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Attitudes toward a cancer coalition: Implications for coalition health communication

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ATTITUDES TOWARD A CANCER COALITION:
IMPLICATIONS FOR COALITION HEALTH COMMUNICATION

A Thesis

Submitted to the Faculty

of

Purdue University

by

Chervin Lam Shih Kian

In Partial Fulfillment of the

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For Jesus Christ, dad, and mom.

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ABSTRACT

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A cancer coalition is a communication hub for cancer patients that may help address cancer by promoting health and mitigating health issues. Attitudes toward a cancer coalition may be important in determining whether or not patients participate or utilize a coalition. However, little is known about the attitudes of cancer patients toward a cancer coalition, its services, and toward participation. This study addresses this gap by investigating these attitudes. The results encourage the development of a cancer coalition in states that do not yet have a coalition. Effective coalition health communication was found to be a pivotal service that cancer patients wanted and that could circumvent potential unfavorable attitudes.

CHAPTER 1. INTRODUCTION

Given that the number of cancer diagnoses is expected to rise (B. D. Smith, G. L. Smith, Hurria, Hortobagyi, & Buchholz, 2009), the need for organizations that may help mitigate the impact of cancer is increasingly pressing. A coalition is an example of an organization that may help address cancer. Specifically, a coalition may promote healthful outcomes through its services, including support groups, educational programs, advocacy, research, and its website. For instance, support groups may provide social support, which is positively correlated with healthful outcomes such as adherence to medical treatment, lower rates of morbidity and mortality, and improved physical and mental health (DiMatteo, 2004; Kroenke et al., 2013; Thoits, 2011; Uchino, 2006). In order for a patient to optimally benefit from a coalition, the patient should hold positive attitudes toward the coalition, which likely will lead to engagement with and participation in the coalition. Conversely, a patient with poor attitudes toward a coalition may not engage or participate fully in the coalition, thus forgoing potential healthful benefits. Although attitude is an important aspect that may influence a patient's level of involvement with a coalition (see Ajzen, 1991), little is known about the attitudes of patients toward a coalition, toward its services, and toward participation. Therefore, this thesis project addresses this gap in the literature by investigating these attitudes.

Coalitions often have a health issue focus, such as obesity, stroke, cancer, and so on. This study specifically considers cancer coalitions because cancer is a growing threat that needs to be urgently addressed (Bray, Jemal, Grey, Ferlay, & Forman, 2012; Bray, Ren, Masuyer, & Ferlay, 2013). It is essential to investigate attitudes toward cancer coalitions because negative attitudes toward a cancer coalition may mean that cancer patients do not engage or are not participating fully in a cancer coalition. For instance, cancer patients may not participate fully because they distrust a cancer coalition, feel that a cancer coalition will not be useful, or feel that a cancer coalition will not meet the needs of individuals (see e.g., Scherr & Mattson, 2012). Also, some cancer patients may have experienced unhelpful social support (see Helgeson & Cohen, 1996) and thus decide against cancer coalition participation. Cancer patients who do not participate in a cancer coalition may not experience the benefits of services provided by a cancer coalition, specifically benefits of support groups, educational programs, advocacy, research, and a coalition's website.

This study was conducted in Indiana, a state that has a cancer consortium, which essentially serves the same functions as a cancer coalition but caters to a wide range of groups and individuals, including patients, physicians, and researchers, among others. However, a patient-centric cancer coalition may be more beneficial for cancer patients as its services may be more targeted to and accessible for cancer patients. Patient-centricity refers to an exclusive focus on patients. For example, a patient-centric coalition website may contain information pertaining only to cancer patients instead of to patients, physicians, and researchers, and therefore information for patients is more accessible. In contrast, a coalition website that is not patient-centric may include information such as

events for physicians or grants for researchers, both of which are not pertinent to cancer patients. A cancer coalition that is patient-centric likely regards its patients as active participants in treatment and care and thus engages patients in a collaborative and relational manner (Epstein & Street, 2011). Therefore, in addition to investigating attitudes toward a cancer coalition, this study also examined attitudes toward the notion of a patient-centric cancer coalition. Specifically, this study investigated the attitudes of cancer patients toward the notion of a cancer coalition including its services, attitudes toward the notion of a patient-centric cancer coalition, attitudes toward participation, and why patients report those attitudes.

1.1 Cancer and Cancer Coalitions

In the United States, there were an estimated 1,665,540 new cancer cases and 585,720 cancer deaths in 2014 (Siegel, Ma, Zou, & Jemal, 2014). The number of cancer survivors is expected to increase and the costs of cancer care in 2020 are projected to be \$157.77 billion (Mariotto, Yabroff, Shao, Feuer, & Brown, 2011). In light of such looming statistics, healthcare organizations need to collaborate in preparation for the imminent increase in cancer cases and work together to assuage costs of healthcare. One approach to organizational collaboration is to form a coalition. A coalition is an alliance of people from various organizations who work together toward a shared goal (Sabatier, 1988; see also Weible et al., 2011) and involves a pooled network of people with a variety of relevant skills and knowledge (Lasker, Weiss, & Miller, 2001a; see also Lasker, Weiss, & Miller, 2001b). A cancer coalition may include physicians, nurses, cancer patients and survivors, grassroots communities, universities, and directors of hospitals and clubs that support cancer patients. Examples of cancer coalitions include

the Fatigue Coalition (Curt et al., 2000), Colorectal Cancer Coalition (Johnston, 2006), and the Breast and Cervical Cancer Coalition (Clark et al., 2009). A coalition may have several functions including outreach, education, and screening interventions (Kluhsman, Bencivenga, Ward, Lehman, & Lengerich, 2006). Coalitions also provide health advocacy and legal support or advice (see e.g., Mattson, 2010). A coalition often aims to improve the health outcomes of people with specific health issues. For example, a cancer coalition often will be focused on improving the health of cancer patients, particularly if the coalition is patient-centric.

A cancer coalition essentially is a communication hub that provides cancer patients with several avenues for communicating through the coalition with healthcare/legal professionals, researchers, and fellow patients. The services available through a cancer coalition allow cancer patients to express themselves, discuss and interact with other patients, obtain information, seek advice, and provide feedback to a cancer coalition. Services typically found through a coalition include support groups, educational programs, advocacy services, research, and a coalition website. These services are outlets that cancer patients may use to communicate: support groups allow cancer patients to communicate feelings and experiences with one another; a cancer coalition can communicate health-related issues or ideas to cancer patients through educational programs; advocacy services allow cancer patients to communicate legal/advocacy concerns to the cancer coalition; research provides an avenue for cancer patients to voice their concerns to researchers; a coalition website can relay health information to cancer patients and receive feedback from patients. Therefore, a cancer

coalition is a communication hub through which cancer patients may communicate with healthcare/legal professionals, researchers, and fellow patients.

1.11 Support Groups

Cancer coalition support groups may help promote better health in cancer patients and are an outlet for cancer patients to discuss and interact with one another. According to Cohen (2004), social integration and support can help one learn various approaches to managing a health issue, alleviate stress, and improve psychological well-being. Discussing coping strategies and sharing experiences may improve cancer patients' psychological welfare. For example, a cancer patient may feel less anxious when another cancer patient in a support group gives advice on coping with fatigue due to chemotherapy (see Goedendorp et al., 2012). Sharing in a support group also may contribute to a sense of similarity and identification among cancer patients. Cancer patients may identify with other patients who engage in healthful lifestyles and thus adopt similar healthful lifestyles (see Oyserman, Smith, & Elmore, 2014). Research also has shown that social support may contribute to other healthful outcomes such as adherence to medical treatment, lower rates of morbidity and mortality, and improved physical and mental health (DiMatteo, 2004; Kroenke et al., 2013; Thoits, 2011; Uchino, 2006).

1.12 Educational Programs

Educational programs are a channel for a cancer coalition to communicate health information and for cancer patients to obtain health information. According to Nutbeam (2000), health education can enhance health literacy, which is the ability to access, understand, and effectively use information for healthful purposes. Patients with poor health literacy may use healthcare services less effectively and have poorer health

outcomes, including having decreased ability to interpret labels and take medication appropriately, more hospitalizations and use of emergency care, poorer health status, and higher mortality rates (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011). A cancer coalition may be able to mitigate the negative consequences of low health literacy through its educational programs. Occasionally, coalitions initiate programs within communities to educate people concerning a specific health issue. Educational programs may inform people about a health issue, recommend solutions to address the health issue, and provide contact details of organizations and support groups to people who may need assistance or support. To complement educational programs, coalitions often have websites that provide helpful information for patients. An example of a coalition that conducts educational programs is the REACH coalition (see Clark et al., 2009), which educates members of the Boston community about health concerns that affect African Americans.

1.13 Advocacy Services

Advocacy services provided by a cancer coalition allow cancer patients to communicate legal concerns pertaining to their healthcare and for seeking legal advice. Advocacy in the context of health involves championing for changes in public policy or regulation so there may be better health outcomes (Lupton, 1994). For example, the Indiana Amputee Insurance Protection Coalition advocated for prosthetic parity in 2008 and successfully persuaded legislators to create a new policy that made prosthetic limbs more affordable (Mattson, 2010). Another example is the National African American Tobacco Prevention Network's effort in 2004 to abolish Kool, a flavored cigarette that targeted African American youth. The network was successful in abolishing Kool and

was awarded a \$1.4 million settlement (Freudenberg, Bradley, & Serrano, 2009). A cancer coalition may provide advice on conducting advocacy, recommend professional advocates to cancer patients, or engage in advocacy on behalf of cancer patients. A cancer coalition can be an effective channel for advocacy because of its extensive network, which allows cancer patients access to legal or advocacy professionals, or for garnering support for an advocacy initiative.

1.14 Research

Research within a cancer coalition allows cancer patients to communicate their experiences to researchers so that better cancer treatment solutions may be developed. Cancer patients may help inform researchers regarding patient receptivity toward various treatments, effects of medication, and effectiveness of treatment, among others. Some coalitions have a primary focus on research. For example, the Fatigue Coalition, which is comprised of patient advocates, medical practitioners, and researchers from various fields, was formed to study the issues of fatigue in cancer patients and to develop treatment guidelines (Curt et al., 2000). Another example is the Colorectal Cancer Coalition, which was formed as an international platform for addressing issues surrounding the colorectal cancer community (Johnston, 2006). When a coalition does not have a primary focus on research, the coalition usually posts relevant research findings on its website. For example, a cancer coalition may post information on research about the prevalence of cancer or coping strategies for cancer patients. Therefore, research in a cancer coalition is important because it can provide useful information for cancer patients. Also, research projects allow cancer patients to communicate treatment experiences to researchers so that better treatment solutions may be developed.

