The Experience of Patient-Centered Care for Autistic Adults: Communication, Relationships, Diversity, and Tension

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Abstract

Patient-centered care is the predominant modern healthcare framework, focusing on healthcare communication and relationships, and understanding of patients wholistically as persons, all of which have been found to be beneficial to patient experiences and objective health outcomes in the general population. However, communication, relationships, and being understood by others is often challenging for autistic adults, and consequently they may differ in their experience of patient-centred care compared to the non-autistic general population. In the present study autistic adults' experiences in healthcare were examined through online open-ended long-answer questions about their experiences navigating healthcare, including communication, relationships, and what they wanted others to understand about them. Responses were coded using constant comparison analysis within the Grounded Theory framework. A limited number of content level themes emerged across participants, such as needing more time for the clinical encounter, wanting a strong relationship with their healthcare provider, and needing communication accommodations and modifications—all of which are consistent with the growing autistic informed literature on healthcare experiences. However, more complex over-arching themes emerged with respect to the tension between diversity and dichotomous experiences (e.g., tension between disclosing diagnosis at the risk of receiving marginalizing responses vs not disclosing diagnosis at the expense of support and accommodation; tension between factors of intergroup diversity and intragroup diversity), and the impact that healthcare interactions have on autistic patients. Discussion of these experiences is presented for deeper understanding of the complexity of the autistic healthcare experience. Implications for a) patient-initiated tools and accommodations and b) healthcare provider training are discussed.

Keywords: Autism, Patient-Centred Care, Grounded Theory, Knowledge Translation, Healthcare Experiences

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The Experience of Patient-Centered Care for Autistic Adults: Communication, Relationships, Diversity and Tension

In the current medical era of patient-centered care (PCC), patients are positioned as active and engaged partners rather than passive recipients in their healthcare (Stewart, 2001). Within PCC, a wholistic understanding of the patient as a person, healthcare communication and relationships are promoted due to their significant beneficial impacts on health and healthcare outcomes (Birkhauer et al., 2017; Clayman et al., 2017; Cloninger, 2011; Stewart, 2001). However, not every patient engages in communication or relationships in conventional ways, and therefore may need support or accommodation. Autistic adults[1] have previously expressed having strengths and challenges in healthcare, both of which can be either helped or hampered by their healthcare provider (HCP; Bradshaw et al., 2019; Nicolaidis et al., 2015; Wright, 2016). However, despite the wide-spread practice of PCC and the higher-than-average medical needs of autistic adults, little is known about how these adults experience PCC in terms of the needs that they identify from *their* perspective. Given PCC is premised on understanding the patient, strong communication and the fostering of strong relationships, these unique needs must be understood if care is to be truly *patient* centered.

Background

Autism Spectrum Disorder

Autism spectrum disorder (ASD) is a neurodevelopmental condition characterized by hallmark challenges with social competence, repetitive or limited behaviours and interests, and unusual sensory experiences (American Psychiatric Association, 2013; Holdnack et al., 2011).

[1] Identity-first language is used in this paper because it is the preferred language of most autistic adults (Kenny et al., 2016; Taboas et el., 2023); n.b., the shift from person-first to identity-first language for this project came after recruitment, therefore recruitment materials within the appendices contain person-first language.

These general criteria and characterizations alone fail to capture the wide range of intellectual and adaptive functioning, the severity of the challenges and behaviours, and the many diverse strengths of individuals on the spectrum, all of which uniquely combine within any given individual resulting in a highly heterogeneous group. For the purposes of this study the term autistic adults will refer to a subgroup of the autistic population who can navigate healthcare independently (i.e., autistic adults without intellectual disability who have autonomous medical decision-making power over their own health and healthcare, hereinafter referred to solely as autistic adults). This independence and autonomy notwithstanding, these individuals often struggle with significant life goals such as obtaining and maintaining relationships, employment and education, as well as the small daily interactions (e.g., interacting with a cashier, bus driver, etc.) that are essential for independent daily living (Barnhill, 2007; Cederlund et al., 2009; Gray et al., 2014; Gutstein & Whitney, 2002; Lawrence et al., 2010).

Understanding Autistic Adults

Social Competencies and Autistic Adults

Social competencies consist of "the skills and strategies that allow individuals to have meaningful friendships; forge close emotion-based relationships; productively collaborate with groups, teams, and work partners; manage public and social settings; and participate in family functioning" (Gutstein & Whitney, 2002, p. 161). With respect to communication, autistic adults may struggle with overly concrete and literal interpretation and use of language, have difficulty with idioms, metaphors, sarcasm and 'reading between the lines', with many autistic adults requesting that others communicate with them in a 'spell it out for me' manner (Lawrence et al., 2010; Muller et al., 2008). Autistic adults may also have "unusual ways of expressing thoughts and emotions, including specific names for symptoms and experiences" that are not used by

others (Gause 2007 as cited in Lawrence, 2010, p. 234). In addition, challenges with conversation 'pragmatics' (e.g., prosody, turn-taking, timing and relevance of response) may also not fit convention and create barriers to real-time and face-to-face conversation (Mitchell, 2008). Finally, challenges with sensory sensitivity and environmental overwhelm (e.g., challenges tuning out background noise, bright lights, and other environmental stimuli), and potentially slower information processing speeds can create additional communication barriers for autistic adults (Haigh et al., 2018; Strömberg et al., 2022).

