13. Smita Menon (Prof. Bruce Austin) Professional & Technical Comm.

Smita Menon, a Professional & Technical Communication major, created an engaging proposal for an empirical research project that is a model for scientific clarity and precision.

Quantitative Research Methods is one of two required communication research methods courses for PTC majors. The course project insists students invent and develop a fully formed proposal for an empirical research study. For many, this kind of thinking and this style of writing is novel. Research proposals must focus on phenomena associated with the communication discipline, carefully articulate the research problem to be investigated and state hypotheses or ask research questions, offer a compelling scholarly and social rationale that legitimizes the enterprise, present a representative and critical review of the related empirical research literature, and specify precisely the scientific procedures to be followed to test hypotheses or respond to research questions. Students are reminded their proposals for research must be so clear that any "kid in the hall" will be able to implement the project and that in empirical research there is no such thing as "you know what I mean."

Smita Menon's ambitious proposal creatively and successfully weaves together mass communications, intercultural communication and health communication theoretical constructs within a context of digital media. Her text engages the reader and clearly lays out a valid and reliable set of self-report measures to be gathered by means of a survey and personal interviews. Smita's research idea and her writing are first-rate. I note that Smita will present results of a different research project, her Senior Thesis,

on 18 April at the Department's fifth annual Conference for Undergraduate Research in Communication and a condensed version of that work will be published in the Proceedings book that accompanies that Conference.

"Don't Worry, Everything Will Be Just Fine:" Caucasian and Indian Women Coping with Pulmonary Hypertension and the Implications of Computer-Mediated Support Groups in Coping.

By
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To
Dr. Bruce Austin
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Abstract

As Pulmonary Hypertension (PH) survival rates continue to improve due to advances in its medical treatments, the focus of PH patients has shifted from death and dying to life and living. Dealing with the psychological effects of PH has become important. While a significant amount of research has been conducted with chronic disease survivors of Caucasian descent, few have focused on the coping strategies of the survivors of Asian, particularly, Indian descent. The purpose of the study is to investigate the coping strategies employed by women with PH in United States and India and explore the implication of computer-mediated support groups as a coping strategy amongst the two different culture.

A total of 44 women with PH (30 Caucasian and 14 Indian) will be recruited through PH clinics in New York, California, Boston and Chicago in United States and Delhi, Mumbai, Bangalore and Chennai in India. Subjects will be mailed a package of three questionnaire surveys. A week after the surveys are returned, the subjects will be interviewed via telephone or in-person. The data collection procedure is expected to take no more than six-seven weeks.

Once the data is collected, responses will be coded respectively and and themes and behaviors will be identified, which would be used to infer the results of the study. The coping strategies and the implications for computer-mediated support groups with culturally diverse groups, United States and India will be discussed.

INTRODUCTION

Pulmonary Hypertension (PH) was first identified in the 1980s. It is a rare condition of high blood pressure in lungs, that causes enlargement of the right side of the heart, and eventually death.

Since its emergence in 1980s and the increase in diagnosis of new cases, PH has become one of the greatest health threats, especially amongst the women (Nauser & Stites, 2001, para 3). This incurable disease continues to exact an astonishing human toll. The most recent statistics shows 15,668 deaths and 260,000 hospital visits among persons with PH between 1998-2001(Center for Diseases Control, 2002). However today, with increased emphasis on advance treatments, PH patients can now live 10 years longer than the three-year prognosis that was given by medical practitioners 10 years ago (Nauser & Stites, 2001, para 39).

With PH no longer categorized as a terminal disease, managing the physical consequences of the disease is no longer the primary concern for the patients. PH patients' focus has shifted from death and dying to life and living in that they are finding ways to deal with fear, anxiety, and depression "associated with functional impairment, increased health care costs" (Lowe, Grafe, Ufer, Kroenke, Grunig, Herzog & Borst, 2004, p. 831). As a result, it is not surprising that these individuals turn to social support, especially support groups for emotional, informational, and instrumental assistance (Kalichman, 2006, p. 537).

According to Kalichman (2006, p. 538), people diagnosed and living with a chronic disease seek the support of computer-mediated support groups for comfort and encouragement; for increasing their knowledge base about the disease itself and any new and improved breakthroughs; and for practical assistance with daily living, such as financial/insurance assistance.

Until recently, face-to-face social support groups were considered the only option to cope with chronic disease. The advent of the Internet and other factors such as (1) lack of proximity to family and

close friends for social support, and (2) progression of the disease itself, leaving the individuals homebound, have led to the emergence of support groups on the digital platform. These support groups, such as www.phassociation.org and computer-based bulletin board systems have been lately seen as a viable source of support to the chronically-ill (Kalichman, 2006, p.538)

While a number of studies (Lowe, et al., 2004; Lacasse, Rousseau & Maltais, 2001; Manen, Bindels, Dekker, Ijzermans, Van der Zee & Schade, 2002) have been conducted on PH patients' quality of life following the diagnosis, few investigations have examined cultural differences and patients' employing the Internet as a source for coping with PH. Most research has focused on support group in the cyberspace and its use by Americans living in the United States; few studies have explored the cyberspace coping abilities of non-Western citizens or have compared the coping strategies across cultures.

Today, with the world becoming more and more linked, it is imperative to acknowledge that every cultural group contains substantial variance. The coping process is highly specific to individuals, and their situation, particularly the inherent cultural differences such as individualism and collectivism.

According to Hofstede (2005):

An individualist culture consists of loosely-linked individuals who see themselves as independent of group. They emphasize on personal achievement and independence. An example of an individualistic culture is United States. Collectivist culture consists of closely-linked individuals who identify themselves as a part of group, such as family, friends, coworkers, tribes and so forth. An example of a collectivist culture is India (p. 73-86).

The present study investigates the PH patients' coping behavior across cultures and the patients' evaluation of the impact of online support group as a means of dealing with psychological distress resulting from PH, and as a means of making health care decisions.