1.15 Coalition Website

A coalition website may be a useful communication outlet for cancer patients to obtain information regarding the aforementioned services such as support groups and advocacy initiatives. Cancer patients also may use a coalition website to provide feedback for improving a cancer coalition's services. Cancer patients may use a cancer coalition's website to obtain health-related information. In a study by Tustin (2010), cancer patients who did not obtain sufficient information, empathy, and quality time with their oncologist had a greater preference for finding health information on the internet. Without a website, communication between cancer patients and a cancer coalition may be inconvenient or difficult. For example, a cancer coalition's contact information may be more difficult to find without a website. Consequently, a lack of feedback may decelerate the growth or improvement of a cancer coalition. Therefore, a cancer coalition should have a website to cater to the information needs of cancer patients. The cancer coalition website also may provide information regarding the aforementioned services such as support groups and advocacy initiatives.

Given that the number of cancer diagnoses is expected to rise (B. D. Smith, G. L. Smith, Hurria, Hortobagyi, & Buchholz, 2009) and the number of new cancer cases in states such as Indiana is estimated to be 35,560 in 2014 (Siegel et al., 2014), organizations that promote better health for cancer patients may increasingly be necessary. A cancer coalition is one example of an organization that may help promote healthful outcomes for cancer patients. However, in order for cancer patients to utilize a cancer coalition effectively, cancer patients need to have positive attitudes toward a cancer coalition (see Ajzen, 1991); conversely, negative attitudes may lead to poor

participation and forgoing of potential healthful benefits. Little is known about the attitudes of cancer patients toward cancer coalitions and their services, therefore this thesis project explores these attitudes, which may be critical for influencing participation levels in cancer coalitions.

This project was conducted in Indiana, a state which has a cancer consortium that functions as a coalition but caters to a range of groups and individuals, including patients, physicians, and researchers, among others. However, a patient-centric cancer coalition may benefit cancer patients in Indiana as it may be more accessible for those patients. For example, a patient-centric cancer coalition may be more accessible for patients because its website may include information that only pertains to cancer patients. Thus, information about research plans, grants, meeting schedules for practitioners, and other information not relevant to cancer patients would not be included on the website. If cancer patients have greater accessibility to the services of a cancer coalition (i.e., support groups, educational programs, advocacy services, research, website), cancer patients may have greater accessibility to the benefits stemming from those services. Thus, in addition to investigating attitudes toward the notion of a cancer coalition and its services, this study also investigated attitudes toward the notion of a patient-centric cancer coalition.

1.2 Attitudes

It is necessary to investigate the attitudes of cancer patients because negative attitudes toward a cancer coalition may result in ineffective or nonutilization of the cancer coalition. On the other hand, positive attitudes toward a cancer coalition may translate into participation in the cancer coalition. According to Krosnick, Judd, and Wittenbrink (2005), attitude is defined as the net evaluation of an object. For example, a

cancer patient's attitude toward a cancer coalition will be the evaluation of the cancer coalition and its associated objects, including evaluation of its support groups, educational programs, advocacy resources, research resources, and website. This thesis project adopts a processing framework posited by Krosnick and colleagues (2005) as the theoretical basis for how an attitude is developed and processed. The processing framework is comprised of three phases: (1) the automatic activation phase, (2) deliberation phase, and (3) response phase.

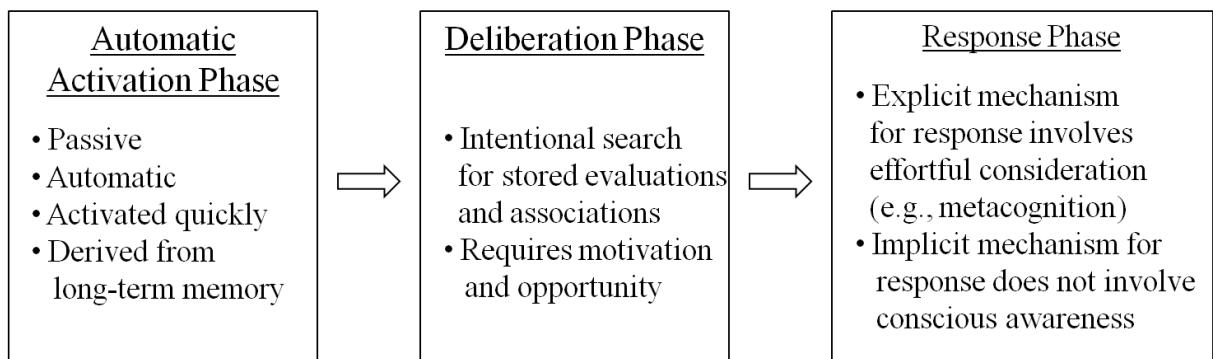


Figure 1: Attitude processing framework

1.21 Automatic Activation Phase

The automatic activation phase involves the initial evaluation processing of an object (e.g., a cancer coalition). This process is passive, automatic, and occurs without conscious effort (Krosnick et al., 2005). The automatic processes are believed to be a result of frequent and repetitive experiences with an object (Shiffrin, & Schneider, 1977). For example, if a cancer patient has repeated negative experiences with a cancer coalition, the patient may strongly and spontaneously associate “bad” when evaluating a cancer coalition. Other associations linked to the evaluated object (e.g., support groups, educational programs, website, etc.) also may be activated and may shape subsequent

responses (Krosnick et al., 2005). For example, a cancer patient asked to evaluate a cancer coalition again may report “lousy support groups” or “poor educational programs.” These associations may be derived from long-term memory (Krosnick et al., 2005; e.g., Morris, Squires, Taber, & Lodge, 2003) and are activated within a few hundred milliseconds after encountering the object to be evaluated (Krosnick et al., 2005). Automatic activation depends on accessibility and consistency of the attitude (Krosnick et al.). Therefore, automatic activation may be triggered especially for strong attitudes, which are more accessible and consistent. For example, a cancer patient who had memorable quarrels (therefore accessible) with staff members of a cancer coalition on numerous occasions (therefore consistent) may likely have strong attitudes against cancer coalitions. Consequently, the automatic activation of “bad” likely may occur for that cancer patient when evaluating cancer coalitions.

1.22 Deliberation Phase

After the initial activation phase, the deliberation phase may follow. The deliberation phase involves an intentional search for stored evaluations and relevant associations of the object being evaluated (Krosnick et al., 2005). For example, the deliberation phase occurs when a cancer patient retrieves a stored evaluation such as “I liked the cancer coalition from where I used to live” and other relevant associations such as “the educational programs in cancer coalitions are helpful.” Motivation and opportunity are necessary for the deliberation phase to take place; without motivation and opportunity, the deliberation phase will not occur and a person’s evaluative response will stem significantly from the automatic activation phase.

A person may be motivated to consider what his or her attitude is when there is a positive consequence associated with making an accurate response and/or costly consequence associated with making an error in judgment (Krosnick et al., 2005). For example, a cancer patient may be motivated to answer accurately if there is a financial incentive (e.g., gift card) given for responses (see Deutskens, De Ruyter, Wetzels, & Oosterveld, 2004) and if perfunctory responses would result in rescinding of the financial incentive. Motivation to deliberate also may be initiated by internal factors. For instance, certain individuals may enjoy thinking (Cacioppo & Petty, 1982) and thus be more inclined to engage in effortful consideration. Also, individuals may be motivated to deliberate if they feel that the object being evaluated (e.g., cancer coalition) is personally significant. For example, a cancer patient may feel that the topic of a cancer coalition is personally significant and therefore invest effort to deliberate on responses.

Opportunity to deliberate also must be present in order for a person to intentionally consider evaluation (Krosnick et al., 2005). Opportunity to deliberate is present if an individual is consciously aware of the object being evaluated and has cognitive resources for deliberation. In contrast, opportunity to deliberate is not present or limited if there is no conscious awareness of the object evaluated and if cognitive resources are strained. For example, a person engaging in multiple tasks simultaneously may have limited cognitive resources available for evaluating an object in addition to performing those multiple tasks. Opportunity to deliberate also may be hampered by physical restraints. For example, cancer patients who undergo chemotherapy may experience fatigue (Goedendorp et al., 2012) and therefore be too tired to engage in effortful deliberation.

1.23 Response Phase

The response generated automatically or by deliberation may be shaped by explicit or implicit mechanisms. The former occurs when there is deliberation, and the latter occurs when an individual is unaware of the connection between evaluation and response (Krosnick et al., 2005). For example, explicit mechanisms are active when a cancer patient ponders about a cancer coalition, concludes that a cancer coalition is good, and provides justifications for why a cancer coalition is good. Metacognition, which involves reflecting on primary cognitions such as evaluations (Scannell & Grouzet, 2010), may be considered an explicit mechanism (Krosnick et al., 2005). For example, if a cancer patient had negative experiences with staff workers in a cancer coalition, the patient may be concerned that the initial evaluation of a cancer coalition was affected by the negative experiences and therefore correct the evaluation so that a more balanced evaluation is reported.

Implicit mechanisms may operate when an individual is not consciously aware of the evaluation. For example, a cancer patient may see a background image of a cancer coalition and have an unconscious evaluation of a cancer coalition. Subsequent responses toward associated objects such as support groups may be influenced by the unconscious evaluation of the cancer coalition. For instance, an unconscious negative evaluation of a cancer coalition may result in negative responses to objects associated with the cancer coalition such as support groups. Another possible way that implicit mechanisms may operate is when an individual does not recognize the link between evaluation and response. For example, a cancer patient may deliberately evaluate a cancer coalition and later evaluate associated objects such as support groups, educational programs, and

advocacy services, but not recognize the connection between evaluating the associated objects and a cancer coalition.

This study adopts the described processing framework as the theoretical basis of how attitudes are developed and processed. Reflection and metacognition by participants in this study are expected because the methods (i.e., focus group and surveys) promote deliberation. Therefore, the expected process of attitude reporting in participants is activation, deliberation, and explicit response. Also, because attitude is a net evaluation (see Krosnick et al., 2005), the attitudes that cancer patients have toward the services of a cancer coalition are important as these attitudes may affect patients' overall attitude toward the coalition. Therefore, this study examines attitudes toward the idea of a cancer coalition and its associated services in order to more comprehensively understand cancer patients' attitudes toward a cancer coalition.

1.3 Attitudes Toward a Cancer Coalition

Research has shown that there may be a connection between attitudes and health outcomes. For example, patients with poorer attitudes toward treatment recommendations may have poorer adherence to treatment, and vice versa (see Horne, 1999; Horne & Weinman, 1999). Therefore, attitudes may determine the extent in which an individual partakes in (or disengages from) healthful routines and thus reap (or forgo) the benefits of those routines. Additional research supports the connection between attitudes and health outcomes. Ajzen's (1991) Theory of Planned Behavior positions attitudes as one of three main factors that determine a person's intention to produce a behavior, the other two factors are subjective norms and perceived behavioral control (see also Fishbein & Ajzen, 1974). For example, if a cancer patient has favorable attitudes toward a cancer coalition

(assuming favorable subjective norms and perceived behavioral control too), the cancer patient likely will enact an intention to participate in the cancer coalition. If so, the cancer patient may benefit from the healthful outcomes stemming from the cancer coalition's support groups, educational programs, and so on (see e.g., Oyserman et al., 2014).

