

PERCEIVED RELATIVE ACCESS TO HEALTH CARE AND FEELINGS OF CONTROL
OVER HEALTH

By

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For Mom, Nanny, and Papa –
You've always been my greatest
supporters, and I'll always be your Mander

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LIST OF TERMS

CHOICES: Community Health Offering Innovative Care and Educational Services: A community-based program that provides a link between primary health care services and workers with low-income. The basic eligibility criteria are as follows: must be a U.S. citizen, must be a resident of Alachua County, must not be eligible for benefits through the Veterans' Association or Medicaid, must not have health insurance coverage (excludes Medicare for seniors), must not be offered affordable health insurance through employer (a formula is used), annual income must be between 100–200% of the federal poverty level, and must be working at least an average of 25 hours per work (exclusion for seniors) (Indigent Care and Trauma Center Surtax (2004); CHOICES' internal documents)

CONTROL: Over health for this research the definition is left intentionally broad to allow for each participant's definition; given the context of the questions regarding control over health, it could be implied to mean how much influence a person exerts over their current health status, how much influence a person feels they may be able to exert in the future, or how much influence a person feels they have to change their health status, and each of these could in turn be applied to health related behaviors (Adapted from Rotter, 1966)

CONTROL BELIEFS: From the Theory of Planned Behavior; factors that impede or facilitate a behavior (Glanz et al., 1997; Terry, Gallois & McCamish, 1993). This research attempts to identify some external impediments.

EXTERNAL FACTORS: Factors that are outside of the individual

HEALTH CARE PROVIDER: For this research, any person that can give any type of health care service, i.e., a doctor, a nurse, a counselor, a dentist, a physician's assistant, a specialist, or a therapist

HEALTH CONCERN: For this research, any state of health or health-related behavior that an individual identifies as important to them

INTERNAL FACTORS: Factors contained within the individual

LOW-INCOME: For this research, the income guidelines for enrollment in CHOICES is used; between 100–200% federal poverty level (CHOICES' internal documents)

MEDICAL EMERGENCY: For this research, a health problem that necessitates immediate medical attention

PERCEIVED ACCESS TO HEALTH CARE: Whether a person thinks they can gain entry to health care services; Represents Perceived Behavioral Control; Combination of Power Beliefs and Control Beliefs – given a specific context, does a person feel they can carry out a specific behavior (Adapted from Azjen & Madden, 1986 and Aday, Andersen & Fleming, 1980)

PERCEIVED LEVEL OF ACCESS TO HEALTH CARE: A measure that compares the resources the participant identifies in what they need for ‘access to health care’ with the resources the participant actually has (Inferred from Aday, Andersen & Fleming, 1980)

PERCEIVED RELATIVE ACCESS TO HEALTH CARE: The participant’s rating of their own resources that contribute to health care access when they compare them with the resources of others in Alachua County (Inferred from Adler, Epel, Castellazzo & Ickovics, 2000)

POWER BELIEFS: From the Theory of Planned Behavior; beliefs regarding the weight of each factor that impedes or facilitates a behavior (Glanz et al., 1997; Terry, Gallois & McCamish, 1993)

PROBLEM WITH DRUGS OR ALCOHOL: For this research, a point where the use of drugs or alcohol is clinically significant. This may include the impairment of daily activities, harm being done to the user or those around them, and/or a situation in which the user wishes to stop consuming but cannot.

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Chair: Carolyn S. Wilken

Major: Family, Youth, and Community Sciences

A mixed methods exploratory case study was conducted. Twenty-three enrollees of a community health services program were interviewed. The Human Ecological Model, Theory of Planned Behavior, and Perceived Unfairness Model were used to elicit information about the participants' perceptions of access to health care, relative access to health care, discrimination, and feelings of control. Many participants had relatively low access to health care, yet felt a lot of control over their health. Despite this, when participants were asked about others, they attributed little or no control to those who have the least access, and a lot or complete control to those with the most. Research should continue to explore relationships among social hierarchies, perceptions and emotions, and health outcomes.

CHAPTER 1 INTRODUCTION

With the increasing cost of medical care and the growing number of uninsured, many people are examining and questioning the structure of our health care system. In the United States, access to health care is inextricably tied to having health insurance, which is in turn, highly correlated with employment (Collins, Schoen, Colasanto & Downey, 2003). According to the Kaiser Family Foundation, 54% of the population of the United States is insured through their employer, 26% through Medicaid or another public program, and 5% are privately insured, leaving 16% uninsured (*StateHealthFacts.org*, 2004).

In Florida, the picture is a bit dimmer: 47% of the population has employer-sponsored insurance, 29% have insurance through Medicaid or another public program, 5% are privately insured, and 19% of the population is uninsured (*Individual State Profiles*, 2004). This translates to over 45.8 million people in the United States that do not have health insurance, and over 3.2 million of them live in Florida. Not only does Florida have a higher than national average rate of uninsured people, it ties with four other states to rank fourth highest in the nation (*50 State Comparisons*, 2004). It is known that national and state-level problems manifest themselves at the local level. In Alachua County, a largely rural county with an urban center, there are about 38,000 people without health insurance (A. J. Campo, presentation, *CHOICES: Improving Access to Health Care Services*, 2005).

Even if one is employed, three conditions must be met to have insurance through an employer: “1) the worker’s company must offer insurance; 2) the worker has to be eligible for the insurance offered; and 3) the worker has to be able to afford the insurance he or she is eligible for” (Collins, Schoen, Colastanto, & Downey, 2003, p. 2). Regarding the first condition, among people who are uninsured in the United States, 60% of them are not offered insurance by

their employer, 22% are offered insurance but do not participate, another 11% are offered insurance but are ineligible, and 7% do not know if their employer offers insurance (Collins et al., 2003). Collins and colleagues (2003) concluded that workers with low wages fare worse than other workers on all three conditions.

Being uninsured in America is a large problem for a number of reasons. People without health insurance, including those who alternate between having insurance and not having it, have higher morbidity and mortality rates than people who have consistent coverage. Many people who do not have health insurance delay looking for health care services, or do not seek them at all (*The Uninsured and Their Access to Health Care*, 2005). Many do not fill prescriptions because of their expense. Using path analysis Wan and Soifer (1974) were able to establish the relative importance of various factors that influence utilization of health care services. Four factors had a direct influence on visiting a doctor: 1) being in poor health, 2) as a response to an illness, 3) having health insurance, and 4) the average cost per visit.¹ Tying all of this together, we can see that having health insurance not only contributes to a person accessing health care services, but also utilizing them. Given the structure of our health care system, the health of people without insurance suffers. It seems that the deleterious effects of not having health insurance might be partially mitigated if health care services could be regularly utilized without insurance.

In an ideal health care system, a health care infrastructure would be in place and one might take utilization for granted: people would recognize when they needed health care and know, or perceive, that they could access the health care they needed. However, there is no an ideal

¹ Medicaid and Medicare were distinct from health insurance in this analysis. The researchers found that participation in these programs did not have either a direct or indirect effect on using a doctor's services (Wan & Soifer, 1974).

system, and there is a difference between utilization, or *realized* access, and *potential* access, which will be discussed more fully in the literature review (Aday, Andersen, & Fleming, 1980).

Our society's emphasis on individuality and responsibility also leads the debates surrounding health care. Individuals hold the keys to healthy living; eating a proper diet and exercising are especially championed. Various programs exist, both in the private and public sectors, to raise awareness about healthy living. These programs vary in their focus. Some simply provide nutrition information while others provide intensive one-on-one training about nutrition, exercise and managing stress. Others provide information about health screenings and immunizations and may also provide these services for free or reduced costs.

There are a few widely-held assumptions behind many of these programs: 1) if people are provided information about the morbidity and mortality risks of living an unhealthy lifestyle, (i.e., not exercising regularly, not managing stress, not eating properly and not receiving regular physical exams), they will change their unhealthy behaviors to avoid those risks, and 2) if people are provided information about the benefits of having a healthy lifestyle they will change their unhealthy behaviors to receive those benefits. Some examples of these include: Advice from Aetna's *Living Well* (2001–2007) web site where the headers are “Your Health,” “Self-Management,” and “Wellness Products and Discounts.” Particularly interesting is the description of “Self-Management,” “How to achieve life's greatest gift—the best possible health. Topics include weight control, eating right, staying fit, overcoming depression and more” (*Living Well*, 2001–2007). Blue Cross and Blue Shield of Florida, Inc. also provides advice:

Good health is good living, and the more you know, the easier it is to stay healthy. That's why Blue Cross and Blue Shield of Florida provides members with helpful resources to keep them informed about health issues. These programs, services and links are another way that we add value to our members' premium dollars and why Blue Cross and Blue Shield of Florida is a company to keep (Health and Wellness, 2004–2006).

This phenomenon goes beyond insurance companies. The American Cancer Society, the American Diabetes Association, and the American Heart Association joined to create the website Everydaychoices.org (n.d.) where anyone can view information focused on the health benefits and risks associated with diet/nutrition, exercise, and getting medical attention. For example,

An Ounce of Prevention... Not smoking (or quitting if you already smoke), making wise food choices, getting enough physical activity, and maintaining a healthy weight can help you reduce your disease risk, feel better and live longer. There's a lot you can do on your own to prevent cancer, diabetes, heart disease and stroke. And your doctor can help you recognize unhealthy aspects of your lifestyle. Your doctor is a great source of advice on how to make the right choices for lifelong health (See Your Doctor, n.d.).

From this site there is also a link to the American Diabetes Association's "A Virtual Grocery Store Tour" (n.d.). This site is promoted by the Centers for Medicare and Medicaid Services in their *Staying Healthy: Medicare's Preventive Services* (2004).

This is not to say that having knowledge is not an essential part of the behavioral change, but this simple, linear logic does not account for the reciprocal interaction of people and their environments. There are many factors that contribute to a person's behavior – and changing that behavior. According to the Transtheoretical Model, (Prochaska, 1979) providing information, or "consciousness raising," is necessary to behavior change, but it is not sufficient (Glanz, Lewis and Rimer, 1997, p. 63). Research has supported other processes that are also needed; these include: self-reevaluation, environmental evaluation, helping relationships, counterconditioning, contingency management and social liberation. According to the Theory of Planned Behavior (Ajzen, 1986), additional factors are: attitude toward the behavior, subjective norms, intention, and perceived behavioral control. Research using the Theory of Planned Behavior has examined decision-making behavior in a number of settings (Some examples are exercise, Zizzi, Keeler & Watson, 2006; nutrition, De Vet, De Nooijer, De Vries & Brug, 2005; drug use, Naar-King,

Wright, Parsons, Frey, Templin & Ondersma, 2006) and for an evaluation of its use as a health behavior intervention Bridle, Riemsma, Pattenden, Sowden, Mather, Watt & Walker, 2005.

The focus of the present research draws from the control portion of a couple of theories that will be presented here and in Chapter 3. In the Theory of Planned Behavior (Glanz, Lewis & Rimer, 1997), perceived behavioral control is composed of two concepts: control and power beliefs. Control beliefs can be either internal or external to a person; they are the perceptions that a person has about what facilitates or impedes the behavior (Glanz et al., 1997; Terry, Gallois & McCamish, 1993). Power beliefs are the perception of how much each facilitator or impediment affects whether or not the behavior is performed (Brown, 1999; Glanz et al., 1997; Terry, Gallois & McCamish, 1993).

Control beliefs and power beliefs combine to yield the concept of perceived behavioral control, which is the perceived amount of control a person has in carrying out a specific behavior in a specific environment (Glanz et al., 1997). So, for example, a person who wishes to quit smoking may have control beliefs surrounding their physical addiction to nicotine and their daily routines that incorporate the behaviors of smoking, both internal impediments. Yet they may also perceive pending social approval for success, an external facilitator, and possible health benefits, an internal facilitator. These control beliefs are then individually assigned weight, or a level of strength, which are the person's power beliefs. In the balancing of these weights, one can then hypothesize about whether or not a person will attempt to quit smoking. The likelihood for quitting is increased if the facilitators outweigh the impediments.

From this we can see a reciprocal relationship between a person and their environment. On one hand there is a person's environment with its various facilitating and constraining factors, such as potential social approval, but there is also the potential to lose some social

interactions from no longer engaging in smoking. And on the other hand, there is the person and their own facilitating or constraining factors, such as addiction, current physical health and goals for future health.

A similar process unfolds with people without health insurance and/or other resources to adequately manage their health. There is interplay of the environment and the person at every level; however, there is the possibility that the environment restricts a person's scope of resources, both external and internal. Is it possible that a person's relatively low access to health care affects the amount of control they feel over their health?

Purpose

This paper will address what can be regarded as the beginning of the process to utilizing health care services²: accessing health care, or more specifically, perceived relative access to health care. This conception of access places emphasis on individuals' experiences while keeping them in the context of their environment. Research has been gaining ground on understanding the relationship between relative income and health. It has also been making advances in explaining the health disparities that persist across races/ethnicities and socioeconomic statuses (SES). One way these avenues of research are related is in trying to establish the means by which people with lower social status have worse health outcomes. One possible explanation is through the perceived lack of control perpetuated by a lack of resources. This research will address these main research questions:

1. RQ1) How do people with low incomes associate feelings of control over their health with having access to health care services?
 - 1a) Is perceived access to health care services associated with any form of discrimination?

² This process will be discussed more in the Chapter 2, the Literature Review.

- 1b) Is perceived relative access to health care services associated with feelings of control over health?
2. RQ2) Do any of the above concepts show patterns of association with:
- a) perceptions of health status,
 - b) diagnosis of any of the following conditions: asthma, diabetes, high blood pressure, congestive heart failure and depression,
 - c) feeling of global satisfaction with one's life,
 - d) frequency of utilization of emergency rooms in the last two years,
 - e) utilization of hospital inpatient services in the last two years,
 - f) frequency of primary health care visits,
 - g) lapse of time since participant's last physical and dental exams,
 - h) perceived primary barrier(s) to utilizing health care services, or
 - i) whether or not participants had a usual source of health care?

Limitations

- Causal relationships cannot be established in the current research because it is an exploratory case study. Knowledge of the interplay of the interdisciplinary concepts utilized is not to the point of allowing for a research design that could establish causality, such as an experiment or a longitudinal case study.
- The sample is limited to participants in the CHOICES program, and the research design precludes statistical generalizability.
- This research is limited in terms of its theoretical generalizability due to the lack of comparison group(s). This is an area for future research.
- Access chart does not include all possible internal and external facilitators and/or impediments.
- Examining emotions related to any form of discrimination or lack of control/power is beyond the scope of this research. This is a significant limitation as emotions may be a pathway for how the environment affects perceptions of health and/or biological functioning.
- Concept of 'control': while the current study alludes to locus of control, it is beyond the scope of this study to identify whether the participants have an internal or external locus of control (Rotter, 1966). In this study, control was left intentionally broad to account for any

sense of control the participant feels, regardless of its categorization. However, this is an area for future research.

CHAPTER 2 LITERATURE REVIEW

The purpose of this research was to explore a potential relationship between perceptions of access to health care and perceptions of control over one's health. This literature review will establish the relevance and importance of this exploratory research. First, access to health care will be discussed, followed by an examination of the relationship between health and feelings of control. Next, the theoretical framework for this research will be reviewed, which includes descriptions of health behavior theories and an emphasis on the Theory of Planned Behavior (Ajzen & Madden, 1986). Finally, there will be a review of various proposed causes for health disparities in the United States.

Access

One precursor to utilizing health care services is the perception that one could use them, or that one has access. Though the concept of "access to health care" is often used, there is a lack of clarity about what "access" means (Chitwood, Comerford & McCoy, 2002; Lillie-Blanton & Hoffman, 2005; and Williams & Jackson, 2005, for examples). Some authors conceptualize it solely as a cost issue (For examples, Federman, Vladeck & Siu, 2005 and Frist, 2005), while others approach it as a multidimensional concept, including cost, language, cultural barriers, and literacy (Kennedy, 2005). One of the most inclusive definitions includes cost, the number of providers in the community, the travel time to the nearest provider, if there are any language barriers, if there are any cultural barriers, if one has a regular person or place to receive health care, and whether or not a person has seen a physician in the past year if they have been ill at any point, or in the past two years if they report good health (Brown, Ojeda, Wyn & Levan, 2000). A widely used concept of access takes account of the, "likelihood of a usual source of care, having an unmet medical need or postponing getting care in the past year, the likelihood of an

ambulatory medical care visit, a visit for a routine health problem or general exam, and a visit to a hospital emergency department” (Cunningham & Hadley, 2004, p. 235).

Gulliford and Morgan (2003) described two themes of medical care access identified through reviewing previous research: 1) “the potential or actual entry of a given individual or population group into the health care delivery system” (p. 5), and 2) “gaining access refers to the initiation into the process of utilizing a service” (p. 5). In other words, health care access can be characterized as accounting for such resources in the community, a person’s external resources, and a history of utilizing the services. The first type of access identified by Gulliford and Morgan’s (2003) focuses on the health care resources in the community, or the lack of them. The present research will not include this type of access since the research site, Alachua County, FL, USA, has a number of locations that provide medical care, including a number of hospitals. This research will use the second type of access, which focuses on utilization of the available services. However, this research will take a step back from actual utilization of medical services to look at the perception of being able to use them. This approach does not assume that once the medical infrastructure is in place people will use it. There are various factors that could affect the decision to use medical services; one being the perception of being able to use them. To clarify this, a more thorough discussion of defining access follows.

Generally, the literature defines access by referring to a proxy, utilization, or realized access (Aday, Andersen & Fleming, 1980). Decades ago Aday and others made a distinction between realized and potential access. Realized access can be measured by accounting for utilization, as in counting the frequency or rate of services that are used, or by patient satisfaction with these services (Aday et al., 1980). On the other hand, potential access includes, “...the characteristics of the delivery system (the availability and distribution of health care providers

and facilities, for example) and characteristics of the population-at-risk in an area (their age, health status, insurance coverage, and income levels, for example) ...” (Aday et al., 1980, p. 25). This way of defining and discussing access does not fit neatly into the two types described by Gulliford and Morgan (2003), which signals that although researchers recognize access as a multi-faceted concept, they have not been consistent in identifying and accounting for these facets. Upon examining Aday and colleagues’ (1980) definitions of access and Gulliford and Morgan’s (2003) descriptions, we see that the populations’ perceptions is not explicitly accounted for, and neither is the impact the health care infrastructure can have on these perceptions. The present research attempts to fill a gap in the literature by examining the possible interaction of the health care infrastructure and a person’s perceptions of their own health and control of it.

Relationship Between Health and Feelings of Control

Research has suggested that feelings of control may be a moderator and/or pathway for external factors to affect an individual’s health. In a recent article Moradi & Hasan (2004) surveyed an under-researched group, Arab Americans, for their experiences of discrimination and self-reported mental health status. More specifically, they were interested in the possible mediating effect of personal control. Through path analysis they found that discrimination was significantly correlated to psychological distress, though causality cannot be determined. They also found that personal control “partially mediated the link between discrimination events and psychological distress” (Moradi & Hasan, 2004, p. 423) (Ruggiero & Taylor, 1997; Link, Lennon & Dohrenwend, 1993).

Bailis, Segall, Mahon, Chipperfield, and Dunn (2001) linked the constructs used in the present research, perceived control and self-rated health status. Using a national probability sample of Canadians, they found, “the indirect effect of SES through perceived control

approximately equaled or exceeded the direct effect” of SES on physical and mental health for women and men (Bailis et al., 2001, p. 1670). Though there is strong evidence for relationships between SES, perceived control, and self-reported physical health, the authors closed with cautioning against causally interpreting the results. They also caution against over-generalizing the perceived control results because the index used measured control over “important life events;” it was not a global measure or a measure related to control over any aspect of health (Bailis et al., 2001, p. 1674).

