Quality of Life Assessments, Autistic Populations and Methodology: A Better Quality of Life Is Only an Illusion

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Abstract

Researchers want to improve quality of life with their many studies, treatments, and care models, but what if the improvements they "find" in the lives of others are merely an illusion? By examining 19 autism spectrum disorder-focused studies, this paper will explore the administration and application of quality of life assessment questionnaires. More importantly, it will discuss the issues and errors made before, during, and after administering them. It will also identify several areas for further research and study in the hopes of making the quality of researchers and autistic individuals' lives better.

Keywords: quality of life, surveys, questionnaires, survey methodology

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Introduction

We dedicate almost our entire lives to improving the quality of life for ourselves, our loved ones, and maybe even those around us. It is normal to seek more money, fulfillment, happiness, and a better life. What is unusual, however, is that we don't know what "quality of life" means or even what a good quality of life is. Some people clearly know what a good quality of life is, but we don't all agree. We continuously measure, compare, judge, and seek to improve our lives without a definition or clear-cut way to measure it. And doesn't something have to be measurable to know whether it has improved or worsened?

Over the last 60 years, experts in psychometrics, healthcare, philosophy, economics, and other disciplines have sought to define and measure Quality Of Life (QOL). Even today, professionals and scientists from all walks of life use carefully crafted surveys and assessments as a gold standard measuring stick to determine the efficacy of everything from healthcare models and policy decisions to treatments and the health of the world's economies. In fact, Google Scholar returns 3,640,000 results for "quality of life," but what if these studies and the decisions they influence are all flawed?

This paper will explore the methodology behind QOL assessments that often go unexamined and unrecorded. It will explore the context behind how these tools are administered and how overlooked variables might influence research findings, resulting in errors that can lead to falsely abandoning or adopting treatments, care models, and more. The goal? To better understand the methodology behind QOL questionnairesin the context of autistic populations, how they may introduce inaccuracies, inconsistencies, errors, and confounding variables, and identify areas for future study.

To measure the change in a participant's quality of life, researchers utilize QOL questionnaires like the WHOQOL, which are general, large-scale measurements used to gauge overall well-being. (The long form of abbreviations for all the tools and assessments

mentioned in this paper can be found in Appendix A.) When professionals want to use QOL assessments in a specific situation or with a unique population, these general tools are tweaked and reworked by experts in psychometrics and assessments into case-specific assessment tools (such as the SFS or PedsQL). In other instances, researchers stitch together concepts from QOL tools, research, and their respective disciplines to create a Frankenstein-like assessment tool that will meet the unique needs of their research.

To determine reliability and validity, researchers compare the results from their chosen QOL tool against domain-specific or other general QOL measurements. And this is where the concept begins to fall apart. In essence, what makes this validation and reliability work may also be its Achilles' heel. Take the validation of these tools, for example. If QOL assessments, and the tools used to judge their accuracy, are administered similarly and contain the same flaws, is it the equivalent of measuring wrong in the same way twice? The result appears to be two tools that agree and appear to validate each other's findings, but are they not both verifying the same erroneous results? We need to know if the results are valid if we are to rely on them to judge the efficacy or failure of something else.

Of course, the questions go far beyond just validation: How stable is QOL? Can humans accurately judge the QOL of someone else? Does the environment or timing bias the results? Are first-person reports superior to third-person methodologies? Are disease or patient-specific measures the better choice?

Even the human ability to assess quality of life appears questionable. As humans, our experiences, values, morals, and personalities taint our judgments and evaluations. Humans cannot accurately predict how long or how much a lottery win would affect them (Brickman et al., 1978). How can we then assume that they can judge their current quality of life accurately enough to be used as evidence for a decision that could drastically impact others?

There are many more questions the methodology behind QOL tools raises beyond

the multitude listed here. The area of QOL research seems plagued by unanswered questions. In fact, you'll find many of them become running themes throughout this paper (and also listed in Appendix G for easy reference).

Background

To better understand the current realm of QOL research, it's important to understand how QOL became an area of interest to medicine and other disciplines. It wasn't always a consideration, after all.

History of Quality of Life as an Area of Interest

The first in-depth mention of QOL, at least regarding academic literature, occurred in PH Long's paper entitled *On the Quantity and Quality of Life* (Long, 1960). At that time, medicine focused on preventing death and extending the number of years lived rather than on the quality of those years. This viewpoint often meant that the medical profession would inflict real or emotional pain on its victims for a prolonged period before death.

> The simple view is that medicine exists to fight death and disease, and that is, of course, its most basic task. Death is the enemy. But the enemy has superior forces. Eventually, it wins. And, in a war that you cannot win, you don't want a general who fights to the point of total annihilation. You don't want Custer. You want Robert E. Lee–someone who knows how to fight for territory that can be won and how to surrender it when it can't–someone who understands that the damage is greatest if all you do is battle to the bitter end. (Gawande, 2014)

Instead of fighting death, medical providers, healthcare professionals, and others use QOL interventions to help their patients, clients, and the public enjoy the time that remains, no matter how much or how little or what their circumstances are. In essence, QOL allows them to create battle plans and fight the battles worth fighting with a full understanding that they will ultimately lose the war. We all will.

The idea of fighting winnable battles instead of attempting to conquer death slowly gained momentum until the US National Library of Medicine MEDLINE computer search included the concept as a Medical Subject Heading (MeSH) keyword in 1977 (Pennacchini et al., 2011). Not long after, QOL became a standard measure used by medical professionals to weigh the pros and cons of treatments and help them choose the best course of action for their patients (Pennacchini et al., 2011).

However, in the 1990s, it was clear that QOL tools had a problem: They had outpaced the theories behind the concept (Albrecht, 1996; Albrecht and Devlieger, 1999). Albrecht wrote, "While problems abound in the design and use of subjective health assessment instruments, indicators of patient satisfaction and 'health-related quality of life' are becoming increasingly used in contemporary medical practice and policy, with promising results" (Albrecht, 1996).

In other words, the world became seduced by an easy way to assess the feelings and happiness of patients and turn those assessments into an objective set of numbers that could be used to justify their decisions. It's easy to understand why. In some ways, it is an opportunity for a medical professional to relieve the feelings associated with realizing the inevitable–there may be no way to prevent death, reverse a disease, or undo a genetic error. It is almost as if QOL assessments give the fiercest fighters in the discipline permission to stop. However, the logistics behind why the medical field continues to use QOL in this way are vast and far outside the scope of this paper.

With the realization that the issues of using a subjective measure as an objective test were only continuing to grow, the World Health Organization began the task of defining QOL as the first step to measure "...the impact of disease and impairment on daily activities and behaviour... to include non-Western populations in the development of such tools, and ...the introduction of a humanistic element into healthcare..." (Group, 2012). What did they find, and how did they solve this complex problem? We'll get to that in a moment. Before we do, however, we need to understand how we use QOL.

Quality of Life in Other Disciplines

The medical and healthcare fields aren't the only disciplines to use quality of life to make decisions. Philosophers, for example, use the concept to make judgments on mercy killings and medical treatments for the severely ill (Pennacchini et al., 2011). To do so, they weigh the quality of life against the additional time a treatment may bring. For example, is extending the life of the dying if they will only suffer the right thing to do?

In this respect, philosophers use QOL as a moral measurement. But, like everything in philosophy, the answer is not so clear. In Dr. Shelly Kagan's famous lecture series on death, for example, it's clear that these decisions require the satisfaction of a two-state argument and the ability to pinpoint the moment when the opportunity cost of life outweighs the cons of non-existence (YaleCourses, 2008). QOL falls desperately short is satisfying the requirements, but again, this is beyond the scope of this paper. The critical thing to note here is that philosophy still doesn't have a definition for the term despite arguing about it for centuries (Ventegodt et al., 2003).

Economics professionals use QOL as an essential component in financial decisions. However, in this context, the measurement is happiness and fulfillment instead of mobility, health, and other tangible domains ("What is quality of life?" n.d.). Like in medicine and healthcare, failure to consider QOL in economics has its consequences, too.

In 1980, economists realized they had made a similar mistake to the medical community: Their economic formulas, such as their coveted GDP, were missing items that didn't come with a price tag, leading to a lower quality of life for all through increasing poverty, inequality, and environmental damage (Stiglitz, 2020). In response, economists began to include QOL elements such as "...health, housing, environment, and safety" in their financial and policy considerations (Canada, 2021). Today, there are a variety of proposed GDP alternatives, including the Human Development Index (HDI), the Better Life Index (BLI), and the Happy Planet Index (HPI) (Decancq, 2015; "Happy Planet Index – How happy is the planet," 2023; Nations, 2023).

In anthropology, quality of life is typically measured as "...the effectiveness of different cultures in providing for the needs of their members" (Wilk, 1999). Here, anthropologists attempt to use the concept to compare societies. However, this method is often controversial. Many professionals argue that QOL centers a white, Western perspective and sets it as a standard, while other non-Western cultures may value different things. In this respect, comparing cultures, or the same culture across time, is inappropriate since situations and values differ dramatically (Wilk, 1999). Relevant here, of course, is the issue of comparing lives that may essentially be very different, using a predetermined standard. These standards? Often that of white, affluent, and well-educated researchers. Much like QOL tools in medicine and healthcare.

The Definition of QOL

The definition of QOL in the context of healthcare and the medical field echoes many of the same themes as in other disciplines. Historically, professionals saw QOL as a mish mash of things they thought made people happy. It wasn't until the WHO published the findings of its multi-year investigation that we had a relatively common definition (Group, 2012). They determined the best definition of QOL to be an:

> ...[I]ndividuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. It is a broad-ranging concept incorporating in a complex way the persons' physical health, psychological state, level of independence, social relationships, personal beliefs and their relationships to salient features of the environment. (Group, 2012)

Along with this definition, the WHO released the WHOQOL, a general tool for assessing quality of life. However, the WHO notes that the assessment merely measures the perception of quality of life at that moment and is not an objective measurement of disease and impairments (Group, 2012). So, while they had set out to create reliable tools to

measure how disease and impairments affected one's quality of life and included non-Western populations, they ultimately failed. They didn't seem to find the objective definition that they expected to get, either:

> This definition reflects the view that quality of life refers to a subjective evaluation, which is embedded in a cultural, social, and environmental context. (As such, quality of life cannot be equated simply with the terms "health status," "lifestyle," "life satisfaction," "mental state," or "well-being"). (Group, 2012)

Despite that, researchers and professionals often use QOL tools to decide the success or failure of treatments, government policies, and more. For example, Braden et al., 2022 used the WHOQOL-BREF to conclude that the "...[f]indings highlight the need to individualize interventions and services and to use age- and sex-based norms for comparing HRQoL outcomes in adults with ASD (Autism Spectrum Disorder)." They also determined that the "...pilot study is the first to identify MBSR-associated benefits to disability-related QoL(sic) in adults with ASD..." (Braden et al., 2022). In other words, they have used QOL assessments to support recommendations and provide evidence for specific treatments or care models.

