8-2008

# Disappointment domains, quality of life, and the impact of mental illness : an evaluation of demographic differences.

Christina Lynn Adkins
*University of Louisville*

## Recommended Citation

DISAPPOINTMENT DOMAINS, QUALITY OF LIFE, AND THE IMPACT OF

MENTAL ILLNESS: AN EVALUATION OF DEMOGRAPHIC DIFFERENCES

By

Christina Lynn Adkins
B.A., University of North Carolina at Chapel Hill, 2000
M.A., University of Louisville, 2005

A Dissertation
Submitted to the Faculty of the
Graduate School of the University of Louisville
in Partial Fulfillment of the Requirements
for the Degree of

Doctor of Philosophy

Department of Psychological and Brain Sciences
University of Louisville
Louisville, KY

August 2008

DISAPPOINTMENT DOMAINS, QUALITY OF LIFE, AND THE IMPACT OF
MENTAL ILLNESS: AN EVALUATION OF DEMOGRAPHIC DIFFERENCES
By

Christina Lynn Adkins
B.A., University of North Carolina at Chapel Hill, 2000
M.A., University of Louisville, 2005

A Dissertation Approved on

April 20, 2007

by the following Dissertation Committee:

_____
Dissertation Chair

_____

_____

_____

_____

# DEDICATION

This dissertation is dedicated to my parents

Mr. Donald V. Adkins

and

Mrs. Jane A. Adkins

who have shown me the true meaning of courage in all of life's endeavors.

# ACKNOWLEDGMENTS

ABSTRACT

DISAPPOINTMENT DOMAINS, QUALITY OF LIFE, AND THE IMPACT OF

MENTAL ILLNESS: AN EVALUATION OF DEMOGRAPHIC DIFFERENCES

Christina L. Adkins

April 20, 2007

The concept of quality of life (QOL) has been the topic of many research projects,

yet several clinically relevant aspects of this concept have been overlooked. Specifically,

few studies have addressed the impact of such demographic variables as race and sex on

the life domains that have been particularly disappointing to patients with mental

illnesses. The current research project aims to contribute to the understanding of the

impact these variables have on quality of life, specifically addressing the following

hypotheses: 1.) Domains of disappointment will vary according to race and sex; 2.) Race

and sex will interact to predict which life domain is most disappointing; and 3.)

Demographic differences will be detected in the level of disappointment with most

disappointing domain.

Patients diagnosed with psychotic and affective disorders (n=125) were

administered an open-ended, semi-structured interview designed to assess

disappointments they have experienced as a result of their mental illness. They were

asked to list the goals they have been prevented from accomplishing, which "loss" was

most disappointing, and to rate that disappointment on a 1-5 Likert scale. Patient responses were coded according to the fourteen life domains listed in the Quality of Life Inventory (QLS-100; Skantze & Malm, 1993). Preliminary chi-square analyses indicated that the domains of Knowledge and Education, Contacts, and Work were most frequently endorsed as disappointing, with no statistically significant differences between sexes and races in the frequency with which these domains were endorsed. Additional analyses again indicated no demographic differences in the report of most disappointing domains. Similarly, no sex or race effects were detected in the level of disappointment.

Post-hoc analyses suggest the importance of other variables in determining which domains are reported as disappointing and the level of disappointment. The current level of patient functioning is associated with the frequency with which the Contacts domain is endorsed as disappointing, with higher functioning patients more frequently reporting this domain as disappointing. A multiple regression analysis to predict the level of disappointment suggests that race and illness duration are the best predictors of disappointment level. Clinical implications of these findings are discussed.

TABLE OF CONTENTS

## LIST OF TABLES

INTRODUCTION

*Quality of Life Background*

Until approximately forty years ago, the focus of psychiatric treatment had been

on disease elimination, as measured by symptom reduction and the ability to prevent

relapse (Katschnig, 2000). The treatment paradigm has since shifted from a symptom-

oriented focus to assessing the impact that the disorder has had on the lives of those

affected by it. The concept of quality of life (QOL) is often used to measure this aspect of

the illness, in terms of the human costs and benefits of treatment on certain life domains

(Gianino, York, Paice, & Shott, 1998).

To fully grasp the concept of quality of life, it is necessary for researchers and

clinicians alike to understand and consider the variables that influence a person's

evaluation of life experiences. Specifically, both clinicians and laypersons are aware of

the ways by which demographic variables impact a person's life, from obtaining

employment to establishing relationships. However, relatively few studies have

investigated race and sex differences in quality of life ratings among people with mental

illnesses.

*Quality of Life Definition*

In an effort to establish an international assessment of QOL, the World Health

Organization Quality of Life (WHOQOL) group encountered the difficulty of clarifying

the concept and definition of QOL (1995). They used literature review methods and

consultation with nearly sixty group members to identify the following constructs of QOL: 1.) quality of life is subjective; 2.) quality of life is multi-dimensional; 3.) quality of life includes positive and negative dimensions. Based on these constructs, they defined QOL as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns" (p. 1405). This definition provides a comprehensive explanation of the concept while taking into account cultural differences of QOL. Due to its extensive collaborative efforts and broad scope, it has been used by other researchers (e.g., Mercier, Péladeau, & Tempier, 1998) as an applicable definition. For the purposes of this project, quality of life is also defined according to the WHOQOL group description, with a particular focus on the evaluation of QOL's negative dimensions as assessed by life disappointments.

*Objective and Subjective Quality of Life Variables*

*Background*

The WHOQOL group identified quality of life as an individual's *perception* of his/her position in life, indicating that this concept is highly dependent on how a person views his/her life circumstances. This subjective aspect of QOL extends to the 1960s, as research in this area began to grow. The initial focus was on the mental health of the nation (Campbell, Converse, & Rodgers, 1976) and was soon expanded to assess the basic well-being of citizens based on their negative and positive affect (Bradburn, 1969). This trend was followed by Cantril's (1965) focus on happiness and overall satisfaction with aspirations, needs, and life situations. Such research was clearly focused on an

2

individual's perception of, and affective reaction to, his/her overall life position (for summary of QOL development, see Campbell et al., 1976).

Following this initial interest in human well-being, Campbell et al. (1976) sought to "monitor the quality of American life" by assessing the life experiences of the nation's general population. Rather than focus on an affective aspect of quality of life (e.g., happiness), or on any other one specific aspect (e.g., global life satisfaction), the researchers chose to concentrate on life experiences that may create differences in quality of life. They followed the report of French, Rodgers, and Cobb (1974) that "people live in an objectively defined environment, and it is to this psychological 'life space' that they respond" (Campbell et al., 1976, p. 13). Ultimately, there exists a quality of life feature that is typically external, measurable, and observable by others. It is this objective aspect upon which individuals base their subjective ratings of quality of life.

*Objective Quality of Life*

Researchers in this field have operationalized objective quality of life in terms of various life domains. These domains involve life experiences that are important to most people and contribute to the overall evaluation of quality of life (Campbell et al., 1976). While the specific domains may vary among researchers (e.g., Lehman, Ward, & Linn, 1982; Oliver, 1991; Skantze & Malm, 1994), most have identified some aspect of physical functioning (e.g., leisure time), economic functioning (e.g., work at home, work at job), and social functioning (e.g., independence, relationships) as important components of objective QOL (Lehman & Burns, 1996).

Life domains may be viewed as "opportunities" that provide individuals with the abilities and resources to meet their basic human needs (Bigelow, Brodsky, Stewart, &

Olson, 1982). For instance, employment provides the opportunity to interact with others, to be appreciated, and to earn money for food. It also requires that a person be active and motivated to achieve these goals. As a result, aspects of life domains ensure that a person's needs will be met, but he/she must also put forth effort to achieve these needs (Bigelow et al., 1982).

*Subjective Quality of Life*

Other researchers report that the external factors in a person's environment are not enough to determine a person's overall well-being—it is the person's assessment of these conditions that is important (Corrigan & Buican, 1995). While objective QOL variables are important, they are not sufficient to fully understand the complexity of a person's quality of life. In Röder-Wanner, Oliver, and Priebe's (1997) sample, the authors reported that subjective QOL indicators alone better predicted satisfaction with life than objective variables. In addition, Evans, Huxley, and Priebe (1999) reported that 1% of overall well-being variance is described by objective variables. However, this statistic increases to 31% among a German sample and to 40% among a British sample when subjective well-being variables are added.

Thus, this cognitive appraisal of external surroundings may account for variability in individual or group responses to environmental demands, as people differ in their interpretations, reactions, sensitivity, and vulnerability to certain events (Lazarus & Folkman, 1984). Each individual assesses an environmental event in the context of primary appraisal (e.g., whether one is in trouble or benefited) and secondary appraisal (e.g., what one can do about the situation; Lazarus & Folkman, 1984). Consequently, subjective quality of life is comprised of these appraisals, which are influenced by such

4

cognitive mechanisms as expectations, aspirations, and comparison standards (Doyle et al., 1999). Although it is evident that this subjective component may be based on objective events, it is in itself necessary to assess a person's life experiences. In fact, some researchers have supported the approach of using only subjective variables in measuring quality of life. Diener (1984) reported that well-being may be influenced by objective factors, but these are not necessary or inherent. Instead, well-being is primarily subjective and includes an assessment of all aspects of a person's life.

Given the cognitive component of subjective QOL, it is expected that a person's evaluation of life circumstances will be influenced by his/her own abilities and attitudes; cognitive elements that are often impacted by the life experiences associated with race, sex, and mental illness. In particular, mental illnesses that impair cognitive functioning and/or affect moods would seem to have a large impact on subjective quality of life.

*Mental Illness and Quality of Life*

Quality of life among people with mental illnesses has become a focus for several areas of research, particularly in the development of QOL scales (e.g., Heinrichs, 1984; Lehman, 1988; Oliver, 1991). Although defining quality of life among all populations has remained a challenge, the additional aspect of incorporating psychiatric symptomatology creates additional difficulties. The following two approaches to measuring QOL provide different means of assessing an individual's life experience: one overlooks the impact of psychiatric symptoms and focuses solely on the individual's experience ("individualist"); the other overlooks the individual's experience to avoid the impact of symptoms on responses ("collectivist").

5

The QOL construct among people with mental illnesses is commonly measured by an "individualist" approach, which asserts the claim that individuals are the only ones to accurately evaluate their own quality of life (Doyle et al., 1999). This approach allows individuals to rate their global well-being and satisfaction with various life domains, which can be influenced by such factors as personal characteristics (e.g., sex and race), objective quality of life domains (e.g., income level), and subjective evaluations of these domains (e.g., satisfaction with income; Doyle et al., 1999). While this appears to be an accurate representation of QOL among most populations, psychiatric populations present with conflicting reports—they tend to report high levels of satisfaction despite objectively poor living conditions (Baker & Intagliata, 1982; Sullivan, Wells, & Leake, 1991). Although subjective quality of life does not necessarily depend on objective circumstances (Skantze, 1998), it is possible that the discrepant objective and subjective QOL ratings among psychiatric populations may be the result of illness symptoms or cognitive limitations.

Doyle et al. (1999) found that a diminished level of insight (as measured by the Insight Scale; Birchwood, et al., 1994) among people with schizophrenia may adversely affect subjective evaluations of life domains. Specifically, they reported a significant (although admittedly modest) positive correlation between subjective and objective life conditions among patients with high levels of insight, but a negative, non-significant relationship among patients with low insight. To contrast, Whitty et al. (2004) report a strong correlation between objective and subjective QOL ratings, a relationship not influenced by level of insight. Gutek, Allen, Tyler, Lau, and Majchrzak (1983) reported

that such cognitive factors as aspiration level and perceived control could potentially influence ratings of life satisfaction. These findings suggest that the cognitive mechanisms used in evaluating life domains may be influenced by the experience and symptoms of mental illness, although such findings are often inconsistent.

The presence, duration, and severity of certain psychiatric symptoms may also impact quality of life ratings among patients with mental illnesses. The duration of a psychotic illness (Shtasel, et al., 1992), length of time of an untreated psychotic illness, number and severity of negative symptoms (Browne, et al., 2000), earlier age of onset, poorer premorbid adjustment, presence of premorbid symptoms (Malla, et al., 2004), and severity of depressed mood (Pyne, et al., 1997) have all been found to be negatively correlated with satisfaction in one or more QOL domains.

Similarly, Packer et al. (1997) reported that among a sample of patients with schizophrenia, there were significant negative correlations between the Brief Psychiatric Rating Scale total score (BPRS; Overall & Gorham, 1962) and a rating of global life satisfaction, as well as between the BPRS total score and ratings of subjective life satisfaction. In addition, they found significant negative correlations between the BPRS negative and positive symptom clusters and global life satisfaction, but a negative relationship only between the BPRS negative symptoms and subjective measures of life satisfaction. Thus, they concluded that patients with schizophrenia experienced diminished satisfaction with their lives as they become more symptomatic (especially with increased negative symptoms), despite little relationship between increased symptoms and objective measures.

It appears that non-psychotic mental illnesses are also associated with lower quality of life. Patients with major depressive disorder score lower on all facets of the WHOQOL-100 measure than respondents from the general public (Trompenaars, Masthoff, Van Heck, Hodiamont, & De Vries, 2006), and reported lower QOL ratings up to six months after the remission of their depressive episode (Angermeyer, Holzinger, Matschinger, & Strengler-Wenzke, 2002). Similarly, a qualitative review of patients diagnosed with bipolar disorder indicated that their QOL was negatively impacted by this disorder, particularly in the domains of education, vocation, financial functioning, and social and intimate relationships (Michalak, Yatham, Kolesar, & Lam, 2006).

However, as with most aspects of QOL, there are conflicting results regarding the relationship between symptoms of mental illness and quality of life ratings. In Malla and Payne's (2005) review of QOL and first episode psychosis studies, they reported that Whitty, et al. (2004) found no symptoms of mental illness to be related to QOL. In addition, neither Malla, Norman, McLean, and McIntosh (2001) nor Addington, Young, and Addington (2003) found an association between duration of untreated illness and any QOL dimensions. The latter findings suggest that an "individualist" approach would provide clinicians with an accurate picture of QOL among people with mental illnesses; however, there remains the possibility that psychiatric symptoms may interfere with ratings. Despite the conflicting reports regarding the influence of psychiatric symptoms on QOL, the argument for the use of this approach is based on the suggestion that the *experience* and *perception* of the patients are of utmost importance. If such experiences are influenced by psychiatric symptoms, then these too must be considered in assessing

quality of life. Several measurements designed to assess QOL among mentally ill populations have taken this approach, via use of self-report questionnaires.

*"Collectivist" Approach to Quality of Life*

Given the potential -- albeit unclear -- influence of mental illness on QOL ratings, an alternative way of evaluating quality of life is with the "collectivist" approach. This perspective argues that only objective outsiders should evaluate patients' quality of life, as the individual may not be the most accurate judge (Doyle et al., 1999).

According to this approach, an accurate assessment of a person's QOL comes from an external standpoint with the use of three information sources: patient self-report, collateral information from a caregiver, and comparison of the patient's current living situation with local and cultural standards (Doyle et al., 1999). However, even when all sources have been incorporated, only a modest correlation between patient and external ratings of QOL existed among a 'high insight' population of patients with schizophrenia. These results suggest that the interpretation of quality of life may differ between patients and clinicians (Doyle et al., 1999).

It is possible that the differences in QOL reports may be due to different measurements of the construct. If the measures depend only on patient reports (i.e., "individualist"), then they are vulnerable to influences of the patients' psychological states. However, the alternative approach of using clinician-administered rating scales of QOL, in addition to caregiver reports (i.e., "collectivist") faces the challenge of separating the influence of symptoms from quality of life ratings (Malla & Payne, 2005). To illustrate the limitations of the latter approach, consider two negative symptoms often present in schizophrenia: avolition and anhedonia. These symptoms are defined by fewer

peer relationships, fewer activities, and an overall decrease in leisure interests. A caregiver or clinician would typically rate the effects of these symptoms as resulting in lower subjective QOL; however, a person with such an illness may not desire more peer contacts or more activities, which would not have an impact on his/her own QOL ratings. Thus, not only is the evaluation of quality of life among the mentally ill complicated by symptomatology, but also by the approach of the assessment.

*Demographic Differences in Quality of Life among Patients with Mental Illnesses*

It is apparent at this point that the already complex conceptualization of quality of life may be further complicated by several aspects of mental illness, including presence and duration of symptoms, as well as issues pertaining to the measurement of quality of life. However, differences in such demographic variables as sex and race have also been found to influence quality of life. Just as these differences may have an impact on the course, symptomatology, and treatment of mental illnesses, they also influence the manner in which an individual perceives his/her own life circumstances. An understanding of such demographic differences may account for aspects of the seemingly inherent QOL ambiguities.

For the purposes of this review and research project, sex is defined by the biological characteristics associated with this variable, while race is defined by the patient's self-report. Although the cultural and social roles associated with gender and ethnicity are important in understanding quality of life, it is each patient's identification with these variables that is currently being reviewed in the context of QOL. It is acknowledged that there exist many facets and complexities specific to the sexes and races that create difficulties in generalizing findings to each group. However, this review

and research project is an attempt to identify similarities within each demographic group, while simultaneously identifying differences among the groups.

*Influence of Sex on Quality of Life*

Previous research has established that there are several differences in physiology and symptomatology between men and women with schizophrenia. Röder-Wanner et al. (1997) and Solomon and Draine (1993) present a summary of such differences, citing several researchers in their respective fields. Although these differences are important in understanding schizophrenia as an illness, a full review of the area is beyond the scope of this project. In keeping with the current focus, only those differences pertaining to specific quality of life are included in the following review.

Röder-Wanner et al. (1997) offer several general statements regarding sex differences in schizophrenia: "schizophrenic women premorbidly seem to be better adapted" (p. 129), "...gender is a predictor of the course of the disorder (p. 130; citing Jablensky et al., 1992)," and "to be female predicts better social functioning in schizophrenia (p. 130)." The authors based these statements on research reporting that, prior to the onset of schizophrenia, women exhibit less social isolation, have more relationships outside the family, and have more relationships with their peers compared to their male counterparts (Childers & Harding, 1990; Foerster, Lewis, Owen, & Murray, 1991; Haas & Sweeney, 1992; Gittelman-Klein & Klein, 1969; Shtasel et al., 1992). In addition, a literature review by Angermeyer, Kühn, and Goldstein (1990) reported that the majority of studies they examined had revealed an overall better clinical course for women with schizophrenia, based on such factors as response to neuroleptic and sociotherapeutic treatment, number of hospitalizations, and length of hospital stay.