These communication challenges are significant, often rising to the extent that they impede reaching the normative developmental potential that would otherwise be predicted by the individual's intellectual abilities (Saulnier & Klin, 2007). This can result in a frustrating dilemma in which explaining one's struggles to others requires strong communication skills, but, as one autistic adult put it, "how do you communicate that you have a communication problem…when you have a communication problem?" (Shepherd, 2008, p. 54). Consequently, these adults often live with other people's negative assumptions that their challenges are indicative of lack of overall competence or a lack of interest in other people and relationships (John et al., 2018; Lim, et al., 2021; Saulnier & Klin, 2007).

However, there are growing alternatives to conventional in-vivo communication, including online formats. Although many autistic adults may have difficulty dealing with multiple social and communication variables (e.g., tone of voice, social anxiety, eye contact), online communication helps to reduce these variables by providing "one channel communication" (Mitchell, 2008, p. 19). This can contribute to more confident communication, removing challenges that come with in-vivo communication, and allowing autistic adults the time to think through and write out the responses that they feel make them best understood at

their own pace (Brownlow, 2010; Mitchell, 2008; Smith & Sharp, 2013). Consequently, researchers who are invested in understanding autistic adults—including their perspectives and their intended meaning in ways that allow these adults to feel most understood—are increasingly incorporating online data collection methods (see Nicolaidis et al., 2012; Sciutto et al., 2012; Smith & Sharp, 2013; Wright, 2016) that have led to in-depth data about the experiences of autistic adults in various contexts.

Alexithymia Traits and Empathy. Further challenges with social competence may stem from challenges related to alexithymia, which consists of persistent challenges identifying and describing emotions and distinguishing bodily sensations from emotional states (Bird & Cook, 2013; Cook et al., 2013). In general, alexithymia traits contribute to social communication issues and social anxiety (Bird & Cook, 2013; Oakley, et al., 2022; Samur et al., 2013; Scheerer et al., 2021[2]), interpersonal problems, and strained relationships (Frye-Cox et al., 2013; Spitzer et al., 2005). Furthermore, challenges reading facial expression and other people's emotions in ASD studies that control for alexithymia consistently link emotional recognition deficits to alexithymia, not to ASD itself (Bird & Cook, 2013; Cook et al., 2013). Therefore, some of the heterogeneity in communication abilities in autistic adults may be due to the presence of strong alexithymia traits, which roughly 50% of autistic adults have compared to 5% of the neurotypical population (Fennel & Johnson, 2022).

Autistic individuals who fail to pick up on the emotions of others and/or fail to respond to others in conventionally empathic ways are often perceived as rude, aloof, deceptive, uncaring, uninterested in maintaining relationships with others and generally lacking empathy (Lawrence et al., 2010; Lim et al., 2021; Fennell & Johnson, 2022). In fact, there is often such a disconnect

[2] This study found a link between alexithymia and lower levels of social competence in *children*

between their intentions and how their behaviour is interpreted that autistic adults report being 'baffled' by other people's negative reactions (Barnhill, 2007; Lawrence et al., 2010). However, these negative perceptions and the assumption that they lack empathy is misguided (Rogers et al., 2007; Fennel & Johnson, 2022). Rogers and colleagues (2007) examined empathy in both autistic and non-autistic adults and found that autistic adults may have more difficulty understanding the perspectives of others and providing a socially-conventional emotionally-empathic response that others perceive as appropriately empathic. However, on measures of "feelings of warmth, compassion, and concern for others" (p. 711) they did not find significant differences between autistic and non-autistic samples. This is consistent with more recent research that demonstrated that low levels of perceived empathy are characteristic of alexithymia and not ASD itself (Bird & Cook, 2013).

The negative misperception that a lack of empathy is a characteristic of ASD has become a point of advocacy within the autism community. Many reference Milton's description of the 'double-empathy problem,' which asserts that concepts such as empathy and theory of mind require the co-creation of understanding between two people, and yet autistic adults are viewed as lacking in this regard despite the fact that non-autistic adults lack ability to understand what is going on inside the minds of adults on the spectrum (Milton, 2012; Mitchell et al., 2021; Sheppard et al., 2016). In fact, the 'double-empathy problem' has been raised by some to the level of a human rights violation. For example, autistic people living in care homes are oft referred to with dehumanizing language that labels them as incapable of empathy or of having feelings (Fletcher-Watson & Bird, 2020), and the perception that a lack of empathy represents a lack of a "key aspect of humanness" (Fennel & Johnson, 2022, p. 1102). In sum, although there are reasons why *some* autistic adults may appear to lack 'empathy', these perceptions may stem

from challenges with social competence and communication, alexithymia traits, and the pre-conceived negative misperceptions of others.