While the studies selected for this paper all use QOL tools as objective measurements (or extrapolate the subjective to the objective), their definitions ignore the WHO recommendation. In all, 12 of the 19 studies either avoid defining QOL or rely on assessment tools to provide a definition implicitly. The problem with relying on the tool to provide a definition is that it's cyclical. Researchers choose a tool that meets the satisfies the objectives of the study. However, by relying on the tool for the definition, the researchers allow the test to decide what it is they're testing. Of course it is going to show results.

All of the 19 studies found significant effects, proving their hypothesis. (A summary of the findings from each paper can be found in Table E) For example, Adorno et al., 2022

has no explicit definition for QOL listed. However, the paper seems to imply that functional independence, reduced anxiety, increased self-esteem, and confidence are outside of "quality of life" or possibly equate to it. Arnold et al., 2019 also fails to define QOL explicitly. Interestingly, the author states that the "primary outcome measure was the GI Module of the PedsQL," suggesting that the tool defines quality of life. However, the study lists GI (gastrointestinal) symptoms and QOL separately, suggesting they are different (Arnold et al., 2019). It is unclear why this confusion occurred. It could be an oversight, avoiding the issues of definition, or simply being unaware of what QOL is.

Braden et al., 2022 and Charlton et al., 2022 made the opposite choice, using the WHO's definition given previously. Raphael et al. (1996) used a humanistic, existential definition in their research, defining quality of life "...as '[t]he degree to which a person enjoys the important possibilities of his/her life.' The enjoyment of important possibilities is relevant to three major life domains: being, belonging, and becoming."

Interestingly, another popular choice in definition is the Schalock definition (Schalock & Keith, 1993):

> ...[I]n addition to encompassing the basic conditions of life such as shelter, adequate food and safety, the construct of individual quality of life incorporates those areas that enrich one's life, such as inclusion in social, leisure and community activities that are based on the values, beliefs, needs and interests of the individuals." (Garcia-Villamisar & Dattilo, 2010)

Tomaszewski et al., 2022 uses another Schalock definition (Schalock, 2004): "Components of quality of life include independence (personal development, self-determination), social participation (interpersonal relations, social inclusion, and rights), and well-being (emotional, physical, and material well-being)." Kandalaft and DeBrabander, 2021 also uses the Schalock definition but words it differently. They list the components of QOL as "...emotional well-being, interpersonal relationships, material well-being, personal development, physical well-being, self-determination, social inclusion,

and human and legal rights." Cuesta-Gomez et al., 2022 provides a Schalock definition as "...a multidimensional perspective, including many other aspects of the person's life, such as physical well-being, health, and leisure, and the subjective satisfaction with all of them." Each of these definitions is similar but clearly different—like the QOL tools themselves, they have been slowly tweaked to suit a specific purpose.

Not even the important resources of today seem to agree with the WHO definition of QOL. Hamm and Yun, 2019 uses the U.S. Department of Health and Human Services definition, which states, "HRQOL is a multidimensional construct based on an individual's subjective view of their health (i.e., physical, mental and social well-being)." Hecht and Sheil, on the other hand, opted for a more medically-driven definition in *The Encyclopedia of the Life Course and Human Development*, defining quality of life as "...the patient's ability to enjoy normal life activities" (Hadad , Ayham et al., 2019).

How to handle this definitional issue? According to some of the leading voices in the field, subjective and objective measures of QOL don't correlate (Emerson et al., 2004). Emerson et al., 2004 suggests QOL is more trait-like and not predicted by personal environmental characteristics. Further, the study finds that personal and environmental characteristics do, however, affect objective measures associated with quality of life. In other words, it's important to distinguish between "subjective well-being or objective life circumstances and experiences." (Schalock, 2004) recommends comparing subjective well-being when examining life satisfaction between groups, and using objective personal experience and circumstance indicators when evaluating treatment, care programs, or environmental solutions.

Quality of Life Domains

With so many variations of the definition of quality of life within and across disciplines, it can be challenging to know what a researcher refers to when using the term. However, experts have reached some consensus within the health and medical fields. The World Health Organization determined that QOL is a general perception of quality of life

and health through six main domains (Group, 2012):

- Physical Capacity - Pain, energy levels, sleep
- Psychological - Positive affect, memory, focus, attention, self-image
- Independence - Mobility, daily activities, work
- Social Relationships - General social support and sexual activity
- Environment - Safety, security, accessibility of care, finances, amenities
- Spirituality - Religion and belief systems

Other QOL tools in the medical and healthcare disciplines utilize a combination of these domains along with other items specific to the task. For example, Arnold et al., 2019 uses a specialty assessment tool called the gastrointestinal module, developed from the more general PedsQL. de Almeida et al., 2021, on the other hand, uses a version of the SFS design to evaluate QOL in the context of oral health.

Interestingly, some studies, such as Ozer et al., 2018, were based on customized QOL assessments created from existing tools. While this does allow them to utilize QOL as a measurement, it also means the tool has no external validation. And interestingly, Ozer et al., 2018 created the parental reporting tool for assessing the QOL in autistic strabismus patients with no QOL definition explicitly stated in the study.

The tool created for Ozer et al., 2018 is also of interest in other respects. Here, parents were asked to answer a series of questions on a three-point scale. There are significant issues with this. First, we don't know if the three points were anchored or defined. (For example, 1 - less, 2 - about the same, 3 - more.) Therefore, parents could have had a broad definition for what constitutes a "1," and so could the scale. Second, the scale asks parents to rate variables such as the amount of eye contact. While this is relevant in the scope of the study, does it equate to an improved quality of life? Can autistic individuals have a good quality of life without it?

Third, there seemed to be some confusion in Ozer et al., 2018 between what the tool measured and what it outwardly appeared to measure. For example, another measurement in their custom QOL assessment was self-confidence. If a child can see better, would they not be more willing to try and do more things? Would they be more confident in the things they read or the tasks they complete?[1] In other words, the study appears to confuse confident actions (what a parent can see) with their inner self-confidence.

In summary, the entire issue of definitions leads to a messy process that fails to hold up to the basics of the scientific method. Why not avoid quality-of-life measurements and utilize more concrete variables such as mobility, social support, or medications consumed?

Given the extensive body of research, quality of life appears to be like creativity–the results are observable but not measurable. "Quality of life" lives at the intersection between a being and its environment at the moment of interaction. It isn't what someone has or even what they feel, but what they have or feel compared to the possibility of what they perceive as other options. These options don't even have to be possible or plausible. These perceptions can change from moment to moment and are highly influenced by experience and an individual's perception of an experience. If this is the case, can observing the components of quality of life provide an accurate indication of the perception of one's quality of life?

Method and Results

Because QOL tools are used in many areas and for various purposes, this paper focuses solely on studies that used QOL tools on individuals diagnosed as being on the autism spectrum or considered as such by the researchers. Autism research was chosen for several reasons: First, it avoids adverse side effects associated with severe illness, disease

[1] Anecdotally, after more than a few mornings of trying to make coffee without glasses, I can confidently say that I am far more hesitant and less sure when I can't see. So, my actions with glasses might appear more confident. To an outsider, I might appear to move and hold a higher self-confidence, but I don't think my sight-independent self-confidence increases.

progression, and threats to mortality that often arise with diseases such as Alzheimer's and cancer. Also, diagnoses related to neurodiversity often occur early in life, and the symptoms follow individuals throughout their lives. Autism remains relatively stable across the lifespan compared to degenerative diseases (Matson & Horovitz, 2010). These individuals may learn coping mechanisms or find alternative ways to perform tasks to avoid the complications autism can bring. However, the symptoms don't necessarily change drastically or dramatically (Matson & Horovitz, 2010). Autism also appears to affect individuals regardless of ethnic background, gender, socioeconomic status, or other factors (Plimley, 2007). With no known prevalence patterns, it provides a more uniform sample, which should help eliminate or minimize the effects of these factors if the sample itself is unbiased.

Other reasons for selecting autism research as the core focus of this paper involve the research itself. Autism researchers often overlook QOL regarding autistic individuals in favour of seeking cures, treatments, and preventative measures. As Cuesta-Gomez et al., 2022 note, "Traditionally, most of the studies on quality of life and ASD... exclude the subjective perspective in consideration of the person's achievements." However, quality of life is at the core of all the topics researchers prefer to focus on, and as such, deserves careful consideration. Finally, autism provides answers that will form the basis of future research projects.

To start this quest for answers, a series of database searches were conducted for this exploration to find studies where the researchers used QOL tools as a form of measurement. APA PsycInfo 1806 to October Week 5, 2022, Web of Science, and PubMed were searched for various terms related to quality of life tools and filtered for English and human research only, which was further limited to full-text versions of studies, trials, and traditional articles between 2011 and 2023 inclusive. (The search terms can be found in Appendix B.) These dates were used to ensure all results would be captured back to the release of the WHOQOL, which is considered the standard, modern measurement. While

some QOL tools were utilized before this time, eliminating earlier tools was done to avoid much of the inevitable uncertainty that naturally occurs during development.

The initial searches provided 6,045 results. Two items were removed because they were videos and other media, and three items were previously retracted. Multiple others were removed because they were books or chapters, corrections, literature reviews, meta-analyses, or did not use QOL tools to measure an improvement or decline in quality of life after testing a treatment or care model. Next, the duplicates were removed, as were any papers that failed to mention specific quality of life tools, those that focused on families, caregivers, or other individuals besides those with Alzheimer's or Autism, or patients with dementia that were not "spontaneously acquired" but were the result of injury, surgical intervention, or other cause.

The final result was 638 studies specific to Alzheimer's and dementia, which will be the subject of future analysis because of time constraints, and 19 studies specific to autism. These were coded and managed using Notion, Zotero, and Notero to form the basis of this paper. A final list of the studies utilized for this paper. The coding and full list of final results can be found in Appendix A.