Finally, women seem to have better social functioning, based on rates of regular employment, less negative professional development, later retirement, more often living with a partner of the opposite sex, more heterosexual activity, more independence, and better family and occupational role functioning (Childers & Harding, 1990; Deister & Marneros, 1992; Haas, Glick, Clarkin, Spencer, & Lewis, 1990; Jablensky et al., 1992; McGlashan & Bardenstein, 1990; Pietzcker, Baebel, & Poppenberg, 1982; Schubart, Krumm, Biehl, & Schwarz, 1986; Test, Burke, & Wallisch, 1990, as cited in Röder-Wanner et al., 1997).

Given the apparent favorable outcomes for women with schizophrenia, it would seem that they would report a better overall subjective and objective quality of life compared to their male counterparts. Indeed, objective conditions may generally be better among women (Röder-Wanner et al., 1997): women exhibit better functioning in social and engagement realms, and experience a better overall quality of life (Shtasel, Gur, Gallacher, Heimberg, Bur, 1992), but they also tend to be less satisfied with their living situation and personal safety (Röder-Wanner et al., 1997). To contrast, Campbell, Converse, and Rodgers (1976) reported no significant sex differences in overall life satisfaction, as measured by individualist ratings. However, the research on this topic reveals that such contradictory findings may be related to other demographic variables.

*Influence of Race on Quality of Life*

The quality of life definition cited in this paper was primarily chosen due to its comprehensive explanation of the QOL concept, as well as its consideration of cultural contexts (WHOQOL, 1995). As a result, it should be apparent at this point that race is an

important aspect of understanding variability in quality of life. However, the research on

race differences in reports of QOL among people with mental illnesses is quite limited.

Overall, research has shown that Caucasians without mental illnesses report a

greater overall life satisfaction than African-Americans without mental illnesses

(Andrews & Withey, 1976; Campbell et al., 1976; Diener, 1984). However, non-

Caucasians with chronic mental illnesses report a lower objective quality of life but

higher subjective ratings than their Caucasian counterparts (Lehman et al., 1995). A

summary of racial differences in specific domains is presented in Table 1.

*Other Sociodemographic Variables*

The primary focus of research for this project is on the race and sex differences in

quality of life, as these are the author's primary areas of interest. However, an

investigation into the realm of sociodemographic variables indicated that several

variables may have an impact on quality of life ratings, including inpatient vs. outpatient

status and age. Unfortunately, an in-depth exploration of all variables is not practical;

however, because the research on age as an impact on QOL has been widely reviewed, a

cursory summary of these findings is presented.

The effect of age on quality of life among non-clinical samples remains disputed.

While some researchers have found no age differences in QOL (e.g., Andrews & Withey,

1976; Corrigan & Buican, 1995; Jarema & Konieczynska, 2001), others report a positive

relationship between age and life satisfaction (Medley, 1980). However, further

investigation by Medley (1980) indicated that this trend only holds true for men, while

life satisfaction for women remains relatively stable throughout their lifetime. Lehman et

al. (1995) also reported a significant sex by age interaction effect among patients with

mental illnesses, with men and women in the youngest age group (<25 years) differing from each other in their reports of general life satisfaction. Men under the age of 25 reported greater life satisfaction than the women; a difference not observed among the older age groups. To contrast, Mercier et al. (1998) reported no significant pattern of global sex by age interactions in overall life satisfaction among people with severe mental illnesses.

While the differences in the findings may be accounted for by such variables as different measures of QOL, dissatisfaction with particular domains, or even psychiatric variables (e.g., duration of illness), the literature on age effects remains contradictory. Although this is an important area to pursue, the effects of age will not be a primary focus of this study, as race and sex are more often associated with treatment and clinical outcome (Kreyenbuhl, Zito, Buchanan, Soeken, & Lehman, 2003; Häfner, Maurer, Löffler, & Riecher-Rössler, 1993).

Despite the limited research in this area, it is evident that demographic variables, particularly sex and race, play an important role in subjective evaluations of life circumstances. It is possible that symptoms of mental illness may also influence such subjective experiences, and indeed, the "individualist" approach to quality of life argues that it is this experience that is most important. Ultimately, the amalgamation of both demographic and psychiatric factors appears to influence a person's quality of life.

*Revised Quality of Life Model*

Relatively few studies have investigated sex and race differences in quality of life ratings among people with mental illnesses, despite the urging of the WHOQOL group to consider the influence of cultural diversity on such ratings (1995). However, as reported

in the previous sections, those that chose to evaluate these differences found several

discrepancies in ratings between males and females, as well as between Caucasians and

non-Caucasians. These differences are best understood in terms of a modified model of

quality of life.

A common and frequently cited view of life satisfaction was formulated by

Campbell et al. in 1976 and is presented in Figure 1. According to this model, an

individual's satisfaction is determined by his/her perception and evaluation of a given

environmental situation. The individual first perceives a situation depending on, but

separate from, the external environment. The person then evaluates the domain

characteristics in terms of personal importance, needs, or values; evaluations that are

influenced by aspirations, expectations, and comparison levels. All factors combine to

create the overall level of satisfaction with an objective domain.

Campbell et al. (1976) acknowledged that this model was oversimplified and

could be elaborated to include personal characteristics (i.e., demographic variables) as

influences on every component. The authors consequently formulated a more complex

model to include the influence of personal characteristics on all aspects (see Campbell et

al., 1976 for an illustration of this model). However, Campbell et al.'s (1976) model does

little to clearly explain specific sex and race differences in reports of QOL and does not

allow for differences in the impact that each characteristic has on a person's evaluation of

QOL domains. In addition, the constructs of QOL as identified by the WHOQOL group

(i.e., QOL is subjective, multi-dimensional, has positive and negative dimensions; 1995)

were not all accounted for in the model. In an effort to better explain the QOL concept in

the context of demographic differences, a revised model is being presented for the

purposes of this research project to account for inconsistent findings in the sex and race

literature. An illustration of this model is presented in Figure 2. To demonstrate this

model, a review of sex and race differences in the QOL literature is presented in terms of

the revised model, with the results summarized in Tables 1 and 2.

*Demographic Differences at the Objective Level*

Tables 1 and 2 summarize the objective differences in quality of life between

Caucasians and non-Caucasians, as well as between males and females. Non-Caucasians

had more family contacts, while Caucasians had more social contacts and financial

adequacy (Lehman et al., 1995). Males had more daily activities, financial adequacy,

employment and amount spent per month (Lehman et al., 1995), better living situations,

more personal safety (Röder-Wanner et al., 1997), and better family relations, while

females had more leisure activities (Thornicroft et al., 2002), were more often working,

more often living with family, and were more often currently (or had been) married

(Röder-Wanner et al., 1997). Based on such results, it appears that race and sex do impact

the external environment in which people live.

In addition, the regression analyses by Lehman et al. (1995) indicate that there

exists a difference between the races and sexes in which objective variables are most

predictive of overall global satisfaction. The process by which individuals determine

which variables are most important involves the evaluation of aspirations, expectations,

and comparisons mentioned by Campbell et al. (1976). Likewise, the WHOQOL group

(1995) emphasized the importance of perception of life conditions in their definition of

QOL. Thus, the perception and evaluation of objective conditions occur concurrently to

create ranked determinants of overall satisfaction.

To illustrate this, race and sex are entered into Figure 2 as variables that impact both objective conditions and the perception of these objective conditions. Although there still remains an element of the process of perception independent of demographic characteristics, there is also a prominent influence by such variables.

*Demographic Influences at the Subjective Level*

As mentioned earlier, many researchers have emphasized the importance of assessing subjective ratings of quality of life, with some even suggesting that measuring objective conditions is unnecessary (e.g., Diener, 1984). It has also been reported that subjective QOL does not necessarily depend on objective circumstances (Skantze, 1998). For instance, Sullivan et al. (1993) reported lower objective conditions in their sample, but higher reports of subjective quality of life. Thus, the concept of subjective QOL may stand relatively independent from objective conditions and instead serve as a primary influence on QOL, separate from the evaluation component. Although the concept may be relatively independent, it is also susceptible to the influence of demographic variables.

As was the case with the objective variables, subjective variables identified as the most important determinants of overall satisfaction varied according to race and sex (see Tables 1 and 2 for summary of results). Likewise, demographic differences existed in reports of satisfaction with certain life domains. However, because subjective ratings are just that – subjective – they are by definition a cognitive evaluation of circumstances, influenced by sex, race, mental illness symptoms, and other life experiences.

*Weighted Domains*

The subjective evaluation of life domains creates a "weighted domains" variable. This concept stems from efforts to incorporate cultural diversity in QOL measures by

emphasizing the importance of allowing diverse cultures to value domains unequally (Chisholm & Bhugra, 1997). A type of hierarchy is created, with certain domains meaning more and having more of an impact on an individual's global quality of life. Given that different sexes and races value domains differently, a model that accounts for this variance should result in more accurate assessments of global QOL. As mentioned previously, the WHOQOL group aimed to address cultural diversity in QOL measurements, a goal that would be met by considering differences in domain importance.

As all dimensions of the revised quality of life model unite to impact ratings of various dimensions, the weighted domain hierarchy is believed to be the amalgamation of all crucial components, including the perception and evaluation of objective conditions and the subjective rating of conditions (as influenced by sex, race, and mental illness). As a result, this is the factor that determines how a person will rate his/her overall quality of life.

*Importance of Current Research*

The revised quality of life model (Figure 2) stresses the importance of an individual's appraisal of various life domains. Demographic variables are believed to play a key role in influencing the evaluation of these domains, thus resulting in dissimilarities between Caucasian and African-American races and sexes in the importance of certain domains. The current research project focuses on patients' subjective evaluation of their life circumstances, as these evaluations are the primary source of the weighted domains variable. It is important that any evaluation of a patient's quality of life take into account these demographic differences in responses.

18

Unfortunately, many existing quality of life measurements do not allow for cultural diversity in responses. Most assessments give equal weight to all domains, which Becker, Diamond, and Sainfort (1993) report should not be the case. Instead, they argue that different racial groups feel that certain domains are more important than others. Providing the opportunity for each respondent to weigh the importance of each domain would allow him/her to convey which area is of most significance, which, according to the revised model, will provide a more accurate assessment of QOL.

The purpose of this research project is to assume the "individualist" mind-set and allow patients with a range of mental illnesses to express through open-ended questions the life domains with which they are most unhappy or disappointed. Approaching quality of life in such a manner provides a unique means of assessing this construct: instead of forcing patients to choose from a predetermined list the areas of life with which they are most frustrated, they are allowed to freely express their disappointments. This particular approach to quality of life allows such factors as race and sex to contribute maximally to each patient's report of disappointments, thus providing clinicians with a more comprehensive picture of the patient's experience.

Both the open-ended structure of the interview and the introduction of sex and race differences in quality of life provide mental health professionals valuable information that is necessary to effectively care for the mentally ill population. As previously mentioned, the treatment paradigm has shifted from a symptom-oriented focus to understanding the impact of the disease on the patient (Gianino et al., 1998). In order to adhere to this paradigm shift, it is essential that clinicians be aware of individual differences among patients. Where one patient may be most frustrated with his/her

19

inability to maintain employment, another may be most affected by a loss of familial or romantic relationships. These are domains by which a patient defines his/her quality of life, and may vary between sexes, among races, or a combination of both. If an individual's disappointments are not addressed, he/she will not experience an improvement in quality of life and thus not be effectively "treated". Ultimately, it is the understanding that not all patients define their quality of life by the same domains that will allow clinicians to fully understand what it means to "treat" their patients.

The revised quality of life model incorporates the influence of both demographic influences and mental illness on subjective quality of life ratings. These variables impact the way a patient evaluates his/her life and determines which domains are of most importance. The most significant domains are believed to have the most impact on overall quality of life. Thus, a focus on these domains will provide a great deal of insight into a patient's experience. Although specific mental illness factors are not directly addressed by hypothesis-testing, it is the overall effect of having a mental illness on quality of life that is of value in understanding which domains are most important. As a result, the cognitive and perceptual differences among the various mental illness diagnoses are not formally addressed as a primary factor in the current research. Instead, it is the overall impact of both psychotic and affective mental illnesses, in conjunction with the influence of sex and race, which are believed to be the primary influences on which domains are reported. The current research project is based on this revised QOL model, in its effort to clarify the importance of demographic differences in quality of life among patients with mental illnesses.

The ultimate goal of the project is to improve clinicians' knowledge of the QOL construct. Ideally, such an understanding will lead to an improvement in quality of care that is provided to patients with mental illnesses. Unfortunately, the existing literature on demographic differences in QOL is relatively limited and does not provide much insight into this issue. Thus, the current research project aims to contribute to this research by addressing the following hypotheses:

1. *The domains of disappointment reported by patients with mental illnesses and measured via the Illness Impact Interview will vary according to sex and race.*

- Female patients will less often report employment as a disappointment domain than males (Evans et al., 1999), while males will less often report that leisure activities are a domain of disappointment than females (Lehman et al., 1995).

- African-Americans will express less disappointment with family and social contacts than their Caucasian counterparts, while Caucasian patients will less frequently report disappointment with finances (as reported by Lehman et al., 1995).

- To date, research in this field has not addressed the interaction of race and sex in reported QOL domains. As a result, the examination of this interaction is exploratory, conducted under the broad hypothesis that there exists an interaction between the two variables in determining which domains are reported.

*2. Sex and race will interact to predict which life domain is most disappointing for patients with mental illnesses.* Based on Lehman et al.'s (1995) multiple regression analyses on the domains that predict global QOL between the races and sexes, the following relationships are expected:

- African-American males will report that issues pertaining to contact with others are most disappointing.

- African-American females will report that leisure activities are most disappointing.

- Caucasian males are expected to report that their living situation is most disappointing.

- Caucasian females will report that difficulties in their contacts with others are most disappointing.

*3. Demographic differences will be detected in the level of overall disappointment.* The expectation that there will be differences in the degree of disappointment is based on the existing literature of demographic differences in QOL; however, the concept of quantifying this degree of disappointment is exploratory.

- No specific predictions are made as to the direction of the sex and race differences in this exploratory analysis. Instead, the potential identification of differences in the degree of disappointment itself is a substantial contribution to the current literature.

METHODS

*Nature and Design of the Study*

The current research aims to identify race and sex influences on quality of life. It is expected that when patients are given the opportunity to freely express the areas of their lives with which they are most disappointed, sex and race will play a major role in determining which domain is reported. The reported domains of disappointment reflect the areas of patients' lives that are insufficient, thus providing an insight into the domains in which quality of life may be lower. These unsatisfactory domains are thought to heavily influence overall quality of life, as these are spontaneously reported as the most disappointing aspects of the patients' lives. As a result, it is important to understand the factors (e.g., race and sex) that contribute to the report of certain domains. Patients provided demographic information and completed an open-ended interview to assess the three study hypotheses.

*Sample*

*Participants*

Data for the current research project were collected from a larger, ongoing research study conducted at the University of Louisville. The inclusion/exclusion criteria and recruitment procedures for the current project reflect those of the larger study.

The participants consist of individuals between the ages of 18 and 55 with DSM-IV Axis I disorders including schizophrenia, schizoaffective disorder, major depression,

and bipolar disorder. Patients meeting DSM-IV criteria for substance dependence/abuse *only* were excluded from the study (i.e., no other Axis I diagnosis). However, other criteria such as substance use, medical conditions, etc, were not exclusionary, as the goal was to obtain as broad a sample of patients as possible.

Recruitment of participants was conducted through the Department of Psychiatry at the University of Louisville, Seven Counties Mental Health Services, and Central State Hospital, such that all patients were seeking inpatient or outpatient mental health treatment at the time of study participation. All appropriate facility and IRB approvals were received for recruitment at these locations. Brochures and posters were displayed at the facilities, describing study goals and procedures. Potential participants were identified by their responses to these materials, or were identified and approached by facility and/or research staff. Participants were given $10 for their involvement in the study.

A power analysis was conducted using the G* power program adapted from Buchner, Erdfelder, and Faul (1997) to determine the number of participants needed to achieve acceptable power for a selected effect size between groups. The limited literature on sex and race differences in quality of life suggests a range of possible effect sizes, from potentially large effects (e.g., Lehman et al., 1995) to no significant effects (e.g., Thornicroft et al., 2002). As a result, a medium effect size was chosen as the "middle ground" between the possible effect sizes. In order to detect a medium effect size of 0.15, with alpha set at 0.05 and power of 0.95 for a multiple regression analysis with 2 predictors (i.e., sex and race), a total sample size of 107 participants is required. The number of participants for this project totaled 125.

*Measures*

The data necessary to address hypotheses of the current research project were collected by obtaining basic demographic and clinical information and conducting a semi-structured interview to assess life disappointments. Research staff members then coded participant responses according to the most appropriate quality of life domain.

*Demographic Information.* Sex, race, and age information were provided by participant self-report, chart review, and/or interviewer observation. The variable of sex was defined by the biological characteristics associated with this classification, while race was defined by a patient's self-reported identification with a particular race. It is the differences in experiences associated with these demographic characteristics, rather than a focus on the social roles implied by these classifications, that are of interest in the current project. Thus, patients were asked to identify their sex and race, rather than gender and ethnicity.

*Clinical Information.* Data on several clinical factors were collected via chart review and patient interview. The current Global Assessment of Functioning score was recorded as the score assigned by the patient's treating psychiatrist in the medical chart. Patient diagnosis was also obtained from chart review.

The age of the patient's first episode was obtained via interview. Patients provided information on when they first began to notice significant symptoms of their illness, confirmed by research staff via chart review. The variable of illness duration was calculated by subtracting the age of first episode from the age at time of interview.

*Disappointments.* The Illness Impact Interview is comprised of five questions designed to assess patients' identification of goals that were not met because of their

psychiatric disorder (see Appendix for copy of Interview). The interview was designed primarily for the ongoing research project and is still in the development process. However, the interview itself provides valuable information on the subjective QOL of patients with mental illnesses and was used in this manner for the current project. At this point, it is important to acknowledge that the Illness Impact Interview is not intended to be a newly-designed measure of global quality of life. Instead, its purpose is as an index of disappointing QOL domains, providing data indicative of subjective quality of life.