RESEARCH RATIONALE

Scholarly Rationale

Support groups, both face to face and online exert a positive influence on the subjective or emotional needs of individuals with illness. "These groups are based on principles of empowerment, inclusion joint decision making, shared responsibility, and a holistic approach to the needs of the individual" (Finn, 1999, p. 221).

Since stress is an inevitable part of chronic illness, coping has attracted much scholarly attention. Numerous studies thus far have focused on using support group as a coping strategy (Cobb, 1976; Flaherty, Pearce & Rubin, 1998; Walther, 1993). Scholars have found support groups to be an effective means of providing self help to chronically-ill patients. Another area that has received scholar's interest in the last 10 years is online support groups, especially those associated with cancer (Spiegel, Bloom & Yalom, 1981; Telch & Telch, 1986; Weinberg, Uken, Schmale & Wessel, 1995). While a few studies have assessed the impact of online support groups on the quality of life of the cancer patients, others have explored the factors that led the patients to visit support groups. However, one cannot fail to notice that these studies have largely focused on the experiences of Caucasians. Understanding the cyberspace coping strategies used by Indians is hindered by the limited number of studies. Also noticeable is the limited research conducted on PH patients. Since PH is rare and is often misdiagnosed and under-diagnosed, very limited research has been conducted on it and the individuals afflicted by the disease (Lowe et al. 2004; Manen et al. 2002; Rousseau & Maltais, 2001).

In view of all the limitations in the scope of the above-mentioned studies, the present study will expand our knowledge about the coping strategies of PH patients across cultures and the patients' evaluation of the impact of online support groups as a means of dealing with psychological distress and as a means of making health care decisions.

Social Rationale

The present study builds upon previous relevant research on PH patients and bridges the limitations of the past research on the impact of computer-mediated support groups on chronically-ill patients wherever possible. The study's results will inform health psychologists, PH specialists and nurse practitioners, counselors, social workers and PH patients about the clinical importance of PH support groups online.

Personal Rationale

My interest in this topic stems from the experiences I have had as an individual living with PH for the last four years. As a PH patient (of an Indian origin), I have so far always avoided going to online support group, phassociation.org. This could be partly due to the 'scary nature' (that I find) of message threads posted in the discussion forum, and partly because the majority of my support comes from my husband, a healthcare practitioner. This behavior has developed an interest in me to ask if there is any difference between PH patients in United States and PH patients in India as far as using Internet as a strategy to cope with their illness is concerned.

LITERATURE REVIEW

Key Definitions and Issues

Pulmonary Hypertension (PH)

PH is high blood pressure in lungs. A rare disease of unknown cause, PH leads to the progressive narrowing of the blood vessels and eventually heart failure. It is estimated that PH affects two in a million (Centers for Disease Control, 2002). The definition of PH as it relates to the study will be limited to PH diagnosed in female adults, aged 25 and more, since this the population that is twice at

risk for the disease. The definition excludes PH patients both, male and children who are diagnosed with PH and patients who have PH secondary to other lung, heart, immune system or liver disorder.

Coping

According to Pearlon and Schooler (1978, p. 3) coping is "any response to external life strains that serves to prevent, avoid or control emotional distress." Lazarus contends that coping is capable of mediating the emotional outcome of stressful encounter. These stressful encounters include any experience or conditions that are traumatic, unalterable and emotion-focused (2000).

Researchers have also conducted studies involving specific subgroups of population to determine the effects of specific life events on the individual's ability to function and cope (Frazier, 2003, p. 1257; Halligan, Michael & Clark, 2003, p. 420). It is from this, a more specific focus on the subgroups of the population experiencing traumatic life experiences, emerge social support and coping research of individuals diagnosed with a chronic illness.

In addition to understanding that individuals resort to coping during a traumatic event in their life, it is also essential to understand the coping strategies that the individuals use. Researchers have divided the coping strategies into four categories: emotion-focused coping, problem-focused coping (Folkman & Moskowitz, 2004), appraisal-focused and social-focused coping (Lazarus, 2000).

According Folkman and Moskowitz (2004) emphasize that coping experience depends primarily on the situation of the individual, in that, coping strategies employed by an individual is not negative or positive. The coping strategies' effectiveness must be assessed within the context of the situation experienced. It is important to acknowledge that coping strategies differ in different cultures, and what strategy (avoidance) is commonly practiced in one culture, are not better or worse in relation to other coping strategies.

Tseng and Hsu (1991) note that cultural traditions and values play an important role in the

extent to which different ethnicities share their private information with outsiders. According to the authors, Caucasians feel more at ease sharing their family problems with outsiders, while Asians are uncomfortable in doing so. This leads to the definition of the two terms that form an integral part of the present study.

According to Peurlon and Schooler (1978, p. 3) coping is "any response to external life strains

Individualism and Collectivism

Hofstede (2005) defines Individualism and Collectivism as:

Societies in which the ties between individuals are loose; everyone is expected to look after himself or herself and his or her immediate family. Collectivism, on the other hand, pertains to societies in which people on birth onward are integrated into strong, cohesive-in groups, which throughout people's lifetimes continue to protect them in exchange of unquestioning loyalty (p.76)

Harmony and avoidance of confrontation is a value embraced by the collectivists. They tend not top express themselves verbally. For them, mind and body are considered inseparable, and are integrally connected; hence psychological problems, coping in this case, manifest as somatic symptom (Sue & Sue, 2003). The individualistic ideology values power and status. They view self as a separate entity from their surroundings, and express their problems and issues more explicitly (Sue & Sue, 2003).

The present study focuses on individualism and collectivism that pertains to disclosing information about self to others for coping with a chronic illness. Instead of defining Asians (Cambodia, China, India, Japan, Korea, Malayasia, Pakistan, Phillipines Thailand Vietnam) as Collectivists and Caucasians or Whites (Irish, German, English, French, Polish, Dutch, Italian, Middle East and North Africa) as individualists, the present study concentrates on Indian collectivism and American individualism. 'American' here is defined as Caucasian that account for 77.1% of the total

United States population (US Census Bureau, 2007).