Both Moradi and Hasan (2004) and Bailis and colleagues (2001) examined specific stressors: discrimination and socioeconomic status. Gallo, Bogart, Vranceanu and Matthews (2005) conducted a broader examination of stress. They found that, “Women with lower SES reported less perceived control and more social strain, and less positive emotion when compared with their higher SES counterparts” (Gallo, et al., 2005, p. 394). While these results provide further support for the idea that perceived control has a relationship with socioeconomic status, they should be generalized carefully given the small sample of women.

This section has reviewed research about the relationship between feelings of control and physical and mental health. Research results lead to questions regarding other factors, specifically other sources of environmental stress, could also be related to feelings of control, as may be measured globally or context-specific. Again, the purpose of the present research is to inquire about whether people with low income perceive themselves as having low levels of control in health care settings; and furthermore, if either or both of these perceptions are associated with their relative level of access.

Theoretical Framework

Several theoretical models will be used to guide this exploratory and interdisciplinary research. The Human Ecological Model (Bronfenbrenner, 1979) serves as the framework for

this research. This model is useful because it uses interacting ecological levels to study human behavior. This research looks at the link between the exosystem and the individual. Specifically, it examines the potential relationship between perceptions of the exosystem and perceptions of the self.

This model also provides a way to critically examine the assumptions of health behavior theories, which also exist in society at large. In general, our society assumes an individual is the starting point and that an individual will seek resources from their environment to fulfill their needs. This assumption is the foundation for many social programs, including health programs. However, according to the Human Ecological Model there is a reciprocal relationship between a person and the environment, a relationship without a clear starting point (Bronfenbrenner, 1979). Furthermore, this model does not assume an individual will have the intention to seek resources, or even that the environment will have the resources. This model is useful because it is critical – it demands a holistic examination of human behavior and societal assumptions.

Theories of Health Behavior

The health behavior theories presented here will be used in varying levels of involvement. The Theory of Planned Behavior (Ajzen & Madden, 1986) is the primary guiding theory since it was developed to better explain behaviors in which influences outside of a person's control affect their behavior (Ajzen & Madden, 1986). Though a dependent behavior, such as health-care seeking behavior, will not be examined in this research, there are a number of reasons for its usefulness in the model. First, it fits with the Human Ecological Model (Bronfenbrenner, 1979) – it accounts for environmental (and internal) factors that affect behavior. Second, it recognizes intention as one of the direct factors affecting behavior. Finally, this theory is general enough to be applied to various health programs.

The Theory of Planned Behavior (Ajzen & Madden, 1986) posits that intention is a direct factor to actual behavior, with other factors affecting intention in turn. The present research challenges this linear relationship and asks if a reciprocal interaction is a more appropriate characterization of the process leading to health care behavior.

The other theories that will be reviewed are: the Perceived Unfairness Model (Jackson et al., 2006), Social Cognitive Theory (Bandura, 1986), the Health Belief Model (Glanz et al., 1997), and the Transtheoretical Model and Stages of Change (Prochaska, 1979). The Perceived Unfairness Model (Jackson et al., 2006) will be used in data analysis, along with the Theory of Planned Behavior (Ajzen & Madden, 1986). The remaining three theories will be briefly discussed because of their prevalence in research examining health behaviors.

The Theory of Planned Behavior (Ajzen & Madden, 1986) was developed from the Theory of Reasoned Action (Fishbein & Ajzen, 1975). It proposes that there are two direct influences on behavior: intention and perceived behavioral control. In turn, perceived behavioral control, subjective norms and attitudes toward the behavior also influence intention (Glanz et al., 1997). Intention is the likelihood of the behavior being performed (Glanz et al., 1997). This research will not review or examine subjective norms or attitudes surrounding any behavior. The process of sample selection will account for intention.

Perceived behavioral control is comprised of two constructs: control beliefs and power beliefs. Control beliefs are the perceived influence of the environment; they are the perceptions of whether or not a person will be able to engage in a particular behavior in a specific context. Power beliefs are the perceptions of the degree to which the environment will impede or facilitate the behavior (Glanz et al., 1997).

The Theory of Planned Behavior (Ajzen & Madden, 1986) has not been used widely in health research, but it has been used extensively to examine exercise behavior (For examples Motl, Dishman, Ward, Saunders, Dowda, Felton & Pate, 2005; Payne, Jones, & Harris, 2002; and Nguyen, Potvin & Otis, 1997), and also to study sexual health and condom use (Bogart, Cecil, & Pinkerton, 2000; De Wit, Stroebe, De Vroome, Sandfort, & Griensven, 2000; Montano, Kasprzyk & Fishbein, 1996, for examples) smoking (For examples, Bledsoe, 2006; Collins & Ellickson, 2004; Wilkinson & Abraham, 2004), nutrition (Robinson & Smith, 2002 or Paisley, Lloyd, Sparks, & Mela, 1995 for examples), health screening and treatment adherence (Orbell, Hagger, Brown, & Tidy, 2006; Steadman & Rutter, 2004; Abraham, Clift, & Grabowski, 1999, for examples), alcohol and drug use (McMillan, Conner, 2003; or Kuther, 2002, for examples), and a myriad of other behaviors, including breastfeeding (Dodgson, Henly, Duckett & Tarrant, 2003, for example), sun protection (For an example Martin, Jacobsen, Lucas, Branch, & Ferron, 1999) and bike helmet use (Quine, Rutter, & Arnold, 2001, for example).

Its use is beneficial for a number of reasons. First, it is designed for use with a particular behavior, as opposed to measuring a person's global capacity to engage in desirous behaviors (Garcia & Mann, 2003). It has been argued that multidimensional health locus of control should be used to assess global capacity instead of perceived behavioral control (Luszczynska & Schwarzer, 2005). Second, and perhaps more importantly, it is used to explain behaviors where a persons exerts little control over the situation in which the behavior is to occur. Finally, it provides a way to examine both internal and external influences on a person's behavior.

For this research, control and power beliefs will represent access to health care. If it is found that perceptions of relative access to health care influence perceptions of control, then the Theory of Planned Behavior (Ajzen & Madden, 1986) may not be the appropriate framework for

research or interventions with populations that perceive themselves as lacking necessary resources and/or perceiving discrimination. One weakness of the Theory of Planned Behavior (Ajzen & Madden, 1986) is that it does not account for possible differences that may occur across socioeconomic statuses, races/ethnicities, or between sexes. The absence of such concepts is a serious concern in light of much research pointing to the social weight attached to these and their relationships with health outcomes. In using the Theory of Planned Behavior (Ajzen & Madden, 1986) in research, one should remain open to the possibilities of these factors affecting and interacting at various points with any of the already-included factors of the theory.

In addition to the Theory of Planned Behavior (Ajzen & Madden, 1986), the Perceived Unfairness Model (Jackson et al., 2006) will be used to interpret the findings of this research. This model emphasizes “the impact of subjective experience on physical health” (Jackson et al., 2006, p. 24). Constructs in the model include: identity, perceived unfairness, helplessness, stress response to perceived unfairness, allostatic load, coping behaviors, morbidity and mortality. “Rather than focusing on the individual, it may be more useful...to consider how the social environment influences health and to recognize the importance of social context in shaping health outcomes” (Jackson et al., 2006, p. 32). It is important to note that this is the first model to link the constructs laid out for this research.

Social Cognitive Theory (SCT) (Bandura, 1986) has a number of concepts that cover perception of the self and the environment, the actual environment, emotions, and behavior. It accounts for the interactive relationship between an individual and the environment through the assumption of reciprocal determinism. One critique of SCT is that it seems infallible because it acts more like a model in that it cannot be disproved and it more of a lens through which to view behavior (Glanz, Lewis & Rimer, 1997). Another critique is its assumption that once a person

knows the benefits of a behavior and that they can perform that behavior, they will indeed carry out the behavior if the perceived costs do not outweigh the perceived benefits. So, while many see SCT as being able to explain any outcome, the explanation may not be plausible because of this assumption. A large number of factors could influence performing the behavior, such as lack of resources or discrimination. A person could know they are capable of carrying out a particular action from an internal perspective, but could feel restricted by external factors. Future research using SCT could challenge this assumption and its infallibility.

The Health Belief Model (Rosenstock, 1966) has many of the same constructs as Social Cognitive Theory. It can be described as a very rational model that accounts for personal-level factors such as personality and SES; however the crux of the model is in determining the likelihood of behavioral change. This likelihood is directly influenced by combining the perceived costs and benefits of the behavior change and by the perceived threat of illness. The likelihood is indirectly affected by the personal factors, and the perceived susceptibility and/or severity of an illness (Glanz et al., 1997). This model is dependent on a person's knowledge of at least illnesses' existence and symptoms, particularly those they may be especially at-risk for.

One of the assumptions of the Transtheoretical Model (Prochaska, 1979) is that one theory will not be able to explain the process of changes in behavior (Glanz et al., 1997). This model is particularly relevant because, like the Human Ecological Model, it asks us to examine our assumptions. Its constructs include numerous processes of behavioral change, five stages of change, self-efficacy, and the costs and benefits of the behavioral change. Information gathered during the current research will be compared to some of these constructs. The purpose of these comparisons will be to see if results are consistent with the predictions of the model. Future

research could use this model to examine if enrollment in a health care program that provides greater access to health care services plays a role in the process of change.

The Human Ecological Model (Bronfenbrenner, 1979), the Theory of Planned Behavior (Ajzen & Madden, 1986) and the Perceived Unfairness Model (Jackson et al., 2006) are central to the present research. The Human Ecological Model (Bronfenbrenner, 1979) is the backdrop; it is used to critically examine the possible relationships between a person's perceptions of themselves and their environment. The Theory of Planned Behavior (Ajzen & Madden, 1986) and the Perceived Unfairness Model (Jackson et al., 2006) take this critical stance a step further by outlining the perceptions of interest: relative access to health care, discrimination and feelings of control over health. The latter two will be used to interpret the research findings.

Health Disparities

As discussed in Chapter One, health disparities exist in the United States. Various explanations for these disparities have been proposed and researched. The remaining body of this literature review is dedicated to discussing some of this research. Explanations included are: race/ethnicity, sex, income, health insurance, socioeconomic status, discrimination and relative social standing. Common themes in the literature will be emphasized with their relevance to the present research.

Race/Ethnicity

Most researchers agree that racial disparities in health are not due to any innate, biological differences in races or ethnicities. One prominent reason is that race is a socially constructed category and therefore it is not linked to genetics (Wu and Schimmele, 2005). This leads to examining various environmental factors for possible explanations of racial and ethnic disparities in health. Studies have indicated that racial residential segregation is one important factor when examining utilization rates of medical services (Skinner, Weinstein, Sporer, and Wennberg,

2003; Williams and Collins, 2001). In a review of literature, Williams and Collins (2001) cited various reasons why residential segregation is an important factor. These reasons include: the influence of community resources and perceptions of safety on people's ability to engage in health behaviors, the link between residential segregation and educational and employment opportunities, the quality of the neighborhood and housing, and the quality of medical care. There are also effects of place – white people with low income tend to live in areas with a lower concentration of poverty than African Americans with low income.

In addition to finding that racial residential segregation is linked to health care utilization, Skinner and colleagues (2003) found that geographical region was a factor. In a more in-depth analysis Baicker, Chandra, Skinner, and Wennberg (2004) found that not only did racial disparities exist by medical procedure within a geographic region, but also across regions. While these results provide useful information, it is important to consider that many of the studies looking at regional differences use Medicare and/or Medicaid data, which does not necessarily control for income, socioeconomic status, the uninsured population or the privately insured population, which could each have varying impacts.

Aside from the relationship found between race and geographic characteristics, race and ethnicity are related to income and socioeconomic status (Skinner et al., 2003; Williams & Collins, 2001; Williams & Jackson, 2005). Retrospective longitudinal mortality data from 1950 to 2000 provided comparisons that are not generally found in research. Williams and Jackson (2005) examined mortality rates for five causes of death: suicide, pneumonia and flu, homicide, heart disease, and cancer. Regarding suicide, the data did not show significant racial disparities at any point in time. Pneumonia and flu are cases where large racial disparities existed in 1950, but no longer exist. They attributed the decrease to the distribution of medical care through

Medicare and Medicaid, an area which “social variations in motivation, knowledge, and resources play a small role” (Williams and Jackson, 2005, p. 331). Racial disparities found in rates of homicide, heart disease, and cancer were often less than the disparities found among socioeconomic groups. “Racial differences in SES contribute to reduced levels of health insurance coverage for African American, and limited access to medical care plays a role in racial differences in disease” (Williams and Jackson, 2005, p. 329). They concluded the article with policy implications. Such policies include decreasing the income gaps and providing greater access to health care among races and ethnicities. As these studies show, it is not race or ethnicity that causes health disparities, but possibly a number of interacting contextual factors (Borrell, Dallo & White, 2006; Lasser, Himmelstein & Woolhandler, 2006; Wu and Schimmele, 2005).

Sex

Physical and mental health disparities can be found between the sexes. Two ecological studies examined the potential relationships between women’s status and autonomy at the state-level and mortality and morbidity rates and depressive symptoms, respectively (Chen, Subramanian, Acevedo-Garcia & Kawachi, 2005; Kawachi, Kennedy, Gupta & Prothrow-Smith, 1999). Both studies found a correlation between these. While the results of Chen and colleagues (2005) held constant across racial and socioeconomic groups, Kawachi and others point out that, “certain types of gender inequality, such as reduced female earnings, are themselves patterned by race, class and other socioeconomic characteristics. In other words, the ill health burden of gender inequality is disproportionately borne by women – and men – with preexisting socioeconomic disadvantage” (1999, p.31).

Income

There is a burgeoning field of research that links income inequities to health outcomes. Kawachi, Kennedy, and Wilkinson (1999) focused on two possible avenues in their recent book. The first is “the link between income inequality and the disruption of social cohesion...” and second “the growing evidence on how social status ‘gets under the skin’ to produce deleterious health effects...” (p. 158). This latter avenue is taken in this literature review and serves as one of the springboards of the research at hand.

Subramanian, Kawachi, and Kennedy (2001) used an ecological framework to analyze people’s self-reported health status with individual and state-level factors. Results indicated that people with middle-income (\$15,000 – \$35,000) are less likely to report poor or fair health than people in the low-income category, and individuals with high-income are even less likely to report such health status than individuals with middle-income. Through Chi-square analyses the researchers found a significant relationship between self-reported health and state-level data, even after controlling for individual-level characteristics. This finding lends support to the idea that an ecological approach is not only appropriate, but needed, in health research. However, the ecological factors do not dismiss the importance of individual-level factors. Subramanian et al. (2001) also found that self-rated poor health was significantly correlated with each low-income and being African American.

Kennedy, Kawachi, and Prothrow-Smith (1996) concluded that the relative distribution of wealth, not just absolute wealth or lack of it, affects mortality rates. They used 1990 Census data to calculate each state’s average household income and mortality data of the same year from the CDC. They used the Robin Hood index to estimate income inequality. This index “estimates the percentage of total income that would need to be taken from the richer half of households and given to the poorer half of households to attain an equal distribution of wealth” (Kennedy et al.,

1996, p. 1004). The data showed that even after accounting for poverty levels, income inequality was positively correlated with mortality rates.

In consideration of the criticisms levied on many ecological studies of populations, Lochner, Pamuk, Makuc, Kennedy & Kawachi (2001) examined whether individual-level mortality risk is associated with state-level income inequality. Individual characteristics to assess risk included age, sex, race/ethnicity, marital status and annual income. Their findings indicated that state-level variables might affect socioeconomic groups differently. Lochner et al. (2001) did not find a relationship between mortality and income inequality for people with high income (\$50,000 or more annually). However, the relationship did exist for people with middle and low incomes (less than 200% of the federal poverty level (FPL)).

Near-poor persons living in states in the lowest income inequality category had significantly lower death rates ...than near-poor persons residing in other states...The same pattern was evident for middle-income persons, although the differences were smaller (Lochner et al., 2001, p. 388).

In general, people with low income had twice the mortality risk of people with high income. Interestingly, they did not find a relationship for those in the fourth income category, those living in poverty according to the FPL. The authors suggested, “for such persons, it is possible that poverty is a more important determinant of mortality than state-level inequality” (Lochner et al., 2001, p. 390).

While it may be argued that individual-level factors play a greater role in determining mortality risk than do state-level data, the authors remind us that “...because income inequality is related to the socioeconomic gradient, it affects mortality risk through SES” (Lochner et al., 2001, p. 390). Similar to the study conducted by Lochner et al. (2001), Kennedy, Kawachi, Glass, and Prothrow-Smith (1998) examined whether state-level income inequalities predicted individual-level morbidity. Fair or poor health was described more by women than men, and

blacks more than whites. Income was strongly associated with fair or poor health with five times as many people with low income (less than \$10,000) reporting it than people with high income (\$35,000 or more). “There is an increased risk of about 30% for fair or poor health for individuals living in states with greater inequalities in income” (Kennedy et al., 1998, p. 923). Though this risk lessened when individual factors were added to the model, the relationship remained significant. This study lends more evidence to the idea that contextual factors far removed from the individual nevertheless affect individual health.

Differences in Measuring Income

Some researchers suggested that the varying indices used to measure income inequality make it difficult to relate it to health measures in meaningful way. Kawachi and Kennedy (1997) addressed this issue using data from the 1990 Census. They used eight indicators of income inequality and analyzed them with mortality rates. They concluded that each of the inequality indicators were highly correlated with each other, poverty rates, and increased mortality rates, respectively. They concluded that the choice of indicator be based on the type of income transfer policies that are in place in the area under research.

Socioeconomic Status

Though socioeconomic status (SES) was not related to functional health status in Wu and Schimmele (2005), it is important to note, as they did, that policy differences between the United States and Canada may be an intervening factor. As stated before, people in Canada do not face the same difficulties in accessing health care because of the universal health care system. Research conducted in the United States points to socioeconomic status again and again as a plausible explanation for health disparities. A few pertinent articles will be described here.

Mechanic (2000) defined class and SES. In trying to measure social class, SES is generally used.

Typically, it is measured by education, income, occupation, and sometimes residential location. These measures are highly associated but commonly explain different components of the relationship between SES and health, suggesting that each acts through somewhat different pathways (paragraph 6).

In their article, “Health disparities by race and class: Why both matter,” Kawachi, Daniels, and Robinson (2005) discussed divergent explanations for the relationship between race and health. The first explanation is that race is biologically meaningful. The second is that race is a proxy for class, and the third: race is a “distinct construct, akin to caste” (Kawachi et al., 2005, p. 343). They argue for treating race and class as separate constructs because then it, “...still leaves open the possibility that race independently influences health through pathways such as personal experiences of discrimination or cultural differences in lifestyles” (Kawachi et al., 2005, p. 347). While they should be regarded as distinct constructs, it is important for research to analyze them together, which has been a rare occurrence.

Insurance

Lillie-Blanton and Hoffman (2005) reviewed literature to address the question of whether, and to what extent does race/ethnicity interact with health insurance to affect a person’s access to health care. Among the four articles they reviewed, they concluded that racial/ethnic disparities in health care access could be reduced by greater equity in health insurance coverage among races/ethnicities (Lasser et al., 2006).

Discrimination

Belle and Doucet (2003) reviewed research on women, particularly with their relation to poverty, poverty’s relation with depression, inequality and well-being, and discrimination and well-being. All of the research concurred that women have less status than men in income,

social mobility, social status, and life opportunities, which are in turn associated with increased morbidity and mortality rates for women. The authors urge researchers “to focus attention on an issue that is more fundamental than the welfare system: ‘the unequal distribution of resources and the economic, political, and psychological processes that maintain it’” (Bullock & Lott, 2001 in Belle & Doucet, 2003, p. 110).

