

SUBJECTIVE EXPERIENCES OF QUALITY OF LIFE IN AUTISTIC ADULTS ACROSS
RACE AND GENDER IDENTITY: A STUDY OF HAPPINESS AND PHYSICAL,
COGNITIVE, AND SOCIAL WELL-BEING

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May 2025

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ABSTRACT

The need for effective programming and intervention to improve the Quality of Life for autistic individuals is well documented. Yet relatively little research is devoted to autistic adults, leaving substantial gaps in programs and services for this subgroup of the autistic population. A review of the current literature emphasized the need for a more robust understanding of predictive indicators of quality of life in the autistic adult population, the inclusion of quality of life domains that are important to the subjective experiences of autistic adults, and more representative samples within autism research. The current study, grounded in Maslow's human needs theory, aimed to address these gaps by exploring the effects of race; gender identity; and Physical, Cognitive, and Social Health and Well-being satisfaction on Global Happiness Ratings in the autistic adult population.

Hierarchical Multiple Regression was used to analyze the results of the study, which had a sample size of $N = 83$ adults who self-identified as being on the autism spectrum. The sample ranged in age from 18 years to 73 years, with a mean age of 34.7 years. Approximately 11% of the sample identified as Black, 69% identified as White, and the remaining 20% identified with

Racial Intersectionality. Regarding gender identity, approximately 41% of the sample identified as Female, 42% identified as Male, and the remaining 17% identified as Gender Non-conforming.

Physical Health and Well-being was found to be a significant positive predictor of Global Happiness Ratings for those who identified as Black. Because the impacts of race on quality of life domains has not been previously explored in the autistic adult population, this finding is the first of its kind to indicate that Black autistic adults may be more impacted by aspects related to Physical Health and Well-being than other demographic groups. Social Health and Well-being emerged as the strongest predictor of Global Happiness Ratings in the autistic adult sample. As Social Health and Well-being increased, so did Global Happiness at a relatively large rate with a high degree of certainty. This finding is consistent with previous studies and supports the inclusion of social health and well-being considerations at all levels of programs and services for autistic adults regardless of race and/or gender identity. In addition to the significant findings, trends were observed in the current study that warrant attention, including negative trends in global happiness for those who have racial intersectionality and those who are gender non-conforming. These trends are consistent with previous studies that have found indications of excess intersectional disparity and lower quality of life in those who live with multiple marginalized identities.

Like all research, the current study had limitation that impacted the interpretability and generalizability of results. Specific limitation included those inherent to cross-sectional survey research and a lack of acceptable reliability in the Cognitive Health and Well-being domain utilized. However, this study contributed to the current body of knowledge of autistic adult quality of life and has several critical implications for clinical practice, administration and

policy, and future research. Administration and policy efforts need to focus on social inclusivity so autistic adults, including those with other marginalized identities, will be seen as equitable members of society. Recommendations for future research include incorporating longitudinal designs in autistic quality of life studies, enhancing diversity within autistic samples, establishing professional consensus on the ideal instrument to use when measuring subjective quality of life in autistic adults, and integrating self- and informant-report measures to improve reliability and validity of findings.

Subjective Experiences of Quality of Life in Autistic Adults Across Race and Gender Identity: A
Study of Happiness and Physical, Cognitive, and Social Well-Being

A Dissertation

Presented to the Faculty of the Department of Addictions and Rehabilitation Studies

East Carolina University

In Partial Fulfillment of the Requirements for the Degree

Ph.D. Counselor Preparation and Research

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May 2025

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ACKNOWLEDGEMENTS

This journey began with a chance meeting with Dr. Sligar to discuss the MS Certificate in Vocational Evaluation. Upon meeting Dr. Sligar, I was quickly shepherded down the hall to meet who would become my champion and mentor, Director of the PhD program, Dr. Leierer. I am not sure what you saw in me, Dr. Sligar, but I thank you for ushering me both down the hall that day and into the next chapter of my life.

Throughout this process, I have often been asked, “How do you do this? No, seriously, how do you write a dissertation, work full-time, and have the energy to be a husband and father?” The truth is, I have not done this alone. I have had the privilege and pleasure of having an amazing team alongside me!

To my family, thank you for your unwavering love and encouragement. I send a special thanks to my amazing wife, Hillary, for being my constant source of motivation and reminding me that there is light at the end of this tunnel, my awe-inspiring son, Nash, for reminding me of the important things in life and keeping me in the present as much as possible, and my loyal companion and dog, Ryder, for keeping me company on countless late nights spent writing and editing.

Next, I would like to thank the entire Department of Rehabilitation and Addiction Studies at East Carolina University. There have been numerous changes in the department throughout my tenure, yet one constant remains: the steadfast, dedicated support of the students and faculty. I would like to specifically thank my committee members within the department. Dr. Crawford, thank you for accepting me as I transitioned to the dark side known as the Clinical tract. I appreciate our candid discussions of your own dissertation experience and your positive outlook. Dr. Pritchard, cohort mate turned committee member. Thank you for paving the way before me

and showing me that it can, indeed, be down; setbacks and all! Dr. Atherton, I am forever indebted to you for taking on the role of my Dissertation Director. Thank you for your consistent encouragement, realistic expectations, and thorough guidance and feedback throughout this process. Finally, I would like to thank Dr. Leierer. From our in-person meetings in your office to our online summits, we spent countless hours discussing the nuances of my analysis, options for presenting the results, and life in-general. From the bottom of my heart, I thank you for your respect and mentorship, as well as your generous sharing of time and wisdom.

I also extend my thanks to my colleagues at TEACCH and the greater UNC community. Thank you all for your prayers and support throughout this process, which included listening to me during stressful times, extending your patience when I took vacation time to work undisturbed in my office, and being an inspiration to strive to do more for the people with whom we serve. I especially want to thank you, Dr. Klinger. As my work supervisor, internship supervisor, and committee member, you have been an instrumental part of this endeavor from beginning to end. Thank you for supporting me and this process!

Last but not least, I thank the autistic community. This work is for and because of you. Thank you for trusting me with your voices and lived experiences so that ,together, we can strive for a world where all autistic people can live with respect for their identity, inclusion, and happiness.

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CHAPTER 1: INTRODUCTION

Introduction to the Study

This chapter provides an introduction to this research study exploring the effects of physical, cognitive, and social health and well-being satisfaction domains on global happiness ratings in the autistic adult population. The analysis also examined the effects of race and gender identity on overall quality of life and global happiness in autistic adults. Further, this study determined if an interaction exists amongst race, gender identity, and physical health and well-being, cognitive health and well-being, and social health and well-being on global happiness ratings in autistic adults. The chapter includes the background of the study, statement of the problem, purpose of the study, theoretical rationale, research questions, study justification, significance of the study, definition of important terms, and a chapter summary. First, however, the chapter begins with a statement regarding this author's views towards neurodiversity and the use of identity first language.

A Statement on Neurodiversity and Identity First Language

There exists a growing alignment of theory, research practices, and clinical interventions with the neurodiversity movement (Botha et al., 2024; Chapman, 2019; Masataka, 2017; Taboas, 2022). Plainly, neurodiversity accounts for the neurocognitive variation found within the human species (Walker, 2014). This dissertation aimed to recognize and support the neurodivergence of autistic people as a trait of the autistic culture. Attempts were made to avoid pathologizing characteristics of autistic identity and neurodiversity, while highlighting themes and patterns of human existence that are often particularly relevant for this group. The term "disorder" can serve in opposition to the neurodiversity movement. This researcher attempted to use the full term

“autism spectrum disorder” sparingly and primarily when the diagnostic framework of identified criteria were discussed. Most often, the terms “autism” and “autistic” were used.

Along with the neurodiversity movement have come robust discussions of person-first language versus identity-first language. Taboas, Doepke, and Zimmerman (2022) found that 87% of autistic adults in their study preferred the use of identity-first language (i.e., autistic person versus person with autism). Professionals, however, seem to be more likely to use person-first language, as it is consistent with professional expectations and training. Throughout the manuscript, this researcher alternates between the use of person-first language and identity-first language in an effort to respect both perspectives.

Background of Study

Current prevalence rate estimates indicate that one in every 36 children in the United States has a diagnosis of autism (Maenner et al., 2023). The Diagnostic and Statistical Manual of Mental Disorders, 5th edition, Text Revision (DSM-5-TR) defines Autism Spectrum Disorder (ASD) as a neurodevelopmental disorder consisting of persistent deficits across two primary areas of functioning: social-communication and restricted/repetitive patterns of behavior and interests (American Psychiatric Association, 2022). While those with autism display many strengths, there is a breadth of literature supporting the array of challenges experienced by autistic individuals and their families. The need for effective programming and intervention in working with autistic individuals is well documented (Shattuck et al., 2018; Hume et al., 2021; Lai et al., 2020) and autistic individuals can display a wide range of symptoms and symptom severity, including significant challenges with co-occurring mental health disorders (e.g., anxiety and depression) and adaptive behavior skills. As many as 84% of autistic people carry a co-occurring anxiety disorder diagnosis (Rodgers et al., 2016), with more conservative estimates

averaging around 40% (Jitlina et al., 2017). Additionally, individuals with ASD typically score well below the population mean on measures of adaptive functioning (Lee & Park, 2007).

Adaptive behaviors encompass everyday skills that are independently initiated, such as effectively communicating with others, participating in community activities, and developing meaningful relationships (Pugliese et al., 2016, p. 1597).

Adult outcomes within the autistic population are multi-faceted and complex. While what is means to be a successful adult with autism is highly contentious, research has tended to focus on the areas of employment, social opportunities, and community engagement (Henninger & Taylor, 2013). More recent literature has highlighted the relevance of living situation and service usage (Dudley et al., 2018; Song et al., 2022). When examining the autistic population with average to above average intellectual ability, Grey et al. (2014) found that more than half of the autistic adults in their sample continued to live with family members for support and only 18% were employed full time. These results were similar to other studies examining living arrangement that have found large percentages of autistic adults, of all levels of functioning, living with family members versus living alone or with roommates or a spouse (Anderson et al., 2014; Farley et al., 2018; Song et al., 2022). However, autistic adults living with roommates or a spouse have reported more satisfaction with current living arrangement than those living with family members (Song et al., 2022). Further, research exploring outcomes in older adults with autism has shown significant increases in physical health conditions, diminished social participation, increased co-occurring mental health conditions, and elevations in cognitive decline (Croen et al., 2015; Hand et al., 2020; Hollocks et al., 2019; Jadav et al., 2022; Klein & Klinger, 2024; Lever & Guerts, 2016; Stewart et al., 2021). All of these factors relate to the singular constructs of physical health and wellbeing, cognitive health and well-being, and social

health and well-being and significantly contribute to a person's subjective experiences, overall wellness, and quality of life.

The World Health Organization (2022) defines quality of life as “an individual's perception of their position in life in the context of culture and value systems in relation to one's goals, expectations, standards, and concerns.” Numerous researchers and theorists, including van Heijst and Geurts (2015) emphasize that quality of life is multidimensional and value the importance of one's subjective well-being, which is how people experience and evaluate their lives (NIH, 2013). Recent autism literature has taken aim at better understanding quality of life and subjective indicators of well-being in the autistic population and prioritizing improving quality of life in clinical research (Oakley et al., 2021). Though quality of life and autism is still considered a relatively new area of research (Holmes et al., 2020), several studies have found that autistic people experience a lower level of quality of life when compared to the general population (Ayers et al., 2018; Grosvenor et al., 2023; Holmes et al., 2020; Kamp-Becker et al., 2010; Mason et al., 2018; Sáez-Suanes & Álvarez-Couto, 2021; Saldaña et al., 2009; Shipman et al., 2011; van Heijst and Geurts, 2015). For over a decade, researchers like Burgess and Gutstein (2007) have been exploring the notion that specific populations, including those with autism, likely have unique indicators that may be more indicative of quality of life for that respective population. Unfortunately, adequate understanding of predictors of quality of life in the autistic adult population continues to be severely limited and quality of life research for this subgroup of the population lags behind the general autism research devoted to children and adolescents on the spectrum (Kirby & McDonald, 2021; Lake et al., 2014; van Huemen, 2016).

Quality of Life in Autism Research

Based current life expectancy, there will be approximately 700,000 individuals age 65 and older with autism in the next 20 years (Wright et al., 2019). However, approximately 80% of autism research is devoted to children and adolescents (van Huemen, 2016), with much recent attention being placed towards later adolescents and young adulthood, often excluding older autistic adults entirely. Autism has been linked to higher rates of various psychiatric conditions, including anxiety, bi-polar disorder, depression, and schizophrenia (Croen et al., 2015). Autistic adults have also been found to have increased risk of suicide attempts (Hedley & Uljarevic, 2018).

These factors make quality of life increasingly important to study in the growing autistic adult population. Current autism research needs to focus on the subjective experiences of autistic adults in the areas of physical, cognitive, and social well-being to inform tailored treatment recommendations, specifically equipping clinicians to better determine the foci of treatment. Drawing relevance from holistic components of human needs theory emphasizes the importance of understanding the interplay of additional considerations, such as race and gender identity, on quality of life outcomes (Costanza et al., 2007).

Race in Autism Research

There exists a startling deficiency in inclusion and representation of race in current autism literature, raising concerns for social justice in autism research. In a meta-analysis of 1013 studies of autism intervention research, Steinbrenner et al. (2022) found that only 25% of those studies collected data on race/ethnicity. Further, the researchers found that most studies that did report demographics on race were significantly over-represented by White participants. In another systematic review of studies analyzing evidence-based practices for ASD, only 30%

of the studies conducted between 2012-2017 reported data on race, while no studies conducted between 1990-2011 did so (Hume et al., 2021). Additionally, in a summary of the National Autism Indicators Report, Shattuck et al. (2018) described that the majority of respondents (i.e., 80%) were White, with Black respondents comprising only 10% of the sample. However, no differences in ASD prevalence rates have been observed between Black and White individuals (Maenner et al., 2023).

Generalizing the vast majority of the results of autism research to the entire autistic population is virtually impossible. Confounding this problem is the indication that factors such as race/ethnicity have a significant impact on the disparities seen across such domains as health, safety, and family well-being (Eilenberg et al., 2019). Davis et al. (2022) also reported that Black young adults with ASD are seldom studied in a way that examines both their racial and disability identities. However, their research indicated that 12% to 30% of Black adults with ASD experience discrimination related to their minority status as well as their disability status, which has an impact on overall happiness and quality of life compared to non-marginalized groups. Including diverse and well-represented minority groups in autism research is imperative.

Gender in Autism Research

Gender differences in the presentation of characteristics associated with autism are well documented. For example, restricted interests and stereotyped behaviors have been found to be a better indicator of autism in males than in females (Duvekot et al., 2017). Due to these differences in presentation, autistic females are more likely to be under-recognized, diagnosed late, or not diagnosed at all (Dworzynski et al., 2012; Harrop et al., 2023; Loomes et al., 2017), which often results in lack of adequate service and intervention provision, negatively impacting quality of life and happiness. However, the diagnostic rate of females has increased consistently

over the past 20 years (Harrop et al., 2023). Unfortunately, autistic females have been found to be more likely to engage in maladaptive behaviors, such as camouflaging and masking, that also have negative implications for cognitive wellness and quality of life (Pearson & Rose, 2021).

While masking often develops as a self-protective mechanism with a goal of promoting chances of social belonging, the consequences of long-term masking include increases in anxiety, depression, overall psychological distress, and burnout (Pearson & Rose, 2021; Scheeren et al., 2016). The increased likelihood of autistic females to engage in camouflaging and masking compared to autistic males (Hull et al., 2020) and the linkage of camouflaging to mental health challenges and reduced well-being (Lai et al., 2015) highlight the need to explore gender differences in quality of life autism research. Autistic individuals also have a higher likelihood of gender incongruence than the general population (George & Stokes, 2018), with gender incongruence significantly more prevalent in autistic females than in autistic males (Cooper et al., 2018). While the term gender incongruence is often used to describe the clinical presentation of one identifying as a gender other than their assigned sex at birth, this researcher prefers the term gender nonconformity to reflect more inclusive and affirming language. Regardless of specific terminology, considerations regarding gender identity versus gender defined as sex assigned at birth are increasingly important in autism research.

Statement of the Problem

Globally, much is unknown about the subjective experiences of autistic individuals as they reach adulthood. Researchers are currently uncertain on how to assess subjective indicators of quality of life and happiness within the autistic population. Yet the first cohorts of children diagnosed with ASD are now entering middle and older age (Hwang et al., 2017) and time is of the essence. Currently, there is an abundance of research, evidence-based practice, and service

recommendations for children and adolescents with ASD; however, relatively little research is devoted to autistic adults. This phenomenon leaves gaps in programs and services for the autistic adult population. Despite understanding the significant need to address quality of life concerns in the autistic adult population, researchers have demonstrated a lack of clarity regarding quality of life indicators important to autistic adults (Burgess & Gutstein, 2007).

Most measures of quality of life used with the autistic population were designed for the general population (Erez & Gal, 2020; McConachie et al., 2018) and neglect to factor in specific subjective indicators that may be unique to this population and other individuals with disabilities. Measurements that include considerations for the subjective experiences of those with autism and other disabilities do exist; however, they are being underutilized. One such instrument is the Perceived Quality of Life (PQoL) Scale, which was developed, in part, by interviewing persons with disabilities (Patrick, 2015). The PQoL Scale is based on human needs theory developed by Abraham Maslow in his original publication of *Toward a Psychology of Being* in 1962 (Maslow, 2013) and includes the life domains of physical health and well-being, cognitive health and well-being, and social health and well-being. The scale also includes a single response item that asks respondents to rate their global level of happiness. In maintaining consistency with human needs theory, these areas of subjective experiences and well-being undoubtedly hold relevance for those with autism.

Researchers have attempted to determine objective indicators of happiness for autistic individuals but have met criticism due to the subjective nature of the construct of happiness and the notion that conventional measures of mood (e.g., congruent facial expressions and tone of voice) may not be relevant or as meaningful to the autistic population (Ramey et al, 2022). However, happiness is a foundational element of quality of life (Ramey et al., 2022) and the

belief that life satisfaction, subjective well-being, and happiness are inter-related is widely agreed upon. Thus, making ratings of happiness a relevant and important subjective indicator for autistic adults; one that should not be ignored.

Physical health and well-being is an essential component of overall quality of life and numerous theories, including human needs theory, assert that human beings are hard wired towards pursuing growth in physical well-being (Williams et al., 2011). Unfortunately, premature mortality rates are significantly higher in the autistic population, with many untimely deaths being attributed to physical health conditions (Hwang et al., 2019; Shavelle et al., 2001; Smith DaWalt et al., 2019). Gathering comprehensive information regarding subjective experiences of physical health and well-being in the autistic population is imperative to address the existing health crisis. Though not synonymous, cognitive functioning and well-being is strongly associated with psychological well-being. Powell et al. (2017) found that autistic adults experienced more significant age-related effects linked to cognitive decline compared to the general population. Cognitive differences associated with the aging process of autistic adults has received international attention and key stakeholders agree on the importance of including cognitive indicators in autism research, including that exploring quality of life (Roestorf et al., 2018). Essential social health and well-being indicators include the quality of one's interpersonal relationships and recreation and leisure skills and opportunities (Verdugo et al., 2005). Social exclusion, particularly relevant to marginalized groups such as the autistic population, has been negatively linked to social wellness and one's ability to effectively navigate social resources (Boreham et. al., 2013). Again, highlighting the need to include exploration of social health and well-being in autism research.

Subjective well-being, often referred to as happiness and satisfaction (Diener et al., 2018), encompasses many aspects of humanity including physical, cognitive, and social well-being. Enrick (2012) asserts that such components of subjective well-being are so inter-related that they are often dependent upon one another. However, much is unknown about the self-reported, subjective adulthood experiences of those with ASD. The literature is saturated with indications of the need for evidence-based research to address the gaps in knowledge related to this subject (Cooper et al., 2014; Lake et al., 2014; Maddox & Gaus, 2019; Raymaker et al., 2020; Pearson & Rose, 2021; & Scheeren et al., 2016); however, adequate understanding of predictors of quality of life continues to be severely limited. In addition, autism researchers have highlighted the need to include effects of race, ethnicity, and gender in research efforts (Hume et al., 2021) yet there exists a startling deficiency in inclusion and representation of race in current autism literature (Steinbrener et al., 2022). The current study addressed these needs by determining the effects of physical, cognitive, and social health and well-being on quality of life and happiness in autistic adults and examining the interaction effects of race and gender identity.

Purpose of the Study

The primary aim of this study was to explore the effects of the physical, cognitive, and social health and well-being satisfaction domains on the PQoL Scale on global happiness ratings in the autistic adult population. The analysis also examined the effects of race and gender identity on subjective indicators of quality of life in autistic adults. Further, this study addressed the interaction effects amongst race, gender identity, and the PQoL Scale domain scores (e.g., physical health and well-being, cognitive health and well-being, and social health and well-being) on global happiness ratings in autistic adults. In addition to the statistical analysis and associated finding and recommendations for clinical practice and future research, the background

of the study explored the theoretical underpinnings supporting the importance of quality of life for all individuals. A thorough review of the current understanding of subjective indicators associated with reports of higher quality of life (e.g., subjective evaluations of physical, cognitive, and social well-being; Williams & Gotham, 2021) in the autistic adult population as they relate to human needs theory was also conducted.

Theoretical Rationale

Michalos (2017) wrote that quality of life is a notion that can be traced as far back to philosophers of the fifth century BCE, beginning with such questions as “What is a good life?” (p. 1). Fast forward to 1962 when Abraham Maslow first established a theory related to quality of life based on one of his most famous works, Maslow’s Hierarchy of Needs. Maslow’s human needs theory is based on the notion that happiness is rooted in a person’s ability to fulfill life’s needs (Ventegodt et al., 2003). Maslow theorized that humans are in constant pursuit of happiness through the attainment of a hierarchy of needs that include:

- physiological needs such as food, water, shelter, and sleep;
- safety and security needs that include health, finances, and employment;
- love and belonging needs that encompass friendship, intimacy, and a sense of connection;
- self-esteem needs that include respect for others, confidence, and achievement;
- and the need for self-actualization that signifies one has discovered the true meaning of their own life (Maslow, 2013; Mcleod, 2024).

Through his writings, Maslow asserted that one must accomplish the fundamental task(s) at each level of the hierarchy before one can attempt to meet the needs of the next level (e.g., a person must have food and water before they can attempt to meet safety and security needs). Many have scrutinized this notion, arguing that meeting the needs at one level is not contingent

upon satisfying the previous (Ventegodt, 2003). However, theorists agree on the multidimensionality of quality of life (Cella, 1994; Felce & Perry, 1995; Verdugo et al., 2005), as is consistent with human needs theory. The dominant need in one's life can vacillate over time (Corey, 2013) just as one's current level of satisfaction can ebb and flow. Ultimately, Maslow's human needs theory, and subsequent hierarchy of needs construct, is philosophized as a source of human motivation meant to turn one's attention towards the positive aspects of human existence, hence the emphasis on satisfaction and happiness. This notion was particularly relevant to this study as the author attempted to shift the focus from pathologizing characteristics of ASD to discovering levels of happiness and subjective quality of life indicators of the autistic population. Likewise, human needs theory is rooted in the conceptual domains of physical health and well-being, cognitive health and well-being, and social health and well-being and the relationship of these domains to happiness. Through this research, professionals will be able to guide autistic individuals towards happiness and satisfaction in domains associated with their needs and relevant quality of life indicators.

Research Questions

This study explored how race, gender identity, and the domains of Physical Health and Well-being, Cognitive Health and Well-being, and Social Health and Well-being effect quality of life and Global Happiness Ratings in autistic adults and whether an interaction exists between these predictors and Global Happiness Ratings. Specifically, this study answered the following research questions:

Main Effects

Research question 1: How does race affect the Global Happiness Rating among autistic adults?

Research question 2: How does gender identity affect the Global Happiness Rating among autistic adults?

Research question 3: What is the effect of the Physical Health and Well-being domain score on the Global Happiness Rating for autistic adults?

Research question 4: What is the effect of the Cognitive Health and Well-being domain score on the Global Happiness Rating for autistic adults?

Research question 5: What is the effect of the Social Health and Well-being domain score on the Global Happiness Rating for autistic adults?

Interaction Effects

Research question 6: Do the effects of the Physical Health and Well-being domain score on Global Happiness Ratings vary by race in autistic adults?

Research question 7: Do the effects of the Cognitive Health and Well-being domain score on Global Happiness Ratings vary by race in autistic adults?

Research question 8: Do the effects of the Social Health and Well-being domain score on Global Happiness Ratings vary by race in autistic adults?

Research question 9: Do the effects of the Physical Health and Well-being domain score on Global Happiness Ratings vary by gender identity in autistic adults?

Research question 10: Do the effects of the Cognitive Health and Well-being domain score on Global Happiness Ratings vary by gender identity in autistic adults?

Research question 11: Do the effects of the Social Health and Well-being domain score on Global Happiness Ratings vary by gender identity in autistic adults?

Research question 12: Do the effects of race on Global Happiness Ratings in autistic adults vary by gender identity?

Study Justification

This study is a vital contribution to the current body of literature devoted to better understanding the subjective experiences of autistic adults. The field of autism research is vast; however, there exist clear gaps in investigating and addressing the needs of the adult population on the autism spectrum, including those related to happiness and overall quality of life.

Researchers cannot simply rely upon knowledge relevant to the general population to inform treatment recommendations for the unique needs of this population. Also, there is a scarcity of autism research that explores the intersection of race and autistic identity (Davis et al., 2022). This study addressed that gap as well. Finally, more autism research needs to be dedicated to understanding the implications, not just the existence, of gender differences found in diagnostic rates, autistic characteristic presentation, and rates and severity of co-occurring conditions (Lai et al, 2015; Mandy & Lai, 2017). In addition to exploring the effects of subjective ratings on physical health and well-being, cognitive health and well-being, and social health and well-being on overall happiness, the study investigated the intersectionality of race, gender identity, and autistic quality of life and happiness. Thus, therapeutic intervention recommendations were better informed and equity and social justice issues in autism research, practice, and advocacy were addressed by this important research.

Significance of the Study

The subjective experiences of autistic adults and the impacts of these experiences on quality of life and happiness are not being adequately assessed (Ayres et al., 2018). Further, there is a current lack of consensus amongst researchers on the domain indicators to consider as predictive factors when assessing autistic quality of life (Burgess & Gutstein, 2007; Sáez-Suanes & Álvarez-Couto, 2021). In maintaining consistency with human needs theory and to address the significant gaps in existing research, the current study demonstrated the effects of physical health and well-being, cognitive health and well-being, and social health and well-being on quality of life and happiness in autistic adults.