Conversely, a cancer patient with negative attitudes toward a cancer coalition unlikely will participate in a cancer coalition and thus forgo the potential benefits of a cancer coalition. Currently, little is known about the connection between attitudes toward a cancer coalition and attitudes toward participation in a cancer coalition. This study posits that cancer patients with favorable attitudes toward the idea of a cancer coalition will likely be more favorable toward the idea of participating in a cancer coalition.

Conversely, cancer patients with unfavorable attitudes toward the idea of a cancer coalition will likely be more unfavorable toward the idea of participating in a cancer coalition. Based on the review of literature, the following hypothesis is advanced:

H1: Cancer patients' attitudes toward the idea of a cancer coalition will be positively correlated with their attitudes toward the idea of participating in a cancer coalition.

Most individuals respond favorably to beneficial goods or services. Given that a cancer coalition should be beneficial to cancer patients, this study postulates that cancer patients will have favorable attitudes toward the idea of a cancer coalition. In particular, cancer patients who have favorable attitudes to the associated services are posited to have favorable attitudes toward the cancer coalition. This is because attitude is a net evaluation (see Krosnick et al., 2005) and thus attitudes toward the services should affect overall attitude toward the cancer coalition. Conversely, cancer patients who have unfavorable

attitudes about the associated communication services are posited to have unfavorable attitudes toward the cancer coalition. Therefore, the following hypothesis is advanced:

H2: Cancer patients' attitudes toward services through a cancer coalition (i.e., support groups, educational programs, advocacy services, research, and website) will be positively correlated with their attitudes toward the idea of a cancer coalition.

Access to services may be better in a patient-centric cancer coalition than a coalition that is not patient-centric. If this is the case, cancer patients should report more favorable attitudes toward the idea of a patient-centric cancer coalition as opposed to a coalition that does not specify patient-centricity. Thus, the following research question is posed:

RQ1: Cancer patients will report more favorable attitudes toward the idea of a patient-centric coalition than a coalition that does not specify patient-centricity.

The reasons behind reported attitudes toward the notion of a cancer coalition also should be explored. In other words, why do cancer patients report favorable or unfavorable attitudes toward the idea of a cancer coalition and its services? In addition, the views of cancer patients in regards to how a cancer coalition may best serve cancer patients also should be investigated. The answers to these research questions may assist in understanding the needs of cancer patients in relation to a cancer coalition and how a cancer coalition may be structured to better serve cancer patients. The following research questions are posed to address these inquiries:

RQ2: Why do cancer patients have favorable/unfavorable attitudes toward the idea of a cancer coalition and its services?

RQ3: What services/aspects does a cancer coalition need to have to best serve cancer patients?

Investigating these attitudinal concerns is important as this investigation may inform researchers and health professionals about whether cancer patients have favorable attitudes toward the notion of a cancer coalition and would fully participate in a coalition, or have unfavorable attitudes toward the notion of a cancer coalition and not participate or not effectively participate in a coalition. Understanding these attitudinal concerns also may help inform the feasibility, demand, and necessity (or the lack of) for a patient-centric cancer coalition in the state of Indiana. If cancer patients in Indiana have favorable attitudes toward the concept of a cancer coalition and are willing to be involved in the coalition, the development of a patient-centric cancer coalition in Indiana may be a reasonable option because patients likely will utilize the coalition. Understanding why those patients report favorable or unfavorable attitudes can help inform whether a patient-centric cancer coalition is needed. For example, if cancer patients in Indiana report favorable attitudes because they have legal concerns related to cancer that such a cancer coalition may address, a patient-centric cancer coalition likely is needed.

The findings of this study also may have theoretical import. Specifically, the findings may inform the connection between attitudes toward an attitudinal object (e.g., coalition) and its associated objects (e.g., support groups, website, etc.). If the connection is a positive correlation, future studies may explore how one may enhance attitudes toward associated objects so that attitudes toward the main object may improve. The findings of this study also may be applied to areas that are not health-related, such as in political attitudes and participation. For example, future studies may explore how

enhancing attitudes toward community events, outreach programs, and government websites may improve attitudes toward that government entity. Also, the findings of this study may inform the connection between attitudes toward an organization and attitudes toward participating in the organization. If the connection is a positive correlation, future studies may examine how one may enhance attitudes toward an organization so that participation in the organization may improve. For example, a study may attempt to enhance attitudes toward a community event, outreach programs, and government websites so that attitudes toward that government entity may improve, and so that community services may increase.

Therefore, investigating the attitudes of cancer patients toward the notion of a cancer coalition is important because it provides insight into whether or not a patient-centric cancer coalition in Indiana is needed. Further, the findings may suggest theoretical contributions that may be applied to health-related concerns and also in areas that are not health-related.

CHAPTER 2. METHOD

This study utilized mixed methods to investigate attitudes of cancer patients toward the idea of a cancer coalition. Specifically, surveys and focus group interviews were conducted. Participants were recruited from referrals of partner organizations that collaborated with a cancer research center within a large Midwest university. A total of four local partner organizations provided access for meeting and recruiting members of its organizations (i.e., cancer patients) for the surveys and focus group interviews. The survey and focus group methods address the hypotheses and research questions.

2.1 Participants

A total of 96 cancer patients and caregivers consented to take the survey; 88 (92%) participants completed the survey. Of these 88 participants, 75 identified themselves as cancer patients and 13 identified themselves as caregivers. For the focus group interviews, there were 3 focus groups, 6 participants in the first group, 7 participants in the second group, and 6 participants in the third group.

2.2 Survey

The survey method is an effective technique for investigating attitudes (see Krosnick et al., 2005). Several considerations went into the survey design including, choice of open or closed-ended questions, number of points on rating scales, and labeling of rating scale points. Open-ended questions allow participants to answer questions in

their own words. In contrast, closed-ended questions only permit participants to respond with the choices provided. Open-ended questions are not frequently used in attitude measurement, perhaps because they can be too time-consuming and complex to utilize. For example, if attitudes of 100 cancer patients were measured using open-ended questions, it may take coders too much time and effort to sort out 100 different responses and to compare responses. Thus, closed-ended questions are a more efficient option and therefore were utilized in this study.

The number of points on rating scales in a survey can affect reliability and validity of the measurement (Krosnick et al., 2005). Thus, consideration must be given to the number of points used on rating scales. For example, rating scales with too few points may not allow for accurate reporting of attitudes, while too many points (e.g., 10 and above) may be excessive and redundant. As a guide, the number of points should adequately reflect the spectrum of an evaluative dimension. For example, the evaluative dimension may be comprised of more evaluations than just “like,” “dislike,” and “neither like nor dislike,” and also may include “somewhat like” and “somewhat dislike.” In addition, the points on rating scales must have different meanings and the meanings should be clear for participants to interpret. According to Krosnick and colleagues (2005) scales with more points (i.e., two or more) have greater reliability and scales with a moderate number of points have greater validity. However, reliability and validity diminishes when there are too many points on a scale (e.g., above 11). In view of this and related findings, Krosnick and colleagues indicated that a 7-point scale may be optimal (see also Lozano, García-Cueto, & Muñiz, 2008; Preston & Colman, 2000). Using a 7-point scale also implies that there is a midpoint, such as “neither like nor dislike.” The

inclusion of midpoints may risk encouraging satisficing, which occurs when participants provide cursory and satisfactory responses as opposed to optimal responses that require thorough reflection (Krosnick, 1999). Satisficing may occur when the survey is too difficult, the participant's cognitive ability is low, or the participant is not motivated to optimize. Given that the survey in this study only had a few questions, the survey should not be considered difficult. Also, participants' cognitive abilities were not expected to be low and participants were expected to be motivated to optimize because the survey topic is related to cancer, a condition that is very pertinent to the participants. Therefore, satisficing was unlikely for the participants in this study. Moreover, Krosnick and colleagues (2005) suggested that the inclusion of a midpoint would enhance reliability and validity of ratings and is desirable. Thus, this study employed a 7-point scale survey.

Another consideration was the labeling of rating scale points. Krosnick and colleagues (2005) posited that reliability is greater when all points are labeled with words compared to when only some points are labeled. Furthermore, participants are more satisfied when there are more labeled points on a rating scale. Labeling points on a rating scale may help participants understand the correct interpretation of those points. For example, a rating scale may have the labels "like a lot," "like moderately," "like a little," "neither like nor dislike," "dislike a little," "dislike moderately," and "dislike a lot" for points on the scale. This will circumvent potential confusion that may arise if a scale that did not have all points labeled was used. The survey point labels in this study utilized "like/dislike" for rating scales and avoided a traditional Likert (1932) approach, in which statements are provided for participants to indicate the extent which they "agree/disagree" with those statements. The latter approach may trigger acquiescence and

was avoided. Acquiescence is the inclination to endorse the assertion made in a statement, regardless of content (Krosnick et al., 2005). For example, if a survey using the traditional Likert approach has a statement that says, “I am in favor of a cancer coalition because of the advocacy services,” some participants may simply respond “agree” even though they may not read or understand the statement. Thus, to avoid acquiescence, this study did not provide statements typical in traditional Likert-scale approaches. Instead, participants were directly asked to evaluate their like or dislike for something. For example, a question in the survey may ask “To what extent would you like the idea of a cancer coalition having support groups?” Each question in the survey was followed by a fully-labeled rating scale which covers the spectrum of “like” to “dislike.” This approach will help avoid acquiescence and enhance reliability and validity (Krosnick et al., 2005). Therefore, the survey used closed-ended questions, a 7-point scale, and labeled points on rating scales.

The survey in appendix A was used to address the hypotheses and RQ1. The survey included questions that examined the extent to which participants would like or dislike the services of a cancer coalition (i.e., support groups, educational programs, advocacy services, research, website). Specifically, these questions were indexed as number 3, 5, 7, 9, and 11 on the survey. Following each of these questions were questions that examined the extent to which participants would like or dislike *using/participating in* those services. Specifically, these questions were indexed as number 4, 6, 8, 10, 12 in the survey. For example, question 3 asked participants the extent to which they would like or dislike a cancer coalition having support groups, and question 4 asked participants the extent to which they would like or dislike participating in a cancer coalition’s support

group. The survey also included question number 13, which examined the extent to which participants would like or dislike the idea of a cancer coalition. H1 would be addressed by comparing question number 13 with questions that examined the extent to which participants would like or dislike using/participating in the services (i.e., question number 4, 6, 8, 10, 12). In order for H1 to be supported, both question number 13 and question number 4, 6, 8, 10, and 12 must generate favorable ratings; other instances would result in H1 being unsupported. A rating of “I like the idea a little,” “I like the idea moderately,” and “I like the idea a lot” constituted favorable ratings. In contrast, “I dislike the idea a little,” “I dislike the idea moderately,” and “I dislike the idea a lot” constituted unfavorable ratings, and “I neither like nor dislike the idea” was regarded as a neutral rating.