Discussion

While the difficulties and imprecision of the definition of QOL are problematic, the application and administration of QOL assessments also prompt some questions. In general, studies rarely pay attention to the context of the tools. Researchers choose third-person reports for various reasons, but the studies rarely include who those proxies are and what their history with the participant might be. First-person reports generally mention little beyond completion rates. Studies sometimes fail to mention where or when participants completed the questionnaires. There is no standard procedure in the application or administration of these tools.

To outline a procedure that would improve the accuracy of QOL assessments, we must first understand the assumptions, goals, purposes, and preparation before data

collection. After all, like painting a house, even the most expensive paint will look like an attempt to cover up a crime scene without the proper preparation. For these reasons, it's essential to begin before the beginning.

Methods, Issues, and the Environment Prior to QOL Assessment

In general, QOL questionnaires are used either as a primary measurement, which researchers use to determine the efficacy of a treatment or care model, or the QOL tools act as a supportive measurement to help bolster other metrics. In both cases, researchers use QOL based on a set of assumptions.

Assumptions and Ceteris Parabis in QOL Research

Researchers back up their assumptions with citations and explorations of a topic, but sometimes, more is needed. Sometimes the assumptions leave out essential variables and concepts. Charlton et al., 2022, for example, begin by assuming that social supports improve quality of life and provide evidence for this assumption. However, the paper fails to address many aspects that become particularly relevant when dealing with special populations such as those with autism.

For example, Charlton et al., 2022 measures QOL with an altered version of the DSSI. The original 35-item questionnaire asks how many individuals the participant has access to, how much time they spend with these individuals, how they help the participant, and how satisfied participants are with those interactions. Some questions also ask if there is one person the participant feels close to and if they are married. The measure has been validated, deemed reliable, and used extensively to measure social support. However, neither the study nor the tool asks about context. Both assume that more social supports and more time with those supports equate to a better quality of life. And that isn't always the case.

Research suggests that extroversion and the desire to seek out social interactions for fulfillment don't have much to do with happiness and life satisfaction. (Hills & Argyle, 2001) found, "...happiness is more closely associated with scale variables that reflect

fulfilment and satisfaction with life rather than extraversion...the most important component factors of the OHI (Ohio Happiness Index) were satisfaction with life and self-efficacy." In other words, life satisfaction and independence were far more impactful on quality of life and happiness than the number of friends and actively seeking social interactions. In fact, the study found that many extroverts were unhappy, and many introverts were quite happy (Hills & Argyle, 2001). While introverts and extroverts spend a similar amount of time in social situations, introverts are often left exhausted by them (Lucas et al., 2000). Also, single, unmarried individuals are known to be just as happy as married couples (Girme et al., 2015). Therefore, the assumptions made by the DSSI in Charlton et al., 2022 are curious.

There are other issues with these measurements, but the point here is that autistic individuals are not a homogeneous group. Pretending that they are particularly with smaller sample sizes suggests there is plenty of room for error and inaccuracies. Charlton et al., 2022 is simply one example that prompts questions.

Tomaszewski et al., 2022 used the number of steps participants took and their QOL measurements. The assumption: Physical activity improves quality of life, and all steps are the same. However, it's important to note that the subjects were overwhelmingly white, affluent, autistic males. Would this study have had the same results if participants were minorities with a low socioeconomic status? What if participants took most of those steps while panhandling or trying to find a job? What if most of the steps were during vacations or time with friends? While the authors can conclude that their finding holds for their specific sample, it should have included a more diverse sample. There was also no record of participants' activities during the week, although the authors did recognize that vocational activities and employment could explain some of their findings. With such low statistical power, this seems problematic.

Dental treatments, mindfulness, personalized care... Every author believes the subject of their study improves the participant's quality of life. It's almost as if the

population's lives would be better if they only had the one thing that the researcher studies. To prove this point, each study assumes that all things are equal when they may not be due to internal or external factors.

What We Are Studying Vs. What We Measure

One of the scientific method's pillars is measuring the variable you're studying. Usually, we think of this as counting the number of red marbles in a bag if that is the variable we have questions about, but this concept plays out a bit differently when researchers use QOL tools.

Studying a young, healthy, well-educated, neurotypical population is relatively straightforward. Supply these individuals with questions, and they'll answer. Specialty populations such as autistic individuals, however, often have educational, communicative, physical, and cognitive challenges. For this reason, researchers choose to work with proxies such as healthcare professionals, trained interviewers, caregivers, friends, or parents.

Unfortunately, once researchers substitute a first-person report with a proxy, QOL tools are no longer measuring the participant's perceptions of their QOL, but another's perceptions of the participant's QOL. This difference seems minimal, but it can make a substantial difference.

Consider the autistic individual who begins to stim or have a temper tantrum. A parent will make causal attributions, chalking up the behaviour to overstimulation. For the autistic individual, however, the behaviour could be a response to an unpleasant sound, texture, or a lack of stimulation. They may not even know why they're acting the way they are (Minot, 2010).

Sometimes, the addition of a QOL measure doesn't make sense. de Almeida et al., 2021, for example, uses the P-CPQ, which is a 31-item survey that includes six items inquiring about oral symptoms, seven questions on functional limitations, eight items for emotional well-being, and ten on various aspects of social well-being. Participants received the questionnaire on their first visit to the dentist. Then, the autistic individual received

dental care, and the researcher administered the survey again three months later.

In this situation, questions about oral health are relevant and should improve with professional dental care (de Almeida et al., 2021). However, many factors contribute to well-being and quality of life, not just oral health. By heavily weighting oral health factors and measuring success in this manner, it opens the door to a multitude of confounding factors. What other things could have occurred simultaneously to affect QOL? Also, three months is a long time, during which we forget, incorporate misinformation, filter memories through biases, and have new experiences. That is a lot of opportunity for confounding factors. It seems less than accurate to rely on someone's memories of someone else's experiences. Our judgements of someone else's QOL requires (and assumes) that we have a good memory and are able to infer information about their inner thoughts during that three-month period.

In summary, the choice of a QOL questionnaire is often curious. For example, in de Almeida et al., 2021, the child's reluctance to return to the dentist, behaviour issues during the treatment, questions about eating habits, and assessment of oral health on subsequent visits may have been better indicators of success. After all, if oral health and diet improve, and the child does well during treatment, a better QOL would be a natural assumption (albeit a questionable in the context of this paper). The point is that all of these issues have the very real potential to be highly problematic not just when attempting to measure QOL or determine the efficacy of a treatment, but the decisions we make based on these findings could affect a significant number of people long after our research concludes.

Populations and Sample Selection

Finding and engaging autistic and other special populations can be difficult. As a result, researchers must choose between a small sample size, a convenience sample, or both. Unfortunately, given their sample choices, many studies leave out demographic information, financial information, ethnicity, race, and other details. Some studies also fail

to report where the sample originated (See Appendix C).

Samples in autism QOL studies are often heavily skewed toward white males from affluent households, which makes sense. Samples from facilities and organizations offering programs and additional help often require participants to have resources and time, so those samples tend to be from households with higher incomes. Also, research suggests that those who choose to actively participate in studies are generally more educated, although this last finding is less consistent (Reinikainen et al., 2018; Scanlon et al., 2021).

While females are often more likely to participate in research studies, males have historically been diagnosed with autism and autistic-like traits four times as often as females (CDC, 2023). A recent finding by D'Mello et al., 2022 suggests females are excluded from research studies due to the way autism assessments and diagnostic questionnaires are structured, hinting at far more profound issues with autism research. Regardless of why these types of biases occur, they matter, and ultimately result in research findings that are less precise while simultaneously failing to accurately represent the real world. And in a situation where the results of QOL assessments can have significant real-world effects, accuracy and precision matter. If we cannot find a way to eliminate these sorts of problems, we need to find another way to determine the efficacy of treatments and care programs.

In QOL studies for autistic individuals, researchers use a mix of methods for diagnosing, identifying, and measuring the severity of autism. While some research requires extensive clinical diagnosis, others require participants only to exhibit autistic-like traits. Some researchers may even accept self-diagnosis. One example is McLean et al., 2021, which didn't assess autism severity or symptoms at all "...because autism severity data were not collected for non-autistic participants." These methodological choices introduce a significant amount of variability. However, the assumption that a clinical diagnosis of autism would standardize participants across a sample isn't accurate, either.

First, suppose researchers accept a previous clinical autism diagnosis as the basis for

inclusion in a study. In this case, inconsistencies in the assessment methods could result in varying degrees of severity and a wide range of traits, which is particularly problematic in small sample sizes. Also, thresholds for meeting a clinical diagnosis are somewhat arbitrary. Generally, governing bodies suggest that surveys should never be the only diagnostic tool used, and a team-based diagnostic approach is highly recommended–potentially for many of the same reasons quality of life studies vary (Anagnostou et al., 2014; Canada, 2021). With no biomarkers or definitive tests, autism diagnoses can differ wildly between professionals. Extrapolating those possibly biased findings to QOL assessments, researchers could inadvertently bias results by using a control or test group with significantly different symptoms of varying degrees. If researchers want to be as accurate as possible and ensure their QOL measurements remain unbiased, they must verify autism diagnoses and standardize symptom severity.

Symptom variability also complicates autistic QOL research. The DSM-V includes a lengthy set of requirements for diagnosis (CDC, 2022). However, these criteria are broad and vague, which can result in a group with widely varying autistic symptoms. So, for example, a group might include individuals who are non-verbal and have extreme communication difficulties, as well as members who seem to have no visible symptoms aside from a little social awkwardness. Stephan, 2008 may have put it best: "Autism Spectrum Disorder (ASD) is a catch-all diagnosis for a set of poorly understood neurodevelopmental disorders that are clinically heterogeneous, with a spectrum of severity, characterized by repetitive self-stimulatory behaviours and communication and socialization deficits."

Some studies control for symptom severity, but others do not. This point may be moot if the purpose of a QOL assessment is to provide evidence that a dental care procedure works with a population that exhibits nothing more than social challenges. However, if the study examines the results of a sports program, a group with more significant social and cognitive deficits could skew results. Therefore, if we hope to use QOL assessments to measure the effectiveness of treatments and answer questions about

autistic individuals, we need to examine the possibility that controling for symptom severity and variability can produce better results.