The study findings have significant implications for clinical practice, research, policy, and self-advocacy. First, study findings contribute to the current knowledge base by providing a background and rationale for applying the use of tailored intervention strategies and services that better meet the diverse needs of the autistic adult population. Second, while attempting to fill current gaps of knowledge within the topic of autistic adult quality of life, this study offers insights into future directions for this important topic of research. Third, the study helps to highlight any existing disparities based on race and gender identity and subjective ratings of happiness, quality of life, and physical, cognitive, and social well-being. As a result, advocacy efforts at the policy level can be enhanced to allow for more accurate representation of needs across the diverse racial and gender identities within the autistic adult population. Finally, by using a self-report measure of subjective indicators of quality of life, well-being, and happiness, this research helps to amplify the voices of the autistic adult community.

Definition of Terms and Concepts

The following section provides an overview of key terms and concepts along with the operational definitions used throughout the current study.

Autism Spectrum Disorder

A neurodevelopmental disorder consisting of persistent deficits across two primary areas of functioning: social-communication and restricted/repetitive pattern of behavior and interests (American Psychiatric Association, 2022).

Neurodiversity

Neurodiversity accounts for the neurocognitive variation found within the human species (Walker, 2014).

Quality of Life

Quality of Life is “an individual’s perception of their position in life in the context of culture and value systems in relation to one’s goals, expectations, standards, and concerns” (World Health Organization, 2022).

Subjective Well-being

“How people *experience* and *evaluate* their lives and specific domains and activities in their lives” (NIH, 2013).

Physical Health and Well-being

Physical health and well-being includes “physical activity, balanced nutrition, getting adequate sleep, and avoiding harmful behaviors. Physical wellness also includes a personal responsibility to understand [one’s] body’s warning signs and recognize when [one is] ill and in need of medical attention” (University of North Georgia, 2024).

Cognitive Health and Well-being

Cognitive health and well-being was operationalized as one's satisfaction with how well one thinks and remembers and how well one carries on a conversation (e.g., speaking clearly, hearing others, and/or being understood; Patrick, 2015).

Social Health and Well-being

Social health and well-being indicators include accepting others as they are, having a positive comfort level with society, feeling that one contributes meaningfully to society, having an adequate understanding of the social world, feeling part of a community, involvement in recreation and leisure opportunities, and perception of the quality of one's interpersonal relationships (Keyes & Lopez, 2002). Other key social health and well-being indicators include the quality of one's interpersonal relationships and recreation and leisure skills and opportunities (Verdugo et al., 2005).

Happiness

Happiness is a multi-faceted, subjective, and complex construct that includes a number of factors such as emotional, cognitive, financial, social, physical, and behavioral well-being (Carruthers & Hood, 2004).

Chapter Summary

This chapter introduced the aims of this study, which were to explore the impacts of physical, cognitive, and social health and well-being satisfaction on subjective quality of life experiences and the effects and interactions of race and gender identity on overall quality of life and happiness in the autistic adult population. The chapter then provided a background for the study and highlighted current problems and gaps in research that the study addressed. Following an outline of the purpose of the study and theoretical rationale, this author detailed the specific

research questions addressed and provided information regarding justification for and significance of the study. The chapter concluded with a listing of key terms and concepts including Autism Spectrum Disorder, neurodiversity, quality of life, subjective well-being, and happiness. In the chapter that follows, a more in-dept exploration of the current body of knowledge related to this topic is provided.

CHAPTER 2: REVIEW OF LITERATURE

Introduction to Literature Review

This literature review begins with an outline of human needs theory as it relates to this study that explored the impacts of physical health and well-being, cognitive health and well-being, and social health and well-being on quality of life and happiness in autistic adults and the impacts of race and gender identity. A thorough review of relevant research and studies examining quality of life in the target population follows. The chapter closes with a summary of conclusions from the current body of research and knowledge regarding the subjective quality of life experiences of autistic adults.

Review of Relevant Theory: Human Needs Theory

Abraham Maslow (1908-1970) first established a theory related to quality of life based on one of his most famous works, Maslow's Hierarchy of Needs, developed from his preceding human needs theory. Maslow's human needs theory is rooted on the foundation that the search for happiness is imbedded in a person's motivation to strive towards fulfilling life's needs (Ventegodt et al., 2003). Maslow theorized that humans are in constant pursuit of happiness through the attainment of a hierarchy of needs that include physiological needs, safety and security needs, love and belonging needs, self-esteem needs, and the need for self-actualization (Maslow, 2013; Mcleod, 2024; Taormina & Gao, 2013).

Needs have been defined by some theorists as having a lack of something that is critical to well-being (Taormina & Gao, 2013). Thus, human needs theory posits that the fulfilment of 1.) physiological needs revolves around the human's need to maintain bodily function (e.g., food and water); 2.) safety and security needs revolve around the human's need for survival and a means of survival (e.g., finances); 3.) love and belonging needs revolve around maintaining

lasting, emotionally pleasant interactions and relationships with others; 4.) self-esteem needs revolve around achieving respect for one's self and respect from others; and 5.) self-actualization, the most abstract need of Maslow's hierarchy, revolves around the need to become self-fulfilled or "who one truly is" (Taormina & Gao, 2013; p. 159). Please refer to Figure 1 for a graphic representation of Maslow's hierarchy of needs organized with the most concrete needs on the bottom to the most abstract needs towards the top of the pyramid. Through his writings, Maslow asserted that one must accomplish the fundamental task(s) at each level of the hierarchy before one can attempt to meet the needs of the next level. This notion has been scrutinized, with researchers such as Ventegodt (2003) arguing that meeting the needs at one level is not contingent upon satisfying the needs of the previous. Likewise, recent research has even suggested the linkage of higher- and lower-level needs, such as encompassing self-actualization within the human need for self-esteem (Kenrick, 2017; Krems et al., 2017). Regardless of where the lines are drawn that separate one area of need from another, theorists agree on the multidimensionality of human needs theory in much the same way as they do the multidimensionality of quality of life (Cella, 1994; Felce & Perry, 1995; Verdugo et al., 2005).

Figure 1

Abraham Maslow's Hierarchy of Needs



Human developmental needs and quality of life are so intertwined that one is innately dependent upon the other (Sirgy, 1986). As one works towards goals within their hierarchy of needs, one is also working towards a better, more fulfilling quality of life. Sirgy (1986) goes on to postulate that human developmental and quality of life goals can be set in such a way that allows an entire culture to move from lower to higher order needs. While there is much heterogeneity within the autism spectrum, the homogeneousness of the neurodevelopmental human behavioral patterns associated with autism has led those in the field to often refer to autism as a culture in and of itself; “the culture of autism” (Mesibov & Shea, 2010). Thus, the needs of members of the autistic culture must be understood and appreciated for their unique strengths, challenges, goals, and aspirations. Only in doing so will professionals be able to improve the quality of life of this population from a human needs perspective.

An emerging concept within the field of autism that relates to human needs theory and quality of life is the importance of self-determination (White et al., 2018), which involves an individual’s ability to act upon their own free will (Wehmeyer, 1992). In fact, White et al. (2018) found a significant positive correlation between self-determination and quality of life. Components of self-determination include problem-solving, self-regulation, choice-making, psychological empowerment, and self-realization (Wehmeyer et al., 2003; Wehmeyer & Palmer, 2003; White et al., 2018); concepts that are integrated within the higher reaches of the hierarchy of human needs theory. Self-determination is considered to be a core feature of quality of life and has even been identified as a key factor within multiple quality of life domains (Kim, 2019; Schalock, 2000). Likewise, human needs theory is rooted in the conceptual domains of physical health and well-being, cognitive health and well-being, and social health and well-being and the relationship of these domains to happiness. Essentially, Maslow’s human needs theory, and

subsequent hierarchy of needs construct, is philosophized as a source of human motivation meant to turn one's attention towards the positive aspects of human existence, hence the emphasis on satisfaction and happiness. This notion is particularly relevant to the current study as this author attempts to shift the focus from pathologizing characteristics of ASD to discovering levels of happiness and subjective quality of life indicators of the autistic population.

Review of Relevant Empirical Research

The vast majority of our lives is spent in adulthood. However, much is unknown about the self-reported, subjective adulthood experiences of those ASD, a life-long neurodevelopmental disability. In their analysis of the Adult Consumer Survey, Roux et al. (2017) reported that, compared to other disability groups (e.g., those with learning disability, speech-language impairments, and intellectual disability), a significantly lower percentage of autistic adults receive needed services after high school. Many diagnosed with ASD also have co-occurring mental health conditions such as anxiety and depression. Additionally, individuals with the complex diagnosis of ASD encounter a number of challenges that exist beyond the scope of measurable cognitive and adaptive skills. Challenges that, at their root, interfere with an individual's ability to carry out a variety of complex functions necessary to gain autonomy and contribute to poorer quality of life for autistic adults (Robertson 2009). Quality of life is a subjective conceptualization of one's own satisfaction with their current life circumstances (McConachie et al., 2020; WHO, 2022). The need for evidence-based research and comprehensive programs designed to address the gaps of services available for adults with ASD is well documented (Cooper et al., 2014; Guas, 2019; Lake et al., 2014; Maddox & Gaus, 2019; Pearson & Rose, 2021; Raymaker et al., 2020; Scheeren et al., 2016); however, availability of such programs and adequate understanding of predictors of quality of life continues to be

severely limited. To fully understand the scope of this issue, we have to also consider the status quo of acceptance and understanding of this population and subsequent implications for subjective quality of life.

Cage et al. (2018) directly relate acceptance from others to overall mental health for adults with ASD and define autism acceptance as:

an individual feeling accepted or appreciated as an autistic person, with autism positively recognized and accepted by others and the self as an integral part of that individual (p. 474).

This definition implies that for one to be accepted or to have acceptance, one has to feel accepted by the larger society for being true to oneself and acting upon one's own accord, which is supported as a key feature of Maslow's human needs theory (Ventegodt et al., 2003). One can safely assert that feeling accepted can lead to more positive perceptions of self and self-acceptance. In support of this notion, Cooper et al. (2017) found a negative correlation between self-esteem and mental health difficulties for autistic adults.

Unfortunately, mental health services for adults with ASD are lacking and, in some cases, non-existent. Research into the needs of this population has not been adequate, nor has academic inquiry expanded at a rate consistent with general autism research (Kirby & McDonald, 2021; Lake et al., 2014). However, the need for robust resources and services for autistic adults is evident. Lugnegård et al. (2011) found that of their sample of adults with ASD, 70% experienced at least one episode of major depressive disorder and 50% met criteria for an anxiety disorder. Other studies examining comorbidity and autism have found similar results, with higher rates of depression and anxiety consistently noted in this population (Cooper et al., 2014; Lake et al., 2014). Confounding this issue is the categorization of autism as a neurodevelopmental disability

on the continuum of service models and delivery. Agencies that provide services for those with developmental disabilities often divert those experiencing psychiatric concerns to mental health care agencies. In turn, these mental healthcare agencies and providers, who are equipped to treat conditions such as anxiety and depression, are reluctant to provide care for autistic adults, leaving these individuals with an increased likelihood of receiving inadequate care (Maddox & Guas, 2019) and, often times, excluded from care altogether (Lake et al., 2014). Unfortunately, these factors have detrimental impacts on happiness, quality of life, and subjective well-being across various domains of functioning.

Untreated mental health concerns have been linked to employment challenges, adaptive functioning impairments, lack of autonomy, low self-esteem, and poor quality of life (Farley et al., 2009; Gillberg et al., 2016; Lake et al., 2014; Robertson, 2009). Cooper et al. (2017) found self-worth to be highly connected with social worth for autistic adults and postulate that autism identification is related to better mental health outcomes. This group of researchers equated autism identification to social identification with other autistic people, in which group members feel a psychological connection to one another. However, those with autism are a highly stigmatized group, which brings about significant challenges with autism identification. Many individuals respond differently to their autistic identity. Ultimately, Cooper et al. (2017) concluded that autistic adults need opportunities to increase positive feelings towards their autism identity as a key factor in overall well-being and quality of life.

Much of the negative social stigma attached to ASD can be attributed to the deficit-focused model in which “autistic people are portrayed as broken humans who require fixing” (Robertson, 2009). Individuals with ASD have many strengths, abilities, and talents that can, at times, be dismissed and labeled as distractions, eccentricities, or even obsessions. These

egocentric labels further devalue and dismiss contributions of those with autism and potentially increase occurrences of marginalization and feelings of being a burden to society (Khan et al., 2012). Historically, ASD has been considered, by some, a disorder to be fixed or solved and many autistic individuals experience marginalization (Pearson & Rose, 2021). This notion is exemplified by the fact that the international symbol for autism is a puzzle piece, implying that ASD is a mystery to be solved or that those with ASD are broken and need to be assembled. Robertson (2009) proclaimed the need to recognize a neurodiversity perspective as a means of acknowledging that living in a non-autistic society can aggravate many of the challenges experienced by the autistic population. Failing to adequately acknowledge and understand these confounding factors can lead to a host of maladaptive and compensatory responses, including camouflaging and masking.

As is typical with other marginalized groups, some with autism, potentially due to trauma that can arise from lifelong stigma, feel pressures to hide or change aspects about themselves to appear less autistic, which is referred to as masking. Pearson and Rose (2021) conducted a study to look more closely at the phenomenon of masking, defined as:

the conscious or unconscious suppression of natural responses and adoption of alternatives across a range of domains including social interaction, sensory experiences, cognition, movement, and behavior (p. 5).

The researchers related that when individuals, such as those with ASD, are habitually presented with the implication that their way of being is inadequate or wrong, masking ensues to alleviate immediate consequences (e.g., alienation). Long-term masking presents significant concerns related to subjective well-being and quality of life. Exploring conditions that lead to and promote masking is extremely important. While masking often develops as a self-protective mechanism

with a goal of promoting chances of social belonging, the consequences of long-term masking include increases in anxiety, depression, overall psychological distress, and burnout (Pearson & Rose, 2021; Scheeren et al., 2016).

Autistic burnout is a syndrome conceptualized as resulting from chronic life stress and a mismatch of expectations and abilities without adequate supports. It is characterized by pervasive, long-term exhaustion, loss of function, and reduced tolerance to stimulus (Raymaker et al., 2020). The following definitions were provided to further explain the results of Raymaker and colleagues' study:

Chronic exhaustion—exhaustion of mental, physical, emotional, and/or social resources.

Loss of skills—skills including thinking, remembering, creating, and executive planning.

Reduced tolerance to stimulus—increased sensitivity to environmental stimuli resulting in more frequent meltdowns/shutdowns and avoidant behaviors.

Further exploration found lack of empathy from neurotypical individuals as a contributing factor of autistic burnout and overall decreased quality of life for autistic adults.

Common quality of life themes highly relevant to the autistic population include difficulties related to a systemic lack of knowledge and acceptance of ASD, fear of loss of resources, sensory concerns, autistic identity, self-determination/autonomy, chronic exhaustion, loss of skills, and issues related to anxiety, stress, and depression (McConachie, 2020; Raymaker et al., 2020). In order to better understand these themes, it is important to delve a little deeper into indicators of overall subjective well-being that were explored in the current study.

Physical Health and Well-Being

The terms physical health, physical wellness, and physical well-being are often used synonymously. Physical well-being can be defined as simply as taking care of one's body.

However, a more comprehensive definition is needed and includes “physical activity, balanced nutrition, getting adequate sleep, and avoiding harmful behaviors. Physical wellness also includes a personal responsibility to understand [one’s] body’s warning signs and recognize when [one is] ill and in need of medical attention” (University of North Georgia, 2024). Boston University (2024) includes the process of taking adequate measures engaged in preventative healthcare in their conceptualization of physical health and well-being.

Physical health and well-being is an important component of overall quality of life and numerous theories assert that humans are hard wired towards pursuing growth in physical well-being (Maslow, 2013; Ventegodt, 2003; Williams et al., 2011). Envick (2012) concluded physical health and well-being to be so integral that other aspects of well-being (e.g., psychological well-being) cannot be achieved in the absence of physical well-being. Sadly, numerous medical conditions and co-morbidities are more common within the autistic population (Warner et al., 2019). Common health-related co-morbidities include metabolic disorders, motor dysfunction, immune impairment, seizure disorders, sensory dysfunction, and gastrointestinal impairment. (Sala et al., 2020). Premature mortality rates are significantly higher in the autistic population, with many untimely deaths being attributed to physical health conditions (Hwang et al., 2019; Shavelle et al., 2001; Smith DaWalt et al., 2019). Gathering comprehensive information regarding subjective experiences of physical health and well-being in the autistic population is imperative to address the existing health crisis.

Cognitive Health and Well-Being

In this study, cognitive health and well-being was operationalized as one’s satisfaction with how well one thinks and remembers and how well one carries on a conversation (e.g., speaking clearly, hearing others, and/or being understood; PQoL, 2016). Cognitive health and

well-being is strongly associated with psychological well-being. Certain psychological maladies (e.g., depression, anxiety) have been linked to poorer cognitive functioning; likewise, higher ratings of psychological well-being have been associated with more favorable cognitive functioning (Llewellyn et al., 2008). Powell et al. (2017) found that autistic adults experienced more significant age-related effects related to cognitive decline compared to the general population. These researchers concluded that cognitive processes, such as cognitive flexibility and executive functioning, seem to be the most disproportionately impacted areas. Executive functioning skills encompass an array of cognitive abilities such as initiation, planning, time management, working memory, attention, and inhibition (Diamond, 2013). Cognitive differences associated with the aging process of autistic adults has received international attention and key stakeholders agree on the importance of including cognitive indicators in autism research, including that exploring quality of life (Roestorf et al., 2018).

Social Health and Well-Being

Posited by Keyes and Lopez (2002), social aspects of well-being include accepting others as they are, having a positive comfort level with society, feeling that one contributes meaningfully to society, having an adequate understanding of the social world, and feeling part of a community. Other key social well-being indicators include the quality of one's interpersonal relationships and recreation and leisure skills and opportunities (Verdugo et al., 2005). Social exclusion, particularly relevant to marginalized groups such as the autistic population, has been negatively linked to social wellness and one's ability to effectively navigate social resources (Boreham et. al., 2013). While social-communication challenges are germane to meeting diagnostic criteria for autism, it is the belief of this author and others (Ayers et al., 2018; Bauminger & Kasari, 2000; Burgess & Gutstein, 2007) that social-communication differences

are not necessarily indicative of levels of social health and well-being for autistic adults. In many aspects (e.g., reciprocal social relationships, social support, group coherence), social health and well-being is dependent upon quality, not quantity of such experiences (Bauminger & Kasari, 2000; Burgess & Gutstein, 2007). However, some studies have found social aspects of quality of life to be rated among the areas of most concerns for autistic adults (Kamp-Becker et al., 2010; Lin, 2014; Mason et al., 2022). Measurement of social-wellness indicators from an autistic versus normative perspective is essential (Roestorf et al., 2018).

Global Happiness

An oversimplification would be to say that happiness is a feeling of being content and fulfilled. On some accounts, one could argue that “happiness is a state of well-being that encompasses living a good life, one with a sense of meaning and deep contentment (Psychology Today, 2024). More broadly, however, happiness is a multi-faceted, subjective, and complex construct that includes a number of factors such as emotional, cognitive, financial, social, physical, and behavioral well-being (Carruthers & Hood, 2004). Susniene and Jurkauskas (2009) concluded that happiness is an important indicator in assessing overall quality of life and is characterized by subjective feelings towards one’s understanding of one’s place in society and meaningfulness of life, a construct highly associated with quality of life. Some studies have attempted to determine objective indicators of happiness for autistic individuals but have met criticism due to the subjective nature of the construct of happiness and because conventional measures of mood (e.g., congruent facial expressions) may not be relevant or as meaningful to the autistic population (Ramey et al, 2022). Happiness is a foundational element of quality of life (Ramey et al., 2022) and the notion that life satisfaction, subjective well-being, and happiness are correlated is widely agreed upon.

Impacts of Demographics on Quality of Life

Studies conducted over the previous decades exploring the general population have indicated that Whites typically report higher ratings in subjective well-being across various domains (e.g., psychological well-being) than other racial/ethnic groups, including those who are Black or Latinx (Barger et al., 2009; Bracy, 1976; Campbell et al., 1976; Clemente and Sauer, 1976; Herzog et al., 1982; Hughes and Thomas, 1998; Iceland & Ludwig-Dehm, 2019; Stevenson and Wolfers, 2012). In many instances, differences in subjective well-being remain, even when researchers control for factors associated with racial inequities, such as social and economic factors (Wadsworth & Pendergast, 2021). Additional studies examining race and subjective well-being in the general population have found strong correlations between racial ethnic identity (i.e., the attachment towards a specific ethnic or racial group) and subjective well-being that have included domains such as mental health, social functioning, and self-esteem (Rivas-Drake et al., 2014; Smith & Silva, 2011; Yoo et al., 2018). That is, those who report a positive identification with their racial ethnic characteristics and behaviors tend to report higher rating in subjective well-being.

While studies have found differences in quality of life related to gender, early studies examining gender differences in quality of life and life satisfaction in the general population were inconsistent (Fujita et al., 1991; Haring et al., 1984; Okun & George, 1984; Pinguart & Sorensen, 2001; Wood et al., 1989). In a more recent meta-analysis on gender and subjective well-being, the largest to-date, (Batz-Barbarich et al., 2018) found no significant gender differences in life satisfaction. Highlighting continued inconsistencies, Batz and Tay (2018) conducted a meta-analysis exploring gender differences in quality of life and the potential influence of gender inequality and found that women reported significantly lower levels of life

satisfaction than men. Batz and colleagues identified several themes that may account for gender differences in subjective well-being and quality of life that include differences in societal expectations, biological differences, and differences in various opportunities based on gender (Fujita et al., 1991; Landers, 1988; Russo & Green, 1993; Tesch-Romer, 2008; Wood et al., 1989).

Autism researchers have highlighted the need to include effects of race, ethnicity, and gender in research efforts (Hume et al., 2021). However, there exists a startling deficiency in inclusion and representation of race in current autism literature, raising concerns for social justice in autism research and significantly impacting the generalizability of research results. In a meta-analysis of 1013 studies of autism intervention research, Steinbrenner et al. (2022) found that only 25% of those studies collected data on race/ethnicity and those that did report demographics on race were significantly over-represented by White respondents. In a summary of the National Autism Indicators Report, Shattuck et al. (2018) reported that the majority of respondents (i.e., 80%) were White, with Black respondents comprising only 10% of the sample, a disparity that is not representative of the autistic adult population (Maenner et al., 2023). Confounding this problem is the indication that factors such as race/ethnicity have a significant impact on the disparities seen across such domains as health, safety, and family well-being (Eilenberg et al., 2019).

Additionally, gender differences in the presentation of characteristics associated with autism are apparent, and the implications of such differences need to be explored in autism research. Autistic females are more likely to be under-recognized, diagnosed late, or not diagnosed at all (Dworzynski et al., 2012; Loomes et al., 2017), which often results in lack of adequate service and intervention provision, negatively impacting quality of life and happiness.

Demographics regarding gender are crucial in developing optimal understanding of the multitude of associated implications. For example, autistic females have been found to be more likely to engage in maladaptive behaviors, such as camouflaging and masking, that also have negative implications for cognitive wellness and quality of life (Pearson & Rose, 2021). The increased likelihood of autistic females to engage in camouflaging and masking compared to autistic males (Hull et al., 2020) and the linkage of camouflaging to mental health challenges and reduced well-being (Lai et al., 2017) highlight the need to explore gender differences in quality of life autism research. Autistic individuals also have a higher likelihood of gender incongruence than the general population (George & Stokes, 2017), with gender incongruence significantly more prevalent in autistic females than in autistic males (Cooper et al., 2018). Considerations regarding gender identity versus gender defined as sex assigned at birth are increasingly important in autism research.

Review of Similar Studies

In one of the first studies to explore quality of life in autistic adults, Renty and Roeyers (2006) set out to “determine the predictive value of disability and support characteristics for quality of life in adults with ASD” (p. 513). The sample consisted of 58 participants; 74% were male. The main findings of the study were that, while disability characteristics were not found to predict quality of life in autistic adults, support characteristics were. In further exploration of these findings, the researchers found that perceived informal support (e.g., perceived availability of others with whom to do things) was positively correlated with quality of life. Also, as the number of unmet formal needs increased, quality of life decreased. This pioneering study helped pave the way for future quality of life research for the autistic population, especially autistic adults. The findings also highlighted the need to more thoroughly assess met and unmet needs in

the adult autistic population, as lack of formal services for perceived needs was a significant predictor of quality of life. While this early empirical study laid a solid foundation, quality of life research for autistic adults did not truly gain momentum until the last decade.

A Chronological Review of Quality of Life Studies Over the Past Decade

Chiang and Wineman (2014) conducted a literature review of studies that examined quality of life of the autistic population. Reinforcing the need to conduct research on the adult population, a total of 4321 individuals were included in the studies; however, less than 10% of total participants were adults. Data was gathered from studies conducted in Sweden, Switzerland, Canada, Germany, Turkey, and the United States. An exploration of overall quality of life for autistic adults yielded conflicting results, as two studies reported good quality of life (Billstedt et al, 2011; Gerber et al., 2008) and two studies reported lower quality of life in the autistic adult population (Kamp-Becker et al., 2010; Saldaña et al., 2009). Other inconsistencies were found in the impacts of work-related activities on the quality of life of adults with ASD. Billstedt et al. (2011) found no association between work and quality of life yet Garcia-Villamizar et al. (2002) reported a positive association between work and the quality of life of autistic adults. An overarching consistency was found in the impact of leisure activities on physical well-being. The studies by both Billstedt et al. (2011) and Garcia-Villamizar et al. (2002) found a positive association between leisure activities and quality of life for autistic adults. Major limitations of the studies reviewed pertain to race and gender. Shockingly, race was not reported in any demographic information discussed. Also, gender demographics were often collected; however, gender differences in the quality of life of autistic adults was not explored in any of the studies reviewed.

Ayers et al. (2018) completed a systematic review of 14 studies examining quality of life in autistic adults. The 14 studies contained a total of 959, predominately male, participants. Of the studies, two were randomized designs, nine were cross-sectional designs, and three were pre-test/post-test intervention studies. A variety of measures of quality of life were used across the studies that included the World Health Organization Quality of Life – BREF (WHOQOL-BREF), Quality of Life Questionnaire (QoL-Q), Quality of Life Inventory (QOLI), Comprehensive Quality of Life Questionnaire (ComQOL), Short Form Health Survey (SF-36), Medical Outcomes Study Short Form Health Survey Version 2 (SF-12 v.2), and Quality of Life Measure 1 & 2 (QOL1 & QOL2), underlining the lack of agreement upon an empirically supported measure of quality of life for use with the autistic adult population. The researchers noted that all measures used were designed and validated for use with the general population, with the exception of the QOL1 and QOL2, which were designed for use with those with autism. Overall, the systematic review showed a trend in lower quality of life for autistic adults than that seen within the typical adult population, with the largest disparities being reported in domains assessing social inclusion and interaction. The researchers' conclusions highlighted the need to develop an autism-specific instrument to measure quality of life based on domains important to the autistic population, especially when comparing results to the general population.