Support Groups

Face-to-face support group is an environment to provide mutual support and health-related information to its members (Kalichman, 2007). Practical, medical, and stylistic barriers account for the under-use of support groups. Practical problems involve difficulties attending meetings, including a lack of transportation, a far distance to travel, or inconvenient meeting times. Medical factors center on the impact of the illness; for example, PH patients may be too weak or too sick to attend meetings (Weinberg, Schmale, Uke & Wessel, 1996, p. 27).

Computer-Mediated support group, on the other hand, is a group communication using computer network and the Internet to facilitate mutual support (Weinert, Cudney & Winters 2005, p. 8). This format allows members to read and respond to every message posted. As in face-to-face support groups, members ask questions, share information, express concerns, and offer advice and support, but from the comforts of their home.

Psychological Distress in a Chronically-ill Patient

Having a chronic illness such as PH, which has no cure, involves adjustment and readjustment of the individual to changing abilities and physical functionality of body. Not only does the individual have to suffer from the ailment's physical repercussions; they also suffer mental agony, such as worries about medical insurance, modifying their aspirations and way of living, re-negotiation of interpersonal relationships with loved ones, make makes things more difficult.

Hatchett, Friend, Symister and Wadhwa (1997) conducted a study of 42 chronically ill patients

who were experiencing end-stage renal disease. They hypothesized that a patient's perceived inability to meet others' expectations about coping with illness would lead to poorer adjustment. The authors' findings confirmed that expectations predicted subsequent decreases in psychological adjustment over a three-month period, even when social support was controlled. Another finding of the study was that optimism increased social support while pessimism predicted losses in social support.

Lowe et al. (2004) conducted a exploratory study on depression, anxiety and mental disorder on 164 patients with PH (70.1% female, mean age: 47.8). The authors found that one-third of patients suffered from depressive disorder and panic disorder. The prevalence of major depression, panic disorder was strongly associated with the level of functional limitation. Work disability in nearly half of the patients with PH and other limitations regarding personal well-being, daily activities, and family life may also contribute to the development of mental disorders, the authors concluded that anxiety and depression are frequent in patients with PH and increase as the severity of disease progresses. The study provides a foundation for the present study in that it demonstrates that PH patients experience anxiety and depression following the diagnosis, which drives the present study to examine the coping strategies PH patients employ to cope with their illness.

Role of Social Support

In his experience in conducting face-to-face support groups for cancer patients, Spiegel (1995) found that social support may influence coping style by shifting the focus from an uncontrollable primary problem, such as advancing to a controllable one such as influencing the effects of cancer, some of which are psychological in nature. This finding can be extended to patients with PH. Even though they cannot control the advancement of PH, what they can control is the psychological effects of PH by establishing vigorous relationships with family, friends, similar peers.

In a research titled, Online help: Cancer patients participate in computer-mediated support group, Weinberg, Schmale, Uke and Wessel (1996) studied an electronic bulletin board established expressly for six breast cancer patients. The authors found that in the 3-month period under study, participants used the forum 158 times, sharing medical and personal information and providing encouragement and support primarily from 7 a.m. to midnight. When analyzing message content of this group the following themes were identified by the authors: (1) discussing medical information about one another; (2) relating personal information about oneself; (3) indicating concerns for other members; (4) reporting on positive aspect of one's own situation; (5) stating favorable feeling about the group; (6) asking other members questions; (7) identifying commonalities with other members; (8) giving other members advice; (9) giving others information; (10) revealing negative aspects of one's own feelings; (11) noting problems in connecting with the board. The authors concluded that that computer-mediated support groups may offer patients many of the therapeutic features of face-to-face groups such as hope, and group cohesion.

Shaw, Hawkins, McTavish, Pingree, McDowell and Gustafson (2006) examined how insightful disclosure within a computer-mediated support group for women with breast cancer affects breast cancer-related concerns, emotional well-being, and self-reported physical well-being. A total of 144 females (mean age: 44.5) with breast cancer agreed to participate in the study through a Comprehensive Health Enhancement Support Group (CHESS), a computer-mediated support group. Surveys were administered just before group access and then two months and five months later. The authors found that insightful disclosure improved emotional well-being and reduced negative mood but did not influence breast cancer-related concerns or self-reported physical well-being. The authors concluded that computer-mediated support groups may serve as a viable forum for communicating about illness in a way that may improve emotional status for women with breast cancer.

In a 2002 study on the effects of computer-mediated support group for people (n=580) suffering

from severe back pain Lorig, Laurent, Deyo, Marnell, Minor and Ritter found that the support group indicated positive outcome. For one year 190 individuals received an intervention including participation in a closed moderated computer-mediated support group, a book and a video on back pain. A control group of 231 individuals with severe back pain received a subscription of choice to a non-health related magazine. The authors found that the experimental group, in comparison to the control group, significantly improved in pain, disability, health stress, and decreased use of other health care services after one year of treatment.

Cultural Differences in the use of Computer-Mediated Support Groups

Studies have shown that the Asian culture's emphasis on collectivism rather than individualism. They turn to family when coping with cancer (Kapoua, 2003; Mokau, Brown & Braun, 1998). This value has been demonstrated in Wellisch, Kagawa-Singer, Reid, Lin, Nishikawa-Lee and Wellisch's 1999 study examining the social support needs of 46 Asian and Anglo American breast cancer survivors (n=13 Anglo-American, n=18 Chinese-American, n=15 Japanese American). The results showed that Anglo-American women indicated a greater need for social support than either of the two Asian-American groups. In addition, the authors found that Asian-American strongly favored a need for smaller and intimate support network, while the Caucasian women relied on larger, more extensive support network.

