Modeling intention to participate in face-to-face and online lung cancer support groups

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Abstract

Background: Lung cancer patients and survivors are significantly less likely to use support groups than those with other cancers. In this study, we evaluated the utility and specificity of the Behavioral Model for Vulnerable Populations for modeling intention to participate in face-to-face (F2F) and on-line lung cancer support groups.

Methods: Adults diagnosed with lung cancer (*n* = 230) completed measures assessing predisposing, enabling, and need factors associated with intention to use support services.

Results: Intention to join a F2F support group (found among 36.4% of survivors) was associated with positive attitude about F2F support groups, fewer perceived time constraints, less travel time from the clinic, and not having enough social support. Intention to join an online support group (34% of survivors) was associated with having more positive attitudes about online support, greater use of avoidance coping strategies, more comfort using computers, and fewer perceived time constraints. Demographics, medical history, health status, and psychological status were not associated with intention to join either type of group.

Conclusions: Reducing barriers to participation and addressing attitudes about support services may be the most effective ways to increase utilization of lung cancer support services. Copyright © 2013 John Wiley & Sons, Ltd.

Introduction

One in 14 individuals will be diagnosed with lung cancer during their lifetime, and 55% are diagnosed after the cancer has metastasized. Studies have consistently shown lung cancer survivors to report higher distress than those with other cancer types [1–4]. Support groups may provide benefit to patients with distress by increasing personal self-efficacy and quality of life [5,6] and by reducing emotional distress and symptoms of depression and anxiety [7–9], yet few lung cancer survivors use support groups resources. The primary goal of the present report was to model intention to participate in face-to-face (F2F) and online support groups (OSGs) in those living with lung cancer in order to better understand how lung cancer survivors make decisions about participating in commonly available supportive services and how we might tailor support services to better reach those who are interested in using them.

We have previously estimated that 50% of those with lung cancer are interested in receiving some type of psychological service [10]. Despite strong interest in psychosocial services, lung cancer patients and survivors are significantly less likely to use support groups than those with other cancers [11,12]. A 2007 study estimated that fewer than 1% of lung cancer patients participated in support group services [12]. The 'participation paradox' between these patients' comparatively high levels of interest in psychosocial assistance and low levels of participation in available psychosocial treatments is poorly understood. In other cancer types, decisions to participate in support services have been linked with a number of factors, such as living far away from treatment facilities and travel time required to access services [13], busy home and work schedules [14], unwillingness to make a commitment to attend regular meetings [15], and disease progression [16]. Online support services have recently shown promise for overcoming time constraints and travel-related barriers to accessing support [17–20], but access remains limited [21].

A key limitation of the existing literature is the lack existing models to identify key correlates of interest in support services. The Behavioral Model for Vulnerable Populations (BMVP) [22] has been used as a theoretical framework for understanding use of support services in women with breast cancer [23] but is untested in those with lung cancer. According to the BMVP, a specific healthcare service is most likely to be utilized by those who (i) have an inclination to use the service (on the basis of the individuals' *predisposing factors*, e.g., demographics and health attitudes), (ii) are able to access the service (*enabling factors*, e.g., perceived barriers), and (iii) have a need to access the

service on the basis of health status (*need factors*) [24,25]. Having a valid model of intention to join either a F2F or OSG could inform our understanding of which patients and survivors might be most likely to access these services.

Because previous work suggests that correlates of use of F2F and OSGs differ considerably [11,13,21], a single model is not likely to apply equally to use of F2F and OSGs. In the present study, we sought to evaluate the utility and specificity of the BMVP for modeling lung cancer survivors' interest in F2F and OSGs. We hypothesized that predisposing, enabling, and need factors would be associated with interest for both F2F and OSGs but that the composition of these factors would differ for the two types of support groups. We hypothesized that lower levels of avoidant coping, higher problem-focused coping, greater mood disturbance, positive attitudes toward the support group modality, fewer time constraints, more need for social support, and fewer pack-years of smoking would be associated with interest in both F2F and OSGs. For F2F support groups, we anticipated that interest in joining would be associated with female gender, less distance from clinic, and better physical functioning. We hypothesized that interest in joining OSGs would be associated with younger age, greater familiarity with computers, and worse physical functioning. We also explored potential associations between other demographic (i.e., education, ethnicity, marital status, and income) and disease-related (i.e., disease stage and time since diagnosis) variables with interest in both intervention modalities.