Administration of QOL Questionnaires

Outwardly, the administration of an autistic-focused QOL survey seems straightforward: Sit the individual down, have them answer the various questions, score their answers, and it's a done deal. However, this process is considerably more nuanced, particularly when dealing with autistic individuals. And like everything previously discussed, QOL questionnaires are more complex than they appear. Many factors influence the administration of a questionnaire.

Types of QOL Assessment Surveys and Questionnaires

QOL tools fall into two categories: first-person self-report and third-person proxy reports. And while the debate over which is better has been so intense as to inspire an entire body of literature, administering them to the autistic community presents unique challenges.

First-Person Self-Reports. Researchers choose self-reports because they allow researchers to avoid having to dedicate time and resources to third-person reports while avoiding the inconsistencies, complications, and problems associated with proxy reports (which we'll get to shortly). However, first-person self-reports have their flaws.

Personality and Surveys. Personality research concerning autistic individuals has relatively mixed results. The Lodi-Smith et al., 2019 meta-analysis found that "...ASD is associated with lower openness, conscientiousness, extraversion, agreeableness, and emotional stability." Schriber et al., 2014 agreed with this finding, stating that "[i]ndividuals with ASD were more Neurotic and less Extraverted, Agreeable, Conscientious, and Open to Experience." However, Schriber et al., 2014 also found that "...individuals with ASD had a tendency to self-enhance, and [typically developed] individuals, [tend] to self-diminish...." This finding brings up an interesting point regarding self-report QOL tools.

Some research suggests personality impacts health-related QOL (Herzberg et al.,

2013; Wintraecken et al., 2022). However, we don't seem to understand how personality affects QOL assessment tool results. Despite this, researchers often don't consider personality to be a confounding factor. None of the studies examined here included any personality assessment[2]. Combine non-standard personality traits (if that is such a thing) with cognitive challenges, variability, and a tendency to self-enhance, and it is entirely possible that self-reports could, knowingly or unknowingly, be collecting measurements in a way that fails to align with the population it's testing.

Identity is another consideration. Think about it: When we post on social media or chat with friends, we share a curated image–what we imagine to be our best selves. We have to know someone pretty well to share things that don't fit the ideal image of us[3]. In a population that often struggles to be themselves and successfully navigate an unforgiving society while under constant pressure to be normal, is there a potential for their personal identities to become prominent in the QOL survey results?

Brenner and DeLamater, 2016 note:

> "The respondent who values physical exercise and sees himself or herself as the "kind of person" who is physically active may not enact the exercise identity at a rate consistent with the identity given the costs of its enactment (e.g., the time needed for a workout or the monetary cost of a gym membership). However, the individual may interpret the survey interview as a low-cost opportunity to enact the identity...."

Combined with a tendency to self-enhance, these issues could have a profound effect on QOL assessments. Simply retesting isn't sufficient to identify this sort of variance, either. Furthermore, while one could argue that this perception is what QOL tools

[2] Personality assessments are a whole other paper

[3] We're even afraid to fart in front of a significant other until we've been with them for six months (Hakala, 2016; Scott, 2016). Are we sure people will admit unflattering things about themselves to strangers who are clearly recording and judging them?

measure, consider this: When a user sculpts an image on Instagram, it isn't a visual reflection of their perception of their own life. It is the perception they want their followers to have of them.

Using the example above from Brenner and DeLamater, 2016, a researcher could measure someone's actual amount of physical activity with their reported levels of physical activity and infer that healthy living or physical fitness is an integral part of an individual's identity. However, if they are getting less physical activity than their QOL result suggests they'd like to have, is that not a lower quality of life? What if their lower physical activity is because they drive a luxury car or have been taking in more theatre productions? The further we get into this topic, the more complicated it gets and the more difficult it is to tease the various factors apart.

As previously discussed, personality, self-enhancement, and identity all challenge QOL research and assessment. Further research should consider administering personality and identity assessments and QOL measures to identify how and by how much these variables affect the outcomes and if this holds for both neurotypical and autistic individuals. At the very least, further research would provide evidence that these variables have minimal effects and support existing research that utilizes QOL assessments.

The Role Participants Play and Self-Reports When completing a QOL survey, researchers ask participants to judge their current "position" in life, but in comparison to what, when, or who? Our past selves? Friends? Other patients? What if we don't know other patients? The answers to these questions may be in the instructions given to participants, but the studies fail to verify that. We also have no way to know if participants followed the instructions or exactly what they made their comparison with.

No matter how hard we try, our judgements are always biased. Our past experiences, present situations, values, knowledge, and perspective act like a pair of tinted glasses, tainting every decision, judgement, and perception of ourselves, our lives, and others (Hamilton et al., 2020). A significant portion of that perspective is determined by

the roles we have. Self-report QOL tools are no different.

Imagine: You're accustomed to living at home with your affluent parents. Then, one of your parents passes away, and you move into a group home. It's a lovely group home. You're well-fed. They have plenty of food and activities, the latest gaming systems, and talented care providers, but it's different. You have to wait for a ride to the bookstore, so you can only go once every two weeks instead of every Friday like you used to. And you have to compromise because several people are living there- each a stranger. Not to mention that you're still depressed and dealing with losing your father. Now, sit down and write down what your quality of life is like there.

Next, imagine the same scenario, but this time, you're from a poor and abusive household. It wouldn't be out of the realm of possibility that you would see your quality of life at the group home very differently. What do QOL questions tell us about the care model in that home in this scenario? Not a lot.

In QOL surveys, researchers rarely note the autistic individual's role or living situation. Are they in a group home situation? At home? The argument against this may be that a mixed sample would balance out and reduce the effects of any bias or inconsistency. But does it? What if one group has more people living in group facilities? What if the sample sizes are 20 or fewer?

Researchers also frequently fail to note the relationship participants have to the individual administering the survey. Are participants a client of the individual requesting the survey? How long have they known that person, and how well? If an autistic individual fills out a survey in the office of a psychologist they've seen for many years, would the results be the same if they completed the survey at their kitchen table with help from a parent? Is there a desire to please the researcher?

Again, many of the studies examined for this paper leave out these details and limit information to simply mentioning that participants completed a QOL questionnaire. While the editing and publishing processes likely require removing seemingly insignificant details,

these are essential. The fact that these details seem insignificant suggests that either they have no significant effects on QOL assessments. Or, those who use QOL questionnaires to measure the results of their treatments aren't aware that they are. At the very least, we should know which one of those two options is correct if we're going to use QOL questionnaires for anything of importance.

If we want to improve QOL assessment tool methodology, further research should examine the relationships mentioned above to determine how they affect the results and in what ways. We also need to examine living situations, the roles participants hold, and how those might alter QOL judgements. Some QOL tools have been developed for residential situations, but they aren't used as often as they should be. They may also be subject to the many issues outlined in this paper, but we won't know for certain without additional research. It would also be beneficial to know if special populations, such as autistic individuals, are affected similarly to others.

Ability and Self-Reports. When trying to choose between first and third-person reports, researchers will undoubtedly need to consider the ability of the participants. Usually, participants need to be able to read, write, answer the questions, and have an attention span that allows them to complete the QOL survey. However, anyone familiar with interviewing children will say this process is more complex than it looks.

In Lyon et al., 2019, the authors mention many issues researchers and professionals encounter when interviewing children as witnesses to a crime. And while we hope that QOL surveys don't involve anything traumatic, QOL interviews are similar—children are still answering questions. Therefore, it is reasonable to consider that some of the findings associated with child witness interviews might also alter QOL assessment outcomes.

For example, research finds that children often answer questions they don't understand, and will even deny misunderstanding the question they were asked (Lyon et al., 2019). Because they're so suggestible, recognition questions tend to be far more inaccurate (and adult-generated) than recall questions. Therefore, specific or direct QOL

questions may be more susceptible to intentional or unintentional falsehoods. Also, children also tend to answer in a way that pleases authority figures and parents (Lyon et al., 2019).

Selten et al., 1993 interviewed schizophrenic patients to examine the stability and reliability of their self-reported ratings on the Subjective Experience of Negative Symptoms (SENS) interview-based measurement tool. Their paper notes that "...few studies have addressed the issue of the stability of the subjective experience of deficit...." The authors noted that previous studies had identified significant variability and instability in rating negative experiences. However, the Selten et al., 1993 study achieved acceptable levels of stability when they presented answers in a forced-choice format.

> "...patients are able to indicate reliably the presence or absence of negative symptoms, but have difficulties in making more subtle distinctions... A more likely source of error is that patients forget the instructions and, more or less systematically, compare themselves with fellow patients and not with people outside the hospital...some patients with severe deficits do not adopt an attitude toward their illness at all." (Selten et al., 1993)

Schizophrenia patients in the 1990s and autistic individuals of today are very different. The SENS and QOL surveys also vary significantly. However, both populations could make similar errors. Without research and experimentation, it's difficult to know for sure.

A multitude of other inconsistencies is possible with first-person surveys. How many of them apply to autistic populations and QOL tools? We don't know. Further research should apply some of the same techniques used to explore the accuracy of child interviews to various survey types often given to young autistics to determine how they process and answer the often lengthy questionnaires.

We know that the quality of answers declines the longer a survey becomes (Galesic & Bosnjak, 2009). For this reason, researchers often shorten QOL tools. Research has found that shorter surveys may outperform their longer counterparts (Kost & de Rosa,

2018). However, we cannot extrapolate this finding to QOL surveys or neurodivergent populations without further study (Cheung et al., 2023).

Where, When, and How of QOL Questionnaire Completion. In research on autistic individuals utilizing QOL tools, there is often no mention of where participants are when they complete their surveys. And while this seems like an asinine detail when the research focus is elsewhere (and QOL is an extra measurement tool), where autistic individuals complete a QOL survey could potentially alter the results.

There has been no research specifically on autistic populations in this regard, but we do have some clues outside of QOL research that suggest this may be an issue to explore to improve QOL methodology. For example, answering questionnaires in a clinical setting may produce different results than questionnaires completed in a more natural environment (Rutherford et al., 2016). However, other studies have found that location during survey completion has no significant results (de Bruijne & Wijnant, 2013). Again, autistic individuals may be more sensitive to their environments. As such, the discipline would benefit from research on location's effects on QOL survey results, including clinical, home, school, and other settings.

