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From Quackery to Control: Perceptions of Complementary and Alternative Medicine from Users
with Mental Health Disorders

A thesis
presented to
the faculty of the Department of Sociology and Anthropology
East Tennessee State University

In partial fulfillment
of the requirements for the degree
Master of the Arts of Sociology

by
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May 2014

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Dr. Joseph Baker

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Research, Mental Illness

ABSTRACT

From Quackery to Control: Perceptions of Complementary and Alternative Medicine from Users
with Mental Health Disorders

by

Rachael Welsh Allen

This study is an investigation into why people with depression and anxiety use complementary and alternative medicines at higher rates than the general population. The study examines perceptions of mental illness and meanings assigned to depression and anxiety, others' perceptions of mental illness, and experiences with conventional medicine. All participants were using complementary and alternative medicine at the time of the study; their reasons for CAM use as well as how CAM affected perceptions of their illness were main research questions. I conducted three focus groups with individuals diagnosed with depression who were using complementary and alternative medicine as forms of treatment. Focus groups were transcribed verbatim and analyzed using the coding software Nvivo. Participants were also given two questionnaires that were analyzed using SPSS. This study shows that complementary and alternative medicine ultimately gives individuals perceived control, a sense of agency, action, and acceptance in regards to their mental illness.

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CHAPTER 1

INTRODUCTION

A close look at the world around us suggests that people are becoming more aware of what they consume, the products they invest in, and the institutions they trust to guide them in the right directions. Recently, this shift has begun to affect the way people view their health, the medications they choose to take, and the practitioners from whom they seek advice. Americans are increasing out-of-pocket medical expenses by spending more money on complementary and alternative medicine (CAM) than they are paying for conventional medical treatments such as out-of-pocket physician services and hospital visits (Barnes et al. 2004).

In the 1990s, Americans were spending between \$36 and \$47 billion dollars a year on complementary and alternative medicine. However, Americans are not the only ones choosing to use these therapies more often; this trend has been identified in many other countries around the world (Fisher and Ward 1994). In fact, Americans have reported lower usage of complementary and alternative medicine compared to other countries including Germany, Canada, France, and Australia (Ernst 2000).

People diagnosed with mental health disorders, specifically depression and anxiety, are more likely than the general population to use complementary and alternative medicine (Kessler et al. 2001). Previous research has focused on rates of use (Grzywacz et al. 2006; Unutzer et al. 2000) and types of complementary and alternative medicine that persons with mental health disorders use (Druss and Rosenheck 2000; Roy-Byrne et al. 2005; Werneke et al. 2006). However, questions of what makes people with mental health disorders turn to complementary

and alternative medicine and whether individuals' beliefs about mental illness affect their decision to use CAM are topics in need of further research.

The purpose of this research is to broaden our knowledge of why people with mental health disorders are more likely than those in the general population to use complementary and alternative medicines. This study will attempt to determine if complementary and alternative medicine use is higher in people with mental health disorders, specifically depression and anxiety, because of their determination that conventional mental health care does not meet their needs. This study will also focus on people's perceptions of mental illness and the meanings they assign to depression and anxiety to determine if views of illness affect the decision to use complementary and alternative medicine and if CAM in turn affects the perceptions of their illness.

CHAPTER 2

LITERATURE REVIEW

Doctors in the biomedical field have not always had the power and authority they hold today. In fact in the early nineteenth century the sick were cared for by family members or their community and many believed that common sense and native intelligence could solve illness (Starr 1982). Because of this complementary and alternative medicine had been very popular in the early twentieth century. It was not until the decades following the 1930s and 1940s that the general public's use of complementary and alternative medicine significantly declined. With the growth of urban towns and cities in the twentieth century, treatment began to shift from families to paid practitioners. Eventually physicians became a powerful profession and the invention of "miracle drugs" and growing prestige of conventional medicine allowed them to shape the structure of American medicine and convince the general public that their views were more effective in the treatment of illness (Baer 2001). This transformation in the view of illness and treatment adversely affected complementary and alternative medicine practitioners.

Eventually, court cases in favor of chiropractic medicine brought many forms of complementary medicine back to the forefront (Winnick 2005). Americans again began to see that they had the choice to incorporate holistic medicine into their views of health and treatment practices. Legal changes, like the decision of the FDA in the 1990s to allow marketing of over-the-counter herbal medicine for dietary use, made complementary and alternative medicine more accessible to the public. Accessibility and visibility of alternative treatments could provide one

explanation for the recent rise of CAM use; however, the medical profession, a dominant authority over health and wellness, has not taken this change lightly.

First responses of spokespersons from the medical community were predominantly negative. Practitioners wrote journal articles expressing disapproval and highlighting the dangers of complementary and alternative medicine (Winnick 2005). In recent years however, biomedical researchers have become involved with the scientific testing of CAM, leading some medical practitioners to have more of an open view of complementary and alternative medicine. Recognizing the rise in use of CAM has led some physicians to stress the need for practitioners to be more knowledgeable about these treatments.

Some researchers suggest that the medical profession will once again incorporate these practices into their biomedical paradigm and that the alternative practitioners will become a thing of the past (Baer 2001; Winnick 2005). Others suggest that the growth in popularity in complementary medicine is more of a cultural shift in the practice and belief of health, and that individuals will begin to incorporate both spiritual and holistic practices into their lives (Astin 1998). Complementary and alternative medicine practitioners are starting to suggest and call for a paradigm shift in research on health and illness (Ernst 2000). Recently complementary and alternative medicine practitioners have begun to standardize licensing procedures for practice (Eisenberg and Cohen 2002). Standardization of practice has the potential to legitimize CAM practitioners and prevent suggested co-optation from the biomedical field.

Demographically, CAM users are predominantly females at the average age of 40 (Barnes et al. 2004; Unutzer et al. 2000). CAM users also tend to have higher levels of education, usually a college degree (Eisenberg et al. 1998), and are more likely to reside in the western part of the U.S. While other traits are interesting and should be noted, such as the fact

that CAM users tended to be former smokers and drinkers, or be part of groups committed to feminism with interests in spirituality and personal growth, this study focuses on the higher usage of complementary and alternative medicine by adults with mental health disorders.

Mental health conditions being treated by complementary and alternative medicine include major depression, anxiety conditions, minor depression (differing from major depression, which is usually a chronic illness), dysthymia, and adjustment disorders (Druss and Rosenheck 2000; Grzywacz et al. 2006; Kessler et al. 2001; Unutzer et al. 2000). People who have self-defined, as well as diagnosed, mental health disorders are more likely to use complementary and alternative therapies compared to people who are mentally healthy. For example, the chance of CAM use is 34% higher among people diagnosed with major depression than those without this diagnosis. And 82% of older adults with either depression or anxiety used alternative therapies in the past year compared to 65% of older adults who used CAM but did not have depression or anxiety.

Praying is cited as the most common form of alternative therapy (Barnes et al. 2004). Following prayer, other common forms are natural products, deep breathing exercises, meditation, chiropractic care, yoga, massage, and diet. The natural products category includes herbal medicine as well as food and supplements, with the most common of these products being Echinacea, ginkgo biloba, ginseng, and garlic supplements. People are typically treating chronic and persisting health conditions with complementary and alternative medicine (Zollman and Vickers 1999). Examples of such conditions include chronic pain and chronic fatigue syndrome (Astin 1998), as well as hypertension and asthma. Depression and anxiety are among the most cited chronic conditions and are more likely to be treated using acupuncture and herbal remedies (Druss and Rosenberg 2000; Roy-Byrne et al. 2005).

An overview of the prevalence of psychiatric disorders is needed to fully understand adults with mental health disorders who use CAM. Mental health disorders are a common occurrence, with about one in four Americans suffering from a diagnosable mental health disorder each year. Depressive disorders affect 5-10% of citizens each year (Croghan 2001), while anxiety is reported by 18% of the population (Kessler et al. 2005). However, these numbers can be misleading. Because of stigmas associated with such disorders, many people go untreated (Pigott et al. 2010). The National Depressive and Manic-Depressive Association states that one-third of people with major depression fail to seek treatment, and only 1 in 10 receives adequate treatment.

People with mental health disorders are more likely to be CAM users, though the reasoning behind this trend is unclear. Perhaps people with mental health disorders become disenchanted with conventional antidepressants over time and seek an alternative mode of treatment (Rickhi et al. 2003). However, some may use CAM in addition to medicine they are already taking in hopes of increasing positive feelings (Werneke et al. 2006). Important areas of research on the subject include the reasons for choosing to use CAM, the effectiveness of treatment, and physicians' views of this phenomenon.

People using complementary and alternative medicine have a more holistic view of their health; they see the mind, body, and spirit as being connected and emphasize the natural treatment of the whole person (Astin 1998; Astin et al. 1998; Ernst 2000; Furnham 2002). Many people begin using complementary and alternative medicine because they think it is interesting to try, wondering if it could be more effective in treating health problems than conventional orthodox medications or, if combined with other medications, if there will be more positive results (Barnes et al. 2004; Rickhi et al. 2003; Vincent and Furnham 1996). The feeling of being

in control of personal health and of taking an active role in maintaining and participating in health decisions was a strong reason for CAM use.

While specific personality and social factors have not been studied in depth, Honda and Jacobson (2004) found that openness to new experience, perceived friend support, and perceived partner or family strain were all positively associated with CAM use. A common assumption is that people turn to complementary medicine because of a lack of trust or strong dislike for conventional orthodox medicine. However, previous literature shows that most CAM use is a complementary medical practice versus an alternative medical practice (Roy-Byrne et al. 2005). CAM users are just as likely (or even more likely in the case of those with mental health disorders) to be receiving conventional medical care as those in the general public (Kessler et al. 2001).