Method

Participants

Participants were recruited from two cancer treatment facilities in Southern California—Loma Linda University Medical Center (LLUMC) and City of Hope (CoH). Both sites received institutional review board approval. Patients were eligible if they were at least 18 years of age, able to read and write in English, and had a previous diagnosis of lung cancer. Participants recruited from CoH were all within 6 months of their initial diagnosis, whereas those recruited from LLUMC were included regardless of time since diagnosis.

Procedures

Details of the recruitment procedure have been reported elsewhere [10]. At LLUMC, 75% of those who were contacted by mail or telephone provided verbal consent to participate, and 66% of these completed the study questionnaire. At COH, eligible participants were identified prior to their surgical or medical oncology appointment, and verbal consent was obtained during clinic visits. Interested patients were provided with the consent form, the study questionnaire, and a stamped return envelope. Approximately 80% of those who were approached consented to participate, and 64% of these completed

the study questionnaire. Of the final sample ($n = 230$), 155 were recruited from LLUMC (67.4%), and 75 were recruited from COH (32.6%).

Measures

Predisposing factors

For both F2F and OSG models, predisposing factors included age, gender, education (in years), ethnicity (white versus nonwhite), marital status (married versus unmarried), coping strategies, and attitudes toward support. Use of avoidant and problem-focused coping strategies specific to the experience of lung cancer was measured using the subscales of the COPE Inventory [26], a 60-item instrument that uses a 4-point Likert scale. Both subscales demonstrated good internal consistency ($\alpha = .72$ for avoidant coping; $\alpha = .82$ for problem-focused coping). Four dichotomous items were used to measure attitudes toward F2F and online support through OSGs: (1) 'a support group for lung cancer patients would be/not be helpful for him or her', (2) 'it would be/not be helpful for me to meet others with lung cancer', (3) 'I would feel comfortable/uncomfortable being part of a support group for lung cancer', and (4) 'it would be comfortable/hard for me to share my feelings with others in a lung cancer support group'. OSG attitudes were measured by replacing the term 'support group' with 'Internet support groups'. The four items were summed such that higher scores indicated more negative attitudes ($\alpha = .78$ for F2F; $\alpha = .90$ for OSGs).

Enabling factors

Enabling factors consisted of income, distance from the healthcare clinic, time required to participate, F2F-specific variables (difficulty traveling to a support group meeting), and OSG-specific variables (time/Internet access and computer familiarity). Time required to participate was measured with the following dichotomous item: 'It would/would not be hard for me to find the time to attend a lung cancer support group/Internet cancer support group.' With respect to F2F support groups, participants were also asked whether 'It would/would not be hard for me to travel to a lung cancer support group.' In regard to OSGs, participants were asked whether 'It would/would not be hard for me to access an Internet lung cancer support group.' Because of the high degree of overlap between the access item and the time item ($r = .57$), a composite 'time/access' variable was created for the OSG. For these variables, higher scores indicate a greater perception of barriers to joining. The composite computer familiarity variable ($\alpha = .83$) consisted of the following yes/no items: (a) 'Have you ever used a computer before?' (b) 'Have you used the Internet or E-mail to interact with others who have lung cancer?' (c) 'Have you used the Internet as a source of information about lung cancer?'

(d) 'Do you have a home computer?' (e) 'Do you have access to a computer outside your home?' (f) 'Do you have an E-mail account of your own?' (g) 'Can you access the Internet from home?' Higher scores on the composite computer familiarity variable indicated greater familiarity with computers.