Researchers also need to answer the "when" question because what happens directly preceding the completion of a QOL survey could also bias results. For example, a respondent's mood can alter results (Heide & Gronhaug, 1991). So, if an autistic individual just had a negative experience on the bus, would they rate their quality of life lower than they would if they had received a gift before filling out their survey? Even something as simple as holding a warm drink can alter our perceptions and judgements (Williams & Bargh, 2008). Again, QOL researchers, particularly regarding autistic and neurodivergent communities, rarely address these issues in any literature that utilizes QOL surveys—or other survey tools, for that matter.

It's important to remember that QOL assessments are rarely the only test administered. Researchers often use other tools, such as symptom assessments, at the same

time. How much do these other assessments (and the order of the questions in the QOL tool) affect the results of the QOL tool itself? Again, if our goal with QOL assessments is to be as accurate as possible, research in this area must be more extensive, particularly with neurodivergent populations.

Interestingly, one study did look at the order of questions. Jones et al., 2015 tested groups of caregivers using symptom assessment questionnaires. In the study, researchers asked three groups of caregivers about their autistic child's historical and current symptoms. One group answered questions about historical and current symptoms at the same time. The second group assessed current symptoms, followed by past symptoms. The third group? They answered questions about historical symptoms first. Then, provided information about current symptoms. The results? The group that provided information about past symptoms first rated their child's current symptoms as less severe than those in the other two groups (Jones et al., 2015).

While the study above involves third-person reports, which we'll get to momentarily, it is reasonable to assume that this would also occur in self-reports. After all, one could hypothesize that the anchoring bias plays a role in this aspect. If a participant focuses on a past QOL, they will use that as an anchor to judge their current QOL, resulting in over or underestimating their current symptoms or abilities. Fading affect bias could also play a role here. With this bias, the affect associated with positive events fades more slowly from memory than that of negative events (Skowronski et al., 2014). Would a negativity bias be more prominent, leading us to think of the past more negatively than our current situation (Luo et al., 2010)? To this point, no known research appears to exist on this topic concerning autistic populations.

We also need to consider the effects of the entire study. If, as in Arnold et al., 2019; Braden et al., 2022; Drusedau et al., 2022, researchers use multiple questionnaires and assessments, does the accuracy of QOL results decline? Research suggests that research participants can get too much of a good thing (Li et al., 2022). Are autistic individuals

more or less sensitive to question and survey fatigue? We don't know and should explore this in future research, too.

Researchers should also consider when participants complete QOL assessments. Usually, participants complete QOL surveys before and after treatment. However, by limiting assessments to these two periods, which are often weeks, months, or years apart, researchers fail to capture data for interactions and experiences during the intervention. And again, some research suggests this can lead to significantly different findings (Bangerter et al., 2017; Bangerter et al., 2019).

If this seems insignificant, consider this: The first time parents filled out the survey for de Almeida et al., 2021, it occurred prior to their child receiving care when they were worried or focused on ensuring their child has a successful visit, costs, and possible complications. The second time researchers administered the P-CPQ, "...the participants were contacted personally at the centers or via a telephone call" (de Almeida et al., 2021). In other words, the parents and caregivers filled out the QOL survey when the treatment was long over, and they were no longer in a dental office facing significant challenges. Finally, as noted in the survey, the study utilized two different collection methods to accommodate participants, which could have introduced additional biases.

The "when" question also brings up the time of day. Several years ago, Danziger et al., 2011 examined how judicial decisions are affected by factors outside the judicial system. It utilized an ego-depletion theory to explain that judges are more lenient after a break. While this study has been heavily criticized and disproven, the concept of timing may still play a very different role when dealing with QOL assessments and autistic populations.

If autistic participants complete an assessment when they would typically perform some other action, or if it is later in the day when younger autistic children (and younger children in general) approach what parents often call "the witching hour," does this affect their perceptions of their quality of life? Research suggests that interview time, combined

with different circadian rhythms, did not affect the accuracy or the amount recalled (Gunia et al., 2014; Yaremenko et al., 2022). Other research suggests that participants act more or less ethically depending on their circadian typography (Gunia et al., 2014). Once again, this area of inquiry seems to have been neglected in autistic populations when utilizing QOL measurement tools.

None of the papers consulted for this study accounted for the time or location of survey completion, question order, survey order, or any of the issues mentioned in this section. These issues all appear minor on their own. However, in combination with small sample sizes, a multitude of other possible flaws, and lower statistical power, there is potential for the variances to add up. Moreover, QOL assessments are highly sensitive and don't always work reliably in all settings.

When translating the P-CPQ, for example, Razanamihaja et al., 2018 noted that the QOL portions of the tool lacked accuracy and correlations between elements were weak. If this is the case, how much are the results affected if researchers use a variety of methods to collect data or collect the data during or after stressful events? It's impossible to know for certain, but we should know. The implications this could have on QOL measurements and the decisions we make as a result of those findings could have far-reaching effects.

Third-Person Reports. Because autistic participants sometimes cannot answer QOL surveys due to writing, reading, cognitive skills, fine motor ability, or focus limitations, researchers will often select third-party reports that others can complete for them–usually a trained interviewer or healthcare professional, caregiver, or parent. Unfortunately, this introduces another set of variables to QOL assessments that can potentially alter findings. For example, children rate their quality of life considerably better than their parents before and after training, and there could be many reasons for this (Drusedau et al., 2022). And there's more.

Effects of Personal Connections on QOL Assessments. One of the most prominent issues is the identity of the third party. In autism and Alzheimer's QOL

research, for example, the person filling out the report for the participant can be:

- Professional interviewer or rater (observational)
- Healthcare professional (Therapist, care provider)
- Friend of the participant (Spend at least some time with the participant daily)
- Family member of the participant
- Spouse

In many instances, researchers will have combinations of the above individuals in the same sample. Therefore, one portion of a sample may include a majority of results from QOL surveys completed by a spouse, another portion by the participant's friends, and another by a healthcare provider. Researchers may also combine self-reports, and third-party observations in some studies, such as Tomaszewski et al., 2022. Still, there are rarely any checks between the two to verify the data or any notes on the inevitable inconsistencies. (Or, researchers detected none and, therefore, didn't report it.)

Let's suppose that your spouse has Alzheimer's, for example. You likely have a lifetime of experience with that person and spend most of your time with them (assuming you're both retired and at home, of course). You'll notice changes before many other people will. This particular knowledge would make QOL surveys filled out by a spouse more sensitive. However, the answers a spouse provides may also be biased.

You likely also have a lifetime of frustrations and biases about your spouse, and the two of you may not get along as well as other couples in the sample do. If you've been home with your spouse for months with little support, you might also be low on patience and cognitive resources and are a bit jaded[4]. And here's how that could potentially out:

[4] If we've learned anything during the pandemic, there is such a thing as too much quality time with a spouse.

Suppose your spouse has always loved to cook. They're highly independent in the kitchen. Or at least they were. Now that they've gotten into advanced stages of dementia, they're constantly wandering into the kitchen, starting to cook or bake something, and wandering off with the oven going and the kitchen tap running. If this happened multiple times before sitting down to fill out a QOL survey, it would be logical to assume that you would rate their independence, ability to complete tasks, and overall life quality lower than you would if you had some extra help in the afternoons.

How likely is this sort of bias in QOL research? It turns out that it's pretty common. Called caregiver bias in Alzheimer's literature, researchers have noticed there are "...[s]ignificant differences between the rating of mental health measures by individuals with dementia and the reports of their caregivers" (Pfeifer et al., 2013). In other words, the more burden and stress a caregiver has, the more significant the discrepancy between what a participant self-reports and what the caregiver reports (Farias et al., 2005; Leicht et al., 2010; Pfeifer et al., 2013; Pfeifer et al., 2017; Schulz et al., 2013a, 2013b). Does this same thing appear in autism research?

We know caregivers of children with developmental disabilities have lower overall health when compared to mothers of neurotypical children, which has the potential to affect their bonds and perceptions of their children (Masefield et al., 2020). We also know that stress levels for caregivers are exceptionally high in the first year after an autism diagnosis (McGrew & Keyes, 2014; Stuart & McGrew, 2009). However, there is insufficient research in this area on autistic populations to say this type of bias would affect QOL responses. Therefore, further research is required not only for QOL research but for other research that focuses on autism and utilizes third-party questionnaire tools.

Context and Judgements. Many of the same variables and contextual elements that affect a first-person report can also affect a third-person report. If we hope to build confidence in the judgements and perceptions gathered using QOL surveys, we need to answer a few questions:

- How location at the time of completion affects QOL tool outcomes in autistic populations?
- How other assessments administered simultaneously may affect the results?
- Does the order of the questions adversely affect report accuracy?
- Would assessing QOL perceptions taken during treatment provide researchers with improved insights?
- Does the time of day affects how others perceive a participant's QOL?

Demand Characteristics. Demand characteristics are commonly confounding factors in all types of interviews and surveys. For example, the attitude or mood of the researcher, staff, third party, and others tend to bias perceptions (and survey answers) (Heide & Gronhaug, 1991). However, there are other ways demand characteristics can be an issue when administering third-party QOL reports.

Take the social norms and self-identity of the third party as an example. QOL survey answers aren't for reporting a parent for neglect, but that doesn't mean parents or caregivers will be eager to admit to things that make them appear like bad parents. If a mother values athletic ability and healthy living, will they report that their autistic son or daughter is not meeting this expectation? And while it may seem that parents deliberately alter their answers, that isn't necessarily the case.

An exciting example of this happening appears in Wood et al., 2019. In this study, the authors noted that parents may have exhibited social desirability bias when they failed to report that their child had a television in their room or that they watched television during meal times. If a parent doesn't want to admit that they watch television during mealtime, they would likely misrepresent themselves when answering questions about their child's QOL.

Of course, the issues could be between the child and the parent. Is it possible for their child, autistic or not, to meet the expectations associated with the traits a parent

prioritizes? Some neurotypical children will say their parents are never satisfied with their life choices. In this case, it is possible that the two don't see the world the same way.

When discussing first-person self-reports, parents, caregivers, and others have values, beliefs, and experiences that subconsciously affect their judgements and perceptions. How does all this affect QOL survey tools? Again, we don't know. However, the presence of an authority figure during survey administration could enhance observer effects.

We base our attributions, inferences, and evaluative judgements on our previous experiences, mental representations, schemas, personality, culture, situational factors, and many other variables (Hamilton et al., 2020). For example, a parent might attribute recent difficulties in specific social situations to the school, other children, or other factors other than the child's skills. Or, the parent might think their child has a great social life except for things beyond their control. We also need to keep in mind that parents have limited knowledge. While they can ask their child, and they may be able to guess what their child does when they're away from home, parents never know with any certainty.