Compared to adults without mental health diagnoses, those diagnosed with mental health disorders are more likely to use herbal medicine, acupuncture, and megavitamins as the CAM of choice. St. Johns Wort, a common herbal medicine taken for treatment of depression, is superior to placebos and is comparable in effectiveness to conventional antidepressants (Croghan 2001; Kessler et al. 2001; Werneke et al. 2006). Studies have also shown that valerian root and passion flower, CAM treatments for anxiety, are comparable to conventional medications used to sedate and calm individuals.

Overall, physicians are becoming more accepting of complementary and alternative medicine (Winnick 2005). Most believe in the efficacy of acupuncture, chiropractic medicine, and massage, but many still cast doubt upon herbal approaches (Astin et al. 1998). Physicians still worry CAM practitioners do not have the extensive knowledge required to diagnose illness properly and that some forms of CAM could be potentially harmful if mixed with conventional

medicine (Astin et al. 1998). On the other hand, with the rise in popularity of complementary and alternative medicine, some physicians have chosen to incorporate and learn techniques, often using CAM themselves (Astin et al. 1998; Baer 2001; Reilly 1983). The medical professions differing opinions on CAM are both interesting and historic. Future research should study the changes that occur in the medical field as more studies are done on the effectiveness and popularity of complementary and alternative medicine.

Alternative methods of treating chronic conditions such as mental illness are not new, but within the past few decades there has been a rise in the popularity and usage of such medicines (Eisenberg et al. 1998). Physicians are beginning to realize the ideological shift towards holistic health is not a passing phase and have started to encourage research on the effectiveness and practice of CAM (Winnick 2005). More Americans are beginning to realize that there is more than one way to view health and wellness and perhaps incorporating a holistic view of both life and health is beneficial. To fully understand the rise in complementary and alternative medicine, social scientists need to focus on populations with higher rates of usage. This study investigates adults with mental health disorders and use of complementary and alternative medicine.

CHAPTER 3

DATA AND METHODS

Research Design

This study was conducted using three focus groups consisting of 3-4 participants of varying age, race, and socioeconomic status with a total of 11 participants. The focus groups were held in Johnson City, Tennessee and Athens, Georgia.

In order to participate in this study, participants had to have a professional diagnosis of major depressive disorder, dysthymic disorder, or minor depression. These disorders were chosen because they affect similar aspects of a person's life (working, sleeping, and enjoying pleasurable activities) and include similar symptoms, with the differences being in duration and reoccurrence of the depressive episode (Blazer et al. 1988). Psychotic Depression, Postpartum Depression, Seasonal Affective Disorder, and Bi-Polar Disorder were beyond the scope of this study and were excluded based on the reasoning that they occur at certain points throughout an individual's life and may include manic episodes and delusions as well as hallucinations (Blazer et al. 1988). Many participants had a co-existing diagnosis of anxiety, typically generalized anxiety. Future studies should look at other forms of depression and anxiety or just anxiety and use of complementary and alternative medicine.

Qualitative focus groups were chosen because they allow for a deeper understanding of the subject matter and can focus on narratives of individuals. Research has shown that while individual interviews elicit individual attitudes and beliefs, focus groups are useful when the researcher wants to obtain multiple views and emotional processes within a shorter amount of

time (Gibbs 1997). I was particularly interested in exploring issues that were important to participants. I wanted to know, in their own vocabulary, not only what participants thought but also why they had certain opinions and views, focus groups are particularly suited for these kinds of research questions (Kitzinger 1995). I also chose to do focus groups because of the synergy involved in them, focus groups are able to produce data beyond just the individual interview because they allow participants the chance to question and explain themselves to others (Morgan 1996). Finally, I believe that a focus group setting was more appropriate given the information being studied. When talking about mental health disorders I believe there would have been more interviewer effects if I did one on one interviews because the participants would have been talking to a researcher instead of other people who were dealing with depression and anxiety themselves.

The moderator guide, available in Appendix C, was used for all focus groups and included opening, key, and closing questions. Sub-questions were asked when the groups' initial answers did not cover all areas of interest. While all groups were asked identical questions in the same sequence, I asked subjects to expand on responses when the information could contribute to the study. This study focused on three themes: perceptions of mental illness, experience with depression or anxiety, and use of complementary and alternative medicine. All focus groups were audio-taped and transcribed verbatim.

In addition to qualitative data focusing on participants' experiences with conventional mental health care and views of mental illness, the participants also filled out a depression questionnaire and a basic demographic data survey, available in Appendices A & B. By collecting basic demographic data it is possible to compare data obtained from participants with mental health disorders with that of previous researchers studying these attributes within the

general population using complementary and alternative medicine (Barnes et al. 2004; Eisenberg et al. 1998). The questionnaire on depressive disorders was adapted from the Beck Depression Inventory and allowed for a more in-depth view of the participants in the study. However, the data I collected are not representative of the entire population, and because of the small sample size, quantitative results will be less stable, so comparisons will be limited.

Research Subjects

The sample for this study was drawn from a population of adults with diagnosed depressive disorders who treated symptoms with complementary and alternative medicine. To be eligible to participate in the study subjects had to (1) be over the age of 18; (2) be English-speaking; (3) have received a diagnosis of one of the depressive disorders listed above; (4) not have been hospitalized within the past 6 months in order to protect participants considered a vulnerable population; (5) have used complementary and alternative medicine within the past 6 months to treat their depressive disorder; (6) and be able to provide informed consent, which was covered before participants filled out the depression questionnaire and demographic survey. Potential participants were screened by phone (see Appendix D) to confirm that they met the eligibility requirements listed above.

Recruitment and Incentives

Participants were identified through flyers posted in natural food stores, natural markets, and complementary and alternative medicine shops/businesses around Johnson City, TN. Examples include Earth Fare, Natural Foods Market, yoga studios, and chiropractors' offices. Flyers were also posted in campus buildings at East Tennessee State University and ads were put

in local newspapers, broadcasted on local radio stations, and posted on craigslist.com. For Athens, Georgia, participants were recruited through an email sent out to the UGA faculty and staff, sent to different women's groups in the area, put into a local newspaper, and posted on craigslist.com. Focus group participants were compensated \$25 for arriving at the session regardless of whether they participated or not.

Originally I was hoping for at least 24 participants in the study; however, recruitment turned out to be significantly more difficult than originally anticipated. I recruited for the focus groups for 6 months and yet was still only able to recruit enough participants for three focus groups. Participants themselves mentioned a mental health stigma that they believed was more prevalent within the southern United States. Research has also shown that members of our society hold prejudices, discriminate, and associate a negative stigma with mental health disorders (Corrigan and Watson 2002; Wahl 1999). I believe that this stigma was a significant barrier in recruitment for the study. Future research should investigate whether the recruitment process is faster in other areas of the United States where stigma may not be as high.

Procedures

Subjects were required to travel to the focus group location, which was held at ETSU's Applied Social Research Laboratory in Johnson City, TN and Two Stories Coffee House in Athens, Georgia in a private room. Informed consent was obtained from participants once they all arrived at the focus group site, including consent to be audio-taped. Participants then took a depression questionnaire and filled out a basic demographic survey. The focus group then commenced following a standard moderator guide used for all groups. Other than the

demographic survey and depression questionnaire, no other identifying information was obtained from participants.

Data Analysis

All focus groups were audio-taped and transcribed verbatim. The moderator guide focused on three themes: perceptions of mental illness, such as how participants viewed their depression; experience with depression, for example how participants felt about conventional medicine's ability to treat depression; and use of complementary and alternative medicine, which included questions such as when participants decided to try alternative therapies and the types they used. I used qualitative grounded theory coding to study the focus group transcripts and examine codes that emerged from the data (Charmaz 2001).

I started by using line-by-line coding, writing memos on patterns and themes in the transcripts one focus group at a time. I then used focused coding to generate more concrete analytical concepts that captured larger patterns in the data. As I went through each focus group transcript, if I found new codes and themes, I would return to other focus groups to determine whether the new codes existed in those transcripts as well. I also used the qualitative coding software NVivo to assist in coding. NVivo allowed me to organize and group specific quotes from the transcripts into the codes found through line-by-line and focused coding. I created nodes for all codes I had and was able to get a better visual picture of the patterns within focus groups, along with greater accessibility to quotes for all codes.

I created two separate data sets in SPSS using answers from the demographic survey and depression questionnaire that participants filled out. I then used descriptive statistics and frequencies to analyze demographic information of participants and assess the severity of

symptoms they were experiencing with depression or anxiety. Even with a small sample size the surveys allowed for a better picture of the types of people participating in the groups.

CHAPTER 4

RESULTS

Demographic Information

In total, there were 11 focus group participants in this study. The ages of participants ranged from 20 to 62 with the average age being 31. Ninety percent, or 10 out of the 11 participants, were women. While 54 percent reported having some college education, participants reported higher levels of education ranging from some college to a master's degree, with one obtaining a doctoral degree. The majority of the participants classified themselves as Caucasian/White; there was only one black participant. Sixty-three percent of the participants were married at the time of the focus groups. Finally, in terms of income I classified a yearly income of \$50,000 and above as upper-class and \$40,000 and below as lower-class, there were no participants who reported an income between \$40,000 and \$50,000. Participants were split relatively equally between the two groups with 45 percent reporting incomes of \$50,000 or more and 54 percent reporting incomes of \$40,000 or below. The demographic information of participants in this study is similar to previous findings on who is more likely to use CAM (Barnes et al. 2004; Eisenberg et al. 1998; Unutzer et al. 2000).

Besides simple demographic information, I did note other interesting trends among participants such as political affiliation and religious identity. The majority, 63.7 percent reported that they were either strong Democrats or Independents leaning Democrat. In terms of religious identity most, 63.6 percent, reported identifying as theologically liberal or as having no

religious identity. When asked about personal beliefs about God 45 percent said that they believed in a higher power or cosmic force.