A couple of studies conducted in the past have discovered that Asian-American women value the concept of self-sacrifice (Ashing, Padilla, Tejero & Kagawa-Singer, 2003; Mok, Chan, Chan & Yeung, 2003). Chinese individuals with disease do not seek outside help (help from support groups), which may be attributable to their cultural tradition of avoidance of placing burdens on others (Mok et al. 2003). This finding is supported by Kagawa-Singer and Wellisch's study in 2002, which investigated ethnic differences in their perceptions of the support provided by their spouses. 46 women who had had

breast cancer six months to three years prior participated in this study (n=13 Euro-American, n=18 Chinese-American and n=15 Japanese-American). The authors hypothesized that few differences would exist in standardized testing, and that cultural differences would be found at the level of semi-structured interviewing. The authors found that in fact few differences existed among the three groups on standardized instruments. At the level of qualitative evaluation, however, it appeared that Asian-American women were expected to be self-sacrificing and nurturing of husband and family, while Euro-American women were able to be dependent. Another major difference existed around the theme of harmony and intimacy, where Asian-American women had a goal of harmony over intimacy, while Euro-American women had a goal of intimacy over harmony. In addition, the authors also discovered that, in the area of communication, with both Asian groups appeared to valued non-verbal communication over verbal, while Euro-American women appeared to value verbal communication over non-verbal.

RESEARCH QUESTIONS

One of the main advantages of computer-mediated support groups for PH or for that matter, any disease, is that they take place without the constraints of time and distance. It is again essential to understand that not everybody use support groups on the Internet as a tool to cope with their illness. Sometimes, cultural differences may affect the use of the Internet as a strategy to cope with a traumatic experience, such as diagnosis of a serious illness like PH. The research questions in the present study focus on investigating the differences, if any, PH patients have in using computer-mediated support groups and then assessing the impact of cyberspace-coping of PH across the cultures. The research questions are stated below:

Research Question 1: What differences are there between PH patients who identify culturally as Caucasian and Indian on their self-reported strategies that they employ to cope with their illness?

Research Question 2: What differences are there between Caucasian and Indian PH patients and the motives they say they have to go to computer-mediated support groups (as compared to face-to-face support groups)?

Research Question 3: What differences are there between Caucasian and Indian PH patients and the features they say they look for on computer-mediated support groups?

Research Question 4: What differences are there between Caucasian and Indian PH patients and the gratification they say they receive from computer-mediated support groups?

METHOD

This section outlines the method that will be used in the present study to address the research questions.

Study Purpose

The principal goals of this study are: (1) to investigate the differences between Caucasian and Indian PH patients on their self-reported strategies they employ to cope with their illness and (2) to investigate the differences between Caucasian and Indian PH patients in their usage of computer-mediated support group. To achieve these goals, the study will use a survey combined with a personal interview.

Participants

Participants in this study will include a total of 44 women diagnosed with PH who are between the age of 25 and 50. The reason for choosing a sample this small in size is because of the rare nature of the disease in that only 500-1000 new cases of PH are diagnosed each year. In addition, PH is often under-diagnosed or misdiagnosed and therefore the known population of PH patients remain small in

size. All participants will fulfill the following eligibility criteria: (1) diagnosed with PH, per the definition of PH provided in the literature review; (2) PH patients of class IV, patients having inability to perform any activity without getting tired, chest pain and shortness of breath; (3) aged 25-50 at the time of study and (4) Caucasian and Indian identity, and (5) ability to speak and write English.

The sample will be composed of two cultural groups, Caucasian, living in United States and Indian, living in India (30 Caucasian, 14 Indian). Because the Caucasian ethnicity is at higher risk for PH than the Indian (Center for Disease Control, 2002), the sample size of the former is greater (68%) than the latter (32%).

Data Collection

The 30 Caucasian subjects will be recruited through PH clinics in New York, California, Boston and Chicago. Justification for the inclusion of the four states in this study include the high population density in the four states. These four states also house few of the most advance PH medical research facilities in United States (Phassociation, 2001) The 14 Indian subjects will be recruited through PH/Heart clinics in India practicing in Delhi, Mumbai, Bangalore and Chennai. Justification for the inclusion of the four states in this study include the high density population in the states and the presence of internationally-recognized medical institutions with specialty in cardio-vascular diseases (STIC Care, 2007). A summary of the research proposal will be submitted to the clinics at each of the locations to solicit their support for the study.

All recruitment procedures for the study will be approved by the Rochester Institute of Technology's Institutional Review Board (IRB), and by related institutions in India. Once the RIT-IRB approval and related approval in India is obtained, the potential subjects will be identified. Fliers describing the study will be distributed to the clinics in United States and India with the permission of the physicians in-charge. The fliers will instruct PH patients interested in participating or who had

questions to contact the principle investigator. Once the potential subjects are identified, the principle investigator will then mail recruitment letters in India and United States describing the study to eligible clients, with a response form indicating whether the recipient accepts or declines participation. These recruitment letters will include the contact information of the researcher should the interested subjects have any question.

Upon the receipt of the response forms, the researcher will mail the Demographic and Medical Information Questionnaire – DMIQ (Appendix B), Coping Operations Preferences Enquiry – COPE (Appendix C), Self-Construal Scale (Appendix D), and an Informed Consent form to those indicating a willingness to participate. The informed consent form will describe the purpose of the study, the survey content, a personal interview guide (Appendix E), and will explain the confidential nature of the survey. Finally, subjects will be asked to sign the informed consent form and return it within two weeks with their completed surveys in the prepaid envelope provided.