Humans also have a tendency to attribute their behaviours (and the behaviours of those we are close to) to situational (external) factors rather than personal (internal) factors. This attributional bias is particularly prominent when the behaviours are outside what is socially acceptable or the social norm, highly personally relevant, or important to us (Hamilton et al., 2020). A QOL assessment of an autistic loved one, or someone we're close to could check all three of those boxes. Unfortunately, as is the case throughout this paper, a lack of research in this area specific to QOL tools and the autistic population means it's difficult to tell how much these aspects affect the results.

After the Assessment: Statistics and Accuracy

While this section may be the ideal place to discuss tool validation and the various statistics to verify the various QOL questionnaires, we will avoid any heavy statistics discussions here. Others with far more statistics knowledge have already done that, and a list of them has been provided in Appendix A. Instead, we'll quickly summarize how the

tools compare to each other and how they're utilized.

Some researchers will attempt to verify self-reports by collecting similar surveys from caregivers, parents, or professionals. (For an example, see Cuesta-Gomez et al., 2022.) In cases where researchers use third-party proxy results, they might cross-reference the data with self-report data. However, most studies do not. And it isn't foolproof.

Response and reporting based biases, such as social desirability or response shift bias, can be accounted for statistically (Rosenman et al., 2011). However, Stochastic Frontier Estimation (SFE) and other response-bias equations, initially used in economics, aren't typically found in autism-focused QOL research (Rosenman et al., 2011). Instead, researchers often draw the line at internal consistency, reliability, and validity to verify self-reports.

When you examine each study individually, the assessment tools themselves seem statistically solid. However, when comparing the statistics between studies, these tools quickly land on shaky ground. For example, the Cronbach's Alpha Coefficient reported for McLean et al., 2021 is $\alpha = 0.49$, which is well below an acceptable level of $\alpha = 0.7$. Other studies such as Arnold et al., 2019, Cuesta-Gomez et al., 2022, and McClean and Grey, 2012 (four participants), boast results of $\alpha = 0.93$ and above, while six of the studies failed to report a coefficient. Now, statistics like Cronbach and Rausch are problematic on their own (Cortina, 1993; Yang & Green, 2011). However, those problems are moot in this context since we're using statistics to better understand how they're used within the context of QOL methodology.

Reliability

Also recognized as test-retest, the purpose of reliability is to test the consistency of answers across time. In performing these statistics, researchers hope to catch confounding variables that may have been missed in the original experimental design while explaining variance. For example, de Almeida et al., 2021 noted that some of the variance found in their study could have potentially been caused by the multi-modal data collection methods

utilized during the study due to accessibility issues.

However, in the studies included in this paper, reliability tests fail to detect bias, system, and pattern noise (Kahneman et al., 2021). Or, sometimes researchers ignore the variances they discovered. All of the 19 studies examined for this paper used the data from QOL measures to support their hypotheses, and all seemed to give their statistical findings equal weight regardless of their alpha numbers (See Appendix E). For example, McLean et al., 2021 mentions that "[r]eliability measures (Cronbach's coefficients) indicate that the questionnaire has good internal consistency (0.49 in most subscales)." Again, this result is far below accepted levels.

The other issue we must keep in mind is one mentioned previously: If the researcher replicates the same errors in the test and the retest, they would not find any difference in results. Therefore, these tests would only catch *occasion noise* (Kahneman et al., 2021).

Validity

Validity is an overall judgement of the study and its relation to other literature. While all studies included a wealth of related studies as evidence for their hypotheses and beliefs, the actual validity is difficult to judge due to insufficient replication, limited research, and variations in opinions within and outside of psychology, in addition to the various concerns raised in this paper.

Conclusion

Before ending this paper, it's important to recognize some limitations of this exploration. (For a recap of the questions proposed for further research in this paper, see Appendix G.) First, researchers very likely took a plethora of steps and considerations not reported in their studies. In some instances, these steps are missing due to editing. In other cases, the various aspects of methodology just didn't seem all that important in the grand scheme of things. And that is the point. The goal of this paper is to shed light on the many forgotten aspects of QOL assessment methodology in an effort to plead for better precision because QOL seems to fall desperately short of anything reliable. At least in the

way it has historically been used.

This author would have loved nothing more than to dig through the data and rework the statistics, the results of which could have been littered throughout this academic-like work in the form of pretty graphs and charts. The original plan for this paper was to compare the outcomes of the studies to the methods used and possible errors. However, there were two issues with this approach: First, all of the papers in the sample failed to reject their hypotheses. While it is impossible to know for sure why this occurred, the likely possibility is believed to be publication bias (Brender, 2006). Second, doing so would have meant that I fell victim to the multiple biases and errors often made in meta-analyses (Brown et al., 2018). And since the purpose of this paper was not to summarize research on a specific treatment but rather explore a methodology in practice (since in situ is not possible), it seemed counterproductive. Therefore, the current format of a formal exploration of the topic of QOL assessment methodology was chosen.

There is also a notable absence in the body of work referenced throughout this paper: existing QOL research, previous criticisms, and meta-analyses of those who came before. This was a deliberate choice. I purposefully ignored those items until after I had already given this area a preliminary examination to avoid biasing what I saw. Essentially, I made this choice to take advantage of my naivety as a student. I was able to take a fresh look not at what research exists, but what is actually happening in the field when QOL assessments are put into practice. I wanted to give you the same fresh look at the literature. There are many prolific authors in this area of research, however, and much of the work truly is fascinating. But this does come with a warning: Some of the items written in this area are fatally flawed, didn't give the methodology a proper going over, fell for the same fallacy I almost did, or just weren't very good. It's very much a reader-beware situation.

As for future research, this exploration highlights a large number of issues that require future investigation[5]. Many of them have already been explored in other areas of

[5] Again, refer to the Appendix as there were too many to summarize here. Tables seemed to be the only

psychology and psychometrics. That body of work is informative and exciting, but very few studies examine the issues in the context of QOL assessment and autism. That oversight must be corrected, particularly with this segment of society, which is already often overlooked.

For something we spend so much time as a species pursuing, it is fascinating to get to the end of this paper and realize that we're pursuing something we don't really know all that much about. It seems like we can't even define it after more than six decades of trying. That's how this author fell into this rabbit hole.

Originally, this concept began because I wanted to use a QOL assessment to measure the success of another project. However, after delving into this literature, it's clear that that is not what these tools are for. There are issues at every layer of this concept as a measurement, regardless of which angle it's examined from. Therefore, I am not prepared to base my work on metrics and measurements that aren't sound. And again, that's the point of this examination.

Before QOL assessments can be used for much more than just gauging the subjective perceptions of a sample or population, we need to address these issues. The issue of bias in proxies in third-party reports are of particular concern, since that seems to be the solution many see as superior. Therefore, I propose this area of questioning as a next step for further research, along with examining the effects of location and demand characteristics of the researcher or professional on QOL questionnaires. Then, and only then, will researchers utilizing these tools be able to pull off a half decent Robert E. Lee and ensure that every battle in the war against time is well fought. And every moment spent in this endeavor is well worth it.

Figure 1

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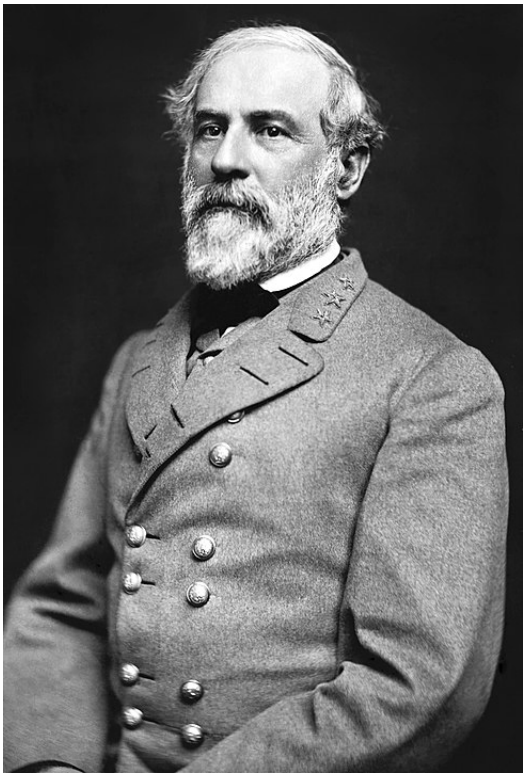
way to manage the sheer amount of information this exploration required. Needless to say, I've learned to really love tables.



General Robert E. Lee, officer of the Confederate Army

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Appendix A

Tool Abbreviations Used

QOL Tools		
CCVA	QOL Evaluation Questionnaire for Adolescent Students	
CHQ-PF50	Child Health Questionnaire (Portuguese)	
CVI-CVIP	Childhood QOL Questionnaire	
FQoL	Family Quality of Life Scale	BCD, 2015
ILK	Inventory for Assessment of QOL in Children & Adolescents	Kamp-Becker et al., 2011
IQVMR	QOL Inventory in Residential Environments	Tremblay, Martin-Laval, et al., 1996
PedsQL-GI	Pediatric QOL Inventory	Varni et al., 2014
QOL-Q	Quality of Life Questionnaire	Schalock and Keith, 1993
SF-36	QOL Short Form Survey	Brazier et al., 1992
WHOQOL	World Health Organization QOL	Masthoff et al., 2005
WHOQOL-BREF	WHO QOL Brief	Kalfoss et al., 2021

ASD-Specific Tools	
ADI-R	Autism Diagnostic Interview-Revised
ADOS	Autism Diagnostic Observation Schedule
AQ-28	Autism Quotient - 28 Item
CARS	Childhood Autism Rating Scale
MASS-R	Maryland Autism Services Survey Rev.
PRAS-ASD	Parent-Related Anxiety Scale - ASD