The Illness Impact Interview is less structured than most QOL measures. The open-ended format allows patients to freely express their disappointments, in the absence of a clinician-imposed response structure. However, if it appears that patients appear to have difficulty in responding independently, they may be provided with prompting by the interviewer on suggested responses, but are in no way required to endorse certain domains over others. All patients included in this sample were given the opportunity to freely respond to the items before being prompted. The free response structure allowed patients to provide information on the domains that are most significant to them, thus providing more weight to these domains.

The interview's focus on disappointments is a variation of such existing measures as Satisfaction with Life Domains Scale (Baker & Intagliata, 1982) that assesses patient satisfaction with certain life domains. It is the understanding of the "…subjectively evaluated … skills, impairments, handicaps, and quality of life goals (p. 41)" that provide clinicians with knowledge about what it means to "be well" (Skantze & Malm, 1994). Thus, a focus on the failure to meet these goals provides a unique perspective on the effects of mental illness on quality of life. The Illness Impact Interview is structured such

that the focus of the questions is on the impact that mental illness has had on patients' life goals. While many QOL measures do not specifically address this aspect, several have been designed for specific use among the mentally ill population, thus indirectly assessing the impact of mental illness. The use of this interview provides a direct assessment of goals that have not been obtained as a result of the illness, a facet of mental illness that is often overlooked, but one that the WHOQOL group reports is necessary (i.e., an understanding of the negative dimensions of QOL).

Three of the five Illness Impact Interview questions form the core of data collection for the current research project. Specifically, question #2 addresses the goals that have been prevented as a result of mental illness. Patient responses to this question provide data for hypothesis #1 (i.e., demographic differences in domains of disappointment), as these indicate specific domains of disappointment in their lives. Question #4A addresses the most disappointing loss for the patient, providing a weighted evaluation of disappointment domains. Information obtained from this response provides data for hypothesis #2, which focuses on sex and race differences in the most important domain that is reported. Finally, Illness Impact question #4B asks the patient to rate his/her level of disappointment on a 1-5 Likert scale, providing data for the hypothesis #3 (i.e., demographic differences in level of disappointment).

*Data Coding*

The responses to the Illness Impact Interview were coded by the research staff according to the QOL domains proposed by Skantze in the Quality of Life Inventory (QLS-100; 1993). The QLS-100 is a measure designed to assess quality of life among patients with schizophrenia and other severe mental illnesses. It consists of 14 life

27

domains, each comprised of 3-7 items that describe the particular domain (refer to Table 3 for list of domains and descriptive items). In the administration of the QLS-100, patients are instructed to circle items that are unsatisfactory. The interviewer further probes into these unsatisfactory domains, inquiring about which aspects of the items are unsatisfactory and whether the patient desires a change in the domain. The authors structured the measure in such a way that patients were allowed to freely express their own "values and preferences", thus making the "…investigator's evaluations of whether the patients' life domains were satisfactory or not seem irrelevant (Skantze & Malm, 1994, p.39)."

The design of the QLS-100 reflects the intentions of the current research project, with its emphasis on allowing patients to express their own unsatisfactory domains, free from investigator evaluation. As a result, its domains were chosen as a basis for coding responses to the Illness Impact Interview. Members of the research staff reviewed patient responses to the interview items and designated each patient response with a number (1-14), reflecting the specific QLS-100 domain that is represented.

<div align="center"><em>Procedure</em></div>

<em>Initial Contact</em>

Patients at those facilities with recruitment materials contacted research staff via phone to express interest in participating in the study. A brief phone screening process was conducted to assess inclusion criteria, namely age and diagnosis. If the potential participant appeared eligible for the study, the research staff member provided a brief explanation of study measures and arranged contact for completion of study procedures.

Patients at inpatient facilities were identified by chart review and/or hospital staff referrals. Members of the research staff conducted a brief chart review of patient information (i.e., age and diagnosis) to assess inclusion/exclusion criteria. Once appropriate patients were identified, they were approached by a member of the research staff and provided an explanation of the study's purpose and procedures. If the patient expressed interest in participating, the research staff member arranged a time to conduct the measures at the inpatient facility.

*Assessment of Participants*

All assessments for the larger study and the current research project were conducted during one session, which lasted approximately two hours. At the beginning of the session, the patient was provided the consent form describing the rationale, procedures, and risks of participating in the study. Once the patient demonstrated understanding of the consent form and had all questions answered to his/her satisfaction, the form was signed and the research procedures were initiated.

The research staff member administered the Illness Impact Interview as the final research measure. The closing portion of the interview focused on coping strategies and involved an informal assessment of patient's mental status following the interview. Each patient was given $10 for participating in the study.

*Training of Interviewers and Raters*

The research staff consisted of six Clinical Psychology doctoral students and one Ph.D. level faculty member at the University of Louisville. All members were trained in the administration of research procedures and in coding of patient interview responses. The first phase of administration training consisted of observing an experienced member

conduct all steps of the research protocol. The staff trainee was then provided the opportunity to ask questions regarding the administration of measures. The second phase allowed the trainee to administer the research protocol while being observed by an experienced member. The experienced member offered input on areas of improvement if necessary. Finally, once the experienced member concluded that the newer research staff member conducted the protocol as instructed, he/she conducted assessments independently. Questions regarding administration often arose throughout the course of data collection, which were addressed during weekly research team meetings. However, because all coding occurred within a relatively brief six-month period, there were no formal reliability checks after the initial training.

Once the interview was completed, the patient's answers were coded according to the QLS-100 domains. All members of the research staff were provided with the rationale for use of the QLS-100 and were encouraged to engage in a discussion regarding the use of this measure as a means of coding. In an effort to establish reliable coding, all research team members were given copies of the same randomly chosen 20 Illness Impact Interview responses and asked to code questions #2 and #4A as QLS-100 domains. Potential issues with coding were addressed at this time, namely discrepant ratings of individual items. These items were compared and discussed until all raters came to a mutual agreement regarding the appropriate domain. The principal investigator of this research project served as the primary data coder, with other rater responses compared and adjusted to this reference scoring. The reliability coefficient (kappa) was at least .80 between all other research team members and the reference rater prior to the initiation of coding procedures. However, the kappa between the two research team members

primarily responsible for coding data (including the principal investigator) was .89 ($p \leq .001$) for Illness Impact item #2 and .95 ($p \leq .001$) for Item #4A.

## Data Analysis

### Preliminary analysis

The descriptive characteristics of the sample are included as a means of addressing potential confounding factors. The number and percentage of patients are reported by sex, race (Caucasian or African-American), diagnostic groups (affective or psychotic diagnosis) and treatment settings (inpatient or outpatient). The average age at time of study participation is also included as a descriptive characteristic. Information on psychiatric severity and history is included as the average current Global Assessment of Functioning (GAF) score, average age of first illness episode, and average length of illness duration.

As a means of comparing these variables between the sexes and races, a preliminary independent sample t-test was conducted between males and females and between Caucasians and African-Americans for age, GAF, age at first episode, and length of illness duration. A comparison of sex and race frequencies between the diagnostic groups and treatment settings was assessed by using the chi-square test of independence. An examination of potential sex/race interactions among these variables was then conducted via a chi-square analysis for the diagnostic group and treatment setting differences and a two-way analysis of variance (ANOVA) for the variables of age, GAF, age of first episode, and illness duration. Due to the possible alpha inflation resulting from the multiple preliminary analyses, a significance level of $p \leq .01$ was used

31

for comparison testing. Finally, a simple correlation matrix was computed to visually assess the bivariate relationships among the variables.

In addition, it was anticipated that the frequency of certain domains on Illness Impact item #2 would be greater than others (i.e., endorsing certain domains as disappointing more often than other domains). A preliminary chi-square analysis was conducted to determine the optimal cut-off point that would maximize the number of participants and minimize the number of domains used. The dominant domains identified by this procedure were used in the analysis of which domains are reported more frequently by demographic groups and in determining demographic differences in the most disappointing domain.

*Disappointment domains*

The hypothesized relationship between demographic variables and reported domains of disappointment was assessed by the chi-square test of independence. This test provides information on whether the frequency with which specific domains were reported varies between the sexes and races, and among the different combinations of sex and race. These variables were examined separately as two chi-square analyses for each domain, to determine whether the proportion of men and women and the proportion of African-Americans and Caucasians differ in their report of certain domains. Only the most frequently reported domains identified in the preliminary analysis were assessed, in order to maintain the minimum expected frequency of 5 in at least 20% of cells (Preacher, 2001). Finally, chi-square tests were conducted for the four possible combinations of sex and race (i.e., African-American men, African-American women, Caucasian men, and Caucasian women), to examine whether the proportion of patients in

these categories differed in their endorsement of each domain. In order to test this, sex was first entered as a layer variable into the chi-square test between race and domains of disappointment. This allowed SPSS to compare the frequency with which the disappointment domains were reported between Caucasians and African-Americans within each sex. Next, race was entered as a layer variable to assess whether a relationship exists in the report of disappointment domains between males and females between each race. Due to the possible alpha inflation resulting from six chi-square analyses for each domain, a more conservative error rate of $p \leq .01$ was used to assess statistical significance.

*Most disappointing domain*

As with the reported domains of disappointment, chi-square tests of independence were conducted to address whether sex and race, or the four combinations of these two variables (i.e., interaction), are related to which domain was reported as the most disappointing. Six separate chi-square tests were calculated to determine whether there appeared to be an association between sex and most disappointing domain, between race and most disappointing domain, followed by chi-square tests to determine the relationship between the four sex/race combinations and which domain was reported as most disappointing. Again, sex was first entered as a layer variable, followed by race as a layer variable. An association between at least one, but not all, combinations of race and sex and the most disappointing domain would indicate an interaction between these two variables in determining which domain is reported as most disappointing.

Again, in order to ensure the expected minimum frequency in 20% of the cells, only the most frequently reported domains identified in the preliminary analysis were

assessed. The conservative error rate of p≤.01 was again used to reduce possible alpha inflation from multiple chi-square analyses.

Finally, a multinomial logistic regression was conducted to address whether sex and race, or an interaction of the two, predicted which domain was reported as the most disappointing. Sex and race were entered separately as categorical independent variables, with the most disappointing domain as the dependent variable. The regression analysis produced a full factorial model, containing all main effects and factor-by-factor interactions.

Only those patients in the sample who endorsed the three primary domains of Knowledge and Education, Contacts, or Work as the most disappointing domain were included in the logistic regression (n=105). SPSS converts these dependent categorical variables into binary codes, which allows for comparisons to a reference group. As a default, SPSS chooses the last category entered as the reference group, which was the domain of Work in this analysis. The reference group is omitted from the model as a means of preventing multicollinearity and becomes the basis for comparison for the remaining groups. The multinomial logistic regression analysis used these comparisons to determine the likelihood that the observed values of the dependent variable may be predicted from the observed values of the independent variables.

*Level of disappointment*

A two-way ANOVA was conducted to assess the main effects of sex and race, in addition to the interaction between these two factors, on the reported level of disappointment. This analysis provided information on whether the demographic variables of interest had an effect on patients' level of disappointment.

RESULTS

*Preliminary Analyses*

A summary of the sample's descriptive characteristics are presented in Tables 4

and 5. The results of the chi-square analyses indicate a relationship between sex and

diagnostic group, with proportionately more women than men diagnosed with an

affective disorder. The value of the test statistic suggests that this relationship is a fairly

weak one (phi=.22, p=.01) and appears to only hold true for Caucasian patients.

To better understand the relationship of each variable to one another, a correlation

matrix was computed among all variables and is presented in Table 6. For the purposes of

data analysis, the descriptive groups were coded with the following dummy variables:

Caucasian=1, African-American=0; female=1, male=0; affective diagnosis=1, psychotic

diagnosis=0; and outpatient status=1, inpatient status=0. The correlation matrix indicates

the presence of several relationships among the variables, including a relationship

between sex and diagnosis, sex and GAF scores, as well as statistically significant

positive relationships between GAF, age, and treatment setting, suggesting that older

patients in this sample appear to be functioning at a higher level than younger patients

and are more likely to be outpatients. GAF scores also appear to be related to diagnostic

group, indicating that patients with affective disorders have higher levels of functioning

than those with psychotic disorders. In general, higher GAF scores and longer illness

durations are associated with outpatient status. Not surprisingly, the duration of illness is positively associated with age.

In an effort to identify the most frequently endorsed domains for Illness Impact item #2, a frequency table was created to summarize all responses. This procedure indicated that the domains of Knowledge and Education, Contacts, and Work accounted for 84.4% of all endorsed responses. Consequently, the chi-square analysis indicated that the frequency of responses on these 3 domains was significantly different from the remaining 11 domains ($\chi^2=14.63$, p=.02). As a result, these three domains were used in the following analyses.

<div align="center"><em>Hypothesis Testing</em></div>

*Disappointment Domains*

Table 7 presents the results of the chi-square tests of independence. The number and percentage of patients from each demographic group endorsing each domain as present are included in this table, as well as the analyses comparing their responses.

*Sex differences.* The results of the chi-square tests of independence do not suggest significant sex differences in the frequency with which the domains of Knowledge and Education, Contacts, and Work were endorsed (Table 7). Based on these results, there is little evidence to support the hypothesis that males and females will differ in the life domains they report as disappointing.

Although not statistically significant, there do appear to be emerging sex differences in the endorsement of Contacts and Work as disappointment domains. More women than men indicated that Contacts were a domain of disappointment (p=.20), while men more often reported Work as a domain of disappointment than women (p=.13).

*Race differences.* Similarly, the chi-square tests do not suggest race differences in the frequency with which the domains of Knowledge and Education, Contacts, and Work were endorsed (Table 7). Again, there appears to be little evidence that African-Americans and Caucasians differ in which domains they report as disappointing.

However, there is a non-statistically significant trend of racial differences in the report of Contacts and Work as disappointment domains. Although the differences are not significant, Caucasians more often report both Contacts and Work as disappointing (p=.09 and p=.12, respectively).

*Sex x race interactions.* When sex was entered as a layer variable into the chi-square test between race and domains of disappointment, the results again did not support the hypothesis of a significant difference among the differing demographic groups (Table 7). Likewise, using race as the layer variable did not provide support for significant differences between the sexes within each race. Thus, it does not appear that Caucasian males, Caucasian females, African-American males, and African-American females differ in the frequency which with they report the domains of Knowledge and Education, Contacts, and Work as disappointing.

There do appear to be non-statistically significant trends in the interaction between sex and race in the reported domains of disappointment. Specifically, when sex is entered as a layer variable in the comparison between races, Caucasian females appear to more frequently endorse Knowledge and Education and Contacts as more disappointing than African-American females (p=.11 and p=.15, respectively). When race is entered as the layer variable, Caucasian males more frequently endorse Knowledge and Education as a domain of disappointment than do their African-American male

counterparts (p=.12). In both analyses with sex and race as layer variables, Caucasian males more often report Contacts as a domain of disappointment than African-American males (p=.18, p=.20, respectively).

*Most Disappointing Domain*

The results of the chi-square tests of independence do not indicate that the variables of sex and race, or an interaction of the two, are related to the frequency with which domain is reported as most disappointing at the $p \leq .01$ level (Table 8). Likewise, the likelihood ratio tests conducted as a component of the multinomial logistic regression suggest that sex, race, or their interaction do not significantly contribute to the model predicting the most disappointing domain. Ultimately, the regression model computed with sex and race as the only independent variables does not adequately predict which domain is reported as most disappointing. Instead, it is possible that other variables may better predict the frequency with which Knowledge and Education, Contacts, and Work are reported as the most disappointing domain.

*Level of Disappointment*

The results of the two-way analysis of variance do not suggest a main effect of either race or sex on the reported level of disappointment ($F(1,123)=1.28$, p=.26; $F(1,123)=.01$, p=.93, respectively). Likewise, the results do not indicate a significant interaction of these two demographic variables on level of disappointment ($F(1,123)=.901$, p=.34).

### Post Hoc Analyses

Due to the findings that neither race nor sex, or any combination of the two, are adequate in determining which domains are reported as disappointing, which domain is

38

the most disappointing, or the level of disappointment, post-hoc analyses were conducted as a means of identifying other variables that may contribute to the relationship. Specifically, because of the significant sex differences in diagnosis, GAF, and illness duration, and their association with the treatment setting, these variables (in addition to age) were entered into chi-square analyses to determine differences in reported domains of disappointment and domain of most disappointment. These variables were then entered into a multiple regression analysis to predict the most disappointing domain and the level of disappointment.

Although reasons of statistical necessity and convenience directed the focus of the current research to the three primary domains of Knowledge and Education, Contacts, and Work, the remaining domains may also provide valuable clinical information regarding areas of disappointment for patients with mental illnesses. As a result, a qualitative review of demographic differences among the remaining domains was explored, as well as sample patient responses to the Illness Impact interview.

*Domains of disappointment*

Five chi-square tests of independence were conducted to assess whether diagnosis, age, GAF, illness duration, and treatment setting independently contribute to the frequency with which each of the domains of Knowledge and Education, Contacts, and Work were endorsed by the sample. Diagnosis was again categorized as psychotic disorder or affective disorder, setting was categorized as inpatient or outpatient, while age was categorized as the younger half of the sample (18-35 years old) or older half (36-55 years). The GAF and illness duration categories were determined by the composition of this sample, with 35 being the median GAF score and 15 years as the median length of

illness. As a result, GAF was categorized as equal to or below a score of 35 and scores over 35. Illness duration was categorized as equal to or less than 15 years, or duration longer than 15 years.

Age and the aforementioned clinical variables were entered separately into chi-square analyses to assess whether there was a difference in the frequency with which the three primary domains were endorsed by each variable group. As before, a conservative error rate of $p \leq .01$ was used to minimize alpha inflation from conducting several analyses. Table 9 presents the results of the chi-square tests of independence. The number and percentage of patients from each group endorsing each domain as present are included in this table, as well as the analyses comparing their responses. These analyses indicated that the diagnostic, age, GAF, illness duration, and treatment setting groups did not statistically differ in their endorsement of the Knowledge and Education and Work domains (Table 9). However, a patient's GAF score does appear to be associated with the frequency with which the Contact domain is reported as disappointing, with higher functioning patients endorsing this domain more often.