Returned surveys will be reviewed to check for completeness. Subjects failing to return their survey within two weeks will receive another letter to determine the status of the survey. Those still willing to participate will be given an additional week for survey completion and contacted again, this time by telephone, after two weeks if the survey has not been received. After the third opportunity, those who had not returned the survey will be considered non-responders. These procedures for identifying eligible participants and administering the survey will be used in both the United States and India. The researcher will then conduct a telephone or personal interview with the Caucasian subjects and the Indian subjects a week after the survey and the signed consent form is returned. The survey and the telephone/personal interview contains no questions common to both the instruments (see the respective Appendices). The survey instruments will collect information about the PH patients and their coping strategies. The survey instrument such as COPE, contains 60 items that can be divided into problem-focused, emotion-focused and maladaptive coping strategies. The items measure the coping

strategy of an individual in an in-depth manner, which a personal interview may not be able to measure.

On the other hand, telephone/personal interview will provide an in-depth understanding of the participants' motives to use computer-mediated support groups as opposed to face-to-face support groups.

The researcher will conduct a personal interview with Caucasian participants in the New York area and an interview via with the Caucasian participants living out of New York. The researcher will use telephone as the primary means to interview the Indian PH patients living in India.

Pretest of the Questionnaire Survey and the Interview Survey

The surveys, questionnaire surveys and Interview survey will be pretested before they are mailed to the participants. The researcher will ask two PH patients, who happen to be the researcher's friends, to complete the survey. The researcher will also conduct a telephone interview with them. During the pretest, the researcher will attempt to notice any problem questions. After the survey completion and telephone interview, the researcher will ask the pretest participants if there was any question that was difficult to understand. Based on the comments from the pretest participants, the researcher will then review the instruments and modify them accordingly.

Measurements

The variables have been operationalized using the following instruments:

Variables and and additional to the month	Instrument used to Operationalize The Variables				
Independent Variables					
Cultural Identities (Caucasian and Indian PH patients)	Self-Construal Scale (SCS)				
Dependent Variables					
Coping Strategies	Coping Operations Preference Enquiry (COPE)				

Motives of CMSG	Telephone/Personal Interview
Features of CMSG	Telephone/Personal Interview
Gratifications of CMSG	Telephone/Personal Interview

Instruments

Demographic and Medical Information Questionnaire (DMIQ)

A uniquely designed questionnaire will be used to assess the characteristics of Caucasian and Indian PH patients. Demographic variables will include age, income, employment status, education, health insurance, birthplace, ethnicity, language and marital status. In addition, the questionnaire will ask medical information, including diagnosis, age at diagnosis, years since diagnosis, PH stage at diagnosis, menopausal status, current medications, other health problems (if any) and side effects (if any).

Coping Operations Preference Enquiry (COPE)

The research will use the 60-item multidimensional coping inventory, Coping Operations

Preference Enquiry or COPE (Carver, Scheier & Weintraub, 1989) to collect information about the
coping strategies the PH subjects in United States and India employ to cope with PH. The coping
inventory consists of fifteen and several other less adaptive coping strategies. Respondents will indicate
how much they perform each behavior in a four-point Likert scale ranging from "1 - I don't do this a
lot" to "4 – I do this a lot." Alpha reliabilities for the subscales range between .62 and .92 except for the
mental disengagement subscale, which has an alpha coefficient of .45. Validity has been established
using measures of optimism, self-esteem and trait anxiety (Carver, Scheier & Weintraub, 1989).

Self-Construal Scale (SCS)

Individualism and Collectivism were measured using Singles' (1994) Self-Construal Scale (Appendix D). The SCS is a 23-item scale (alpha = .93) that measured the strengths of an individual's independent and inter-dependent self-construal. Respondents will indicate how much they agreed or disagreed with each each statement in a five-point scale ranging from "1 – Strongly agree" to 5 – "Strongly disagree." Validity for the SCS has been established in inter-ethnic comparisons (Singelis, 1994; Singelis & Sharkey, 1995), and by convergence with other methods of collectivism.

Interview

The research will use an interview guide (Appendix E) that contains 14 questions to conduct a telephone or personal interview with the participants. The content of the interview is divided into the following sections: (1) membership in a support group or CMSG; (2) features the subjects look for in a CMSG; (3) personal support the subjects receive; (4) impact of the CMSG in their social life and (5) impact of CMSG in PH coping. The interview will be audio-taped after permission is obtained from the participants along with the notes that will be maintained by the principle researcher. A standard interview format will be used and all participants will be asked the same questions.

Once the interview is conducted, the principle researcher will (1) manually analyze the transcripts and identify themes and behaviors that emerged within or between the groups; (2) assign code numbers to the themes and behaviors; (3) label with appropriate code numbers the segments of text that supported a particular theme; (4) compare the codes and similar ones will be placed in categories, and (5) compare individual transcripts of the two cultural groups (Caucasian in United States and Indian in India) for similarities and differences. These steps are expected to help the researcher to answer the research question two, three, four of the study.

CONCLUSION

Limitations and Expected Challenges of the Study

This research proposal has limitations, which are detailed below:

One of the most important limitations of the research will be the non-random nature of the sample. Since the sample will be drawn using a convenient sample (the samples will be referred by physicians), population generalizations about the coping strategies, the motives to use CMSG, the features that are looked for on CMSG and gratification received from CMSG, cannot be made.

Another important limitation of the research will be the instruments. The present research will rely upon self-reported data. It can be expected that the respondents may not report some experiences or occurrences due to several reasons. Due to the absence of the researcher when the respondents will fill the survey questionnaire, it will be difficult to control for or discuss the respondent's behavior. The assumption is that the respondents will answer the survey questionnaire in an honest manner, without the help of their family members.

The recruitment of PH patients in India may pose as the biggest challenge of the study. Due to extreme bureaucracy, the researcher may face a few institutional barriers associated with assessing potential participants in the hospital setting.

Avenues for Further Research

The present research proposal stands as a strong model for understanding the differences between Indian and Caucasian PH patients and their use of computer mediated support groups for coping with their illness. What would be interesting to study is a research that focuses on support groups for cross-cultural men facing PH. Though previous research conducted on the U.S. mainland suggests that support groups for chronically-ill diseases, such as cancer are dominated in membership by White males (Weber & Sherwill-Navaro, 2005), this study points to the participation of men of

Indian origin. Also interesting will be to explore the elements of a support group that ilicit membership from men of various cultural backgrounds.