H2 would be addressed by comparing questions that examine attitudes toward the services (i.e., question number 3, 5, 7, 9, 11) with question number 13 (i.e., attitude toward cancer coalition). In order for H2 to be supported, both the former and latter questions must have favorable ratings; other instances would result in H3 being unsupported.

RQ1 would be tested by comparing question number 13 with question number 14. Both questions examined attitudes toward the idea of a cancer coalition, but only question number 14 specifies patient-centricity. RQ1 would be supported if question number 14 generated higher favorable ratings than question number 13. RQ1 would not be supported if question number 14 had lower favorable ratings than question number 13.

The bivariate correlation approach was used to test H1 and H2, and the paired samples T test was used to test RQ1 (see Sprinthall, 2012). The statistical software,

Statistical Package for the Social Sciences (SPSS), was used to run the bivariate correlations and paired samples T test analyses.

2.3 Focus Groups

A focus group is a planned discussion with a small group of people regarding a specific topic (Guest, Namey, & Mitchell, 2013). Focus groups can be used to complement other methods such as quantitative techniques (Lindlof & Taylor, 2011). In particular, focus groups often are used along with surveys (Morgan, 1996). This study conducted focus groups to complement the survey so that a better understanding of participant attitudes may be achieved. Specifically, the focus group interviews could help address the *why* aspect (Guest et al., 2013) of attitudinal experiences. The focus group interviews may provide further insights into reported attitudes and may help answer the study's research questions. For example, if in the survey, cancer patients report positive attitudes toward the notion of a cancer coalition, focus group interviews may probe why those positive attitudes were reported. For instance, patients may have reported positive attitudes because those patients liked the idea of having more educational programs through the coalition. Focus groups are useful for extracting richer information for research (Hydén & Bülow, 2003) and, therefore, is an optimal method for addressing RQ2 and RQ3 in this study.

According to Rabiee (2004), several scholars recommend three or four focus groups for less complex research questions, with six to eight participants in each group (see also Krueger & Casey, 2009). Following this recommendation, this study conducted three focus groups, with six participants in the first group, seven in the second, and six in the third group. Participants in the focus group also should be homogeneous (Hydén &

Bülow, 2003), which this study adhered to by recruiting only cancer patients/survivors and a few of their caregivers. Caregivers needed to be present because of the medical conditions of cancer patients in the focus group. However, inclusion of those caregivers did not compromise homogeneity because their experiences are closely tied to the cancer patients they provide care for. After transcribing the dialogue from the focus groups, inductive thematic analysis (see Guest et al., 2013) was used to extract reasons for the attitudes reported. The inductive thematic analysis process utilized open coding and in vivo coding (Lindlof & Taylor, 2011). The former involved examination of data in the transcript, line by line, to extract themes, while the latter involved selecting terms used by participants in the focus groups. For example, open coding would have occurred if “support” was the extracted theme from the transcripts, and in vivo coding would have occurred if “care” was determined to be a recurrent word choice in the transcripts. The constant-comparative approach involved consistent coding and comparing of incidents and was used in this study to narrow down extracted themes. Through this filtering process, repeated themes were eliminated and the most compelling and relevant themes and terms remained. Nvivo, a software program for qualitative research, was used throughout the process. Nvivo is useful for inductive thematic analysis as it helps with coding and categorizing of emergent themes.

The dialogues from the three focus groups in this study were transcribed, themes were extracted from the data, and convergent themes were grouped together. For example, if “support groups” and “community support” emerged from analysis of the data, those themes would have been converging and grouped as a reason (e.g., “support”) for reported attitudes. On the other hand, if “support groups” and “financial profit”

emerged from analysis of the data, those themes would be divergent and would be classified as two different reasons. Triangulation across focus groups was used to ensure validity (Lindlof & Taylor, 2011). Specifically, emergent themes were compared across data from all three focus groups. If all themes derived from the three groups resonated and were congruent, there would be strong validity. For instance, if “support” was a recurring theme throughout the three focus groups, the validity of “support” as a reason for reported attitudes would be strong. In contrast, if data from one focus group produced a theme that was not apparent in the data of the other two focus groups, that theme may have low validity. For example, if the theme “financial profit” emerged from the data of one focus group but not in other focus groups, the theme “financial profit” may have low validity. If there was such a theme with low validity, more focus groups would have been conducted until similar themes emerged. If the additional focus groups did produce similar themes, the theme with low validity would have been reported as a theme with low validity.

RQ2 would be addressed by asking participants in the focus groups if they are in favor of or against the idea of a cancer coalition and its services and why they are in favor of or against the idea. The participants’ views would be examined through inductive thematic analysis and emergent themes would be grouped into two categories: reasons for favorable attitudes and reasons for unfavorable attitudes. For example, the theme “support” may be listed as a reason for favorable attitudes and “uncertainty” may be listed as a reason for unfavorable attitudes. The constant-comparative approach would ensure that redundant or overlapping reasons would be subsumed by a broader reason.

For instance, “support groups” and “community support” would be subsumed into the broader reason, “support.”

RQ3 would be addressed by asking participants what aspects of a cancer coalition may be improved to better serve cancer patients. RQ3 also would be examined through the inductive thematic analysis and constant-comparative approaches. For example, “expand support to include caregivers” may be a theme that emerged during coding. If another converging theme such as “expand support to smaller counties” emerged, both themes would have been grouped under a broader theme such as “expand area of support.”

CHAPTER 3. RESULTS

A survey and three focus group sessions were conducted. The survey was administered through Qualtrics, an online survey software. Participants who completed the survey were given a \$5 gas gift card as an incentive. The focus group sessions were held at locations conducive for research and convenient for participants, such as in a conference room at a large Midwest university or in a room at a local cancer-care organization. Participants who attended the focus group sessions were each given a \$5 gas gift card as an incentive.

3.1 Survey

The survey was used to address H1, H2, and RQ1. Specifically, bivariate correlations were used to test H1 and H2, and a paired samples T test was used to determine RQ1.

H1. H1 posited that cancer patients' attitudes toward the idea of a cancer coalition will be positively correlated with their attitudes toward the idea of participating in a cancer coalition. In order to address H1, question number 13 was tested with questions 4, 6, 8, 10, and 12 for possible correlations. Using SPSS to test for a bivariate correlation, a significant positive correlation was found between attitudes toward the idea of a cancer coalition (i.e., question 13) and attitudes toward the idea of participating in a cancer coalition (i.e., questions 4, 6, 8, and 10). Specifically, a significant positive correlation

was found for attitudes toward the idea of a cancer coalition and attitudes toward participating in a cancer coalition's support group, $r(75) = .55, p < .01$, attitudes toward participating in a cancer coalition's educational health program, $r(75) = .51, p < .01$, attitudes toward using advocacy/legal services provided by a cancer coalition, $r(75) = .53, p < .01$, attitudes toward participating in a cancer coalition's research, $r(75) = .45, p < .01$, and attitudes toward obtaining information from a cancer coalition website, $r(75) = .44, p < .01$. Therefore, given that attitude toward the idea of a cancer coalition has a significant positive correlation with attitudes toward the idea of participating in a cancer coalition at $p < .01$, H1 is supported. Table 1 provides a summary of the bivariate correlations.

Table 1: Bivariate Correlation for H1 (2-tailed)

		Participatin g in support groups	Participating in educational programs	Using advocacy/leg al services	Participatin g in research	Using websit e
Attitude toward cancer coalitio n	Cancer patients (n = 75)	.55**	.51**	.53**	.45**	.44**
	Sig.	.00	.00	.00	.00	.00
	Caregiver s (n = 13)	.73**	.54	.59*	.59*	.94**
	Sig.	.01	.06	.04	.03	.00

** $p < 0.01$

* $p < 0.05$

H2. H2 advanced that cancer patients' attitudes toward services through a cancer coalition (i.e., support groups, educational programs, advocacy services, research, and website) will be positively correlated with their attitudes toward the idea of a cancer coalition. In order to address H2, questions 3, 5, 7, 9, and 11 were tested with question

number 13 for possible correlations. Using SPSS to test for bivariate correlations, a significant positive correlation was found between attitudes toward associated services (i.e., questions 3, 5, 7, 9, and 11) and attitudes toward the idea of a cancer coalition (i.e., question 13). Specifically, a significant positive correlation was found for attitudes toward the idea of a cancer coalition and attitudes toward the idea of a cancer coalition having support groups, $r(75) = .74, p < .01$, attitudes toward the idea of a cancer coalition having educational health programs, $r(75) = .62, p < .01$, attitudes toward a cancer coalition having advocacy/legal services, $r(75) = .63, p < .01$, attitudes toward a cancer coalition also focusing on research, $r(75) = .39, p < .01$, and attitudes toward a cancer coalition having its own website, $r(75) = .43, p < .01$. Therefore, given that attitudes toward associated services are significantly and positively correlated with attitudes toward the idea of a cancer coalition at $p < .01$, H2 is supported. Table 2 provides a summary of the bivariate correlation of the above variables.

Table 2: Bivariate Correlation for H2 (2-tailed)

		Support groups	Educational health programs	Advocacy services	Research	Website
Attitude toward cancer coalition	Cancer patients (n = 75)	.74**	.62**	.63**	.39**	.43**
	Sig.	.00	.00	.00	.00	.00
	Caregivers (n = 13)	1.00**	.61*	.75**	.84**	.94**
	Sig.	.00	.03	.00	.00	.00

** $p < 0.01$

* $p < 0.05$

RQ1. RQ1 posited that cancer patients will report more favorable attitudes toward the idea of a patient-centric coalition than a coalition that does not specify patient-

centricity. A paired samples T test was used to answer RQ1. Specifically, question number 14 was compared with question number 13 across all participant responses. A mean difference of 0.19 was found in and therefore the difference was not statistically significant. That is, attitudes toward the idea of a patient-centric coalition and non patient-centric coalition were the same. This may have been so because participants may not have been certain what the difference was between patient-centric and non patient-centric coalitions. Another possibility may be that participants favored the idea of a cancer coalition so much that ratings for both types of cancer coalition were too high ($M_{\text{patient-centric}} = 6.69$, $M_{\text{non patient-centric}} = 6.51$) to observe substantial mean difference. In any case, participants favored the notion of a cancer coalition. Table 3 below presents a summary of the paired samples T test results:

Table 3: Paired Samples T Test (2-tailed)

	Attitude toward patient-centric cancer coalition	Attitude toward cancer coalition	Mean difference
Mean (Cancer patients) (n = 75)	6.69	6.51	.19
Standard deviation	.64	.83	
Mean (Caregivers) (n = 13)	6.62	6.31	.31
Standard deviation	.87	1.1	
95% confidence interval			

3.2 Focus Group Interviews

RQ2 asked “why do cancer patients have favorable/unfavorable attitudes toward the idea of a cancer coalition and its services?” RQ3 asked “what services/aspects does a cancer coalition need to have to best serve cancer patients?” RQ2 and RQ3 were addressed through analyzing the dialogue with focus group participants. Using inductive

thematic analysis (see Guest et al., 2013), themes that addressed RQ2 and RQ3 were extracted and categorized. Through the constant-comparative approach, repeated themes were eliminated and the most compelling and relevant themes remained. As a note, the thematic analysis conducted through Nvivo documented that participants had more reasons for favorable attitudes toward the idea of a cancer coalition than for unfavorable attitudes.