*Most disappointing domain*

As with the a-priori hypothesis testing, chi-square analyses were again conducted to assess the variables believed to be related to the domain of most disappointment. Diagnostic group, age group (18-35 or 36-55), GAF category ($\leq 35$ or $> 35$), illness duration group ($\leq 15$ years or $> 15$ years), and treatment setting group were dummy coded (18-35 years = 0, 36-55 years = 1; GAF $\leq 35$ = 0, GAF $> 35$ = 1; duration $\leq 15$ years = 0, duration $> 15$ years = 1) and entered into separate chi-square tests of independence to assess whether the frequency with which the three primary domains

were endorsed as most disappointing differed among each group. Again, in order to ensure the expected minimum frequency in 20% of the cells, only the most frequently reported domains identified in the preliminary analysis were assessed. The conservative error rate of $p \leq .01$ was again used to reduce possible alpha inflation from multiple chi-square analyses. Based on these analyses, there is not sufficient evidence to conclude that the variables of diagnosis, age, level of functioning, illness duration, or treatment setting are related to the domain that is reported as most disappointing at the $p \leq .01$ alpha level (Table 10), although there is a non-statistically significant trend between most disappointing domain and diagnostic group.

It is important at this point to acknowledge the fact that each variable was categorized into two groups that may oversimplify the sample's diversity and fail to accurately represent the distribution of continuous variables (e.g., age and GAF). As a result, a potential relationship with the most disappointing domain may not have been detected. In order to address this potential variable oversimplification, three separate multiple regression analyses were conducted with the independent variables of diagnosis, age, GAF, illness duration, and treatment setting. Each of the three primary domains was dummy coded as 0 (not reported as the most disappointing domain) or 1 (reported as the most disappointing domain) and entered as a dependent variable into separate regression analyses. The continuous independent variables of age, GAF, and illness duration were entered as continuous variables, while diagnosis group and treatment setting were entered as dummy coded categorical variables. The three regression analyses indicated similar results: the combination of the continuous and categorical independent variables did not predict whether the domains of knowledge and education, contacts, or work were

reported as most disappointing ($r^2$=.05, p=.58; $r^2$=.09, p=.23; $r^2$=.13, p=.07, respectively). Thus, the inclusion of relevant information from continuous variables does not improve the predictability of the most disappointing domain.

*Level of disappointment*

Multiple regression analyses were conducted to assess whether the combination of the aforementioned variables were better predictors of patients' reported level of disappointment than sex and race alone. When sex and race are entered as the only predictors of disappointment level, the regression model does not appear to adequately fit the data or explain the variation in the dependent variable (Table 11, Model 1). However, the addition of diagnosis, age, GAF, illness duration, and treatment setting to the variables of race and sex in a multiple regression analysis creates a model that appears to better fit the data but does not adequately explain the variation in the level of disappointment (Table 11, Model 2). Thus, it initially appears that a better understanding of a patient's level of disappointment takes into account multiple demographic and clinical variables.

In an effort to identify the fewest variables that best predict a patient's level of disappointment, all variables were entered into a backwards stepwise regression analysis. This procedure indicated that race and illness duration alone are the best predictors of disappointment level (Table 11, Model 3). Both variables significantly contribute to this model, with both race and illness duration having a positive relationship with the level of disappointment.

An analysis of variance was conducted to assess the interaction of race and illness duration on the level of disappointment. This analysis suggested that the interaction of

these two variables approached significance (F(1,78)=1.80, p=.19), as there is a greater difference in mean level of disappointment between short and long duration African-Americans (.7) than between short and long duration Caucasians (.02). However, neither main effects of race or illness duration on the level of disappointment (Table 12) was significant. Results from separate multiple regression analyses for African-Americans and Caucasians, in which illness duration was entered as an independent variable predicting level of disappointment for each race, suggest that illness duration only predicts level of disappointment for African-Americans, but not Caucasians (F=6.72, p=.01; F=1.85, p=.18, respectively).Thus, it appears that illness duration better predicts the level of disappointment among African-Americans than among Caucasians, as the length of illness leads to more of an increase in disappointment among the former group.

*Demographic differences in non-primary domains*

Although the frequency with which the remaining 11 domains were reported as disappointing renders statistical comparisons between demographic groups inappropriate, a qualitative analysis between groups may provide valuable clinical information. The frequency of patients reporting the remaining domains as disappointing are presented in Table 13, with the exception of Housing Environment and Community Services -- domains not endorsed by any patients in the sample.

Sex differences are particularly salient in the reports of disappointment with the Housing domain. Of all patients that reported this domain as disappointing, all were women, and the majority were Caucasian women. As noted in Table 3, this domain addresses the physical characteristics of the home (e.g., house size, running water, etc).

Another domain of note is Inner Experience, which was endorsed by 16% of the sample to be a domain of disappointment. This domain encompasses the feeling of self-reliance, inner harmony, and an overall peace with oneself (Table 3) and has major clinical implications. The impact that mental illness has on patients may be expressed primarily in the terms of relationships, occupation, and education, but there is also a shared disappointment across sexes and races in the ability to enjoy life and value oneself.

While there appear to be sex and race differences in the Housing domain, disappointments with the remaining domains do not appear to be specific to one particular sex or race. As was discovered in analyzing the primary domains, the issue of disappointment may not be simply explained by demographics, but may also be associated with clinical variables. Regardless of the variables that predict which domains are reported, patients across sexes and races are experiencing many disappointments in their lives that may not be as obvious to clinicians. The patient responses presented in Table 14 illustrate the wide range of disappointments with these domains.

In summary, it appears that neither sex nor race, or the combination of the two, are sufficient in determining which quality of life domains are reported as disappointing, most disappointing, or even the level of disappointment. Instead, it appears that the impact of mental illness on life domains is more complicated. The post-hoc analyses indicate that the domains of disappointment are primarily affected by a patient's GAF score, with higher functioning patients reporting Contacts as disappointing more

frequently than lower functioning patients. Similarly, the level of disappointment that

patients have experienced as a result of their mental illnesses is not predicted by race and

sex, but instead by race and illness duration.

DISCUSSION


The current research project initially predicted sex and race differences in which

life domains were reported as disappointing, which domain was reported as most

disappointing, and the overall level of disappointment. The data did not support the

simplistic original model. Rather, the evidence suggested that level of functioning is

related to the frequency with which patients report the Contacts domain as disappointing,

while race and illness duration best predict the overall level of disappointment. The

following discussion first explores the original hypotheses, then addresses the

interpretation of the post-hoc analyses.

*Hypotheses*

*Disappointment Domains*

Contrary to the initial hypotheses, race and sex alone are insufficient in predicting

differences in life disappointments, indicating that males, females, African-Americans,

and Caucasians do not significantly differ in the disappointments they have experienced

as a result of mental illness. Instead, it appears that disappointments with the primary life

domains of Knowledge and Education, Contacts, and Work are relatively equally

endorsed across the races and sexes, suggesting that in terms of life disappointment, the

men/women and African-American/Caucasian groups are more alike than not. However,

it is important to acknowledge important trends emerging in the data, though the

differences did not meet statistical significance. Specifically, more Caucasians than African-Americans reported the domain of Contacts as disappointing, indicating that they were more frequently prevented from establishing and maintaining relationships as a result of mental illness (p=.09, Table 7).

When additional clinical factors were added to these analyses as post-hoc variables, the current level of patient functioning (as measured by the GAF) was related to whether patients report the Contacts domain as disappointing, with patients in the higher GAF group reporting the Contacts disappointment domain more frequently than patients with lower levels of functioning. Thus, as patients progress and overall functioning improves, they become increasingly aware of the importance of social support and are disappointed with the effect the mental illness has had on these relationships.

A non-statistically significant trend also emerged when clinical variables were entered into the chi-square analyses. It appears that the relationship between treatment setting and the Work domain approached clinical significance, with more outpatients than inpatients endorsing this domain as disappointing (p=.04, Table 9). Patients in the outpatient facilities may be more aware of this disappointment, as they are most likely facing current employment challenges.

*Most Disappointing Domain*

When patients are asked to express which life domain has been the most disappointing, they are providing information in support of their particular "weighted domain," i.e., the domain most important to them. It was hypothesized that sex and race would influence this domain, as evidenced by differences in the frequencies with which

the sexes and races endorsed each domain as most disappointing. This hypothesis was not supported, as the chi-square analyses did not indicate any significant differences between the demographic groups. However, there was an emerging non-statistically significant trend among the data, with racial differences among females in the frequency with which they endorsed each domain as most disappointing. The addition of age and clinical variables to the chi-square analyses also resulted in no significant differences with which the domains were endorsed as the most disappointing, although there was a non-significant trend indicating the frequency with which patients with psychotic and affective disorders differed in which domains they reported as most disappointing.

When all variables are entered into three multiple regression analyses to predict each of the three primary domains as most disappointing, none of the models sufficiently fit the data or explained the variance in the dependent variable. Thus, even when all possible values of the variables are included in the model, none adequately predict which domain is reported as most disappointing.

*Level of Disappointment*

Patients were asked to rate their level of disappointment on a 1-5 Likert scale, with 1 indicating no disappointment and 5 indicating intense disappointment. It was hypothesized that race and sex would influence the level of disappointment reported by patients with mental illnesses. When sex and race were entered into a multiple regression to predict the level of disappointment, the resulting model did not sufficiently fit the data or explain the variation in the dependent variable. However, when all demographic and clinical variables were entered into the multiple regression analysis, only race and illness duration predicted the overall level of disappointment.

48

*Premorbid Functioning, Expectations, Resources, and Disappointment*

The primary focus of this research project was to identify the impact of the most salient demographic characteristics on a patient's evaluation of his/her life circumstances. However, the results of the analyses indicate that race and sex only minimally influence the domains that are reported as disappointing, most disappointing, or the level of disappointment. Instead, other variables more strongly influence patients' evaluations and reports of these domains. Although several non-statistically significant trends were identified in the analyses, it appears that level of functioning is significantly related to the frequency with which Contacts are reported as disappointing, while race and illness duration predict a patient's level of disappointment. The importance of these relationships is discussed in the context of clinical utility and importance.

*GAF and Contacts*

Overall, patients from the sex, race, diagnostic, age, illness duration, and treatment setting groups do not differ in the frequency with which they endorse the domains of Knowledge and Education, Contacts, and Work as disappointing. However, patients in the higher GAF group (i.e., higher functioning) tend to endorse Contacts as disappointing more frequently than patients in the lower functioning group. Although there was a correlation between GAF and diagnosis among patients in this sample, in which patients diagnosed with psychotic disorders are characterized by lower GAF scores, there is no relationship between diagnosis and disappointment with the Contacts domain (Table 9). Thus, it is the improvement in the overall level of functioning, rather than an improvement in diagnosis-specific psychotic or affective symptoms, that is related to the disappointment with Contacts. Such results suggest that, as functioning

49

improves, patients become more aware of the impact their mental illness has had on their relationships. Simultaneously, they become more aware of the need for these relationships, as social support is necessary to feel connected and "normal."

It is possible that the relationship between social relationships and higher levels of functioning may also be explained by the descriptions of the differing GAF groups. By definition, the Global Assessment of Functioning score addresses the negative aspects of QOL that are assessed in this project, such as social relationships and impairments in school and work. This could potentially create difficulties in differentiating whether the GAF/Contacts relationship is a valid one, or is merely restating the description of the GAF (i.e., higher functioning patients by definition have better social relationships).

According to the DSM-IV (1994), patients with GAF scores above 35 are characterized by major impairments in such areas as school, work, and family relations, whereas GAF scores 35 or below reflect serious impairments resulting from psychiatric symptoms (e.g., behavior is influenced by delusions or hallucinations, inability to function in almost all areas). Although higher GAF scores are at least partially defined by impairments in social relationships, these scores are also characterized by school and work impairments, suggesting that several areas of functioning contribute to the GAF score. Thus, higher functioning patients are not described only by adequate social functioning – they must be functioning well in several areas of their lives. However, they may also meet the scoring guidelines for higher GAF ratings by better functioning in occupational or school settings. For example, the rating of 51-60 on the GAF is described as the following: "Moderate symptoms OR moderate difficulty in social, occupational, or school functioning (DSM-IV, 1994, p. 34)." Conversely, one cannot score low on the

GAF only as a result of poor relationships; there must be other functional impairments present (e.g., GAF 21-30: "Behavior is considerably influenced by delusions or hallucinations OR serious impairment in communication or judgment OR inability to function in almost all areas (DSM-IV, 1994, p. 34)"). Although the GAF scores are partially defined by social relationships, these are not sufficient to determine the rating. As a result, there appear to be other explanations that better describe the relationship between GAF scores and disappointment with Contacts.

Due to the fact that the relationship between GAF and the Contacts domain is correlational in nature, it is important to acknowledge the possibility that it is the converse of this relationship that is true, or that the presence of other clinical factors impact and enhance this relationship. Specifically, a focus on the finding that patients with lower GAF scores endorsed Contacts as disappointing less often than those with higher GAF scores may provide better insight into this relationship. In understanding this aspect, one must take into account patient functioning prior to the diagnosis of a mental illness, i.e., premorbid functioning. Among patients with schizophrenia, those with poorer premorbid social functioning are more frequently and chronically hospitalized than those patients with good premorbid social functioning (Cannon-Spoor, Potkin, & Wyatt, 1982). In their literature review of premorbid symptoms among patients with psychotic disorders, Malla and Payne (2005) report that poor social adjustment during childhood and adolescence may be a marker for future negative symptoms, specifically the symptoms of apathy and avolition. Not only have patients not had the opportunity to develop meaningful social relationships prior to the onset of their illnesses, but they no longer feel they need these relationships or choose to seek them. Thus, patients with

poorer premorbid social functioning are characterized by a less favorable mental illness prognosis (i.e., lower levels of functioning), have little desire to form relationships, resulting in little or no disappointment with this domain (i.e., Contacts).

Although the relationship between lower GAF and Contacts was presented in terms of premorbid social functioning among patients diagnosed with psychotic disorders, the correlation has also been found among patients with affective disorders. Poorer premorbid social functioning is associated with adults diagnosed with bipolar disorder as compared to a normal sample, although this is to a lesser degree than patients diagnosed with schizophrenia (Cannon et al., 1997). Similarly, patients diagnosed with depressive disorders tend to have lower levels of social functioning at baseline, as compared to the general population. Although the improvement of depressive symptoms is related to increased social functioning (Airaksinen, Wahlin, Larsson, & Forsell, 2006), the actual duration of recovery time is not related to an improvement in social activities (Spijker et al., 2004). These findings suggest that social functioning improves in relation to symptom improvement, but is unrelated to the duration of time that passes. Often, as patients emerge from depressive episodes, they expect their relationships to improve as their symptoms diminish, and expect this to occur in a relatively short period of time. However, this is not the reality for many people. Instead, as their overall functioning improves and they become more involved with daily activities (i.e., GAF improves) they are disappointed when they find their relationships are not progressing as rapidly as expected.

*Race, Illness Duration, and Level of Disappointment*

The relationship between race and overall disappointment is one that is supported in the literature, as non-Caucasian patients often report a higher level of global life satisfaction than Caucasian patients (Lehman et al., 1995). Research on racial differences in QOL suggests that different predictors of global satisfaction exist among the races, with overall satisfaction among Caucasians best predicted by daily activities, family, social relations, living situation, and financial adequacy, respectively. Global satisfaction among non-Caucasians is best predicted by daily activities, social relations, living situation, and family, respectively (Lehman et al., 1995; Table 1). Although non-Caucasians reported lower objective levels of social contact, they were subjectively more satisfied with social relations than Caucasians. In addition, non-Caucasians reported both objectively and subjectively higher ratings of family contact than their Caucasian counterparts (Lehman et al., 1995). Thus, it appears that although non-Caucasians may report lower objective conditions, they are more satisfied with their lives in general.

These racial differences provide the framework for understanding the relationship between Caucasians and their reported level of subjective disappointment. Typically, people with mental illnesses rely heavily upon their families and social networks for support and meeting goals necessary for overall life satisfaction (as indicated by the predictors of global satisfaction for both racial groups in Lehman et al., 1995). When this support is lacking, patients are more likely to report lower levels of global satisfaction. As a result, Caucasians are expected to report lower satisfaction with their lives as a whole. Although the results from hypothesis testing in the current project did not indicate that patients in the Caucasian group reported the Contacts domain to be disappointing

significantly more often than the African-American group, this trend approached

significance (p=.09, Table 7), consistent with Lehman's report.

Racial differences in the overall level of disappointment may also be described as a contrast between life expectations and reality. Lehman et al. (1995) argue that non-Caucasians are generally more economically disadvantaged in American society than Caucasians, and may be raised in a culture that holds lower expectations for their future. To contrast, Caucasians are raised in more advantaged backgrounds, with the belief that they will have the same opportunities for success as their parents. As a result, when diagnosed with chronic mental illnesses, Caucasians experience more of a "downward social drift (p.163)," as the realities of their lives become more discrepant from their expectations. The authors present support for this argument in their finding that, although Caucasians report better objective conditions (e.g., more likely to be employed, better financial adequacy), they report lower levels of general life satisfaction (i.e., greater disappointment).

Although the Lehman et al. (1995) argument for the expectation/reality discrepancy is presented in terms of racial differences, it may also be understood in terms of differences in socioeconomic status. Lower SES has been linked to anxiety and depressive disorders among children (Johnson, Cohen, Dohrenwend, Link, & Brook, 1999) and to lower scores on several measures of neurocognitive functioning (Lewine & Caudle, 2000), while higher parental SES has been linked to increased symptom severity and decreased GAF among males (Parrott & Lewine, 2005). Although SES was not included as a primary demographic variable in the current research project, its potential ability to eliminate race effects in predicting overall disappointment could not be

disregarded. In order to assess its effects, parental education, a variable often used as a measure of SES (e.g., Parrott & Lewine, 2005), was added to the variables of race and illness duration in a backward stepwise multiple regression analysis predicting level of disappointment. This analysis suggested that the regression model consisting of race and illness duration better predicted overall level of disappointment than did the non-statistically significant model consisting of race, illness duration, and parental education (p=.09). Thus, the contribution of race in predicting level of disappointment appears to be independent of patient SES, suggesting that the experiences associated with one's self-reported race and length of illness best predict level of disappointment.