Final Thoughts

The present study builds on a growing body of research with a focus on how PH patients cope with their illness and the implications of computer-mediated support groups in coping with their illness.

The study provides the beginning of a foundation for research exploring the differences in coping patterns and the implication of computer-mediated support groups among PH patients of Caucasian and Indian decent.

While the surveys will act as an effective instrument for exploring the differences between Caucasian and Indian PH patients in their coping behavior, the in-depth telephone/personal interviews will help the researcher in understanding (1) the motives of the respondents to go to CMSG; (2) the features the respondents look for in CMSG; (3) the gratifications the respondents receive from CMSG and effectively answer the research questions posed in the study.

It is hoped that the future research can continue to build on these findings in order to guide interventions in social work with PH patients living anywhere in the world.

APPENDIX A SOURCES SEARCHED

DATBASE SEARCHED	KEYWORDS USED	TIMEFRAME
Psychology (PsycArticles via EBSCO)	coping, coping, coping & Stress	staring 2007 onward
Psychology (PsycArticles via EBSCO	trauma, rape, sexual assault, traumatic experience	2007 - 1980
Academic Search Elite via EBSCO Also searched Google Scholar	collectivism, communication in collectivist society, communication and collectivism	2004-1994
Health Source: Nursing/Academic Version via EBSCO Psychology (PsycArticles via EBSCO	support groups, support groups for cancer patients, support groups for chronically-ill, support groups for patients	2007-1990
Communication and Mass Media Complete via EBSCO	support group in cyberspace, online support groups, support on the Internet, computer- mediated support group, communicating traumatic events	2005-1999 2006-1995 2006-1999
Psychology(PsychArticles via EBSCO)	social support, adjusting to chronic illness, diagnosis and adjustment to chronic illness	2005-1992 and represent and glad in
Psychology(PsychArticles via	depression and anxiety,	2004-1985
Also searched Google scholar for cases related to PH	depression and anxiety in patients, psychological distress in cancer patients, stress and anxiety in chronically-ill patients anxiety and depression in PPH patients	2005-1994
Academic Search Elite via EBSCO	social support and collectivism social support and culture support groups in Asia, social support in Asian countries, support groups in Asia, support groups in China	2006-1995 2006-1997

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APPENDIX B

Participant number: Date:

Demographic and Medical Information Questionnaire (DMIQ)

Name:				
Address.	_			
Phone Number: Home:	Work:	Date of Birth:	Bachciors Degree Mastani Degree Rid, MD, JD	
Ethnic Background: (check o	one)			
IrishPolish				
ItalianNorth Africa				
GermanFrenchIndian	sted (Please spec		od participate in any physica Type	
Occupation:				
■ Skilled labor				
Managerial				
Professional				
Homemaker/parentOther (please specify))		Only shart distances	
Are you currently working?				
Yes, Full time				
Yes, Freelance				

Marital Status:

Married

Yes, Work-from-home

■ Had to quit because of pulmonary Hypertension (PH)

Single
Separated
Divorced
Widowed
In a committed relationship

Number of childre	n
Ages of children	

Education

- Less than high school
- High school graduate
- High school plus some college
- Bachelors Degree
- Masters Degree
- PhD, MD, JD
- Other (please specify)

MED	CAL.	CONT	ITION
TATELL		COLIE	TITUL

When were you first diagnosed with PH?	(month, year)
Do you participate in any physical activities? Type	

Do you drive?

- Yes
- No
- Only if somebody else is also in the car
- Occasionally
- Rarely
- Only short distances

Do you do grocery alone?

- Yes
- No
- Sometimes, when the load is not heavy
- Accompanied by somebody to do grocery

Please indicate with an X any of the medical conditions that apply to you currently or in your history, in addition to PH:

- Back Pain
- High or Low Systolic Blood Pressure

Neurological Disorder
Neck Pain
Asthma
Hearing Loss

- HeadachesOther Respiratory Conditions
- Visual Loss
- Joint Pain
- Digestive Disorders
- Learning Disorder
- Broken Bones
- Liver Disease
- Depression
- Surgeries
- Reproductive Disorders
- Smoking
- Diabetes
- Urinary Tract Disorders
- Alcoholism
- Anemia
- Cancer
- Chemical Addiction
- Heart Disease
- Autoimmune Disorder
- Anxiety
- Other (please specify)

Please explain any of the above that you checked.

Please check the medication(s) you take currently?

- Flolan
- IV Remodulin
- Sub-q Remodulin
- Ventavis
- Revatio
- Bosentan (Tracleer)
- Ambrisentan
- Sitaxentan
- Coumadin or any other blood thinner
- Any Diuretic
- Potassium
- Oxygen
- Other (Please specify) ____

Please specify the condition it is prescribed for

Does the Insurance cover for your medication? If so, what percent?

Were you hospitalized in the hospital anytime in the last two years? If so, why?

APPENDIX C

Identification Number: Date:

We are interested in knowing how people respond to stressful situations. Different individuals use different strategies to deal with a traumatic event. This questionnaire asks you to indicate what you generally feel and do when you are faced with a stressful situation. Think about what you do under a lot of stress.

Respond to each of the following item by circling one number on the scale below each item, using the response choices given below. Please choose your answer THOUGHTFULLY. Please answer every item. There are no "right" or "wrong" answers, so please choose the most accurate that would be as true as possible for you. Indicate what you actually do when you face with a stress situation – and not what everyone does.