Experience with Depression and Anxiety

Participants had been experiencing symptoms of depression and anxiety for various amounts of time, with the minimum being 2 years and the maximum being 44 years. Sixty-three percent of the participants had been diagnosed by a family practitioner, doctor, or physician with only 27.3 percent reporting diagnosis by a psychiatrist. Most of the participants, 72 percent, had taken two or more anti-depressant or anti-anxiety medications, though some had taken many more, for example one participant had taken nine different medications at the time of the study. Fifty-four percent of the participants were treating their depression or anxiety with both conventional medications and alternative therapies. Four of the 11 were only using alternative therapies as treatment, and one reported only using anti-depressants, though to be qualified for the study participants had to have used alternative therapies within the past six months prior to the study.

Experience with Complementary and Alternative Medicine

The age that participants started using alternative therapies varied among participants with about half reporting that they started using them when they were younger, or under 20, and half reporting that they started when they were older, or above 30. Among these participants meditation was the most commonly used alternative therapy, with 81.8 percent of the participants reporting that they practiced meditation as a form of treatment. About half, or 45.5 percent of the participants, had used natural supplements or massage to treat their depression or

anxiety. Thirty-six percent of the participants had been to a chiropractor or changed their diet. Acupuncture was the least commonly used alternative therapy among these participants with only 3 of the 11, or 27.3 percent, reporting trying acupuncture to treat depression or anxiety.

Depression Questionnaire

The depression questionnaire was adapted from Beck's Depression Questionnaire (Beck et al. 1961). The questionnaire for this study does not include the numerical values that the original has but instead used bullet points. In Beck's Depression Questionnaire answers are numbered, for example, the question "Loss of Energy" has 4 responses; "I have as much energy as ever" (0 points); "I have less energy than I used to have" (1 point); "I don't have enough energy" (2 points); and "I don't have enough energy to do anything" (3 points). Most of the questions on this survey have 4 answer choices. Once a participant fills out the original survey the responses are added up and there are different ranges of depression depending on the numerical value a person gets.

I went back through my participant's depression questionnaires and added up their answers to see where my participants fell on the scale of depression. The focus group participants for this study were split relatively equally, with 5 out of the 11 qualifying as having a mild mood disturbance, and 4 out of the 11 having moderate depression. There was one participant who qualified with extreme depression and one with ups and downs that are considered normal. Lower valued answers, which are the first or second choices for the questions will tend to lead to a lower overall numerical value while higher answer choices, the third or fourth choices will lead to a higher numerical value. Lower values are associated with less extreme forms of depression while higher values are associated with more extreme forms. Using

SPSS I used frequency statistics to see which types of answers my participants were most likely to choose.

A majority of the participants were equally split between the first and second answer choices. For example, the question about sadness has four answer choices; “I do not feel sad” (0 points); “I feel sad much of the time” (1 point); “I am sad much of the time” (2 points); and “I am so sad or unhappy that I can’t stand it” (3 points). In this question, as well as many others, participants were split with 54.5 percent selecting the first answer choice and 45.4 percent selecting the second answer choice. However, there was variation among 8 of the 21 questions.

In a question asking about past failure, 54.5 percent responded “I have failed more than I should have.” Fifty-four percent of participants also said “I cry more than I used to” as well as “I have less energy than I used to have” and “I can’t concentrate as well as usual.” A large majority of participants, 72.7 percent, responded that “I am more irritable than usual” as well as 63.6 percent for agitation; “I feel more restless or wound up than usual.” In a question asking about indecisiveness participants were split between selections 1; “I make decisions about as well as ever” and selection 3 “I have much greater difficulty in making decision than I used to.” Finally, when asked about suicidal thoughts a majority, 63.6 percent responded “I don’t have any thoughts of killing myself.”

Personal Struggle and Loss of Control

A majority of participants described a process that led them to see themselves as emotionally deviant from others. When speaking of personal struggle with depression and anxiety, many described a time in which they experienced a lack of control over themselves and their emotions.

The anxiety just you know affected my health because I wasn't sleeping, wasn't eating, couldn't concentrate and was always in tears. So I just was having a really hard time (Female, Focus Group 2).

The lack of control, struggle, and stress of trying to appear normal to others were factors that led them to get diagnosed and eventually seek their own paths of treatment. Though depression and anxiety may affect people differently, these respondents' struggles and experiences significantly affected their lives. Some people can function at high levels while dealing with depression; however, many of the participants in these focus groups described another extreme, an inability to deal with daily life and responsibilities.

Participants with anxiety described that they could not meet other people's expectations for social interaction and thus experienced significant amounts of social anxiety. This social anxiety kept participants from engaging in social activities with others and at times would induce panic when thinking about upcoming events, work, or family holidays. Several participants with depression mentioned crying often. These individuals said that in the depths of a depressive episode they would not go to work, would not bathe, and would not want to do anything. Their personal struggle led to a lack of motivation in terms of work and personal responsibility as well as an inability to handle the emotions they were experiencing to the point that they described emotional breakdowns as a common occurrence.

I've definitely tried to turn to drugs and alcohol to deal with my depression and that of course got me nowhere. A glass of wine is wonderful but you know 4 bottles is a little excessive (Female, Focus Group 2).

In response to these experiences some described developing unhealthy ways to cope, including self-medicating with drugs or alcohol or self-mutilation, to manage their depression

and anxiety. Many blamed their severe lack of control on not being taught how to cope or deal with emotions correctly by their families. While this type of coping arguably led participants to feel even more out of control with their lives and emotions, it may have also been a way for them to postpone diagnosis and the label of “mentally ill.” Though participants knew that they were different from others, they still desired the control others had over their emotions and went through processes of masking their emotions to meet standards others had of them.

The cycle that participants went through in terms of conventional medicine shows that they initially rejected the stigma and label others assign to people with mental illness. Many had gone off and on medications several times and had been to various counselors. The trend seemed to be that they would take a medication or see a professional until they felt that they had their depression or anxiety under control, they would then stop their treatment. This cyclical pattern shows a strong desire for control over illness. Respondents also said things had not always been this bad; they used to have everything under control, they used to feel energized and happy. While participants eventually came to accept their depression or anxiety, initially participants rejected these labels and instead struggled with emotions and performances for others.

I’ve always had certain expectations just because of the family I’m from and I found a lot of pressure to meet those expectations...so I felt like I was always having to put on a show for people and like act it out and it was exhausting to be honest I’d get home and it would just be like it wasn’t even me so it just left me with like a lot of exhaustion (Female, Focus Group 1).

Those people I interact with don’t know the real me, they’re seeing the person I show them. The real me is not judged because they don’t know the real me they know the person I portray (Female, Focus Group 2).

In describing their struggle with depression or anxiety many focus group participants discussed a performance to make themselves appear “normal.” Instead of accepting their differences, they attempted to put on a show for others, a mask of what they thought others expected from people with “normal” emotions. In an attempt to fit in they made an effort to repress their emotions. The mask or show could have been a way to avoid judgments from others that seemed to bother focus group participants; however, the fact that participants felt they needed to mask their emotions again shows a lack of control. If they had their emotions in control they would not have to put on a performance for others. Many said that this mask added more emotional stress to their days. Eventually stress, the realization that they could not suppress their emotions forever, and the perceptions others had of mental illness including expectations for control led participants to diagnosis and conventional medicine.

The participants in these focus groups went through what Peggy Thoits termed a self-labeling process, which led them to experience a norm-state discrepancy in which they felt emotionally deviant from others (Thoits 1985). Failed emotional management techniques eventually led participants to voluntarily seek professional help. Thoits argues that in the self-labeling process the actors recognize that they are violating normative expectations for emotions and behavior, which assumes that there is a cultural agreement upon appropriate behavior. Violation of appropriate behavior results in the label of “mentally ill” or “crazy.” Individuals experience a norm-state discrepancy when they realize that their private experiences of emotions are not in line with normative expectations. However, the individual is motivated to conform to social expectations and thus engages in emotion work in an attempt to change their emotions and feelings to the normative standard.

Hochschild argues that emotion work is guided by what she terms feeling rules in our culture (Hochschild 2011). Hochschild claims that we actively try to shape our emotions to fit what we believe we should be experiencing or expressing in social situations. One way to do this is by disguising inappropriate emotions and displaying normative emotions. Participants in these focus groups described this process when discussing the show they put on for others. Participants said they would put on a mask in front of others and that others did not know the “real them” because they only saw the side they portrayed, the socially appropriate one. Participants also noted negative emotion management techniques, such as using drugs or alcohol to change their emotional states.

While this worked for a brief period of time, Thoits notes that when emotions are recurrent or prolonged, such as with chronic illnesses like depression or anxiety, emotion management becomes much harder to sustain. Thoits argues that when people are constantly reminded of the necessity and only temporary success of emotion management they will end up concluding that something is wrong with them or that they are crazy. When this happens professional help is sought voluntarily.

Role of Others in Shaping Perceptions of Mental Illness

Throughout their own personal struggle with depression or anxiety participants became highly aware and observant of others perceptions of mental illness. Most noted common patterns in how their families and communities talked about and dealt with depression and anxiety. When speaking to community views of depression participants noted that mental illness was not something that was talked about but rather dealt with in the immediate family unit. Within this family unit some participants felt that they were treated more delicately because family members

were afraid that something they said could trigger a depressive cycle. Others said they were not taught to deal with emotions because they grew up in the south or that people would just label them as overly emotional.

I know for jobs and stuff like that if you tell them that you have problems with depression or you're going through a hard time in life it's almost like they don't think they can count on you to take on certain tasks and stuff like that and it's like they're walking on egg shells or they don't know how it affects you physically (Female, Focus Group 3).