Lehman et al.'s (1995) report that Caucasians are more disappointed with their lives is supported by the current data, as the absolute level of disappointment is slightly higher among Caucasians than among African-Americans in this sample (Table 12). However, Lehman and colleagues did not take into account the impact of illness duration on the level of disappointment between the races; a variable identified by this project's post hoc analyses to be crucial in understanding racial differences in level of disappointment (Table 11). While Caucasians in the shorter illness duration group ($\leq 15$ years) report higher levels of disappointment, African-Americans in the longer illness duration group ($>15$ years) report the highest level of disappointment. These results suggest the following: 1.) Lehman et al.'s (1995) findings of, and explanations for, racial differences may be true for a subset of patients (i.e., those with shorter illness durations), but are not necessarily true for patients who have been diagnosed with mental illnesses for longer periods of time; and 2.) The disappointment level among African-Americans increases more as the length of illness duration increases than it does for Caucasians.

Lehman et al.'s (1995) expectancy/reality discrepancy explanation provides a means of understanding the initial differences in overall satisfaction between African-Americans and Caucasians. However, it appears that other factors play a primary role in affecting level of disappointment as the length of illness duration progresses, particularly among African-Americans. Lehman et al. (1995) reported that non-Caucasians in their sample reported lower levels of objective satisfaction, particularly in regards to social contacts, financial adequacy, and employment (Table 1), resources important in a person's quality of life. Although the non-Caucasians were more satisfied with their lives despite these lower objective conditions at the time of assessment, it is possible that their satisfaction diminished the longer they were forced to cope with such conditions.

It is reasonable to assume that longer periods of time without employment, money, and social support will contribute to life circumstances in which it is difficult to access many of the resources necessary for a satisfactory existence. For instance, an inability to maintain steady employment necessary for financial income creates difficulties in obtaining a stable living environment, in obtaining adequate nutrition, and in obtaining proper care for mental illness, all of which become more difficult to cope with as time progresses. As a result, African-American patients with mental illnesses may become more disappointed as they live without these resources over time.

*Limitations*

Overall, this research project has provided valuable insights into the importance of race and illness duration as predictors of overall level of disappointment. There are several strengths to this project, including the use of an open-ended interview to assess domains of disappointment, using disappointment as a means of assessing aspects of

56

QOL, the use of a large and diverse sample, and the potential to contribute to the limited literature in this area. However, there are also limitations to the current project that may be addressed in future research.

1. The current research project does not employ a formal quality of life measure. However, as discussed in the introduction, the absence of a structured measure is also a strength of this project, as it allows patients the freedom to express their domains of disappointment. Nevertheless, there is no empirical support for the use of the Illness Impact Interview as a quality of life measure. Instead, the rationale for its use is to provide data indicative of subjective quality of life with an emphasis on its negative aspects.

2. There is no measure for objective quality of life domains. Several researchers have reported demographic differences in objective QOL domains (e.g., Lehman et al., 1995, Röder-Wanner et al., 1997). As Figure 2 illustrates, the perception and evaluation of these domains contributes to overall quality of life. However, the subjective rating of such conditions may in fact stand alone as a contribution to quality of life, as the evaluation does not always correspond to the status of the objective conditions. Instead, it is the experience of the patient that is of most importance in the current project. Even so, future research may benefit from addressing demographic differences in objective domains as well.

3. The structure of the Illness Impact Interview may bias the responses of ambivalent patients. Patients are initially given the opportunity to freely respond to question #2 (see Appendix) with their list of disappointments. However, if they appear to have difficulty in responding to the question, they were prompted to consider the areas of

education, work, and interpersonal relationships, domains often reported as most negatively impacted by such mental illnesses as bipolar disorder (Michalak et al., 2006). Such prompts may influence their responses to include these domains; however, preliminary data collection suggested that several patients reported that they have not had disappointments in these domains. It appears that patients will not endorse these domains as disappointing based on suggestion alone. Despite how they came to report their disappointing domains, the significance lies in the domains that are reported. Nonetheless, future research should focus on the use of more open and non-leading prompts to allow for a genuinely free response.

4. The wording of Illness Impact Interview item #4A may provide responses not measured by this research project. Specifically, its inquiry into the domains that have been the most disappointing or *frustrating* allows patients to express frustrations, in addition to their life disappointments. The focus of the data analyses in this project has been to address disappointment domains, as these are used to indicate areas in which to improve quality of life. However, areas of frustration may also provide information for life domains of improvement, as these represent goals not obtained as a result of a mental illness.

5. Only two races are examined as part of the racial differences analyses. Although the racial distribution of patients in the sample approximates the distribution of African-Americans and Caucasians in the Louisville area, there are few sample patients from other ethnic groups. As a result, the racial differences analyses were only conducted with the African-American and Caucasian patients in the sample. Future research should address racial differences in various ethnic groups.

6. The significant findings of this research project were discovered via post-hoc analyses. The statistical relationships were not derived from theory, but instead included as a means of learning more about this particular sample. However, the information provided via these analyses provides a promising foundation for future research in the quality of life field.

7. Although several explanations were provided as possible bases for the post-hoc findings, it is important to recall that these analyses were correlational in nature. As such, it is unjust to present the relationships as unidirectional and to indicate that such clinical variables as GAF *cause* patients to be more often disappointed with their relationships. Instead, fewer relationships may cause patients to decompensate, leading to a decline in level of functioning. Regardless of the limitations resulting from correlational analyses, these relationships present several avenues for future research to address the specific direction of the relationship.

*Clinical Implications*

The findings of this research project present several implications for clinicians in their treatment of the severely mentally ill population. It is not accurate to assume that all patients are experiencing disappointment with the same areas of their lives or are experiencing the same level of disappointment, nor is it meaningful to divide these domains only along demographic lines. The differing sex and race groups appear to be no different in the domains they endorse as disappointing, providing no additional clinical information. Instead, it is important to consider the relationship between level of functioning and domains of disappointment, as well as the relationship between the

59

variables of race and illness duration and their impact on level of disappointment in treating patients with severe mental illnesses.

The primary hypotheses of this research project focused on identifying race and sex differences in life disappointments. These demographic variables were chosen as the topic for investigation due to their association with treatment and outcome, as well as their often salient means of identification. The primary intention of choosing these variables was to provide clinicians with an opportunity to rapidly identify and treat issues associated with the unique experiences associated with race and sex. However, the relationship between these variables and the measured quality of life indicators was not identified in the current research. Instead, clinicians must assume a more challenging role of assessing the influence of clinical variables on disappointments. Though these variables are often ambiguous and difficult to identify, the understanding of their impact on a person with mental illness will ultimately allow clinicians to improve patient quality of life.

The relationship between GAF and disappointment with relationships emphasizes the need for professionals to seriously consider the impact of lost relationships on their patients, specifically the patients whose level of functioning is increasing. Those patients who appear to show improvement in their symptoms continue to cope with the loss of relationships due to their mental illnesses, whereas those with lower levels of functioning are not significantly disappointed with this domain. As a result, it is essential for clinicians to consider the relationship between the overall level of functioning and a need (or lack thereof) for relationships in identifying treatment goals. For example, an initial treatment goal for higher functioning patients approaching hospital discharge or

outpatients reaching medication stabilization would be to increase the number of social contacts. As the patients improve, the goals become more demanding as they move toward the establishment of new relationships. Conversely, those patients whose GAF baseline is relatively low or patients in an acute psychotic and/or mood episode may not be concerned with establishing relationships and would be better served by alternate treatment goals.

The finding that race and illness duration predicts overall life disappointment presents several clinical implications. First, it is important for clinicians to be aware of the factors that contribute to the level of life disappointment among their patients. Often, we assume that to improve a patient's life is to improve their symptoms, but the global assessment of functioning rating does not appear to be a primary predictor of the level of disappointment in this sample. In addition, only 16% of all patients in the sample endorsed disappointments with the Inner Experience domain, the domain that captures specific symptoms that impact "inner harmony" (Table 13). Instead, particular focus should be directed to the Caucasian patients who have had shorter periods of illness duration, and to the African-American patients who have experienced symptoms of mental illness for longer periods of time. Understanding the social support systems and the expectations Caucasian patients have encountered, and the inability to meet these expectations will provide insight into their overall level of disappointment and quality of life relatively early in their mental illness. Second, it is important to acknowledge the potential impact of limited resources on African-Americans diagnosed with mental illnesses for longer periods of time. As time progresses for this group of patients, they may have considerable difficulty in accessing the resources necessary to maintain a

satisfactory quality of life. Understanding the impact of limited resources on the level of overall disappointment is crucial in formulating treatment plans and promoting accessibility to the resources they require for overall quality of life.

Although the variables identified by this research project to be associated with the specific domains of disappointment and overall level of disappointment are not as easily identified as sex and race, they provide a great deal of clinical value. Clinicians must be able to identify these variables and understand the impact of these variables on life disappointments. This awareness will provide the knowledge and understanding necessary to improve their patients' quality of life.

*Directions for Future Research*

Given the findings and limitations of the current research project, there are various areas in which future research can expand and improve upon this information to make significant contributions to the quality of life literature. Specifically, the use of more open-ended interviews, continuing to address the negative QOL dimension, and evaluating the impact of outsiders' expectations on life disappointments/quality of life may provide further insight into the much debated quality of life concept.

As mentioned on several occasions throughout this paper, the use of the Illness Impact Interview provided patients with the unique opportunity to openly express disappointments with many areas of their lives. Too often, clinicians and researchers rely heavily on structured interviews for information, and with good reason (e.g., reliability, standardization, etc.). However, much information is lost in these interviews, including an opportunity to understand the spontaneously expressed experience of the patient. When patients were asked at the conclusion of the interview if they have talked about

their disappointments to anyone, many replied that they have not and would like to, if given the opportunity. As a result, future QOL research may benefit from the use of open-ended interviews.

Often, the focus of quality of life interviews are on the positive aspects of a patient's life, almost to the extent of ignoring the "cold, hard facts" of mental illness and its impact on life goals. Although it is acknowledged and supported here that building upon positive coping strategies can be very beneficial to patients, it is also important to understand *all* of the ways they have been impacted by mental illness – both positive and negative. Recall the report of the WHOQOL group that QOL has both positive and negative dimensions (1995); however, it appears that many research groups focus on the positive (i.e., satisfaction) QOL aspects, overlooking the negative (i.e., disappointment) dimensions. As reported in this project, there are trends among the different levels of functioning, races, and varying lengths of illness duration that predict which domains are disappointing and the level of overall disappointment. To this author's knowledge, such trends have not been identified in the current QOL literature, possibly attributed to the predominant focus on positive dimensions. In order to gain a comprehensive understanding of QOL, future research should also address the negative quality of life dimensions.

The relationship between race, illness duration, and overall level of disappointment identified in this project is believed to be the result of differential future expectations and accessibility to resources among African-Americans and Caucasians, and the ways that mental illness has prevented them from meeting these goals. Although the relationship of familial and cultural expectations to the emergence, manifestation, and

63

severity of various psychiatric symptoms has been investigated, little is known about the relationship of these expectations to quality of life among patients with mental illnesses. Unfortunately, this relationship was not investigated in the current project, but it does present an important line of future research in the quality of life field. An understanding of the impact of racial expectations on level of disappointment will guide future treatment strategies and goals.

Similarly, further investigation into the specific resources that may contribute to an increase in disappointment among African-Americans was not investigated as part of the current research. Future research would benefit from understanding which life aspects have become more disappointing over the course of mental illness for African-Americans. Ultimately, the purpose of this research is to provide clinicians with the guidelines necessary to understand the experiences of their patients, with the goal of improving the quality of life among people with mental illnesses.

Table 1

<u>Race Differences in Quality of Life</u>

| | Sample Size | Demographic Composition (% Caucasian) | Method of Analysis | Objective Differences[a] | Subjective Differences[a] | Differences in Global QOL[a] |
|---|---|---|---|---|---|---|
| **Quality of Life Interview** | | | | | | |
| *Lehman, 1988* | (1) n=278<br><br>(2) n=99<br><br>(3) n=92 | (1) 74.8<br><br>(2) 78.8<br><br>(3) 90.2 | Correlation of demographics with General Life Satisfaction (1=Caucasian, 0=Non-Caucasian) | - | - | (1) r=-.06 (NS)<br><br>(2) r=-.13 (NS)<br><br>(3) r=.10 (NS) |
| *Lehman et al., 1995* | n = 1805 | 53.0 | MANOVA | Overall race difference (F=5.87***) | Overall race difference (F=5.30***) | - |
| | | | Univariate Analysis | **Non-Caucasians**<br>Family contacts<br>(F=21.38***) | **Non-Caucasians**<br>Satisfaction w/family (5.08*)<br>Social relations (F=12.69***) | **Non-Caucasians**<br>Life satisfaction<br>(F=14.15***) |
| | | | | **Caucasians**<br>Social contacts (F=4.92*),<br>Financial adequacy (F=0.65*),<br>Employed (F=8.64**) | - | - |
| | | | Multiple Regression (DV: Global Life Satisfaction) | **Non-Caucasians**<br>Most impt determinants of global satis: Social relations***, daily activities***, financial adequacy* ($r^2$=.112***) | **Non-Caucasians**<br>Most impt determinants of global satis: Daily activities***, family****, social relations***, living situation** ($r^2$=.488***) | - |
| | | | | **Caucasians**<br>Most impt determinants of global satis: Financial adequacy***, social relations***, amt spent/month***, daily activities/victimization** ($r^2$=.149***) | **Caucasians**<br>Most impt determinants of global satis: Daily activities***, social relations***, living situation*, family* ($r^2$=.419***) | - |

*p≤.05, **p≤.01, ***p≤.001, NS=Not significant

a: Results reported as race with highest scores on reported domains

Table 2

## Sex Differences in Quality of Life

| | Sample Size | Demographic Composition (% of Males) | Method of Analysis | Objective Differences[a] | Subjective Differences[a] | Differences in Global Quality of Life[a] |
|---|---|---|---|---|---|---|
| **Satisfaction with Life Domains Scale** | | | | | | |
| *Baker & Intagliata, 1982* | n=118 | 39.0 | Correlation | - | - | NS |
| *Mercier et al., 1998* | n=165 | 59.5 | Multiple Regression (DV: SLDS scores) | NS | NS | NS |
| **Lehman Quality of Life Interview** | | | | | | |
| *Lehman, 1988* | (1) n=278 (2) n=99 (3) n=92 | (1) 65.5 (2) 52.5 (3) 42.9 | Correlation (0=Male, 1=Female) | - | - | (1) r=.04 (NS) (2) r=.01 (NS) (3) r=-.09 (NS) |
| *Lehman et al., 1995* | n=1805 | 54.0 | MANOVA | Overall gender difference (F=6.64***) | Overall gender difference (F=7.36***) | - |
| | | | Univariate Analysis | **Males** Daily activities (F=11.99***), Financial adequacy (F=5.84*), Employment (F=4.87*), Amount spent/mo (F=16.92***), More often arrested (F=22.57***) | **Males** Daily activities (F=4.32*), Family relations (F=4.46*), Safety (F=22.23***) | **Males** QOL (F=4.97*) |
| | | | Multiple Regression (DV: Global Life Satisfaction) | **Females** Most impt determinants of global life satis: Daily activities***, financial adequacy**, social relations*, victimization* (r²=.104***) | **Females** Most impt determinants of global life satis: Daily activities***, social relations***, family**, living situation* (r²=.426***) | - |
| | | | | **Males** Most impt determinants of global life satis:Financial adequacy***, family contact***, amount spent/month**, # times arrested*, employed* (r²=.141***) | **Males** Most impt determinants of global life satis:Daily activities***, family***, social relations***, living situation*** (r²=.466***) | - |
| *Vandiver, 1998* | n=102 | 65.0 | Means Comparison | NS | NS | NS |
| *Solomon & Draine, 1993* | n=94 | 52.0 | Means Comparison | - | NS | - |

*p≤.05, **p≤.01, ***p≤.001, NS= Not significant

a: Results reported as highest scores on reported domains

b: Coefficient of Congruence

# Table 2 (Continued)

| | Sample Size | Demographic Composition (% of Males) | Method of Analysis | Objective Differences[a] | Subjective Differences[a] | Differences in Global QOL[a] |
|---|---|---|---|---|---|---|
| **Quality of Life Scale** | | | | | | |
| *Heinrichs et al., 1984* | n=111 | 53.0 | Principal Component Factor Analysis | - | **Females** Sense of Purpose loads on factor w/curiosity, empathy, emotional interaction (CC[b]=.53) | - |
| | | | | - | **Males** Curiosity and Aimless Inactivity items load on Interpersonal Relatons factor (CC[b]=.50; .59) | - |
| *Shtasel et al., 1992* | n=107 | 54.2 | Means Comparison | - | **Females** Social (t=3.03**) Engagement (t=1.90*) | **Females** QOL(t=2.34**) |
| **Lancashire Quality of Life Profile** | | | | | | |
| *Röder-Wanner et al., 1997* | n=617 | 56.2 | Means Comparison | **Females** Working (35.8%)*** Married (23.7%) *** Contact w/medical care (54.4%)** | | - |
| | | | | | **Males** Personal safety (M=5.0)*** | - |
| | | | Multiple Regression (DV: Subjective QOL, Objective QOL) | **Males** Most important determinants of obj. QOL: recent contact w/friend (Multiple R = .19) | **Males** Most important determinants of subj. QOL: getting on with others, finances, mental health, living, leisure (Multiple R =.56) | - |
| | | | | **Females** Most important determinants of obj. QOL: age, finances, # of leisure activities (Multiple R = .32) | **Females** Most important determinants of subj. QOL: mental health, leisure, friends, safety, living (Multiple R = .57) | - |
| *Evans et al., 1999* | UK: n=279, Germany: n=386 | UK: 53.1 Germany: 49.2 | Means Comparison | - | **UK Females** Work (t=-3.48)*** Employment (t=-3.58)*** | - |
| | | | | - | **Germany Females** Safety (t=-2.96)** | - |
| | | | | - | **UK Males** Safety (t=3.05)** Family (t=2.66)** Health (t=2.27*) | - |
| *Thornicroft et al., 2002* | n=404 | 43.0 | Means Comparison | **Males** Family relations (95% CI: 0.02 to 0.56)* | NS | - |
| | | | | **Females** Leisure (95% CI: 0.05 to 0.47)* | NS | - |