1 - I don't do this at all

2 - I do this a little bit

3 - I do this more than a little bit

4 - I do this a lot

COPING WITH PH

1.	Hope	a	miracle	would	happen
----	------	---	---------	-------	--------

1 2 3 4 don't do do a lot

2. Talk to others with PH to find out more

don't do do a lot
3. Try to keep feeling to myself

1 2 3 4 don't do do a lot

4. Focus on the next step

1 2 3 4 don't do do a lot

5. Go ahead as if nothing had happened

1 2 3 4 don't do do a lot

6. Mak		not to r	make matters	worse by				
1 don't do	2	3	4 do a lot					
7. Lea	ve ever	ything	on fate					
don' do	2	3	4 do a lot					
8. Try	to get p	rofessi	onal help to g			ress		
1 don't do	2	3	4 do a lot					
9. Loo	ked for	sympa	thy and under	standing fr	om famil	y		
don't do	2	3	4 do a lot					
10. Am	inspire	d to be	creative					
1 don't do	2	3	4 do a lot					
11. Talk	about	my feel	ings with fan	ily and frie	ends			
1 don't do	2	3	4 do a lot					
12. Mal	ce a pla	n of act	ion and follow	ved it				
1 don't do	2	3	4 do a lot					
13. Avo	id hain	a with n	eonle					
don't do	2	3	4 do a lot					
14. Get	Upset a	and I am	really aware	of it				
1 don't do	2	3	4 do a lot					

15. Ref	use to t	hink ab	oout it				
1 don't do	2	3	4 do a lot				
16. Hav	e becor	me moi	re spiritual than	ever			
1 don't do	2	3	4 do a lot				
17. Hav	e redis	covered	d priorities in lif	e			
1 don't do	2	3	4 do a lot				
18. Get	upset a	nd take	my feelings ou	t			
1 don't do	2	3	4 do a lot				
19. I an	n prepai	red for	the worst				
1 don't do	2	3	4 do a lot				
20. Wis	h the si	tuation	would go away				
1 don't do	2		4 do a lot				
			ow how bad th	ngs were			
don't do	2	3	4 do a lot				
22. Pray	7						
1 don't do	2	3	4 do a lot				
23. Trea	it the ill	ness as	a challenge				
1 don't do	2	3	4 do a lot				

24. Talk	to peer	s, i.e.,	others with the same illness	
1 don't do	2	3	4 do a lot	
25. Try t	o find o	out abo	ut the disease as much as I could f	
1 don't do	2	3	4 do a lot	
26. Depe	end on	family	to handle things	
1 don't do	2	3	4 do a lot	
27. Take	it out o	on fami	ly	
1 don't do	2	3	4 do a lot	
28. Lool	for sy	mpathy	and understanding from strangers	19. I am prepared for the worst
don't do	2	3	4 do a lot	
29. Try 1	new this	ngs in l	ife	
1 don't do	2	3	4 do a lot	
30. Try 1	o keep	my fee	lings from interfering	
1 don't do	2	3		
31. Ask	friends	for adv	rise	
1 2 don't do	3	4	do a lot	
32. I hol	d off do	oing any	thing about it until the situation p	ermits
1 don't do	2	3	4 do a lot	

33. Pre	tend tha	at it has	not happened				
1 don't do	2	3	4 do a lot				
34. Con	centrate	e on otl	ner things such as	go to movies, watch TV to think	about i	t less	
1 don't do	2	3	4 do a lot				
35. Put	all my t	rust in	God				
1 don't do	2	3	4 do a lot				
36. Acc	ept this	can't b	e changed				
1 don't do	2	3	4 do a lot				
27 Toll	to som	aone II	ho could do some	thing concrete			
1 don't do	2	3	4 do a lot	mt a ob			
	en come	thing n	ew from the exper	riance			
1 don't do	2	3	4 do a lot				
39. Lea	rn to liv	e with	it				
1 don't do	2	3	4 do a lot				
40. Kee	p myse	lf from	getting distracted	by other thoughts or activities.			
1 don't do	2	3	4 do a lot				
41. Ref	use to tr	y					
1 don't do	2	3	4 do a lot				

51. Kee	p mysel	f busy i	n other thin	gs to distract from the real	probler	n		
1 don't do	2	3	4 do a lot					
52. Slee	ep more	than us	ual					
1 don't do	2	3	4 do a lot	our naswer THOUGHTFUL curate that would be as true				
53. I fo	rce myse	elf to w	ait for the ri	ight time to do something.				
1 don't do	2	3	4 do a lot					
54. Lea	ve it on	destiny						
1 don't do	2	3	4 do a lot					
55. Ma	ke jokes	about i	t					
1 don't do	2	3	4 do a lot					
56. Get	a lot of	informa	ation					
1 don't do	2	3	4 do a lot					
57. Loc	ok for sy	mpathy	and unders	tanding from family				
don't do	2	3						
58. Do	n't put in	extra e	ffort on any	rthing				
1 don't do	2	3	4 do a lot					
59. Say	to myse	elf "this	isn't real"					
1 don't do	2	3	4 do a lot					
60. Dri	nk alcoh	ol or tal	ke drugs to	think less about it				

don't do

8.	It is in	-		_	ect decisions made by t	he group				
	1	2	3	4	beging with person					
9.	I will	stay in	the gro	up if the	ey need me, even when	I am not ha	ppy wi	th the gr	roup	
	1	2	3	4	5					
10.	If my	brother	or siste	er fails,	I feel responsible					
	1	2	3	4	5					
11.	Even	when I	strongl	y disagr	ee with group member	s, I avoid a	argum	ent		
	1	2	3	4	5					
12.	I woul	d rathe	r say 'n	o' direc	tly than risk being 'mis	understood'				
	1	2	3	4	5					
13.	Speak	ing up	during a	a meetii	ng is not a problem for	me				
	1	2	3	4	5					
14.	Havin	g a live	ly imag	gination	is important to me					
	1	2	3	4	5					
15.	I am c	omforta	able wit	th being	singled out for praise	or rewards				
	1	2	3	4	5					
16.	I am t	he same	e persor	at hon	ne that I am at work					
	1	2	3	4	5					
17.	Being	able to	take ca	re of m	yself is the primary con	ncern for m	е			
	1	2	3	4	5					
18.	I act th	he same	way no	ot matte	er who I am with					
	1	2	3	4	5					
		comfort than I a		ing som	neone's first name soon	after I mee	t them,	even w	hen they	are much
	1	2	3	4	5					