Respondents also noted a negative stigma attached to depression and anxiety within their broader community. This stigma influenced the ways they handled depression and was also one of the reasons some participants waited such a long time to get diagnosed, instead trying to meet cultural values of individualism through putting on a mask or show. Some said the view held by their community could be different because they live in the south, which suggests that respondents believed that southerners may handle mental illness and emotions differently than those in other areas of the country. This stigma could also be a result of a lack of understanding by others of the depression or anxiety experience.

People my age, I'm 61, "get over it" you know. I had one of my coworkers say what is wrong with you can't you just get over it I just started crying and left (Female, Focus Group 2).

My dad gets really irritated with my mother when the depression sets in he's just like "why doesn't she just get up, why doesn't she just do stuff?" And I'm like cause she can't (Female, Focus Group 3).

A majority of the participants reported a lack of understanding or judgment from others regarding their experience with depression or anxiety. Individuals were asked why they couldn't just "get things together" when it came to their depression; something they said was not possible when in the depths of a depressive episode. Participants reported that other people would say that their depression was simply a "cope out" or a way to avoid situations or responsibilities. This lack of understanding and stigma made the depressive experience harder for participants.

So in our ethic and our culture it was always "pull yourself up by your bootstraps" and "just get doing something and you'll feel better" (Female, Focus Group 1).

It's always been a just suck it up its just growing pains and even with depression it was just like you're just stressed with school just get your work done you know people aren't as quick to think something may actually be wrong and are definitely not as open to talking about it or even talking to a doctor to get treatment for it (Female, Focus Group 1).

If I'm going through a depressive cycle, she's [mother] like get your head out of your ass this isn't how it's supposed to work you're supposed to get up and you're not doing that well enough and don't do anything half assed and it's constantly just push push push (Female, Focus Group 3).

Participants also noted a clear cultural value of individualism within families and communities that influenced how mental illness was discussed and treated or not treated. Respondents were told that they needed to fix something in order to change how they were feeling and that taking action against their emotions would solve their problems, contrary to the biomedical view of depression. Respondents in the focus groups were experiencing a lack of

control and struggle within their own lives while also having to face the perceptions and stigmas people assign to those with mental illnesses, this led to an additional burden in how they viewed themselves and their depression or anxiety. On top of all this many people would tell participants that they simply needed to gain control or do something about their mental illness. Ultimately participants were unable to keep up the show of normalcy and were also unable to exert the level of control that others expected of them, resulting in participants seeking treatment through conventional and alternative routes.

Individual Experience with Conventional Medicine

Participants struggle with their own depression or anxiety, as well as the stress of trying to keep up with the expectations of others, often resulted in participants reaching a breaking point that led them to finally get diagnosed, a point at which they knew things could not go on the way they had been going.

I think it really helped when he [practitioner] said this is not your fault, this is the way your body was made. Your brain doesn't make the serotonin, it's not that big of a deal (Female, Focus Group 1).

It was just finally someone accepted it and it made me feel normal and gave me something to work towards in how to manage it (Female, Focus Group 3).

This concept of a breaking point is similar to the idea of “hitting rock bottom” for alcoholics and drug users (Cunningham et al. 1994). Rock bottom is the lowest point in an addiction, a time at which the addict finally realizes that enough is enough and begins to seek treatment for addiction. For some this breaking point is a significant event. For example, one

woman in my focus groups reported breaking down in front of a professor. For others it is just the realization that they can't keep going on the way they had been living. Many said they knew before they got diagnosed that they had depression or anxiety but they were avoiding going to a professional for help. This avoidance was the result of not wanting to be on medication as well as the fear of judgment due to the stigma that people assign to those with mental illness.

The avoidance of diagnosis among participants aligns with research on health seeking behaviors and negative stigmas associated with mental health disorders. Researchers have shown a clear stigma against those diagnosed with mental illnesses in our society that comes from a variety of sources, for example, families, coworkers, and communities (Corrigan and Watson 2002; Wahl 1999). This discrimination and stigma becomes a barrier to help seeking; higher perceived stigma is associated with lower rates and negative attitudes towards seeking help for mental illness (Conner et al. 2010; Wrigley et al. 2005). While participants were told that they should gain control over their illness, the same people telling them this also held negative views of mental illness that initially deterred these individuals from seeking in order to avoid the public stigma created and reinforced by members of our society.

However, when they finally went to a professional for help, they said that the diagnosis was a relief because it took away the feeling of responsibility for their feelings. They could now attribute it to something their bodies did, so that depression was not their fault or choice. They also described that the emotions they had been experiencing were finally validated by someone and that they were not crazy. The lack of control they were feeling was not their fault; it was their bodies, which led to a hope of one day being able to have control over the depression or anxiety.

Respondents all described their experiences with conventional medicine within the focus groups. While initially the diagnosis came as no surprise or was a relief to participants, ultimately conventional medicine did not provide the perceived control they were looking for. Instead, some started viewing conventional medicine negatively, as a crutch or as something or someone that was controlling their emotions for them.

Seeing a traditional doctor can be very frustrating because it takes me almost a month to get an appointment so then I go in and I get my prescription and then I have to wait like another month to see if it's even going to work and then it takes me another month to get an appointment back to see if they can change anything. It's been very frustrating dealing with traditional doctors because when I go in there I feel like they're like "ok well she's probably here to change her depression medication" and they probably feel like they just saw me yesterday and in the meantime it's been a month where I've not been keeping up with school and work and all that so it's been kind of frustrating (Female, Focus Group 1).

They gave me Paxil and that didn't work so then I went on Celexa and that worked so I took that for a while and tried a myriad of counselors, psychologists all that stuff but I was always so guarded and reserved that it didn't work... so after you know 5 or 6 sessions I was done...um tried Wellbutrin for a while in college, that made me a zombie yawning all the time and yet feeling like I had energy and then I'd find myself staring at a wall for no reason and not having a single thought. So I stayed with Celexa for a long time and then got off it. Mmm tried Effexor that stuff makes you bat shit crazy- I'm not kidding- Ativan,

Clonazepam, Xanax, mm all those are pretty much for anxiety or sleeping. Prozac will make me hurt somebody (Female, Focus Group 3).

Despite all the side effects you also don't know what it's doing to your body. I mean you take Prilosec and it depletes or how do I say other antacids and that depletes calcium from your body you know and just stuff like that. Everything gets processed, most things get processed through your liver and it's like how much can you really take before your organ checks out on you? (Female, Focus Group 3)

I think that the traditional medicine aspect of it is trial and error and if the person isn't persistent enough or if your doctor isn't listening very closely or willing to explore what else might be working... they're too willing to write a prescription like you've said and if you don't have a good relationship or a good follow up to me it's like it could backfire (Female, Focus Group 1).

When discussing conventional medicine, a majority of the participants mentioned a dislike of both practitioners and medications. Common claims were that conventional medicine is frustrating because certain medicines didn't work, traditional medicine is less personalized, and practitioners didn't listen to their feelings and were quick to prescribe anti-depressant or anti-anxiety medications. All participants had changed medication several times and even with the same medication reported switching the dosage of the medicine periodically. Participants also described negative side effects that came along with the conventional medicine including nausea, lack of concentration, weight gain, and increased energy to the extent that they needed to take sleeping medications to calm themselves.

Though most of the participants noted a dislike for conventional medicine, there were a few who said they eventually found a practitioner of medicine they liked. Though this view was only held by two or three people, the theme is important because the reasons they liked particular practitioners or medications was that they held the qualities that participants wanted, and did not experience with other practitioners and medications. As stated, a main complaint was that practitioners were too quick to prescribe medicine and did not listen to patients feelings. When talking about practitioners they liked, the difference was that these practitioners actually listened to them and talked about other forms of treatment. Listening to problems and interacting with patients was what separated the good from the bad.

I just I don't like taking medicine and I was really opposed to being put on any type of depression medication because I knew once I started that I probably wouldn't be able to stop and I would be on another pill for the rest of my life (Female, Focus Group 1).

Half the reason I don't like being on it is because I know how strong they are. It's kind of scary taking something like that to control how I feel (Female, Focus Group 1).

Respondents also expressed a fear of becoming dependent on the medication. Although in some cases medicine would help with depressive symptoms, the respondents did not like having to take medicine on a day-to-day basis. Participants did not like the idea of a medication controlling their emotions and were suspicious of the medicine because they said they didn't know what it was doing to their bodies.

This fear of dependency on conventional medicine connects with the theme of cultural individualism; participants were told that they needed to be in control of their illness; however, being dependent on a medication was not the same thing as being in control. Being dependent on and taking a medication every day was also an acceptance of the sick role, while participants eventually came to accept that they were going to have to deal with depression or anxiety for the rest of their lives, they still rejected the sick role and sought out other treatments that made them feel less dependent on conventional medicine. Respondents ultimately wanted to feel like they were also participating in treatment and doing something to help themselves. The need for greater control and dislike of side effects of medications is what led many participants to try CAM in the first place.

Participants' experiences with conventional medicine are similar to what David Karp has found in his research with individuals diagnosed with depression (Karp 2011). Karp claims that many times the psychiatric view neglects the fact that drugs affect the individuals' identity. While there are good psychiatrists and counselors, many times they can seem more like pill pushers than helpers. This pill pusher role was a common complaint among participants. In Karp's research participants resisted taking medication because they believed it would lead to a loss of control and responsibility for feelings. The participants in these focus groups had similar reactions, claiming that being dependent on medications meant that they were not in control of their illness.

Karp argues that we have contradictory messages about personal responsibility. While the biomedical model of mental illness initially is accepted because it relieves people of responsibility for their illness, this relief can also lead to a sense of powerlessness. I found this pattern in the responses of my focus group participants. After being on depression or anxiety

medication for extended periods of time, Karp also claims that people may begin to wonder whether their emotions are “me or the meds.” This can result in further feelings of loss of control and leads many to try to personally control their illness and emotions through alternative measures such as complementary and alternative medicine.