*p≤.05, **p≤.01, ***p≤.001, NS= Not significant

a: Results reported as highest scores on reported domains

b: Coefficient of Congruence

67

Table 3

## QLS-100 Domains (Skantze & Malm, 1993)

| QLS-100 Domains | 1. Housing | 2. Household & Self-Care | 3. Housing Environment | 4. Community Services | 5. Knowledge & Education | 6. Contacts | 7. Dependence |
|---|---|---|---|---|---|---|---|
| Descriptives | Size of housing | Shopping | Pollution | Public transportation | Understands English | Relationship with mother, father | Need to live with others |
| | Lighting | Food and diet | Neighbors | Mail services | Magazines available | Relations cohabitant/spouse | Need company to travel |
| | Heating | Hygiene | Discrimination | Telephone services | Books available | Relations children | Need help handling money |
| | Hot water | Clothing | Safety | Bank services | Basic schools | Relations other relatives | |
| | Drinking water | Laundry | Pedestrian paths, bicycle paths | Shop services | College, university | Friendships same sex | |
| | Kitchen | House cleaning | Roads | | Vocational education | Friendships opposite sex | |
| | Toilet | Garbage | Street lighting | | | Sexual relationship | |
| | Bath/Shower | | | | | Relations co-workers | |
| | Appearance of housing | | | | | Relationship staff | |
| | Peace and quiet | | | | | | |
| | Privacy | | | | | | |

| QLS-100 Domains | 8. Finances, Savings | 9. Inner Experience | 10. Religion | 11. Mental Health | 12. Physical Health | 13. Work | 14. Leisure |
|---|---|---|---|---|---|---|---|
| Descriptives | Benefits, pension | Inner harmony | Church activities | Sleep | Physical health care | Vocational positions | Being with others |
| | Income from work | Pleasure from life | Religious experiences | Psychiatric care | Dental care | Regular activities | Hobbies |
| | | Self-fulfillment | | Psychotherapy | | | Movies |
| | | Feeling needed | | Drug treatment | | | Radio |
| | | Sense of identity | | | | | TV |
| | | Self-reliance | | | | | Music |
| | | Freedom | | | | | Theatre |
| | | Love experiences | | | | | Art |
| | | Feeling understood by others | | | | | Reading papers |
| | | Enjoyment of things | | | | | Reading books |
| | | | | | | | Courses, adult education |
| | | | | | | | Active sports |
| | | | | | | | Exercise |
| | | | | | | | Nature experiences/hikes |
| | | | | | | | Travels |
| | | | | | | | Holiday |

Table 4

Descriptive Data and Sex/Race Group Comparisons

| | | Sample | Male | Female | Sex Differences | Caucasian | African-American | Race Differences |
|---|---|---|---|---|---|---|---|---|
| | n | 125 | 67 (53.6%) | 58 (46.4%) | - | 72 (57.6%) | 53 (42.4%) | - |
| Diagnostic Group[a] | | | | | | | | |
| | Psychosis | 69 (55.2%) | 44 (65.7%) | 25 (43.1%) | p=.01* | 36 (50.0%) | 33 (62.3%) | p=.17 |
| | Affective | 56 (44.8%) | 23 (34.3%) | 33 (56.9%) | | 36 (50.0%) | 20 (37.7%) | |
| Treatment Setting[a] | | | | | | | | |
| | Inpatient | 91 (72.8%) | 49 (53.8%) | 42 (46.2%) | p=.93 | 52 (57.1%) | 39 (42.9%) | p=.87 |
| | Outpatient | 34 (27.2%) | 18 (52.9%) | 16 (47.1%) | | 20 (58.9%) | 14 (41.2%) | |
| Age[b] | | 35.7 | 34.3 | 37.2 | p=.09 | 34.7 | 36.9 | p=.21 |
| Global Assessment of Functioning[b] | | 37.6 | 34.3 | 41.3 | p=.03 | 38.0 | 37.2 | p=.81 |
| Age at First Episode[b] | | 21.1 | 22.4 | 19.6 | p=.18 | 19.2 | 23.9 | p=.05 |
| Duration of Illness in Years[b] | | 14.5 | 12.4 | 17.0 | p=.05 | 16.0 | 12.4 | p=.18 |

[a] Frequency of patients in each group; chi-square tests performed to assess sex and race differences

[b] Mean scores; t-tests performed to assess sex and race differences

* Indicates statistical significance

69

Table 5

## Descriptive Data and Sex by Race Group Comparisons

| | | Caucasian Males | Caucasian Females | African-American Males | African-American Females | Sex Differences Among Caucasians | Sex Differences Among African-Americans | Race Differences Among Males | Race Differences Among Females |
|---|---|---|---|---|---|---|---|---|---|
| n | | 44 | 28 | 23 | 30 | - | - | - | - |
| Diagnostic Group[a] | | | | | | | | | |
| | Psychosis | 27 (61.4%) | 9 (32.1%) | 17 (73.9%) | 16 (53.3%) | p=.02 | p=.13 | p=.30 | p=.10 |
| | Affective | 17 (38.6%) | 19 (67.9%) | 6 (26.1%) | 14 (46.7%) | | | | |
| Treatment Setting[a] | | | | | | | | | |
| | Inpatient | 14 (60.9%) | 25 (83.3%) | 35 (79.5%) | 17 (60.7%) | p=.07 | p=.08 | p=.10 | p=.05 |
| | Outpatient | 9 (39.1%) | 5 (16.7%) | 9 (20.5%) | 11 (39.3%) | | | | |
| | | | | | | Sex x Race Interactions | | | |
| Age[b] | | 34.0 | 35.8 | 34.8 | 38.6 | p=.57 | | | |
| Global Assessment of Functioning[b] | | 35.2 | 42.3 | 32.1 | 40.4 | p=.87 | | | |
| Age at First Episode[b] | | 20.5 | 17.1 | 26.1 | 22.2 | p=.92 | | | |
| Duration of Illness in Years[b] | | 14.1 | 18.9 | 9.0 | 15.1 | p=.80 | | | |

[a] Frequency of patients in each group; chi-square tests performed to assess sex and race differences

[b] Mean scores; two-way ANOVA performed to assess sex by race interactions

Table 6

Correlation Matrix among Descriptive Variables

| | Sex | Race | Age | GAF | Duration of Illness | Diagnostic Group | Treatment Setting |
|---|---|---|---|---|---|---|---|
| Sex | - | .18 | .15 | .23* | .18 | .23* | .01 |
| Race | .18 | - | .11 | -.03 | -.14 | -.12 | -.02 |
| Age | .15 | .11 | - | .23* | .52** | .04 | .24** |
| GAF | .23* | -.03 | .23* | - | .18 | .46** | .58** |
| Duration of Illness | .18 | -.14 | .52* | .18 | - | .13 | .26** |
| Diagnostic Group | .23* | -.12 | .04 | .46** | .13 | - | -.01 |
| Treatment Setting | .01 | -.02 | .24** | .58** | .26** | -.01 | - |

*p≤.05; **p≤.01; ***p≤.001

71

Table 7

## Comparison of Disappointment Domains along Demographic Boundaries

| | Domain: Knowledge and Education | | | Domain: Contacts | | | Domain: Work | | |
|---|---|---|---|---|---|---|---|---|---|
| | Present[a] | $\chi^2$ (1, n=125) | p | Present[a] | $\chi^2$ (1, n=125) | p | Present[a] | $\chi^2$ (1, n=125) | p |
| **Sex** | | | | | | | | | |
| Male | 30 (44.8%) | 0.94 | 0.33 | 45 (67.2%) | 1.68 | 0.20 | 56 (83.6%) | 2.29 | 0.13 |
| Female | 31(53.4%) | | | 45 (77.6%) | | | 42 (72.4%) | | |
| **Race** | | | | | | | | | |
| Caucasian | 38 (52.8%) | 1.08 | 0.30 | 56 (77.8%) | 2.81 | 0.09 | 60 (83.3%) | 2.44 | 0.12 |
| African-American | 23 (43.4%) | | | 34 (64.2%) | | | 38 (71.7%) | | |
| **Sex x Race** | | | | | | | | | |
| Male | | | | | | | | | |
|    Caucasian | 20 (45.5%) | 0.02 | 0.88 | 32 (72.7%) | 1.80 | 0.18 | 38 (86.4%) | 0.72 | 0.40 |
|    African-American | 10 (43.5%) | | | 13 (56.5%) | | | 18 (78.3%) | | |
| Female | | | | | | | | | |
|    Caucasian | 18 (64.3%) | 2.56 | 0.11 | 24 (85.7%) | 2.06 | 0.15 | 22 (78.6%) | 1.03 | 0.31 |
|    African-American | 13 (43.3%) | | | 21 (70.0%) | | | 20 (66.7%) | | |
| Caucasian | | | | | | | | | |
|    Male | 20 (45.5%) | 2.44 | 0.12 | 32 (72.7%) | 1.67 | 0.20 | 38 (86.4%) | 0.75 | 0.39 |
|    Female | 18 (64.3%) | | | 24 (85.7%) | | | 22 (78.6%) | | |
| African-American | | | | | | | | | |
|    Male | 10 (43.5%) | 0.00 | 0.99 | 13 (56.5%) | 1.03 | 0.31 | 18 (78.3%) | 0.86 | 0.35 |
|    Female | 13 (43.3%) | | | 21 (70.0%) | | | 20 (66.7%) | | |

[a] Refers to number of patients endorsing domain.

# Table 8

## Demographic Differences in Most Disappointing Domain

| | Sex/Race Differences in Most Disappointing Domain[a] | | | | | | Sex and Race as Predictors of Most Disappointing Domain[b] | | |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| | *Knowledge and Education*[c] | *Contacts*[c] | *Work*[c] | $\chi^2$ *(2, n=96)* | *p* | | *-2 Log Likelihood of Reduced Model* | $\chi^2$ *(2, n=96)* | *p* |
| **Sex** | | | | | | | **Sex** | | |
| Male | 7 | 25 | 20 | 0.24 | 0.89 | | 25.26[d] | - | - |
| Female | 7 | 22 | 15 | | | | | | |
| **Race** | | | | | | | **Race** | | |
| Caucasian | 9 | 25 | 24 | 2.09 | 0.35 | | 25.26[d] | - | - |
| African-American | 5 | 22 | 11 | | | | | | |
| **Sex x Race** | | | | | | | **Sex x Race** | | |
| Male | | | | | | | | | |
|   Caucasian | 5 | 17 | 14 | 0.04 | 0.98 | | 26.77 | 1.51 | .47 |
|   African-American | 2 | 8 | 6 | | | | | | |
| Female | | | | | | | **Model Fitting Information** | | |
|   Caucasian | 4 | 8 | 10 | 3.45 | 0.18 | | *-2 Log Likelihood* | $\chi^2$ *(2, n=96)* | *p* |
|   African-American | 3 | 14 | 5 | | | | | | |
| Caucasian | | | | | | | *Intercept Only* | | |
|   Male | 5 | 17 | 14 | 0.68 | 0.71 | | 29.04 | - | - |
|   Female | 4 | 8 | 10 | | | | | | |
| African-American | | | | | | | *Final* | | |
|   Male | 2 | 8 | 6 | 1.01 | 0.61 | | 25.26 | 3.78 | .71 |
|   Female | 3 | 14 | 5 | | | | | | |

[a] Compared by use of chi-square test of independence.

[b] Calculated by use of multinomial logistic regression.

[c] Refers to number of patients endorsing each domain as most disappointing.

[d] Reduced model is equivalent to final model; no chi-square computed.

Table 9

*Comparison of Disappointment Domains along Age and Clinical Boundaries*

| | Domain: Knowledge and Education | | | Domain: Contacts | | | Domain: Work | | |
|---|---|---|---|---|---|---|---|---|---|
| | Present[a] | $\chi^2$ | p | Present[a] | $\chi^2$ | p | Present[a] | $\chi^2$ | p |
| **Diagnosis[b]** | | | | | | | | | |
| Psychotic D/O | 30 (43.5%) | 1.75 | .19 | 46 (66.7%) | 2.17 | .14 | 53 (76.8%) | .23 | .63 |
| Affective D/O | 31 (55.4%) | | | 44 (78.6%) | | | 45 (80.4%) | | |
| **Age[c]** | | | | | | | | | |
| Younger (18-35) | 33 (52.4%) | .65 | .42 | 45 (71.4%) | .02 | .89 | 48 (76.2%) | .37 | .55 |
| Older (36-55) | 28 (45.2%) | | | 45 (72.6%) | | | 50 (80.6%) | | |
| **GAF[c]** | | | | | | | | | |
| GAF ≤ 35 | 21 (44.7%) | .16 | .69 | 28 (59.6%) | 7.84 | .01* | 35 (74.5%) | 1.88 | .17 |
| GAF > 35 | 21 (48.8%) | | | 37 (86.0%) | | | 37 (86.0%) | | |
| **Illness Duration[d]** | | | | | | | | | |
| ≤ 15 yrs | 26 (43.3%) | 1.50 | .22 | 44 (73.3%) | .07 | .80 | 51 (85.0%) | 1.00 | .32 |
| > 15 yrs | 27 (55.1%) | | | 37 (75.5%) | | | 38 (77.6%) | | |
| **Treatment Setting[e]** | | | | | | | | | |
| Inpatient | 42 (50.0%) | .34 | .56 | 61 (72.6%) | 2.15 | .14 | 66 (78.6%) | 4.16 | .04 |
| Outpatient | 19 (55.9%) | | | 29 (85.3%) | | | 32 (94.1%) | | |

[a] Refers to number of patients endorsing domain.

[b] Degrees of freedom = 1, n=125

[c] Degrees of freedom = 1, n=90

[d] Degrees of freedom = 1, n=109

[e] Degrees of freedom = 1, n=118

* Indicates statistical significance

Table 10

Differences in Most Disappointing Domain along Age and Clinical Boundaries

| | Most Disappointing Domain | | | | |
|---|---|---|---|---|---|
| | Knowledge and Education[a] | Contacts[a] | Work[a] | $\chi^2$ (2, n=96) | p |
| **Diagnosis** | | | | | |
| Psychotic D/O | 4 | 23 | 23 | 5.89 | .05 |
| Affective D/O | 10 | 24 | 12 | | |
| **Age** | | | | | |
| Younger (18-35) | 8 | 19 | 20 | 2.68 | .26 |
| Older (36-55) | 6 | 28 | 15 | | |
| **GAF** | | | | | |
| GAF ≤ 35 | 5 | 17 | 13 | .18 | .91 |
| GAF> 35 | 5 | 18 | 11 | | |
| **Illness Duration** | | | | | |
| ≤ 15 yrs | 7 | 21 | 18 | .99 | .61 |
| > 15 years | 5 | 22 | 12 | | |
| **Treatment Setting** | | | | | |
| Inpatient | 9 | 36 | 22 | 2.03 | .36 |
| Outpatient | 5 | 11 | 13 | | |

[a] Refers to number of patients endorsing each domain as most disappointing.

Table 11

Variables Predicting Level of Disappointment

| | Beta Weight | $R^2$ | F | p |
|---|---|---|---|---|
| **Model 1** | | .05 | 2.02 | .14 |
| Sex | .10 | | | |
| Race | .18 | | | |
| **Model 2** | | .16 | 1.91 | .08 |
| Sex | .07 | | | |
| Race | .22 | | | |
| Diagnosis | -.17 | | | |
| Age | -.03 | | | |
| GAF | .01 | | | |
| Illness Duration | .30* | | | |
| Treatment Setting | .07 | | | |
| **Model 3** | | .13 | 5.62 | .01** |
| Race | .24* | | | |
| Illness Duration | .30** | | | |

*p≤.05; **p≤.01

Table 12

Average Level of Disappointment in Race by Illness Duration Groups*

| | | Illness Duration Group | | | ANOVA: Race Main Effect | | ANOVA: Illness Duration Main Effect | |
|---|---|---|---|---|---|---|---|---|
| | | ≤15 yrs | >15yrs | Difference | F(1,78) | p | F(1,78) | p |
| African-American | 3.76 | 3.44 | 4.09 | 0.65 | 0.97 | 0.34 | 0.82 | 0.37 |
| Caucasian | 3.84 | 4.04 | 4.06 | 0.02 | | | | |

*Scale of Disappointment: 1=No Disappointment; 5=Intense Disappointment

Table 13

## Demographic Differences in Report of Non-Primary Disappointment Domains

| | | n | Disappointment Domains[a] | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | Housing | Household & Self-Care | Dependence | Finances & Savings | Inner Experience | Religion | Mental Health | Physical Health | Leisure |
| All Patients | | 125 | 5 (4%) | 4 (3.2%) | 3 (2.4%) | 4 (3.2%) | 20 (16%) | 1 (.8%) | 2 (1.6%) | 1 (.8%) | 6 (4.8%) |
| Men | | 67 | - | 1 (1.5%) | 2 (3.0%) | 1 (1.5%) | 12 (17.9%) | - | 1 (1.5%) | - | 2 (3%) |
| Women | | 58 | 5 (8.6%) | 3 (5.2%) | 1 (1.7%) | 3 (5.2%) | 8 (13.8%) | 1 (1.7%) | 1 (1.7%) | 1 (1.7%) | 4 (6.9%) |
| African-American | | 72 | 1 (1.4%) | 2 (2.8%) | 1 (1.4%) | 1 (1.4%) | 10 (13.9%) | - | 1 (1.4%) | - | 3 (4.2%) |
| | Men | 44 | - | 1 (2.3%) | 1 (2.3%) | - | 6 (13.6%) | - | 1 (2.3%) | - | 1 (2.3%) |
| | Women | 28 | 1 (3.6%) | 1 (3.6%) | - | 1 (3.6%) | 4 (14.3%) | - | - | - | 2 (7.1%) |
| Caucasian | | 53 | 4 (7.5%) | 2 (3.8%) | 2 (3.8%) | 3 (5.7%) | 10 (18.9%) | 1 (1.9%) | 1 (1.9%) | 1 (1.9%) | 3 (5.7%) |
| | Men | 23 | - | - | 1 (4.3%) | 1 (4.3%) | 6 (26.1%) | - | - | - | 1 (4.3%) |
| | Women | 30 | 4 (13.3%) | 2 (6.7%) | 1 (3.3%) | 2 (6.7%) | 4 (13.3%) | 1 (3.3%) | 1 (3.3%) | 1 (3.3%) | 2 (6.7%) |

[a] Number and percentage of patients in each group reporting domains as disappointing.