Mason et al. (2018) utilized a sample of 370 autistic adults in the United Kingdom (UK) to examine the self-reported quality of life of autistic adults compared to UK norms and to determine potential predictors of quality of life for autistic adults. Participants were 17 years of age and older. The sample included 199 males and 158 females. Race was not reported. The researchers found that, based on the WHOQOL-BREF, the UK autistic adult population scored lower in all four domains of quality of life measured (i.e., Physical, Social, Psychological, and

Environmental) when compared to the UK general population. When examining within-group statistics, autistic males reported higher physical quality of life than autistic females and autistic females reported higher social quality of life than autistic males. Additional findings included that having significantly lower quality of life scores on psychological and environmental domains could be contributed to being female. Having a higher severity of autistic symptoms, measured by the Social Responsiveness Scale, and having a current mental health diagnosis were also predictors of lower quality of life in both males and females. Being employed was a predictor of higher physical quality of life, receiving support was a predictor for higher social and environmental quality of life, and being in a relationship was linked to higher social quality of life. The authors highlighted the importance of using the study findings to identify and intervene with the most vulnerable autistic groups within the UK and recommended future longitudinal studies as an area of importance.

Danish researchers Knüppel et al. (2018) conducted a study in which 1,738 Danish adolescents and adults with autism were included to determine potential factors associated with quality of life. The study included both self-reports and parental proxy-reports. The researchers utilized a quality of life scale with the subdomains of self-determination, rights, social inclusion, emotional well-being, interpersonal relationships, personal development, physical well-being, and material well-being. Factors such as adaptive behavior, level of autistic symptoms, mental health co-morbidity, maladaptive behavior, sleeping difficulty, residence, intellectual ability, and main daytime activity were explored. Overall, the highest rated quality of life domains were found in rights and material well-being. The lowest rated domains were emotional well-being and interpersonal relationships. In examining factors associated with quality of life, psychiatric co-morbidity, having intellectual disability, experiencing sleeping difficulty, higher ratings of

autistic symptomology, and the presence of maladaptive behaviors were all significantly associated with lower ratings of quality of life. Having greater skills in adaptive functioning and being involved in any job-related occupation or enrolled in education were associated with higher quality of life ratings. Finally, individuals living independently without support reported significantly higher ratings in quality of life than did autistic participants either living with parents or living outside the home with support. One major limitation of this study was the use of parental proxy-report. Parents have been shown to rate overall functioning versus quality of life (Jonsson et al., 2017), thus often under-estimating quality of life when compared to matched self-report. Knüppel and colleagues assert that parental proxy-report may be used as a source of alternative information but should not be used as a substitute for self-report in autistic adults.

In a UK based study the following year, Mason et al. (2019) set out to determine how subjective quality of life is associated with depression and anxiety in older autistic adults (i.e., 55 years old and older). A sample of 48 males and 21 females was administered the WHOQOL-BREF and Hospital Anxiety and Depression Scale (HADS). Racial demographics were not reported. The researchers concluded that those who scored in the clinical range for depression reported lower quality of life in all four domains of the WHOQOL-BREF. Those who scored in the clinical range for anxiety reported lower quality of life in three of the four WHOQOL-BREF domains (i.e., Physical, Environmental, and Psychological). The researchers also wanted to determine how anxiety and depression combined versus one or none of these conditions impacted quality of life in autistic adults. Not surprisingly, those who indicated the presence of clinically significant anxiety or depression reported lower quality of life than those who reported no presence of anxiety or depression. Finally, quality of life scores were significantly lower for

participants who reported the presence of both anxiety and depression when compared to those who reported the presence of one, but not both, of the conditions.

Holmes et al. (2020) sought to test the feasibility of the lifespan Patient-Reported Outcomes Measurement Information System (PROMIS) Autism Battery (PAB-L), compare the PAB-L score for autistic participants to the general population, and explore gender differences in the PAB-L. The authors developed the PAB-L to be used as a lifespan measure of quality of life for the autistic population. The study included participants across the age range, including a category for those age 18 to 65 years. The sample included 227 autistic adults, with approximately 46% being female, 79% being White, and four percent being Black. Holmes and colleagues found the PAB-L to meet sufficient feasibility and acceptability criteria, indicating that the measure is useful and appropriate. However, additional research is needed to determine reliability and validity. When compared to the general population, autistic adults reported significantly less desirable outcomes in quality of life. Finally, autistic women reported less favorable outcomes for Social Isolation, Sleep Disturbance, Cognitive Function, and Global Physical Health than did autistic males.

A study by Williams and Gotham (2021) aimed to test the psychometric properties of the Autism Spectrum Quality of Life (ASQoL), which was developed as an add-on measure to the WHOQOL-BREF and Disabilities Module (WHOQOL-DIS). The ASQoL holds particular relevance in the field because it was the first measure of quality of life to include feedback from autistic voices in its conception. The researchers administered the nine-item self-report ASQoL questionnaire and a subset of five items from the WHOQOL-BREF to 700 autistic adults between the ages of 18 and 45. Non-Hispanic, White, college-educated, female participants comprised the majority of the sample. Overall, the ASQoL was found to have significant

psychometric problems, especially regarding differential functioning of the items across subgroups of the autistic population. Specifically, the ASQoL was found to exhibit a bias related to sex/gender that resulted in a significant underestimate of quality of life in autistic females. Although the ASQoL was developed to be used in conjunction with the WHOQOL-BREF and WHOQOL-DIS, the researchers recommended continued adjustment to the ASQoL before it can be reliably used as a measure of quality of life in the autistic adult population.

Sáez-Suanes and Álvarez-Couto (2021) conducted a systemic review of autistic quality of life literature with an aim of determining common factors often associated with quality of life in those with autism. The review included a total of 11 studies with a combined sample size of 1005 autistic participants between the ages of 17 and 80. Overall, there was an over-representation of male participants. Demographics on race within the study samples were not reported. The researchers found that the most common dimensions of quality of life studied in the autistic population were social, physical, environmental, and psychological. Of the studies that contained control groups, autistic adults reported lower quality of life scores than the general population in all dimensions. However, studies that did not compare autistic participants to those from the general population found good quality of life scores. The most common predictors studied in autistic adult quality of life research included psychopathological comorbidity, perceived stress, leisure, level of independence, cognitive variables, and ASD traits. Regarding comorbidity, anxiety and depression were consistently found to negatively impact autistic quality of life (Hong et al., 2016; Lin & Huang, 2019; Mason et al., 2019; Moss et al., 2017; Vincent et al., 2020). Perceived stress has been linked to lower quality of life. Specific positive mediators of perceived stress have been found in social participation (Bishop-Fitzpatrick et al, 2017) and personal support networks (Mason et al., 2018). Participation in leisure activities, including

physical activity (Hamm & Yun, 2019), having an increased level of independence (Hong et al., 2018), and increased levels of executive functioning (Dijkhuis et al., 2016) have been linked to higher levels of quality of life in the autistic adult population. Traits often associated with ASD, including sensory hypersensitivity, have been shown to negatively impact quality of life (Mason et al, 2018). Sáez-Suanes and Álvarez-Couto concluded that the need to design and/or use assessment instruments with factors important to autistic adults when measuring quality of life is of vital importance. The researchers also noted the necessity of including diverse participants in autism research.

To determine individual variability in quality of life among autistic individuals and how the differences are related to varying levels of core autism traits and symptoms of anxiety and depression, Oakley et al. (2021) utilized the European Autism Interventions Multicentre Study for Developing New Medications longitudinal database to collect a sample of 344 autistic individuals aged six to 30 years. In determining the sample to be consistent with those used in previous studies, the group recognized that autistic individuals reported lower quality of life than a non-autistic comparison group. However, this study substantiated significant variability in quality of life in the autistic sample. Approximately 35% to 55% of autistic adults in the sample reported good quality of life, supporting the importance of individual considerations when interpreting results, versus emphasizing group-level findings only. Of the additional predictors considered (i.e., levels of core autism traits, anxiety, and depression), the researchers found depressive symptoms to be a significant predictor of quality of life. That is, increased depressive symptoms were significantly associated with lower overall quality of life and decreased quality of life in the specific domains of physical health, psychological health, and social relationships.

Citing a major limitation, the study did not explore gender differences, nor was race/ethnicity reported.

In continued efforts to determine a valid and reliable quality of life scale to use with the autistic adult population, Mason et al. (2022) examined the structural validity of the WHOQOL-BREF. The study included 352 participants with a mean age of approximately 42 years. Of the sample, 189 participants were male and 133 were female. Demographics on race were not reported. The research team concluded the WHOQOL-BREF to be a valid measure of quality of life for autistic adults; however, recommended the use of caution when interpreting some results. For example, as a consequence of follow-up focus groups, it was determined that some questions were interpreted differently than intended by autistic participants and; therefore, needed careful interpretation. The researchers advised adding additional information when presenting the questionnaire to offset issues with interpretation.

To explore age-related differences in quality of life between younger and older autistic adults, UK based Yarar et al. (2022), compared younger and older autistic adults with a non-autistic control group. The study included a total of 136 participants. Seventy-nine of the participants had autism. Race and gender of participants were not reported. The WHOQOL-BREF was used as the measure of quality of life in the autistic group and non-autistic control group. The researchers found that overall quality of life was significantly lower in the autistic group when compared to the non-autistic control group. These results are consistent with previous findings (Ayres et al., 2018; van Heijst & Geurts, 2015). Age did not have an effect on overall quality of life. However, older autistic adults reported higher quality of life in the social relationships domain than did younger autistic adults. No significant effects across domains were found by age in the control group. To explore possible predictors of quality of life, participants

were also administered self-report measures of autism symptoms and mental health symptoms. Results for the autistic and non-autistic control groups were consistent. Self-reported autism symptoms, anxiety, and depression were correlated with lower quality of life. Consistent with other studies, the most significant predictor of quality of life for both groups was self-reported depressive symptoms.

Grosvenor et al. (2023) conducted a study measuring well-being in autistic adults using the Positive emotion, Engagement, Relationships, Meaning, and Accomplishment (PERMA) Profiler. The measure, developed by Bulter and Kern (2016) examines well-being in the five domains for which it is named. The study by Grosvenor and colleagues utilized a sample of 517 autistic adults between the ages of 18 and 84 years. The overall well-being rating for the autistic sample was lower than that previously found in the general population. Domain scores were highest for Engagement and Accomplishment. Relationships, Meaning, and Positive emotion were virtually identical. The researchers concluded that autistic adult well-being may best be formulated as a unidimensional factor (e.g., overall well-being or happiness rating), as opposed to a combination of multiple factors. The researchers noted that 80% of the sample was well-educated and White, limiting generalizability of findings.

Conclusions and Limitations From Reviews

While conducting the review of previous studies, a few common themes emerged. First, quality of life in the autistic population is generally lower than quality of life measured in the general population. Many researchers continue to search for answers and predictive indicators of autistic adult quality of life to provide rationale and support for this phenomenon. However, caution should be used when interpreting results, as Oakley et al. (2021) found much variability in quality of life reports of autistic adults. Plainly, the quality of life for autistic adults being

lower than the general population does not equate to their general quality of life being poor.

Many autistic adults thrive, and individual experiences should be considered. Second, depressive symptoms have emerged as a significant predictor of quality of life in autistic adults. This finding is consistent with studies of the general population. Mental health challenges and their association with quality of life have long been documented, bringing light to the importance of comprehensive services for more vulnerable populations, such as those with autism.

Third, scholars have agreed upon the need to develop a measure of autistic quality of life that encompasses the aspects of quality of life that are important to the autistic population. Most measures currently being used were initially designed and validated for use with the general population and do not account for what it means to be autistic (i.e., autistic identity). Some attempts have been made, however, concerns around validation and the inclusion of meaningful factors continue. Until an empirically supported measure of quality of life designed for the autistic population that incorporates factors important to those with autism is created, researchers need to utilize existing measures that encompass as many relevant indicators as possible. The current study will utilize the Perceived Quality of Life Scale, which includes items representative of nine out of thirteen quality of life themes identified by McConachie et al. (2020) as particularly relevant to autistic adults.

Fourth and finally, major limitations of the studies reviewed pertain to race and gender. Most studies have been conducted in Europe, utilizing predominately Caucasian male samples. Consistent with previous findings, most of the studies reviewed did not so much as collect data on race/ethnicity (Steinbrenner et al., 2022). This finding is startling given recent movements in the importance of accurate representation and social justice in autism research, a gap this researcher addressed. Though the majority of studies collected data on gender, very few explored

gender differences as a component of their findings (Billstedt et al, 2011; Garcia-Villamizar et al. 2002; Gerber et al., 2008; Kamp-Becker et al., 2010; Saldana et al., 2009). Again, leaving massive gaps in the current understanding of autistic experiences of quality of life across various aspects of the population.

Chapter Summary

This chapter provided a thorough review of human needs theory as it relates to this study and an in-depth overview of existing empirical knowledge based on the academic inquiry of subjective quality of life experiences of autistic adults. Within the autistic population, adults remain a significantly under-researched subgroup that is overdue for comprehensive services and supports tailored to the unique needs of the population. Many autistic adults are under-served and display an array of maladaptive behaviors that result from alienation and lack of support for perceived needs. A review of the current literature highlighted the need for a more robust understanding of predictive indicators of quality of life in the autistic adult population, the inclusion of quality of life domains that are important to the subjective experiences of autistic adults, and more representative samples within autism research. The current study addressed these needs by exploring the effects of physical, cognitive, and social health and well-being on quality of life and happiness and analyzing the impacts of race and gender identity on overall quality of life and happiness in the autistic adult population. The following chapter provides a detailed description of the research design, sampling techniques, instrumentation, data collection procedures, and statistical analysis of the study.

CHAPTER 3: METHODS

Introduction to the Methods

This chapter provides information regarding the methods used to carry out this study. The research questions are presented, with a focus on the rationale behind the importance of understanding perceived quality of life for adults with autism. The Perceived Quality of Life (PQoL) Scale was used to examine the effects of the physical, cognitive, and social health and well-being domains on global happiness ratings in the autistic adult population. The analysis also examined the effects of race and gender identity on overall quality of life and global happiness ratings in autistic adults. Further, this analysis explored whether physical health and well-being, cognitive health and well-being, and social health and well-being vary by race and gender identity and how race and gender identity interact to impact global happiness ratings in autistic adults. Methods used for recruiting participants and collecting, managing, and storing data, as well as a detailed description of the statistical analysis used to examine the research questions is described. The chapter concludes with ethical considerations pertaining to the study.

Research Questions

This study aimed to explore how race, gender identity, and the domains of Physical Health and Well-being, Cognitive Health and Well-being, and Social Health and Well-being effect quality of life and Global Happiness ratings in autistic adults. Further, this study determined whether the physical health and well-being, cognitive health and well-being, and social health and well-being satisfaction domains vary by race and gender identity. Specifically, this study answered the following research questions:

Main Effects

Research question 1: How does race affect the Global Happiness Rating among autistic adults?

Research question 2: How does gender identity affect the Global Happiness Rating among autistic adults?

Research question 3: What is the effect of the Physical Health and Well-being domain score on the Global Happiness Rating for autistic adults?

Research question 4: What is the effect of the Cognitive Health and Well-being domain score on the Global Happiness Rating for autistic adults?

Research question 5: What is the effect of the Social Health and Well-being domain score on the Global Happiness Rating for autistic adults?

Interaction Effects

Research question 6: Do the effects of the Physical Health and Well-being domain score on Global Happiness Ratings vary by race in autistic adults?

Research question 7: Do the effects of the Cognitive Health and Well-being domain score on Global Happiness Ratings vary by race in autistic adults?

Research question 8: Do the effects of the Social Health and Well-being domain score on Global Happiness Ratings vary by race in autistic adults?

Research question 9: Do the effects of the Physical Health and Well-being domain score on Global Happiness Ratings vary by gender identity in autistic adults?

Research question 10: Do the effects of the Cognitive Health and Well-being domain score on Global Happiness Ratings vary by gender identity in autistic adults?

Research question 11: Do the effects of the Social Health and Well-being domain score on Global Happiness Ratings vary by gender identity in autistic adults?

Research question 12: Do the effects of race on Global Happiness Ratings in autistic adults vary by gender identity?

Research Design

A quantitative, cross-sectional research design was used in this study. Cross-sectional designs are sometimes described as taking a snapshot of a particular population (Carlson & Morrison, 2009), as they offer a way of collecting data from a population at a single point in time and can be particularly useful in describing features of a population and better understanding determinants of health (Wang & Cheng, 2020). Advantages of cross-sectional designs include the ability to compare differences between groups, limited ethical concerns due to the typical data collection procedures, and the ability to explore multiple predictors and outcomes simultaneously (Thomas, 2023; Wang & Cheng, 2020). Additionally, the cross-sectional research design is an excellent choice for exploratory research (Spector, 2019), such as the current study. This study incorporates the use of a self-report demographic survey and a self-report measure of perceived quality of life and happiness. Self-report measures have shown to be valid when measuring quality of life in the autistic adult population (Sandercock et al., 2020). Participants were recruited through local community outreach and utilization of the University of North Carolina at Chapel Hill (UNC) Autism Research Registry. The primary aim was to

examine the effects of physical health and well-being, cognitive health and well-being, and social health and well-being satisfaction on global happiness rating for autistic adults. The effects of race and gender identity on happiness ratings was also explored, as well as the interaction effects of race, gender identity, and pertinent quality of life domains (i.e., physical health and well-being, cognitive health and well-being, and social health and well-being) on happiness ratings in autistic adults.

Variables

The dependent variable analyzed in this study was the Global Happiness Rating, as identified by item 20 on the PQoL Scale. Happiness is a multi-faceted, subjective, and complex construct that includes a number of variables such as emotional, cognitive, financial, social, physical, and behavioral well-being (Carruthers & Hood, 2004). Happiness is a foundational element of quality of life (Ramey et al., 2022) and the notion that life satisfaction, subjective well-being, and happiness are correlated is widely agreed upon. Susniene and Jurkauskas (2009) concluded that happiness is an important indicator in assessing overall quality of life and is characterized by subjective feelings towards one's understanding of one's place in society and meaningfulness of life. Item 20 on the PQoL Scale asks respondents to rate the question "How happy are you?" on a scale from 0 to 10, with 0 being "extremely unhappy" and 10 being "extremely happy." This item is used to examine convergent validity within the instrument and highly correlates with the PQoL Scale total score (PQoL, 2016), supporting the theoretical underpinnings linking the constructs of happiness and satisfaction, with happiness being a subjective representation of the fulfillment of a multitude of life's needs (Maslow, 2013).

The current study utilized two categorical independent predictors, race and gender identity. Race is often included in research in oversimplified categories such as "white" and

“non-white” (Dirette, 2014), which is likely due, at least in part, to the demographic make-up of the general population in many areas. For example, over half of the population in the United States, including the southeastern United States, is White (i.e., 58% and 54% respectively; Census Reporter, 2022). However, such broad categories as “non-white” significantly overgeneralize populations and hinder application of results to real world environments; therefore, this study included a broader array of racial identities. Participants were asked to self-identify race on the demographic survey. Self-identified levels of race included 1.) American Indian; 2.) African American/Black; 3.) Asian Indian; 4.) Caucasian/White; 5.) Chinese; 6.) Japanese; 7.) Pacific Islander, and 8.) Other Race. Participants were also asked to self-identify gender identity on the demographic survey. Self-identified levels of gender identity included 1.) Female; 2.) Male; 3.) Non-binary; 4.) Trans female; 5.) Trans male; 6.) Genderfluid, and 7.) Other Gender Identity.

This study also included three continuous independent predictors: 1.) Physical Health and Well-Being, 2.) Cognitive Health and Well-Being, and 3.) Social Health and Well-Being. Physical health and well-being includes “physical activity, balanced nutrition, getting adequate sleep, and avoiding harmful behaviors. Physical wellness also includes a personal responsibility to understand [one’s] body’s warning signs and recognize when [one is] ill and in need of medical attention” (University of North Georgia, 2024). Ratings of physical health and well-being satisfaction were determined by calculating the mean of items 1, 2, 4, 5, and 19 on the PQoL Scale. Cognitive health and well-being was operationalized as one’s satisfaction with how well one thinks and remembers and how well one carries on a conversation (e.g., speaking clearly, hearing others, and/or being understood; Patrick, 2015). Ratings of cognitive health and well-being satisfaction were determined by calculating the mean of items 3 and 6 on the PQoL

Scale. Social health and well-being indicators include accepting others as they are, having a positive comfort level with society, feeling that one contributes meaningfully to society, having an adequate understanding of the social world, feeling part of a community, involvement in recreation and leisure opportunities, and perception of the quality of one's interpersonal relationships (Keyes & Lopez, 2002). Other key social well-being indicators include the quality of one's interpersonal relationships and recreation and leisure skills and opportunities (Verdugo et al., 2005). Finally, social health and well-being satisfaction was determined by calculating the mean of items 8, 9, 10, 11, 12, 13, 14, 15, 16, 17, and 18 on the PQoL Scale. Table 1 provides an item-by-item listing of the questions that comprise the PQoL Scale. The table is divided into the three subdomains of Physical, Cognitive, and Social Health and Well-being satisfaction. The table concludes with the Global Happiness Rating item.

Table 1*Perceived Quality of Life Scale Items*

<i>How dissatisfied or satisfied are you with:</i>	
<i>Physical Health and Well-Being</i>	(Q1) Your physical health (the health of your body)? (Q2) How well you care for yourself, for example, preparing meals, bathing, or shopping? (Q4) The amount of walking you do? (Q5) How often you get outside of the house, for example, going into town, using public transportation or driving? (Q19) The amount and kind of sleep you get?
<i>Cognitive Health and Well-Being</i>	(Q3) How well you think and remember? (Q6) How well you carry on a conversation, for example, speaking clearly, hearing others, or being understood?
<i>Social Health and Well-Being</i>	(Q8) How often you see or talk to your family and friends? (Q9) The help you get from your family and friends, for example, helping in an emergency, fixing your house, or doing errands? (Q10) The help you give your family and friends? (Q11) Your contribution to your community, for example, a neighborhood, religious, political, or other group? (Q12) Your retirement or current job? (Q13) The kind and amount of recreation or leisure you have? (Q14) Your level of sexual activity or lack of sexual activity? (Q15) The way your income meets your needs? (Q16) How respected you are by others? (Q17) The meaning and purpose of your life? (Q18) The amount of variety in your life?
<i>Global Happiness Rating</i>	(Q20) How happy are you?

Population

The diagnostic criteria for Autism Spectrum Disorder have gone through numerous changes and restructuring since first identified by Leo Kanner as ‘infantile autism’ in his 1943 publication. Other names for the disorder have included, childhood disintegrative disorder, autistic disorder, pervasive developmental disorder, and Asperger’s Syndrome. Autism Spectrum Disorder is characterized by challenges related to two broad areas of functioning: social-communication and restricted/repetitive patterns of behavior and interests (American Psychiatric Association, 2022). The first cohorts of children diagnosed with ASD are now entering middle and older age (Hwang et al., 2017). In fact, based on current life expectancy of school-age children with ASD, there will be approximately 700,000 individuals age 65 and older with ASD in the next 20 years (Wright et al., 2019).

This study focused on individuals age 18 and above who are their own legal guardian and self-reported as being on the autism spectrum. As previously stated, throughout various versions of the Diagnostic and Statistical Manual (DSM), the diagnostic label for those on the autism spectrum has evolved. The latest iteration, DSM-5-TR, specifies that all previous labels fall under the current continuum of Autism Spectrum Disorder. Therefore, participants were asked to self-report a diagnosis of either autism, autism spectrum disorder, autistic disorder, pervasive developmental disorder, and/or Asperger’s Syndrome depending on which version of the DSM was used at the time of diagnosis. Distinctions in the diagnostic label were not explored in the current analysis due to the person-centered nature of this study, versus a focus on diagnostic categorization. To participate, respondents were required to independently complete the self-report demographic questionnaire and the self-report PQoL Scale, indicated by being their own legal guardian. The developers of the PQoL Scale were contacted to obtain information

regarding the average reading level required for self-administration of the measure. Statistics regarding the reading level of the PQoL Scale were not available and the developers recommended utilizing reading level software (D. Patrick, personal communication, May 21, 2024). According to Readable (2024), the PQoL Scale has an approximate sixth grade reading level as measured by the Flesch-Kincaid scale, which is a widely used readability formula that calculates approximate grade equivalents for selected texts according to norms in the United States. A sixth grade reading level is suitable for approximately 85% of the general public. Additionally, those who self-reported co-occurring diagnoses, including physical and mental health conditions, were not excluded from the current study, as co-occurrence is common among those on the autism spectrum and was analyzed as representative of the population. Table 2 provides an overview of the inclusion and exclusion criteria.

Table 2

Inclusion and Exclusion Criteria

Inclusion Criteria:

- ✓ Self-reported diagnosis of Autism, Autism Spectrum Disorder, Autistic Disorder, Pervasive Developmental Disorder, or Asperger's Syndrome
- ✓ Chronological age of 18 years or above and identify as own legal guardian
- ✓ Able to independently complete the self-report questionnaires

Exclusion Criteria:

-
- ✗ No self-reported diagnosis of Autism, Autism Spectrum Disorder, Autistic Disorder, Pervasive Developmental Disorder, or Asperger's Syndrome
 - ✗ Under 18 years of age
 - ✗ Not own legal guardian
 - ✗ Unable to independently complete the self-report questionnaires

Sample & Sampling

The population examined in this study consisted of autistic adults age 18 and over who are their own legal guardian. Sampling techniques included a combination of convenience and purposive sampling. With convenience sampling, participants were recruited from a local clinical setting. Purposive sampling was two-fold. Recruitment information about the study was distributed to professional contacts in the local community who have access to the target population. Additional purposive sampling was conducted by accessing participants through the UNC Autism Research Registry, which is supported as a component of the Research Participant Registry Core housed within the Carolina Institute for Developmental Disabilities.

The Research Participant Registry Core links eligible participants with research studies, maintains a confidential database of those interested in participating in UNC-Chapel Hill supported research, and alerts registry participants of advancements in research (Carolina Institute for Developmental Disabilities, 2024). The registry core maintains separate databases pertaining to those with intellectual and developmental disorders, autism, Fragile X, and typical childhood development. This research study recruited participants from the autism-specific database (i.e., UNC Autism Research Registry), which is a “confidential database maintained for the purpose of matching qualified participants who have a confirmed diagnosis of ASD with research studies” (Carolina Institute for Developmental Disabilities, 2024). Research registry eligibility requirements include a current diagnosis on the autism spectrum and North Carolina residency. Participants can join the research registry by completing the enrollment process while accessing services through several regionally based outpatient centers and clinics throughout the state of North Carolina or by enrolling on-line through the registry’s secure portal. After use of the UNC Autism Research Registry was approved by the registry administrators, the registry

manager conducted a database query and distributed study materials to potential participants who met inclusion criteria based on the specifications set by the researcher. Specific filters of the database were set to collect a potential sample that had a confirmed diagnosis on the autism spectrum, was 18 years of age or older, was their own legal guardian, and was inclusive of racial and gender identity diversity. Demographic parameters were set in an attempt to recruit participants across groups until the overall sample size target, discussed in detail below, was met. In order to do so, the strategy of oversampling was used.