It is like a light switch somewhere. Something in there at some point in time threw off your chemical balance and most of the time you are down, you have a bad time, you have a bad day.... but in there somewhere that light switch goes off, there's that chemical, so I strongly believe that depression is more chemical as opposed to situational, situational just turns the chemical on (Female, Focus Group 3).

A majority of the participants believed that the cause of depression and anxiety was both chemical and environmental/situational rather than one or the other. Because depression and anxiety ran in many of the participants' families, they also said that it was hereditary. A few mentioned how they were raised, for example with a strict parent, contributed to their depression and anxiety. Many participants felt that their depression and anxiety had always been part of them, making it “chemical”, but that a life event or trigger set the dormant depression or anxiety into motion, making it situationally significant. This view suggests that the participants had not embraced the biomedical explanation for depression or anxiety, as a neurological lack of a chemical component in the brain, because they also thought that nurture and the environment play a role in the cause of depression or anxiety.

These factors play into why people chose to use CAM in the first place and ultimately why CAM worked for them. Individuals had been feeling a lack of control over their emotions and daily lives in terms of experience with depression and anxiety. They were then told by others

that the solution was to gain control over their emotions. Others' perceptions and the inability to meet requirements for control led them to get diagnosed and seek treatment; however, conventional medicine did not give them the perceived control they needed because they still felt like they were dependent on the medications and practitioners, and they did not like the side effects of conventional medicine.

Complementary and Alternative Medicine

Participants had come to learn about CAM in a number of different ways. While some had been told about CAM from friends or family members, others had researched alternative therapies on their own or seen alternative treatments for depression and anxiety in magazines or newspaper articles they read.

I was just reading a magazine about something and it was about flat lining, about how people just have no joy and just mood is kind of like “noise “and that just really resonated with me I was just like oh my gosh that’s me and they were talking about some things like St John’s Wort and you don’t necessarily have to go see a doctor... so mine actually started from recognizing myself in a magazine article (Female, Focus Group 1).

Although participants had tried many types of alternative therapies and had differing opinions on which one worked best, all noted the effectiveness of complementary and alternative medicine and had common responses to a question that asked why they chose to use CAM in the first place.

Just cause of the side effects of some of them like the citalopram would make me nauseous and make me kind of like a space cadet, I'd take it before bed with a sprite to try to keep from puking my guts out then wake up the next morning kind of like... "ok I'm going to get up and get dressed and go." I was like this is just not working so it was mostly the side effects and mostly the um yea I guess that's it just the side effects were driving me crazy and making me feel worse then I actually felt to begin with (Female, Focus Group 3).

I guess I would say it was part of the buck up thing it was like what can I do for myself? Ok if I know this about myself now what do I need to do to make this better? (Female, Focus Group 1).

I've always leaned more to a natural route, my grandfather used to call me Al Gore Jr. when I was in elementary school and I've always been more on the natural side of things (Female, Focus Group 1).

Participants liked using complementary and alternative therapies because they perceive them as more natural and holistic. While they may not have felt in control of the traditional medications they were taking, alternative therapies offered a way for participants to decide for themselves what they wanted to take to help with depression or anxiety. Many times a fear of dependency and dislike of conventional medicine, including side effects, was why participants chose to use CAM in the first place. Participants also noted that they felt like they understood the effects that alternative therapies had on their bodies whereas they were unsure of the chemical compounds found in anti-depressants and how they worked. This is ironic because more is known about the effects of conventional medicine versus complementary and alternative medicines.

I mean just like I can tell if I forget to take my Prozac I can tell if I forget to do something I was going to do naturally to help my depression. If I forget to go to yoga or I forget to take my herbs for a few days I can tell the difference so I definitely couldn't go just on traditional medicine without the alternative medicine (Female, Focus Group 1).

A majority of the respondents claimed that alternative therapies are effective treatments for their anxiety or depression. While all respondents were using or had used alternative therapies within the past six months, at the time of the focus groups 4 out of the 11 participants were only using alternative therapies as treatment, while the other 7 were using both conventional medicine and alternative treatments. Responses of participants indicate that there are differences in experiences and views of treatment options that led them to solely use alternative therapies or to use alternative therapies as a complementary treatments to conventional medicine.

I just went to the regular family doctor to get diagnosed and get a prescription and then I went back several times because I felt like it wasn't working. I'd go back and they'd change the dose or whatever and they changed the drug one time. Then I went to see a counselor or psychologist or whatever a few times and I didn't really think he was all that helpful (Male, Focus Group 1).

I'm much better off now that I was on the drugs they had me on. With the acupuncture I don't consider myself to have depression anymore. I'm happier and more functional than I was on whatever drugs I was on. So yea for me it [CAM] works better I get better results (Male, Focus Group 1).

Those who were only taking alternative therapies claimed that they felt happier and better off than they had when they were on anti-depressant or anti-anxiety medications. They also mentioned that conventional medicine did not work for them. While they had tried different medications and seen counselors or psychiatrists, they felt that these treatment options did not work or were not as effective in treating their depression or anxiety as CAM was. These participants also noted a stronger dislike of dependency on medications. While a majority of participants noted a dislike of conventional medicine, participants taking only alternative therapies could have had a stronger dislike of conventional medicine which led them to forgo these types of treatments and use only alternative therapies.

I truly believe that you can't have one without the other, you need the conventional medicine but you need the alternative things as well so that you can deal with things better and stay on an even kilter (Female, Focus Group 2).

I mean just like I can tell if I forget to take my Prozac I can tell if I forget to do something I was going to do to naturally help my depression. Like if I forget to go to yoga or I forget to take my herbs for a few days I can tell a difference. So I definitely couldn't go just on traditional medicine without the alternative medicine (Female, Focus Group 1).

Those who were using conventional medicine as well as alternative treatments said that they needed both, it could not be one without the other. Respondents said they could also feel differences in their depression and anxiety symptoms when they were not taking or practicing alternative treatments. At times the participants using both conventional medicine as well as CAM would warn or advise those using only alternative treatments of the dangers of going off of

medication. However, even those using both treatments held a general dislike for conventional medicine, even though they said they needed them. These views may seem ironic or contradictory to each other; however, their responses indicate that they were trying to work around the sick role. While they knew that they needed conventional medicine, they also did not want to be dependent on it and still wanted perceived control over their illness, which was a reason for using alternative treatments. Giving advice to other participants also suggests that they saw themselves as experts of their illness who could give advice to others, thus they were able to play practitioner and reject the sick role (Hill et al. 2000).

Participants in all three focus groups also mentioned having a support group that helped with their depression and anxiety. This group of people ranged from friends and roommates, to spouses, partners, and parents. Members would encourage the participants to get help with their depression or anxiety or suggest ways to alleviate symptoms. This support group could be a prerequisite for trying CAM that others dealing with depression or anxiety may not have. Because participants felt supported in dealing with depression and anxiety, this gave them more leeway to branch out and try alternative methods of treatment for their mental illness. Many people in these support groups were also using CAM and suggested that participants try things like breathing or meditation as forms of treatment. In this way the support group also showed respondents that “normal” people used CAM to treat and control other kinds of symptoms.

Action, Control, Acceptance

Throughout all focus groups there were three overarching themes: acceptance, control, and action. These themes came up when people were describing their own experience with depression, as well as when they discussed complementary and alternative medicines. At the

time of these focus groups a majority of the participants had come to accept their depression as a permanent attribute in their lives. They also noted that they had control over their own depression, though they also said that they had not always felt this way.

I have to do yoga on certain days and I have to go swimming on certain days and I have to take my herbal supplements. If I don't do that I can tell so it's just something I have to think about as something I have to do every day to keep it under control (Female, Focus Group 1).

Mine I feel like I've got it under control now I've been getting acupuncture for probably two and a half years and I really think it works I was on medication for about two and half years and it helped it made me functional but I still wasn't happy but I kind of weaned myself off the medication I started meditating and running (Male, Focus Group 1).

There are things you can do on your own and you're not giving into big pharma (Female, Focus Group 3).

Before using CAM participants had felt a lack of control over their emotions and were also being told that the solution for their depression or anxiety was to be in control. While conventional medicine did not provide this control, complementary and alternative medicine did because participants were able to decide which alternative therapy they would take or participate in. For some having a self-prescribed routine to follow in terms of which days to take or do certain alternative therapies also led to further feelings of stability and control. Ultimately participants described their experience with depression or anxiety as a success story, and many felt that CAM had successfully given participants the perceived control and agency they had been seeking.

Alternative treatments thus allowed for a feeling of acceptance and perceived control and because participants were able to actively do something to help with their depressive symptoms. In other words, people were *actively* deciding which CAM they would try, whereas with conventional medicine they felt that they were being controlled instead, and they were active participants in their treatment though participating in activities like yoga or meditation, instead of just taking a pill every day. This action gave them *perceived control* and agency over their depression or anxiety because they were choosing what to do. Finally, this perceived control and agency led to an *acceptance* of depression or anxiety because they knew there were ways for them to control it.

Changed Views of Depression Because of CAM

One of the concluding questions on the moderator guide asked participants if their views of depression had changed since they started taking alternative therapies. Participants in all focus groups noted a greater acceptance of depression and anxiety in their lives and an understanding that it was something they needed to deal with. At the same time, however, participants also felt that they had gained control over their depression throughout the years. For example, while one man reported fear that his depression would come back, alternative therapies helped him realize that he would be able to deal with it.

I'm not afraid of it [depression]. I used to be afraid that it would come back or it would be stronger and you know that it would win but I don't think that can happen now, I think I can deal with it (Male, Focus Group 1).