Other	
ABC(-C)	Aberrant Behavior Checklist (Child)
CBCL	Child Behavior Checklist
CCB	Checklist of Challenging Behaviours
CGI-I	Clinical Global Impressions scale - Improvement
CSHQ	Children's Sleep Habits Questionnaire
DAS	Disability Assessment Schedule
DIKJ	Depression Inventory for Children and Adolescents
DSSI	Duke Social Support Index
FIM	Functional Independence Measure
GLTEQ	Godin Leisure-Time Exercise Questionnaire
KAP	Knowledge, Attitudes, and Practices
LLP	Leisure Lifestyle Profile (Ad-hoc)
PSI-SF	Parenting Stress Index - Short Form
PSQI	Pittsburgh Sleep Quality Index
PSS	Perceived Stress Scale
SCQ	Social Communication Questionnaire, Lifetime
SDQ	Strength and Difficulty Questionnaire
SFS	Birchwood Social Functioning Scale
SRS	Social Responsiveness (Reactivity) Scale
SRS-2	Social Responsiveness (Reactivity) Scale
SSS	Stress Survey Schedule (ASD & pervasive developmental disabilities
TSR	Target Symptom Rating
WHODAS	World Health Organization Disability Schedule
WSP	Work Skills Plus

Appendix B

Quality of Life Search Procedures

Figure B1

PsychInfo Database Search Process

Ovid®

Search | Journals | Books | Multimedia | My Workspace | What's New

▼ Search History (19)

	# ▲	Searches	Results	Type
☐	1	exp Dementia/ or exp Alzheimer's Disease/ or *Cognitive Impairment/ or Alzheimer.mp. or *Brain/	159257	Advanced
☐	2	limit 1 to (full text and all journals and english language)	24242	Advanced
☐	3	autism.mp. or exp Autism Spectrum Disorders/	63674	Advanced
☐	4	limit 3 to (full text and all journals and english language)	10709	Advanced
☐	5	asperger*.mp.	4670	Advanced
☐	6	limit 5 to (full text and all journals and english language)	810	Advanced
☐	7	2 or 4 or 6	34730	Advanced
☐	8	Quality of life.mp. or exp *Quality of Life*/	102981	Advanced
☐	9	exp *Health Related Quality of Life*/ or QOL.mp.	18023	Advanced
☐	10	well being.mp. or exp Well Being/	114085	Advanced
☐	11	life satisfaction.mp. or exp Life Satisfaction/	21660	Advanced
☐	12	8 or 9 or 10 or 11	213913	Advanced
☐	13	7 and 12	1412	Advanced
☐	14	limit 13 to human	1387	Advanced
☐	15	survey.mp.	323582	Advanced
☐	16	scale.mp.	719059	Advanced
☐	17	exp Psychometrics/ or exp Questionnaires/ or questionaire.mp.	230317	Advanced
☐	18	15 or 16 or 17	1075930	Advanced
☐	19	14 and 18	809	Advanced

Save | Remove | Combine with: AND | OR

Figure B2

Pubmed Database Search Process

Search	Actions	Details	Query	Results	Time
#11	•••	⌄	Search: **((((((alzheimer[Title/Abstract]) OR (dementia[Title/Abstract])) OR (cognitive decline[Title/Abstract])) OR (autism[Title/Abstract])) OR (asperger[Title/Abstract])) AND (((((("quality of life"[Title/Abstract]) OR (QOL[Title/Abstract])) OR ("health related quality of life"[Title/Abstract])) OR (HRQOL[Title/Abstract])) OR ("well being"[Title/Abstract])) OR (wellbeing[Title/Abstract])) OR ("life satisfaction"[Title/Abstract]))) AND ((((scale[Title/Abstract]) OR (survey*[Title/Abstract])) OR (questionnaire*[Title/Abstract])) OR (psychometric*[Title/Abstract]))** Filters: **Free full text, Full text, English, Humans, from 2011/1/1 - 2023/11/11** (("alzheimer"[Title/Abstract] OR "dementia"[Title/Abstract] OR "cognitive decline"[Title/Abstract] OR "autism"[Title/Abstract] OR "asperger"[Title/Abstract]) AND ("quality of life"[Title/Abstract] OR "QOL"[Title/Abstract] OR "health related quality of life"[Title/Abstract] OR "HRQOL"[Title/Abstract] OR "well being"[Title/Abstract] OR "wellbeing"[Title/Abstract] OR "life satisfaction"[Title/Abstract]) AND ("scale"[Title/Abstract] OR "survey*"[Title/Abstract] OR "questionnaire*"[Title/Abstract] OR "psychometric*"[Title/Abstract])) AND ((ffrft[Filter]) AND (fft[Filter]) AND (humans[Filter]) AND (2011/1/1:2023/11/11[pdat]) AND (english[Filter]))	1,021	13:11:02

Figure B3

Web of Science Search Process

Database: Web of Science Core Collection
Entitlements:

- WOS.SSCI: 1900 to 2022
- WOS.AHCI: 1975 to 2022
- WOS.CCR: 1985 to 2022
- WOS.BHCI: 2005 to 2022
- WOS.ISTP: 1990 to 2022
- WOS.ESCI: 2017 to 2022
- WOS.SCI: 1900 to 2022
- WOS.BSCI: 2005 to 2022
- WOS.ISSHP: 1990 to 2022
- WOS.IC: 1993 to 2022

Searches:

1: AB=(alzheimer*) OR AB=(dementia) OR AB=("cognitive decline") OR AB=(autis*) OR AB=(asperger*)
Date Run: Fri Nov 11 2022 10:26:49 GMT-0700 (Mountain Standard Time)
Results: 296217

2: ((((((TS=("quality of life")) OR TS=(QOL)) OR TS=("health related quality of life")) OR TS=(HRQOL)) OR TS=("well being")) OR TS=("wellbeing")) OR TS=("life satisfaction")
Date Run: Fri Nov 11 2022 10:30:14 GMT-0700 (Mountain Standard Time)
Results: 683631

Figure B4

Web of Science Search Process (Cont.)

3: (((TS=(scale*)) OR TS=(survey*)) OR TS=(questionnaire*)) OR TS=(psychometric*)
Date Run: Fri Nov 11 2022 10:31:45 GMT-0700 (Mountain Standard Time)
Results: 4652404

4: #1 AND #2 AND #3 Date Run: Fri Nov 11 2022 10:31:57 GMT-0700 (Mountain Standard Time) Results: 5234

5: #1 AND #2 AND #3 and Article or Review Article (Document Types)
Date Run: Fri Nov 11 2022 10:32:41 GMT-0700 (Mountain Standard Time)
Results: 5167

6: (#1 AND #2 AND #3) AND (DT==("ARTICLE" OR "REVIEW") AND LA== ("ENGLISH")) Timespan: 2011-01-01 to 2023-11-11 Date Run: Fri Nov 11 2022 10:33:12 GMT-0700 (Mountain Standard Time) Results: 4215

Appendix C

Search Results

Study Details				
Author	Tools Used	Sample Population	Sample Size	Characteristics
Adorno et al., 2022	SF-36 FIM CARS KAP	Convenience Dance program	N = 11	Male n = 1 Female n = 10
Arnold et al., 2019	ADI-R CSHQ ADOS PedsQL (GI module) PRAS-ASD TSR ABC SRS	Unknown	N = 10	Female (Placebo) n = 3 Female (treat.) n = 1
Continued...				

Tools & Features (Continued)				
Author	Tools Used	Sample Size	Characteristics	
Braden et al., 2022	SF-36 WHOQOL-BREF WHODAS	Cross-sectional of previous study, research & resource orgs. Snowballing Community flyers	N = 132	ASD n = 67 Non-ASD N = 66
Charlton et al., 2022	WHOQOL DSSI AQ-28	Online via research organization	N = 388	Male n = 161 Female n = 277 Majority white, highly educated
Cuesta-Gomez et al., 2022	CVI-CVIP CCVA Scale INICO-FEAPS	National ASD organizations	N = 276	Pros n = 143 ASD n = 60 Caregivers n = 73
de Almeida et al., 2021	Sociodemographic questions P-CPQ	Dental clinic patients	N = 115	Male n = 99 Female n = 16
Continued...				

Tools & Features (Continued)				
Author	Tools Used	Sample Size	Characteristics	
Drusedau et al., 2022	SRS CBCL SDQ ILK DIKJ	Via university dept., government, practitioners, local organizations	N = 25	Male n = 23 Female n = 2
Eskow et al., 2015	MASS-R FQoL	Families getting support or registered & waiting (government agency)	N = 552 (Matched families)	Diverse 84.6% mothers
Garcia-Villamisar and Dattilo, 2010	QOL SSS LLP	Day program	N = 71	Treat. n = 37 (22m) Control n = 34 (19m)
Gerber et al., 2011	IQVMR ABC CARS	Two care programs	N = 31	Male n = 23 Female n = 8 Program n = 20 No prog. n = 11
Continued...				

Tools & Features (Continued)				
Hamm and Yun, 2019	WHOQOL-BREF GLTEQ	5% of Facebook 25% ASD orgs 70% Qualtrics	N = 320	Female n = 177 Male n = 138 Unknown n = 5 ASD n = 143 86% non-ASD highly educated (56% w/ASD)
Kandalaft and DeBrabander, 2021	WHOQOL-BREF SFS SCQ WSP	Pilot study & Institute	N = 7	Unknown
McClean and Grey, 2012	Behavior records CCB HoNOS–LD QoLS	Resident program	N = 4	Male, severe ASD comorbidities
McLean et al., 2021	PSQI PSS WHOQOL-BREF	Previous study & autism-related volunteers	N = 64	ASD n = 40 Non-ASD n = 24
Continued...				

Tools & Features (Continued)				
Ozer et al., 2018	Ad hoc	Hospital patients	N = 41	Male n = 31
Shaffer et al., 2019	CBCL ABC-C PedsQL CGI-I	Referral	N = 34	Male n = 26
Tomaszewski et al., 2022	QOL-Q	Online & local groups(state)	N = 52	71.1% Male 68.4% White 32.4% $99k+/yr
Toscano et al., 2018	CHQ-PF50 CARS	Local healthcare center	N = 90	Intervention = 46 Control n = 23 Intervention n = 67 (Control - higher mass, smaller waist)
Varni et al., 2012	PedsQL	National clinical study (post-hoc analysis)	N = 316	Fixed Treat. n = 166 Flexible Treat. n = 47 Placebo Fxd n = 52 Placebo Flex. n = 51
End of Table				

Appendix D

Quality of Life Definitions

QOL Definitions Utilized in Research	
Author	Definition
Adorno et al., 2022	No definition.
Arnold et al., 2019	No definition.
Braden et al., 2022	WHOQOL definition.
Charlton et al., 2022	WHOQOL definition.
Cuesta-Gomez et al., 2022	"Quality of life is a concept that must require a multidimensional perspective, including many other aspects of the person's life, such as physical wellbeing, health, and leisure, and the subjective satisfaction with all of them."
de Almeida et al., 2021	No definition.
Drusedau et al., 2022	No definition.
Eskow et al., 2015	No definition.
Garcia-Villamisar and Dattilo, 2010	"...[T]he basic conditions of life such as shelter, adequate food and safety, the construct of individual quality of life incorporates those areas that enrich one's life such as inclusion in social, leisure and community activities that are based on the values, beliefs, needs and interests of the individuals.
Gerber et al., 2011	No definition.
Continued...	