Previous studies have reported a significant over-representation of White participants (Maenner et al., 2023; Shattuck et al., 2018; Steinbrenner et al., 2022). Oversampling is used when collecting sufficient data from subsets of the target population is important to the research findings, though may be challenging (Vaughan, 2017), such as it was in the current study regarding racial and gender identity. For example, current male-to-female prevalence rates are 4:1, meaning that for every four males diagnosed with autism, one female is diagnosed (Maenner, 2023). This prevalence rate discrepancy results in higher autism diagnostic rates among males and means that males are typically easier to sample. Therefore, oversampling was used as a strategy to ensure that the sample includes adequate representation across racial and gender identity groups since specific demographics are often under-represented in autism research (Ayers, 2018; Maenner, 2023).

In determining the sample size for this study, several variables were taken into consideration. One of those variables was effect size, which indicates the strength of the relationship between the independent and dependent variables (Ary et al., 2019) and can help determine if changes made to the dependent variable are of enough significance to support the study findings. Maintained by Cohen (1992), an effect size of 0.2 is considered small, and effect

size of 0.5 is considered medium, and an effect size of 0.8 is considered large (Leary, 2012). The larger the effect size, the more emphasis can be placed on the results. This study was the first to utilize the PQoL Scale with a solely autistic population. Therefore, an effect size estimate obtained from a meta-analysis conducted by Virues-Ortega et al. (2013) on a study examining a program for individuals with ASD, consistent with the primary method of sampling that was conducted for the current study, was used as a guide. These researchers found a mean effect size of 0.47, approximately medium.

Another consideration related to effect and sample size is power or sensitivity. Cohen (1992) recommends a minimally acceptable power of 0.80 (i.e., 80%). A design with high power will detect actual results that are present, while a design with low power may fail to pick up effects that are present, increasing the likelihood of a Type II error (Brownlee, 2020; McClanahan, 2019). Another variable that can impact sensitivity is alpha level. Due to the exploratory nature of the current study, this researcher set an *alpha level* of 0.10

These considerations led this researcher to conduct a power analysis to calculate the minimum sample size required to maintain the desired power (i.e., 80% or higher) at a specified effect size (i.e., 0.47) and level of significance (0.10) using G*Power software (Mayr et al., 2007). The power calculation showed an effect size of 0.47, at a 0.10 significance level, and power of 81% with a sample size of 57 participants ($N = 57$). However, because of the uniqueness of oversampling to attempt to obtain adequate representation across gender identity and racial groups, the actual sample size consisted of 83 participants. A total of 96 participants initiated the survey process. Eighty-six participants completed the demographic questionnaire, which was the first step in the process. An additional three participants dropped out during completion of the PQoL Scale, resulting in the total sample size of 83 participants ($N = 83$),

which exceeded the original goal of 57 participants; thereby, increasing the power of the analysis (Hair et al., 2019).

Procedures

Participants were recruited through local community outreach and utilization of the UNC Autism Research Registry. Potential participants were provided with a study information sheet, which outlined the purpose and description of the study, confidentiality procedures, and name and contact information of whom to contact in the event of questions and/or concerns. Participants were then instructed to complete a brief demographics survey followed by the self-report PQoL Scale. A step-by-step outline of the data collection procedures is detailed below.

1. A study information sheet was generated and submitted along with the research proposal to the University & Medical Center Institutional Review Board (UMCIRB) at East Carolina University.
2. The demographic survey and the PQoL Scale was generated electronically using Research Electronic Data Capture (REDCap).
3. Upon approval from the UMCIRB:
 - a. the registry administrator of the UNC Autism Research Registry was contacted regarding participant recruitment.
 - b. all applicable data retrieval, storage, and sharing procedures were reviewed by the principal investigator for all applicable consent.
 - c. participants were accessed and recruited via email through the UNC Autism Research Registry.
 - d. participants were recruited from a local outpatient clinical setting.

- e. recruitment information about the study was distributed to professional contacts in the local community.
4. Participants were provided with the study information sheet and asked to complete the brief demographic survey followed by the self-report PQoL Scale.
 - a. In the event that strong, difficult to manage emotions were evoked before or after completion of the research protocol, information for contacting the Crisis Lifeline, 988, was provided within the study information sheet.
5. Electronic versions of completed research protocols were stored in the secure REDCap online platform.
6. Physical copies of the completed research protocols were stored in a locked cabinet in the principal investigator's office.
7. Once the needed data was collected, data was entered into Version 29.0.2.0 of IBM SPSS Statistics software on a password protected computer for analysis.

Instrumentation

The section that follows provides an overview of the instrumentation used in this study. First, the demographic survey is described, followed by the PQoL Scale.

Demographic Survey

Participants were asked to complete a demographic survey that provided basic demographic information. To obtain information relevant to the current study, participants were asked to provide their diagnostic status (i.e., Autism, Autism Spectrum Disorder, Autistic Disorder, Pervasive Developmental Disorder, or Asperger's Syndrome), gender identity, and race. In maintaining consistency with recommendations for adult autism research (Roestorf et al., 2019) and in consideration of other factors that are relevant in the current study, participants

were also asked to provide information regarding their age in years, sex assigned at birth (i.e., female, male), ethnicity (i.e., Hispanic, Non-Hispanic), highest level of education (i.e., some high school, high school diploma, some college, associate's degree, bachelor's degree, master's degree, professional degree, PhD or equivalent), current employment (i.e., unemployed, full-time employment, part-time employment, other employment), living arrangement (i.e., alone without support, alone with support, with partner, with parent(s) and/or guardian(s), assisted living facility, other), current relationship status (i.e., single, married, divorced, living with partner, other), and other diagnoses including mental and physical health conditions.

Perceived Quality of Life Scale

This subsection provides detailed information about the PQoL Scale, including its' development, measurement, reliability and validity, administration guidelines, and scoring. The subsection concludes with a description of the rationale for use of the PQoL Scale in this study.

Development of the PQoL Scale

In collaboration with other researchers, Drs. Donald Patrick and Marion Danis developed the PQoL Scale using human needs theory and qualitative information gathered through interviews with individuals with disabilities, older adults, and well persons (PQoL, 2008). The PQoL Scale is designed for those 18 years and older and is based on a model that considers quality of life to be an appraisal of various categories of fundamental life needs (Patrick, 2015). The measure is suitable for those with an approximate sixth grade or higher reading ability (Readable, 2024). The PQoL Scale investigates the relationship between functional status and an individual's satisfaction with their own functioning in the areas of physical health and well-being satisfaction, cognitive health and well-being satisfaction, and social health and well-being satisfaction.

Perceived Quality of Life Scale Measurement

The original version of the PQoL contained 12 items. The current version containing 19 subscale items plus one item on global happiness was normed on those with varying levels of health and disability and asks respondents to rate present day levels of satisfaction/dissatisfaction. Items 1-19 are rated on an 11-point scale ranging from extremely dissatisfied (0) to extremely satisfied (10). Item number 20 is rated on an 11-point scale ranging from extremely unhappy (0) to very happy (10). This item is used to examine convergent validity within the instrument and highly correlates with the PQoL Scale total score (Patrick, 2015), supporting the theoretical underpinnings linking the constructs of happiness and satisfaction. Happiness is conceived as a subjective representation of the fulfillment or satisfaction of a multitude of life's needs (Maslow, 2013), as reflected in the subscales of the PQoL Scale. Item number 7 (i. e., How satisfied or dissatisfied are you with the kind and amount of food you eat?) is best used on its own and/or as part of the overall score, as it does not clearly fall into any of the subscales. Item number 7 was excluded from the current analysis. Item numbers 1, 2, 4, 5, and 19 make up the physical health and well-being subscale. Item numbers 3 and 6 comprise the cognitive health and well-being subscale, while the remaining items, 8-18, make up the social health and well-being subscale. For additional support in individual item ratings, the anchors in Table 3 that follows were provided for reference during administration.

Table 3

Perceived Quality of Life Scale Anchors

0	Extremely dissatisfied / unhappy
1 or 2	Somewhat dissatisfied / unhappy
3 or 4	A little dissatisfied / unhappy
5	Neither satisfied/happy or dissatisfied/unhappy
6 or 7	A little satisfied / happy
8 or 9	Somewhat satisfied / happy
10	Extremely satisfied / happy

Reliability and Validity

A population mean PQoL score of 7.5 has been observed across a variety of populations, including older adults, well persons, and those with chronic health conditions ($N = 3359$; PQoL, 2008). Interpretation of the measure in cross-sectional use has led to a score of 7.5 being classified as the cutoff between dissatisfied and satisfied. Information has not been published regarding individual subdomain means. Internal consistency was examined in a sample of 90 respondents in which the Guttman-Cronback alpha was 0.91 (Patrick et al., 2001). The current study explored the reliability of the use of this measure with autistic adults via Cronbach's alpha, as the PQoL Scale had not been previously used with an autistic only sample. The PQoL Scale total score was calculated to have a Cronbach's Alpha reliability statistic of 0.94, which indicates high reliability for this measure.

Administration of the Test

The PQoL Scale consists of 20 total questions and can be self-administered or administered by an interviewer. Specific instructions on administration are outlined in the PQoL Scale User's Manual. For the current analysis, self-administration was used.

For each item, the respondent is to rate their level of satisfaction on a scale of 0 to 10 where 0 is *extremely dissatisfied/unhappy* and 10 is *extremely satisfied/happy* (Patrick, 2015; p. 16).

Administration guidelines instruct respondents to identify the number that indicates how dissatisfied or satisfied they are with various aspects of their lives. "A response of 5 means that you are neither dissatisfied nor satisfied" (Patrick, 2015; p. 18).

Scoring

This study utilized the individual subscale scores and global happiness rating (i.e., item 20) of the PQoL Scale. The mean of each subscale was calculated. Item number 7, which does not fall into a specific subscale, was not included for analysis in the current study.

Instrument Justification

McConachie et al. (2020) conducted a qualitative study by holding a series of discussion groups with autistic participants to determine common relevant themes to consider when measuring quality of life for autistic people. A total of nine discussion groups were held in four countries: the United Kingdom, Singapore, Argentina, and Australia. The sample consisted of 38 autistic participants. The researchers developed 13 distinct themes based on a review of transcripts from the nine discussion groups. The items on the PQoL Scale represent a respectable number of the themes identified; nine out of 13. Identified themes are indicated below in bold, with corresponding examples of representation from the PQoL Scale in italics.

1. **Difficulties because of other people’s lack of knowledge about autism and acceptance of differences:** *“How satisfied or dissatisfied are you with how respected you are by others?”*
2. **External support and services:** *“How satisfied or dissatisfied are you with the kind and amount of recreation or leisure you have?”*
3. **Fear of loss of resources, including financial:** *“How satisfied or dissatisfied are you with the way your income meets your needs?”*
4. **Family support:** *“How satisfied or dissatisfied are you with the help you receive from family and friends?”*

5. **Other characteristic associated with autism:** *“How satisfied or dissatisfied are you with how well you carry on a conversation?”*
6. **Social engagement:** *“How satisfied or dissatisfied are you with how often you get outside of the house?”*
7. **Friendships:** *“How satisfied or dissatisfied are you with how often you see and talk to family and friends?”*
8. **Economic uncertainty and work:** *“How satisfied or dissatisfied are you with your retirement or current job?”*
9. **Contributions to others:** *“How satisfied or dissatisfied are you with your contributions to your community?”*

Data Collection, Storage, and Management

This study utilized data that was collected on the autistic adult population. Data was collected and stored electronically through REDCap software, which is a “secure web application for building and managing online surveys and databases” (Harris et al., 2019). REDCap is secure, Health Insurance Portability and Accountability Act (HIPAA) compliant, and free for use for researchers at East Carolina University. The HIPAA privacy rule provides standards for protecting individually identifiable health information and requires the use of specific safeguards to ensure the privacy of protected health information (United States Department of Health and Human Services, 2024). In 2004, researchers at Vanderbilt University created REDCap out of a need for a secure data collection tool that is HIPAA compliant (Harris et al., 2019). “Users of REDCap must adhere to all ECU computer policies, regulations, rules and standards” (East Carolina University, 2024). Data was also collected via physical copies of the research protocol. Completed physical copies were stored in a locked cabinet in the principal

investigator's office. Personal Health Information (PHI), such as name, address, email address, date of birth, or phone number was not collected.

Statistical Analysis

Version 29.0.2.0 of IBM SPSS Statistics software was used to examine the results of the current study. The specific statistical analysis technique of Hierarchical Multiple Regression (HMR) was employed to explore the research questions presented. However, before conducting the HMR, performing several preliminary tests to ensure the validity and reliability of the findings was important. Key considerations included testing to ensure:

- linearity (i.e., linear relationship between independent and dependent variables),
- homoscedasticity (i.e., equal variances across groups),
- normality of residuals (i.e., residuals are bell-shaped),
- independence of the error distribution (i.e., independent observations within and between groups), and
- the absence of multicollinearity (i.e., no highly correlated variables; Jeong & Jung, 2016).

Hierarchical Multiple Regression aims to determine how much of the variability found in a dependent variable can be linked to specific predictors (i.e., independent variables) that are entered into the equation in stages or blocks (Hoyt et al., 2006; Jeong & Jung, 2016). An advantage of utilizing HMR is the ability of the analysis to examine multiple predictor variables against a single outcome (Huck, 2012). This technique also allows an examiner to control for confounding variables by entering them into the equation prior to introducing the variables of primary interest; thereby examining the amount of variance that is contributed by the predictors of interest that is above and beyond that which can be explained by the potentially confounding

variables (Huck, 2012; Nielson, 2003). Hierarchical Multiple Regression has the capability to analyze the impacts of categorical variables on a dependent variable, the impacts of continuous variables on a dependent variable, and the interaction effects of two or more predictors on an outcome (Hoyt et al., 2006). In highlighting the applicability of HMR to this analysis, the categorical predictors of race and gender identity were analyzed for their impacts on Global Happiness Ratings in autistic adults, followed by the continuous predictors of Physical Health and Well-being, Cognitive Health and Well-being, and Social Health and Well-being. Finally, the analysis was used to explore the predictive values of the interactions between race and gender identity, and the predictive values of the interactions between race and gender identity and each of the continuous predictors.

As previously highlighted, the current study has a dependent variable of the Global Happiness Rating on the PQoL Scale; categorical independent predictors of race and gender identity; and continuous independent predictors of Physical Health and Well-being, Cognitive Health and Well-being, and Social Health and Well-being. The HMR was conducted in the following sequence to determine the features of the current study design, with an alpha level of 0.10 ($p = .10$).

Step 1: *Race and Gender Identity* were entered in Block 1 of the HMR equation to determine their main effects on Global Happiness Ratings in autistic adults. The subgroups of “Identifies as White” and “Identifies as Male” were used as the reference groups for this block of the analysis.

Step 2: For Block 2, the interaction variables of *race by gender identity* were added to the HMR equation to determine the interaction

effects of these predictors on Global Happiness Ratings in autistic adults. The specific interaction terms were as follows:

*Intersectional Race*Female, Black*Female, Black*Male, White*Female, White*Male, White*Gender Non-conforming, Intersectional Race*Male, Black*Gender Non-conforming, and Intersectional Race*Gender Non-conforming.* The subgroup of *White*Male* was used as the reference group for this portion of the analysis.

Step 3: For Block 3, the continuous predictors of *Physical Health and Well-being, Cognitive Health and Well-being, and Social Health and Well-being* were added to the HMR equation to determine their impacts on Global Happiness Ratings in autistic adults after accounting for the impacts of race and gender identity and their interaction terms.

Step 4: Finally, the interaction terms for *Race and Gender Identity* by the subjective *Physical, Cognitive, and Social Health and Well-being* domains were entered in Block 4 of the HMR equation to determine the effects of the interactions of these predictors on Global Happiness Ratings in autistic adults. The subgroups of *Identifies as White* and *Identifies as Male* were used as the reference groups for this portion of the analysis. The specific interaction terms were: *Female*Physical Health and Well-being, Gender Non-conforming*Physical Health and Well-being,*

*Black*Physical Health and Well-being, Intersectional Race*Physical Health and Well-being, Female*Cognitive Health and Well-being, Gender Non-conforming*Cognitive Health and Well-being, Black*Cognitive Health and Well-being, Intersectional Race*Cognitive Health and Well-being, Female*Socioal Health and Well-being, Gender Non-conforming*Socioal Health and Well-being, Black*Socioal Health and Well-being, and Intersectional Race*Socioal Health and Well-being.*

Ethical Considerations

Approval of this research study was obtained from the University Medical Center Institutional Review Board (UMCIRB) at East Carolina University (see Appendix D). In accordance with UMCIRB approval, the rights and welfare of the human research participants were protected. Such protections included procedural designs minimizing the risk to subjects; ensuring equitable selection of subjects within study criteria; providing information to potential participants regarding the purpose of the study; and maintaining adequate data collection, storage, and management procedures. In the event that strong, difficult to manage emotions were evoked during or after participation in the research study, information for contacting the Crisis Lifeline, 988, was provided.

The study also attended to the increasing ethical need to include representative considerations for intersectionality within autistic identity in autism research, which takes into account other forms of diversity (e.g., race and gender identity) of lived experiences (Cascio & Racine, 2018). Cascio et al. (2021) concluded that the exclusion of intersectionality from autism research serves to further alienate marginalized subgroups within the autistic population.

Inclusive research that attends to intersectionality is more generalizable and promotes social justice and equity. Therefore, this study prioritized inclusivity. Current literature supporting best practice for diverse subgroups within the autistic population is extremely limited. Ethical considerations that relate to the current lack of adequate understanding of best practice for various subgroups include non-maleficence, beneficence, autonomy, and justice. For example, counselors and mental health professionals need to be better equipped to protect autistic adult clients from harm based on the diverse perspectives and presentations found within the autistic community. This protection can come in many forms including advocacy efforts, community inclusion, and psychotherapeutic intervention. It is imperative that those serving the autistic adult population are equipped with knowledge that promotes overall well-being for all autistic adults, allows autistic adults to practice self-determination based on their unique needs and characteristics, and provides a framework for equitable treatment.

Chapter Summary

The preceding chapter provided an overview of the research design; instrumentation; and procedures for data collection, storage, and management. The chapter concluded with a description of the statistical procedure that was used to analyze the results, as well as ethical considerations that were upheld throughout the study. The cross-sectional research design supported this study exploring the impacts of race, gender identity, physical health and well-being, cognitive health and well-being, and social health and well-being on global happiness ratings in the autistic adult sample.

CHAPTER 4: RESULTS

Introduction to the Results

This chapter provides a detailed description of the results for the current study exploring the effects of race, gender identity, and physical, cognitive, and social health and well-being satisfaction domains on global happiness ratings in the autistic adult population. The chapter also includes an analysis of the interaction effects of race by the Perceived Quality of Life (PQoL) subscale domains, gender identity by the PQoL subscale domains, and race by gender identity on global happiness ratings. First, information regarding the sample size of the study is provided, followed by the sample demographics. Next, the data analysis begins with the descriptive statistics of the independent and dependent variables and an outline of the Hierarchical Multiple Regression (HMR) analysis procedures. The results of all research questions pertaining to both the main effects and interaction effects of the study are provided.

Sample Demographics

The sample for the current study consisted of 83 ($N = 83$) autistic adults age 18 years to 73 years. The *mean* age of participants was 34.7 years, with a *standard deviation* of 14.1 years and *median* age of 29 years. This age range represents a wide variety of lived experiences that add to the applicability of results. The following subsections explain the make-up of the sample based on participant responses to the Demographic Survey. The purpose of this overview is to provide a descriptive summary of the entire sample. However, the most relevant demographic information to the current study is race/ethnicity and gender identity. While not all demographic information was analyzed in the current study, this researcher elected to remain consistent with recommendations for adult autism research that supports the collection of additional information related to sex assigned at birth, highest level of education, current employment, living

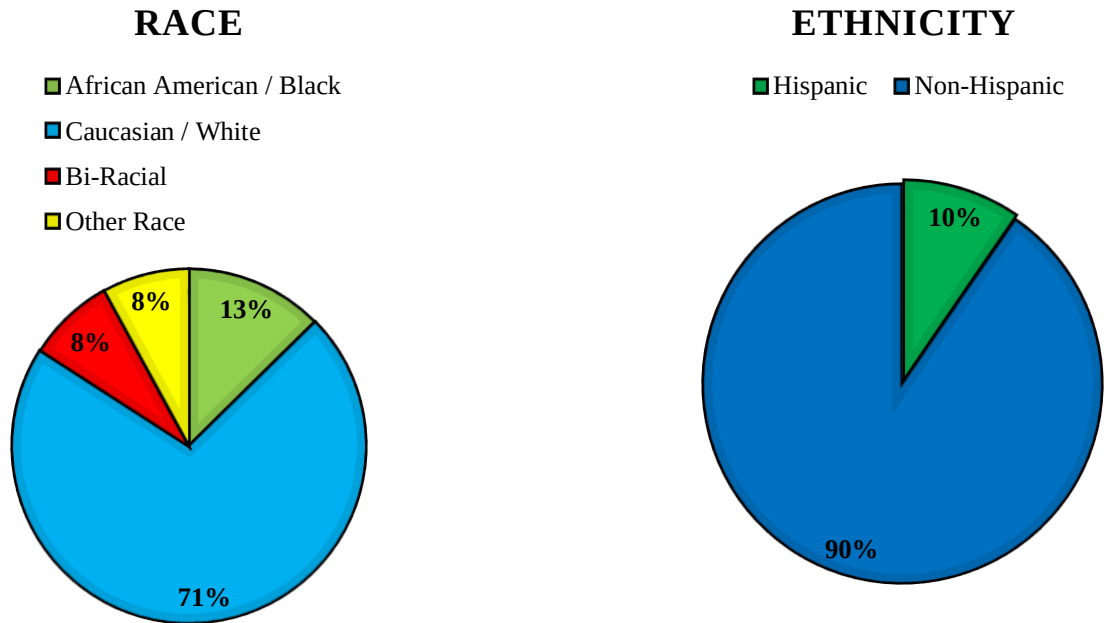
arrangement, current relationship status, and other diagnoses including mental and physical health conditions (Roestorf et al., 2018). Including descriptive statistics for these demographics adds to the robustness of the study findings.

Race and Ethnicity

Caucasian/White participants comprised 73.5% ($n = 61$) of the sample, while African American/Black participants accounted for 13.3% ($n = 11$), those who identified as Other Race accounted for 8.4% ($n = 7$), and Bi-Racial participants comprised 4.8% ($n = 4$) of the sample. Other race identifications comprised of unknown ($n = 1$), Vietnamese ($n = 2$), South Korean ($n = 1$), Filipino ($n = 1$), Mexican ($n = 1$), and Hispanic ($n = 1$). Bi-racial identities included American Indian and White ($n = 2$), Pacific Islander and Black ($n = 1$), and Azorean Portuguese and White ($n = 1$). Regarding ethnicity, 75 participants (90.4%) identified as Non-Hispanic, while the remaining 8 participants (9.6%) identified as Hispanic. Consistent with previous studies, White participants formed the majority of the current sample. Notable, however, is the collection of demographic data related to race and ethnicity and the opportunity to explore the impacts of race in autism research, as the inclusion of this data has been lacking in other studies (Steinbrenner et al., 2022). Figure 2 uses a series of pie charts to provide a visual representation of the approximate percentage distribution of race and ethnicity across the sample. As highlighted in the text, the majority of the sample was White, with approximately 30% being Non-White. Additional information about how race was categorized for the analysis is provided within the study findings.

Figure 2

Demographics by Race and Ethnicity

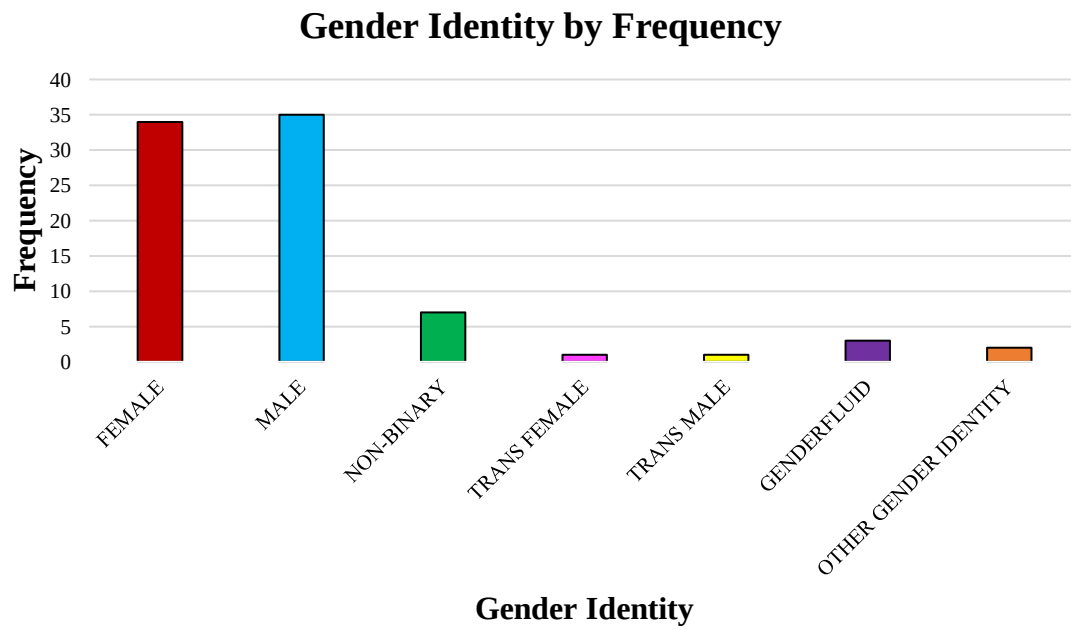


Sex and Gender Identity

Demographic data regarding both sex assigned at birth and gender identity was collected for the current study. With higher rates of variance in gender expression in the autistic population, collecting and analyzing data about gender identity versus sex assigned at birth is increasingly important in autism research (Cooper et al., 2018). Forty-six respondents (55.4%) reported their sex assigned at birth as female, while 37 (44.6%) reported their sex assigned at birth as male. A variety of gender identities were represented in the current study, including male ($n = 35$, 42.2%), female ($n = 34$, 41.0%), non-binary ($n = 7$, 8.4%), trans female ($n = 1$, 1.2%), trans male ($n = 1$, 1.2%), genderfluid ($n = 3$, 3.6%), and other gender identity ($n = 2$, 2.4%). Other gender identities consisted of “questioning” ($n = 1$) and “none” ($n = 1$). As highlighted in the review of current literature, most studies have a large majority of male respondents. An advantage of the current study is the almost equal representation of the gender identities of male and female, as well as the substantial number of respondents who identify with gender non-conformance, which will be explained in more detail as it relates to a primary study predictor. Figure 3 provides a bar chart of gender identity distribution by frequency. Subsequent information in this chapter provides additional descriptives on how gender identity was categorized for the analysis.