It's not a roller coaster nor does it have to be like society projects um one of the things I have is fight or flight syndrome and um I haven't really had that for a

while because not only am I dealing with it in therapy I am learning how to control my own responses you know through meditation and yoga and breathing and stuff like that (Female, Focus Group 3).

I know that before I really started trying to control it on my own, I mean there was some level of acceptance I knew that this was something I was going to have to deal with, but it was more that I was going to have to deal the bad symptoms forever. But once I started experimenting with other things and found things that helped its more been, I accept that I have to deal with it, but I also know that I'm going to be able to find things to help me for forever. There's so many things that you can try and do so if one thing doesn't help me I can always try something else. I feel like it's a lot easier to manage it and I don't get so anxious about having to manage it when I know there are things I can do on my own to help (Female, Focus Group 1).

Alternative therapies offered reassurance that there would always be something participants could do on their own to help themselves and that they had other options that did not include conventional medication that they could choose from. This choice ultimately led to a greater acceptance of depression because they knew they could control it on their own with complementary and alternative medicine or with both CAM and conventional medicine.

CHAPTER 5

DISCUSSION AND CONCLUSION

These focus groups shed light on the narratives and personal experiences of individuals diagnosed with depression and anxiety who chose complementary and alternative medicine as a sole or supplemental treatment for their illness. This study looked at constructions and perceptions of depression or anxiety as well as participants' CAM careers at the time of the focus group. Ultimately CAM gave participants the perceived control, agency, and ownership over their illness that others expected of them and allowed them to incorporate an illness identity into their sense of self.

Participants' identities were continuously being constructed through looking at others' expectations of them and meeting those expectations through using CAM. Participants in the focus groups went through a process of reworking their biographies at different stages of their depression, as shown through discussion of perceptions of mental illness initially, while using conventional medicine, and finally while using CAM. Participants changed the wording and descriptions of their depression or anxiety experience when incorporating their own and others' perceptions of mental illness from an overall struggle to an overall acceptance and control over their depression and anxiety through CAM use.



Figure 1 Initial Problems with Perceptions of Depression

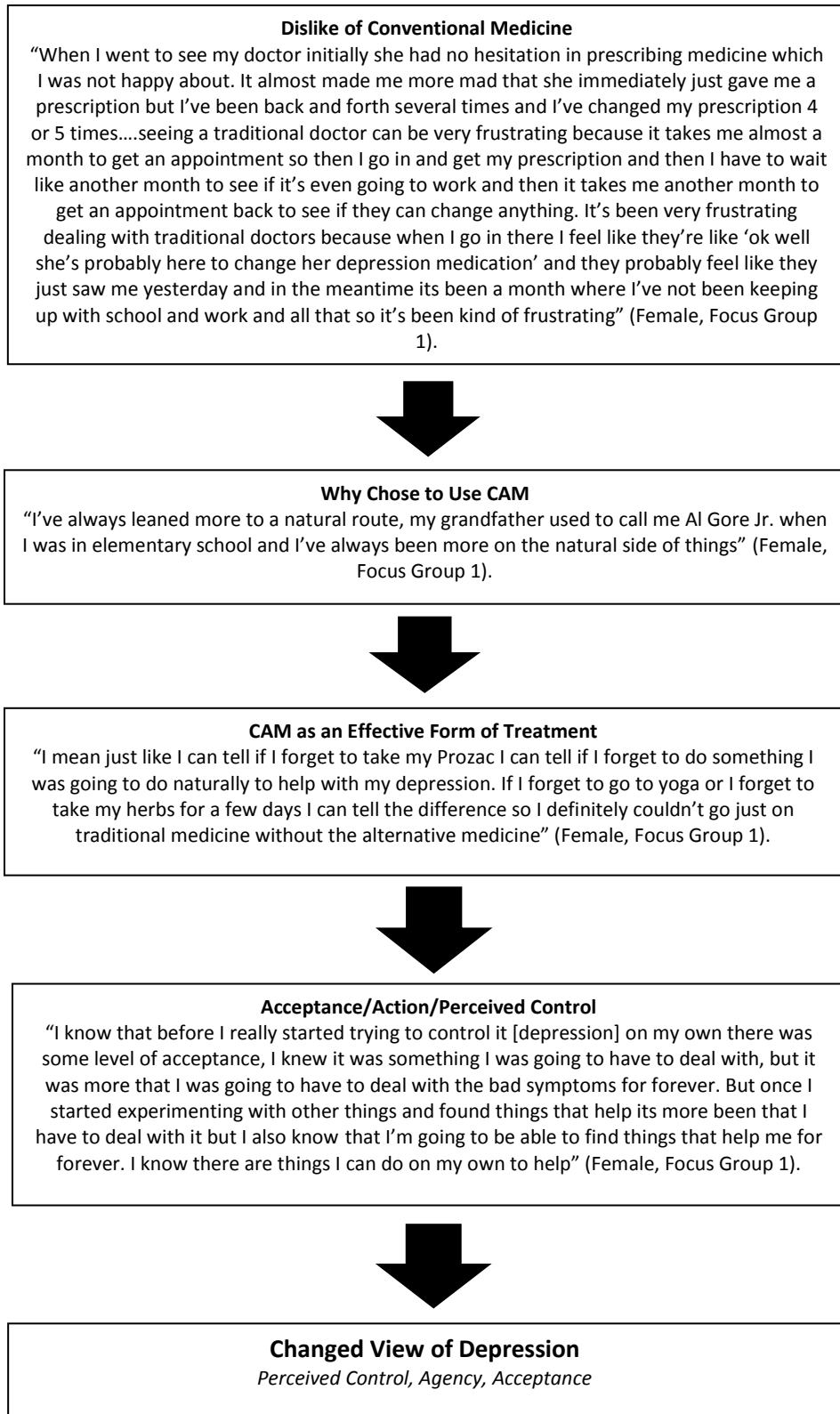


Figure 2 CAM Use and Changed Views of Depression

As shown in Figure 1, initially participants felt a lack of control over their depression or anxiety and struggled with their emotions. Participants felt that they needed to put on a mask or show of normalcy for others and in some cases developed negative coping mechanisms to deal with their emotions. This struggle along with expectations of others to have things under control led them to seek treatment. However, as Figure 2 shows, conventional medicine did not provide the control they were seeking as they felt dependent on the medications and did not like the side effects of the medications. This dislike of conventional medicine led participants to try CAM in the first place. Participants saw CAM as a more natural and effective treatment for their depression and anxiety. CAM also provided a way for participants to actively be involved with their treatment through choosing the alternative therapies they wanted to take.

This action led to the perceived control they had been seeking and allowed for an overall acceptance of their depression or anxiety. Complementary and alternative medicine also changed participant's views of their own depression. In the end this idea of coming to grips with depression or anxiety was a success story for participants. They acknowledged that they would have to deal with depression or anxiety for the rest of their lives, but this was something they accepted because they believed they had control over it.

Throughout the study there were contradictions and unexpected patterns in some responses of individuals. First, there was only one male in the sample. While previous research suggests that women are more likely to use CAM (Barnes et al. 2004; Unutzer et al. 2000), I still would have expected there to be more males. It is possible that many males go untreated for depression or anxiety because of the societal expectations of masculinity that include being strong and not showing or focusing on emotions. This expectation could also be a reason that

males may not have wanted to participate in focus groups, they didn't want to talk about their emotions or experiences with a larger group of people that they didn't know.

Second, only four participants in the focus groups were treating their depression or anxiety solely with CAM, all others were using CAM as a supplemental treatment, though they noted that they could tell when they weren't taking CAM. This is surprising because participants had such a strong dislike of conventional medicine; complaining of side effects, dependency, and inattentive practitioners, and yet the majority were taking anti-depressant or anti-anxiety medications at the time of the focus group. It is possible that speaking negatively about conventional medicine was a way to show that they were not dependent on it. Participants said that medications were flawed while at the same time acknowledging that they needed them. Speaking to flaws and problems with conventional medicine may have been a way to show that they were not completely invested in this form of treatment or biomedicine.

Participants may have seen dependency on medications as giving into the sick role, but CAM allowed participants a way to reject the sick role (Hill et al. 2000). While psychiatrists and counselors would be considered the principal legitimators of the sick role in this situation, the role was not accepted by others surrounding them who believed that depression or anxiety was a cop out or that participants were just not doing enough for themselves. CAM allowed respondents the ability to work around the sick role by giving them the opportunity to treat themselves and play the role of the practitioner in terms of the alternative therapy they wanted to use. Once depression had been accepted by individuals, this practitioner role extended beyond just choosing which treatment to take to diagnosing other members of their family who they thought had depression but may have not been diagnosed. In this way, the participants felt that

they had become experts, not only in dealing with their own depression or anxiety, but also with diagnosing others' anxiety and depression.

Third, participants claimed that they understood the effects of different types of CAM whereas they didn't know what conventional medicine was doing to their bodies and feared the long-term repercussions of taking psychiatric medicine every day for the rest of their lives. This is ironic because significant amounts of research on the workings and effects of anti-depressant and anti-anxiety medications have been published, whereas there is not as much research on how CAM affects the body. In fact, some researchers have suggested that CAM could be dangerous to take with certain pharmaceutical medications and have commented on problems associated with the fact that natural health food products and stores are largely unregulated (Mills et al. 2003). I think that individual choice played a large role in this view of CAM and conventional medicine. Practitioners prescribing and giving medicine to participants seemed suspicious to them, while some saw it as a way to control their emotions. However, when they chose what treatment to take this was seen as acceptable. Feeling like they were controlling their emotions and bodies in some way seemed safer than another person controlling the medications they took.