In a literature review, Williams, Neighbors, and Jackson (2003) found fifty-three “population-based empirical studies that examined the association between perceptions of racial/ethnic discrimination and a particular indicator of health” (Williams et al., 2003, p. 200). None of the studies that examined mental health showed a negative correlation, and all but four reported positive association between discrimination and the outcome examined, for example, psychological distress, anger, major depression, and generalized anxiety disorder. There were various studies that examined discrimination with physical health status. Of these, the majority showed a positive association, and a couple reported either a conditional association or no association. The authors urge readers to consider the following in light of their results, “The literature on stress and health indicates that stressors influence physical illness primarily through causing negative emotional states such as anxiety and depression, which in turn can have a direct effects on biological processes or patterns of behavior that affect disease risk” (Williams et al., 2003, p. 205).

Karisen and Nazroo (2002) analyzed the relationship “between racism, social position, and health among ethnic minority groups” (Karisen & Nazroo, 2002, p. 625). Concurring with the results from Kennedy et al. (1998), they found “statistically significant associations between self-assessed fair or poor health, the experience or perception of racism, social class, age, and sex...” (Karisen & Nazroo, 2002, p. 626–627). Additionally, women were 60% more likely than men to

report fair or poor health. The analyses done by Karisen and Nazroo (2002) provide evidence more that perceptions of lower social status are associated with health status.

Harrell, Hall, and Taliaferro (2003) reviewed studies that studied physiological responses to discrimination. While laboratory studies that looked at possible moderating variables, such as coping style, have had inconsistent results, studies examining physiological response and cultural orientation are relatively consistent. Other laboratory experiments are inconsistent. Some studies found increased physiological response in a discriminatory context, while others concluded that the physiological response was similar under discrimination as other stressors.

The combined findings of self-reporting surveys are generally inconsistent as well. Some have shown an inverse relationship between discrimination and health outcomes, others have shown a positive correlation, and still others conclude that no relationship exists. Harrell et al. (2003) concluded, “It is not possible to argue from the existing findings that the different responses to racism are unique” (p. 247). However, “researchers have been generally successful in demonstrating that racist material...elicits physiological arousal” (Harrell et al., 2003, p. 247). They postulated that “racism increases the volume of stress one experiences and may contribute directly to the physiological arousal that is a marker of stress-related diseases” (Harrell et al., 2003, p. 247).

Kessler, Mickelson, and Williams (1999) evaluated the “prevalence, distribution and mental health correlates of perceived discrimination in the U.S.” (Kessler et al., 1999, p. 208). Although perceived discrimination did not link mental health problems with race/ethnicity, gender or education, it did account for part of the association between mental health problems and people with low income. The authors provide two possible explanations for the failure to

link mental health problems with most of the “disadvantaged statuses” (Kessler et al., 1999, p. 223).

First, although reported exposure was generally higher among people in disadvantaged than advantaged subsamples, these associations were not generally strong. And, second, while there was some variation in the strength of the association between discrimination and the mental health outcomes across subsamples ...this variation was neither consistent nor strong (Kessler et al., 1999).

Although the data did not support their hypothesis, they concluded that perceived discrimination may actually be a larger problem than they had previously thought because of its prevalence among the participants; one-third had experienced “at least one major” discriminatory event and “over 60% experience day-to-day perceived discrimination” (Kessler et al., 1999, p. 224).

Finally, Schulz, Gravelle, Williams, Israel, Mentz, and Rowe (2006) conducted a longitudinal study of the relationship between “everyday discrimination” and “symptoms of depression and general self-reported health among African American women in Detroit, Mich” (p. 1265). The findings were very clear and significant. There was a positive relationship between experiences of discrimination over time and depressive symptoms, and “there is a negative relationship between a change in discrimination over time and a change in self-reported health status” (Schulz et al., 2006, p. 1267). Both of these relationships held significance after controlling for the possible confounding variables of “age, income, education, discrimination and health status at baseline” (Schulz et al., 2006, p. 1267).

Relative Social Standing

Adler, Epel, Castellazzo, and Ickovics (2000) introduced an instrument for measuring subjective SES. It is a drawing of a ten-rung ladder given with instructions to “place an X on the rung that best represents where they think they stand on the ladder” while imagining the people at the top being the “best off” and the people at the bottom being the “worst off” (Adler et al., 2000, p. 587). Additionally, measures of objective SES, self-rated health, negative affect,

pessimism, and perceived control over life were collected. Adler et al. (2000) found that subjective SES was significantly related objective SES. Subjective SES was positively correlated with self-rated health, and was associated with all of the psychological variables as well. “The higher the women placed themselves on the ladder, the lower was their chronic stress, subjective stress, negative affect, pessimism and passive coping and the greater was their perceived control over life and active coping” (Adler et al., 2000, p. 589). On the other hand, objective SES was only associated with decreased pessimism and a passive coping style. Some limitations to note however are that all of the women were white, all of them had at least a high school degree, they were recruited for a main study to be healthy, and most of the subjective SES responses were toward the top of the ladder.

Summary of Health Disparities

As the research has shown, none of the factors that contributes to health disparities acts alone. Research supports the idea that various factors that contribute to a person’s physical health contribute to whether or not a person has regular access to health care services. The majority of research presented here can be brought together under one common theme: there are hierarchical differences between various groups, and the groups lower in the hierarchy tend to have poorer health outcomes. In extrapolating this theme and applying it to health care we have the general idea of some groups receiving “less” health care, which could occur in quality or quantity.

Drawing from the above literature the following relationships are proposed: greater personal and environmental resources are correlated with better health, as is regular medical care. Greater personal and environmental resources are correlated with regular medical care. While both quality and quantity are important factors in describing health care, a person must receive some form of health care prior to evaluating its quality. Yet there are steps even before

this—the environment must contain health care providers and a person must perceive that they can access them. The concept of perceived relative access has been inferred from this research.

Given the interdisciplinary nature of this literature review, a number of areas can be identified for further research. One research path, and the one taken in this project, leads to questions of whether socioeconomic status and self-reported health are related to perceived control over health or a health behavior. This path of research may provide some explanations for the findings that “...changes in these health practices over time are patterned by social status. Disadvantaged racial groups and those with low SES are less likely to reduce high-risk behavior or to initiate new health-enhancing practices” (Williams & Jackson, 2005, p. 327). While the current research project will not be able to draw causal relationships, it will ask the following: whether people with low income perceive themselves as having low levels of control over their health, and if this is broadly associated with perceptions of their access to health care resources in the community, as compared with their perceptions of others’ access to such resources.

CHAPTER 3 METHODS

This chapter describes the methods used to explore the potential relationship between perceptions of access to health care and perceptions of control over one's own health. The primary investigator was not aware of any research linking these constructs, however, recently Jackson and colleagues (2006) published the Perceived Unfairness Model, which proposes a relationship. A case study design with mixed methods was used for this exploratory research. The details of this project follow.

Research Site Selection

Alachua County, Florida, was an appropriate place to conduct this research due to the large gap in the distribution of resources among areas of Alachua County, even within its one urban area, Gainesville. Gainesville, a large urban area of Alachua County, houses the University of Florida, Santa Fe Community College, and a large student population which contribute to these disparities. In addition to the social and material inequities here, Alachua County offered a unique site to conduct this research because the voters expressed a commitment to addressing health care disparities. In 2004, voters approved a seven-year 0.25% sales tax to fund a local program that would provide uninsured workers with low-income access to primary health care services; this program has a component with fewer benefits for citizens 65 years of age or older that does not necessitate being uninsured. This ballot initiative was passed after years of many concerned citizens raising awareness of rising health care costs, the increasing numbers of uninsured, and the lack of health care associated with being uninsured. This community-based program, Community Health Offering Innovative Care and Educational Services (CHOICES) Health Services, began in October 2005, and has over 460 enrollees to date (As of 10/27/06).

Research Design

Given the community's initiative to provide access to health care to workers with low-income, this was a prime location to explore the idea that perceived access to health care is related to an individual's perception of their ability to manage their health. A case study design was suited for this exploratory research. In a case study, participants can be chosen on a common outcome, homogeneity, just as in experiments, so internal validity is strengthened (de Vaus, 2001). In this research, all of participants had a low-income and were enrolled in CHOICES. This case study was used to build and explore the Theory of Planned Behavior (Ajzen & Madden, 1986) and the Perceived Unfairness Model (Jackson Kubansky & Wright, 2006) by examining whether or not access to health care and/or social class are associated with feelings of control over health.

Sample Selection

The theoretical population for this research was all people with low-income. The theoretical sample included all of the people enrolled in CHOICES Health Services Program. Randomized sampling techniques were not a concern for this study "since cases are used for theoretical rather than statistical generalization..." (deVaus, 2001, p. 240). Due to the rate of enrollment in CHOICES and the sample size goal of 15–25, ongoing sampling with new groups of enrollees was required. Subjects were interviewed within three weeks of enrollment in CHOICES to minimize the possibility that subjects perceptions and responses might change as result of participation in the program.

Instrumentation

The interview was designed to study two main variables: perceived relative access to health care and perceived feelings of control over health. In addition to the interview schedule

designed specifically for this research, the CHOICES Enrollee Health Questionnaire was administered to each participant.

In addressing access to health care it was important to balance the existing research knowledge with attempting to learn the experiences and perceptions of the participants in this study. In other words, it was important to frame questions according to previous research, but also to allow the participants to use their own definitions in responding. The open-response questions inquired about their perceived level of access and were supplemented by questions about their perceived relative access. Perceived relative access was, in part, measured by the ladder instrument adapted from Adler and colleagues (2000). Although the depiction of the instrument was different and the instructions were altered to specifically address access to health care and the population of Alachua County, the concept of social relativity was the same. The remaining questions regarding perceived relative access were created for this project and asked about feelings of discrimination in health care and were constructed with the foundation of perceived behavioral control from the Theory of Planned Behavior (Ajzen & Madden, 1986).

Perceived control over health was the other important variable in this research. Prior research has indicated that people with low-income feel less control over their lives than people with higher incomes (Adler et al., 2001; Bailis et al., 2001; and Gallo, et al., 2005 for examples). However, no research has been identified that examined the possible relationship between feelings of control over health and perceived relative access to health care.

CHOICES Enrollee Health Questionnaire: As previously mentioned, the CHOICES Enrollee Health Questionnaire was administered with the interview schedule. This multiple-choice/short answer questionnaire elicits the following information: 1) perceptions of health status, 2) diagnoses of the following conditions: asthma, diabetes, high blood pressure,

congestive heart failure and depression, 3) global satisfaction with life, 4) frequency of utilization of emergency rooms in the last two years, 5) utilization of hospital inpatient services in the last two years, 6) frequency of primary health care visits, 7) length of time since last physical and dental exams, 8) primary barrier to utilizing health care services, and 9) whether or not they had a usual source of health care prior to enrolling in CHOICES (CHOICES internal documents, 2006). The instrument is comprised of items used in the Behavioral Risk Factors Surveillance Survey (BRFSS), the National Health Insurance Survey (NHIS), and the JaxCare, Inc. Needs Assessment. Although there has been research on the validity and reliability for the BRFSS and the NICH, neither of these instruments was used in their entirety in the present research. The author was unaware of any data regarding the validity or reliability for the JaxCare, Inc Needs Assessment, but it was not used in its entirety either.

Administration

Once data collection began, each week an introductory letter was sent to all new enrollees that fit the criteria for this study, people that enrolled in the previous week. This letter was shortly followed by a phone call inviting the subject to participate and to arrange a meeting time if the enrollee was willing to participate. At least 3 postal days transpired after the letter had been mailed and an enrollee was contacted via telephone. Based on standard recruitment protocol and after weighing time and resources, it was decided that each enrollee would be contacted by phone five times (Lavrakas, 1993).

Interviews were held at a public location of the participant's choosing. The day before the interview, each participant received a reminder call. Prior to beginning each interview, the informed consent form was reviewed. Each participant was asked if they had any questions and written consent was obtained. All participants were asked if they consented to being tape-recorded. In the few cases where the participant did not consent, the interview was not recorded.

The interviews that were tape-recorded were later transcribed for analysis. The tape recorder was not turned off until the participant had left “since interviewees sometimes ‘open up’ at the end of the interview”(Bryman, 2004, p. 333). For the interviews that were not tape-recorded, responses were typed out, as if transcribed, for later analysis.

Analysis

Some of the interview data were analyzed using thematic analysis of the transcribed interviews (Kossak, 2005). This analysis included constant comparison of the responses in order to identify concepts, categories, and themes that emerge from the data (Marshall & Rossman, 2006; Strauss & Corbin, 1998). The first step in thematic analysis was to describe concepts, which, in the case of this research, was the phrases or statements that stand out in a participant’s response (Strauss & Corbin, 1998). Next, categories were formed by combining concepts. Strauss and Corbin (1998) provide two reasons for this: first, it pares down the amount of material; and second, it allows the researcher to begin explaining and predicting the data. After categories were created, they were then collapsed into themes. Themes were then, the product of this inductive process (Marshall & Rossman, 2006). Analyses were done manually to allow the researcher complete immersion in the data. Though qualitative data was the focus, frequencies were calculated of the emergent concepts, categories, and themes.

Each participant’s codes were compared with their responses to the scalar instrument and the CHOICES’ Enrollee Health Questionnaire. The results from this process were compiled and reviewed for trends. The trends were then compared to the concept pattern developed prior to data collection and is similar to that described in Bailis and colleagues (2001).

Chi-square analyses were performed for various combinations of the constructs and demographics. Frequencies of the responses and demographics were calculated. The results of these and the qualitative analyses are presented in the next chapter.

Concerns/Critiques

There was a concern regarding the amount of time spent administering the instrument package. The length of time could affect respondents and the interviewer by prompting respondent fatigue or instrument decay – which would decrease the internal validity of the research (deVaus, 2001). This concern was somewhat abated after pre-testing showed an average of 20–25 minutes for each participant.

There was a concern about response rate. For this reason a monetary incentive of \$15.00 was offered to each participant. This was stated in the introductory letter (Appendix F).

People who were contacted for participation were eligible to receive services since the Alachua County Office of Social Services (OSS) had approved them for the CHOICES program. The Office of Social Services does the eligibility screening for CHOICES; however, the approved applicants have not necessarily completed the enrollment process. After a person has been approved by OSS, their name, contact information and demographics are sent to CHOICES. At this point CHOICES mails them an enrollment package, which includes forms that must be completed, signed and returned in order for some services to be received and the enrollment process to be complete. The decision to contact enrollees after OSS has determined eligibility, rather than waiting until the enrollment process has been completed, was based on the following:

- Once they have been approved by OSS, they can use the prescription benefit;
- Once they are approved by OSS, they are sent information that informs them they are enrolled in CHOICES, which could have a psychological impact.

In an attempt to obtain a more homogenous sample, a time limit needed to be set for how long a person could be in the program and still be contacted for participation; and

Four weeks was chosen after considering the amount of time allowed for mailing letters prior to contacting enrollees via phone, the amount of time allotted for attempting and making

phone contact, allowing for the interviews to be scheduled up to one week in advance of the phone contact when a person agreed to participate. This time was seen as short enough in that the chances of a person returning the necessary forms to CHOICES, seeing a doctor and receiving a prescription and obtaining any type of medical test was fairly small.

CHAPTER 4 RESULTS

This chapter presents the results of the exploratory case study, which inquired about perceptions of access to health care and perceptions of control over one's health. Twenty-three people who are enrolled in CHOICES Health Services participated in this research. First, demographics of the participants will be described. Next, the quantitative findings will be presented, followed by the qualitative results. The chapter will conclude with a summary of a few of the most significant results.

Response Rate and Demographics of Sample

The response rate was 29.11%. The characteristics of the sample are as follows:

- The mean age was 37.6 years, with a range from 21–59 years. (Distribution in Figure 4-1 on p. 81)
- Twelve women (52.2%) and eleven men (47.8%) participated.
- The distribution of race/ethnicity of the sample is (Figure 4-2 on p. 81):
- African American: 34.8%
- Caucasian: 60.9%
- Latino¹: 4.3%

Aside from those who were excluded, there were three categories in addition to participants: those that refused participation, those that agreed to participate, but did not come to the interview, and those who were unable to be contacted via telephone. A t-test was run with a Bonferroni adjustment to see if any of these groups significantly differed from the participants regarding age. Chi-square analyses were run to compare these groups to see if there were

¹At the time data was collected, the Office of Social Services (OSS), which collects the demographic information from enrollees for CHOICES, did not include Latino as an option. Other races and ethnicities that OSS specified at that time included Asian, Native American, Bi-Racial, and Other. The Latino participant in this study was documented as Caucasian by OSS. For this reason, they have been categorized as Caucasian for the analyses that follow.

significant differences in race/ethnicity, sex, or marital status. These analyses revealed that none of the groups were significantly different from the participants on the measured demographics.

Quantitative Analysis

Quantitative analysis was used to explore perceived access to health care services, perceived relative access to health care services, and the CHOICES questionnaire, as well as trend within these. The results of these analyses follow.

Perceived Access to Health Care Services

Access chart

There were eighteen items on the Access Chart, most of them external resources. Participants were asked to place a mark next to each factor they considered important to being seen by a doctor or other health care professional. Extra spaces were offered and it was suggested that they could add anything else they deemed important. After this, they were asked to rank the top five factors from those they initially marked as important. Finally, the participants were asked if they had each factor on the list two months ago and if they had it now. The responses to each of these follow.

Important access chart factors

- Participants identified an average of 12 factors as important.
- Five participants added one factor to the original list.
- More than half of the participants indicated the following were important: having a regular doctor (95.7%), trusting the doctor (95.7%), having health insurance (87.0%), knowing about how much it will cost ahead of time (87.0%), knowing they could see a specialist if the doctor referred them (87.0%), knowing they could get lab work done if the doctor suggested it (87.0%), knowing they could get prescriptions if the doctor prescribed them (82.0%), a doctor with a payment plan (78.3%), being able to get off of work (73.9%), having cash or credit (69.6%), transportation (69.6%), participating in a government program (56.5%), a doctor's office open at nights or on weekends (56.5%), and being able to walk-in without an appointment (52.2%) (Figure 4-3 on p. 82).

- The remaining factors and percentage of participants that included them as important are as follows: knowing they could change health-related behavior if the doctor recommended it (47.8%), knowing someone that goes to the doctor they are thinking of seeing (26.0%), babysitter (21.7%), and an item added by a participant (21.7%).

Ranked important access factors

- Two factors were included in the top five ranked important factors: health insurance (65.1%) and having a regular doctor (60.7%). Health insurance was generally ranked first, while having a regular doctor was generally ranked third.
- Three additional factors were included regularly by participants at 43% of the sample each: trusting the doctor, being able to get prescriptions if the doctor prescribes them, and being able to see a specialist if the doctor refers them.