Need factors

Disease stage, weeks since diagnosis, mood disturbance, physical functioning, smoking behavior, and social support were evaluated as potential indicators of need for support services. Mood disturbance was measured using a composite of the Center for Epidemiologic Studies Depression Scale (CES-D) [27] and the Impact of Event Scale—Revised (IES-R) [28]. The CES-D contains 20 items on a 4-point Likert scale to assess depressive symptoms. Internal consistency of the items was good ($\alpha = .79$). The 7-item intrusiveness subscale of the IES-R was used in the current study (e.g., 'Any reminder brought back feelings about it', and 'I had waves of strong feelings about it'), and the items exhibited strong internal consistency ($\alpha = .89$). Scores from the CES-D and IES-R were standardized and summed to create a composite mood disturbance variable. The 10-item physical functioning subscale of the 36-item Medical Outcomes Study Short Form-36 [29] was used in the current study to assess the impact of one's health on daily-living activities as well as ability to engage in moderate-to-vigorous physical activity. Need for support was assessed using a single dichotomous item: 'I have/could use support when it comes to coping with my lung cancer.' Intention to join F2F groups was indicated by the average of two items ($\alpha = .96$), rated on a 7-point Likert scale (1 = 'strongly disagree'; 7 = 'strongly agree'): (a) 'If a lung cancer support group were available at the place where I receive my medical care, I would be interested in being involved,' and (b) 'If a lung cancer support group were available at the place where I receive my medical care, I would become a member.' Intention to join OSGs was indicated by the average of two items ($\alpha = .99$), rated on the same 7-point Likert scale: (a) 'If a lung cancer support group were available to me over the internet, I would be interested in being involved', and (b) 'If a lung cancer support group were available to me over the Internet, I would become a member.'

Data analysis

To test the BMVP, intentions to participate in F2F or OSGs were regressed separately into predisposing, enabling, and need factors. A final multivariate model was tested using only salient independent predictors from the predisposing, enabling, and need factors. The Dunn–Bonferroni correction procedure was used to control type I error rates, resulting in a more restrictive p-value for each model

(i.e., $p < .006$ for predisposing and need factors and $p < .013$ for enabling factors). Power for the current study was analyzed using G*Power. Power to detect a medium-sized effect ($f^2 = 0.15$) on intention to join a support group was calculated for each model tested and varied from .83 for the regression of OSG intentions on the need factor (with nine independent variables tested) to .93 for regression of F2F and OSG intentions on the enabling factor (with four independent variables tested).

Results

Characteristics of participants

The sample as a whole was generally representative of the population of prevalent cases of lung cancer with respect to age, gender, and ethnicity. Full details of the sample are provided in Table 1. Few participants had ever used a support group (11.3%), and only 1.7% were currently attending support groups. On the basis of CES-D cut points, 37.6% of participants reported experiencing clinically significant levels of depression. The majority of participants had a home computer (83.8%) and accessed the Internet from home (77.8%), but most had not interacted with others who have lung cancer via the Internet (89.5%).

Modeling intention to participate in face-to-face support groups

Results of hierarchical and multivariate models predicting intent to join a F2F group are provided in Table 2. Positive intentions to join a F2F group (average intention > 4) were reported by 36.4% of participants. Predisposing factors (model 1) were not associated with intention to participate. Among predisposing factors, negative attitudes about F2F support was associated with lower intention to participate ($\beta = -.45$, $p < .01$). Enabling factors (model 2) uniquely explained 30% of variance in intentions to join a F2F group, $F(4, 39) = 4.14$, $p = .007$, $R^2 = .30$. Specific enabling factors included perceived difficulty finding time to attend a support group ($\beta = -.35$, $p < .05$) and greater distance from the clinic ($\beta = -.49$, $p < .01$), each associated with lower intention to participate. Model 3 included need factors, which were associated with intention to participate and explained 43.7% of the variance in intentions to join, $F(8, 37) = 2.30, p < .05, R^2 = .437$. The perception of having enough support in coping with cancer was related to lower intention to join an F2F group ($\beta = -.54$, $p < .01$). A multivariate model composed of significant univariate correlates from previous models (attitudes toward F2F support, distance from the clinic, difficulty finding time to join an F2F group, and having enough support) explained 39.6% of the variance in intention to join an F2F group, $F(4, 183) = 29.35$, $p < .001$. In the fully adjusted model, negative attitudes about F2F support groups ($\beta = -.36$ $p < .001$), difficulty finding time to