Finally, while things like stigma, a culture of individualism, and a dislike of conventional medicine led participants to try CAM and ultimately feel like they have perceived control over their illness, one has to wonder if in the end they are reinforcing the things that make being mentally ill difficult. Participants were expected to be in control over their illness, and CAM did this for them; however, they are then justifying others' perceptions of mental illness. In many cases they also internalized the mental health stigma, at times calling themselves crazy or nuts. Their actions are a reaction to others' expectations and the stigma assigned to those with mental illnesses; however, are their actions also reinforcing those beliefs? If so, does this do anything to

change the stigma assigned to these individuals or the prospects of those with mental health disorders? In the end, are respondents saying that people just need to accept that they have depression and anxiety and meet other people's standards to be in control of things?

While this research leads to further questions about the intricacies of the CAM experience, it also sheds light on the depression and anxiety experience of individuals and shows how CAM ultimately changed people's views of depression and anxiety. Previous research only focused on the types of CAM (Grzywacz et al. 2006; Unutzer et al. 2000) and rates of use by those with mental health disorders (Druss and Rosenheck 2000; Roy-Byrne et al. 2005; Werneke et al. 2006). This study is an initial step in looking at *why* people, specifically those with depression or anxiety, choose to use CAM and how it changes their perceptions of themselves and their mental illness. To completely understand a social phenomenon it is important to look at it both quantitatively and qualitatively, to look beyond just numbers to the reasons that the pattern is occurring.

The ways that CAM changed focus group members' perceptions of their depression or anxiety are significant. The research shows why societal expectations of those with mental illnesses as well as the stigma people with mental health disorders face every day is so important. There is a difference between acknowledging a mental health stigma and looking at how it truly affects people who face it every day. This study shows that people in these focus groups felt a significant need to be in control of their illness. This need was so desperate that they turned to alternative therapies because conventional medicine did not meet their need for control. It is possible that there could be things other than CAM that could give people a sense of agency over their illness, CAM could just be one thing that helps. This study should also make us wonder; do all people with depression or anxiety seek this control and do they feel out of control initially

because of societal expectations? If so, what does this say about our society and the cultural standard of individualism?

This study also shows problems with conventional medicine and treatments for anxiety and depression, especially in terms of practitioners, from the point of view of focus group participants. Perhaps those who treat it don't really understand the need for control that their patients feel. This study highlights areas of improvement for conventional medicine practitioners within the field of mental health, namely that they need to listen to their patients more and also not be too quick to prescribe medicine. I think if practitioners really listened to their patients and understood the societal expectations for control as well as the stigma that their patients face, it could make them better practitioners.

Finally, this study could help other people who are dealing with depression and anxiety. If others' experiences are anything like the participants in these focus groups, it is possible that there are other people out there who feel the same lack of control or pressures from others to get their depression or anxiety in control. It is always helpful to know that there are others out there who struggle with the same issues and to be able to look at ways that other people have gained perceived control and agency over their illness.

Limitations

While community and family views in the Southeastern United States could influence the need for control, there is still an overall stigma held by others when it comes to mental illness (Corrigan and Watson 2002). It would be interesting to see if results would be similar in different geographical locations. This study had a small sample size and is thus only an initial picture into the CAM experience, why people with depression and anxiety choose to use CAM, and how

CAM use changed their perceptions of mental illness. The small sample size also means that this study cannot generalize to all people with depression and anxiety but can instead only show what focus group participants in this study felt at the time of the focus groups.

Future Research

This study deals only with those diagnosed with depression and anxiety, further research should include other forms of mental illness. Future research should also include larger sample sizes and should also look at different geographical locations. It is possible that other areas of the country do not hold such negative views of mental illness and perhaps in these areas people diagnosed with depression or anxiety may not feel as great of a need to be in control of their illness. Future research should also use locus of control scales to see whether individuals with mental health disorders who are using CAM have an internal or external locus of control and whether perceived types of control change with use of CAM.

While participants said they liked using complementary and alternative treatments because they were more “natural” and “holistic,” this study was particularly focused on reasons for using CAM. Future research should unpack what people mean when they say treatments are “natural” or “holistic” to get a better idea of perceptions of complementary and alternative medicine. Future research should also look at specific types of CAM to see if different types are considered more natural than others. Finally, to be included in this study, participants need to have a professional diagnosis of depression. Future research should look at the CAM experience and perceptions of depression by those who were not professional diagnosed but instead self-diagnosed themselves.

Even with its limitations, this study provides an initial view into why people with depression and anxiety use complementary and alternative medicine. The process of the CAM experience and potential benefits that result from taking alternative therapies including action, control, and acceptance of depression or anxiety. These questions are relevant to psychiatrists and counselors who diagnose and treat persons with depression and anxiety, as well as those suffering from depression and anxiety. This research also makes a contribution to the growing body of literature on the reasons and implications for the rise of complementary and alternative medicine use in the United States.

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APPENDICES

Appendix A: Demographic Survey

1. What is your birthdate?

____/ ____ / ____

mm dd yyyy

2. What is your gender?

- Female
- Male

3. What is the highest level of education you have completed?

- Grammar School
- High School or Equivalent
- Vocational/Technical School
- Some College
- Bachelor's Degree
- Master's Degree
- Doctoral Degree
- Professional Degree
- Other _____

4. How would you classify yourself? Check all that apply.

- Arab
- Asian/Pacific Islander
- Black
- Caucasian/White
- Hispanic
- Latino
- Multiracial
- Other _____

5. What is your current marital status?

- Never Married
- Married

- Living as married
 - Separated
 - Divorced
 - Widowed
6. Generally speaking, do you consider yourself to be a(n):
- Strong Democrat
 - Not so strong Democrat
 - Independent leaning Democrat
 - Independent
 - Independent leaning Republican
 - Not so strong Republican
 - Strong Republican
 - Other
 - Don't Know
7. What is your current household income?
- \$ _____ . _____
8. How long have you been experiencing symptoms of depression or anxiety? Fill in the number of months and/or years below.
- _____ months _____ years
9. At what age you were diagnosed with depression or anxiety? _____
10. Who diagnosed you with depression or anxiety?
- Counselor
 - Psychiatrist
 - Social Worker
 - Family Practitioner/Doctor/Physician
 - Other _____
11. About how many traditional medications have you tried to treat depression or anxiety? By traditional medicine we mean things like Zoloft, Prozac, Lexapro, Ativan.. _____
12. What are you currently using to treat depression or anxiety?
- Alternative Therapy Only
 - Anti-Depressant and Alternative Therapy
 - Anti-Anxiety Medication and Alternative Therapy
 - Anti-Depressant Only
 - Anti-Anxiety Medication Only
 - Other _____

13. At what age did you start using Alternative Therapies? _____

14. Which Alternative Therapies have you tried?

- Natural Supplements
- Yoga
- Meditation
- Chiropractic Care
- Acupuncture
- Massage
- Diet
- Other _____

15. How tall are you without shoes? _____ ft. _____ in.

16. How much do you weigh without shoes? _____ lbs.

17. Have you ever been told by a doctor or other health professional that you had hypertension, also called high blood pressure?

- Yes
- No
- Don't Know

18. Have you ever been told by a doctor or other health professional that you had coronary heart disease?

- Yes
- No
- Don't Know

19. Have you ever been told by a doctor or other health professional that you had any kind of heart condition or heart disease (other than the one I just asked about?)

- Yes
- No
- Don't Know

20. Have you ever been told by a doctor or other health professional that you had asthma?

- Yes
- No
- Don't Know

21. During the past 12 months, have you had an episode of asthma or an asthma attack?

- Yes
- No
- Don't Know

22. Have you ever been told by a doctor or other health professional that you had an ulcer?
This could be a stomach, duodenal, or peptic ulcer.

- Yes
- No
- Don't Know

23. Have you ever been told by a doctor or other health professional that you had high cholesterol?

- Yes
- No
- Don't Know

24. Have you ever been told by a doctor or other health professional that you have any of the following: pre-diabetes, impaired fasting glucose tolerance, borderline diabetes or high blood pressure?

- Yes
- No
- Don't Know

25. Are you now taking insulin?

- Yes
- No
- Don't Know

26. Are you now taking diabetic pills to lower your blood sugar? These are sometimes called oral agents or oral hypoglycemic agents.

- Yes
- No
- Don't Know

27. Have you smoked at least 100 cigarettes in your entire life?

- Yes
- No
- Don't Know

28. Do you now smoke cigarettes every day, some days, or not at all?

- Every Day
- Some Days
- Not at All
- Don't Know

29. On average, how many hours of sleep do you get in a 24 hour period? _____ hrs.

30. Please indicate the one term that best describes your religious identity

- Born-Again
- Bible-Believing
- Charismatic
- Theologically Conservative
- Evangelical
- Fundamentalist
- Theologically Liberal
- Mainline Christian
- Pentecostal
- Seeker
- Religious Right
- Moral Majority
- None of these

31. How often do you attend religious services?

- Never
- Less than once a year
- Once or twice a year
- Several times a year
- Once a month
- 2-3 times a month
- About weekly
- Weekly
- Several times a week

32. The last time you prayed, what did you pray about?

- Praise or adoration
- General world concerns and affairs
- Confessing sins/asking about forgiveness
- Your family
- Someone you know personally
- Someone you do not know personally
- People listed in a church bulletin, program, or newsletter
- Your personal financial security
- Your personal health

- Your spiritual life/relationship with God
- Other personal needs

33. Which one statement comes closest to your personal beliefs about God?

- I have no doubt that God exists
- I believe in God, but with some doubts
- I sometimes believe in God
- I believe in a higher power or cosmic force
- I don't believe in anything beyond the physical world
- I have no opinion

Appendix B: Depression Questionnaire

Instructions: This questionnaire consists of 21 questions. Please read each question carefully, and then pick out the one answer that best describes the way you have been feeling during the past week, including today. Circle the box beside the answer you have picked. Choose the statement that comes closest to your opinion.