Table 14

## Sample Patient Responses to Illness Impact Interview Question #2

| | "What have you been prevented from acccomplishing because of _____ disorder?" | | | |
| --- | --- | --- | --- | --- |
| | Male | Female | Caucasian | African-American |
| Housing | - | "...I wanted marriage, job security and home security,...a stable life." | "...not having things I want, like a house." | "...a new car, nicer furniture, without limitations due to disability." |
| Household & Self-Care | "...was scrounging for food..." | "...simple tasks like housework." | "Being able to cook." | "housekeeping" |
| Knowledge & Education | "...keeps me from finishing college." | "I want meds correct so I can get back to college and sit down for 25 minutes in class." | "Should've had my bachelor's at least by now. Would've remained in school if judgment wasn't impaired. I couldn't get out of bed some days to go to class." | "Didn't get my high school diploma." |
| Contacts | "...can't have a family, it's a family oriented world. Don't even fit in at church because I don't have a family." | "I'm too paranoid to be in a relationship...convinced [partner] wouldn't be faithful." | "People don't want to date a schizophrenic, they're too afraid. If not for schizophrenia, I'd be married and have kids." | "No groups...Anger is destroying my life." |
| Dependence | "...able to do more, more independence." | "...can't handle money...lost it all." | - | "My illness has taken its toll on my boxing...I can't travel [alone] anymore." |
| Finances & Savings | "I need the income to become more independent." | "Financial future...can't make the money I want." | "Limitations due to disability income." | "...financial stability..." |
| Inner Experience | "...my future...I have no future, just a day by day situation...I can't concentrate and get emotionally distraught because I am a perfectionist." | "I don't feel like I've grown up. I'm afraid to face life and responsibilities." | "My everyday prayer is for schizophrenia to go away so I can pursue my plans." | "Can't perform at the best of my ability." |
| Religion | - | "...going to church..." | - | - |
| Mental Health | "Good sleep...keep me up all night talking." | "Can't get a good night's sleep." | - | - |
| Physical Health | - | "...staying away from drugs." | - | - |
| Work | "Never got to go down either white collar or blue collar path because of illness. Can bag groceries, but that is for teenagers, not enough money for an adult." | "Stopped showing up b/c of voices." | "took away motivation and willingness." | "Couldn't hold a job because of hearing things, sedated because of meds, too paranoid." |
| Leisure | "Playing football" | "Go on trips..." | "Don't enjoy doing a lot of things I used to do -- sewing, don't paint, nothing artistic, don't care about plants like I used to." | "Can't follow through with hobbies." |

Standards of Comparison
Aspirations, Expectations, Etc.

The Objective Attribute → The Perceived Attribute → The Evaluated Attribute → Domain Satisfaction

Figure 1. Campbell et al.'s (1976) abbreviated QOL model of relationships between objective environment and level of satisfaction. *Note.* From "The Quality of American Life," by A. Campbell, P. E. Converse, & W. L. Rodgers, p. 13. Copyright 1976 by the Russell Sage Foundation.

Figure 2. Model of Sex and Race Differences in Quality of Life among People with

Mental Illnesses. Solid lines and referenced authors indicate supported relationships;

dashed lines (---) indicate relationships hypothesized by cited authors; hypothesized

relationships not fully examined in the current review are indicated by dotted

lines (----------). *Note.* Adapted from "The Quality of American Life," by A. Campbell, P. E. Converse, & W. L.

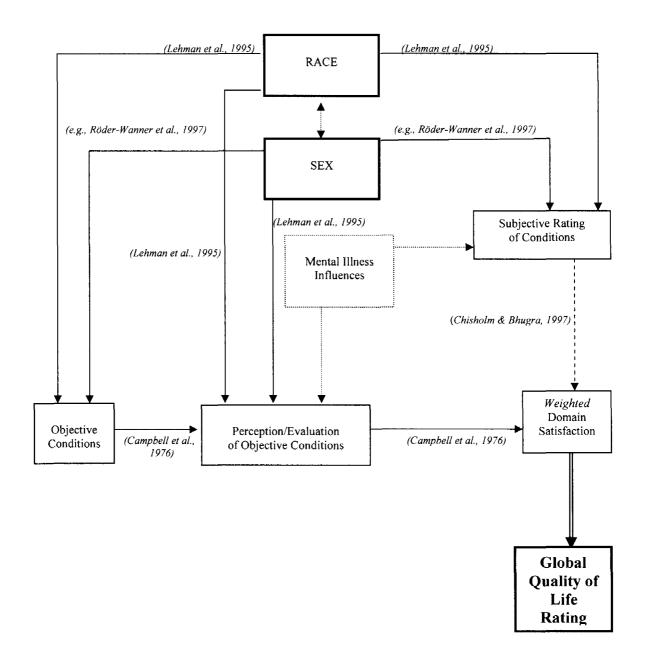Rodgers, p. 13. Copyright 1976 by the Russell Sage Foundation.

# REFERENCES

Addington, J., Young, J., & Addington, D. (2003). Social outcome in early psychosis. *Psychological Medicine, 33(6),* 1119-1124.

American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington, DC: Author.

Andrews, F. M. & Withey, S. B. (1976). *Social indicators of well-being: Americans' perceptions of life quality.* New York: Plenum Press.

Angermeyer, M. C., Holzinger, A., Matschinger, H., Strengler-Wenzke, K. (2002). Depression and quality of life: Results of a follow-up study. *International Journal of Social Psychiatry, 48(3),* 189-199.

Angermeyer, M. C., Kühn, L., & Goldstein, J. M. (1990). Gender and the course of schizophrenia: Differences in treated outcomes. *Schizophrenia Bulletin, 16,* 293-307.

Airaksinen, E., Wahlin, A., Larsson, M., & Forsell, Y. (2006). Cognitive and social functioning in recovery from depression: Results from a population-based three-year follow-up. *Journal of Affective Disorders, 96,* 107-110.

Baker, F. & Intagliata, J. (1982). Quality of life in the evaluation of community support systems. *Evaluation and Program Planning, 5,* 69-79.

Becker, M., Diamond, R., & Sainfort, F. (1993). A new patient focused index for

    measuring quality of life in persons with severe and persistent mental illness.

    *Quality of Life Research, 2,* 239-251.

Bigelow, D. A., Brodsky, G., Stewart, L., & Olson, M. (1982). The concept and

    measurement of quality of life as a dependent variable in evaluation of mental

    health services. In G. J. Stahler, & W. R. Tash (Eds.), *Innovative approaches to*

    *mental health evaluation* (pp. 345-366).

Birchwood, M., Smith, J., Drury, V., Healy, J., Macmillan, F., & Slade, M. A self-report

    Insight Scale for psychosis: reliability, validity, and sensitivity to change. *Acta*

    *Psychiatrica Scandinavica, 89,* 62-67.

Bradburn, N. M. (1969). *The structure of well-being.* Chicago: Aldine.

Browne, S., Clarke, M., Gervin, M., Waddington, J. L., Larkin, C., & O'Callaghan, E.

    (2000). Determinants of quality of life at first presentation with schizophrenia.

    *British Journal of Psychiatry, 176,* 173-176.

Buchner, A., Erdfelder, E., & Faul, F. (1997). How to use G* Power *[WWW document].*

    URLhttp://www.psycho.uduesseldorf.de/aap/projects/gpower/how_to_use_gpowe

    r.html.

Campbell, A., Converse, P. E., & Rodgers, W. L. (1976). *The quality of American life.*

    New York: Russell Sage Foundation.

Cannon, M., Jones, P., Gilvarry, C., Rifkin, L., McKenzie, K., Foerster, A., & Murray, R.

    (1997). Premorbid social functioning in schizophrenia and bipolar disorder:

    Similarities and differences. *American Journal of Psychiatry, 154(11),* 1544-

    1550.

Cannon-Spoor, H. E., Potkin, S. G., & Wyatt, R. J. (1982). Measurement of premorbid

adjustment in chronic schizophrenia. *Schizophrenia Bulletin, 8*, 470-484.

Cantril, H. (1965). *The pattern of human concerns.* New Brunswick, NJ: Rutgers

University Press.

Castro, J. R., & Rice, K. G. (2003). Perfectionism and ethnicity: Implications for

depressive symptoms and self-reported academic achievement. *Cultural Diversity

and Ethnic Minority Psychology, 9(1),* 64-78.

Childers, S. E., & Harding, C. M. (1990). Gender, premorbid social functioning and long-

term outcome in DSM-III schizophrenia. *Schizophrenia Bulletin, 16,* 309-318.

Chisholm, D., & Bhugra, D. (1997). Sociocultural and economic aspects of quality of life

measurement. *European Psychiatry, 12,* 210-215.

Corrigan, P. W., & Buican, B. (1995). The construct validity of subjective quality of life

for the severely mentally ill. *Journal of Nervous and Mental Disease, 183(5),*

281-285.

Deister, A., & Marneros, A. (1992). Geschlechtsabhängige unterschiede bei endogenen

psychosen: Ein vergleich zwischen schizophrenen, schizoaffecktiven und

affektiven psychosen. *Forischritte der Neurologie und Psychiatrie, 60,* 407-419.

Diener, E. (1984). Subjective well-being. *Psychological Bulletin, 95(3),* 542-575.

Doyle, M., Flanagan, S., Browne, S., Clarke, M., Lydon, D., Larkin, E., & O'Callaghan,

C. (1999). Subjective and external assessments of quality of life in schizophrenia:

relationship to insight. *Acta Psychiatrica Scandinavica, 99,* 466-472.

Evans, S., Huxley, P., & Priebe, S. (1999). A comparison of the quality of life of severely

    mentally ill people in UK & German samples. *International Journal of Social*

    *Psychiatry, 46(1),* 47-56.

Foerster, A., Lewis, S., Owen, M., & Murray, R. (1991). Pre-morbid adjustment and

    personality in psychosis. *British Journal of Psychiatry, 158,* 171-176.

French, J. R. P., Rodgers, R., & Cobb, S. (1974). Adjustment as person-environment fit.

    In G. V. Coelho, D. A. Hamburg, & J. E. Adams (Eds.), *Coping and adaptation*

    (pp. 316-333).

Garson, D. (2006). Logistic regression *[WWW document].* URL

    http://www2.chass.ncsu.edu/garson/PA765/logistic.htm.

Garson, D. (2006). Chi-square significance tests *[WWW document].* URL

    http://www2.chass.ncsu.edu/garson/pa765/chisq.htm.

Gianino, J. M., York, M. M., Paice, J. A., & Shott, S. (1998). Quality of life: Effects of

    reduced spasticity from intrathecal baclofen. *Journal of Neuroscience Nursing,*

    *40,* 47-54.

Gittelman-Klein, R., & Klein, D. F. (1969). Premorbid social adjustment and prognosis in

    schizophrenia. *Journal of Psychiatric Research, 7,* 35-53.

Gutek, B., Allen, H., Tyler, T., Lau, R., & Majchrzak, A. (1983). The importance of

    internal referents as determinants of satisfaction. *Journal of Community*

    *Psychiatry, 11,* 111-120.

Haas, G. L., Glick, J. D., Clarkin, J. F., Spencer, J. H., & Lewis, A. B. (1990). Gender

    and schizophrenia outcome: A clinical trial of an inpatient family intervention.

    *Schizophrenia Bulletin, 16,* 277-292.

Haas, G. L., & Sweeney, J. A. (1992). Premorbid and onset features of first episode

    schizophrenia. *Schizophrenia Bulletin, 18,* 373-386.

Häfner, H., Maurer, K., Löffler, W., & Riecher-Rössler, A. (1993). The influence of age

    and sex on the onset and early course of schizophrenia. *British Journal of*

    *Psychiatry, 162,* 80-86.

Heinrichs, D. W., Hanlon, T. E., & Carpenter, W. T. (1984). The quality of life scale: An

    instrument for rating the schizophrenic deficit syndrome. *Schizophrenia Bulletin,*

    *10(3),* 388-398.

Hines, P. M., & Boyd-Franklin, N. (1996). African-American families. In M.

    McGoldrick, J. Giordano, & J. K. Pearce (Eds.), Ethnicity and family therapy (2nd

    ed., pp. 66-84). New York: Guilford Press.

Jablensky, A., Sartorius, N., Ernberg, G., Anker, M., Korten, A., Cooper, J. E., Day, R.,

    & Bertelsen, A. (1992). Schizophrenia: Manifestations, incidence, and course in

    different cultures. A World Health Organization Ten-Country Study.

    *Psychological Medicine, Monograph Supplement 20.*

Jarema, M., & Konieczyńska, Z. (2001). Quality of life in schizophrenia: Impact of

    psychopathology, patients' gender and antipsychotic treatment. *International*

    *Journal of Psychiatry in Clinical Practice, 5,* 19-26.

Johnson, J. G., Cohen, P., Dohrenwend, B. P., Link, B. G., & Brook, J. S. (1999). A

    longitudinal investigation of social causation and social selection processes

    involved in the association between socioeconomic status and psychiatric

    disorders. *Journal of Abnormal Psychology, 108(3),* 490-499.

Katschnig, H. (2000). Schizophrenia and quality of life. *Acta Psychiatrica Scandinavica,*
*102 (Suppl. 407),* 33-37.

Kreyenbuhl, J., Zito, J. M., Buchanan, R. W., Soeken, K. L., & Lehman, A. E. (2003).
Racial disparity in the pharmacological management of schizophrenia.
*Schizophrenia Bulletin, 29(2),* 183-193.

Lazarus, R. S., & Folkman, S. (1984). *Stress, Appraisal, and Coping.* New York:
Springer Publishing Company.

Lehman, A. F., Ward, N. C., & Linn, L. S. (1982). Chronic mental patients: The quality
of life issue. *American Journal of Psychiatry, 139(10),* 1271-1276).

Lehman, A. F. (1988). A quality of life interview for the chronically mentally ill.
*Evaluation and Program Planning, 11,* 51-62.

Lehman, A. F., & Burns, B. J. (1996). Severe mental illness in the community. In E.
Spilker (Ed.), *Quality of life and pharmacoeconomics in clinical trials, $2^{nd}$ edition*
(pp. 919-924).

Lehman, A. F., Rachuba, L. T., & Postrado, L. T. (1995). Demographic influences on
quality of life among persons with chronic mental illnesses. *Evaluation and*
*Program Planning, 18(2),* 155-164.

Lewine, R. R. J., & Caudle, J. (2000). Racial effects on neuropsychological functioning
in schizophrenia. *American Journal of Psychiatry, 157,* 2038-2040.

Malla, A. K., Norman, R. M., Takhar, J., Manchanda, R., Townsend, L., Scholten, D., &
Haricharan, R. (2004) Can patients at risk for persistent negative symptoms be
identified during their first episode of psychosis? *Journal of Nervous and Mental*
*Disease,192(7),* 455-463.

Malla, A. K., Norman, R. M., McLean, T. S., & McIntosh, E. (2001). Impact of phase-specific treatment of first episode of psychosis on Wisconsin Quality of Life Index (Client Version). *Acta Psychiatrica Scandinavica, 103(5),* 355-361.

Malla, A. K., & Payne, J. (2005). First-episode psychosis: Psychopathology, quality of life, and functional outcome. *Schizophrenia Bulletin, 31(3),* 650-671.

McGlashan, T. H., & Bardenstein, K. K. (1990). Gender differences in affective, schizoaffective, and schizotypic disorders. *Schizophrenia Bulletin, 16,* 319-329.

Mercier, C., Péladeau, N., & Tempier, R. (1998). Age, gender, and quality of life. *Community Mental Health Journal, 34(5),* 487-500.

Medley, M. (1980). Life satisfaction across four stages of adult life. *Aging and Human Development, 11,* 193-209.

Michalak, E. E., Yatham, L. N., Kolesar, S., & Lam, R. W. (2006). Bipolar disorder and quality of life: A patient-centered perspective. *Quality of Life Research, 15,* 25-37.

Oliver, J. P. J. (1991). The social care directive: Development of a quality of life profile for use in community services for the mentally ill. *Social Work and Social Sciences Review, 3(1),* 5-45.

Overall, J., & Gorham, D. (1962). The brief psychiatric rating scale. *Psychological Reports, 10,* 799-812.

Packer, S., Husted, J., Cohen, S., & Tomlinson, G. (1997). Psychopathology and quality of life in schizophrenia. *Journal of Psychiatry and Neuroscience, 22(4),* 231-234.

Parrott, B., & Lewine, R. (2005). Socioeconomic status of origin and the clinical expression of schizophrenia. *Schizophrenia Research, 75,* 417-424.

Pietzcker, A., Gaebel, W., & Poppenberg, A. (1982). Prognose des verlaufs nach

klinikentlassungen bei schizophrenen kranken. In K. Heinrichs (Ed.), *Der*

*schizophrene ausserhalb der klinik* (pp. 92-104).

Preacher, K. J. (2001, April). Calculation for the chi-square test: An interactive

calculation tool for chi-square tests of goodness of fit and independence

[Computer software]. Available from http://www.quantpsy.org.

Pyne, J. M., Patterson, T. L., Kaplan, R. M., Gillin, J. C., Koch, W. L., & Grant, I. G.

(1997). Assessment of the quality of life of patients with major depression.

*Psychiatric Services, 48(2),* 224-230.

Röder-Wanner, U., Oliver, J. P. J., & Priebe, S. (1997). Does quality of life differ in

schizophrenic women and men? An empirical study. *International Journal of*

*Social Psychiatry, 43(2),* 129-143.

Schubart, C., Krumm, B., Biehl, H., & Schwarz, R. (1986). Measurement of social

desirability in a schizophrenic patient group. *Social Psychiatry, 21,* 1-9.

Shtasel, D. L., Gur, R. E., Gallacher, F., Heimberg, C., Cannon, T., & Gur, R. C. (1992).

Phenomenology and functioning in first-episode schizophrenia. *Schizophrenia*

*Bulletin, 18(3),* 449-462.

Shtasel, D. L., Gur, R. E., Gallacher, F., Heimberg, C., & Gur, R. C. (1992). Gender

differences in the clinical expression of schizophrenia. *Schizophrenia Research, 7,*

225-231.