Figure 3

Gender Identity by Frequency



Level of Education

The majority of the sample was college educated, with over 75% having at least some college. Specifically, levels of education from highest to lowest percentage included 26.5% ($n = 22$) with some college, 24.1% ($n = 20$) with a Bachelor's degree, 16.9% ($n = 14$) with a high school diploma, 13.3% ($n = 11$) with a Master's degree, 10.8% ($n = 9$) with an Associate's degree, 4.8% ($n = 4$) with a Professional degree, 2.4% ($n = 2$) with some high school, and 1.2% ($n = 1$) with a Ph. D. or equivalent. In part, this information helps to contribute to the general knowledge regarding levels of functioning and lived experiences within the sample and helps combat stereotypes that autistic adults are mostly uneducated and/or incapable of achieving higher levels of education.

Current Employment Status

Twenty-eight participants (33.7%) reported full-time employment, 26 (31.3%) indicated they were unemployed, 23 (27.7%) reported part-time employment, and 6 (7.2%) indicated other employment status. Other employment statuses comprised of full-time student ($n = 2$), self-employed ($n = 2$), volunteer ($n = 1$), disabled ($n = 1$), and communal living with shared responsibilities ($n = 1$). This demographic information highlights that the majority of the sample reported some type of current employment (68%), which, similar to level of education, is likely reflective of the overall levels of functioning of the current sample.

Living Arrangement

To gain more insight into additional functional capacities of the sample, participants were asked to provide information regarding their current living arrangement. Participants were asked to select from the following categories, with the resulting response rate in parentheses: With Parent(s) and/or Guardian(s; $n = 32$, 38.6%), Alone Without Support ($n = 19$, 22.9%), With a

Partner ($n = 17$, 20.5%), Alone With Support ($n = 7$, 8.4%), Other Living Arrangement ($n = 7$, 8.4%) and Assisted Living Facility ($n = 1$, 1.2%). Other living arrangements reported by the sample included communal living ($n = 1$), with a roommate ($n = 3$), in a dormitory ($n = 1$), and with other family members ($n = 2$). Highlighted in these descriptive statistics is the variety of living arrangements and experiences of autistic adults.

Relationship Status

Participants were also asked to report their current relationship status. Forty-eight (57.8%) participants were single; 15 (18.1%) were married; 9 (10.8%) reported other relationship status, 6 (7.2%) were living with a partner, and 5 (6.0%) were divorced. Other relationship statuses included dating ($n = 1$) and being in a committed relationship ($n = 8$).

Co-occurring Diagnoses

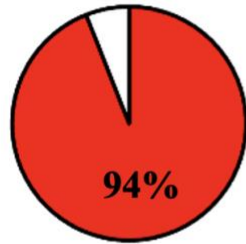
Previous studies have found disproportionately significant rates of co-occurring mental and physical health conditions within the autistic population. Estimates of co-occurring anxiety and depression have ranged from 50% to 70% (Lugnegård et al., 2011), with premature mortality rates due to physical health conditions being significantly higher in the autistic population (Hwang et al., 2019; Shavelle et al., 2001; Smith DaWalt et al., 2019). To assess the presence of co-occurring mental and physical health conditions in the current sample, respondents were first asked to report other co-occurring mental health diagnoses. Responses consisted of anxiety ($n = 61$, 73.5%), depression ($n = 50$, 60.2%), attention deficit / hyperactivity disorder ($n = 46$, 55.4%), other ($n = 25$, 30.1%), and none ($n = 5$, 6%). Other self-reported co-occurring mental health diagnoses included post-traumatic stress disorder, obsessive compulsive disorder, panic disorder, sensory processing disorder, borderline personality disorder, bipolar disorder, schizoaffective disorder, and body dysmorphia. Many respondents reported experiencing multiple co-occurring

mental health diagnoses. Figure 4 provides a series of pie charts to help visualize the of percentages of the sample living with one or more co-occurring mental health condition. The top left pie chart represents the percentage of participants who endorsed one or more diagnosis. Each additional pie chart represents a different diagnosis, with the percentage of participants who endorsed that diagnosis in red. Finally, providing additional insight into the sample, a host of co-occurring physical health conditions were reported. Common physical health conditions (i.e., at least three occurrences) were migraines, seizures, high blood pressure, gastro-intestinal challenges, asthma, and visual impairment.

Figure 4

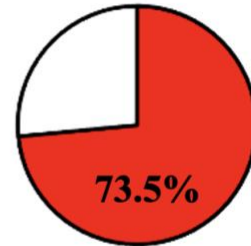
Prevalence of Co-Occurring Mental Health Diagnoses

**Co-Occurring Mental
Health Diagnosis**



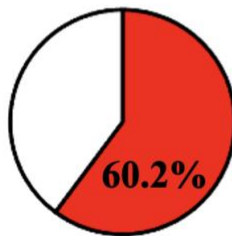
■ YES □ NO

Anxiety



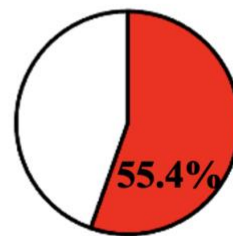
■ YES □ NO

Depression



■ YES □ NO

ADHD



■ YES □ NO

Assumptions Testing for Hierarchical Multiple Regression

Prior to conducting the statistical analysis (i.e., HMR) for the current study, several preliminary tests were run to ensure the validity and reliability of the findings. One key factor in examining the distribution of the Global Happiness Ratings was to test for the assumption of normality. To achieve this, the Kolmogorov-Smirnov test was conducted with an *alpha level* of 0.005. The decision to use the more stringent alpha level of 0.005 was made to decrease the likelihood of a Type 1 error because of the sensitivity of the Kolmogorov-Smirnov test; thus, requiring very strong evidence to reject normality (Huck, 2012). With this more stringent alpha level, the Global Happiness Ratings were found to be normally distributed ($p = 0.008$). Visual inspection of the data also yielded confirmation of the assumption of linearity, which supported moving forward with the regression analysis.

Next, Levene's Test was used to assess equality of error variance across groups at the traditional *alpha level* for this test of 0.05. The *p-values*, ranging from 0.08 to 0.92, were above the 0.05 level of significance. Therefore, the assumption of homogeneity of variances was supported. Finally, testing for multivariate normality and outliers was conducted utilizing the Mahalanobis Distance test. Results of the Mahalanobis Distance test were not significant at the 0.05 *alpha level*; *p-values* ranged from 0.22 to 0.98. Therefore, the model met the assumption of multivariate normality and was not affected by outliers.

Data Analysis for Research Questions

Version 29.0.2.0 of IBM SPSS Statistics software was used to examine the results of the current study. Introduced in Chapter 3, the specific statistical analysis technique of HMR was employed to explore the research questions presented. Hierarchical Multiple Regression aims to determine how much of the variability found in a dependent variable can be linked to specific

predictors (i.e., independent variables) that are entered into the equation in stages or blocks (Hoyt et al., 2006; Jeong & Jung, 2016). The current study consisted of four blocks of analysis to explore the main and interaction effects. An advantage of utilizing HMR is the ability of the analysis to examine multiple predictor variables against a single outcome (Huck, 2012). Hierarchical Multiple Regression has the capacity to analyze the impacts of categorical predictors on a dependent variable, the impacts of continuous predictors on a dependent variable, and the interaction effects of two or more predictors on an outcome (Hoyt et al., 2006). In highlighting the applicability of HMR to the current analysis, the categorical predictors of race and gender identity were analyzed for their impacts on Global Happiness Ratings in autistic adults, followed by the interaction effects of these demographics. Next, the continuous predictors of Physical Health and Well-being, Cognitive Health and Well-being, and Social Health and Well-being were analyzed, followed by the interaction effects between race and gender identity and each of these continuous predictors on Global Happiness Ratings.

Due to the exploratory nature of the current study, this researcher set an *alpha level* of 0.10 instead of the more tradition *p value* of 0.05. The primary objective of this study is to detect potential patterns in indicators of quality of life in autistic adults. Setting a significance level of 0.10 ($p = 0.10$) allowed the analysis to be more sensitive to potential predictors and helped set the stage for future exploration (Cohen, 1992). Another important aspect of the analysis to note is that preliminary correlation coefficients were calculated prior to the interpretation of HMR results. The correlations are reported as they provide initial insight into the potential findings of the HMR analysis. Correlations can be significant while overall predictions are not because predictors in the regression model represent the unique contribution of each variable after for

which the other predictors are accounted, thereby, addressing issues related to shared variance (Nathans et al., 2012).

Though the assumption of non-multicollinearity was satisfied with testing of the primary predictors, Beta (b) values outside the expected range of -1.00 to +1.00 were noted for several interaction terms upon initial analysis. This can be an indicator of coefficient instability (Kalnins, 2018). Diagnostic tests, including the calculation of Variance Inflation Factor (VIF) were conducted to assess potential underlying issues. Among the interaction predictors, only *Black*Gender Non-conforming*, *Intersectional Race*Male*, and *Intersectional Race*Gender Non-conforming* had VIF values below 10.00, which indicates severe multicollinearity with the remaining interaction terms resulting in inflation of standard errors and coefficient instability (Kalnins, 2018). Therefore, the variables in the current analysis were centered, which involved establishing a standardized mean of zero to mitigate impacts of collinearity. Emphasizing the relevance of centering for the current analysis, one condition under which centering is most appropriate is when examining interaction effects between variables that are entered into the same block of a regression analysis (Enders & Tofighi, 2007).

The HMR analysis was conducted to explore the unique and combined impacts of the predictors on Global Happiness Ratings. Results of the predictions include both unstandardized coefficients (i.e., B) and standardized coefficients (i.e., β). When explaining the results of the current study, this researcher interprets the findings through the lens of the unstandardized coefficient. While b is typically used in academic research due to the ability to directly compare predictors and the sensitivity to detecting issues with multicollinearity (Tong, F., 2006), other metrics, such as B , offer information relevant for more practical applications of findings by keeping the original units of measurement intact (Ntumi, S. & Effrim, P. K., 2022). Each unit of

measurement in the current study is equal to 1-point change in both the continuous predictors and the dependent variable. An overview of results of the main and interaction effects follows. First, however, descriptive statistics for the dependent variable, which applies to all blocks of the HMR analysis, are provided. Detailed descriptive statistics of the predictors are reported along with the results of the HMR analysis.

Descriptives for the Dependent Variable – Global Happiness Rating

The dependent variable analyzed in the current study was the Global Happiness Rating, as identified by item 20 on the PQoL Scale. Item 20 on the PQoL Scale asked respondents to rate the question “How happy are you?” on a scale from 0 to 10, with 0 being “extremely unhappy” and 10 being “extremely happy.” In the current study, the PQoL Scale total score was calculated to have a *Cronbach’s Alpha* reliability statistic of .94, which indicates excellent reliability for this measure. Establishing convergent validity for use of the Global Happiness Rating instead of the total score in the current analysis, the Global Happiness Rating was determined to be highly correlated with the PQoL Scale total score, with a *Pearson Correlation* coefficient of $r = .74$. Actual scores on the Global Happiness Rating ranged from 0 to 10, with a *mean* of 6.10 and *standard deviation* of 2.62. This sample mean was lower than the mean of 7.5 that has been observed across other populations (PQoL, 2008), suggesting lower overall happiness ratings for the current autistic adult sample. Examining the following correlations allowed the researcher to obtain a foreshadowing of how the predictors of interest may be associated with Global Happiness Ratings.

Preliminary Correlation Analysis

Prior to interpreting the results of the HMR, a preliminary correlation analysis was conducted to gain insight into the relationship between the study variables. As in the HMR

analysis, an *alpha level* of .10 was used. Several significant positive correlations were detected and are written in Table 4. The strongest significant correlations were found in the associations between *Physical Health and Well-being* and *Global Happiness Ratings* ($r = .65, p < .001$) and between *Social Health and Well-being* and *Global Happiness Ratings* ($r = .75, p < .001$). This finding suggests that as satisfaction with the associated subjective domain increases, so does overall Global Happiness. Several negative associations were indicated as well and are also summarized in Table 4. All negative correlations involved the demographic variable of *Gender Non-conforming*, which suggests that those who identify as Gender Non-conforming are associated with lower overall Global Happiness Ratings ($\eta^2 = -.24, p = .015$). Table 4 below includes only the significant correlations of the analysis.

Table 4*Significant Correlations*

Global Happiness	Global Happiness	
	<i>p-value</i>	<i>Sig.</i>
Global Happiness	1.000	
Female	.20	.03**
Gender Non-conforming	-.24	.02**
Female*Intersectional Race	.20	.03**
Gender Non-Conforming*Black	-.23	.02**
Gender Non-Conforming*Intersectional Race	-.19	.05**
Physical Health and Well-being	.65	<.001***
Cognitive Health and Well-being	.39	<.001***
Social Health and Well-being	.75	<.001***
Female*		
Physical Health and Well-being	.44	<.001***
Gender Non-Conforming*		
Physical Health and Well-being	.24	.01**
Black*		
Physical Health and Well-being	.20	.04*
Intersectional Race*		
Physical Health and Well-being	.35	.001***
Female*		
Cognitive Health and Well-being	.28	.01**
Gender Non-Conforming*		
Cognitive Health and Well-being	.15	.09*
Black*		
Cognitive Health and Well-being	.15	.09*
Intersectional Race*		
Cognitive Health and Well-being	.16	.08*
Female*		
Social Health and Well-being	.51	<.001***
Gender Non-conforming*		
Social Health and Well-being	.32	.001***
Black*		
Social Health and Well-being	.16	.07*
Intersectional Race*		
Social Health and Well-being	.37	<.001***

Note. Eta Squared Correlations are used for categorical variables (e.g., Female)

Pearson Correlations are used for continuous variables (e.g., Physical Health and Well-being)

* = $p < 0.10$

** = $p < 0.05$

*** = $p \leq 0.001$

Hierarchical Multiple Regression

As previously highlighted, the current study has a dependent variable of the Global Happiness Rating on the PQoL Scale; categorical predictor variables of race and gender identity; and continuous predictor variables of Physical Health and Well-being, Cognitive Health and Well-being, and Social Health and Well-being. The HMR exploring the main and interaction effects of the current study was conducted with an *alpha level* of 0.10 ($p = .10$). Table 5 provides an overview of each block of the analysis, including the predictors and specific research questions addressed. A detailed description of each block of the analysis is in the section that follows.

Table 5*Hierarchical Multiple Regression Overview*

Block	Predictors	Research Questions
1	<i>Race</i> <i>Gender Identity</i>	<i>Question 1:</i> How does race affect the Global Happiness Rating among autistic adults? <i>Question 2:</i> How does gender identity affect the Global Happiness Rating among autistic adults?
2	<i>Race*Gender Identity</i>	<i>Question 12:</i> Do the effects of race on Global Happiness Ratings in autistic adults vary by gender identity?
3	<i>Physical Health and Well-being</i> <i>Cognitive Health and Well-being</i> <i>Social Health and Well-being</i>	<i>Question 3:</i> What is the effect of the Physical Health and Well-being domain score on the Global Happiness Rating for autistic adults? <i>Question 4:</i> What is the effect of the Cognitive Health and Well-being domain score on the Global Happiness Rating for autistic adults? <i>Question 5:</i> What is the effect of the Social Health and Well-being domain score on the Global Happiness Rating for autistic adults?
4	<i>Race*</i> <i>Physical Health and Well-being</i> <i>Race*</i> <i>Cognitive Health and Well-being</i>	<i>Question 6:</i> Do the effects of the Physical Health and Well-being domain score on Global Happiness Ratings vary by race in autistic adults? <i>Question 7:</i> Do the effects of the Cognitive Health and Well-being domain score on Global Happiness Ratings vary by race in autistic adults?

Table 5 (continued)

Block	Predictors	Research Questions
	<i>Race*</i> <i>Social Health and Well-being</i>	<i>Question 8:</i> Do the effects of the Social Health and Well-being domain score on Global Happiness Ratings vary by race in autistic adults?
	<i>Gender Identity*</i> <i>Physical Health and Well-being</i>	<i>Question 9:</i> Do the effects of the Physical Health and Well-being domain score on Global Happiness Ratings vary by gender identity in autistic adults?
	<i>Gender Identity*</i> <i>Cognitive Health and Well-being</i>	<i>Question 10:</i> Do the effects of the Cognitive Health and Well-being domain score on Global Happiness Ratings vary by gender identity in autistic adults?
	<i>Gender Identity*</i> <i>Social Health and Well-being</i>	<i>Question 11:</i> Do the effects of the Social Health and Well-being domain score on Global Happiness Ratings vary by gender identity in autistic adults?

Hierarchical Multiple Regression – Block 1

Block 1 of the HMR analysis explored the predictive values of the demographic predictors of race and gender identity on Global Happiness Ratings, specifically addressing the following research questions:

Question 1: How does race affect the Global Happiness Rating among autistic adults?

Question 2: How does gender identity affect the Global Happiness Rating among autistic adults?

Race and *Gender Identity* were entered in Block 1 of the HMR equation to determine their main effects on Global Happiness Ratings in autistic adults. The subgroups of “Identifies as White” and “Identifies as Male” were used as the reference groups for this block of the analysis. With an *adjusted R square* value of .03 and a significance level of $p = .20$, this block did not account for a significant amount of variation in Global Happiness Ratings. To fully appreciate these variables, understanding their composition is important. Therefore, descriptive statistics of these variables are provided along with the results.

Race. To best support analyzing differences between groups based on the study sample, this analysis explored three racial categories as follows: Black ($n = 9$), White ($n = 58$), and Intersectional Race ($n = 16$). The intersectional race category consists of individuals who reported intersectionality among their ethnic and racial backgrounds. This method of categorization allowed for the examination of differences between those with ethnic/racial intersectionality and those who reported a singular racial identification, as racial intersectionality may be an indicator of further marginalization, referred to as excess intersectional disparity (Jackson et al., 2016). The intersectional race category includes participants who identified as Hispanic, bi-racial, and other race.

Analyzing the effects of race allowed the researcher to determine how much of the variance in overall Global Happiness Ratings could be predicted by race. Race was not found to be a significant predictor of Global Happiness Ratings for the current autistic adult sample in Block 1 of the HMR analysis. Please refer to Table 6 for specific results.

Gender Identity. To best support analyzing differences between groups based on the study sample, the following gender identity categories were explored: Female ($n = 34$), Male ($n = 35$), and Gender Non-conforming ($n = 14$). The gender non-conforming category is comprised of participants who do not identify with binary gender constructs (Valentine & Shipherd, 2018; i.e., trans, genderfluid, non-binary, questioning, and no gender identification). Research has shown that individuals who are gender non-conforming often face additional marginalization when compared to cis-gender controls that may contribute to quality of life ratings (Valentine & Shipherd, 2018). Thereby supporting the decision to analyze those who identify as gender non-conforming based on this shared group identity.

Analyzing the effects of gender identity determined how much of the variance in overall Global Happiness Ratings could be predicted by gender identity. Gender identity was not found to be a significant predictor of Global Happiness Ratings for the current autistic adult sample. Those who identified as Female reported a trend towards higher ratings of Global Happiness ($B = .69$, $\beta = .13$, $t = 1.11$, $p = .27$), and those who identified as Gender Non-conforming reported a trend towards lower ratings of Global Happiness ($B = -1.34$, $\beta = -.19$, $t = -1.62$, $p = .11$) than the Male reference group, neither were at a statistically significant level of variance. Those who identified as Gender Non-conforming were trending towards the $p = .10$ level of significance set for the current study and the substantially lower ratings of Global Happiness for this group are particularly important to note. Table 6 provides an overview of the Block 1 HMR analysis

results. Figure 5 that follows provides a bar chart that is helpful in visualizing the positive and negative trends in the unstandardized coefficients. As indicated by the grey columns, those who identified with Intersectional Race and Gender Non-conformity displayed negative trends in global happiness, while those who identified as Female showed positive trends.

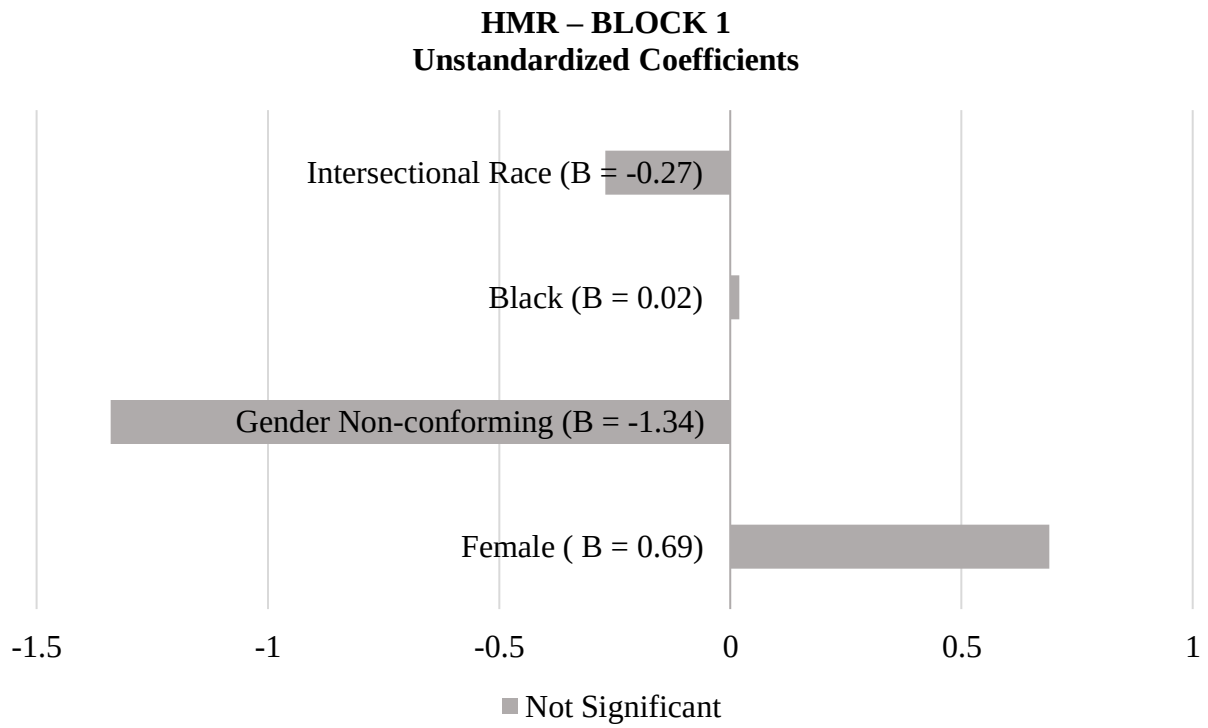
Table 6*Block 1 Results*

		Unstandardized Coefficient	Standardized Coefficient		
Block		<i>B</i>	<i>β</i>	<i>t</i>	<i>Sig.</i>
1	(Constant)	-.02		-.03	.97
	Female	.69	.13	1.11	.27
	Gender Non-conforming	-1.34	-.19	-1.62	.11
	Black	.02	.003	.02	.98
	Intersectional Race	-.24	-.04	-.32	.75

Note. Dependent Variable: How happy are you?

Figure 5

Block 1 Unstandardized Coefficients



Note. Results that are not significant are shown in grey.

Hierarchical Multiple Regression – Block 2

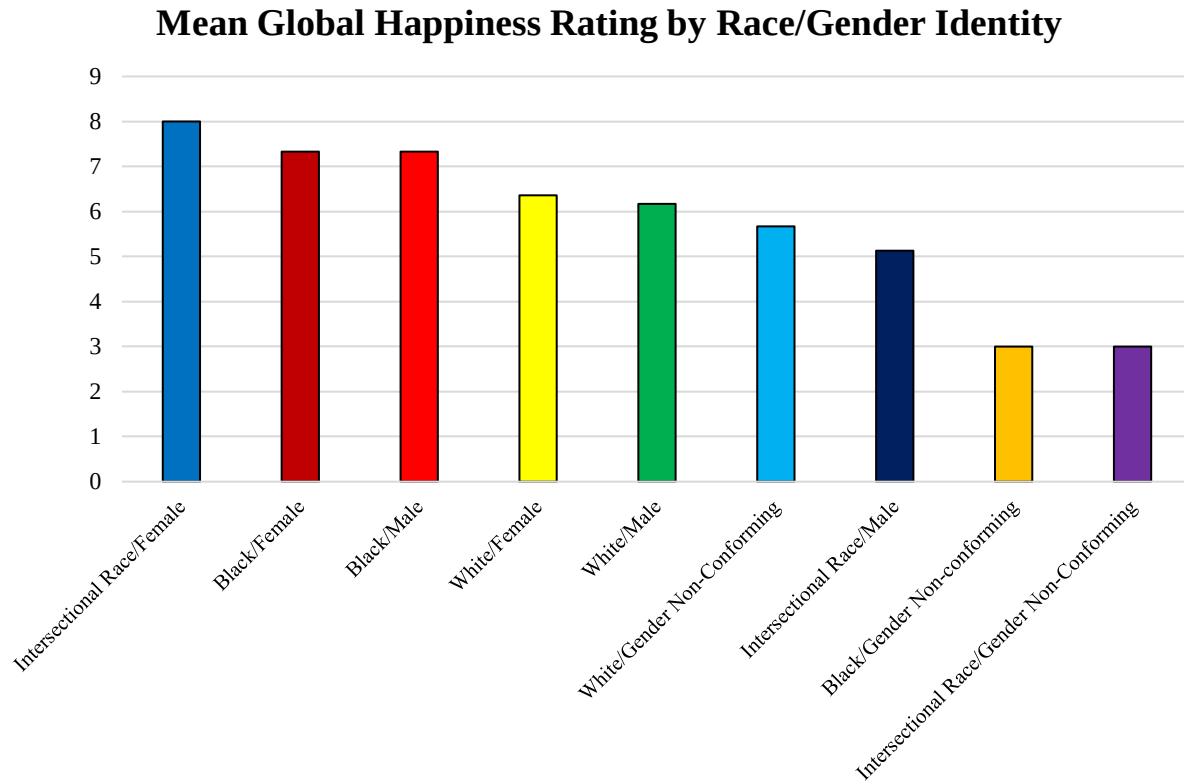
Block 2 of the HMR analysis explored whether there is an interaction between race and gender identity that resulted in a significant variation in Global Happiness Ratings across the various racial and gender identity subgroups, specifically addressing the following research question:

Question 12: Do the effects of race on Global Happiness Ratings in autistic adults vary by gender identity?

For Block 2, the interaction variables of *race by gender identity* were added to the HMR equation to determine the interaction effects of these predictors on Global Happiness Ratings in autistic adults. The specific interaction terms are as follows: *Intersectional Race*Female*, *Black*Female*, *Black*Male*, *White*Female*, *White*Male*, *White*Gender Non-conforming*, *Intersectional Race*Male*, *Black*Gender Non-conforming*, and *Intersectional Race*Gender Non-conforming*. The subgroup of *White*Male* was used as the reference group for this portion of the analysis. With an *R Square* value of .16 and a significance level of $p = .12$, these interactions did not account for significant variation in Global Happiness Ratings among the participants. However, the level of significance was close to the *p-value* of .10 set for the current study. Figure 6 provides a bar chart of all mean Global Happiness Ratings by race/gender identity subgroups, organized from highest to lowest mean Global Happiness Rating. The *Intersectional Race*Female* subgroup had the highest mean, while the *Intersectional Race*Gender Non-conforming* subgroup had the lowest. The reference group, *White*Male*, was the median subgroup.