Table 1. Demographic characteristics of lung cancer patients' and survivors' predisposing, enabling, and need factors (*n* = 230)

Variable	x̄ (SD)	%
Predisposing factor		
Age (years)	67.1 (10.5)	
Gender (% female)		57.0
Education (number of years)	13.4 (2.7)	
Ethnicity		
White		81.1
African American		5.0
Asian-American		6.3
Latino		5.0
Other		2.8
Marital status (unmarried)		33.0
Coping strategies		
Avoidant	10.8 (3.2)	
Problem focused	20.3 (5.3)	
Attitudes toward support group membership		
OSG would be helpful to me		38.6
F2F group would be helpful to me		36.1
OSG meeting others with LC helpful		38.6
F2F meeting others with LC helpful		54.4
OSG comfortable with SG membership		38.2
F2F comfortable with SG membership		51.4
OSG comfortable sharing feelings in SG		47.3
F2F comfortable sharing feelings in SG		62.2
Enabling factor		
Median annual household income	55,166 (55,360)	
Distance to clinic (miles)	38.7 (49.0)	
OSG easy to find time		51.2
F2F easy to find time		40.9
OSG easy to access		56.9
F2F easy to travel		28.0
OSG computer familiarity	4.60 (1.9)	
Have a home computer		83.8
Can access the Internet from home		78.5
Have own email account		68.0
Have previously used a computer		81.1
Have used the Internet to gain LC information		53.5
Have used the Internet to contact others with LC patients		10.5
Need factor		
Physical functioning	45.0 (29.1)	
Depressive symptoms (CES-D)		37.6
Intrusive thoughts (IES-R intrusion)	8.7 (8.1)	
Clinical stage of disease		
Stage I		14.3
Stage II		9.4
Stage III		17.9
Stage IV		30.0
Uncertain		28.3
Time since diagnosis (weeks)	52.2 (75.1)	
Smoking behavior (pack-year history)	41.2 (32.0)	
Could use support for coping with LC		36.1
Intention to join group		
Degree of intent to participate in F2F	3.91 (1.92)	36.4
Degree of intent to participate in OSG	3.45 (2.02)	34

SD, standard deviation; SG, support group(s); OSG, online support group(s); F2F, face-to-face; LC, lung cancer; CES-D, Center for Epidemiologic Studies Depression Scale; IES-R, Impact of Event Scale—Revised.

Table 2. Regression analysis summary for lung cancer patients' and survivors' predisposing, enabling, and need factors predicting intention to join face-to-face (F2F) groups

Variable	B (SEB)	β	R^2
Predisposing factor			.253
Age (years)	.00 (0.5)	.01	
Gender (female)	.38 (1.02)	.05	
Education (number of years)	−.03 (.22)	−.02	
Ethnicity (white)	.32 (.98)	.05	
Marital status (unmarried)	.32 (.97)	−.13	
Coping strategies			
Avoidant	−.10 (.08)	−.02	
Problem focused	.06 (.17)	.06	
Negative attitudes toward F2F groups	−2.02 (.67)	−.45 **	
Enabling factor			.298 **
Annual household income	.00 (.00)	−.01	
Distance to clinic (miles)	−.04 (.01)	−.49 **	
F2F difficult to find time	−2.55 (1.10)	−.35 *	
F2F difficult to travel	.90 (1.17)	−.13	
Need factor			.437 *
Physical functioning	.04 (.02)	−.30	
Mood disturbance	.37 (.30)	.21	
Clinical stage of disease			
Unknown versus Stages I and II	.24 (1.36)	.29	
Stage III versus Stages I and II	2.25 (1.87)	.21	
Stage IV versus Stages I and II	1.82 (1.33)	.23	
Time since diagnosis (weeks)	−.01 (.01)	−.11	
Smoking behavior (pack-year history)	−.01 (.02)	−.07	
Have enough support for coping	−4.68 (1.28)	−.54 ***	
Multivariate model			.396*
Negative attitudes toward F2F membership	−.97 (.22)	−.36 ***	
F2F difficult to find time	−1.25 (.53)	−.16 *	
Distance to clinic (miles)	−.004 (.01)	−.04	
Have enough support for coping	−1.60 (.62)	−.20 *	

Four separate models are presented, and the variables are simultaneously entered for each model. R^2, total variance explained; β, standardized coefficient; B, unstandardized coefficient; SEB, standard error of the regression coefficient.
*$p < .05$.
**$p < .01$.
***$p < .001$.