3.21 Reasons for favorable attitudes. There were four reasons for favorable attitudes that emerged from inductive thematic analysis. Specifically, these were (1) shared resources, (2) may benefit other people, (3) potentially useful for them, and (4) directs patients to centralized information. Table 4 provides the number of times that these reasons were coded during inductive thematic analysis.

Table 4: Theme Frequency Count (Favorable)	
Reasons	Count
Shared resources	5
May benefit other people	3
Potentially useful for them	9
Directs patients to centralized information	4
Total count	21

Shared resources. Some participants had favorable attitudes toward a cancer coalition because they believed that there would be shared resources. These participants felt that sharing of resources could help cancer patients in general. For example, one participant said: “I think it would be good to be able to pull together the good ideas that can help the total.” This perspective resonates with Roberts-DeGennaro’s (1987) suggestion that a coalition may help in gaining resources and bringing in new ideas, perspectives, and technologies.

May benefit other people. The belief that a cancer coalition may benefit other people was another reason for favorable attitudes toward a cancer coalition. For example, one participant said:

Yeah I guess I wonder, I feel like my needs were met, but I'm right here in Indianapolis, where there are a lot of resources. Yeah but there might be people in other parts of Indiana that don't have a cancer support center.

Thus, some participants were in favor of a cancer coalition because they felt that there may be people who do not have adequate support and would benefit from a cancer coalition. The concern seemed to be about health inequity, which may involve people having similar needs but dissimilar access to resources, or people having greater needs but not given greater resources (Starfield, 2011).

Potentially useful for them. Some participants were favorable toward the idea of a cancer coalition because they felt that a cancer coalition may potentially be useful for them. For example, one participant said: "If it's something that could help me, you know, I'll be there." Although these participants were open to the concept of a cancer coalition, most wanted more information about the cancer coalition, such as what it will entail and how it will work. One participant compared the notion of a cancer coalition with the concept of hospice. Specifically, the participant suggested that, like hospice services, people may initially be uncertain about a cancer coalition and only understand its benefits at a later time. The participant said:

I happen to think of, you know, how many years ago did hospice start? And the strange feelings we went through about "what are you doing? What is hospice doing?" And yet that has served a tremendous amount of

people... But until that's really spelled out, then it's hard to say "well certainly! You know, I would come, I wanna be part of it."

Thus, although some participants felt that a cancer coalition may potentially be useful for them, these participants wanted more information regarding the cancer coalition. This will be addressed further in RQ3, which looks into the aspects of a cancer coalition that may be improved to better serve cancer patients.

Directs patients to centralized information. Some participants were in favor of the notion of a cancer coalition because they believed that a cancer coalition may help direct patients to centralized information. Centralized information may be desirable because online information can often be challenging and arduous to navigate. For example, one participant said:

It's so overwhelming, I agree. When I first got my diagnosis and there was all these options and stuff, it was all very overwhelming. And if there could be one place to go and, you know, have all the resources and, you know, bet the phone number is all the resources they gonna all be physically located together. I think that would be helpful.

This finding resonates with literature describing how patients can sometimes feel overwhelmed by health information (Eysenbach, 2003; Skinner, Biscope, Poland, & Goldberg, 2003). Thus, centralized information may circumvent the feeling of being overwhelmed by providing relevant information in one accessible location. Another participant also felt that centralized information would be helpful and said: "I think it's a good idea from the standpoint that you would have more generalized information, and the information would be... everyone would be seeing the same thing." Another patient also

was in favor of centralized information, and indicated that an organization with a large network (such as a cancer coalition) could be responsible for the centralized information.

That participant said:

... if you're diagnosed in Indiana and you say "oh, here's a resource for you, that will help you, it's a big network, you can use it as you like, it has different agencies, you know, and here's how you can maneuver through it, to help you one-on-one or in support group, or you know." ... maybe that would have been helpful.

In addition, a participant felt that centralized information may help cancer patients with a variety of concerns that often may be pertinent to them, such as nutrition, health bills, and insurance concerns. One participant said:

... you wanna learn more about nutrition or you wanna learn more about how to manage your health bills or insurance questions, things like that, where you had these different avenues that you can go to, but at the center of this is this coalition and they give this to you and say "... you are a new cancer patient in Indiana. If you wanna use our resources here it is. If you go to a local hospital then go do something else. You know, but here is what we have to offer in Indiana." I would be definitely open to something like that.

Therefore some participants were favorable toward the idea of a cancer coalition because they believed that a coalition could help direct cancer patients to centralized information. These participants felt that centralized information could help cancer patients navigate through different questions or concerns related to cancer.

3.22 Reasons for unfavorable attitudes. There were three reasons for unfavorable attitudes that emerged from the inductive thematic analysis of focus group data. Specifically, these reasons were (1) overlapping concerns, (2) need more information about coalition, and (3) network or resource concerns. Table 5 provides the number of times these reasons were coded during inductive thematic analysis.

Table 5: Theme Frequency Count (Unfavorable)

Reasons	Count
Overlapping concerns	5
Need more information about coalition	10
Network or resource concerns	2
Total	17

Overlapping concerns. There were participants who expressed unfavorable attitudes toward the idea of a cancer coalition because of overlapping concerns. Specifically, their concern was: what would a cancer coalition do that current cancer-care organizations do not already do? These participants were concerned that services from a cancer coalition may be redundant as current cancer-care organizations may already be offering similar services. For example, one participant said:

Why wouldn't they get that from cancer services? What is it that a coalition would offer that an independent cancer services or another organization might not offer? You know, and I'm not saying it's not good, I just want to know what it is they would offer.

However, participants were not strongly opposed to the idea of a cancer coalition. Rather, they wanted more information about how a cancer coalition could contribute in a way that current cancer-care organizations are not already contributing. This was reflected in

one participant's response:

It's just... It's like ok, that's not to say that we wouldn't want to be a part of that. I think it's important to be a part of that. But, what is it that a coalition is gonna enhance I guess?

Therefore, a cancer coalition may need to be intentional in conveying the uniqueness of its services so that cancer patients do not perceive those services as overlapping or redundant.

Need more information about coalition. The need for more information about the cancer coalition was a reason for unfavorable attitudes toward the idea of a cancer coalition. Specifically, participants were unsure about what the cancer coalition would offer and how it would operate. One participant said:

I guess I'd have to see a little bit more about what it looks like. I'm still kinna confused. I mean, erm. I'm still kinna confused as to who would be coordinating all that.

Some participants were uncertain about how a cancer coalition would operate. For example, one participant expressed her concern: "If I lived in Indiana and I receive treatment in Illinois, which cancer coalition am I a part of?" Another participant also expressed similar concerns when she said:

I'm not sure how this consortium would uh... what would it, who would it report to? How would that... you get a group of people that get out there and then, what does that information, where would it go?

However, participants were not strongly opposed to the notion of a cancer coalition.

Instead, their apprehension stemmed from wanting more information. For example, one

participant commented: “I think that there are things that would be helpful for us in Indy that we’re not meeting some needs somewhere or other... [I’m] open for. I just want information, you know.” One participant wanted evidence to show that a cancer coalition would be useful in Indiana. The participant said:

You could do a coalition, small, large, medium, you know, we are saying Indiana, why? Are there any other states where we have examples and say that this has worked for cancer patients or this has not worked for cancer patients? You know where do we have the pluses and minuses of examples elsewhere that would say Indiana would need something different?

The need for more information about a cancer coalition echoes results of studies that examine patients’ need for health information (see e.g., Jenkins, Fallowfield, & Saul, 2001; Rutten, Arora, Bakos, Aziz, & Rowland, 2005). That is, patients often desire information pertaining to their health concern, and, therefore, it should not be surprising that participants desired more information regarding a cancer coalition.

Network or resource concerns. Some participants voiced concerns about how a cancer coalition would network and share resources effectively with partner cancer-care organizations. One participant had a misconstrued perception that resources would be withdrawn:

In my experience I didn’t have any problem finding resources. You know, so I, to me it feels like a new coalition it would be, yeah overlapping. And I am afraid that it would draw resources away.

However, such concerns may be dispelled by providing accurate and relevant information concerning the coalition. Such concerns reinforce the need for a cancer coalition to engage in effective health communication with cancer patients, an aspect that will be addressed when answering RQ3.

Although the above themes may be categorized as unfavorable attitudes, it should be noted that the focus group participants were not strongly against the idea of a cancer coalition. Rather, participants were apprehensive because they had uncertainties regarding the cancer coalition, such as concerns over resources and overlapping services. Thus, the extent of the unfavorable attitudes seemed to be minor. On the other hand, favorable attitudes seemed to be strong. This was reflected in the greater number of coded reasons for favorable attitudes than for unfavorable attitudes. Therefore, it seemed that favorable attitudes in the focus groups outweighed unfavorable attitudes toward the idea of a cancer coalition.

3.23 What a cancer coalition needs to have. In response to RQ3, participants in the focus groups suggested four aspects that a cancer coalition needs to have: (1) effective health communication, (2) include involvement of cancer survivors, (3) expanded scope of support, and (4) a positive environment. Table 6 below shows the number of times that each reason was coded during inductive thematic analysis.

Table 6: Theme Frequency Count (Coalition Needs)

Reasons	Count
Effective health communication	13
Include involvement of cancer survivors	1
Expanded scope of support	4
A positive environment	5
Total	23

Effective health communication. Participants felt that a cancer coalition should have effective health communication. Specifically, participants felt that cancer-related information and the cancer coalition's purpose should be effectively communicated to cancer patients. Participants desired useful, current, and accessible information, particularly cancer-related information. For example, some participants wanted explanations for their medical concerns. One participant said:

Some second party can help straighten things out, because we have lots of friends, you know, not only with cancer but other diseases, they just don't know what the medical profession is really telling.

Participants wanted a cancer coalition to have a website that provided cancer-related information. Participants wanted the information to be current, updated, and not overwhelming with details. One participant specifically wanted statistical information, saying:

I'd like to see some statistics... Well about the mastectomy or lumpectomy. I mean, that's a big decision to make, and usually the doctor wants to make the decision for you. And so I would like some information about that. If they're pushing lumpectomies how many people go? How many years? You know, and don't have a recurrence in that same breast? You know. Those type of statistics. How many people like have a mastectomy? Did they have a recurrence in the other breast? Or what? What's going on with all that? You know. Some of those things I think would be helpful in making the decision whether you want to have a mastectomy or lumpectomy. More information about that. That kinna thing.