Figure 6

Global Happiness Rating by Race/Gender Identity



Before exploring the results of the interaction terms added in Block 2, it is important to note that there were no changes in significance for the predictors entered in Block 1 of the HMR equation. When running the analysis for Block 2, the statistical software (i.e., SPSS Version 29.0.2.0) excluded several interaction terms from the model due to continued issues with multicollinearity with the specific interaction terms of *White*Female*, *Black*Male*, *Intersectional Race*Male*, *White*Gender Non-Conforming*. To investigate, the VIF values for these predictors were analyzed and found to be well above the acceptable cutoff of 10.00. To mitigate the impacts of collinearity with other predictors in the model, these interaction terms were entered into a separate regression equation. The interaction terms of *White*Female* ($B = .23, \beta = .04, t = .34, p = .74$), *Black*Male* ($B = 1.20, \beta = .09, t = .76, p = .45$), *Intersectional Race*Male* ($B = -1.01, \beta = -.11, t = -.98, p = .33$), *White*Gender Non-Conforming* ($B = -.47, \beta = -.06, t = -.47, p = .64$) were not found to be significant predictors of the Global Happiness Ratings for the current autistic adult sample. Table 7 provides an overview of the results of these excluded predictors.

Table 7*Excluded Predictors*

		Unstandardized Coefficient	Standardized Coefficient		
Block		<i>B</i>	<i>β</i>	<i>t</i>	<i>Sig.</i>
1	(Constant)	.04		.08	.94
	Female*White	.23	.04	.34	.74
	Male*Black	1.20	.09	.76	.45
	Intersectional Race*Male	-1.01	-.11	-.98	.33
	Gender Non-conforming*White	-.47	-.06	-.47	.64

Note. Dependent Variable: How happy are you?

As for the predictors introduced in Block 2, statistically significant interaction effects were not found for the following subgroups in the current autistic adult sample: *Black*Female* ($B = -.19, \beta = -.01, t = -.09, p = .93$) and *Intersectional Race*Gender Non-conforming* ($B = -1.63, \beta = -.10, t = -.73, p = .47$). The statistical significance found within the remaining subgroups is described below along with brief descriptive statistics for context. Of these subgroups, *Black*Gender Non-conforming* had a very small group size; $n = 3$. To be inclusive of all race and gender identity subgroups the findings are reported. However, caution should be exercised due to the small subgroup size.

Intersectional Race*Female. Those who identify as *Intersectional Race*Female* were found to have a positive statistically significant interaction effect ($B = 2.68, \beta = .28, t = 1.74, p = .09$) when compared to the *White*Male* reference group. This statistically significant interaction effect means that for every 1-point increase in Global Happiness in the reference group, those who as identify as *Intersectional Race*Female* in the current sample reported an additional increase in Global Happiness of 2.68.

Black*Gender Non-conforming. Those who identify as *Black*Gender Non-conforming* were found to have a negative statistically significant interaction effect ($B = -3.83, \beta = -.28, t = -1.67, p = .10$) when compared to the *White*Male* reference group. This statistically significant interaction effect means that for every 1-point increase in Global Happiness in the reference group, those who as identify as *Black*Gender Non-conforming* in the current sample reported a decrease in Global Happiness of 3.83. Table 8 provides an overview of the Block 2 HMR analysis results. Figure 7 that follows provides a bar chart of the results with significant results shown in green.

Table 8*Block 2 Results*

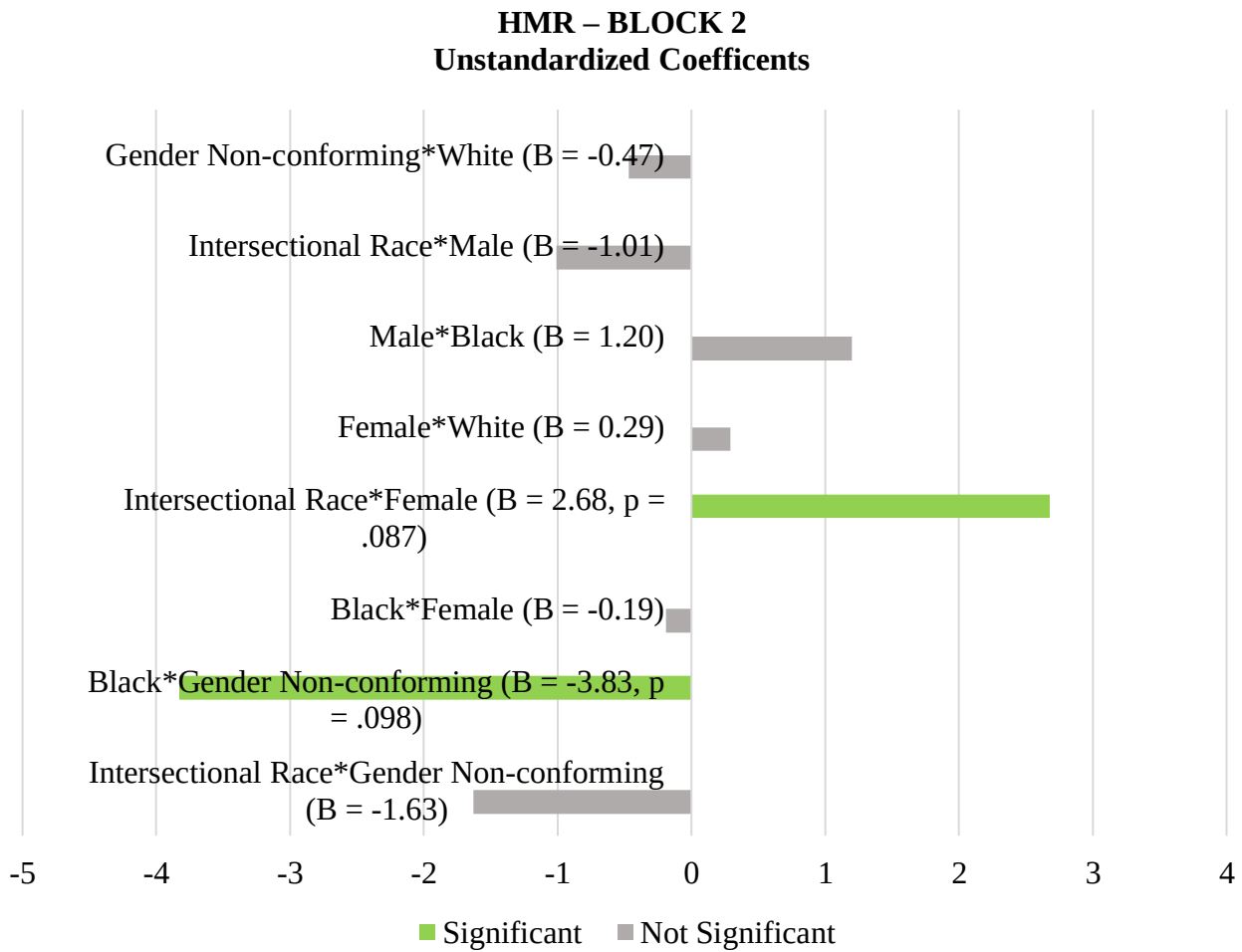
Block		Unstandardized Coefficient	Standardized Coefficient	<i>t</i>	<i>Sig.</i>
		<i>B</i>	<i>β</i>		
2	(Constant)	.07		.14	.89
	Female	.19	.04	.27	.79
	Gender Non-conforming	-.50	-.07	-.51	.61
	Black	1.17	.14	.75	.45
	Intersectional Race	-1.04	-.16	-1.01	.32
	Intersectional Race*Female	2.68	.27	1.74	.09
	Black*Female	-.19	-.01	-.09	.93
	Black*Gender Non-conforming	-3.83	-.28	-1.67	.10
	Intersectional Race*Gender Non-conforming	-1.63	-.10	-.73	.47

Note. Dependent Variable: How happy are you?

Significant results with p-values less than 0.10 are shown in boldface

Figure 7

Block 2 Unstandardized Coefficients



Note. Results that are not significant are shown in grey.
Significant results are shown in green.

Hierarchical Multiple Regression – Block 3

Block 3 of the HMR analysis explored the predictive values of the continuous predictors of Physical Health and Well-being, Cognitive Health and Well-being, and Social Health and Well-being after accounting for the impacts of race and gender identity on Global Happiness Ratings. Analysis of these predictors allowed the researcher to address the following research questions specifically:

Question 3: What is the effect of the Physical Health and Well-being domain score on the Global Happiness Rating for autistic adults?

Question 4: What is the effect of the Cognitive Health and Well-being domain score on the Global Happiness Rating for autistic adults?

Question 5: What is the effect of the Social Health and Well-being domain score on the Global Happiness Rating for autistic adults?

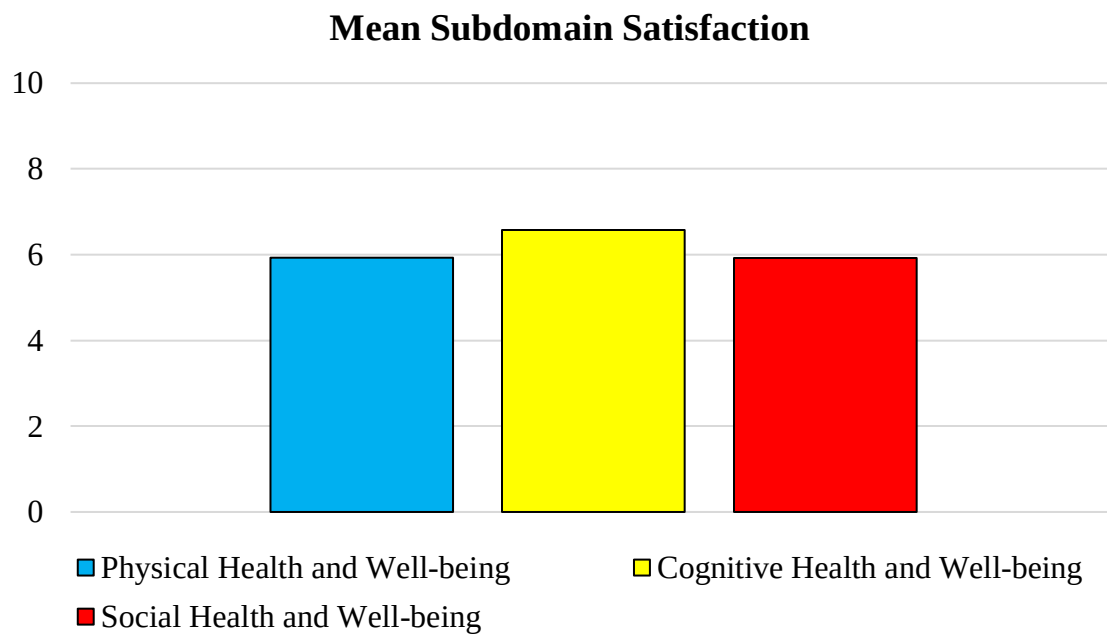
For Block 3, the continuous predictors of *Physical Health and Well-being*, *Cognitive Health and Well-being*, and *Social Health and Well-being* were added to the HMR equation to determine their impact on Global Happiness Ratings in autistic adults after accounting for the impacts of race and gender identity and their interaction terms. With an *R Square* value of .63, *R Square Change* value of .47, and significance level of $p < .001$, this model did account for statistically significant variance in Global Happiness Ratings. In fact, approximately 60% of the variance in Global Happiness could be explained by the addition of the domains of Physical, Cognitive, and Social Health and Well-being to the equation. In addition to main effects findings, when these continuous predictors were introduced to the equation, statistical significance was no longer found in the interaction effects between 1.) *Intersectional Race*Female* on Global Happiness Ratings or 2.) *Black*Gender Non-conforming* on Global

Happiness Ratings. This shift in significance indicates that the predictors introduced in Block 3 better account for the variances observed in Block 2, thereby, mitigating their individual impacts.

To fully understand the impacts of these variables, further contextualization is needed. Therefore, descriptive statistics of Physical Health and Well-being, Cognitive Health and Well-being, and Social Health and Well-being are provided. For all domains, participants were asked to rate a series of questions on a scale from 0 – 10, with 0 being “extremely unsatisfied” and 10 being “extremely satisfied.” Satisfaction scores on the Physical Health and Well-being domain resulted in a *mean* of 5.93 with a *standard deviation* of 2.07. Satisfaction scores on the Cognitive Health and Well-being domain resulted in a *mean* of 6.58 with a *standard deviation* of 1.89. Satisfaction scores on the Social Health and Well-being domain resulted in a *mean* of 5.93 with a *standard deviation* of 2.07. Figure 8 provides a bar chart of the mean satisfaction scores for each of the three subdomains examined in the current study. Physical Health and Well-being and Social Health and Well-being had equal means and standard deviations, while Cognitive Health and Well-being was slightly higher.

Figure 8

Mean Subdomain Satisfaction



Physical Health and Well-being. The Physical Health and Well-being domain mean was comprised of five individual items and was calculated to have a *Cronbach's Alpha* reliability statistic of .82, which indicates high reliability of this domain.

Analyzing the predictive value of the Physical Health and Well-being domain score on the overall Global Happiness Ratings for autistic adults in the sample determined how much of the variance in overall Global Happiness Ratings could be predicted by subjective indicators of Physical Health and Well-being. In Block 3 of the analysis, Physical Health and Well-being satisfaction was found to be a statistically significant predictor of Global Happiness Ratings in the current autistic adult sample. Specifically, more positive satisfaction ratings of Physical Health and Well-being were linked to higher Global Happiness Ratings after accounting for the impacts of race and gender identity, though the margin was relatively small ($B = .29$, $\beta = .23$, $t = 1.69$, $p = .10$). This relatively small margin means that for every 1-point increase in Global Happiness, respondents indicated an additional .29 increase in Physical Health and Well-being satisfaction.

Cognitive Health and Well-being. The Cognitive Health and Well-being domain mean was comprised of two individual items and was calculated to have a *Cronbach's Alpha* reliability statistic of .58, which is below the traditionally acceptable reliability threshold of .60. Limitations related to the use of this domain in the current analysis are discussed in detail in Chapter 5.

Analyzing the predictive value of the Cognitive Health and Well-being domain score on the overall Global Happiness Ratings for autistic adults in the sample determined how much of the variance in overall Global Happiness Ratings could be predicted by subjective indicators of Cognitive Health and Well-being. Block 3 results of the analysis found that Cognitive Health and

Well-being satisfaction was not a statistically significant predictor of Global Happiness Ratings in the current autistic adult sample after for which the impacts of race and gender identity were accounted. While not statistically significant, there was a negative trend in the impacts of Cognitive Health and Well-being on Global Happiness Ratings in the autistic adult sample ($B = -.19$, $\beta = -.14$, $t = -1.26$, $p = .21$), which suggests that as Cognitive Health and Well-being satisfaction increases, Global Happiness may decrease.

Social Health and Well-being. The Social Health and Well-being domain mean was comprised of 12 individual items and was calculated to have a *Cronbach's Alpha* reliability statistic of .91, which indicates high reliability for this domain.

Analyzing the predictive value of the Social Health and Well-being domain score on the overall Global Happiness Ratings for autistic adults in the sample determined how much of the variance in overall Global Happiness Ratings could be predicted by subjective indicators of Social Health and Well-being. In Block 3 of the analysis, Social Health and Well-being satisfaction was found to be a strong statistically significant predictor of Global Happiness Ratings in the current autistic adult sample after for which the impacts of race and gender identity were accounted ($B = .82$, $\beta = .65$, $t = 5.31$, $p = <.001$). Specifically, more positive satisfaction ratings of Social Health and Well-being were linked to higher Global Happiness Ratings, with a strong predictive value. For every 1-point increase in Global Happiness, respondents indicated an additional .82 increase in Social Health and Well-being satisfaction. Table 9 provides an overview of Block 3 of the HMR analysis results. Figure 9 that follows provides a bar chart of Block 3 results, with significant results shown in green and changes in significant from the previous block shown in yellow.

Table 9*Block 3 Results*

Block		Unstandardized Coefficient	Standardized Coefficient	<i>t</i>	<i>Sig.</i>
		<i>B</i>	<i>β</i>		
3	(Constant)	.04		.12	.91
	Female	-.14	-.03	-.28	.78
	Gender Non-conforming	-.30	-.04	-.44	.66
	Black	.11	.01	.10	.92
	Intersectional Race	.66	.10	.90	.37
	<i>Intersectional Race*Female</i>	.39	.04	.36	.72
	Black*Female	-.07	-.01	-.04	.97
	<i>Black*Gender Non-conforming</i>	-2.20	-.16	-1.41	.16
	Intersectional Race*Gender Non-conforming	-.87	-.05	-.55	.59
	PHW	.29	.23	1.69	.10
	CHW	-.19	-.14	-1.26	.21
	SHW	.82	.65	5.31	<.001

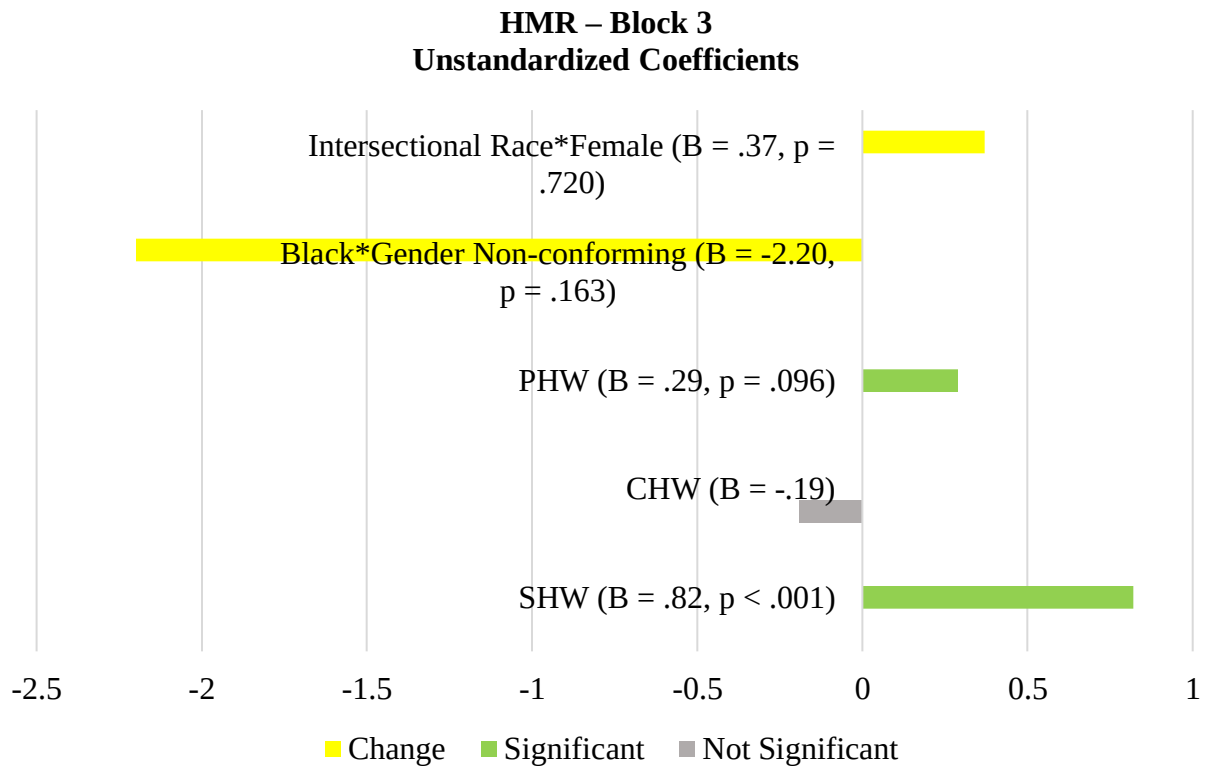
Note. Dependent Variable: How happy are you?

Significant results with p-values less than 0.10 are shown in boldface.

Predictors with a change in significance from the previous block are shown in italics.

Figure 9

Block 3 Unstandardized Coefficients



Note. Results that are not significant are shown in grey.

Significant results are shown in green.

Changes in significance from the previous block shown in yellow.

Hierarchical Multiple Regression – Block 4

Block 4 of the HMR analysis explored the predictive values of the interaction terms between the demographic predictors of Race and Gender Identity and the continuous predictors of Physical, Cognitive, and Social Health and Well-being on Global Happiness Ratings, specifically addressing the following research questions:

Question 6: Do the effects of the Physical Health and Well-being domain score on Global Happiness Ratings vary by race in autistic adults?

Question 7: Do the effects of the Cognitive Health and Well-being domain score on Global Happiness Ratings vary by race in autistic adults?

Question 8: Do the effects of the Social Health and Well-being domain score on Global Happiness Ratings vary by race in autistic adults?

Question 9: Do the effects of the Physical Health and Well-being domain score on Global Happiness Ratings vary by gender identity in autistic adults?

Question 10: Do the effects of the Cognitive Health and Well-being domain score on Global Happiness Ratings vary by gender identity in autistic adults?

Question 11: Do the effects of the Social Health and Well-being domain score on Global Happiness Ratings vary by gender identity in autistic adults?

The interaction terms for *Race* and *Gender Identity* by the subjective *Physical*, *Cognitive*, and *Social Health and Well-being* domains were entered in Block 4 of the HMR equation to determine the effects of the interactions of these predictors on Global Happiness Ratings in autistic adults. The subgroups of *Identifies as White* and *Identifies as Male* were used as the reference groups for this portion of the analysis. With an *R Square* value of .69, *R Square Change* value of .05, and significance level of $p = .63$, interaction terms added at this block did

not account for additional statistically significant variance in Global Happiness Ratings.

Important to note is that when these interaction terms were introduced to the equation, statistical significance was no longer found in the main effects of Physical Health and Well-being. This shift in significance indicates that the predictors introduced in Block 4 better account for the variances observed in Physical Health and Well-being in Block 3. Social Health and Well-being continued to be a strong positive predictor of global happiness ratings ($B = 1.04$, $\beta = .82$, $t = 3.12$, $p = .003$).

In Block 4, two interactions were found to have statistical significance: *Physical Health and Well-being*Race* and *Social Health and Well-being*Race*. The remaining interaction terms were not found to have statistical significance: *Physical Health and Well-being*Gender Identity*, *Cognitive Health and Well-being*Race*, *Cognitive Health and Well-being*Gender Identity*, and *Social Health and Well-being*Gender Identity*. For specific results, refer to Table 10. The statistical significance found within *Physical Health and Well-being*Race* and *Social Health and Well-being*Race* is described below. Because understanding their composition is important to fully recognize the potential impacts of the interaction effects between these variables on Global Happiness Ratings, brief descriptive statistics of these interaction terms are provided along with the results.

Physical Health and Well-being by Race. The Physical Health and Well-being domains by race comprised of the following subgroups with the accompanying sizes and Physical Health and Well-being *means* and *standard deviations*: Black ($n = 9$, $M = 6.33$, $SD = 2.62$), White ($n = 58$, $M = 5.99$, $SD = 2.02$), and Intersectional Race ($n = 16$, $M = 5.45$, $SD = 1.95$).

This analysis explored whether the relationship between Physical Health and Well-being scores and Global Happiness Ratings significantly varied by race in the current sample of autistic

adults. Block 4 of the analysis did find statistically significant results for the current autistic adult population. Physical Health and Well-being was found to be a significant positive predictor of Global Happiness Ratings for those who identified as Black (*Black*PHW*: $B = 2.09$, $\beta = .66$, $t = 2.03$, $p = .05$). These results indicate that for every 1-point increase in Global Happiness, those who identify as Black have a rate of additional increase in Physical Health and Well-being satisfaction ($B = 2.09$) that significantly varies from the White reference group. Therefore, Physical Health and Well-being was indicated as a significant predictor of Global Happiness for those who identified as Black.

Social Health and Well-being by Race. The Social Health and Well-being domains by race had the following subgroups with the accompanying sizes and Social Health and Well-being means and standard deviations: Black ($n = 9$, $M = 6.37$, $SD = 1.96$), White ($n = 58$, $M = 6.13$, $SD = 1.95$), and Intersectional Race ($n = 16$, $M = 4.97$, $SD = 2.42$).

This analysis explored whether the relationship between Social Health and Well-being scores and Global Happiness Ratings significantly varied by race in the current sample of autistic adults. Block 4 results of the analysis found a statistically significant negative interaction effect between those who identified as Black and Social Health and Well-being on Global Happiness ratings (*Black*SHW*: $B = -2.02$, $\beta = -.48$, $t = -2.25$, $p = .03$). These results would indicate that for every 1-point increase in Global Happiness, those who identify as Black have a statistically significant decrease in Social Health and Well-being satisfaction ($B = -2.02$) when compared to the White reference group. Because this finding trended in the opposite direction than expected given the overall impacts of Social Health and Well-being, further exploration was conducted. In a scatterplot analysis, it was determined that one data point stood out from the others as an outlier. One respondent, in spite of reporting Social Health and Well-being satisfaction above the

mean, had a Global Happiness Rating well below the mean. This outlier skewed the interaction effects of *Black*Social Health and Well-being*; therefore, this result is invalid as it is not considered to be representative of this interaction term. Having a larger subgroup size would have likely minimized the impacts of the outlying data point. Table 10 provides an overview of the Block 4 HMR analysis results. Figure 10 that follows provides a bar chart of Block 4 results, with significant results shown in green and changes in significant from the previous block shown in yellow.

Table 10*Block 4 Results*

Block		Unstandardized Coefficient	Standardized Coefficient	<i>t</i>	<i>Sig.</i>
		<i>B</i>	β		
4	(Constant)	.08		.22	.82
	Female	-.27	-.05	-.52	.61
	Gender Non-conforming	-.44	-.06	-.60	.55
	Black	-1.72	-.21	-.93	.36
	Intersectional Race	.65	.10	.73	.47
	Intersectional Race*Female	.34	.03	.23	.82
	Black*Female	3.65	.26	1.50	.14
	Black*Gender Non-conforming	-1.35	-.10	-.65	.52
	Intersectional Race*Gender Non-conforming	-.64	-.04	-.31	.76
	<i>PHW</i>	.001	.001	.002	.99
	CHW	-.13	-.09	-.51	.61
	SHW	1.04	.82	3.12	.003
	Female*PHW	.20	.10	.49	.63
	Gender Non-conforming*PHW	.17	.06	.28	.78
	Black*PHW	2.09	.66	2.03	.05
	Intersectional Race*PHW	.46	.15	.99	.32
	Female*CHW	.11	.05	.30	.76
	Gender Non-conforming*CHW	-.14	-.05	-.24	.82
	Black*CHW	-1.02	-.32	-1.32	.19
	Intersectional Race*CHW	-.07	-.02	-.15	.89
	Female*SHW	-.05	-.02	-.13	.90
	Gender Non-conforming*SHW	-.13	-.05	-.27	.79
	Black*SHW	-2.02	-.48	-2.25	.03
	Intersectional Race*SHW	-.31	-.13	-.70	.49

Note. Dependent Variable: How happy are you?