Access factors they have now

- Regardless of the importance placed on each factor by the participant, less than half of the participants had the following factors from the Access Chart: cash or credit, health insurance, participation in a government program, babysitter, knowing someone that sees the doctor they are thinking of seeing, a doctor's office open nights or weekends, being able to walk-in, a regular doctor, trusting the doctor, being able to see a specialist if the doctor refers them, being able to get lab work if the doctor recommends it, knowing they could change health-related behavior if the doctor recommends it, and items added by the participant.
- Regardless of the importance placed on each factor by the participant, more than half of the participants had the following items from the Access Chart: transportation, can get off work, knowing the cost of a visit ahead of time, and being able to get prescriptions if the doctor prescribes them.
- On average, participants had 40.54% of the factors they marked as important and 42.63% of the factors they included in their top five important factors.
- Most of the participants had half or less than half of either the factors they marked as important (69.6%). Another 21.7% had between 51–75% of the factors they indicated were important. The remaining 8.7% had over 75% of the factors they considered important to seeing a doctor.
- There were no significant differences on any of the above measures between sexes or races, or among ages or age groups.
- Participants ranged from 0–100% for the percentage of factors they have now that were included in their top five important access factors. Most had half or less of the items they included in their top five factors (65.2%). The distribution is as follows (Figure 4-4 on p. 83):

- 0–24% of resources: 43.5% of participants
 - 25–49% of resources: 21.7% of participants
 - 50–74% of resources: 0% of participants
 - 75–100% of resources: 34.8% of participants
- Of the participants that reported they had 75–100% of the top five factors they marked as important the majority of them (75%) indicated they had health insurance. Since one of CHOICES’ eligibility requirements is that an applicant not be insured, one could presume the participants were not insured, but thought that CHOICES was a type of insurance, if this were the case, the distribution would be as follows (Figure 4-5 on p. 84):
 - 0–24%: of resources: 43.5% of participants
 - 25–49% of resources: 21.7% of participants
 - 50–74% of resources: 26.1% of participants
 - 75–100% of resources: 8.7% of participants

Perceived Relative Access to Health Care Services

After completing the Access Chart, participants were asked to place a mark on the step where they would stand of a ten-rung ladder. The participants were then asked to imagine that everyone in Alachua County got to stand on this ladder. The people standing on the top step had everything they needed to see any doctor or health care provider, while the people standing on the bottom step did not have what they needed. The top and bottom steps included possible examples of people who could be standing there, the coaches at the University of Florida, doctors themselves, and people that are homeless or cannot find a job right now, for each step respectively. These examples were included after pilot testing and were chosen over providing examples of actual resources the people would have, or not have, at each step.

- Participants placed themselves on steps one–seven. The median was four. Steps one and five received the highest number of participants with five and six respectively (Figure 4-6 on p. 85).
- Ninety–one percent of the participants placed themselves on the bottom half of the ladder (steps one through five). The remaining 8.7% placed themselves on the top half.
- There were no significant differences between sexes or races, or among ages or age groups.

Perceived Access

Participants were asked a series of four questions about whether or not they could get the care they needed if they were slightly sick, like if they had a cold or the flu, if they had a medical emergency, if they were depressed, and if they had a problem with drugs or alcohol. At least half of the participants felt they could get care if they were slightly sick, had a medical emergency, or if they had a problem with drugs or alcohol (56.5%, 60.9%, and 56.5%, respectively). Just below half of the participants (47.8%) indicated they could get care if they were depressed.

In each circumstance there were some that felt they would not get the care they needed (slightly sick 17.4%, emergency 17.4%, depressed 21.7%, and problem with drugs or alcohol 26.1%). However, the responses were not categorically yes or no. For each question there were participants who responded that they would not take that concern to a doctor or medical professional (26.1%, 8.7%, 13.0%, and 8.7%, respectively). Additionally, there were participants who were not sure or did not know if they could get care if they had a medical emergency (8.7%), were depressed (13.0%), or had a problem with drugs or alcohol (8.7%). Finally there were two “depends” responses from two participants for either a medical emergency or if they were depressed. These responses will be included in the qualitative analysis section later in the chapter. There were no significant differences between sexes or ages, or among ages or age groups.

Level of Control

Participants were asked to rate the level of control they felt they had over their health from a list five responses. The multiple choice responses were a) no control, b) that their health was out of their hands, c) a little control, but not a lot, d) a lot of control, but not complete, or e) complete control. Over half of the participants (65.2%) agreed that they had a lot of control over

their health. The remaining participants were split almost evenly between having no control (13.0%) and a little control (17.4%). One participant (4.3%) felt they had complete control. There were no significant differences between sexes or ages, or among ages or age groups.

Participants were asked to pick which statement the people standing on the top and bottom steps of the Relative Access Ladder might agree with. The response options were the same, however worded in third person instead of first. The results were very clear. The majority of participants attributed either a lot (56.5%) or complete (30.4%) control to those standing at the top step, cumulatively 87.0%. The remaining 13.0% indicated those on the top step have a little control over their health. Again, a majority of 87.0% attributed the lesser levels of control to those on the bottom step: no control (26.1%), their health was out of their hands (43.5%), or little control (17.4%). Of the remaining responses, 8.7% indicated that those on the bottom step had a lot of control and 4.3% did not choose a step on the ladder, but said that it depends. There were no significant differences between sexes or ages, or among ages or age groups.

Perceived Discrimination Scenario

Participants were asked a series of questions about whether or not they felt certain groups would have an easier time getting in to be seen by a doctor given that the example person in each group had been having trouble breathing lately and wanted to see a doctor about it. They were asked if there were differences between sexes, whether or not someone has health insurance, whether or not someone has the ability to pay cash up front, if there were differences between African Americans and Caucasians, and if there were differences between other races or ethnicities. Participants were asked to limit their responses to what they perceived in Alachua County. If the participant indicated that there was a difference within each section of the scenario, they were asked a follow-up question to confirm or indicate which group they thought was favored. Additional follow-up questions asked them how the disadvantaged person (the

term disadvantaged was not used; they were asked how the person might feel knowing they don't have or are not (insert variable) given that they know their situation might be different if they had or were (insert variable). They were asked what advice they might give the disadvantaged person. Finally, after all the variables were reviewed, participants were asked which variable would weigh more than the others, of those they had indicated would make a difference. (The question posed to them included listing back the variables they had previously indicated.) The responses to most of these questions will be described in the qualitative analysis section of this chapter. Briefly, the general responses of whether or not there were differences, and what groups were favored, are described below.

- Does sex makes a difference? Most participants (69.6%) stated that there is not a difference between women and men. However, 4.3% said that is depends, and 26.1% said that there is a difference. Of those who indicated that there would be a difference or that it depends, 71.4% identified females as having an easier time and 28.6 identified males.
- Does insurance make a difference? The majority of participants indicated that it does make a difference (82.6%). The remaining responses were distributed over the responses that it would not make a difference (4.3%), that they did not know if it would make a difference (4.3%), and that it would depend (8.7%). Of those who indicated that insurance would make a difference, it was unanimous that the person with insurance would have an easier time.
- Does the ability to pay cash make a difference? Over half (65.2%) stated that it would make a difference, 26.1% said that it would not make a difference, and 8.7% said that it depends. Of those that indicated it would make a difference, 60.9% were clear that the ability to pay cash would be favored.
- Is there a difference between African Americans and Caucasians? There was not majority in agreement in responses. Almost half (43.5%) of participants indicated that there was not a difference, and an equal number (26.1%) each indicated that it depends or that they hope not/it should not. One participant (4.3%) stated they did not know.
- Is there a difference between other races or ethnicities? Just over half (56.5%) stated that there was not a difference. Another 17.4% responded either that it depends or that they did not know/hadn't had the experience. One participant (4.3%) replied that they hoped not and another (4.3%) replied that there was a difference.
- The most important variable? Almost half of the participants (47.8%) indicated that health insurance alone was the most important. Another 43.5% indicated another reason that

generally included both health insurance and the ability to pay cash. The remaining 8.7% indicated cash alone was the most important.

- There were not any significant differences between races or ages for any of the above questions. However, through chi-square analysis, it was found that there was a significant difference between age groups when asked if there was a difference between sexes ($\chi^2=18.847$, significant at 0.016 with 95% confidence). Two-thirds (66.7%) of the participants between 45–54 years of age indicated that there was a difference. There were two variables that differed significantly by sex: ability to pay cash and if there was a difference between African Americans and Caucasians. Regarding the ability to pay cash, 90.9% of the men indicated that it made a difference, whereas 35.7% of women stated that it did ($\chi^2=6.302$ significant at 0.043 with 95% confidence). Finally, regarding difference between African Americans and Caucasians, 72.7% of men indicated that it did not make a difference, but only 14.3% of women said the same ($\chi^2=7.905$ significant at 0.048 with 95% confidence).

CHOICES' Health Questionnaire

The CHOICES' Health Questionnaire was the last instrument to be given to the participants. The results are as follows:

a. Perceptions of health status

Participants were asked to rate their health as excellent, very good, good, fair, or poor. Most participants reported they had either very good or good health (39.1% each). 13.0% indicated that they had fair health and 8.7% said their health was poor. There was not any significant difference between sexes or races, or among ages or age groups.

b. Number of poor physical health days

Participants were asked how many days during the past thirty had they had poor physical health, which included injury or illness. The range was zero to thirty days with an average of five days. There was not any significant difference between sexes or races, or among ages or age groups.

c. Number of poor mental health days

Participants were asked how many days during the past thirty days had their mental health been poor; this included stress, depression, and problems with emotions. The range was zero to thirty days with an average of 9.5 days. There was not any significant difference between sexes or races, or among ages or age groups.

d. Number of days poor physical or mental health hindered daily activities

Participants were asked how many days during the past thirty days had either poor physical or mental health stopped them from doing their usual activities, which included going to work, self-care, and recreation. The range was zero to thirty days with an

average of 8.5 days. There was not any significant difference between sexes or races, or among ages or age groups.

e. Diagnosis of any of the following conditions: asthma, diabetes, high blood pressure, congestive heart failure and depression,

Participants were asked if they had any of the four health conditions targeted by CHOICES, and depression, which is currently not covered under the program.

- Most of the participants (60.87%) had at least one of the conditions.
 - 13.04% reported having asthma
 - 13.04% reported having diabetes
 - 21.74% reported having high blood pressure
 - 4.35% reported having congestive heart failure
 - 34.78% reported having depression, though not all of them had been clinically diagnosed

There was not any significant difference between sexes or races, or among ages or age groups.

f. Global satisfaction with life

Choosing from a list of responses, participants were asked how satisfied they were with their life, very satisfied, satisfied, dissatisfied, or very dissatisfied. The majority (87.0%) of the participants were either very satisfied (26.1%) or satisfied (60.9%). One participant (4.3%) was very dissatisfied, and two participants (8.7%) indicated they were between being satisfied and dissatisfied. There was not any significant difference between sexes or race, or among ages or age groups.

g. Number of emergency room visits in the past two years

Participants were asked how many times they had visited the emergency room in the past two years. Responses choices were 0, 1, 2, 3, or 4 or more. While it is a conservative estimate, if four visits are used as the upper bound, the range was zero to four visits with an average of 1.48 visits. There was not any significant difference between sexes or among ages or age groups. A significant difference was found between races². A chi-square analysis revealed significance of 0.034 at 95% confidence ($\chi^2=8.673$). Subsequently a t-test was conducted, which resulted in significance of 0.021 at 95% confidence ($t=2.503$). African Americans had a total of 20 visits and Caucasians had a total of 14 visits, which represent 8 and 15 participants respectively.

h. Number of hospitalizations in the past two years

² For the purposes of analysis, the racial categories included African American and Caucasian. The Latino participant was included in the Caucasian category since this matched how race and ethnicity was being recorded with the Office of Social Services at the time of data collection.

Participants were asked how many times they had been hospitalized in the past two years. Response choices were 0, 1, 2, 3, or 4 or more. The responses ranged the answer choices, however only one participant (4.3%) responded with four or more. The majority (73.9%) of participants had not been hospitalized in the past two years. The remaining responses are that two participants (8.7%) had been hospitalized once and three (13.0%) were twice. There was not any significant difference between sexes or race, or among ages or age groups.

i. Number of health care visits in the past year

- Participants were asked how many times they had been to a doctor's office or other clinic in the past twelve months, excluding the emergency room visits and hospitalizations. Answer choices were none, 0, 1, 2–3, 4–5, 6–7, 8–9, 10–12, 13–15, and 16 or more. The number of visits ranged from zero to 13–15. The majority (87.0%) of participants had 5 or less visits. The average, median, and mode were two visits. The complete distribution is as follows:
 - 0 visits: 17.4% (4 participants)
 - 1 visit: 17.4% (4 participants)
 - 2–3 visits: 30.4% (7 participants)
 - 4–5 visits: 21.7% (5 participants)
 - 6–7 visits: 0% (0 participants)
 - 8–9 visits: 4.3% (1 participant)
 - 10–12 visits: 4.3% (1 participant)
 - 13–15 visits: 4.3% (1 participant)

There was not any significant difference between sexes or race, or among ages or age groups.

j. Length of time since last physical

Participants were asked how long it had been since they had had a routine physical, which was not a check-up regarding a specific injury or condition. The response choices were within the past year, within the past two years, within the past five years, or more than 5 years. The responses, showing a bi-modal distribution, were as follows:

- Within the past year: 43.5% (10 participants)
- Within the past two years: 4.3% (1 participant)
- Within the past five years: 13.0% (3 participants)
- More than five years: 39.1% (9 participants)

There was not any significant difference between sexes or race, or among ages or age groups.

k. Length of time since last dental exam

Respondents were asked how long it had been since they had been to a dentist or dental clinic for any reason. The response choices were within the past year, within the past two years, within the past five years, or more than 5 years. Half (52.2%) of the participants had seen a dentist within the past year, but for many (39.1%) it had been at least two years. The distribution is as follows:

- Within the past year: 52.2% (12 participants)
- Within the past two years: 8.7% (2 participants)
- Within the past five years: 21.7% (5 participants)
- More than five years: 17.4% (4 participants)

There was not any significant difference between sexes or race, or among ages or age groups.

l. Barriers to utilizing health care services

Participants were asked if any of the following had stopped them from going to the doctor in the past six months: cost, transportation, office hours, or language barriers. The majority (73.9%) of participants indicated that cost was a barrier, 26.1% indicated that it was not. Substantially fewer participants perceived barriers of inconvenient office hours and transportation, 13.0% and 8.7%, respectively, most did not (inconvenient hours 87.0% and transportation 91.3%). There was not any significant difference between sexes or race, or among ages or age groups. None of the participants perceived language as a barrier, however all of the participants were fluent in English and it cannot be assumed that this is not a barrier for anyone participating in CHOICES or living in Alachua County who might be eligible for the program.

m. Usual source of health care?

Participants were asked whether or not they had a usual doctor's office, clinic, or other place they go to if they are sick or need advice about their health. Half of the participants (56.5%) indicated that they did have a usual source of care, and slightly less than half (43.5%) said they did not. There were not any significant differences between sexes or among ages or age groups. However, a significant difference between races was found. All of the African Americans indicated they had a usual source of care, while 38.5% of the Caucasians indicated the same. ($\chi^2=9.436$ at 0.002 significance at 95% confidence).

There is a discrepancy between the number of participants that responded affirmatively to this question and the percent that indicated they had a regular doctor while completing the Access Chart. It is likely that while there would be some overlap, having a regular doctor is not the same as having a usual place to go when one is sick. Taken together the results of this question and the one inquiring about the number of emergency room visits in the past two years could have implications for health care usage and program planning and outreach activities.

Quantitative Responses to Research Questions

RQ1. How do people with low incomes associate feelings of control over their health with having access to health care services?

Chi-square analysis was run to see if there was an association between participant's level of control over their own health and their perceived access to health care, which included the percent of important Access Chart resources they have now, the percent of the five ranked Access Chart resources they have now, and the quartile they fit in for the five ranked resources. Statistical significance was not found between the participant's level of control and their perceived access to health care.

RQ1a. Is perceived access to health care services associated with any form of discrimination?

Chi-square analysis was run to see if there was an association between participant's perceived access to health care and the various variables included in the Scenario, principally if the participant's perceived differences in ability to access services between sexes, health insurance status, ability to pay cash, and among races and ethnicities. Statistical significance was not found among any of these variables.

RQ1b. Is perceived relative access to health care services associated with feelings of control over health?

Chi-square analysis was run to see if there was an association between the participant's perceived relative access, which included where they placed themselves on the ladder, their ladder quartile, whether they placed themselves on the bottom or top half of the ladder, and whether or not they felt they could get the care they needed under various circumstances, and the level of control they felt over their health. Statistical significance was not found between perceived relative access to health care services and control over health.

The second research question inquired about possible relationships between the concepts examined in the first research question and the responses to the CHOICES' Questionnaire. A few of the questions from the questionnaire were chosen for chi-square analysis either because the concept is prominent in prominent in the literature or because it might be particularly useful information to the CHOICES program. The selected questions addressed health status, if the participant had any of the specified conditions, life satisfaction, number of emergency room visits in the past two years, number of doctor's visits in the past year, and if the participant had a usual source of care.

RQ2a. Are feelings of control associated with selected questions from the CHOICES' questionnaire?

Only one question from the questionnaire was significantly associated with participants' level of control, the number of emergency room visits in the past two years ($\chi^2=17.868$ at 0.037 with 95% confidence). Participants that had not been to the emergency room in the past two years felt they either had a lot of control over their health (88.9%) or complete control (11.1%), which represents 39.1% of the participants. Participants that had been to the emergency room at least once in the past two years (60.9% of the participants) ranged in responses among having no control (21.4%), a little control (28.6%), or a lot control (50.0%) over their health.

One other question approached statistical significance, life satisfaction ($\chi^2=16.502$ at 0.057 with 95% confidence). Over half of the participants (65.2%) indicated that they had either a lot or complete of control over their health and that they were satisfied or very satisfied with their life. The remaining combinations are as follows: 8.7% indicated that they were very satisfied with their life and had no control over their health; 13.0% stated that they were satisfied with their life and had a little control over their health; 4.3% stated that they were very dissatisfied with their life and that they had no control over their health; and the remaining two participants

felt they were between being satisfied and dissatisfied with one (4.3%) feeling that they had a little control over their health, and one (4.3%) feeling that they had a lot of control over their health.

RQ2b. Is perceived access associated with selected questions from the CHOICES' questionnaire?

No statistical significance was found among any of the questions addressing perceived access to health care and any of the selected questions from the CHOICES' questionnaire.

RQ2c. Is discrimination associated with selected questions from the CHOICES' questionnaire?

Chi-square analysis was run to see if there was an association between whether or not participants perceived differences between any of the groups presented in the Scenario, and if so, what status was favored. Statistical significance was found when asking if there was a difference between sexes when compared to the participant's health status ($\chi^2=19.912$ at 0.003 with 95% confidence). Another chi-square analysis was then done with these and compared by races and were found to be significant for African Americans ($\chi^2=8.000$ at 0.018 with 95% significance) and Caucasians ($\chi^2=13.200$ at 0.040 with 95% significance). It was found to be significant when comparing women ($\chi^2=13.440$ at 0.009 with 95% confidence) and men ($\chi^2= 7.975$ at 0.047 with 95% confidence).

All of the participants that indicated there was not a difference between sexes reported that they were in very good or good health, whereas those that reported there was a difference between sexes, or that it depended, ranged from good to poor health (28.6% reported good health, 42.9% reported fair health, and 28.6% reported poor health).

RQ2d. Is perceived relative access associated with selected questions from the CHOICES questionnaire?

No statistical significance was found among the questions addressing perceived relative access and any of the selected questions from the CHOICES' questionnaire.

After the above results were found, additional chi-square analyses were run to see if there was a relationship between any of the following:

- Access Chart – if they have cash or credit now, if they have health insurance now and if they have a regular doctor now
and
- Step on the ladder, ladder quintile, whether the participant was on the top or bottom half of the ladder, if they felt they could get the care they needed under various circumstances, level of control over their own health, and from the CHOICES' questionnaire: health status, if they had any of the specified conditions, the number of emergency room visits in the past two years, the number of doctor's office visits in the past year, and if they had a usual source of care.

There were three statistically significant associations, all with having cash or credit now: step on the ladder ($\chi^2=36.827$ at 0.006 with 95% confidence), ladder quintile ($\chi^2=27.371$ at 0.001 with 95% confidence), and whether the participant was on the top or bottom half of the ladder ($\chi^2=12.204$ at 0.007 with 95% confidence).

Summary of Quantitative Analysis

Given that the majority of questions asked of the participants for the above analyses focused on external facilitators of perceived access to health care it is not surprising that these were identified as important. It is noteworthy, however, that one salient potential internal barrier on the Access Chart, knowing that one could make health-related behavior changes if the doctor recommends it, was not included as important by over half of the participants. Yet it was included by a substantial number of participants so it should be further explored.

