our website attracting the high risk population?

In the 8 weeks since the study was launched, 1,898 users have viewed the page; 487 (25.7%) reached the page via an organic google search, 127 (5.53%) via the Adwords campaign, 539 (28.4%) navigated to the link directly, 674 (35.5%) were referred from other websites (e.g. symptomfind.com) and the remaining 71 (3.7%) were referred via Social Media. The high proportion of organic searches indicates our website is findable to those researching their symptoms online. The website has a click-through

rate of 2.9% in its Adword Campaign, receiving 1,133 clicks after 39,076 impressions. The average click-through rate on Adwords paid search ads is 2%, suggesting our campaign resulted in above average click through rates.

We compared static feedback pages with personalized feedback pages in terms of attrition rates and found no significant differences for symptom information, risk factor information and the summary page. For the page providing theory-based information, however, we found a significantly higher attrition rate when it was static (30.8%) as compared to personalized (3.9%) ($z = -2.6, p = 0.01$). This suggests an important role of theory-driven content in engaging users of health websites.

Although we used a block randomization procedure to promote equal sample sizes across groups, differential dropout from the four conditions resulted in uneven sample sizes. More participants were recruited in the UC condition ($n = 42$) than in TP, P, and T ($n = 15, 17$ and 23 respectively). It seems plausible to assume lower attrition rates in the UC condition are related to shorter length of this condition, as previous research shows that users prefer concise health websites [14]. Thus our study has shown that it is infeasible to conduct this trial with varying lengths of the tool versions, as this leads to differential dropout, thus counteracting the randomization procedure and reducing the validity of our findings. A future study needs to ensure the tool versions are concise and of equal length to enhance comparability.

3.2 Are we engaging the target population?

Sample characteristics are shown in Table 1. So far, 97 users (mean age $M = 49.1, SD = 16.2, 18 - 83$ years) have completed our online study. The symptom most commonly reported by participants is coughing (81.4%), followed by back/shoulder/chest pain (64.9%). Based on UK clinical guidelines [10], we defined help-seeking as appropriate when any symptom reportedly persisted for 3 weeks or longer, or if it was reported as ‘severe’, or if hemoptysis, recurring chest infections or finger clubbing had taken place. Based on participant responses, help-seeking was appropriate in 97.9% ($n = 95$) of cases. This shows our intervention was successful in reaching individuals with symptoms warranting help-seeking.

Table 1. Sample characteristics. $N = 97$.

	n (%)
Male	30 (30.9%)
Female	67 (69.1%)
Below 40 years	23 (23.7%)
Above 40 years	74 (76.3%)
No formal education	3 (3.1%)
Secondary School	30 (30.9%)
School leaving qualification (e.g. A levels)	19 (19.6%)
Undergraduate degree	25 (25.8%)
Postgraduate degree	20 (20.6%)

The distribution of users across education levels (Table 1) indicates our tool engages users from a variety of educational backgrounds. A third (34%) report levels below school leaving qualification, demonstrating that our tool successfully retains users with low educational level. Only three participants report no education. Possibly, new advertising strategies need to be introduced to reach these individuals, such as advertisement in public social settings (e.g. pubs, local markets, sports clubs) and advertisement via housing associations.

3.3 Are we addressing barriers to accessing health services?

We were interested in whether participants’ self-reported intention to report to health services following interaction with our tool differed depending on personalization and theory-driven content, and therefore compared the TP, T, and P conditions (Figure 2).

Figure 2. Mean self-reported intention to seek help following exposure to three different version of our symptom appraisal tool: TP is theory-driven and personalized, P is personalized only, and T is theory-driven only. Error bars are 95% confidence intervals.

For pairwise comparisons between the three versions of the website, the significance level was adjusted using Bonferroni correction to account for inflation of Type I error across multiple comparisons ($\alpha_{adj} = 0.05/3 = 0.016$).

We found that the TP group ($n = 15, M = 5.58, SD = 2.4$) reported significantly higher intention to seek help than the P group ($n = 17, M = 3.5, SD = 2.0$), thus confirming hypothesis 1 ($p = 0.01, r = 0.46$). However the TP group did not differ significantly from the T group ($n = 23, M = 5.08, SD = 2.5$), which does not support hypothesis 2 ($p = 0.27, r = 0.12$). Self-reported intention in the T group was marginally significantly higher than in the P group ($p = 0.04, r = 0.34$). It should be noted that the study may be underpowered to detect this effect at present due to small sample sizes, because data collection is currently still underway.

Overall, the P group showed the lowest self-reported intention to seek help. The difference between the P group and the other two conditions is that P does not include theory-based information. Thus our results suggest the theory-driven component, which consisted of quotes from health professionals targeting psychological constructs such as worry about wasting doctors’ time, impacted positively on participants’ intention to seek help.

Effect sizes indicate that the difference between the TP condition and the P condition was larger than the difference between T and P (Table 2). This suggests theory-based information has a stronger impact on help-seeking when it is personalized than when it is presented in a static, generic format. We are unable to carry out an interaction analysis to confirm this effect as we did not include an unpersonalized, non-theory-based condition in the feasibility trial in an effort to reduce the number of conditions as we anticipated low recruitment rates. A future full trial should include this condition, so that a 2x2 factorial design is achieved and a two-way ANOVA with interaction analysis can be carried out.

The TP group did not differ significantly from the UC group ($U = 147.0$, $p = 0.21$). We hypothesize that the conciseness of the UC condition, which consisted of only one page whereas the other conditions consisted of 3-5 pages, meant that this information was read in more detail, increasing its impact on participants' intentions. Previous research indicates that users prefer concise online health interventions, particularly when health literacy levels are low [14].

Age was not significantly associated with intention ($r = 0.14$, $p > 0.05$). Education level was significantly negatively associated with intention to seek help ($r = -0.49$, $p < 0.01$), such that users with low education levels report higher intention. This could mean When2Go is successful in augmenting intentions among low education groups, though it could also mean it has no impact, or impacts negatively, on users with high education levels. Overall this indicates tailoring information to different educational levels may be beneficial and maximize impacts on subsequent behavior.

4. CONCLUSIONS AND FUTURE WORK

The vast majority of participants report symptoms which warrant help-seeking, and a third report education levels below school leaving qualification. This demonstrates that our approach is suitable for identifying and engaging high-risk individuals, though more strategies are needed to target individuals with education levels below Secondary School.

Furthermore, our findings suggest that theory-based content encourages help-seeking, as the condition lacking theory-based components lead to the lowest reported intention to seek help. This suggests we have identified a suitable method of addressing barriers like fear and embarrassment. Our findings regarding comparisons between the conditions need to be interpreted with caution, however, as these are only interim results and data collection is not completed yet.

The UC condition, which was also the shortest, retained more participants than the remaining three. The When2Go tool should be shortened for a future trial. This will enhance comparability across experimental conditions and may also improve recruitment rates. Moreover, this is likely to enhance engagement of users with the content, particularly for users with low health literacy.

Overall, our findings are promising in terms of recruitment rates and engagement with the website. It appears our advertising strategies have been successful in reaching the relevant user group. It also appears that including content based on psychological theory in health websites can empower individuals to make health decisions such as when to seek help for symptoms. Thus we have shown how online health information can play an important role in health education and patient empowerment. Our future experimental trial will allow more definite inferences, thus allowing us to make specific recommendations to health websites.

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