Two participants dialogued and suggested a true/false section on the website. They said:

A: ... *I'm going to make broad statements – like, mammograms are rarely right. They are hardly ever right, and you should have 2 or 3, and then, then they're probably not right. And if you eat cauliflower a day, your risk of having cancer is 80 percent less. I mean I'd like some of these things that, when we were in our group when I say "did you hear about this? They got a cure for breast cancer by doing x, y, and z?" Then they'll say "no, no. That's not right. That was blown out of the water." I would like, when they come out with things, you know, they tell us about, you know, that we don't have to hear it 3 years later.*

B: *Maybe they would do a little research and give a statement about true or false or something.*

A: *It'll be like Snoops. Have you ever gone to Snoops? You know, just to see if it's true or not. Because I'll read an article and I'll think "Yeah." And then I'll find out it's not true.*

B: *And most of the public media wants you to do that.*

A: *Yeah! Yeah. So I get very confused. I mean I was even, I even heard or gone TV or Reddit and it said "a huge percentage of mastectomies were not needed. They shouldn't have done them. That there wasn't even any breast cancer there."*

B: *Well they also were saying that bilateral were not necessary.*

A: *Yeah, I mean it's stuff like that when you hear it kinna knocks the pins out from under you. It makes you feel like "what was I – a fool?" You know, did the medical profession use me as a guinea pig? Or am I just, stupid? You know. So I'd like to be treated as somebody that has a brain. And that, you know, they can tell me things. You know, they seem to love to tell you if you've got cancer, but*

they don't seem to want to tell you about the research, and, you know, things that would [...] impact my life. You know, 'cause I know a lot of people now that you know, [our friend] has it 3 times, our friend's had it 3 times and, it scares me. You know, I don't wanna walk around being scared all the time.

Besides wanting effective communication of cancer-related information, participants also wanted the purpose of a cancer coalition to be effectively communicated to cancer patients as well. For example, one participant suggested:

I'm like "what else am I missing?" You know what else is out there? So that would be my view. I would be for it if it hold it all together in a way that people can understand them, what the purpose is, and how to utilize it most effectively.

Importantly, some participants suggested that cancer patients should be informed about the existence of a cancer coalition if it is developed. Cancer patients who are not informed may not be aware that there is a cancer coalition. One participant said:

People may not know to ask. I mean, who do you ask? And if it's available, and the center or, even a doctor's office, somehow to get people, to get them to know about it. Because it doesn't make any difference if it's there if they're not communicated with, if they're not told.

Therefore, effective health communication is a critical aspect that a cancer coalition needs to have. Specifically, a cancer coalition should provide accurate, accessible, current, and relevant cancer-related information. Additionally, a cancer coalition should effectively communicate its purpose and services to cancer patients.

Include involvement of cancer survivors. Besides effective health communication, it may be important to include involvement of cancer survivors in a

cancer coalition. One participant expressed this, going to the extent of implying that people who have been through cancer are “real people”:

There's this personal side, emotional side, there's the reality of the health bills, there's the, you know, how do you live through chemo? Do you work, do you not work? But, there's such a reality that there's, I don't know, I would get real people involved in this that have been through cancer.

It may be important to include involvement of cancer survivors in a cancer coalition because cancer patients may respond better to such individuals. For example, cancer patients may be encouraged by someone who is similar and has already overcome the battle with cancer (Taylor & Lobel, 1989). Also, cancer patients may feel that a cancer survivor may better empathize and relate to their experiences with cancer (Thoits, 1986).

Expanded scope of support. Another aspect which participants felt a cancer coalition needs to have is an expanded scope of support. For example, support from a cancer coalition also should be extended to the families and caregivers of cancer patients. This concern resonates with Buhse's (2008) finding that providing care can take a toll on the caregiver. Two participants said:

A: *I would probably suggest expanding that to their families... because that affects them as much as, if not more, in many ways than patients. To deal with it.*

B: *Yeah exactly, the whole family has to come up with a new “normal”.*

Another participant voiced concern regarding the availability of support for cancer patients in smaller counties. Because smaller counties may lack resources such as social services (see Ruben & Pender, 2004), cancer patients may not have access to services from a cancer coalition. The participant said:

you know we're fortunate here in our county, we're the larger county 'cause there's resources, but people who live in the smaller counties are just... there's just nothing available, you know, it's very very difficult for them. And if you're in treatment, you know, financially, emotionally, physically, you're drained, you're not gonna drive, you know, 45 minutes into Fort Wayne to go to something.

Other participants suggested that a cancer coalition should extend its support to focus on people who are newly diagnosed with cancer. One participant said:

Well, the question you had before about how to manage cancer and uh to me, right when the diagnosis of cancer comes, that first month or two, is the most critical time. And so that cancer coalition could really offer assistance there in managing and helping them sort through all the major decisions you gotta make in that first month.

The period right after a person is diagnosed with cancer can be a challenging time; newly diagnosed cancer patients may experience stress, anxiety, and depression (Compas et al., 1999; Epping-Jordan et al., 1999; Gallagher, Parle, & Cairns, 2002). Thus, and as suggested by the participant, newly diagnosed cancer patients may benefit from cancer coalition services that focus on the critical period right after diagnosis (see e.g., Cameron, Booth, Schlatter, Ziginskis, & Harman, 2007).

A positive environment. Participants also suggested that a positive environment is an important aspect for a cancer coalition to have. For example, participants wanted to be assured and treated respectfully. A participant also suggested that a cancer coalition should organize activities because activities help circumvent the feeling of being overwhelmed. The participant said:

I think one thing that the [local cancer-care organization] does so well is that they have, you know, fun, sort of active programs, services or whatever, and the information, and the other resources are there along with it. So it isn't like, I think, as a new cancer patient it could be overwhelming if I was, well you know "here's a coalition, you have to go to this coalition." And there's like, this myriad of services and information that could all be sort of overwhelming whereas if it's a cooking class or a yoga class or an art course or something, and then on the side there's the things that as you are making your drawing and saying, you know, "I'm having trouble with my insurance." Someone could say, you know, "you could talk to this person and get help."

Also, participants were concerned about competition between healthcare organizations.

One participant said:

I'm worried about that. I did my surgery with [a local hospital] and my radiation with [with another local hospital] because of personal situations, and they worked together seamlessly. They were just beautiful, and you know when I said "I'm gonna be downtown – I need my radiation downtown." That was put together, and the communication was great. So, but I did worry about it because you're right they seem to compete!

Therefore, a cancer coalition may want to consider emphasizing collaboration among healthcare organizations rather than competition among healthcare organizations. This, along with activities and respectful treatment of cancer patients, may contribute to a positive environment for cancer patients.

DISCUSSION

This study set out to investigate the connection between cancer patients' attitudes toward the idea of a cancer coalition, the idea of participating in a cancer coalition, and services through a cancer coalition. This study postulated that cancer patients will report more favorable attitudes toward the idea of a patient-centric coalition than a coalition that does not specify patient-centricity. Also, this study attempted to understand why cancer patients have favorable/unfavorable attitudes toward the idea of a cancer coalition and what services are needed to best serve cancer patients. The research methods used were survey and focus group interviews. The survey was used to address H1, H2, and RQ1, while the focus group interviews examined RQ2 and RQ3.

H1

H1 posited that cancer patients' attitudes toward the idea of a cancer coalition will be positively correlated with their attitudes toward the idea of participating in a cancer coalition. The survey results indicated a significant positive correlation between attitudes toward the idea of a cancer coalition and attitudes toward the idea of participating in a cancer coalition, thus supporting H1. The correlation was found in all five associated services, including support groups, educational programs, advocacy services, research, and coalition's website. The strongest correlation was found between attitudes toward the idea of a cancer coalition and attitudes toward the idea of participating in support groups

($r(75) = .55, p < .01$). This finding resonates with literature that emphasizes the importance of support groups for patients (see e.g., Cohen, 2004; DiMatteo, 2004; Goedendorp et al., 2012; Kroenke et al., 2013; Thoits, 2011; Uchino, 2006). Given the importance of support groups for cancer patients and that support group services are available through a cancer coalition, it is unsurprising that the strongest correlation was found in attitudes toward the idea of participating in support groups. It also should be noted that the other services had significant positive correlations as well. This is important because positive attitudes toward the idea of a cancer coalition alone may not justify the development of a cancer coalition in Indiana; there also should be an indication that a cancer coalition, if developed, will be utilized. Thus, the finding that cancer patients' attitudes toward the idea of a cancer coalition are positively correlated with their attitudes toward the idea of participating in the coalition encourages development of a cancer coalition in Indiana because patients likely will utilize the coalition. It also is important to note that survey participants were generally in favor of the idea of a cancer coalition. This is crucial because it is possible to have H1 supported but with generally poor attitudes toward the idea of a cancer coalition. For example, out of 88 participants, 2 individuals may report favorable attitudes toward the idea of a cancer coalition and the idea of participating in a cancer coalition, while the remaining 86 individuals may report unfavorable attitudes the idea of a cancer coalition and the idea of participating in a cancer coalition. In such a situation, H1 would still be supported, but attitudes toward the idea of a cancer coalition would generally be poor. This, however, was not the case for this study. From the 88 participants who completed the survey, the mean attitude toward the idea of a cancer coalition was 6.48 out of a maximum 7 high

($M_{\text{cancer patients}} = 6.51$, $M_{\text{caregivers}} = 6.31$). Therefore, participants on average strongly favored the idea of a cancer coalition. The results encourage the development of a cancer coalition in Indiana because participants on average had strong favorable attitudes toward the idea of a cancer coalition and are likely to utilize the coalition.

H2

H2 posited that cancer patients' attitudes toward services through a cancer coalition (i.e., support groups, educational programs, advocacy services, research, and website) will be positively correlated with their attitudes toward the idea of a cancer coalition. The survey results indeed showed a significant positive correlation between attitudes toward services through a cancer coalition and attitudes toward the idea of a cancer coalition. The correlation was found for all five services, including support groups, educational programs, advocacy services, research, and coalition's website. The strongest correlation was found between attitudes toward the support groups service and attitudes toward the idea of a cancer coalition ($r(75) = .74$, $p < .01$). Again, this finding is congruent with literature that highlights the importance of support groups for patients. The positive correlation found between attitudes toward services through a cancer coalition and attitudes toward the idea of a cancer coalition may have theoretical import; the correlation may indicate a connection between attitudes toward an attitudinal object (e.g., coalition) and its associated objects (e.g., support groups, website, etc.). That is, enhancing attitudes toward associated attitudinal objects may improve attitudes toward the main object. For example, if attitudes toward support groups and the coalition's website were enhanced, attitudes toward the coalition also may improve. However, one should note that the connection found was a correlation, not cause-and-effect. Thus, any

future studies that seek to further probe this connection should be aware that although there is correlation, there may not necessarily be direct or indirect causation. In order to investigate for causation, there must first be an associated object with low evaluation rating. For example, if attitudes toward advocacy services were poor, a study may explore if attitudes toward the cancer coalition improved after attitudes toward advocacy services improved. In this study, however, attitudes toward all associated services (i.e., support groups, educational programs, advocacy services, research, and website) and attitudes toward the coalition were strong. Therefore, a before-and-after causation study could not be conducted. However, that there was a connection between an attitudinal object and its associated objects is encouraging and should be further explored by future studies.