It is notable that there were not any significant differences between sexes on the majority of the above analyses. While there was one significant difference among age groups in the Perceived Discrimination Scenario, this should be interpreted carefully since there were not many people within each category. As seen, there were two health care utilization questions where statistical significance was seen between races. Though it is understood the sample size prohibits statistical generalizability, the significance found within each question could be partially explained by the corresponding question. This is an area that deserves further research.

Overall, the participants generally do not have what they feel they need to access health care, principally health insurance and a regular doctor. This corresponds with where they placed their health care access when they compared it with other citizens in Alachua County, at the bottom half, or less than at least half of Alachua's citizens. It corresponds to the results of the Perceived Discrimination Scenario that placed high importance on health insurance and the ability to pay cash in order to have an easier time accessing health care. Despite the lack of resources and generally low perceived access to health care, participants reported that they have a lot of control over their health, are in good health, and are satisfied with life. Many are still utilizing health care to some degree, whether it is through emergency rooms, doctor's offices, dental clinics, or some combination of these. These experiences with the health care community could be partially reflected in their responses to feeling they could get the care they need under various circumstances. In the qualitative analysis that follows, the participant's perceived relative access, and the remaining interview questions, will be discussed.

Qualitative Analysis

Qualitative analysis was done to answer the main research question and its two sub questions. The first step of the analysis established codes, which were the actual words of the participants. From these codes thirty categories were created:

- Scenario – Most important factor
- Feelings for not having resource identified in scenario
- Advice for person in scenario
- Tell lawmakers
- ‘Ideal’ health care system
- Health and accompanied feelings
- Control over health
- Associations with health insurance
- Relative Access to Health Care
- Associations with the ladder (perceived relative access to health care)
- Feelings accompanying finances
- Work and health
- Medical bills
- Health care costs
- Thoughts on the emergency room
- Doctors’ perceptions
- Dentists’ perceptions
- Money and doctors
- Medical community
- Thoughts on the community of Alachua County
- CHOICES’ reputation
- What is wanted out of CHOICES
- Name of CHOICES
- Why did I apply?
- Applying for CHOICES
- CHOICES’ services
- Recruiting for CHOICES
- In addition to CHOICES’ Questionnaire
- Women
- Men

Concepts from the three main theories used in this research, the Human Ecological Model (Bronfenbrenner, 1979), the Theory of Planned Behavior (Ajzen & Madden, 1986), and the Perceived Unfairness Model (Jackson et al., 2006), were used to synthesize the categories into themes. This was done because it was seen as a clear way to explore the large amount of data through the lenses of each theory. Constant comparison of the data was done until the reviewers came to consensus.

Each theory lent itself to a different facet of the data's wide extent. Each section below will contain two parts, an introduction to the theory and its relevant concepts and a discussion of the data with quotes from the participants.

Themes: The Human Ecological Model

The Human Ecological Model (Bronfenbrenner, 1979) served as the framework for this research. The participants' responses described relationships at each of the four levels in the model. Beginning with the most immediate, each level will be discussed in terms of its theoretical importance followed by participants' responses.

Microsystem

The microsystem is the most proximal system according to the Human Ecological Theory (Bronfenbrenner, 1979). Examples of particularly relevant microsystems are the relationship between a patient and their doctor, the relationship between a client and a social worker, and the relationships between individual citizens and their family members, friends, and neighbors.

A series of four questions asked whether or not participants felt they could get the care they needed under various health circumstances. These questions were asked as a component of their perceived access to health care. When asked if they felt they could get care if they were slightly sick many responded that they would take care of that themselves, by getting over the counter medication, "If I get a cold or flu I don't usually go to the doctor." Some also indicated that they would go to their mothers, even in a medical emergency. Sometimes friends or coworkers were mentioned. They were generally described as people with plight similar to that of the participant, but not as resources for information or support.

Some participants mentioned having a doctor they would normally go to, but are concerned now because that doctor is not listed as participating with CHOICES. Generally, people did not mention having a relationship with a doctor; although through the CHOICES Health

Questionnaire most indicated that they have utilized some aspect of the health care system in the past two years. Responses to questions about possible discrimination in potential encounters with doctors' offices can be categorized at the micro level. Many people that indicated that racism may exist saw it as an individual issue not a systemic one. For example, "It comes down to who's in the receptionist's office," and "I think, honestly, I think it all depends who's on the other side of the counter."

Mesosystem

The mesosystem can be described as the links between the microsystems (Bronfenbrenner, 1979). The relationship between doctors and staff of the CHOICES program is a critical aspect in the success of the program. Other mesosystems include primary care doctors' relationships with specialists and lab technicians, and the relationship between the social workers and the staff of CHOICES.

Participants described a fractured system, one that is not 'fixing' the problems with the affordability of and access to health care. One participant voiced her awareness of the large number of people that have been without health insurance for a long time, and how this has contributed to the progressed state of many of their health problems. A couple of participants described seeking information and help only to be told that they have to contact other people, who would in turn, refer them to yet others. As part of the scenario, participants were asked what advice they would have for a person who would have a more difficult time getting in to be seen by a doctor; often times the participant concluded that this person was having a difficult time because they did not have health insurance or the ability to pay for the visit. Many advised that the person should apply for CHOICES or save to buy insurance. One response in particular from a 48-year old woman captured the sense of a general lack of options or *choices*:

I don't know what resources to go to... Often times a lot of the information is hard to get a hold of, nobody offers it; they act like it's a huge secret. So, I wouldn't know what to tell them. I really wouldn't because I have done it all, including owing Shands and ruining my credit.

Exosystem

In the exosystem policies and organizations are created. It could be likened to a kind of social infrastructure where the values and mores of a society become more concrete through the formation and maintenance of such institutions (Bronfenbrenner, 1977). For example, CHOICES Health Care Program is part of the exosystem. It is a program supported and staffed by the Alachua County government and impacts the citizens.

Within the disjointed system participants identified in Alachua County, they emphasized the importance of CHOICES. When asked whether or not they could get care if they were slightly sick, one participant responded that now that they are enrolled in CHOICES, "I would say yes." When asked what they would tell the lawmakers of Alachua County about the health care system here, the CHOICES program was positively recognized. These responses include women and men, African Americans and Caucasians, and span the range of ages in the sample:

"I went to the doctor for the first time last week because of CHOICES. I hadn't been before."

"On a roll with getting CHOICES going for the uninsured."

"Give the CHOICES program a chance."

"CHOICES is a good start."

"Right now it's doing okay, there's CHOICES. Without CHOICES I'd still have this broken tooth in my mouth."

"I'm appreciative. I think it's great, 'cause I wouldn't have any otherwise."

Macrosystem

Unlike the other ecological levels, the macrosystem does not describe a set of relationships. The macrosystem is the body of values and priorities of a given society (Bronfenbrenner, 1979). For example, American society values the structure of the Western medical system. It is generally believed that this system is open to those who would like to use its services. There is a growing sentiment that health care should be more affordable, which can be exemplified by the CHOICES program and others similar to it.

Participants were given a brief scenario with gradually more information about two people who wanted to see a doctor about a health concern they had been having. This scenario posed questions about the potential for differences in the ease of getting in to be seen between sexes, between having and not having health insurance, the ability (or lack of it) to pay cash, and among races and ethnicities. Overall, what mattered was having health insurance and the ability to pay, not sex, race, or ethnicity. This theme was summed well with the response of a 51-year old man to the scenario:

“Money. Green. That’s the one color, green. Insurance, credit card, they see that...only color America sees is green.”

Some participants did indicate that discrimination exists at the macro level between sexes, races, and socioeconomic status. A couple of men pointed to WIC and other programs that they perceived as giving women an easier time of getting in to see a doctor. A young African American woman indicated that although there should not be differences between African Americans and Caucasians in the ease of getting in to be seen by a doctor, she also said that, “It shouldn’t, but some people might do things differently.” She further pointed to the different society younger people were raised in as compared to older people. A young Caucasian woman described an interaction,

“You know, it depends if, you know, they’re poor. I mean, if they’re a rich white person and a poor black person; if it’s a white person with health insurance or black person, or vice versa, then yeah (race is going to make a difference).”

Themes: The Theory of Planned Behavior

The Theory of Planned Behavior (Ajzen & Madden, 1986) served as the theoretical foundation for many of the interview questions. The concepts of control and power beliefs were of interest, more specifically, the potential relationship between a person’s feelings of control over their health and their perceived access to the community’s health care services. Although it was not specifically asked about, many participants shared how perceived access to health care services affects the decision to seek these services, or intention.

Control beliefs

Control beliefs are the perceived influences of an environment on a behavior (Glanz et al. 1997). The participants’ feelings of control over their health do not seem to be positively related to their perceived access to health care. It seems that different factors influence the amount of control one feels over their own health and the amount of control one feels in being able to obtain health services in the community. As seen by their responses to the CHOICES Health Questionnaire, participants are generally utilizing some aspect of the health care system. However, some answers as to how much and under what circumstances they are using it, and why they are *not* using it are found throughout the interviews.

Some reasons for not going to the doctor were that they could not afford it, they did not have health insurance, and that they tried to take care of the concern on their own. Participants said they went to the doctor when they were really sick, if they knew they could work out a payment plan with a doctor, if they knew the doctor would not do ‘unnecessary’ lab work, or if they would be able to get in-office discounts. Some reasons for not going to the emergency

room were that there was a long wait, it is embarrassing, cost, and they had been treated poorly previously because they did not have health insurance. Despite all of the reasons the emergency room was avoided, it was seen as a place to go where you do not need health insurance or the money to pay for services, a place to if you really needed to be seen, a single place to get a lot of different services, and a place where family and friends go.

Power beliefs

Power beliefs are the degree to which the environment impedes or facilitates a behavior (Glanz et al., 1997). After participants identified environmental factors that affected whether or not they go to a doctor or the emergency room, a subsequent question would be to what extent do these factors affect the health care seeking behavior. The following are some responses to the question of whether or not the participant felt they could get care they needed in a medical emergency. Their answers speak particularly to the seriousness of their injury or illness and the cost. Again, these responses span the demographics of the sample.

“Mm, I mean, I could go to the emergency room, but it would be an insane bill, you know, but if I *really* had to I would go. So, I would, but I would go at the very, very, very last second, you know.”

“Yeah, if I’m obviously have (sic) broken bones or bleeding, yeah, I’d get to (the) emergency room.”

“Definitely not; the emergency room is killing me. I mean, I don’t know what to do with these bills.”

“I would have to do whatever I would have to do. I would just go to the hospital, they would take care of me and I would pay for the rest of my life is what would happen.”

“Well, yes and no. Well, it depends on the medical emergency...if I need something that costs \$200,000, I doubt that, but I mean, if I broke my leg, of course”

“Well, I do, but it’d take a long time. Last time I went to the emergency room it took almost seven hours.”

Other information was shared at different times throughout the interviews.

When responding to the access chart, one 53-year old participant commented that, “Money has been an issue and I actually have resisted going to the doctor, knowing that he’s going to prescribe antibiotics that won’t be able to afford. So what’s the point of going to the doctor?”

Participants were asked about how the person without insurance might feel, given they are sick and want to see a doctor. A particularly relevant response was from a 21-year old woman, who said, “(They) wouldn’t want to go to the doctor, like me.”

Participants played on the name ‘CHOICES;’ it’s lay meaning was used with it and it was an underlying current. For example, one reason a participant did not have the money right now for doctor’s visit was because they were making car repairs. Another participant used the money they had been saving to repair their car and so they “...fortunately had it, but unfortunately too,” they are struggling with transportation. “If you constantly savin’ up, but you won’t be because the money’s gonna go to bills...” Another participant, an African American woman, described the money they would have to pay to see a specialist as the same as a utility bill,

...so you’re making a choice. I mean, either pay my phone bill, my utility bill, or not make a car payment because I need to see a doctor. But \$400 is certainly a lot less than going to the emergency room and paying \$4000. So there are *not* many *choices*, that I’m learning. We make the decisions that are best for us...

Themes: The Perceived Unfairness Model

As previously stated, the Perceived Unfairness Model (Jackson et al., 2006) is a new model proposed to explain the paths by which perceived unfairness might affect physical health. To the author’s knowledge, this is the first research using this model. There are numerous constructs in this model. The participant’s responses were analyzed according to the definitions provided in

the article by Jackson and colleagues (2006) with the understanding that these constructs may be refined over time with research.

Perceived unfairness

Jackson and colleagues (2006) openly defined perceived unfairness as "...encompassing a breach of entitlements or of psychological contracts related to group membership or to individual experiences" (p. 24). Some of the participants' responses overlap between this perception, the accompanying emotions, and their identities, but for these constructs will be separated to some extent for analysis. Participants' perceptions of unfairness are found throughout the interviews. The responses that follow are presented in the order in which the interview questions were asked.

When asked if they felt they could get the care they needed if they had a medical emergency, a participant replied that they had contacted a social worker at Shands about emergency room bills and found out that, "...I'm not approved because I fell between the cracks. Because I work, I support myself, barely. Fall through the cracks. I don't fit in any program."

In going through the scenario, one of the people presented, John, does not have insurance. The following are replies to how he might feel, given that he has a medical concern and wants to see a doctor about it.

In response to John's not having insurance, one young man replied that, "...he might do what he can, but still, anybody with health insurance would still, still be seen first."

Another man identified with John as man perceiving discrimination between the sexes, "Well, it's not equal. It's not equal at all."

A 39-year old woman identified with John not having insurance,

Well, if I were John, and I've experienced both, both ends of that... you've just got to get the doctor to see him, regardless. ... It's just the way the doctors have treated me, versus, you know, it's like I go to the doctor with insurance then it's like, I didn't have insurance and went to a specialist and I paid him money, you know, gave him the full price for it, no problem, but he didn't even want to look at me, his attitude towards me was that you don't

have insurance, what are you even seeing me for, I'm a surgeon? Well, you know, I'm in pain, I have a problem, I want to know what it is. He didn't give me the time of day. I paid \$300 bucks for that, and he said, no you don't have an infection and left. And um, because I didn't have insurance and he's a surgeon and he's a specialist, and I felt that was really negative...

The next couple of statements were also responses in the scenario regarding insurance and the ability to pay cash. These responses represented the demographics of the sample.

"Yeah, everybody who has health insurance will get seen by a doctor quicker than everybody else."

"I felt...I work, I pay my taxes, I do the best that I can. And there's just nothing available. I have searched and searched for something to help me and nothing."

"I think, sometimes it's like who you know too...it kind of feels like a scam."

Participants indicated that a person needs health insurance and/or cash to receive 'thorough,' 'optimal' care, care that makes one feel like a citizen, a human being, care that one gets with a 'real' job. Although it was not asked of them, some participants offered the association of a good job with education, health insurance, and the ability to get health care.

All of the participants were asked what they would like to get out of CHOICES. One 46-year old man responded broadly and with some disgust, "...to not be able to be seen by a doctor or dentist, to go years at a time without, in *this* country, of *this* wealth, with *this surplus* of medical talent, buildings, facilities..."

When asked about the feelings of control people at the bottom step of the ladder might feel, a 45-year old man responded: "They want to find a job, but ain't no job available."

Some of the problems of the health care system in Alachua County that they would share with lawmakers are that: "There are a lot of people out there who provide health care, but it's not affordable;" and, "I've been treated ugly in an emergency room because I didn't have any insurance and I owed Shands." Additional comments about the broader system include: "I wish

everybody could get health care. It shouldn't be a problem, I don't think;" and, "I need help. I don't have no (sic) medication. I need some medication. Well, we can't help you. It's like you're out for dead."

Identity

In the Perceived Unfairness Model, identity is simply "one's concept of self" (Jackson et al., 2006, p. 25). Again, the concept of identity can be seen at various points of the interview. The scenario drew out the most here, with participants describing differences between sexes: "Men have a tendency to just be able to make more, earn more, and to do more for themselves. Meanwhile, women are runnin' around trying to take care of their children first." "...but you know, white male, you're left to forge ahead on your own..."

"Being a man, I feel like I'm kind of taken advantage, even though I'm not still..."

Another woman had seen women sometimes get preferential treatment and witnessed African Americans being treated worse than Caucasians, but they had seen everyone being treated the same. Despite these possible differences, she felt that health insurance would make it easier.

The following are responses to not having health insurance or cash:

"If you don't have it, you can forget it. You're last of the last, bottom line."

"They'll feel out of place. They'll feel like, not being a citizen, not being human."

"Yeah that (insurance) could sway it either way. But now, if you're a minority and you *don't* have insurance, that's even, that's the worst situation." (In the scenario the African American had insurance and the Caucasian did not).

When asked to describe what level of control the people at the top of the ladder might feel, two responses were: "These people are aliens to me;" and, "Well, see, you cannot compare the people up here to down there..." In the additional comments below, the juxtaposition between feeling like one is part of the community and yet is not part of it, a "second class citizenship,"

where people who are working, are not treated like people, with respect. “I do pay a lot of money in taxes.” “Help me, just please help us.” From CHOICES one participant hoped that they would not “...have to be turned away in the emergency room like an alien.”

Emotion

While perceptions and identity contribute to the perceptions of unfairness, emotions are one of the responses that accompany such perceptions (Jackson et al., 2006). As stated by Jackson and colleagues (2006), this emotional response is not necessarily negative and could be neutral, and the emotional reaction could lead to both negative and positive responses to the perceptions, such as stress and motivation for collective action. Participants did not express the motivation for collective action. When asked in the scenario how a person might feel without having health insurance participants ranging in the demographics of the sample indicated that they would feel, “Left out.”

Or, “...if it’s like a consistent condition, maybe some sort of depression, anxiety, probably, maybe a little frustration...it’s probably frustration...”

Furthermore, if a person did not have health insurance or cash:

“I think they’ll feel worse. If you ain’t got it, you can’t do nothing.”

“Upset, worried, scared.”

“If he’s sick, might feel helpless.”

“Discouraged.”

“I can tell you exactly what it’s like because I’ve been going through it for years. Nobody cares. The doctors don’t care, the hospitals don’t care.”

Participants were asked what level of control might be attributed to the people at the bottom step of the ladder:

“Been there, felt completely out of control.”

“They don’t have any (control).”

“Some people when, in these situations, they fell like, some of the people feel like they can have some kind of hope and some just don’t. Kind of like, just don’t wanna, kind of give up. Nobody cares, you know, always negative...it all depends on the person.”

Coping behavior

Like emotions, coping behaviors are other responses to the perceptions of unfairness (Jackson et al., 2006). Participants expressed the use of avoidance.

A 45-year old participant discussed the emergency room, “Most times you go to the emergency room, you’re there until 6 o’clock, 11 o’clock at night. That’s embarrassing, really embarrassing; I don’t like to go through that. I don’t want to go. I just be hurting and taking some Advil and go to bed.”

The situation of not having health insurance was particularly salient, people do not want to go to the doctor: As a 24-year old woman said, “...going to the doctor without having insurance, people don’t do it if they don’t have insurance.”

This was concurred with the response of a 26- year old woman, He may see it as a one-time deal. I really do think, I’m just gonna go ahead and pay this one-time fee and take care of my health and all my issues. He may think this is a one-time thing and it’s not. You have to have health insurance (with it) you can go anytime. He sees it as a one-time thing; he only going to the hospital when it’s necessary.

This was explained even more by a 25-year old man,

He has to pay a lot of money up front. So, like myself, I might pay up front,... I don’t like to think about going to the doctor. \$95 for what, you know, going’ to the doctor and they don’t really tell you anything. I could do something else with that money, I could pay another bill or something. That could be sometimes on his mind as far as actually going to the doctor, you know, most people with health insurance, they just go and they just pay their \$20 or whatever it is, it’s nothing really on their mind. I think that’d be one of the main things, so, I’m just going to spend a little bit of money now and you know maybe the bill’s covered for the rest of it, so I can go check just make sure. But somebody who doesn’t they won’t just go check to make sure, they’re gonna say well, they said it was nothing. Just gotta keep believing.