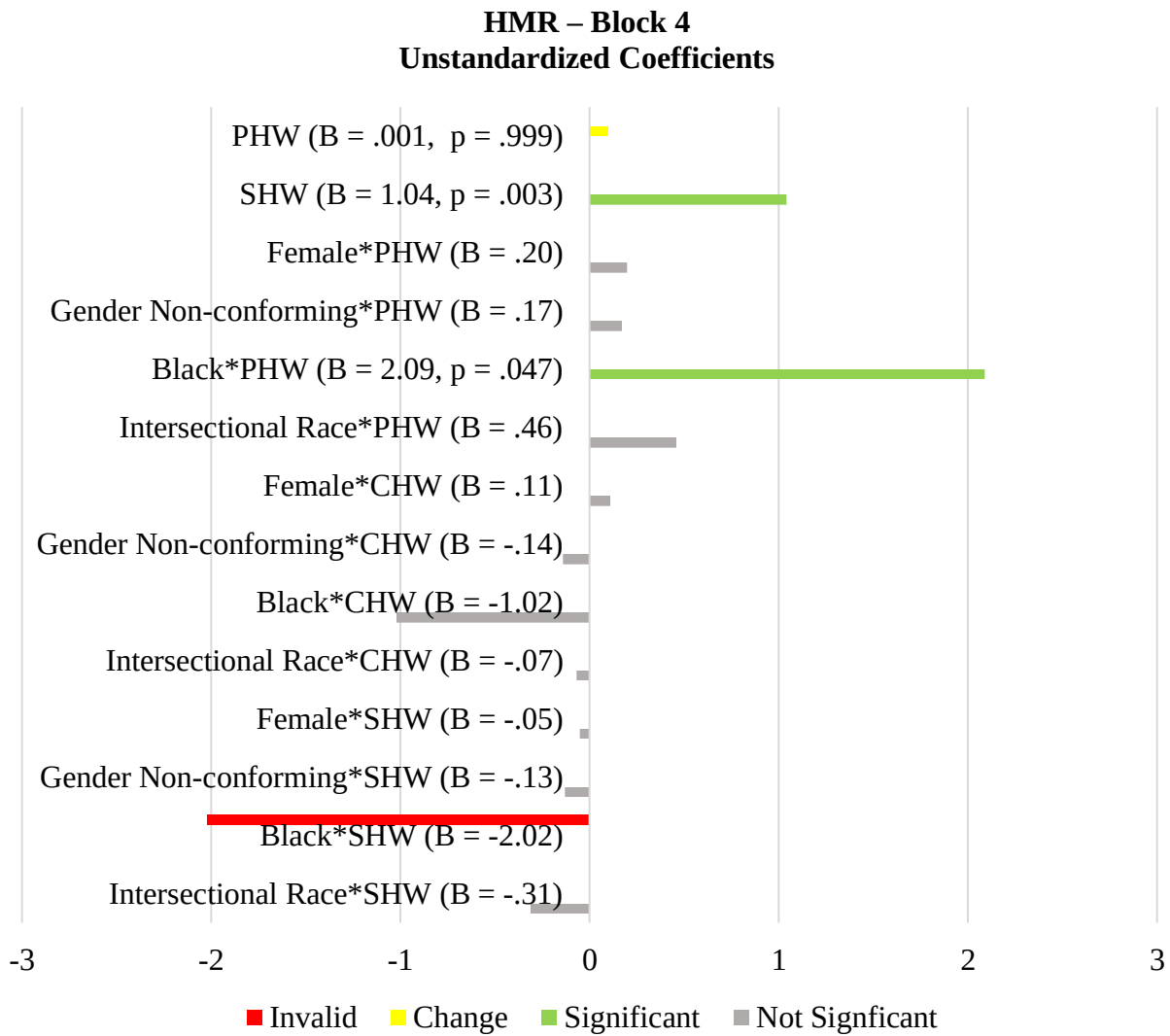
Significant results with p-values less than 0.10 are shown in boldface.

Predictor with a change in significance from the previous block is shown in italics.

Invalid result due to an outlier is shown with a strikethrough.

Figure 10

Block 4 Unstandardized Coefficients



Note. Results that are not significant are shown in grey.

Significant results are shown in green.

Changes in significance from the previous block shown in yellow.

Invalid result shown in red.

Chapter Summary

The current study explored the effects of Race; Gender Identity; and Physical, Cognitive, and Social Health and Well-being domains on Global Happiness Ratings in autistic adults. The study also analyzed the interaction effects of Race by the PQoL subscale domains, Gender Identity by the PQoL subscale domains, and Race by Gender Identity on Global Happiness Ratings. Hierarchical Multiple Regression was employed to analyze the results of the study. Results indicated that neither Race nor Gender Identity were significant predictors of Global Happiness Ratings in the autistic adult sample. The interaction effects of *Race*Gender Identity* were also not significant.

Social Health and Well-being emerged as the strongest overall predictor of Global Happiness Ratings, regardless of race or gender identity. Physical Health and Well-being was a statistically significant predictor of Global Happiness Ratings but lost predictive power once additional interaction terms were entered into the equation. A positive statistically significant interaction effect was found in the interaction between those who identified as Black and Physical Health and Well-being on Global Happiness Ratings; however, the inclusion of such interaction terms in Block 4 of the analysis did very little to improve the overall predictive power of the analysis. This, again, emphasizes the importance of the predictive power of Social Health and Well-being on Global Happiness Ratings. Table 11 provides a summary of the analysis.

These findings highlight the need for robust, tailored interventions and support services for the autistic adult population. The chapter that follows will provide a more in-depth discussion of these results, with a focus on implications for future research, clinical practice, and administration.

Table 11

Hierarchical Multiple Regression Summary Table

Block		Unstandardized Coefficient	
		<i>B</i>	<i>Sig.</i>
1	(Constant)	(-.02)	(.97)
	Female	.69	.27
	Gender Non-conforming	-1.34	.11
	Black	.02	.98
	Intersectional Race	-.24	.75
2	(Constant)	(.07)	(.89)
	Female	.19	.79
	Gender Non-conforming	-.50	.61
	Black	1.17	.45
	Intersectional Race	-1.04	.32
	Intersectional Race*Female	2.68	.09
	Black*Female	-.19	.93
	Black*Gender Non-conforming	-3.83	.10
3	Intersectional Race*Gender Non-conforming	-1.63	.47
	(Constant)	(.04)	(.91)
	Female	-.14	.78
	Gender Non-conforming	-.30	.66
	Black	.11	.92
	Intersectional Race	.66	.37
	<i>Intersectional Race*Female</i>	.39	.72
	Black*Female	-.07	.97
	<i>Black*Gender Non-conforming</i>	-2.20	.16
	Intersectional Race*Gender Non-conforming	-.87	.59
	PHW	.29	.10
	CHW	-.19	.21
	SHW	.82	<.001
4	(Constant)	(.08)	(.82)
	Female	-.27	.61
	Gender Non-conforming	-.44	.55
	Black	-1.72	.36
	Intersectional Race	.65	.47
	Intersectional Race*Female	.34	.82
	Black*Female	3.65	.14
	Black*Gender Non-conforming	-1.35	.52
	Intersectional Race*Gender Non-conforming	-.64	.76
	<i>PHW</i>	.001	.99
	CHW	-.13	.61
	SHW	1.04	.003
	Female*PHW	.20	.63
	Gender Non-conforming*PHW	.17	.78
	Black*PHW	2.09	.05
	Intersectional Race*PHW	.46	.32
	Female*CHW	.11	.76
	Gender Non-conforming*CHW	-.14	.82
	Black*CHW	-1.02	.19
	Intersectional Race*CHW	-.07	.89
	Female*SHW	-.05	.90
	Gender Non-conforming*SHW	-.13	.79
	Black*SHW	-2.02	.03
	Intersectional Race*SHW	-.31	.49

Note. Dependent Variable: How happy are you?

Significant results with p-values less than 0.10 are shown in boldface.

Predictor with a change in significance from the previous block is shown in italics.

Invalid result due to an outlier is shown with a strikethrough.

CHAPTER 5: DISCUSSION

Introduction to Discussion

This chapter provides a thorough discussion of the current study that aimed to explore quality of life predictors in autistic adults. The chapter begins with a summary of the study that includes demographic considerations, an overview of the subjective quality of life domains, and an outline of the study justification. Discussions of the interpretation of results, study limitations, implications of the study, and recommendations for future research follow the summary of the study. A conclusive summary is provided at the end of the chapter.

Summary of the Study

This research study explored the effects of race; gender identity; and physical, cognitive, and social health and well-being satisfaction on global happiness ratings in the autistic adult population. The study also examined the interactions among these predictors on global happiness ratings in autistic adults and was grounded in Maslow's human needs theory, which is based on the notion that happiness is fixed in a person's ability to fulfill life's needs (Ventegodt et al., 2003). The necessity for effective programming and intervention in working with autistic adults is well documented (Hume et al., 2021; Lai et al., 2020; Shattuck et al., 2018). Autistic individuals can display a wide range of symptoms and symptom severity, including significant challenges with co-occurring mental health disorders (e.g., anxiety and depression) and adaptive behavior skills. While autism has been linked to higher rates of various psychiatric conditions (Croen et al., 2015), approximately 80% of autism research is devoted to children and adolescents (van Huemen, 2016). Adult outcomes within the autistic population are multi-faceted and complex and are not being adequately assessed. Quality of life has become increasingly

important to study in the growing autistic adult population. This study addressed the gaps in current autism literature by exploring the subjective quality of life experiences of autistic adults, taking into consideration specific demographic features and quality of life domains relevant to this population

Demographic Considerations

Attending to the deficiency in inclusion and representation of race in current autism literature despite the lack of ASD prevalence rate differences between various racial groups (Maenner et al., 2023), this study explored the effects of race and gender identity on quality of life and happiness in autistic adults. Based on the sample, this study explored the three racial categories of Black, White, and Intersectional Race. Racial disparities are seen across such domains as health, safety, and family well-being (Eilenberg et al., 2019), and this study aimed to determine how these themes impact the autistic adult population. Gender differences in the presentation of autism has contributed to autistic females being more likely to be under-recognized, diagnosed late, or not diagnosed at all (Dworzynski et al., 2012; Harrop et al., 2023; Loomes et al., 2017), and understanding how gender differences impact happiness and quality of life is vital. Based on the sample, this study explored the three gender identity categories of Female, Male, and Gender Non-conforming. In addition to these demographic predictors, the current study explored the impacts of Physical Health and Well-being, Cognitive Health and Well-being, and Social Health and Well-being on Global Happiness Ratings.

Subjective Quality of Life Domains

Gathering comprehensive information regarding subjective experiences of physical, cognitive, and social health and well-being in the autistic population is essential. For example, co-occurrence of various medical conditions (Warner et al., 2019) and premature mortality rates

(Hwang et al., 2019; Shavelle et al., 2001; Smith DaWalt et al., 2019) have highlighted the need to explore physical health satisfaction. Also important are the emerging cognitive differences seen in the aging process of autistic adults (Roestorf et al., 2018), as well as understanding the impacts of co-occurring psychiatric conditions, which have been linked to poorer cognitive functioning (Llewellyn et al., 2008). Finally, social aspects of quality of life have been rated among the areas of most concern for autistic adults (Kamp-Becker et al., 2010; Lin, 2014; Mason et al., 2022), making social health and well-being a key factor in exploring adult outcomes. Considering these domains of subjective satisfaction in the context of human needs theory allows for the application of programs and services that are aimed at meeting the needs that are most relevant to the autistic adult population.

The subjective quality of life domains of physical, cognitive, and social health and well-being were operationalized as follows:

- *Physical Health and Well-being:* Physical well-being includes “physical activity, balanced nutrition, getting adequate sleep, and avoiding harmful behaviors. Physical wellness also includes a personal responsibility to understand [one’s] body’s warning signs and recognize when [one is] ill and in need of medical attention” (UNG, 2024).
- *Cognitive Health and Well-being:* Cognitive well-being will be operationalized as one’s satisfaction with how well one thinks and remembers and how well one carries on a conversation (e.g., speaking clearly, hearing others, and/or being understood; Patrick, 2015).
- *Social Health and Well-being:* Social well-being indicators include accepting others as they are, having a positive comfort level with society, feeling that one

contributes meaningfully to society, having an adequate understanding of the social world, feeling part of a community, involvement in recreation and leisure opportunities, and perception of the quality of one's interpersonal relationships (Keyes & Lopez, 2002). Other key social well-being indicators include the quality of one's interpersonal relationships and recreation and leisure skills and opportunities (Verdugo et al., 2005).

Study Justification

Within the autistic population, autistic adults remain an under-researched subgroup that is overdue for comprehensive services and supports tailored to their unique needs. Many autistic adults are under-served and display an array of maladaptive behaviors that result from alienation and lack of support for perceived needs. Utilizing the foundation provided by Maslow's hierarchy of needs, the current study explored the role of happiness as it relates to the satisfaction of perceived needs at multiple levels of well-being. As Maslow (2013) posits, satisfaction and happiness are highly related subjective constructs. As individuals successfully navigate the various levels of their hierarchy of needs, one is in pursuit of happiness; thereby, asserting that satisfaction of perceived needs brings one closer to a state of happiness. A review of literature emphasized the need for a more robust understanding of predictive indicators of quality of life and happiness in the autistic adult population, the inclusion of quality of life domains that are important to the subjective experiences of autistic adults, and more representative samples within autism research. The current study attempted to address these needs. The following section provides a summary of the results.

Interpretation of Results

This section provides a summary of the research results of this study. The section begins with a snapshot of the sample demographics and how these demographics compare to other studies of autistic adults. Next, descriptive statistics for the predictors and dependent variable are summarized. Finally, the section concludes with an overview of the research study results, with an emphasis on implications compared to other studies.

Sample Demographics

This study gathered data from the autistic adult population. Participants were recruited from a local clinical setting, distribution of recruitment information to professional contacts in the local community, and through the UNC Autism Research Registry. A total of 96 participants initiated the survey process. Eighty-six participants completed the demographic questionnaire. An additional three participants dropped out during the completion of the Perceived Quality of Life (PQoL) Scale, resulting in a total sample size of 83 participants ($N = 83$) with a completion rate of 86%. In an analysis of 25,080 web surveys, Liu and Wronski (2018) found an average completion rate of 87% with a standard deviation of 10%. Therefore, the completion rate of the current study was in proportion to rates observed in other survey research. Meaning, there were no inherent limitations within the survey design, length, platform, or questions that negatively impacted completion rate.

Participants were asked first to complete a demographic survey. To obtain information most relevant to the current study, participants were asked to provide their diagnostic status (i.e., Autism, Autism Spectrum Disorder, Autistic Disorder, Pervasive Developmental Disorder, or Asperger's Syndrome), gender identity, and race. The sample consisted of 83 ($N = 83$) autistic adults age 18 years to 73 years, with a mean age of 34.7 years. In the context of similar studies of

autistic adults, this sample size and age range is comparable. While more extensive studies exploring quality of life in the autistic adult population certainly exist (Grosvenor et al., 2023; Mason et al., 2018; Oakley et al., 2021), several of the previous studies reviewed reported sample sizes ranging from 52 to 92 participants (Ayers et al., 2019; Hong et al., 2016; Lin & Huang, 2019; Mason et al., 2019; Moss et al., 2017; Vincent et al., 2020). Similarities in age supported the comparability of the results of the current study to previous studies' ranges as well. Sáez-Suanes and Álvarez-Couto (2021) conducted a meta-analysis of 11 studies in which participants ranged in age from 17 years to 80 years, Holmes et al. (2020) included an age range of 18 years to 65 years in their study, and a study conducted by Mason et al. (2022) had a mean age of 42 years.

Approximately 11% of the sample identified as Black, 69% identified as White, and the remaining 20% identified with Racial Intersectionality. Consistent with previous studies, the disproportionately White sample continues to highlight a significant gap in adequate representation in autistic adult research. For example, previous studies, that did report racial demographics, had samples consisting of predominately White participants, with Black participants ranging from 4% to 10% of the sample sizes (Holmes et al., 2020; Shattuck et al., 2018). No previous studies reviewed reported racial categories other than “White” and “Black.” Again, that is, if racial demographics were reported at all (Steinbrenner et al., 2022).

Regarding gender identity, approximately 41% of the sample identified as Female, 42% identified as Male, and the remaining 17% identified as Gender Non-conforming. This almost equal representation differs greatly from previous studies, which have included predominately male samples (Ayers et al., 2018; Mason et al., 2019; Mason et al., 2022; Renty & Reoeyers, 2006). As a result, the current study could make more direct and reliable comparisons between

the Male and Female subgroups of the autistic adult sample. Previous studies have neglected to differentiate between sex assigned at birth and gender identity, making the current study the first of its kind to explore gender identity as a defining demographic characteristic and to include quality of life data for participants who identify as gender non-conforming.

Perceived Quality of Life Domains and Global Happiness Ratings

The current study utilized the PQoL Scale, which was designed for those 18 years and older and is positioned strongly on the foundation of human needs theory and based on a model that considers quality of life to be an appraisal of various categories of fundamental life needs (Patrick, 2015). The PQoL Scale investigates the relationship between functional status and an individual's satisfaction with their own functioning in the areas of Physical Health and Well-being satisfaction, Cognitive Health and Well-being satisfaction, and Social Health and Well-being satisfaction. The scale has a total of 20 items, with items 1 through 19 being rated on an 11-point scale ranging from extremely dissatisfied (0) to extremely satisfied (10) and item number 20 being rated on an 11-point scale ranging from extremely unhappy (0) to very happy (10). In the current study, the Physical Health and Well-being domain had a mean satisfaction of 5.93; the Cognitive Health and Well-being domain had a mean satisfaction of 6.58; and the Social Health and Well-being domain had a mean satisfaction of 5.93. The dependent variable, Global Happiness Rating, had a mean of 6.10.

Unfortunately, direct comparisons of the subdomain mean scores to other populations or studies was not feasible due to the lack of publication regarding subdomain means of the PQoL Scale. However, the Global Happiness Rating has been found to have a population mean of 7.5, placing the responses of the current survey below what is expected of the general population. The finding of lower quality of life compared to the general population is consistent with other

studies exploring quality of life in autistic adults (Ayers, et al., 2018; Grosvenor et al., 2023; Holmes et al., 2020; Kamp-Becker et al., 2010; Mason et al., 2018; Oakley et al., 2021; Sáez-Suanes & Álvarez-Couto, 2021; Saldana et al., 2009; Yazar et al., 2022). A contributing factor to this finding is likely the comorbidity of anxiety and depression, as 94% of the sample of the current study reported a co-occurring diagnosis of at least one psychiatric condition. Numerous studies have established a connection between experiencing significant symptoms of anxiety and/or depression to lower overall quality of life and happiness (Hong et al., 2016; Lin & Huang, 2019; Mason et al., 2019; Moss et al., 2017; Oakley et al., 2021; Vincent et al., 2019; Yazar et al., 2022).

Summary of Research Question Results

Hierarchical Multiple Regression (HMR) was employed to analyze the results of the study, which utilized an *alpha level* of 0.10. In Block 1, the main effects of the study were analyzed by entering the independent race predictors and independent gender identity predictors into the regression equation. The subgroups of White and Male were used as the reference groups for this portion of the analysis. Results indicated that race was not a significant predictor of Global Happiness Ratings in the autistic adult sample. No previous studies have explored the impacts of race and quality of life in the autistic adult population. However, in the general population, those who identify as White typically report higher ratings in subjective well-being and quality of life than other racial/ethnic groups (Barger et al., 2009; Bracy, 1976; Campbell et al., 1976; Clemente & Sauer, 1976; Herzog et al., 1982; Hughes & Thomas, 1998; Iceland & Ludwig-Dehm, 2019; Stevenson & Wolfers, 2012). For autistic adults, the marginalized identity of being autistic may mitigate some of the social/cultural determinants typically associated with racial identity. Similarly, gender identity was not a significant predictor of Global Happiness

Ratings in the current study's autistic adult sample. Though inconsistencies can be found in the literature exploring gender differences in the quality of life of those in the general population, more recent meta-analyses are consistent with a lack of significance in gender-based differences (Batz-Barbarich et al., 2018). Holmes et al. (2020) found less favorable outcomes for certain components of quality of life (e.g., Social Isolation and Global Physical Health) for autistic women when compared to autistic men. Yet, consistent with the current study, significant gender-based differences in the overall quality of life of autistic adults has not been documented.

Though results were not significant for the predictors of race and gender identity, trends in Global Happiness Ratings should be explored. Most notable was the negative trend in Global Happiness Ratings for those who are Gender Non-conforming ($B = -1.34$, $\beta = -.19$, $t = -1.62$, $p = .11$). This p-value was just above the 0.10 alpha level set for this exploratory study and, paired with the relatively large unstandardized coefficient (i. e., $B = -1.34$), suggests that additional emphasis should be placed on improving the quality of life for those who identify as Gender Non-conforming.

The *race*gender identity* interaction terms were next entered into the regression equation for Block 2. Those who identified as *Intersectional Race*Female* were found to have a positive statistically significant interaction effect ($B = 2.68$, $\beta = .27$, $t = 1.74$, $p = .09$) when compared to the *White*Male* reference group. Those who identified as *Black*Gender Non-conforming* were found to have a negative statistically significant interaction effect ($B = -3.83$, $\beta = -.28$, $t = -1.67$, $p = .10$) when compared to the *White*Male* reference group. This trend is expected, given increased understanding brought about by excess intersectional disparity (Jackson et al., 2016). However, neither of these results continued to be significant once the predictors of Physical,

Cognitive, and Social Health and Well-being were added to the regression equation, indicating that the latter variables had a more substantial predictive value.

In Block 3, Physical Health and Well-being satisfaction was found to be a statistically significant predictor of Global Happiness Ratings in the current autistic adult sample ($B = .29$, $\beta = .23$, $t = 1.69$, $p = .10$). This finding is not surprising given the higher rates of health-related comorbidities within the autistic adult population (Hwang et al., 2019; Sala et al., 2020; Shavelle et al., 2001; Smith DaWalt et al., 2019; Warner et al., 2019). Cognitive Health and Well-being satisfaction was not a statistically significant predictor of Global Happiness Ratings in the current autistic adult sample after for which the impacts of race and gender identity were accounted. While not significant, there was a negative trend in the impacts of Cognitive Health and Well-being on Global Happiness Ratings in the autistic adult sample ($B = -.19$, $\beta = -.14$, $t = -1.26$, $p = .21$). This trend should be explored further due to cognitive-related challenges noted in previous studies (Llewellyn et al., 2008; Powell et al., 2017). Social Health and Well-being satisfaction was found to be a strong statistically significant predictor of Global Happiness Ratings in the current autistic adult sample, after for which the impacts of race and gender identity were accounted ($B = .82$, $\beta = .65$, $t = 5.31$, $p = <.001$).

In fact, Social Health and Well-being emerged as the strongest predictor of Global Happiness Ratings in the autistic adult sample. As Social Health and Well-being increased, so did Global Happiness at a relatively large rate ($B = .82$) with a high degree of certainty. This finding is consistent with previous studies (Kamp-Becker et al., 2010; Lin, 2014; Mason et al., 2022) and supports the inclusion of social health and well-being considerations at all levels of programs and services for autistic adults regardless of race and/or gender identity.

Physical Health and Well-being did not maintain significance once the Block 4 interaction terms were added to the equation, decreasing the power of this predictor. Limitations related to the use of the Cognitive Health and Well-being satisfaction domain in this study are outlined in the section that follows; however, trends in these results are important to note. While far from significant, there is a slightly negative trend in the impacts of Cognitive Health and Well-being and Global Happiness Ratings. This finding suggests that as satisfaction with cognition increases, happiness decreases. Initially, this notion may seem counterintuitive yet has practical implications. More cognitively able autistic adults likely have an increased awareness of their limitations and challenges, thus resulting in lower ratings of happiness and quality of life.

Finally, the interaction terms for *Race* and *Gender Identity* by the subjective *Physical*, *Cognitive*, and *Social Health and Well-being* domains were added to the regression equation. As previously stated, Physical Health and Well-being no longer held statistical significance; however, Social Health and Well-being continued to be a strong predictor of Global Happiness Ratings ($B = 1.04$, $\beta = .82$, $t = 3.12$, $p = .003$).

In Block 4, *Physical Health and Well-being***Race* and *Social Health and Well-being***Race* were found to have statistical significance. Physical Health and Well-being was found to be a significant positive predictor of Global Happiness Ratings for those who identified as Black (Black * PHW: $B = 2.09$, $\beta = .66$, $t = 2.03$, $p = .05$). Because the impacts of race on quality of life domains have not been formerly explored in the autistic adult population, this finding is the first of its kind to indicate that Black autistic adults may be more impacted by aspects related to Physical Health and Well-being than other demographic groups. When working with this subgroup of autistic adults, promoting physical health and well-being is of increased importance.

Analyzing the impacts of Social Health and Well-being satisfaction by Race on Global Happiness Ratings found a statistically significant negative interaction effect between those who identified as Black and Social Health and Well-being on Global Happiness Ratings ($B = -2.02$, $\beta = -.48$, $t = -2.25$, $p = .03$). Upon further analysis, this result was determined to be invalid due to an outlier in the data set. Specific limitations of this finding are discussed in the study limitations. In summary, overall results support the impact of social health and well-being satisfaction as the strongest and most consistent predictor of global happiness ratings in the current autistic adult sample.

Study Limitations

Reporting limitations is a necessary component of any research study. Failure to do so may encourage the placement of more emphasis on the research results than warranted (Price & Murnan, 2004). This section provides detailed information about the known limitations of this study, including those related to the research design and sampling techniques. The section concludes with transparency about how the limitations of the study impact the interpretability and generalizability of the results.

Research Design

This study utilized a quantitative, cross-sectional research design, which are sometimes described as taking a snapshot of a particular population (Carlson & Morrison, 2009). Cross-sectional designs offer a way of collecting data from a population at a single point in time and can be advantageous when comparing differences between groups and exploring multiple predictors and outcomes simultaneously (Thomas, 2023; Wang & Cheng, 2020). However, cross-sectional designs have several inherent limitations, including distinguishing between age-related and cohort-related results and the need for larger sample sizes than other research designs

(Cummings, 2021; Hofer et al., 2002). One limitation particularly relevant to the current study is the inability of cross-sectional designs to establish causality, which is often a more appropriate aim for longitudinal studies (Taris et al., 2021). In the current study, for example, this researcher was able to determine that Social Health and Well-being had a strong predictive value on Global Happiness Ratings; however, this researcher cannot conclude that positive social satisfaction causes happiness.