Modeling intention to participate in online support groups

Positive intentions to join an OSG (average intention > 4) were reported by 34% of participants. Results of hierarchical and multivariate models are provided in Table 3. A set of predisposing factors (model 1) were associated with intention to participate in OSGs and significantly explained 47.3% of the variance of the model, $F(8, 42) = 5.71$, p 0.001, $R^2 = .473$. Only having more negative attitudes about OSGs was associated with lower intentions to participate in OSGs, ($β = −.68$ $p < .01$). Enabling factors in the second model significantly explained 62% of the variance in intention to join an OSG group, $F(4, 39) = 14.07$, $p < .001$, $R^2 = .62$. Greater computer familiarity was associated with stronger intentions ($β = .57$, $p = .00$), and difficulty finding time to access OSGs was associated with lower intentions ($β = −.38$, $p < .05$). Need factors (model 3) were not

participate ($β = −.16$ $p < .05$), and having enough social support ($β = −.20$ $p < .01$) remained significantly associated with lower intention to join an F2F group.

Table 3. Regression analysis summary for lung cancer patients' and survivors' predisposing, enabling, and need factors predicting intention to join online support groups (OSGs)

Variable	B (SEB)	β	R^2
Predisposing factor			.473***
Age (years)	.01 (.05)	.02	
Gender (female)	1.48 (.99)	.18	
Education (number of years)	.04 (.20)	.03	
Ethnicity (white)	−.08 (.95)	−.01	
Marital status (unmarried)	.61 (.88)	.08	
Coping strategies			
Avoidant	−.04 (.09)	−.05	
Problem focused	−.15 (.16)	−.13	
Negative attitudes toward OSGs membership	−1.73 (.31)	−.68***	
Enabling factor			.617***
Annual household income	.00 (.00)	−.09	
Distance to clinic (miles)	−.02 (.01)	−.16	
OSG difficult to find time/access	−1.97 (.60)	−.38**	
OSG computer familiarity	1.40 (.29)	.57***	
Need factor			.623
Physical functioning	.01 (.03)	.05	
Mood disturbance	.08 (.35)	.04	
Clinical stage of disease			
Unknown versus Stages I and II	−2.96 (1.63)	−.33	
Stage III versus Stages I and II	1.11 (2.16)	.09	
Stage IV versus Stages I and II	1.88 (1.54)	.21	
Time since diagnosis (weeks)	−.00 (.01)	−.03	
Smoking behavior (pack-year history)	−.03 (.02)	−1.24	
Have enough support for coping	−2.66 (1.52)	−1.76	
Multivariate model			.70***
Negative attitudes toward OSGs	−1.54 (.19)	−.58***	
OSG difficult to find time/access	−.35 (.34)	−.08	
Computer familiarity	.32 (.14)	.14 *	
Avoidant coping strategy	.06 (.05)	.07	

Four separate models are presented, and the variables are simultaneously entered for each model. R^2, total variance explained; β, standardized coefficient; B, unstandardized coefficient; SEB, standard error of the regression coefficient.

*$p < .05$.
**$p < .01$.
***$p < .001$.

associated with intention to participate in OSGs. A multivariate model including each of the significant univariate correlates from previous models explained 70% of the variance in intention to join an OSG, $F(4, 168) = 38.25$, $p < .001$. In the full model, only negative attitudes about OSGs ($β = −.58$, $p < .01$) and familiarity with computers ($β = .14$, $p < .05$) remained significant predictors of intention to join an OSG.