Despite all of the behaviors that may seem be types of avoidance, all of the participants still heard about CHOICES and applied, which they described as neither an easy nor a quick process. Yet, many participants would still advise others to apply and some are actively telling others to do so. The majority intend on taking advantage of the services that CHOICES offers. An understated coping behavior seen in all of the participants is that each of them are still seeking to change their health care situation.

Responses to Utilizing CHOICES' Services and Thoughts for Lawmakers

Many of the participants described a specific health care service, such as dental work, prescriptions, or exams that they would like to access now that they are enrolled in CHOICES. However, there were a number of people that expressed the desire for security and having the *choice* to get health care.

I want security. I want a little; I was *so* afraid that I was gonna have to have a \$20,000, \$30,000 operation and it was gonna put me so far out of financial control of my life, that this would help so much. They would at least pay for some (lab tests). I know they wouldn't pay for the operation, but I would feel like I can have doctors I can talk to...Most stuff is really easy to take care of.

“The security of knowing that I have something, that I could get care.”

“I'm trying to take better care of myself...finding out what's wrong with me.”

“Just to go to a regular doctor's appointment for an affordable rate; go to get prescriptions.

And be able to go to a specialist if I needed to, cause I know they don't offer that now.”

“Health care that makes me feel like the human being that I am.”

“You know what I mean, something to fell back on, you know.

Generally, participants wanted to tell lawmakers how appreciative they are of the CHOICES program, and urged them not to cancel it.

“Help me, just please help us.”

“Just don’t let ‘em cut the program out. I need something, and we need it...”I’m appreciative of what they do...So, if they’re willing to help, I think it’s great.”

“Give the CHOICES program a chance.”

Yet at the same time, many were dissatisfied at the state of the health care system. Many feel that the program needs to be expanded to include more choices – more dentists and primary health care providers; add specialists, vision care, and mental health counselors. Other suggestions were including some emergencies, such as broken bones, or perhaps urgent care centers. On a broader level, a number of participants desired to see a coordinated health care infrastructure, one that would include the whole family, “once you’re in, you’re in.” Perhaps one that incorporated some of the ideas used to provide affordable housing on a sliding scale to “Make it available for everybody.”

Qualitative Responses to Research Questions

RQ1. How do people with low incomes associate feelings of control over their health with having access to health care services?

As stated earlier, there seems to be a disconnect between feelings of control over health and access to health care services. As seen in the quantitative analysis, generally participants felt they had a lot of control over their health, despite half of them having half or less of the resources they felt they needed to gain access.

RQ1a. Is perceived access to health care services associated with any form of discrimination?

As seen in the scenario, most participants did not feel that sex, race, or ethnicity impacted the ability to access health care services. However, the majority identified the person without health insurance as disadvantaged and many indicated that lacking the ability to pay for the visit would be a disadvantage. Although the participants did not initiate the use of the word

‘discrimination,’ the current of discrimination based on the ability to pay for services (through insurance or otherwise) was apparent.

RQ1b. Is perceived relative access to health care services associated with feelings of control over health?

The result here is similar to that in RQ1; participants did not seem to positively associate their perceived relative access to health care with the feelings of control over their health.

Despite the fact that most of the participants placed themselves on the bottom half of the ladder, most felt they had a lot of control over their health.

RQ2. Do any of the above concepts, control over health, perceived access to health care, discrimination in health care, and perceived relative access to health care, show patterns of association with responses from the CHOICES Questionnaire?

To answer this question in a qualitative manner would require asking questions that were not included in the current interview schedule. Such questions may need to be very specific, such as, whether or not a person feels that having a medical condition, asthma for example, is related to their feelings of access to the system. This line of questioning may not be particularly illuminating in some circumstances. For example, it may seem intuitive that a person who does not have a chronic medical condition would most likely not rank knowing they can get prescriptions when they need them as highly as a person who does have a chronic condition. What one may find in such research, however, is that *knowing* may provide a kind of psychological security that any person, with or without a chronic condition, could want.

Summary of Qualitative Analysis

As described by the Human Ecological Model (Bronfenbrenner, 2001) it is apparent that each system impacts individuals, as does their interactions, or their lack of it, as seen in the meso- and exosystems. Participants identified positive and negative aspects of their health care ecologies, though the negative aspects hold the weight. From the perspective of the Theory of

Planned Behavior health insurance and the ability to pay for health care were the dominant factors. “Insurance, I think, is a key part to a better health anyway. And cash, it help (sic) attain insurance.” The Perceived Unfairness Model added depth and humanity to the data that was described through the other two theories. Future research using these theories, as well as policy and program implications of this research follow in the next chapter.

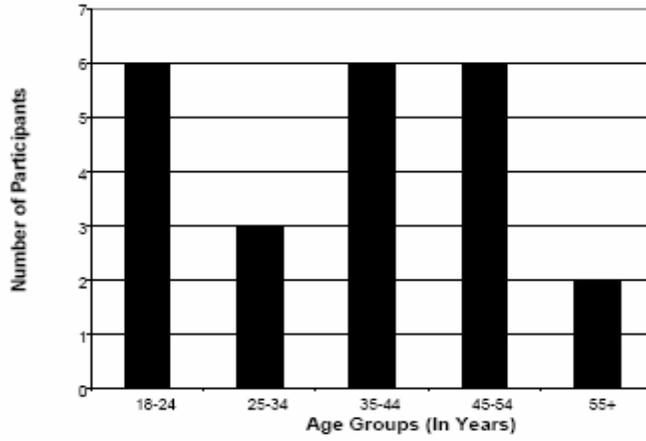


Figure 4-1. Distribution of participants by age group

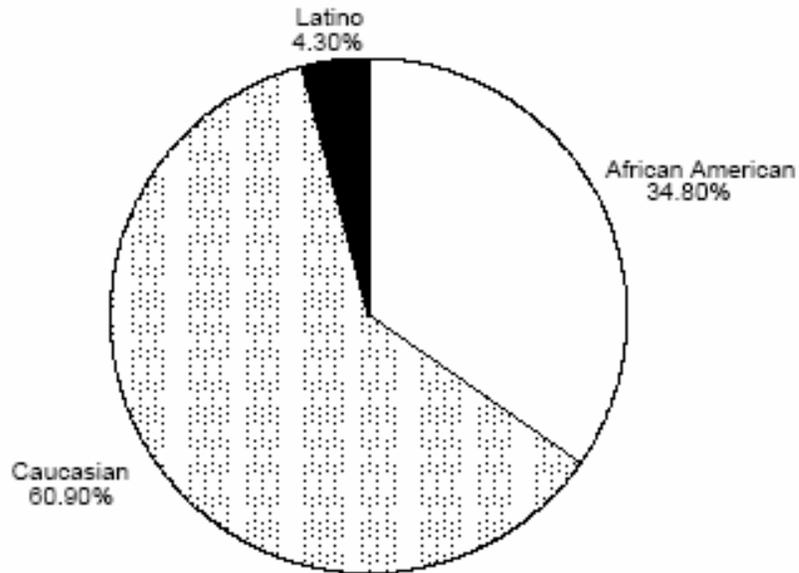


Figure 4-2. Distribution of participants by race and ethnicity

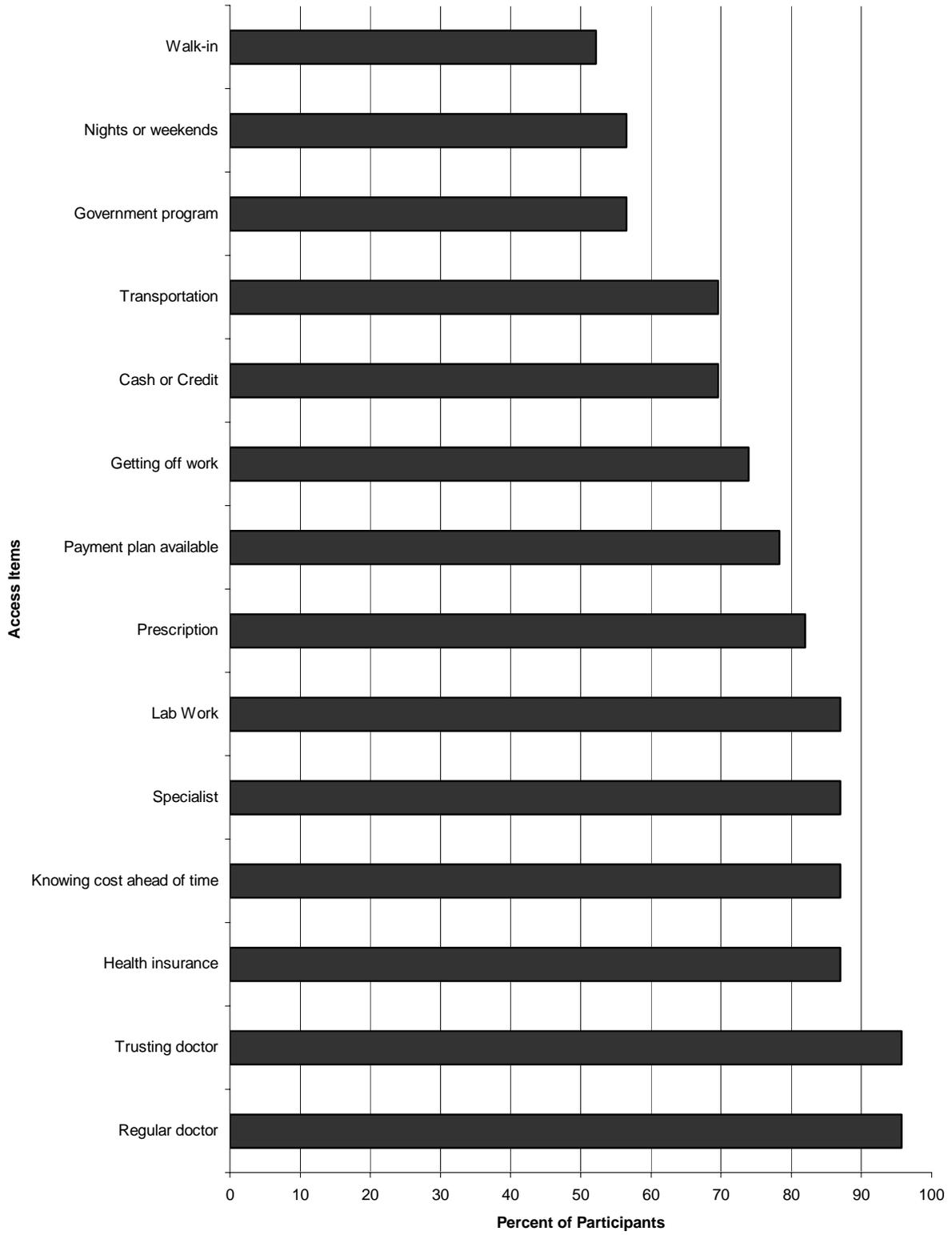


Figure 4-3. Distribution of access chart factors that were marked as important

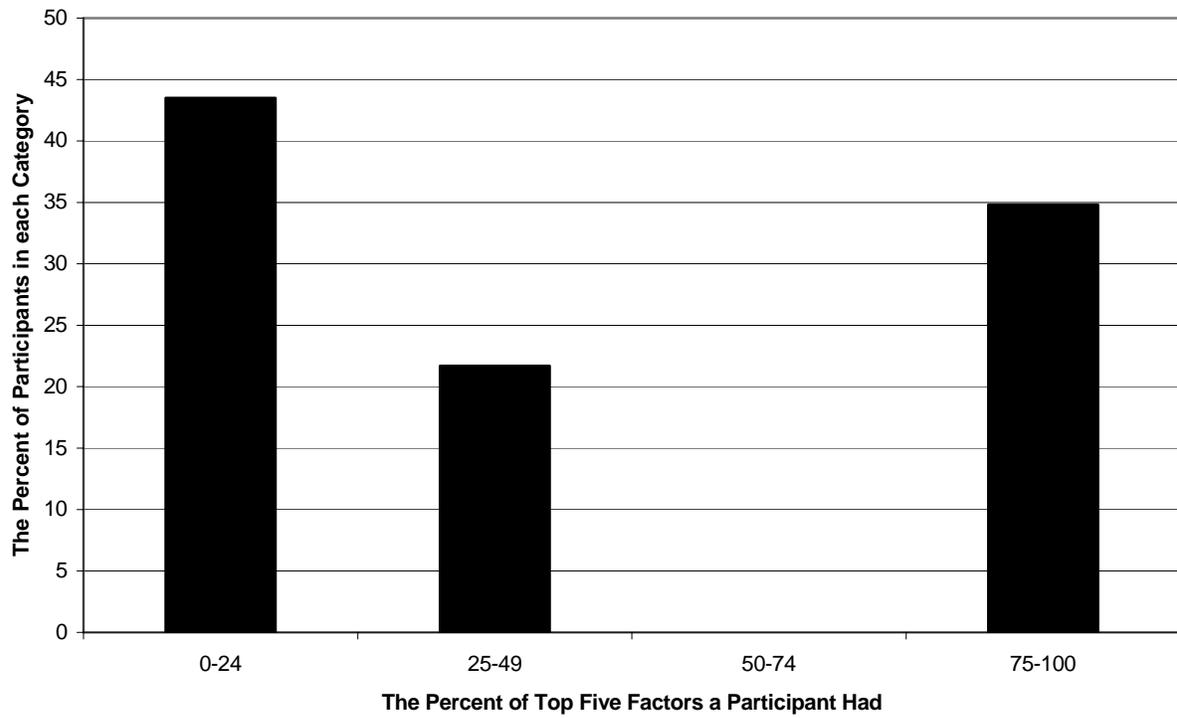


Figure 4-4. Distribution of participants in each quartile of the top five factors they indicated they had which facilitate their access health care

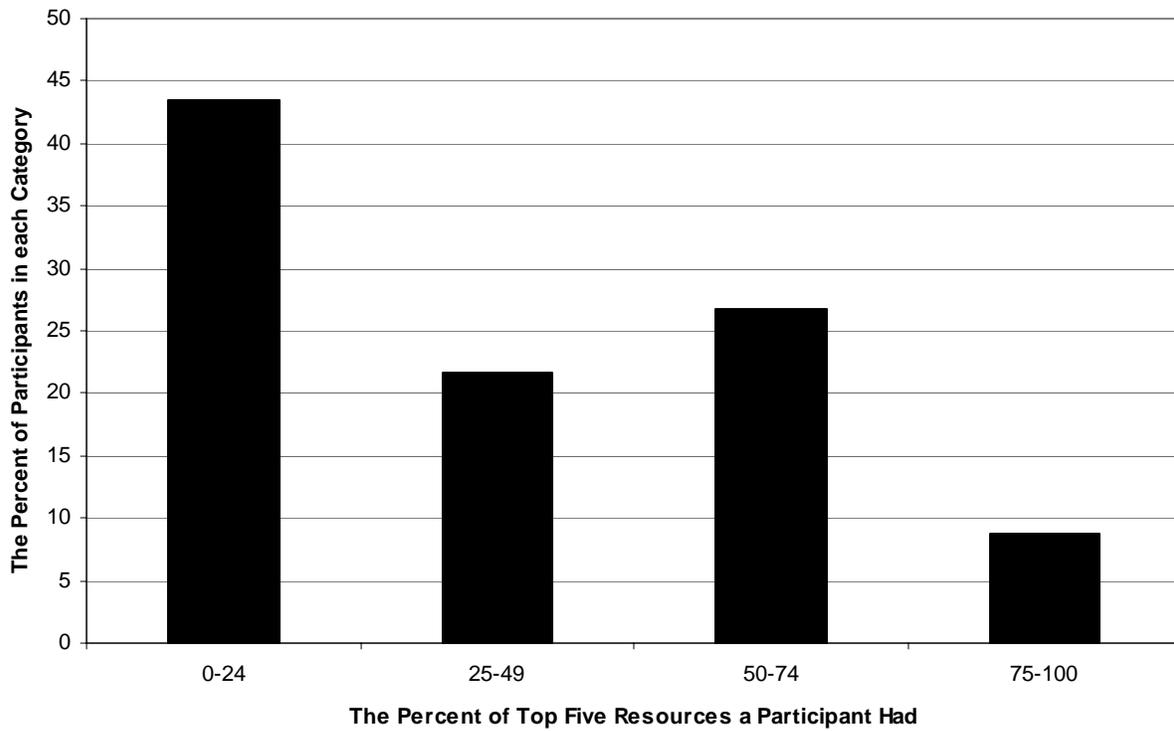


Figure 4-5. Distribution of participants in each quartile of the top five access factors they indicated they had if health insurance is taken away

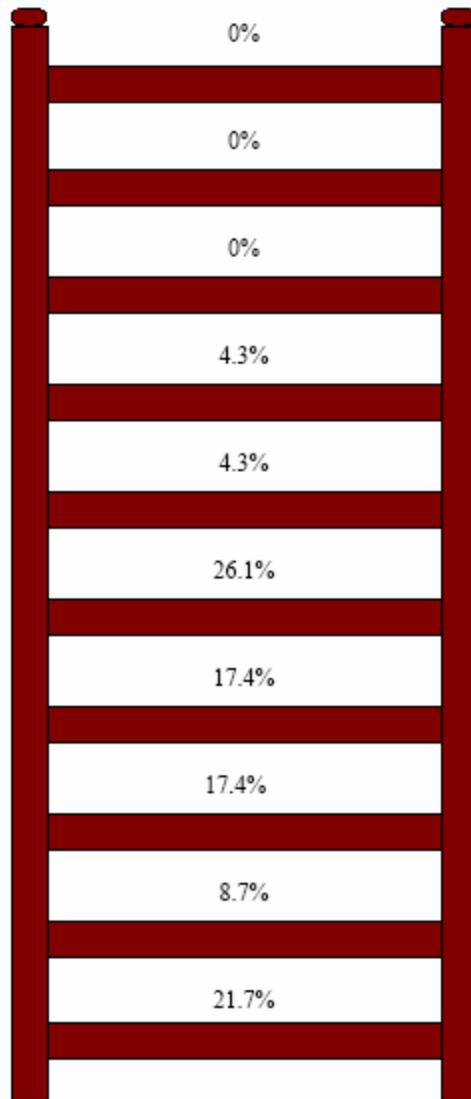


Figure 4-6: Distribution of participants' perceived relative access to health care relative to others in Alachua County

CHAPTER 5 FUTURE RESEARCH AND POLICY IMPLICATIONS

The first part of this chapter will review some of the key findings of this research. This will be followed by a more in depth discussion of the qualitative data in the context of the theories. The chapter will conclude with implications and recommendations for future research, the CHOICES program, and health care policy.

Review of the Results

As was seen in the quantitative data, responses did not significantly differ between sexes, races, or age groups. The qualitative data did not reveal substantial differences in these regards either. Some participants did perceive sexes and races being treated differently and these perceptions should not be taken lightly, especially since they can be accompanied to feelings of “being left out for dead.” The access chart revealed that a majority (95.7%) of the participants thought that having a regular doctor and trusting the doctor were important to being seen. Participants were then asked to rank the factors they felt were important; A majority of participants agreed on only two factors, having a regular doctor (60.7%) and health insurance (65.1%). This brings us to the salience of all of the factors surrounding not having health insurance and/or the ability to pay for health care, from exams and prescriptions to emergencies and surgeries. While it cannot be assumed that either or both of these were the predominant factors influencing the participants’ perceptions of their relative access to health care, which step they placed themselves on the ladder, the data is corroborative. Furthermore, the relative access instrument was administered following the series of questions of whether or not they had the resources indicated on the chart. A significant association between having cash or credit to pay for services and the ladder was found.

Research Question 1

RQ1. How do people with low incomes associate feelings of control over their health with having access to health care services?

Neither the quantitative nor qualitative data found that people associate control over their health with having access to health care services.

RQ1a. Is perceived access to health care services associated with any form of discrimination?