An additional design limitation is in the use of self-report questionnaires, which can be confounded by self-report bias—a variation between self-reported and actual values (Bauhoff, 2024). Surveys containing questions regarding cognitive processes and social desirability, such as those used in the current study, are often plagued by self-report bias. In the current study, self-report bias may have led to an over- or under-estimation of various aspects of subjective well-being. For example, some respondents may have reported higher global happiness due to social desirability. Researchers exploring the impacts of autistic traits in adults with autism have found strong indications of self-report bias, leading to recommendations to utilize multiple informants as a control (Mörücke et al., 2016). However, there is currently no literature outlining the impacts of self-report bias in autistic adult quality of life research. Nevertheless, future studies could utilize multiple informants, along with self-report, to mitigate the impacts of self-report bias.

Sampling

The sample was recruited through community outreach, convenience sampling, and utilization of the UNC Autism Research Registry. This study focused on individuals age 18 and above who are their own legal guardian and self-reported as being on the autism spectrum. Confirmed diagnosis of an identification on the autism spectrum was a major advantage of utilizing the UNC Autism Research Registry. The sample was predominantly college educated,

which is reflective of the autistic adult population targeted in the current study. However, the inclusion criteria limited representation of the entire autistic population. For example, those with higher support needs and/or co-occurring intellectual disability were not represented in the current study, which hinders generalizability of results.

The sample of the current study also consisted of unequal group sizes, which is not in itself a limitation of regression analyses. Due to the distribution of demographics within the sample, however, some group sizes were exceptionally small, especially when exploring the interaction terms of the analysis. For example, the *Black/Female*, *Black/Male*, and *Black/Gender Non-conforming* subgroups consisted of 3 participants each and the *Intersectional Race/Gender Non-conforming* subgroup consisted of only 2 participants. As previously stated, this researcher elected to keep these small group sizes in the analysis in an effort to be as inclusive as possible. However, this decision limits the interpretability of results involving small groups due to the potential for larger standard errors and less reliable estimates for these subgroups. To address the underrepresentation of minority subgroups, future research should aim to collect data from a larger sample with more balanced group sizes.

Interpretation of Results

Caution should be used when interpreting results related to the PQoL Scale domain of Cognitive Health and Well-being satisfaction. The Cognitive Health and Well-being domain had a *Cronbach's Alpha* reliability statistic of .58, which is below the acceptable reliability threshold of .60 (Tavakol & Dennick, 2011). The below-threshold *Cronbach Alpha* value is likely due to the limited number of items within the Cognitive Health and Well-being domain (i. e., 2 items), which did not allow for trustworthy consistency. Future studies involving cognitive health and well-being should consider use of a scale with higher reliability. At best, the negative trends

noted between Cognitive Health and Well-being and Global Happiness Ratings in the current study should be noted for further exploration. However, whether this trend will uphold in future studies that incorporate cognitive measures with greater reliability is yet to be determined.

As illustrated in Chapter 4, many interaction terms of the analysis had a high Variance Inflation Factor (VIF), which can be an indication of multicollinearity. These high VIF values were dealt with by removing the interaction terms with a VIF above 10.00 from the regression equation and entering them into a separate analysis to gain insights into how they may interact with global happiness in autistic adults. The high VIF values combined with the small sample sizes of the *race*gender identity* interaction terms rendered overall exploration of the interaction effects problematic. While insights were gained, a true reading of how these interaction terms behaved amongst all of the predictors in the analysis was not obtained.

Generalizability of Results

In addition to the implicit limitations of the small group sample sizes on the generalizability of results, another limitation relates to the restricted geographic region from which the data was collected. Most, if not all, participants were located in the state of North Carolina, evidenced by their affiliation with this researcher's clinical setting or their enrollment in the UNC Autism Registry. North Carolina has over 18 urban areas and has the second largest rural population in the United States (Cline, 2023). While North Carolina consists of both rural and urban areas, results cannot be generalized to autistic adults in other parts of the United States or world due to lack of geographic representation. Also, data related to socioeconomic status was not collected. Socioeconomic status has meaningful impacts on quality of life; however, the application of results of the current study to various socioeconomic groups is not feasible. In

future studies, collecting data related to socioeconomic status will be helpful in determining how this predictor impacts quality of life and happiness.

Implications of the Study

The current study has several implications that make meaningful contributions to the field of research devoted to improving the quality of life of autistic adults. This section begins with a description of implications for clinical practice followed by implications for administration and policy.

Implications for Clinical Practice

The demographic predictors of race and gender identity were not found to have a significant impact on global happiness in this autistic adult sample. This finding supports the intertwining nature between human needs theory and the culture of autism discussed in the review of relevant literature. That is, human needs for satisfaction and happiness are relevant to all people, regardless of specific demographics. However, demographic considerations are still important to consider, especially when addressing the needs of marginalized groups such as racial and gender identity minorities. Trends were observed in the current study that warrant attention, including negative trends in global happiness for those who have racial intersectionality and those who are gender non-conforming. These trends are consistent with previous studies that have found indications of excess intersectional disparity and lower quality of life in those who live with multiple marginalized identities (Jackson et al., 2016; Valentine & Shipherd, 2018). Clinicians need to be aware of how multiple marginalized identities (e.g., autistic and gender non-conforming) impact the quality of life of their clients to address them from a person-centered, holistic perspective.

Of the three quality of life domain predictors, Social Health and Well-being satisfaction was consistently determined to be a significant predictor of Global Happiness Ratings in the autistic adult sample of this study, consistent with the human need for a sense love and belonging incorporated within Maslow's Hierarchy of Needs. This finding has several clinical implications such as highlighting the importance of subjective social assessment, prioritizing individualized subjective experiences and notions of social satisfaction, and promoting social exploration. One aim of improving social health and well-being should be to increase one's positive feelings towards their autism identity (Cooper et al., 2017). Understanding the context of social satisfaction is vital when determining implications on an individual and group level, beginning with an effective strategy for assessment that incorporates exploration of human needs related to a sense of belonging.

Clinicians need to approach social assessment with a reconditioning of their own preconceived notions of what it means to be socially satisfied, and neurotypical norms should not be arbitrarily applied to the autistic population. A search of the literature for "autistic adult social assessment" yielded a majority of results that were focused on identifying deficit-based characteristics as they relate to social performance. These measures are instrumental due to their diagnostic validity but are not intended to provide clarity around clinical intervention.

Subjective social assessment is more nuanced and should focus on an individual's own subjective social needs, satisfaction, and desires. Take, for example, the Social Health and Well-being satisfaction domain of the PQoL Scale used in this study, which is outlined in Table 12. The domain consists of 11 items that range from satisfaction with family and friends to satisfaction with income and employment, exploring an array of social contributors to health and satisfaction. Individual item analysis of such an assessment tool should be used in clinical

intervention to better inform treatment goals and outcomes based on addressing human need satisfaction versus strictly relying upon skill-based strategies and outcomes. With item analysis, tailored conversations with clients can be conducted in a way that allows for reflection of current levels of satisfaction and desires for future outcomes. Clinicians and clients can then work together through a collaborative process that empowers autistic adults to pursue social health and well-being satisfaction that is meaningful and consistent with their own individualized needs.

Table 12

Social Health and Well-being Satisfaction Domain Items

<i>Social Health and Well-being</i>	<u>How satisfied or dissatisfied are you with:</u>
	How often you see or talk to your family and friends?
	The help you get from your family and friends, for example, helping in an emergency, fixing your house, or doing errands?
	The help you give your family and friends?
	Your contribution to your community, for example, a neighborhood, religious, political, or other group?
	Your retirement or current job?
	The kind and amount of recreation or leisure you have?
	Your level of sexual activity or lack of sexual activity?
	The way your income meets your needs?
	How respected you are by others?
	The meaning and purpose of your life?
	The amount of variety in your life?

The findings of this study also support the promotion of social exploration within clinical practice. Once adequate assessment has been completed, clinicians should engage autistic clients in active, solution-focused exploration of social opportunities, including those related to recreation and leisure interests. Social opportunities could include those involving work, volunteer opportunities, community engagement, learning a new skill, recreation, and scheduling a visit with friends and/or family. Opportunities do not always have to include social interactions and engagement with others, as simply getting out of the house may be sufficiently satisfying for some. Additionally, online social opportunities should be included in exploration. Due to documented executive functioning challenges for those with autism (Johnson et al., 2019; St. John et al., 2022), clinicians must incorporate evidence-based practices, such as visual supports, to aid in generating goal-directed plans and action steps to promote follow-through outside of the therapeutic environment.

Finally, clinicians should be mindful to engage in additional exploration involving satisfaction with physical health and well-being with clients who identify as Black. Just as suggested for subjective social assessment, similar techniques can be used to assess satisfaction with physical health and well-being. A formalized measure, such as the PQoL Scale, can be used, or a clinician may elect to develop their own questions regarding physical health satisfaction. Incorporating items to reflect satisfaction with physical health and fitness, caring for oneself, and sleep hygiene is important. Previous research has also linked the beneficial impacts of leisure activities on physical health and well-being and quality of life (Billstedt et al., 2011; García-Villamizar et al., 2002). For reference, Table 13 outlines the 5 specific items that make up the Physical Health and Well-being satisfaction domain on the PQoL Scale.

Table 13

Physical Health and Well-being Satisfaction Domain Items

<i>Physical Health and Well-being</i>	<u>How satisfied or dissatisfied are you with:</u>
	Your physical health (the health of your body)?
	How well you care for yourself, for example, preparing meals, bathing, or shopping?
	The amount of walking you do?
	How often you get outside of the house, for example, going into town, using public transportation or driving?
	The amount and kind of sleep you get?

Implications for Administration and Policy

This study can help inform advocacy efforts at the policy level to allow for a more accurate representation of needs across the autistic adult population. The necessity for robust programs and services for autistic adults is apparent and has been well-documented (Roux et al., 2017). This study strengthens the requirement for social programming and supports throughout the lifespan for those with autism to enrich their overall life satisfaction and well-being. Unfortunately, extremely limited federal and local funding is allocated for programs and services to meet the complex social needs of autistic adults. These needs take many forms and include needs for educational services, vocational training, recreation and leisure, and community involvement. New legislative policy is essential in earmarking funding for the creation and enhancement of programs within local communities to target the autistic adult population.

It is important to note that community involvement encompasses both receiving support from the community and contributing to the overall needs of the community. Additional work is essential to be inclusive of autistic adults in communities in a way that adequately values their strengths and contributions. For decades, advocacy efforts have focused on autism understanding and acceptance. However, it is time to move past acceptance and towards the public commitment of inclusion

Social inclusivity can be measured on a number of dimensions, including visibility and access to social interaction with others, consideration of needs and rights, such as the right to be different, to work and to participate in the cultural life of society, and the resources to enable people to exercise these rights (Dillenburger et al., 2015, p. 331). Administration and policy efforts need to focus on social inclusivity so autistic adults, including those with other marginalized identities, will be seen as equitable members of society.

Recommendations for Future Research

Numerous recommendations for future research can be drawn from this study that explored predictors of autistic adult quality of life. Primary recommendations discussed in this section relate to sampling, research design, and instrumentation for future studies.

Future research should focus on including increased diversity within study samples to best reflect the level of diversity within the autism spectrum. Previous studies have neglected to explore factors related to race (Steinbrenner et al., 2022), which has implications for providing programming and services that address the unique needs of all on the autism spectrum. While this study did represent a wide variety of racial backgrounds and gender identities, the overall sample sizes of marginalized groups were relatively small, especially for those with intersecting marginalizations. For example, the *Black/Female*, *Black/Male*, and *Black/Gender Non-conforming* subgroups consisted of 3 participants each and the *Intersectional Race/Gender Non-conforming* subgroup consisted of only 2 participants. Though they were included to increase representation in the current study, the small subgroup sizes drastically hindered the interpretability of results and ability to effectively understand and address the unique needs of these subgroups. Future research should aim to collect data from a larger sample with more balanced group sizes to increase the generalizability of results. To bolster this holistic perspective, tracking the same individuals over time can also be advantageous.

Longitudinal studies that collect data regarding the quality of life of autistic adults at several time intervals will greatly enhance the understanding of quality of life indicators. While longitudinal studies have their own challenges, specific advantages include the ability to provide information about within individual change and lessen the impacts of cohort effects, such as age and external impacts at the time of measurement (Caruana et al., 2015; Farrington, 1991). As

levels of satisfaction and needs evolve, following and measuring the same autistic adults over time will allow for data to be collected on individual and group changes to subjective quality of life indicators.

Future research will benefit from professional consensus on the ideal instrument to use when measuring subjective quality of life in autistic adults. Scholars have agreed upon the need to develop a measure of autistic quality of life that encompasses the aspects of quality of life that are important to the autistic population (Burgess & Gutstein, 2007; McConachie et al., 2020), though most measures being used were designed and validated for use with the general population and do not account for what it means to be autistic. Some attempts have been made; however, concerns around validation and the inclusion of meaningful factors continue. Having a universally agreed upon measure of quality of life with input from the autistic population will increase the comparability of results across studies and significantly enhance this field of research.

A specific instrumentation consideration resulting from this study relates to the measurement of Cognitive Health and Well-being satisfaction. As discussed in the limitations of this study, the Cognitive Health and Well-being domain had a *Cronbach's Alpha* reliability statistic of .58, which is below the acceptable reliability threshold of .60. Future studies need to use a more reliable measure of cognitive aspects of well-being, which, highlighting the previous recommendation, may best derive from development of an instrument specifically designed for and by autistic adults.

Finally, future studies should include both self-report and informant-report measures. Informant-report measures can be developed alongside self-report instruments and will offer, not only, the opportunity to compare results, but mitigate the impacts of self-report bias as well. Care

and consideration should be given when explaining the rationale for incorporating informant reports when discussing research opportunities with autistic adults. Researchers need to be clear that utilization of informant reports does not minimize the validity of their own self-report, nor does the inclusion of this data infer that others know the autistic adult better than they know themselves or diminish their self-determination.

Conclusions

The purpose of this study, grounded in Maslow's human needs theory, was to explore the effects of race and gender identity on overall quality of life and global happiness ratings in autistic adults, as well as investigate the impacts of the Physical, Cognitive, and Social Health and Well-being satisfaction domains on Global Happiness Ratings in the autistic adult population. Further, this analysis explored whether physical health and well-being, cognitive health and well-being, and social health and well-being vary by race and gender identity and how race and gender identity interact to impact global happiness in autistic adults. Quality of life has become increasingly important to study in the growing autistic adult population and this study aimed to contribute to the body of knowledge concerning predictors of quality of life from the subjective perspective of autistic adults.

A cross-sectional research design was used to collect data from participants in the form of a demographic questionnaire and the PQoL Scale. The sample consisted of 83 autistic adults who were asked to complete the study protocol independently. The demographic questionnaire was used to identify applicable subgroups of the sample. Racial and Gender Identity categories consisted of those who identified as *Black*, *White*, *Intersectional Race*, *Female*, *Male*, and *Gender Non-conforming*. Results of the current study indicated that Social Health and Well-being satisfaction was a strong statistically significant predictor of Global Happiness Ratings in

the autistic adult sample. Also, Physical Health and Well-being was found to be a significant positive predictor of Global Happiness Ratings for those who identified as Black.

Like all research, this study had several limitations and implications. Limitations impacted both the interpretability and generalizability of results and included those inherent to cross-sectional designs and the sampling techniques used. However, this study contributed to the current body of knowledge of autistic adult quality of life and has several critical implications for clinical practice, administration and policy, and future research.

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APPENDIX A: DEMOGRAPHIC SURVEY

Demographic Survey

Please take a few minutes to answer a few questions about yourself.
Place an X in the appropriate box or write in the space provided.

1. I identify as being on the Autism Spectrum (i.e., Autism, Autism Spectrum Disorder, Autistic, Autistic Disorder, Asperger's, Pervasive Developmental Disorder).

☐

YES

☐

NO

2. I am my own legal guardian.

☐

YES

☐

NO

3. Age in years: _____ years

4. Sex Assigned at Birth:

☐

MALE

☐

FEMALE

Gender Identity:

☐

FEMALE

☐

MALE

☐

NON-BINARY

☐

TRANS FEMALE

☐

TRANS MALE

☐

GENDERFLUID

☐

OTHER GENDER IDENTITY:

5. Ethnicity:

☐

HISPANIC

☐

NON-HISPANIC

6. Race (indicate all that apply):

☐

AMERICAN INDIAN

☐

AFRICAN AMERICAN / BLACK

☐

ASIAN INDIAN

☐

CAUCASIAN / WHITE

☐

CHINESE

☐

JAPANESE

☐

PACIFIC ISLANDER

☐

OTHER RACE:

7. Highest Level of Education:

☐

SOME HIGH SCHOOL

☐

HIGH SCHOOL DIPLOMA

☐

SOME COLLEGE

☐

ASSOCIATE'S DEGREE

☐

BACHELOR'S DEGREE

☐

MASTER'S DEGREE

☐

PROFESSIONAL DEGREE

☐

PHD OR EQUIVALENT

8. Current Employment:

☐

UNEMPLOYED

☐

FULL-TIME EMPLOYMENT

☐

PART-TIME EMPLOYMENT

☐

OTHER EMPLOYMENT:

9. Living Arrangement:

- | | |
|---|--|
| ☐ ALONE WITHOUT SUPPORT | ☐ ALONE WITH SUPPORT |
| ☐ WITH PARTNER | ☐ WITH PARENT(S) AND/OR GUARDIAN(S) |
| ☐ ASSISTED LIVING FACILITY | ☐ OTHER: _____ |

10. Current Relationship Status:

- | | |
|---------------------------------------|--|
| ☐ SINGLE | ☐ MARRIED |
| ☐ DIVORCED | ☐ LIVING WITH PARTNER |
| ☐ OTHER: _____ | |

11. Other Diagnoses (indicate all that apply):

- | | |
|---------------------------------------|---|
| ☐ NONE | ☐ ANXIETY |
| ☐ DEPRESSION | ☐ ATTENTION DEFICIT / HYPERACTIVITY DISORDER |
| ☐ OTHER: _____ | |

12. Please list any known medical conditions (e.g., seizures, high blood pressure, visual/hearing impairment, Celiac, metabolic conditions).

- | | |
|--------------------------------|--------------------------------|
| ☐ _____ | ☐ _____ |
| ☐ _____ | ☐ _____ |
| ☐ _____ | |

APPENDIX B: PERCEIVED QUALITY OF LIFE SCALE

**THE PERCEIVED QUALITY OF LIFE
SCALE[©] (PQOL)**

U.S. English Version



**University of Washington
Seattle, Washington
United States of America**

Emblem...Soul Catcher: a Northwest Coast Indian symbol of physical and mental well-being. Artist: Marvin Oliver

Satisfaction with Health and Life

We would like to know how satisfied you are with different aspects of your life. Each item below has a scale where “0” is Extremely Dissatisfied and “10” is Extremely Satisfied. [For each item, mark an ☒ in the box of the number that shows your own level of satisfaction.]

How dissatisfied or satisfied are you with:

1. Your physical health (the health of your body)?

Extremely dissatisfied	Extremely satisfied
τ	τ
0	10
1	9
2	8
3	7
4	6
5	5
6	4
7	3
8	2
9	1
10	0
☐	☐

2. How well you care for yourself, for example, preparing meals, bathing, or shopping?

Extremely dissatisfied	Extremely satisfied
τ	τ
0	10
1	9
2	8
3	7
4	6
5	5
6	4
7	3
8	2
9	1
10	0
☐	☐

3. How well you think and remember?

Extremely dissatisfied	Extremely satisfied
τ	τ
0	10
1	9
2	8
3	7
4	6
5	5
6	4
7	3
8	2
9	1
10	0
☐	☐

(Please turn the page)

How dissatisfied or satisfied are you with:

4. The amount of walking you do?

Extremely dissatisfied	Extremely satisfied
---------------------------	------------------------

τ 0 1 2 3 4 5 6 7 8 9 10 τ

□

□

□

□

□

□

□

□

□

□

□

5. How often you get outside the house, for example, going into town, using public transportation or driving?

Extremely dissatisfied	Extremely satisfied
---------------------------	------------------------

τ 0 1 2 3 4 5 6 7 8 9 10 τ

□

□

□

□

□

□

□

□

□

□

□

6. How well you carry on a conversation, for example, speaking clearly, hearing others, or being understood?

Extremely dissatisfied	Extremely satisfied
---------------------------	------------------------

τ 0 1 2 3 4 5 6 7 8 9 10 τ

□

□

□

□

□

□

□

□

□

□

□

7. The kind and amount of food you eat?

Extremely dissatisfied	Extremely satisfied
---------------------------	------------------------

τ 0 1 2 3 4 5 6 7 8 9 10 τ

□

□

□

□

□

□

□

□

□

□

□

(Please turn the page)

How dissatisfied or satisfied are you with:

8. How often you see or talk to your family and friends?

Extremely dissatisfied	Extremely satisfied
---------------------------	------------------------

τ 0 1 2 3 4 5 6 7 8 9 10 τ

9. The help you get from your family and friends, for example, helping in an emergency, fixing your house, or doing errands?

Extremely dissatisfied	Extremely satisfied
---------------------------	------------------------

τ 0 1 2 3 4 5 6 7 8 9 10 τ

10 . The help you give to your family and friends?

Extremely dissatisfied	Extremely satisfied
---------------------------	------------------------

τ 0 1 2 3 4 5 6 7 8 9 10 τ

11 . Your contribution to your community, for example, a neighborhood, religious, political or other group?

Extremely dissatisfied	Extremely satisfied
---------------------------	------------------------

τ 0 1 2 3 4 5 6 7 8 9 10 τ

(Please turn the page)

How dissatisfied or satisfied are you with:

12 . Your retirement or current job?

Extremely dissatisfied	Extremely satisfied
---------------------------	------------------------

τ τ

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

13. The kind and amount of recreation or leisure you have?

Extremely dissatisfied	Extremely satisfied
---------------------------	------------------------

τ τ

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

14. Your level of sexual activity or lack of sexual activity?

Extremely dissatisfied	Extremely satisfied
---------------------------	------------------------

τ τ

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

15. The way your income meets your needs?

Extremely dissatisfied	Extremely satisfied
---------------------------	------------------------

τ τ

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

(Please turn the page)

How dissatisfied or satisfied are you with:

16 . How respected you are by others?

Extremely dissatisfied	Extremely satisfied
---------------------------	------------------------

τ 0 1 2 3 4 5 6 7 8 9 10 τ

17. The meaning and purpose of your life?

Extremely dissatisfied	Extremely satisfied
---------------------------	------------------------

τ 0 1 2 3 4 5 6 7 8 9 10 τ

18 . The amount of variety in your life?

Extremely dissatisfied	Extremely satisfied
---------------------------	------------------------

τ 0 1 2 3 4 5 6 7 8 9 10 τ

19 . The amount and kind of sleep you get?

Extremely dissatisfied	Extremely satisfied
---------------------------	------------------------

τ 0 1 2 3 4 5 6 7 8 9 10 τ

(Please turn the page)

20. How happy are you?

Extremely unhappy											Extremely happy																																																																																																																								
τ											τ																																																																																																																								
0											1											2											3											4											5											6											7											8											9											10																					
☐											☐											☐											☐											☐											☐											☐											☐											☐											☐											☐											☐										

APPENDIX C: RESEARCH INFORMATION SHEET

East Carolina University

Research Information Sheet

Title of Research Study: Subjective Experiences of Quality of Life in Autistic Adults Across Race and Gender Identity: A Study of Happiness and Physical, Cognitive, and Social Well-Being

You are being invited to participate in a research study titled “*Subjective Experiences of Quality of Life in Autistic Adults Across Race and Gender Identity: A Study of Happiness and Physical, Cognitive, and Social Well-Being*” being conducted by *Daniel Liles*, a student at East Carolina University in the *Department of Addictions and Rehabilitation Studies*. The goal is to survey at least 60 adults who identify as having autism. The survey will take approximately 20 minutes to complete. It is hoped that this information will assist us to better understand factors that help predict Quality of Life and happiness in autistic adults.

Your responses will be kept confidential and no data will be released or used with your identification attached. Your participation in the research is **voluntary**. You may choose not to answer any or all questions, and you may stop at any time. We will not be able to pay you for the time you volunteer to participate in this study. There is **no penalty for not taking part** in this research study. Some individuals may experience strong, unexpected emotions when answering questions about their Quality of Life and happiness. In the event that you experience strong, difficult to manage emotions during or after participation in this research study, you can contact crisis support by dialing 988.

Please contact Daniel Liles at lilesd00@students.ecu.edu for any research related questions or the University & Medical Center Institutional Review Board (UMCIRB) at 252-744-2914 for questions about your rights as a research participa

APPENDIX D: INSTITUTIONAL REVIEW BOARD APPROVAL LETTER

8/26/24, 9:32 AM

epirate.ecu.edu/App/sd/Doc/0/BU83EOR3KS8UV55AHQVP0LI000/fromString.html



EAST CAROLINA UNIVERSITY
University & Medical Center Institutional Review Board
Willis Building · Mail Stop 682
600 Moye Boulevard · Greenville, NC 27834
Office 252-744-2914 · Fax 252-744-2284
rede.ecu.edu/umcibr/

Notification of Exempt Certification

From: Social/Behavioral IRB
To: [Daniel Liles](#)
CC: [William Atherton](#)
Date: 8/26/2024
Re: [UMCIRB 24-001519](#)
Subjective Experiences of Quality of Life in Autistic Adults

I am pleased to inform you that your research submission has been certified as exempt on 8/23/2024. This study is eligible for Exempt Certification under category # 2AB.

It is your responsibility to ensure that this research is conducted in the manner reported in your application and/or protocol, as well as being consistent with the ethical principles of the Belmont Report and your profession.

This research study does not require any additional interaction with the UMCIRB unless there are proposed changes to this study. Any change, prior to implementing that change, must be submitted to the UMCIRB for review and approval. The UMCIRB will determine if the change impacts the eligibility of the research for exempt status. If more substantive review is required, you will be notified within five business days.

Document	Description
Demographic Survey(0.01)	Data Collection Sheet
Demographic Survey(0.01)	Surveys and Questionnaires
Email Scripts(0.01)	Recruitment Documents/Scripts
PQoL Scale(0.01)	Surveys and Questionnaires
Research Proposal Document(0.01)	Study Protocol or Grant Application
Study Information Sheet(0.01)	Recruitment Documents/Scripts
Study Information Sheet(0.01)	Consent Forms

For research studies where a waiver or alteration of HIPAA Authorization has been approved, the IRB states that each of the waiver criteria in 45 CFR 164.512(i)(1)(i)(A) and (2)(i) through (v) have been met. Additionally, the elements of PHI to be collected as described in items 1 and 2 of the Application for Waiver of Authorization have been determined to be the minimal necessary for the specified research.

The Chairperson (or designee) does not have a potential for conflict of interest on this study.

IRB00000705 East Carolina U IRB #1 (Biomedical) TORG0000418
IRB00003781 East Carolina U IRB #2 (Behavioral/SS) TORG0000418

<https://epirate.ecu.edu/App/sd/Doc/0/BU83EOR3KS8UV55AHQVP0LI000/fromString.html>