1. Sadness

- I do not feel sad
- I feel sad much of the time
- I am sad all of the time
- I am so sad or unhappy that I can't stand it

2. Pessimism

- I am not discouraged about my future
- I feel more discouraged about my future than I used to be
- I do not expect things to work out for me
- I feel my future is hopeless and will only get worse

3. Past Failure

- I do not feel like a failure
- I have failed more than I should have
- As I look back, I see a lot of failures
- I feel I am a total failure as a person

4. Loss of Pleasure

- I get as much pleasure as I ever did from the things I enjoy
- I don't enjoy things as much as I used to
- I get very little pleasure from the things I used to enjoy
- I can't get any pleasure from the things I used to enjoy

5. Guilty Feelings

- I don't feel particularly guilty
- I feel guilty over many things I have done or should have done
- I feel guilty most of the time
- I feel guilty all of the time

6. Punishment Feelings

- I don't feel like I am being punished
- I feel I may be punished
- I expect to be punished
- I feel I am being punished

7. Self-Dislike

- I feel the same about myself as ever
- I have lost confidence in myself
- I am disappointed in myself
- I dislike myself

8. Self-Criticalness

- I don't criticize or blame myself more than usual
- I am more critical of myself than I used to be
- I criticize myself for all of my faults
- I blame myself for everything bad that happens

9. Suicidal Thoughts or Wishes

- I don't have any thoughts of killing myself
- I have thoughts of killing myself, but I would not carry them out
- I would like to kill myself
- I would kill myself if I had the chance

10. Crying

- I don't cry any more than I used to
- I cry more than I used to
- I cry over every little thing
- I feel like crying, but I can't

11. Agitation

- I am no more restless or wound up than usual
- I feel more restless or wound up than usual
- I am so restless or agitated that it's hard to stay still
- I am so restless or agitated that I have to keep moving or doing something

12. Loss of Interest

- I have not lost interest in other people or activities
- I am less interested in other people or things than before
- I have lost most of my interest in other people or things than before

- It's hard to get interested in anything

13. Indecisiveness

- I make decisions about as well as ever
- I find it more difficult to make decisions than usual
- I have much greater difficulty in making decisions than I used to
- I have trouble making any decisions

14. Worthlessness

- I do not feel I am worthless
- I don't consider myself as worthwhile and useful as I used to
- I feel more worthless as compared to other people
- I feel utterly worthless

15. Loss of Energy

- I have as much energy as ever
- I have less energy than I used to have
- I don't have enough energy to do very much
- I don't have enough energy to do anything

16. Changes in Sleeping Pattern

- I have not experienced any change in my sleeping pattern
- I sleep somewhat more than usual
- I sleep somewhat less than usual
- I sleep a lot more than usual
- I sleep a lot less than usual
- I sleep more of the day
- I wake up 1-2 hours early and can't get back to sleep

17. Irritability

- I am no more irritable than usual
- I am more irritable than usual
- I am much more irritable than usual
- I am irritable all the time

18. Changes in Appetite

- I have not experienced any change in my appetite
- My Appetite is somewhat less than usual
- My appetite is somewhat greater than usual
- My appetite is much less than before

- My appetite is much greater than usual
- I have no appetite at all
- I crave food all the time

19. Concentration Difficulty

- I can concentrate as well as ever
- I can't concentrate as well as usual
- It's hard to keep my mind on anything for very long
- I find I can't concentrate on anything

20. Tiredness or Fatigue

- I am no more tired or fatigued than usual
- I get more tired or fatigued more easily than usual
- I am too tired or fatigued to do a lot of the things I used to do
- I am too tired or fatigued to do most of the things I used to do

21. Loss of Interest in Sex

- I have not noticed any recent changes in my interest in sex
- I am less interested in sex than I used to be
- I am much less interested in sex now
- I have not lost interest in sex completely

Mental Health Disorders and the Use of Complementary and Alternative Medicine

RESEARCH OBJECTIVE

The purpose of this research is to broaden our knowledge of why people with depression and anxiety are more likely than those in the general population to use alternative therapies. This study will attempt to determine if complementary and alternative medicine use is higher because conventional medicine does not meet specific needs. This study also focuses on individuals beliefs of mental illness to determine if views of illness affect the decision to use complementary and alternative medicine.

I. INTRODUCTION

Objective: Explain the purpose of the focus group and establish rapport with the respondents.

- A. Moderator introduction.
- B. Audio recording, confidentiality, use of first name only, etc.
- C. Respondent introduction (ice-breaker activity): If you could travel anywhere in the world, where would it be and why?

II. PERCEPTIONS OF MENTAL ILLNESS

Objective: To understand participant's perceptions of mental illness and how this may have influenced their use of complementary and alternative medicine.

- A. Tell me about how depression or anxiety has affected your everyday life? Probe:
 1. Work
 2. Relationships
 3. Activities
- B. In your experience, have you ever felt like you have been treated differently because you have depression or anxiety? Explain
 1. Would you say these experiences changed over time? How so?
 2. Is anyone's experience different than that?
- C. Tell me a little about how you view your depression or anxiety? Probe:

1. Significant problem in your life (weakness)
2. Something you've come to accept (acceptance)
3. Something that makes you stronger (how?)
4. Something you accept but others worry or judge you for (explain or give an example)
5. Is anyone's experience different than that?

D. What would you say is the cause of depression or anxiety in general? Probe:

1. Chemical Imbalance
2. Dietary Imbalance
3. Significant life-change
4. A more holistic view (mind-body balance)

III. EXPERIENCE WITH DEPRESSION OR ANXIETY

Objective: To understand when participants were diagnosed, and what treatments have been used for depression or anxiety

A. Tell me about how you felt when you were first diagnosed with depression or anxiety.

1. Is anyone's experience different than that?

B. Let's talk about past experiences with physicians, therapists, or doctors. What have been your experiences with conventional medicines? Probe:

1. What kinds of physicians/doctors are you currently seeing? Why?
2. How many physicians/doctors have you seen for your anxiety or depression? Why?

C. Overall, how do you feel about conventional medicines ability to treat depression or anxiety?

- For each: What do you like about this therapy? What do you dislike about this therapy?

D. What conventional treatments have you used previously? Probe: If previous treatment mentioned, why did you switch?

E. What are things you like about conventional mental health care? What are things you do not like?

1. Less individualized
2. Too expensive
3. Medications were not effective
4. Not the approach you wanted to take toward your health
5. Other

IV. USE OF COMPLEMENTARY MEDICINE

Objective: To understand why respondents have turned to complementary medicine, and how they perceive its effectiveness.

A. How did you learn about treating depression and anxiety with alternative therapies?

Probe:

1. Magazine
2. Journal article
3. Google or internet resource
4. Friends or family
5. Other

B. How did you come to try alternative therapies? Reasons for deciding to try alternative therapy? Probe:

1. Side-Effects of conventional medicine
2. Friend or family member suggested
3. Physician recommended
4. Medication was not effective
5. Looking for a healthier alternative
6. Other

C. What alternative therapies do you find to be most effective? Why? Probe:

1. More control over mental health illness
2. More holistic view of health
3. Less side effects
4. More positive feelings? If so, describe these feelings
5. Other

D. Are there any downsides to using alternative therapies?

E. Has there been any change in how you view anxiety or depression since taking alternative therapies?

1. More control over illness
2. Mind and body are connected so if I take care of my body my mind will follow (holistic approach)
3. Complementary and alternative medicine matches my view of what a mental illness is
4. Is anyone's experience different than that?

V. WRAP-UP

Objective: Interview conclusion.

A. Final thoughts.

B. Thank you for your time.

Appendix D: Screener

(Participant calls about the study)

Researcher: “Hello, this is _____”

(Participant mentions hearing about the study and is interested in participating)

Researcher: “Great! Thank you so much for your interest in the study! I have a few questions to go over with you to make sure that you can participate, is that ok?”

(Participant agrees)

Researcher: “Are you over the age of 18?”

Participant needs to be over the age of 18

Researcher: “Have you been diagnosed with either a panic disorder or a depressive disorder?”

Need to have been diagnosed with either of these disorders

Researcher: “Which panic disorder were you diagnosed with?” or “Which depressive disorder were you diagnosed with?”

For panic disorders: generalized anxiety disorder, panic disorder, social anxiety disorder

For depressive disorders: major depression, minor depression, dysthymic disorder

Researcher: (if participant has been diagnosed with both) “Which would you say has the most effect on your life?”

Whichever disorder the participant mentions will be the focus group the participant is assigned to

Researcher: “Who diagnosed you?”

Can be a general practitioner, psychiatrist, counselor, family doctor..

Researcher: “Have you taken any conventional medications in the past to treat your depression or anxiety?”

It is important that the participant has had some interaction with conventional mental health care, whether this be taking medications or seeing a counselor

Researcher: “Have you been hospitalized within the past six months due to depression or anxiety?”

Participant cannot have been hospitalized within the past six months

Researcher: “Have you used alternative therapies (such as natural supplements, acupuncture, yoga, meditation, chiropractic care) to treat your disorder within the past six months?”

Participant needs to have used complementary and alternative medicines

(If participant did not meet one of the eligibility criteria):

Researcher: “I’m sorry, but you do not qualify for this particular study, thank you for your interest in the study and I hope you have a nice day.

(If participant did meet the eligibility criteria)

Researcher: “You are a great candidate for this study! This research is looking at two things; the first being experiences with conventional mental health care, as well as experience with depression or anxiety, and the second looks at individuals views of mental illness held by people who have been diagnosed with depression or anxiety and use alternative therapies to treat their disorders. Are you still interested in participating in this study?”

(If participant is not interested)

Researcher: “Ok, well again I thank you for your time and I hope you have a nice day.”

(If participant is interested)

Researcher: “Great! Let me set up a time for you to come to a focus group”
Times and location of focus group to be determined

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