20. I p	refer to b	e direc	t and fo	rthright	t when de	ealing w	ith peopl	e I ha	ave just	met	
1	2	3		5							
21. I e	njoy bein	ng uniqu	ue and o	lifferen	t from ot	hers in n	nay respe	ect			
1		3									
22. My	persona	ıl identi	ty indep	pendent	of other	s is very	importa	nt to	me		
1	2	3					5				
23. I v	alue bein	g in go	od heal	th above	e everyth	ning					
1	2		4								

APPENDIX E

Identification Number:

Personal/Telephone Interview Guide

Thank you for taking time for participating in this study. The information you give will help to understand the needs of Pulmonary Hypertension (PH) patients. The purpose of the study is to discover how PH patients in United States and India use support groups as a tool for coping with their illness. Your insights regarding the issue will be very helpful.

The interview will last at least ____ hour. You nay choose not to answer any questions and you may terminate the interview at any point. The interview will be audio-recorded only with your permission. Your name will not be on this recording and your answers will remain confidential. Once the recording is transcribed, it will be destroyed. There is no right or wrong answer in this interview. We are only interested in your experiences as a PH patient.

These are few questions that will ask you about your membership in a support group for Pulmonary Hypertension (PH)

- 1. Have you been a member of a traditional or face-to-face support group for PH? Probe: If so, for how long?
- 2. How did you come to know about the support group?
- 3. Have you been a member of a computer-mediated support group (CMSG) for PH for 1 year?
- 4. Are you an active member of the CMSG? Probe: If your answer is No, please tell the reason why you stopped your participation? Probe: For how long are/ were you its member?
- 5. What motivated you to go to CMSG as opposed to face-to-face support group? Probe: What would you say is the most important reason that motivated you to go to a CMSG?

The next set of questions will ask you about the features you looked for/did you look for/would you look for in CMSG

6. What features did you look for in a CMSG?

Probe: What is the racial mix?

Probe: Does the racial mix make a difference to you?

Probe: Does the size of the CMSG make a difference to you?

The next set of questions will ask you about the personal support you have received after the diagnosis of PH

- 7. Tell me about the support you have from your family (spouse, children, parents) and/or friends
- 8. How does the support you receive from CMSG add to the social support you receive from your family and friends?

The next set of questions will ask you about the impact of CMSG on your social life

9. Did you notice any difference in your social life after joining a support group or CMSG?

10. Does CMSG help you at times you feel really depressed about PH?

Probe: If yes, in what ways?

Probe: If possible, can you provide instances.

- 11. Do you consider any other member from the CMSG as friends?
- 12. Do you feel your presence in the group is helpful to other members of the group? If yes, please explain in detail?

The next set of questions will ask you the impact of CMSG in coping with PH. This is the last set of question(s)

13. Do you think that your participation on CMSG has helped you in dealing with PH? Probe: If yes, please give details and instances.

Thanks you very much for your willingness to share your experiences. They have been very helpful.

APPENDIX F

CONSENT FOR PARTICIPATING IN THE RESEARCH

inflicted with this deadly ,	voluntarily consent to participate in this study. I certify that I
(print name)	
have been explained this rese mind have been answered to	earch and had ample opportunity to ask any question. All questions on my my satisfaction. I have read and I have understood the research.
Participant (signature)	Date has sent the less than th
ups in dealing with our	
I,	certify that I have explained the study and research
(print name)	I have a related all the language have site and the right apparatus of with the
	I have explained all the known benefits and the risks associated with the ve answered all the questions that the participant had prior to consenting
their participation.	
would be happy to send	is a copy of the rotally if you wish to consider to be community persons. I v
Researcher (signature)	and the box "I would Lit sale because a Copy of the Study" in the consent

APPENDIX G Recruitment Letter*

1	Dear	MAG	
ı	Jeal	IVIS.	

It is always a pleasure to know that medical science is making advancement in developing treatment for Pulmonary Hypertension (PH). It is a relief for people like us, inflicted with this deadly disease. PH specialists and scientists have successfully provided us with better treatments and now that the focus has shifted to life and living, they have even referred to us avenues to deal with our illness, such as the PH face to face and online support groups. However, they somehow overlook the significance of such groups to Ph patients like us. You are one of the small number of individuals whose opinion and thoughts would count the most in this matter.

As a part of my research, I wish to determine the coping strategies that PH patients employ to deal with their illness and the implication of computer-mediated support groups in dealing with our illness. We all deal with our illness in different ways. While some people find solace in talking to strangers about their illness, some just keep it to themselves. While some find close friends in these support groups, some are scared to go to these support groups.

The results of the study is completely dependent on the thinking of brave and courageous people like you. Enclosed with the letter are the surveys and the consent form to participate in the study. I assure of complete confidentiality. Your name will never appear on the survey form or in the results.

The results of the study will be made available to the Department of Communication, Rochester Institute of Technology, New York, and the interested community persons. I would be happy to send you a copy of the result, if you wish to receive it. In case you would like a copy of the result, please check the box "I Would Like to Receive a Copy of the Study" in the consent form.

Should you have any concerns and/or questions regarding the study, please e-mail or call xxxxxxxxxx. I would be happy to answer them.

Thank you for your assistance.

Sincerely,

Smita Menon Investigator

^{*}The researcher has borrowed the letter for the recruitment from **Dr. Bruce Austin, Chair, Department of Communication, Rochester Institute of Technology, New York**. The wordings shall be completely changed prior to mailing them to the participants.