Skantze, K. (1993). *Defining subjective quality of life goals in schizophrenia: The Quality of Life Self-Assessment Inventory, QLS-100, a new approach to successful alliance and service development.* Gothenburg, Sweden: Department of Psychiatry, Sahlgrenska Hospital, University of Gothenburg.

Skantze, K. (1998). Subjective quality of life and standard of living: a 10-year follow-up of out- patients with schizophrenia. *Acta Psychiatrica Scandinavica, 98,* 390-399.

Skantze, K., & Malm, U. (1994). A new approach to facilitation of working alliances based on patients' quality of life goals. *Nordic Journal of Psychiatry, 48,* 37-51.

Solomon, P., & Draine, J. (1993). An assessment of gender as a factor among severely mentally disabled case management clients. *Social Work in Health Care, 19(1),* 39-60.

Spijker, J., de Graaf, R., Bijl, R. V., Beekman, A. T. F., Ormel, J., Nolen, W. A. (2004). Functional disability and depression in the general population. Results from the Netherlands Mental Health Survey and Incidence Study (NEMESIS). *Acta Psychiatrica Scandinavica, 110,* 208-214.

Sullivan, G., Wells, K. B., & Leake, B. (1991). Quality of life of seriously mentally ill persons in Mississippi. *Hospital and Community Psychiatry, 42(7),* 752-755.

Test, M. A., Burke, S. S., & Wallisch, L. S. (1990). Gender differences of young adults with schizophrenic disorders in community care. *Schizophrenia Bulletin, 16,* 331-344.

Thornicroft, G., Leese, M., Tansella, M., Howard, L., Toulmin, H., Herran, A., & Schene, A. (2002). Gender differences in living with schizophrenia. A cross-sectional European multi-site study. *Schizophrenia Research, 57(2-3),* 191-200.

Whitty, P., Browne, S., Clarke, M., McTigue, O., Waddington, J., Kinsella, T., Larkin, C., & O'Callaghan, E. (2004). Systematic comparison of subjective and objective measures of quality of life at 4-year follow-up subsequent to a first episode of psychosis. *Journal of Nervous and Mental Disorders, 192(12),* 805-809.

WHOQOL Group (1995). The World Health Organization quality of life assessment (WHOQOL): Position paper from the World Health Organization. *Social Science Medicine, 41(10),* 1403-1409.

Zautra, A., & Goodhart, D. (1979). Quality of life indicators: A review of the literature. *Community Mental Health Review, 4(1),* 1, 3-10.

APPENDIX

Illness Impact Interview

---

**LOST POTENTIAL**

*Introduction*

People experiencing emotional or mental difficulties often find that they are unable to pursue some of the plans they had before the onset of their problems. Sometimes there are specific goals or expectations they had that the disorders prevent them from meeting. The following questions are intended to gain a better understanding of what you believe you've lost because of the disorder you have. There are no right or wrong answers as the focus is on your experience.

---

*Questions*

1.    When did you first begin to realize that things were not going as you had expected in your life? What led you to this conclusion?


2.    What have you been prevented from accomplishing because of _____ [disorder]? [Inquire specifically about each of the following: education; work; interpersonal]


3.    What did you expect to be doing at this time in your life before you developed problems with _____ [disorder]? [Inquire specifically about each of the following: education; work; interpersonal]

4A.    Of the different "losses" you've described, which has been the most disappointing or frustrating? What is it about not being able to _____ [loss of potential] that is disappointing or frustrating?

4B.    Please rate the level of your disappointment (circle one):

1 = none;    2 = minimal;    3 = somewhat;    4 =moderate;    5 = intense

4C.    To whom have you talked about these disappointments? Would you like to talk about [lost potential] if you had the chance?


5.        How have you tried to cope with your disappointment? What doesn't work? What works best? What advice would you give someone who is has the same disorder as you? [Note: the interview should end on a positive note that emphasizes the patient's strengths and successes.]

92

# CURRICULUM VITAE

**Christina L. Adkins**
Department of Psychological and Brain Sciences
University of Louisville
Louisville, KY 40292

## Education:

**Ph.D.**      University of Louisville (Expected graduation, 2008)
             Clinical Psychology (Full APA accreditation)

**M.A.**       University of Louisville, December 2005
             Psychology

**B.A.**       University of North Carolina at Chapel Hill, May 2000
             Psychology (with Honors)

## Professional Experience:

**Study Coordinator**                                    September 2000-May 2003
Comprehensive NeuroScience, Inc
Psychiatric Institute of Washington, Washington, DC
Responsible for coordinating research study, including but not limited to: certified rating of psychiatric symptoms, accurate documentation of medical and psychiatric management and testing, and laboratory parameters to ensure patient safety and research accuracy. Also served as a liaison between pharmaceutical companies and site operations.

**Research Assistant Volunteer**                              June 2002-May 2003
University of Maryland, College Park, MD
Research team participant in the Clinical Psychology department, assisted in the review of a Masters Thesis and data collection.

**Research Associate**                                    July-September 2000
Comprehensive NeuroScience, Inc
Psychiatric Institute of Washington, Washington, DC
Responsible for assisting in coordinating research study, including but not limited to: accurate documentation of medical and psychiatric management, testing, and laboratory parameters to ensure patient safety and research accuracy.

**Professional Experience (Continued):**

**Habilitation Aide**                                           April 1999-April 2000
Residential Services Incorporated, Carrboro, NC
Provided care to developmentally disabled group home residents, implemented resident plans and training, administered physical and occupational therapy, provided written documentation of resident progress, established and maintained therapeutic relationships with residents.

**Community Partner – volunteer**                              April 1999-April 2000
Arc of Orange County, Chapel Hill, NC
Met with a developmentally disabled adult on a weekly basis and facilitated partner's involvement in the community.

**Clinical Research Experience:**

**Study Coordinator**                                           July 2000-April 2003
Comprehensive NeuroScience, Inc, Washington, D.C.
*Supervisor: Dr. Adam Lowy, M.D.*
*Client Population: Persons diagnosed with Schizophrenia, Treatment-Resistant Schizophrenia, Schizoaffective Disorder, Bipolar Disorder, Major Depressive Disorder, Major Depressive Disorder with Psychotic Features, Treatment-Resistant Major Depressive Disorder, or Panic Disorder*

Open Label Trial Exploring A Switching Regimen From Oral Neuroleptics, Other than Risperidone, To Risperidone Depot Microspheres.

Open Label, Long Term Trial of Risperidone Long Acting Microspheres in the Treatment of Subjects Diagnosed with Schizophrenia

A Multicenter, Double-blind, Randomized Comparison of the Efficacy and Safety of Sustained-released Formulation Quetiapine Fumarate and Placebo in the Treatment of Patients with Schizophrenia

The Study of Olanzapine plus Fluoxetine in Combination for Treatment-Resistant Depression without Psychotic Features

A Double-Blind, Placebo-Controlled, Parallel-Group, Flexible-Dose Study of Venlafaxine ER in Adolescent Outpatients with Panic Disorder.

The Efficacy and Safety of Risperidone in the Treatment of Children and Adolescents with Schizophrenia

The Efficacy and Safety of Risperidone in the Treatment of Children and Adolescents with Schizophrenia: a Follow up Trial of RIS-USA-231

## Clinical Research Experience (Continued):

A Multicenter, Double-blind, Randomized Comparison of the Efficacy and Safety of Quetiapine Fumarate and Risperidone in the Treatment of Patients with Schizophrenia

A Phase III, Randomized, Double-Blind, Placebo-Controlled Study of Safety and Efficacy of C-1073 (Mifepristone) in Patients with Major Depressive Disorder with Psychotic Features

A Phase III, Randomized, Double-Blind, Placebo-Controlled Study of Safety and Efficacy of C-1073 (Mifepristone) in Patients with Major Depressive Disorder with Psychotic Features who are not receiving Antidepressants or Antipsychotics

Olanzapine versus Risperidone in the Treatment of Bipolar I Disorder, Manic or Mixed

The Efficacy and Safety of Flexible Dosage Ranges of Study Medication vs. Placebo in the Treatment of manic episodes associated with Bipolar I Disorder

A nine-week, open-label, multi-center, safety trial of flexible dosage ranges of study medication in the treatment of manic episodes associated with Bipolar I Disorder.

A Controlled Trial of study medication Versus Quetiapine in the Treatment of Schizophrenic and Schizoaffective Subjects with Prominent Negative Symptoms

A Multicenter, Randomized, Double-Blind, Placebo Controlled, 26 Week Study of a Fixed Dose of study medication in the Treatment of Stabilized Patients with Chronic Schizophrenia

A Double-Blind, Placebo and Halperidol-Controlled, Multicenter Study Evaluating the Safety and Efficacy of study medication in Schizophrenic Patients

A Double-Blind, Placebo and Haloperidol-Controlled Multicenter Study Evaluating the Safety and Efficacy of study medication in Schizophrenic Patients

A Three-Week, Multicenter Randomized, Double-Blind, Placebo-Controlled Safety and Efficacy Study of Extended-Release study medication in Patients with Bipolar Disorder

A Six-Month, Open-Label, Multicenter Study of Extended-Release study medication in Patients with Bipolar Disorder – An Extension of Protocols 105.301 and 105.302

A Multicenter, Randomized, Double-Blind, Placebo Controlled Study of Three Fixed Doses Of study medication In the Treatment of Patients with Acute Schizophrenia

## Clinical Research Experience (Continued):

A randomized, double-blind, placebo— and risperidone-controlled, multicenter study to evaluate the efficacy and safety of two nonoverlapping dose ranges of study medication given b.i.d. for 42 days to schizophrenic patients followed by a long-term treatment phase with study medication given q.d.

Study medication depot (microspheres) vs. placebo in the treatment of subjects with schizophrenia

Study medication depot (microspheres) in the treatment of subjects with schizophrenia or schizoaffective disorder

A prospective, randomized, double-blind and active-controlled, multicenter study to evaluate the efficacy and safety of three fixed doses of study medication (4, 8, and 12 mg/day) given bid for 42 days to schizophrenic patients with acute or subacute exacerbation, followed by a double blind, active-controlled, flexible dose, long term, 20 week phase with study medication (4, 8, 12 or 16 mg/day) given q.d.

A randomized, double-blind, placebo— and risperidone-controlled, multicenter study to evaluate the efficacy and safety of two nonoverlapping dose ranges of study medication given b.i.d. for 42 days to schizophrenic patients with acute or subacute exacerbation, followed by a risperidone-controlled, long-term treatment phase with study medication given q.d.

## Clinical Practicum Experience:

**Inpatient Group Leader**                                      June 2004-Present
University of Louisville Hospital, Louisville, KY
*Supervisor: Dr. Richard Lewine, Ph.D.; 1hr/wk on rotational basis*
*Client Population: Psychiatric hospital inpatients with range of Axis 1 diagnoses, including: Schizophrenia, Schizoaffective Disorder, Bipolar Disorder, Major Depressive Disorder*

Co-led weekly psychosocial and psychoeducational groups on an inpatient adult psychiatric unit.

**Psychology Clinic Therapist**          June 2004-June 2005; July 2006-Present
University of Louisville Psychological Services Center, Louisville, KY
*Supervisor: Dr. Richard Lewine, Ph.D.*
*Client Population: Persons diagnosed with Bipolar Disorder, Major Depressive Disorder*

Administered diagnostic assessments and provided psychotherapy to clients. Trained in psychological treatment of severe mental illness.

## Clinical Practicum Experience (Continued):

**Psychology Clinic Therapist**                                              July 2005-July 2006
University of Louisville Psychological Services Center, Louisville, KY
*Supervisor: Dr. Tamara Newton, Ph.D.*
*Client Population: Persons diagnosed with Posttraumatic Stress Disorder, Major Depressive Disorder*

Administered PTSD-focused diagnostic assessments and therapy to clients. Trained in assessment of PTSD, consisting of PDS and CAPS administration; trained in treatment of PTSD, consisting of therapy with CBT focus.

**Outpatient Psychiatry Practicum Placement**                        August 2005-May 2006
University of Louisville Hospital, Louisville, KY
*Supervisor: Dr. Tracy D. Eells, Ph.D.; 20hrs/wk placement*
*Client Population: Persons diagnosed with range of Axis I and Axis II disorders, including: Posttraumatic Stress Disorder, Major Depressive Disorder, Dysthymia, Panic Disorder, Borderline Personality Disorder, Bipolar Disorder*

Provided psychotherapy to outpatient psychiatry patients, administered intake interviews to new clinic patients, administered clinical assessments to psychiatric hospital inpatients and outpatients. Assessments included evaluation of cognitive functioning in geriatric inpatients, inpatient diagnostic assessment, and outpatient ADHD testing.

**Testing Practicum/Psychiatry Placement**                              August 2004-May 2005
Central State Hospital, Louisville, KY
*Supervisor: Dr. J. Wayne Putnam, Psy.D.; 20 hrs/wk placement*
*Client Population: Psychiatric hospital inpatients with range of Axis I diagnoses, including: Schizophrenia, Schizoaffective Disorder, Bipolar Disorder, Major Depressive Disorder*

Administered, scored, and reported various clinical assessments to state psychiatric hospital inpatients, including diagnostic, symptom, and risk assessments. Presented results in daily multidisciplinary treatment team meetings. Co-led weekly Anger Management groups.

## Academic Research Experience:

**Graduate Researcher**                                             July 2003-Present
Department of Psychological and Brain Sciences (Psychosis Lab)
University of Louisville, Louisville, KY
*Supervisor: Dr. Richard Lewine, Ph.D.*
*Client Population: Persons diagnosed with Schizophrenia or other Psychotic Disorders*

Graduate researcher for an academic study examining young men's loss of work potential after being diagnosed with schizophrenia. Recruited study subjects, administered and scored neuropsychological assessments as well as self-report questionnaires.

**Graduate Researcher**                                             November 2004-Present
Department of Psychological and Brain Sciences (Psychosis Lab)
University of Louisville, Louisville, KY
*Supervisor: Dr. Richard Lewine, Ph.D.*
*Client Population: Persons diagnosed with mental illness*

Graduate researcher for an academic study examining impact of mental illness on psychiatric patients. Administered and scored clinical interviews and self-report questionnaires.

## Teaching Experience:

**Teaching Assistant**                                             August 2003- May 2004
Department of Psychological and Brain Sciences
University of Louisville, Louisville, KY
*Supervisors: Richard Lewine, Ph.D. (fall semester), and Abbie Beacham, Ph.D. (spring semester)*

Prepared course materials, graded exams, lead study sessions, and co-taught undergraduate Personality Psychology courses.

**Teaching Assistant**                                             August - December 2006
Department of Psychological and Brain Sciences
University of Louisville, Louisville, KY
*Supervisor: Suzanne Meeks, Ph.D.*

Prepared course materials, graded exams, lead study sessions, and co-taught undergraduate Abnormal Psychology courses.

## Conference Presentations:

Walker, K., Adkins, C., & Lewine, R. (2007, March). *Differences Among Psychotic and Affective Disorders In Reported Domains of Disappointment*. Poster session presented at the annual meeting of the Academic Mentoring Conference of the Kentucky Psychological Association, Lexington, KY.

Adkins, C. & Lewine, R. (2005, October). *Racial differences in the relationship between subjective quality of life and patients' reported losses*. Poster accepted for presentation at the annual meeting of the Society for Research in Psychopathology, Coral Gables, FL.

Adkins, C. & Lewine, R. (2005, April) *Sociodemographic variables as moderators between psychotic symptoms and tardive dyskinesia: A comparison of schizophrenia and schizoaffective patients*. Poster session presented at the annual meeting of the International Congress on Schizophrenia Research, Savannah, GA.

Adkins, C., Lewine, R., Parrott, B., Cadle, C., & Wilson, T. (2004, May). *Race moderates the relationship between tardive dyskinesia and symptoms of schizophrenia*. Poster session presented at the annual meeting of the American Psychological Society, Chicago, IL.

Cadle, C., Adkins, C., Parrot, B., & Wilson, T. (2004, May). *Variables correlated with schizophrenia and violence*. Poster session presented at the annual meeting of the American Psychological Society, Chicago, IL.

Parrott, B., Lewine, R., Cadle, C., Wilson, T., & Adkins, C. (2004, May). *Job acceptability and socioeconomic status of origin: Clinical implications*. Poster session presented at the annual meeting of the American Psychological Society, Chicago, IL.

Adkins, C. (2000, April). *Self-esteem vs. self-acceptance as a better predictor of mental health*. Poster session presented at the annual meeting of the University of North Carolina undergraduate poster presentations.

## Professional Activities:

**Public Education Committee Student Member**                    May 2006-Present
Kentucky Psychological Association

Participated in various community programs to enhance public awareness of psychology and psychological services.

## Professional Activities (Continued):

**Hurricane Katrina Crisis Training**                                May 2006
Kentucky Psychological Association

Participated in training session on special issues pertaining to crisis intervention and treatment with Hurricane Katrina victims.

**Health Fair Representative**                                     March 2006
Kentucky Psychological Association

Represented KPA at local health fair, provided information to visitors on psychological services for state of Kentucky.

**Extra-Curricular Rorschach Training**                    January-April 2004
University of Louisville

Participated in voluntary training sessions on the administration, scoring, and interpretation of the Rorschach Inkblot Test.

**Family-to-Family Course Consultant**            September-November 2003
National Alliance for the Mentally Ill

Provided psychoeducational information for family members of people with mental illnesses in weekly group meetings.

**Crisis Intervention Training**                             October 2003
Louisville Metro Police Department

Assisted in training local police force in techniques used in emergencies involving mentally ill people.

## Professional Memberships:

**Kentucky Psychological Association**                    September 2003-Present
Graduate student affiliate

**American Psychological Society**                        September 2003-Present
Graduate student member

## Honors and Awards:

| | |
|---|---|
| **James Henley Thompson and Evelyn Barnett Thompson**<br>**Undergraduate Research Award**<br>University of North Carolina | 2000 |
| **Two-hundred and fifty dollar grant to fund undergraduate thesis**<br>University of North Carolina | 2000 |
| **Dean's List 7 semesters**<br>University of North Carolina | 1997-2000 |
| **Graduated cum laude**<br>University of North Carolina | 2000 |
| **Psi Chi member**<br>University of North Carolina | 1998-2000 |