Another limitation was that although this study established a significant positive correlation between attitudinal object and its associated objects in the context of a cancer coalition, the study did not include *unassociated* objects in the survey. For example, if an unassociated object such as banking service in a coalition was included in the survey, and attitudes toward banking service also were rated as highly as attitudes toward associated services and the coalition, the suggested theoretical contribution would be in question. In contrast, if attitudes toward banking service in a coalition were rated poorly and attitudes toward associated services and the coalition were rated favorably, the suggested theoretical contribution would be more convincing. An even more convincing scenario would involve the enhancement of attitudes toward an unassociated service such as banking service in a coalition without significant effect on attitudes toward the coalition; in that way, a study can be more confident in claiming a connection between an attitudinal object and its associated objects. To be sure, this study did not attempt to

establish such a connection; this study simply suggested that the findings may indicate that such a connection may be possible, and is an area to be explored for future studies. Furthermore, because this suggested connection was not the focus of this study, unassociated objects, which could have confused survey participants, were not included in the survey.

Future studies also may want to examine the connection between attitudes toward an attitudinal object and its associated objects in other contexts, such as in a government entity. This study only looked at the context of a cancer coalition, and therefore the external validity (see Calder, Phillips, & Tybout, 1982) for the suggested theoretical contribution is yet determined. Future studies may explore, say, the connection between attitudes toward a government entity and attitudes toward its associated services such as community events, outreach programs, and government websites, and if enhancing attitudes toward associated services would improve attitudes toward the government entity.

It should be emphasized that theoretical contribution or not, the practical contribution of the findings in H2 cannot be overlooked; the results indicate that cancer patients in Indiana likely will be in favor of services available through a cancer coalition. Therefore, if a cancer coalition is developed in Indiana, cancer patients likely will be favorable toward not just a few services but all the five typical services found through a coalition (i.e., support groups, educational programs, advocacy services, research, and website). The findings encourage the development of a cancer coalition in Indiana.

RQ1

RQ1 advanced that cancer patients will report more favorable attitudes toward the idea of a patient-centric coalition than a coalition that does not specify patient-centricity. Through paired samples T test, a mean difference of only 0.19 was found and therefore the attitudes toward the idea of a patient-centric and non patient-centric coalition were the same. There are two possible explanations for why the difference was not statistically significant. First, participants may not have been clear what the difference is between patient-centric and non patient-centric coalitions. The survey did briefly explain that a patient-centric coalition is one that focuses on cancer patients. However, this brief explanation may not have elucidated the difference sufficiently. Although a more detailed explanation may result in a larger mean difference between the attitudes toward patient-centric and non patient-centric coalition, such lengthy details may be too draining for participants, and the likelihood of satisficing may increase (see Krosnick, 1999). Therefore, to avoid satisficing, this study avoided a detailed explanation of patient-centricity. Future studies may want to explore differences in attitudes when detailed explanations are provided. Second, participants may have favored the idea of a cancer coalition so much that ratings for both types of cancer coalition were too high ($M_{\text{patient-centric}} = 6.69$, $M_{\text{non patient-centric}} = 6.51$) to observe substantial mean difference. If the survey scale was expanded from a limit of 7 to, say, 15, the mean difference may be wider. However, literature on survey design warned against having too many points on a scale (e.g., above 11), as reliability and validity would diminish (Krosnick et al., 2005). Furthermore, literature on survey design recommended the use of a 7-point scale (Krosnick et al., 2005; Lozano et al., 2008; Preston & Colman, 2000). For these reasons,

the survey in this study adhered to a 7-point scale. Given that providing a detailed explanation for patient-centricity may increase the likelihood of satisficing, and that expanding the survey scale may compromise reliability and validity, there is little that can be done to improve the method for investigating RQ1. Future studies that wish to further explore differences in attitudes toward patient-centric and non patient-centric coalitions may attempt to explain patient-centricity; however, the challenge would be in ascertaining how much explanation would be regarded as too much for participants.

RQ2

RQ2 asked “why do cancer patients have favorable/unfavorable attitudes toward the idea of a cancer coalition and its services?” Although the survey indicated highly positive attitudes toward the idea of a cancer coalition ($M(88) = 6.4773$) and its services (see Appendix B), this positive result was an average value, which means that there were a few participants who could have had reported unfavorable attitudes (i.e., evaluations of 3 or lower on a 7 point scale). Indeed, the survey had 22 participants who reported unfavorable attitudes at least once. Therefore, although attitudes toward the idea of a cancer coalition and its services generally were very positive, there were a few who reported unfavorable attitudes. The focus group interviews thus were conducted with the aim to understand why there may be unfavorable attitudes and also why there may be favorable attitudes; that is, the focus group interviews were conducted to address RQ2. From the inductive thematic analysis, four reasons were found for favorable attitudes and three reasons were found for unfavorable attitudes.

The four reasons for favorable attitudes were (1) shared resources, (2) may benefit other people, (3) potentially useful for them, and (4) directs patients to centralized

information. Some participants felt that sharing resources could help cancer patients in general. This perspective is congruent with Roberts-DeGennaro's (1987) view that a coalition may help in gaining resources and bringing new ideas, perspectives, and technologies. Some participants felt that a cancer coalition may benefit other people, such as people who do not have adequate cancer-care support. Participants also felt that a cancer coalition may potentially be useful for them. However, participants desired more information regarding the coalition, which RQ3 addressed. Lastly, participants had favorable attitudes because they believed a cancer coalition may help direct patients to centralized information. This centralized information may help patients navigate health information and concerns, as well as circumvent the feeling of being overwhelmed by a barrage of information (see Eysenbach, 2003; Skinner et al., 2003).

The three reasons for unfavorable attitudes were (1) overlapping concerns, (2) need for more information about coalition, and (3) network or resource concerns. Some participants were concerned that a cancer coalition, if developed, would have overlapping services that already are provided by current cancer-care organizations. This highlights the need for a cancer coalition to communicate the uniqueness of its services. The need for more information about the cancer coalition also was a reason for unfavorable attitudes. Specifically, participants were uncertain about what the coalition would offer and how it would operate. This need for information is congruent with studies on patients' need for health information (see e.g., Jenkins et al., 2001; Rutten et al., 2005). Again, the importance of communication for a coalition is underscored. Lastly, some participants were concerned about how a cancer coalition would network and share resources effectively with partner cancer-care organizations.

It should be noted that the focus group participants were not strongly against the idea of a cancer coalition. Rather, participants were apprehensive due to uncertainties regarding the coalition. Thus, the unfavorable attitudes seemed minor in contrast to the favorable attitudes which seemed strong. This was reflected in the greater number of coded reasons for favorable attitudes than for unfavorable attitudes. It also should be noted that all three reasons for unfavorable attitudes may be addressed through good communication. A cancer coalition may dispel potential unfavorable attitudes by communicating how its services are unique, what the coalition would offer and how it would operate, and how it would network and share resources effectively with partner cancer-care organizations. Indeed, this is congruent with one of the themes found in addressing RQ3 – effective health communication.

RQ3

RQ3 asked “what services/aspects does a cancer coalition need to have to best serve cancer patients?” The inductive thematic analysis revealed four aspects that a cancer coalition needs to have: (1) effective health communication, (2) include involvement of cancer survivors, (3) expanded scope of support, and (4) a positive environment.

Effective health communication was a theme consistently found in the focus group interviews. Participants wanted accurate, accessible, current, and relevant cancer-related information. For example, participants wanted statistical information on cancer treatment and a true/false section on a coalition website. In addition, participants wanted to be informed about the existence of a cancer coalition if it is developed. Also, participants wanted to be informed about the purpose and services of the coalition. The

need for effective communication is central to health communication research (see e.g., Jenkins et al., 2001; Rutten et al., 2005) and this study is no exception. Judging from the responses of the focus group participants, it would seem that effective health communication would be pivotal to the success of a cancer coalition if it is developed. Specifically, effective health communication may be pivotal in two ways: (1) it may circumvent the potential reasons for unfavorable attitudes found in addressing RQ2 and (2) effective health communication seemed to be a desired service that would help cancer patients with decision-making and in navigating health-related information. Given these reasons, developers of a cancer coalition should prioritize effective health communication as one of the coalition's main goals and services.

Some participants also wanted cancer survivors to be involved in the cancer coalition. Cancer patients may be encouraged by someone similar and has already overcome the battle with cancer (Taylor & Lobel, 1989) and may perceive that a cancer survivor may better empathize and relate to their experiences with cancer (Thoits, 1986). In light of this, developers of a cancer coalition should consider recruiting cancer survivors as hired staffs or volunteers within the coalition. For example, cancer survivors may lead and conduct support groups through the cancer coalition or be speakers for educational health programs.

Another desired coalition service is an expanded scope of support. For example, participants wanted support from a cancer coalition to be extended to families and caregivers of cancer patients, to smaller counties, and to focus on people who are newly diagnosed with cancer.

Lastly, participants suggested that it is important for a coalition to have a positive environment. For example, participants wanted to be assured and treated respectfully. One participant also suggested a cancer coalition should organize activities because activities may circumvent the feeling of being overwhelmed. Participants also were concerned about competition between healthcare organizations. A cancer coalition should have a positive environment in which patients do not need to worry about bad treatment, competition with healthcare organizations, and being overwhelmed. Again, effective health communication may address these concerns and help a coalition in building a positive environment for cancer patients. The cancer coalition should also emphasize collaboration among healthcare organizations instead of competition among healthcare organizations.

CONCLUSION

Cancer is a pressing health issue and a cancer coalition, which involves people and organizations working toward mitigating the impact of cancer, may help address cancer. In particular, the services typically found through a cancer coalition may contribute to healthful outcomes in cancer patients. These services are support groups, educational programs, advocacy, research, and the cancer coalition's website. Attitudes toward a cancer coalition and its services are important because positive attitudes may result in participation in the cancer coalition. Conversely, negative attitudes may result in disengagement from a cancer coalition, and the healthful benefits stemming from services through a cancer coalition may be forgone because of disengagement. Little is known about the attitudes of cancer patients toward a cancer coalition, toward its services, and toward participation in a cancer coalition. This study addressed this gap by investigating these attitudes. The study found that cancer patients had generally favorable attitudes toward the idea of a cancer coalition, its services, and participation in a cancer coalition. The study found significant positive correlations between attitudes toward the idea of a cancer coalition and the idea of participating in a cancer coalition, and also between attitudes toward services through a cancer coalition and attitudes toward the idea of a cancer coalition. These findings encourage the notion that a cancer coalition would be utilized if it is developed. The study did not find significant differences between attitudes

toward a patient-centric cancer coalition and attitudes toward a non patient-centric coalition. Effective health communication was found to be pivotal in circumventing potential unfavorable attitudes and was a service that patients desired a coalition to have. Effective health communication includes (1) assuring patients that there is no overlapping of services, competition for resources, and competition between healthcare organizations, (2) informing patients and caregivers regarding the coalition, how it would operate, its purpose, and its services, (3) providing cancer-related information that is accurate, accessible, current, and relevant, (4) interacting with patients in an assuring and respectful manner. Given the potential benefits of a cancer coalition, a state that does not have a patient-centric cancer coalition such as Indiana should consider initiating one. In order to develop an effective patient-centric cancer coalition, developers of the coalition will have to prioritize effective health communication. When this is done correctly, a cancer coalition will better achieve its purpose of being a supportive health communication hub for cancer patients.