Conclusions

This study utilized the BMVP as a framework to identify predisposing, enabling, and need factor variables associated with intentions to join an F2F or OSG in those living with lung cancer. For F2F support services, the strongest correlates of intention to use these services were the availability of time to participate, distance from the clinic,

attitudes about the use of support groups, and the need for social support from others. Attitudes about F2F support groups were the most salient correlate of intention to join. These results have clear implications for the delivery of F2F services to those with lung cancer. Integrated, onsite psychosocial services and warm hand-offs between healthcare providers and psychosocial service providers have been shown to improve utilization of psychological care [30], and this type of integration could be highly effective in positively changing attitudes about psychosocial care. Additionally, very little is known about how attitudes about support groups or other psychosocial services develop or are maintained over time. Given the ongoing stigma associated with mental health services [31], further efforts to understand attitude formation will be important for optimizing the delivery of F2F psychosocial services for those with lung cancer.

With respect to OSGs, intention to join was associated most strongly with attitudes about online support, familiarity with the use of computers, and availability of time to participate in OSG. In addition to the stigma associated with mental health services, attitudes toward OSGs are also likely to reflect feelings of ambivalence about using the computer, rather than F2F contact, to obtain support from others. These feelings of ambivalence appear to be independent of one's familiarity and comfort in using computers. Such feelings of ambivalence toward computers and the Internet as a way of delivering support are common, even among new facilitators of Internet-based support groups for cancer [32], but it is important to note that, for many, such feelings often dissipate with experience using online services [33]. Whether attitudes about support (for F2F groups or OSGs) are malleable is a question that has not been addressed in the literature.

Somewhat surprisingly, our findings fail to replicate previously identified demographic correlates of support group use in survivors of other cancer types. Gender, age, educational attainment, and ethnicity were not associated with interest in either F2F groups or OSGs in adults living with lung cancer. Further, physical functioning and psychological functioning were independent of interest in either type of support service. This may be due to potential overlap between demographic characteristics and negative attitudes about support groups, which were both included as predisposing factors in block 1 of each model. In post hoc analyses, we found that older age ($r = .27$, $p < .001$) and lower levels of education ($r = −.24$, $p = .001$) were associated with more negative attitudes about F2F support groups. More negative attitudes about OSGs were associated with older age ($r = .25$, $p < .001$), being male ($t(193) = −3.59$, $p < .001$), and having lower levels of education ($r = −23$, $p = .002$). Thus, demographic factors are likely to effect interest in support group services but may exert their effects indirectly through attitude formation.

The present study has several limitations. First, we measured intention to join F2F and OSGs rather than whether or not participants went on to join such groups. It is important to note that at the time of the study, there were no nearby lung cancer-specific support services available to our participants and measurement of behavioral intention is commonly used as a proxy when it is not possible to capture actual behavior [34–36]. Second, additional research is needed to better understand factors, such as attitude formation about psychosocial services and perceived time constraints, that represent strong but nonspecific predictors of interest in F2F and OSGs. Although our models of intent to use F2F and OSGs explained a substantial 40% to 70% of the variance in behavioral intention, additional work is needed to replicate these findings and to identify other potentially salient indicators of interest.

Interest in both online and F2F support groups was moderate in this population (34% and 36%, respectively), with over 20% reporting strong interest in *both* types of support groups. We conclude that the BMVP can be successfully adapted to the prediction of interest in specific types of psychosocial services, with our models

explaining 44–70% of the variance in intent to join a group. Intent to join F2F and OSGs is not associated with demographic factors or physical or emotional functioning, suggesting that relying on common distress screening procedures [37] could overlook many nondistressed patients who might desire and benefit from psychosocial care but who might not otherwise receive a referral. Including nondistressed cancer survivors in support groups creates opportunities for social comparison and peer modeling that are likely of benefit for many distressed patients [38]. Additional research is needed to better understand the role of attitudes in connecting survivors with support services. It may be that attitudes are modifiable, particularly through having meaningful conversations with oncology care providers about psychosocial services [39].

Acknowledgements

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