Although statistical significance between perceived access to health care and perceptions of discrimination were not found, the qualitative data revealed otherwise. The perceived differences between having health insurance and not having it, and having the ability to pay for care, and not having that ability were prominent. Additionally, participants spoke of differences between sexes and races. While these discriminations were not supported by a majority, they are nevertheless present and substantively significant.

RQ1b. Is perceived relative access to health care services associated with feelings of control over health?

Neither the quantitative nor qualitative data found that people associate control over their health with their perceived relative access to health care services.

Research Question 2

Research question two was only answered quantitatively in this research and a brief summary of these results follows.

RQ2a. Are feelings of control associated with selected questions from the CHOICES' questionnaire?

Statistical significance was found between the amount of control a person felt over their health and the number of emergency room visits in the past two years. More participants that had not been to the emergency room in the past two years felt they either had a lot of control over their health (88.9%) than those who had been to the emergency room at least once (50.0%).

RQ2b. Is perceived access associated with selected questions from the CHOICES' questionnaire?

Statistical analysis did not reveal any significance between perceived access to health care and any of the selected questions from the CHOICES' questionnaire.

RQ2c. Is discrimination associated with selected questions from the CHOICES' questionnaire?

Of the selected questions from the CHOICES' questionnaire, only one was statistically associated with one type of discrimination, health status and sex. Statistical significance was found for African Americans and Caucasians and for women as well as men. The participants that did not perceive differences between the sexes reported very good or good health status, while those that perceived sexual discrimination ranged over good, fair, and poor health status.

RQ2d. Is perceived relative access associated with selected questions from the CHOICES' questionnaire?

Statistical significance was not found among any of the questions addressing perceived relative access and any of the selected questions from the CHOICES' questionnaire.

Data in the Context of Theories

The Human Ecological Model

The Human Ecological Model was an invaluable resource because it allowed the participants' responses to be viewed from the different levels of the environment. Of particular interest in this study was the relationship of the participants with the health care system. The microsystems that the participants described with individual units of the medical system were both positive and negative. The participants had good experiences with doctors and other medical staff, but also poor experiences. Interestingly, these experiences were characterized by how doctors and staff behaved on the issues of the participant not having health insurance, not having the ability to pay for all of the services immediately, or needing to not have

“unnecessary” services to reduce the overall cost. Participants generally did not mention other aspects of health care. The exceptions were of a couple of participants mentioning a specific doctor, they felt comfortable talking with about their health concerns (one woman’s experience was a doctor she had about twenty years ago), one participant mentioning that they called all of the CHOICES’ providers and none of them could see him for at least a month (although he had a case of shingles), and a few participants mentioning the length of waiting time in the emergency room. This can be summarized by stating that the participants lack stable and predictable microsystems in the health care system. As Bronfenbrenner (1992) postulates, “The degree of stability, consistency, and predictability over time in any element of any level of the systems... is critical for the effective operation of the system in question. Extremes either of disorganization or rigidity in structure of function represent danger signs for potential psychological growth...” (p. 163). Unfortunately, many of the participants have a history of the health care system costing them resources, both internally and externally. This kind of consistency is not congruent with an “optimal condition for human development” (p. 163).

It is possible that the participants share a macrosystem, in the sense of a subculture (Bronfenbrenner, 1979), which places greater emphasis on accessible health care for all than the macrosystem of the larger American culture. This hypothesis springs from the despair and disgust when describing the current meso- and exosystems of health care, and the earnestness with which they wish for a defragmented infrastructure and more inclusive health care policies. The participants may be part of a large culture that share such values, but in a society where other values, such as individualism and profit-making, have shaped the structure the meso- and exosystems of health care.

This lack of connection with significant others and cognitive dissonance could contribute to the feelings of unfairness, which will be discussed in more depth below. Furthermore, the negative experiences and perceptions seem to impact the participants' health care seeking behavior, specifically by avoiding the system. Such behavior could then impact the system by having entire groups of people that postpone or neglect addressing their health concerns and do not trust that they will receive "thorough" care once a medical professional sees them. The consequences of such behavior increase the risks of poor health outcomes and stress not only on the individual, but also for the system that attempts to only help those once they are drowning downstream¹ (Egan & Cowan, 1979) or have proven themselves to be deficient enough to warrant assistance² (Bronfenbrenner, 1988b).

The Theory of Planned Behavior

Although the constructs representing those from the Theory of Planned Behavior, control over health and perceived access to health care, did not have a relationship that could be encapsulated by perceived behavioral control, the theory still lent itself to analysis of the data. Participants did not express broad discomfort with their ability to access health care, for example, making appointments, being able to secure transportation, or having a lack of knowledge about the services that are available. However, some participants expressed that they were not sure how to find a doctor, even with the list of CHOICES' providers that they must choose from, they felt that they did not have enough information about the doctors to make a decision. Such thoughts could be categorized as a person's internal prohibiting power beliefs. Prominent power beliefs seen in the data were external barriers. The degree to which these

¹ From a fable that tells of a person who went upstream to find out who was pushing all of the drowning people in the water in order to stop it so that they would not be continuously just pulling people out of the water.

² Bronfenbrenner's Deficit Model describes America's social policy.

barriers, lack of health insurance and the ability to pay for services, cannot be quantified with the current data. The qualitative data reveal that these barriers are certainly in place (control belief) and that they strongly influence their ability to access health care (power beliefs). The qualitative data additionally communicated that such thoughts affect intention to access health care, and with less surety, the actual behavior of accessing health care when the participant perceives it is needed, and the motivation to act on advice from others if it involves seeking care.

Using the lens of the Theory of Planned Behavior, judgements can be made that are similar to those made using the Human Ecological Model. The consequences for having rigid, external barriers to health care may be far-reaching. The continued use of the Theory of Planned Behavior with the Human Ecological Model could be very useful as it may be able to account for factors at each ecological level that contribute to a specific behavior. The rewards for learning of such factors are then solid foundations with which to develop health care policy that increases people's perceived behavioral control and intention to perform health-improving behaviors.

The Perceived Unfairness Model

It was stated earlier, but the fact that this model provides a theoretical framework for conceptualizing peoples' emotions and thoughts, which can be used in turn to generate systems that help those same people, cannot be understated. This model provides a way to capture both the profound feelings of despair at not being treated like a human and the resilience to keep trying. It could be used in conjunction with the Human Ecological Model. When participants were asked about sex and racial discrimination many participants reported that it just depends who is on the other side of the counter. This finding may be important in two ways: First, it could signal that there is a decrease of such discrimination, and second, this possible constant alert could contribute to an increase in allostatic load, which is a construct in the Perceived Unfairness Model that could have implications for poorer health outcomes.

Future Research

There are many routes for future research, especially since this was an exploratory investigation. Some methodological considerations will be addressed first, followed by theoretically based avenues.

Methodological Considerations

Building on the same theoretical basis that was used in the present study, there are many options for future research. These include having a larger sample and utilizing a longitudinal design. It includes having a control group, which may vary depending the angle of the research. Potential control groups include people that have been enrolled in CHOICES for a given amount of time, people that have been denied from CHOICES, people that have not applied for CHOICES – with possible sub-groups for those who are aware the program exists and those that do not, people that are privately insured and have been for a given amount of time, people that are enrolled in other government programs, such as Medicaid, people that cycle between being insured and not being insured, whether it is privately or through the government, and finally, people that have never been insured.

Human Ecological Model

It is important to keep in mind that the perspective represented here is the individual. As stated before, the individual is affected by each system and the interactions of the systems. What is not represented in the data is a significant component of the Human Ecological Theory: the effects individuals have on each system and their interactions (Bronfenbrenner, 1979). To capture this information, questions would need to be directed toward members of the participants' meso- and exosystems, such as doctors, social workers, and county lawmakers to see the impact individual citizens and populations of people that are uninsured and/or have low income. Another level of the theory that was not included in this research was the chronosystem.

The chronosystem captures the aspect of time, implied and necessary when discussing human development (Bronfenbrenner, 1988a). Future research should be conducted at the individual level to construct a more complete picture of the perceived environments of others in similar circumstances.

The Theory of Planned Behavior

As stated previously, research on health care that utilizes the Theory of Planned Behavior should incorporate the Human Ecological Model. More specific areas of future research include exploring internal barriers and facilitators of the intention to access health care and the behavior of accessing care. Additionally, research should be done to explore the factors contributing to a person's sense of control in the health care system. Finally, the other constructs of the Theory should be explored as they pertain to the effects they could have on a person's perceived behavioral control, intention, and behavior in accessing health care.

The Perceived Unfairness Model

There are many constructs in the Perceived Unfairness Model that were beyond the scope of the present research which need to be explored, such as stress responses, allostatic load, morbidity, and mortality, particularly their potential relationships with the constructs used in the present research. Not only will such research explain more about how the environment affects physical health, it could shed light on how it affects mental health, and have implications for designing programs and policies that develop peoples' coping behaviors and a sense of empowerment.

Future research using this model should consider using it in conjunction with the Human Ecological Model since some of the basic precepts of the Human Ecological Theory fit well with it. The Human Ecological Model is a theory, "...in which the perceived is viewed as more important than the actual, the unreal as more valid than the real, where the motivation that steers

the person's behavior inheres in external objects, activities, persons, and groups, and...where the content of all these complicated structures remains unspecified" (Bronfenbrenner, 1977, p. 43).

Other Areas of Future Research

Research examining various aspects of control could explore numerous directions. This research may include identifying locus of control over one's health, the amount of control one feels in a health care setting, and how much control a person feels in their community. In turn, research could focus on how each of these might influence help-seeking behavior within health care and broader social services, and how each of these might interact and influence physical and mental health.

In the present research, participants were asked to indicate where they stood in the community in terms of access to health care using a ten-rung ladder. Statistical analysis indicated that where they placed themselves on the ladder was not associated with whether or not they had a regular doctor or health insurance, but it was associated with having the ability to pay cash or credit for services. The lack of significance with health insurance and a regular doctor could be a result of the small sample size, but this is an area for future research. One might delve more deeply into what factors contribute to where a person places themselves, and how these might be related to factors that affect physical and mental health. For example, if research finds that the ability to pay for health care services directly and significantly affects where a person places themselves in their community with respect to access to health care, what implications might this have in terms of a person's perceptions of attachment to and acceptance within the community, and what implication might this have for public policy – how can the health of a nation be drastically improved when the gaps in incomes continue to widen?

Implications and Recommendations for Alachua County's CHOICES Health Services

Though this investigation did not examine the CHOICES program directly, there are a number of recommendations that could be made from the results. A few are mentioned here. First, implement multi-layered, ecologically based evaluations of the program that include the perspectives of all of those involved in the program, particularly the enrollees. The evaluation plan should include pre- and post-test measures, where possible, to account for what changes and what does not, for example, given enrollment in the program or use of specific services. One may start thinking about an internal evaluation of factors affecting enrollment by examining the model presented at the end of this chapter (Figure 5-1 on p. 98). Similar models could be developed to inform other evaluations and potential consequences of program decisions.

Although research is just beginning to explore the relationships between social status and health, between emotions and health, and the pathways by which these relationships exist, it is important that policies within the program are aware that these relationships exist. This could generate policies within the program that are empowerment based and flexible; that recognize the enrollees as knowledgeable about their health and circumstances, and can work with the enrollees to identify health concerns and solutions. This approach is in opposition to the goals of simply educating ignorant enrollees about their health and how their behaviors influence it.

Given the results of this study, the program should expand its services and providers. The participants felt that they do not actually have many choices and this was associated with feelings of discomfort. Along these lines, outreach needs to be expanded. The participants were not clear what CHOICES was, even after hearing advertisements on the radio and television. It was suggested that reasons should be given as to why people should apply and not simply rely on the emergency room. One participant succinctly stated that the reasons for applying need to make sense to those at the bottom (referring to the ladder). Talk about helping the community

and government do not mean anything because the people at the bottom are surviving from day to day. Supplementing with other responses, it could be that the people on the bottom are disenchanted and do not feel sympathy or want to participate in what CHOICES refers to as the community since they feel excluded from it.

Implications and Recommendations for Health Care Policy

The Human Ecological Model explains how other exosystems and other ecological layers affect this part of the exosystem, and in turn, it exerts itself on them. However, in the end, health care is focused on taking care of individuals. By looking at the health and functioning of individuals in their microsystems, one can see the success of health care policy.

As was recommended for CHOICES, health care policy could foster empowerment-based approaches for medical professionals to work with patients. People should be included in more of the decision-making processes of health care. As one of the participants stated, “We make the decisions that are best for us.” These are not ignorant people simply neglecting their health or arbitrarily avoiding medical care.

Although the few participants that used the terms “national” or “universal” health care were aware of the unpopularity of such terms and used them with hesitation, the basic ideas were the same: health care should be affordable for everyone and the health care infrastructure should be less fragmented; the ‘running’ around associated with seeking help for medical care or medical bills, and the numerous rejections should be curtailed, for example, by having one application that for both adults and children, so the family would be covered. Such policy changes are not impossible to implement, though they may require shifts in existing power structures and changes in the profitability of certain economic markets. As seen from the data, it is possible that the current health care system discourages people who do not have the ability to pay for care from seeking it. Taking this one step further, this behavior could be reinforced by

avoiding the stress associated with incurring medical bills that they will never be able to pay off. Forestalling such changes may become more costly to the economy and hazardous to the health of people, particularly those that perceive the injustice of the system.

Conclusion

In conclusion, there needs to be more research examining the factors that affect health care-seeking behavior, more research examining the relationships among the environment, perceptions, and health outcomes. There also needs to be evaluations of health care programs and policies that are informed by talking with people and using their knowledge and perceptions, and in turn using these to further research, policy making, and program planning as well. All of the factors are interwoven; all of them can learn from and build onto the others.

Drastic changes in our health care system call for changes in our macrosystem. As a society, it must be recognized that it not only takes a village to raise child, but it takes a village to foster development at every age in the lifespan. It must be recognized that things occurring in the various ecological levels, and their interactions, have consequences for individuals and families. It is too idealistic to conceive of a world where no one is discriminated against. It is not unrealistic to conceive of a world where people have voices in their families and communities. Voices from which they can build resilience and strong identities to buffer or counteract the negative consequences that could include persistent stress and feelings of helplessness and isolation, which could translate to poor physical and mental health. “When we understand, we can act. If we know how to make human beings human, we are obligated to do our best to do so” (Hamilton & Ceci, 2005, p. 284).

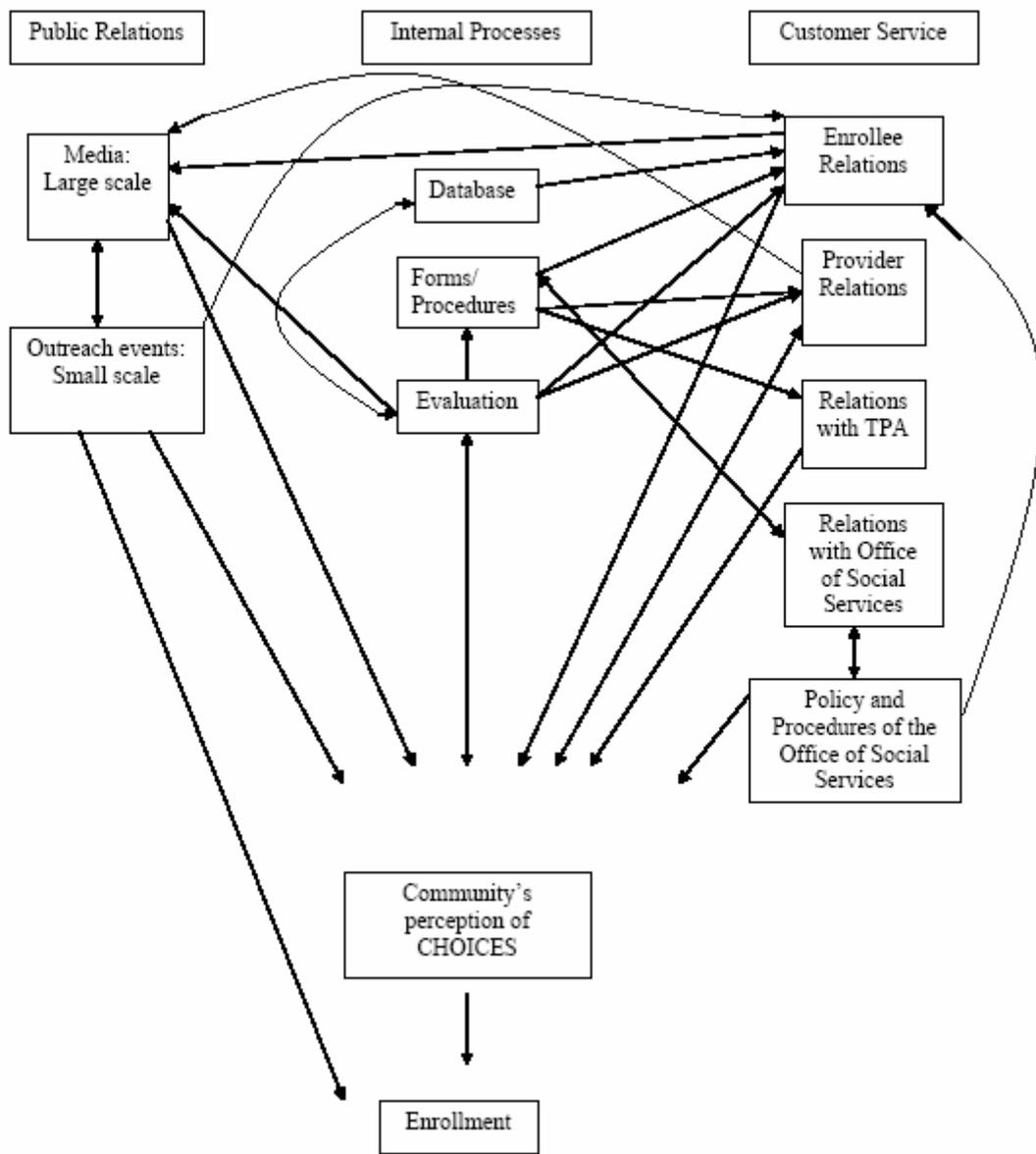


Figure 5-1. Ecological view of factors affecting CHOICES' enrollment

APPENDIX A
CONSTRUCT/THEORY/PURPOSE CHART

Table A-1. Construct/theory/purpose chart

Concept	Question	Literature/Theory	Construct	Purpose/Analyze
Access	1–5	1) Aday: potential and realized 2) Health theories: is perceived access generally assumed?	(N/A)	1) Purpose of research: Look at perceived access among workers with low-income 2) Get participants' definitions of access 3) Get participants' access by own definition (2 mo ago and current)
Relative access	6	1) Relative status 2) Relative income 3) Discrimination 4) Effects on physical and mental health	(N/A)	Purpose of research: Does relative access affect perception of control over health?
Perceived access to community resources	7–10	Building on perceived access and relative access concepts	(N/A)	Should correspond with Questions 1–6
Control beliefs	11, 13, 15, 17	Theory of Planned Behavior – Azjen et al.	Perceived behavioral control	Identify perceptions of discrimination – factors that impede behavior

Table A-1. Continued

Concept	Question	Literature/Theory	Construct	Purpose/Analyze
Power beliefs	12, 14, 16, 18, 22	Theory of Planned Behavior – Azjen et al.	Perceived behavioral control	Identify impact of perceived discrimination
Perceived behavioral control	19	Theory of Planned Behavior – Azjen et al.	Perceived behavioral control	Should correspond with Questions 11–22 if discrimination has impact If people who have more resources have more control resources are a significant factor; May provide evidence that other forms of discrimination are not prominent at this time, although it does not mean they do not play an important role
Relative access and control	20	(N/A)	(N/A)	
Health and emotions	21–28	Building on ideas of emotions affecting health	(N/A)	(N/A)
Possible Alternate explanation	29	(N/A)	(N/A)	To be used in data analysis – Is it appropriate to think that because someone enrolls in a health care program they intend to perform additional health-promoting behaviors?