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APPENDICES

Appendix A: Survey

Thank you for participating in the survey. Please read the short paragraph below before answering the survey questions:


A cancer coalition is a network of cancer organizations with the aim of preventing, controlling, and curing cancer. For example, a cancer coalition in Indiana will comprise of relevant cancer clinics and cancer support communities within Indiana. A cancer coalition can provide several resources. For example, educational programs educate people about preventing, detecting, or controlling cancer. As another example, advocacy services provide legal assistance to cancer patients who may have legal concerns related to cancer. Currently, Indiana Cancer Consortium provides such services and caters to patients and health professionals. We want to understand what you think about the idea of a **patient-centric** cancer coalition (that is, focuses on cancer patients) using this survey

For each question, please select the option that best describes how you feel.

Please click the arrow-icon on the lower-right corner of the screen to start the survey.


(1) Which role do you think best describes you in relation to cancer?

Cancer
patient/survivor Caregiver




(2) What is your age?

18 years to 29 years old 30 years to 39 years old 40 years to 49 years old 50 years to 59 years old 60 years to 69 years old 70 years to 79 years old 80 years old and above

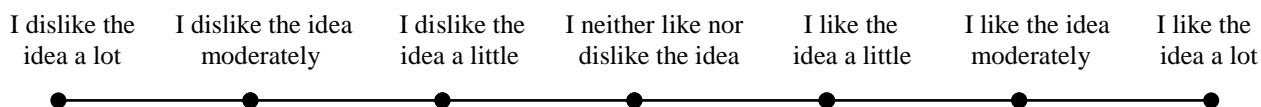


(3) To what extent would you like the idea of a cancer coalition having support groups?

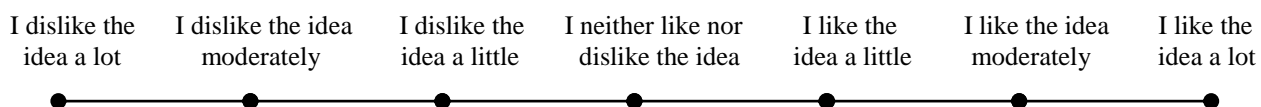
I dislike the idea a lot I dislike the idea moderately I dislike the idea a little I neither like nor dislike the idea I like the idea a little I like the idea moderately I like the idea a lot



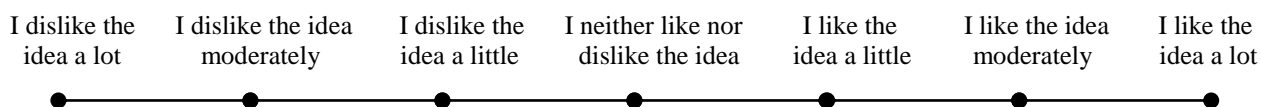
(4) To what extent would you like the idea of participating in a cancer coalition's support group?



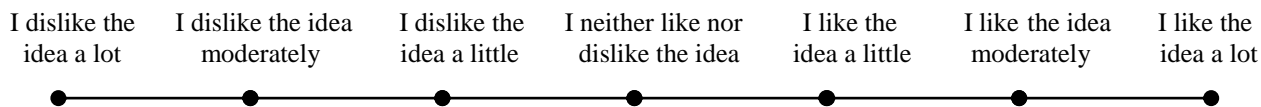
(5) To what extent would you like the idea of a cancer coalition having educational health programs?



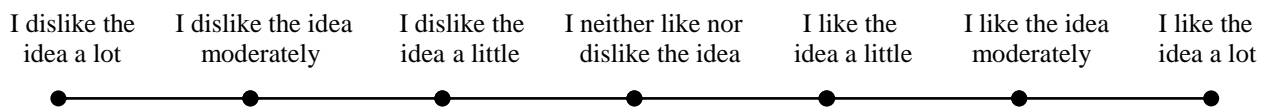
(6) To what extent would you like the idea of participating in a cancer coalition's educational health program?



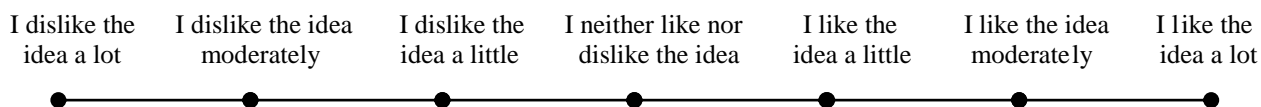
(7) To what extent would you like the idea of a cancer coalition having advocacy/legal services?



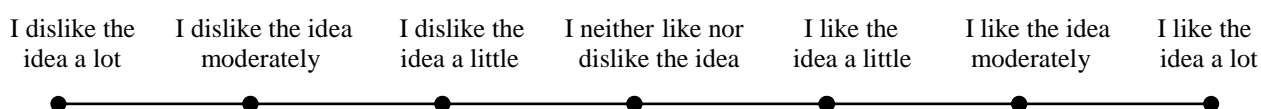
(8) If you have legal concerns, to what extent would you like the idea of using the legal services provided by a cancer coalition?



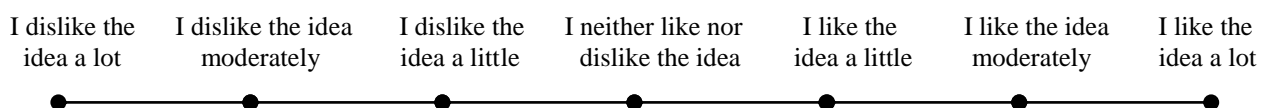
(9) To what extent would you like the idea of a cancer coalition also focusing on research? (that is, clinical and non-clinical research)



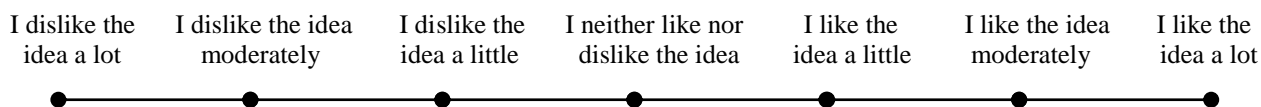
(10) To what extent would you like the idea of participating in a cancer coalition's research? (that is, clinical and non-clinical research)



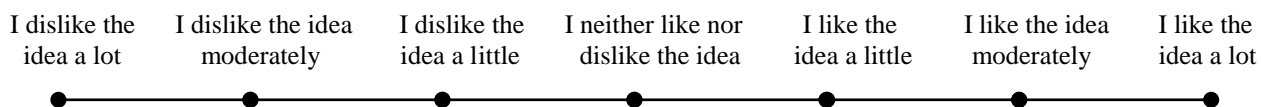
(11) To what extent would you like the idea of a cancer coalition having its own website?



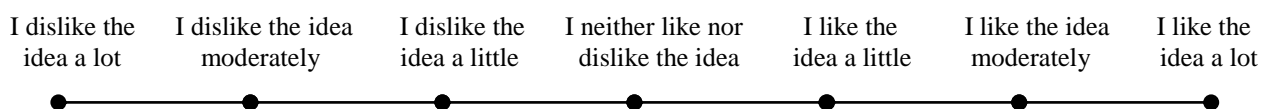
(12) To what extent would you like the idea of obtaining information from a cancer coalition website?



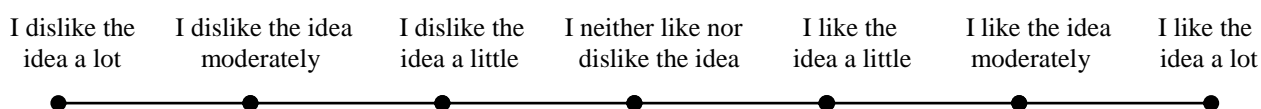
(13) To what extent would you like the idea of a cancer coalition?



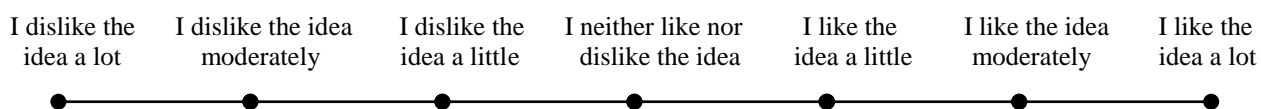
(14) To what extent would you like the idea of a cancer coalition that is patient-centric? (that is, focuses on patients)



(15) To what extent would you like the idea of a cancer coalition being disease-specific, that is focusing on a particular type of cancer?



(16) To what extent would you like the idea of a cancer coalition having a broader focus on many cancers?



Which cancer organization are you participating in? (pick the one you are most involved in)

- ☐ St. Vincent Cancer Care
- ☐ Cancer Support Community
- ☐ YWCA Women's Cancer Program

Please type your name (first, last name) in the box below to verify that you have taken the survey so that we can distribute a \$5 gas gift card to you (please collect from your cancer organization office at the end of the month).

Appendix B: Mean Attitudes Toward Services Through a Cancer Coalition

Table B1: Cancer patients' mean attitudes toward services through a cancer coalition

	Mean	Standard deviation	Mean difference from scale average (i.e., 4)
Support groups	6.40	0.99	2.40
Participating in coalition's support group	5.83	1.33	1.83
Educational health programs	6.67	0.60	2.67
Participating in coalition's educational programs	6.36	0.88	2.36
Advocacy	6.15	1.28	2.15
Using coalition's advocacy services	5.79	1.39	1.79
Research	6.52	1.07	2.52
Participating in coalition's research	6.15	1.29	2.15
Website	6.52	0.89	2.52
Obtain information from coalition's website	6.49	0.98	2.49
Patient-centric cancer coalition	6.69	0.64	2.69
Non patient-centric cancer coalition	6.51	0.83	2.51

n = 75

Table B2: Caregivers' mean attitudes toward services through a cancer coalition

	Mean	Standard deviation	Mean difference from scale average (i.e., 4)
Support groups	6.31	1.11	2.31
Participating in coalition's support group	5.85	1.41	1.85
Educational health programs	6.08	1.19	2.08
Participating in coalition's educational programs	5.46	1.27	1.46
Advocacy	6.23	1.01	2.23
Using coalition's advocacy services	5.69	1.18	1.69
Research	6.15	1.28	2.15
Participating in coalition's research	5.54	1.51	1.54
Website	6.46	0.97	2.46
Obtain information from coalition's website	6.46	0.97	2.46
Patient-centric cancer coalition	6.62	0.87	2.62
Non patient-centric cancer coalition	6.31	1.11	2.31

n = 13