QOL Definitions Utilized in Research (Continued)	
Author	Definition
Hamm and Yun, 2019	"HRQOL is a multidimensional construct based on an individual's subjective view of their health (ex. physical, mental and social well-being)."
Kandalaft and DeBrabander, 2021	QoL is a multidimensional construct that generally includes the following domains: emotional well-being, interpersonal relationships, material well-being, personal development, physical well-being, self-determination, social inclusion, and human and legal rights.
McClean and Grey, 2012	No definition.
McLean et al., 2021	No definition.
Ozer et al., 2018	No definition.
Shaffer et al., 2019	No definition.
Tomaszewski et al., 2022	"Components of quality of life include independence (personal development, self-determination), social participation (interpersonal relations, social inclusion, and rights), and well-being (emotional, physical, and material well-being)"
Toscano et al., 2018	No definition.
Varni et al., 2012	No definition.
End Table	

Appendix E

Findings

Research Findings	
Author	Findings
Adorno et al., 2022	"Children' "quality of life" reported by parents showed changes in functional capacity, vitality, mental health, physical and social aspects, and general state of health domains. These findings suggest that regular dance practice can underlie psychosocial adjustments in children..."
Arnold et al., 2019	"The VISBIOME formulation was safe and suggested a health benefit in children with ASD and GI symptoms who retained Lactobacillus."
Braden et al., 2022	"...both interventions were more effective for HRQoL improvements in women with ASD."
Charlton et al., 2022	"Social support is an important contributor to the QoL of middle-aged and older autistic adults..."
Cuesta-Gomez et al., 2022	"There is a need to increase the practice of sport among people with ASD in order to promote their health, social participation and personal satisfaction..."
de Almeida et al., 2021	"According to the perception of the caregivers, dental treatment had a positive impact on the OHRQoL of children and adolescents with ASD.
Continued...	

Research Findings (Continued)	
Author	Findings
Drusedau et al., 2022	"...symptoms with respect to emotional and social problems, externalizing behavior, and attentional and schizoid-compulsive behavior substantially declined."
Eskow et al., 2015	"...participants in the waiver group reported more improvement in independent living skills and family quality of life over the last year compared to those on the registry.
Garcia-Villamisar and Dattilo, 2010	"...participation in recreation activities positively influenced the stress and quality of life of adults with ASD.
Gerber et al., 2011	"The PAMS programme has a positive and indirect influence on QoL by reducing CB."
Hamm and Yun, 2019	"Practitioners should...utilize physical activity as a tool for improving health-related quality of life."
Kandalaft and DeBrabander, 2021	"Significant change was found on the SFS-M and two WHOQOL-BREF domains: psychological and environmental."
McClean and Grey, 2012	"Substantial reductions in target behaviours were observed, along with incremental improvement in mental health scores and quality-of-life scores.
Continued...	

Research Findings (Continued)	
Author	Findings
McLean et al., 2021	"Autistic adults reported worse sleep quality compared to non-autistic adults. Poorer sleep quality was significantly associated with lower quality of life for all participants in the study."
Ozer et al., 2018	"Significant improvements were noted after management in functional limitations ($P < 0.01$), psychosocial interactions ($P < 0.01$), and ocular alignment ($P < 0.01$) subscales."
Shaffer et al., 2019	"...this program is feasible and associated with high caregiver satisfaction. Pre-and-post outcome results indicate statistically significant improvement on behavioral measures, but did not demonstrate significant improvement on the Pediatric Quality of Life Family Impact Module."
Tomaszewski et al., 2022	"Increased average daily step count was significantly associated with quality of life."
Toscano et al., 2018	"The experimental group showed beneficial effects on metabolic indicators,... autism traits, and parent-perceived quality of life."
Varni et al., 2012	"...aripiprazole was associated with improved HRQOL, as assessed using 3 PedsQL scales...
End Table	

Appendix F

Reliability & Questionnaire Type

Rather than determine how "good" an assessment is or infer accuracy, Cronbach's Alpha Coefficient is used here for comparison purposes only to better understand how repeatable the results are in comparison to each other. However, it is important to note that this method has drawbacks—one of which is its tendency to overestimate reliability (Cortina, 1993; Yang & Green, 2011).

This chart does not determine the effectiveness of the treatments or hypotheses utilized in the studies. Instead, the purpose is to compare the reported use and methodology behind QOL assessments in each study. Simply, it is to help compare the consistency and specificity of the assessment methodology reported.

Measurement Guide	
Cronbach's Alpha Coefficient	70 - Satisfactory 80 - Good 90 - Excellent
Person Separation Reliability (PSR)	Degree to which responses fit the corresponding model. Closer to 1 = Better fit.
Pearson's Correlation Coefficient	Closer to -1 or 1 reflects stronger correlations.

Validity, Reliability, & Questionnaire Type		
Author	Type	Reliability
Adorno et al., 2022	Parent	Not reported.
Arnold et al., 2019	Self-report & parent	Test-retest α= 0.88 (12 days) α= 0.86 (24 days) To sample: α= 0.93 & 0.92 With parent report: r = 0.33 - 0.66
Braden et al., 2022	Self-report & parent	SFS to WHOQOL-BREF Physical r= 0.79 & Mental r= 0.69 Informant & child α= 0.81 & 0.82
Charlton et al., 2022	Self-report	Across domains α= 0.73–0.86 WHOQOL-BREF Test–retest: r = 0.66 - 0.87 ASQOL Internal consistency: α= 0.82 (Previously reported.) Test–retest ICC= 0.76
Cuesta-Gomez et al., 2022	Interviewer Focus Groups (Rater)	CVI PSR α= 0.88 CVIP PSR α= 0.83, CCVA α= 0.84 INICO-FEAPS (Previous.) α= 0.937 Self-report: α= 0.893
de Almeida et al., 2021	Parent Dental professional	Not reported.
Continued...		

Validity, Reliability, & Questionnaire Type (Continued)		
Author	Type	Reliability
Drusedau et al., 2022	Self-report Parent	Not reported.
Eskow et al., 2015	Parent	MASS-R α= .88 MASS-R subscale α= .74–.90 ASD severity α= .783
Garcia-Villamisar and Dattilo, 2010	Therapist	QOL α= 0.90, Inter-rater r = 0.83 Test–retest r = 0.87 With sample (Table 1), Pg. 614
Gerber et al., 2011	Self-report	IQVMR α= 0.90 Inter-rater α= 0.80 Test–retest α= 0.84) CARS α= 0.90 Inter-rater α= 0.80 Test–retest α= 0.84
Hamm and Yun, 2019	Self-report	WHOQOL-BREF Overall α= 0.82 Domains: Physical health α= 0.81 Psychological α= 0.78 Environment α0.81 Social relationships α= 0.75
Kandalaft and DeBrabander, 2021	Self-report	WHOQOL-BREF Internal α= 0.79 Original SFS Internal α= 0.80 Inter-rater r = 0.94 SFS-m Internal α= 0.72 WSP internal α= 0.74
Continued...		

Validity, Reliability, & Questionnaire Type (Continued)		
Author	Type	Reliability
McClean and Grey, 2012	Professional	Behavior recordings Inter-rater α= .88 - 1.00 CCB Inter-rater (frequency measure) r = .87, r = .92, r = .96 for the 3 periods. Inter-rater (episodic severity) r = .88, r = 1.0, r = .94 Inter-rater (episodic management difficulty) r = .83, r = .87, r = .88.
McLean et al., 2021	Parent	α= 0.49
Ozer et al., 2018	Caregiver	Not reported.
Shaffer et al., 2019	Self-report	Not reported.
Tomaszewski et al., 2022	Self-report Raters	QOL-Q Internal α= .90 Inter-rater r = .83, Test-retest r = .87 "...evidence of construct and concurrent validity."
Toscano et al., 2018	Rater	Not reported.
Varni et al., 2012	Parent	PedsQL α= 0.81 Emotional α= 0.69 Social α= 0.71 Cognitive α= 0.86
End Table		

Appendix G

Questions for Further Research

1. How stable is QOL over time in autistic populations?
2. How accurate are we at judging someone's QOL? Does that differ from our perceptions of QOL in autistic populations?
3. Are first-person reports superior to third-person in autistic populations?
4. Are autistic-specific QOL tools more accurate?
5. Does defining QOL in the context of a study affect results?
6. Are custom-designed QOL tools for autistic populations accurate?
7. Under what circumstances should QOL tools not be used?
8. Would utilizing other metrics be better than QOL?
9. In what ways do third-party perceptions of someone's quality of life differ?
10. Does the location where a QOL questionnaire is administered influence/alter the results?
11. Are autistic populations sensitive to historical happenings that occur before completing a QOL assessment?
12. How does the diversity of autism samples affect the outcomes of QOL measures?
13. Does controlling for symptom types or severity improve QOL questionnaire results?
14. How do autistic personalities differ from neurotypical populations, and do those traits affect QOL assessment outcomes?
15. How does identity in autistic populations influence QOL perceptions?
16. Does an individual's life circumstances affect their perceptions of QOL significantly?

Continued...

17. How does a third party's relationship with an autistic participant change QOL perceptions?
18. Are autistic populations more or less prone to survey and question fatigue?
19. Do autistic populations vary when reporting negative incidents compared to positive ones?
20. Are shorter QOL surveys more accurate than longer versions with this population?
21. Does time of day influence QOL findings, and are autistic populations more sensitive to these interactions?
22. Does the order in which tests are administered, or questions are asked affect the final results of QOL assessments?
23. Should we be taking QOL measurements during treatment as opposed to just before and after?
24. Are demand characteristics causing some of the variance in QOL assessments?
25. Do the attributions of third parties alter QOL perceptions?
26. How can researchers verify their results? Is there a better way to validate QOL studies and check their reliability?
27. Is test-retest or inter-rater testing sufficient to catch errors and explain variance?