Table A-1. Continued

Concept	Question	Literature/Theory	Construct	Purpose/Analyze
Miscellaneous	Questions 30–32	Question 30 – Statement to lawmakers – Empowerment Question 31 – Any additional information offered by participant Question 32 – Questions for me	(N/A)	(N/A)
CHOICES Enrollee Health Questionnaire	Fourteen Multiple choice/ short-answer questions	(N/A)	<ol style="list-style-type: none"> 1) Perceptions of their health 2) Diagnoses of the following conditions: asthma, diabetes, high blood pressure, congestive heart failure and depression 3) Global satisfaction with their life 4) Frequency of utilization of emergency rooms in the last two years 5) Utilization of hospital inpatient services in the last two years with name of local hospital(s) 6) Frequency of primary health care visits 7) Length of time since respondents' last physical and dental exams 8) Primary barrier to utilizing health care services 9) Prior to enrolling in CHOICES, whether of not respondents had a usual source of health care 	<p>Could be used in data analysis – Are:</p> <ol style="list-style-type: none"> 1) feelings of control over health 2) health emotions 3) perceptions of access 4) perceived behavioral control 5) perceived discrimination related to perceptions of health, diagnoses, global life satisfaction, utilization of health care services, length of time since last physical and dental exams, and/or whether or not they had a usual place of health care? 6) Are the participants' responses in agreement with other research on people with low income?

APPENDIX B
CONCEPT PATTERN

104

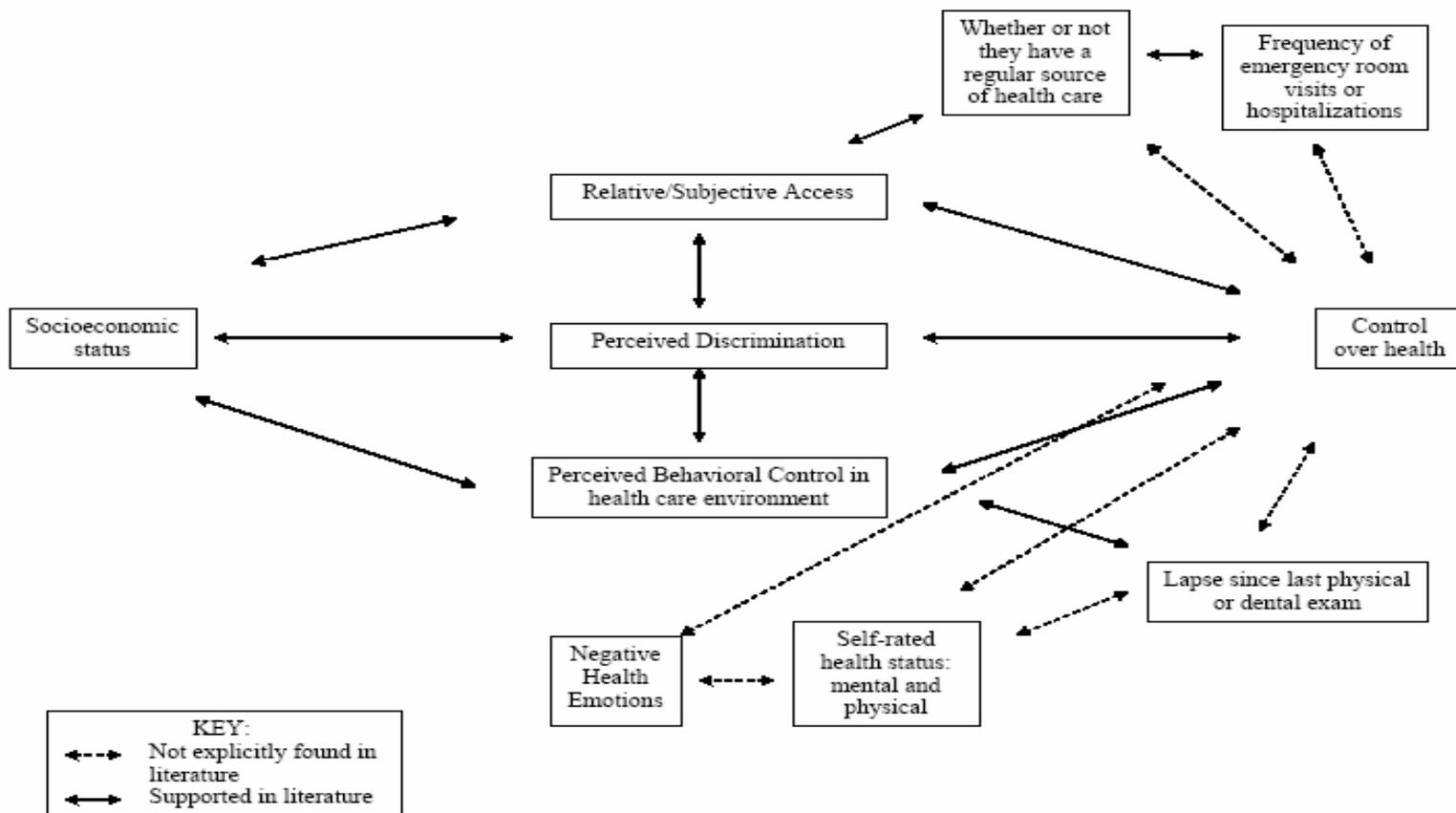


Figure B-1. Pattern of potential relationships among concepts

APPENDIX C
INTERVIEW SCHEDULE AND KEY

1. Introduce myself
2. Review IRB-Approved Authorized Consent Form
3. Ask if they have any questions before we begin
4. Turn on tape recorder

I've asked you to participate in this research because you are a CHOICES participant. We are conducting this research because it is important to learn what people think and how they feel about issues related to their health and health care. That's why we are interested in what you think about health care. Remember there aren't any right or wrong answers; it's all your thoughts and ideas.

Administer access chart (Appendix D)

This is a list of things that other people have said are needed to see a doctor or other health care provider.

- 1a. What else you can think of that is important to getting to see a health care provider?
- 1b. Could you mark all of the things that you think are needed?
- 1c. Of the things you marked, could you rank the top 5 things, with 1 being the most important, 2 being the next, and so on? (Appendix D)

2. (ATTACH ADDITIONAL CARD TO CHART) (Appendix D) Keeping all of these things marked in mind, even the ones not ranked, if you think back two months ago, which of these did you have and which ones didn't you have?

What about now?

Administer Percieved Relative Health Care Access Scale (Appendix E)

For the next couple of questions you can just answer yes or no.

	YES	NO
Do you feel like you could get the care you needed if you were slightly sick, like if you had a cold or the flu?	<input type="checkbox"/>	<input type="checkbox"/>
What if you needed if you had a medical emergency?	<input type="checkbox"/>	<input type="checkbox"/>
Do you feel like you could get the care you needed if you were depressed?	<input type="checkbox"/>	<input type="checkbox"/>
8. What if you had a problem with drugs or alcohol?	<input type="checkbox"/>	<input type="checkbox"/>

Now I'm going to describe a scenario and you can ask me whatever you

need to to answer the questions that follow.

Marie and John have been having trouble breathing lately. Both of them think it's time to see a doctor about it.

Do you think that one of them will have an easier time getting in to be seen here in Alachua County?

(The questions asked could show where the participant places importance in access; may correspond to access chart already completed. Not every question will necessarily be asked and the order of questions cannot be determined either. Questions will be asked based on the participant's own follow-up questions and subsequent responses until information is gathered on each topic.)

In a conversation-like way, will also ask about the following:

9a. Do you think there's a difference because Marie is a woman and John's a man? **[If no, skip to 9d.]**

9b. If there is a difference based on sex, how do you think that makes Marie/John feel? (Will insert whomever fares worse)

9c. What would you have to say to Marie/John; would you have any advice for her/him? (Will insert whomever fares worse)

10a. What if you learned that Marie has health insurance and John doesn't? Do you think that would affect who gets to see a doctor first?

10b. **[Read if not previously discussed feelings]** If there is a difference based on health insurance, how do you think that makes Marie/John feel? (Will insert whomever fares worse)

[Read if they have talked about feelings] Would Marie/John would feel differently than what you have already described?

10c. **[Read if not previously given advice]** What would you have to say to Marie/John; would you have any advice for her/him? (Will insert whomever fares worse)

[Read if already given advice] Would you say something different to Marie/John than what you said before?

11a. **[Read only if both sex and health insurance status are factors]** Do you think (insert whomever fared worse on sex) being a woman/being a man matters more, less or about the same as (insert whomever fared worse on health insurance status)?

12a. So, now we now that Marie has health insurance and John doesn't. What if we also found out that Marie is an African American and John is white? Do you think their different races/ethnicities would affect who gets to see a doctor first here in Alachua County?

12b. Do you think it would be different for any other races or ethnicities?

12c. **[Read if not previously discussed feelings]** If there is a difference based on race/ethnicity, how do you think that makes Marie/John/People who are of participant-identified race(s)/ethnicity(ies) feel? (Will insert whomever fares worse)

[Read if they have talked about feelings] Would Marie/John would feel differently than what you have already described?

12d. **[Read if not previously given advice]** What would you have to say to Marie/John/People who are of participant-identified race(s)/ethnicity(ies); would you have any advice for her/him? (Will insert whomever fares worse)

[Read if already given advice] Would you say something different to Marie/John than what you said before?

11b. **[Read only if both sex and race/ethnicity are factors]** Do you think (insert whomever fared worse on sex) being a woman/being a man matters more, less or about the same as (insert whomever fared worse on race/ethnicity)?

11c. **[Read only if health insurance status and race/ethnicity are factors]** Do you think (insert whomever fared worse on health insurance status) being a woman/being a man matters more, less or about the same as (insert whomever fared worse on race/ethnicity)?

13a. So now we know that Marie has health insurance and is an African American, but we also learn that her job doesn't pay enough for her to be able to make the co-payments that are required by her insurance, so she would need to find a doctor that would let her make payments for her visit. On the other hand, John, who is white, makes enough money to pay cash for his visit, even though he doesn't have insurance. Do you think their ability to pay will make it easier for one of them to see a doctor?

13b. **[Read if not previously discussed feelings]** If there is a difference based on ability to pay, how do you think that makes Marie/John? (Will insert whomever fares worse)

[Read if they have talked about feelings] Would Marie/John would feel differently than what you have already described?

13c. **[Read if not previously given advice]** What would you have to say to Marie/John would you have any advice for her/him? (Will insert whomever fares worse)

[Read if already given advice] Would you say something different to Marie/John than what you said before?

Ask the following as needed to determine ranking of factors:

11d. **[Read only if both sex and income are factors]** Do you think (insert whomever fared worse on sex) being a woman/being a man matters more, less or about the same as (insert whomever fared worse on income)?

11e. **[Read only if health insurance status and income are factors]** Do you think (insert whomever fared worse on health insurance status) being a woman/being a man matters more, less or about the same as (insert whomever fared worse on income)?

11f. **[Read only if race/ethnicity and income are factors]** Do you think (insert whomever fared worse on race/ethnicity) being a woman/being a man matters more, less or about the same as (insert whomever fared worse on income)?

14. Please answer yes or no for whether or not you agree with the following statements: **[Stop once their level of control is stated]**

	YES	NO
I can't do anything to change my health.	<input type="checkbox"/>	<input type="checkbox"/>
My health is out of my hands.	<input type="checkbox"/>	<input type="checkbox"/>
I have some control over my health, but not a lot of control.	<input type="checkbox"/>	<input type="checkbox"/>
I have a lot of control over my health, but not complete control.	<input type="checkbox"/>	<input type="checkbox"/>
I have complete control over my health.	<input type="checkbox"/>	<input type="checkbox"/>

15. Looking again at this ladder and imagining absolutely everyone who lives in Alachua County, do you think the people standing on the top step of the ladder would answer the following statements with 'yes' or 'no'? BRING OUT CUE CARD WITH THE FOLLOWING AND READ THEM OFF (End of Appendix): **[Stop once level of control is stated]**

- | | | |
|---|--------------------------|--------------------------|
| a. That they can't do anything to change their health. | <input type="checkbox"/> | <input type="checkbox"/> |
| b. That their health is out of their hands. | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Would they say they have some control over their health, but not a lot of control. | <input type="checkbox"/> | <input type="checkbox"/> |
| d. That they have a lot of control over their health, but not complete control. | <input type="checkbox"/> | <input type="checkbox"/> |
| e. Or that they have complete control over their health. | <input type="checkbox"/> | <input type="checkbox"/> |

16. Repeat Question 15 for people standing on the top step of the ladder until level of control is stated.

Now a couple unrelated questions –

17. What do you want to get out of being in CHOICES? [**OPEN RESPONSE, BUT I WANT TO BE CLEAR ABOUT THEIR EXPECTATIONS, SO A FOLLOW-UP IS LIKELY.**]

18. If you could tell lawmakers one thing about the health care system in Alachua County what would it be?

The last group of questions is about your health and visits to a health care provider.

(Administer CHOICES Enrollee Questionnaire)

19. Is there anything else you would like to add before we finish?

20. Do you have any questions for me?

Thank you very much for talking with me. I really appreciate it. Have a good day.

Cue Card for Questions 15 and 16

- a. That they can't do anything to change their health.
- b. That their health is out of their hands.
- c. They have some control over their health, but not a lot of control.
- d. That they have a lot of control over their health, but not complete control.
- e. Or that they have complete control over their health.

INTERVIEW SCHEDULE KEY

Question 1: Definition of health care access

Question 2: Level of health care access two months ago

Question 3: Current level of health care access

Question 4: Relative Health Care Access Scale

Questions 5–8: Perception of access to community health care resources

Question 9–13: Control and Power Beliefs scenario/discussion

Question 14: Assessing perceived control over health

Question 15: Perception of control people on the top step of the ladder feel over own health

Question 16: Perception of control people on the bottom step of the ladder feel over own health

Question 17: Expectations about participation in CHOICES

Question 18: Statement to lawmakers

(Administer CHOICES Enrollee Health Questionnaire)

Question 19: Additional information offered by participant

Question 20: Answer participant's questions, if any

APPENDIX D
ACCESS CHART

Please mark each thing you think is important in being able to see a doctor or other health care provider.

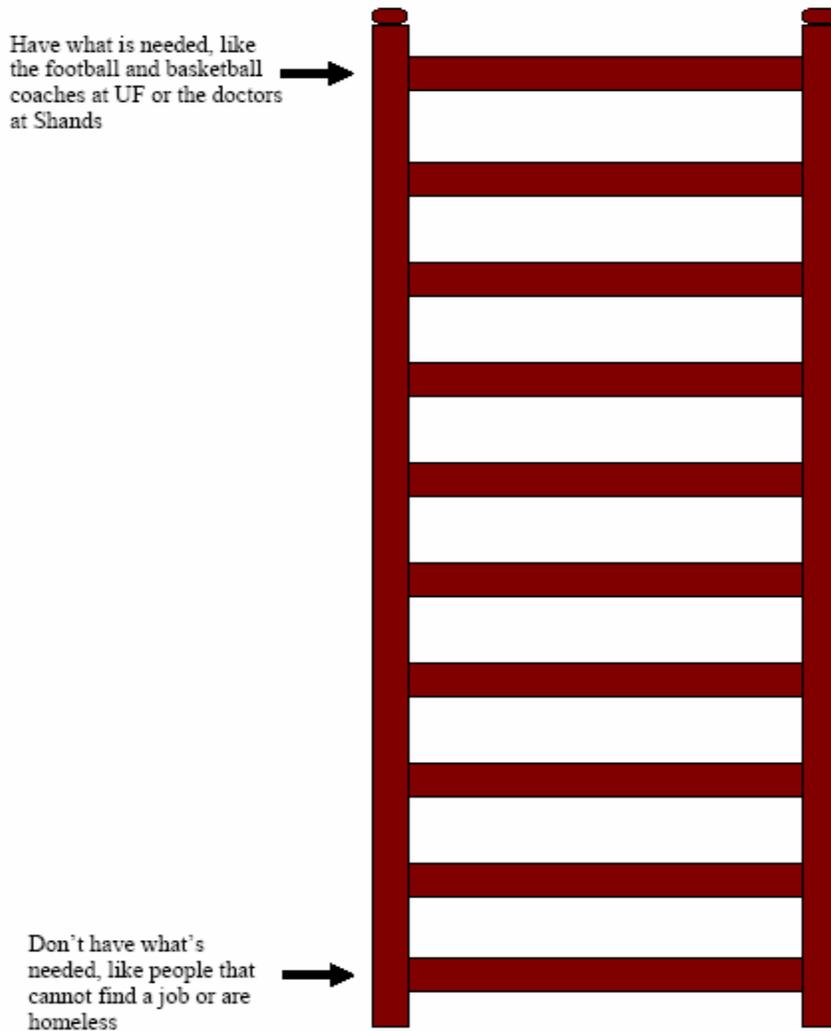
Having cash or a credit card to pay for services	
Having health insurance	
Being in a government program like Medicaid	
Having a car or other transportation	
Having doctor that will set up a payment plan	
Getting time off work	
Knowing about how much it will cost before you see the doctor	
Getting a babysitter	
A doctor's office being open at night or on the weekend	
Being able to walk in and be seen without an appointment	
Having a regular doctor	
Trusting the doctor you're thinking of seeing	
Knowing someone that goes to the doctor you're thinking of seeing	
Knowing ahead of time that you will be able to get a prescription if the doctor wants you to get one	
Knowing ahead of time that you will be able to go to a specialist if you are referred	
Knowing ahead of time that you will be able to get lab work, like blood work or X-rays if the doctor wants you get them done	
Knowing ahead of time that you will be able to change behaviors, like eating different foods, exercising or smoking, that the doctor recommends	

A

Figure D-1. Factors that contribute to a participant accessing health care, how the participant ranks these factors, and whether they have the factors

APPENDIX E
PERCEIVED RELATIVE HEALTH CARE ACCESS SCALE

Imagine that everyone in Alachua County got to stand on this ladder. On the top step would be all of the people that have what they need to see any health care provider. On the bottom step would be all of the people that don't have they need to see a health care provider. Please mark the step where you would stand.



APPENDIX F
SAMPLE INTRODUCTORY LETTER

May 10, 2007

[Enrollee's First Name] [Enrollee's Last Name]
[Street Address]
[City], [State] [Zip Code]

Dear Ms./Mr. [Enrollee's Last Name]:

My name is Amanda Holzworth. I am a graduate student at the University of Florida and an intern at CHOICES Health Services Program. I am interested in learning about your ideas and experiences with health care in Alachua County.

As part of a research project, I will be doing interviews to find out what people in CHOICES think about health care in Alachua County. Your answers would help build an understanding of what people think about health care and their experiences in Alachua County. Your answers will help look at the impact of CHOICES and also help future program planning.

I know that you are busy, but your participation is important to the success of this study. I would like to meet with you to hear about your experiences with health care. I will be calling you soon to arrange a time that we could meet. To encourage participation, I will be offering all participants \$15. Please keep in mind that although I am working with CHOICES, this money is not from them. Please feel free to contact me with any questions, or for more information, at (352) 271-7305, or via email at anicole8@ufl.edu.

Thank you in advance for your time and support. I look forward to meeting with you and learning about your experiences in this community.

Sincerely,

Amanda N. Holzworth
Graduate Student and
Intern at CHOICES Health Services Program

Carolyn S. Wilken, Ph.D., Research Advisor
Associate Professor, FYCS

Susan Myers, Ed.S.
CHOICES Interim Director

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BIOGRAPHICAL SKETCH

Amanda Holzworth received her bachelor of science in psychology from the University of Florida in 2003. She received her master of science in family, youth, and community sciences from the same institution in 2007. After graduation, she will pursue professional interests that allow for a balance with all other aspects of her life.