Invisibility of Challenges

Autistic adults often face challenges related to having an 'invisible disability' in general (Harder, 2009; McClure, 2011), where the lack of 'obvious' challenges results in a lack of awareness about the challenges they face, and consequently a lack of recognition that these challenges require support. Despite their challenges, many autistic adults do not appear to be struggling and therefore are vulnerable to common stereotypes (e.g., 'loner' not lonely, 'rude' not struggling, 'impatient' not overwhelmed, etc.). This often results in others blaming them for their behaviour, believing that their non-conventional behaviours are intentional, and perceiving them as capable of changing their behaviour if they tried (Bailey, 2011; Lawrence et al., 2010; Tantam, 2003). The resultant lack of support and understanding is based on other people's misattributions about the meaning or causes of their behaviour, putting autistic adults in a position of having to fit in with the expectations of people who do not understand or accept them (Brownlow, 2010; Howlin, 2000). Therefore, in addition to the struggles inherent in having ASD, these individuals are faced with challenges that arise from the poor understanding of others, consistent with the social model of disability (Shakespeare, 2013).

Invisibility may be further exacerbated by the fear of being stigmatized, leading many adults to choose not to disclose their diagnosis to others (e.g., peers, teachers, employers; Thompson-Hodgetts et al., 2020) including HCPs (Lum et al., 2014; Nicolaidis et al., 2016). Furthermore, alexithymia may also contribute to invisibility due to challenges identifying and differentiating feelings and emotional states, as well as distinguishing them from physical sensations (e.g., distinguishing anger from hunger; Fennell & Johnson, 2022). This may be

especially true in situations where self-report of physical and emotional experience is essential (e.g., effective reporting of physical pain after a car accident, distinguishing grief from a physical medical emergency after the loss of a loved one). These challenges may lead the experiences of individuals with alexithymia to remain "invisible" from others.

Some of this invisibility may stem from the phenomenon known as social camouflaging: the imitation of social behaviours observed in others or the attempt to learn rules about social interaction without understanding what underpins those rules. This often results in the successful ability to 'fake neurotypicality' to the extent that in some cases even highly experienced clinicians cannot detect camouflaging in assessment settings unless the patient brings it up first (Green, 2019; Lai et al., 2011). As opposed to social skills, camouflaging is exhausting, stressful, requires hiding or betraying one's identity, and does not increase feelings of genuine connection on the part of the person camouflaging (Gould, 2019; Green, 2019; Lai et al., 2011). Further, this 'ability' to camouflage is often misinterpreted as social competence, which once again hides individual social challenges and the need for support (Gould, 2019; Green, 2019; Lai et al., 2011). Put plainly, when one camouflages their very identity along with their challenges these aspects are, by definition, invisible to those they are interacting with.

Differences in Relationships

Autistic adults may define quality relationships differently than non-autistic adults. For example, they may appear to prioritize a shared activity over the friend they share it with, and consequently may appear disengaged or uncaring (Lawrence et al., 2010), and potentially perpetuate the misperception that autistic adults do not care about friendships. However, this perception is often inaccurate as autistic adults frequently report experiencing loneliness and desiring meaningful relationships (Fennell & Johnson, 2022; Mazurek, 2014; Muller et al.,

2008). In sum, autistic adults report struggling and feeling misunderstood when communicating, but also report feeling misunderstood wholistically as individual persons.

Inclusion of Autistic Adults in Research

Research that focuses on autistic adults as individuals is historically limited (Barnhill, 2007). The bulk of ASD research in general examines children with ASD (especially those with greater intellectual and functional challenges), is informed by parents and professionals not by individuals with ASD themselves, and does not represent adults with less obvious challenges. The lack of representation of autistic adults who are more independent potentially stems from reduced support and advocacy once these individuals reach adulthood. There is often a "paucity of parental advocacy groups for adults,…lower empathy with and tolerance for adults than children, and [a] lack of education for professionals about adults with ASD" (Bailey, 2011, p. 1). These are compounded by the impacts of having an 'invisible disability' wherein others may not recognize challenges, which precludes providing support for those challenges. Alternatively, the misconception that these challenges are indicative of low intellectual ability has led to the exclusion of those with more obvious challenges from research (Muller et al., 2008). Consequently, autistic adults are faced with the damaging, and irrational, misperception that they are simultaneously too capable to be in need of support and understanding, and too 'incapable' to have anything of meaning or value to contribute to research on their own behalf.

Even when research does examine issues relevant to autistic adults, autistic adults themselves were historically excluded as participants. This has led to interventions and programming that is based on others' (e.g., parents, teachers, social workers) data which have failed in implementation as they do not meet the needs that would have been identified by autistic adults themselves (Griffith et al., 2001). However, within the emerging research that

increasingly consults autistic adults to contribute on their own behalf, there is a growing understanding of the unique experiences and perceptions of these adults wholistically as persons. Multiple studies have found that autistic adults can make themselves fully understood in research interviews, demonstrating that exclusion based on communication challenges is unwarranted (Muller et al., 2008). Furthermore, these adults have identified their specific struggles and needs in ways that challenge common and damaging misperceptions, including awareness of their 'awkwardness' in social situations, the desire for patience and caring from others rather than the desire to be left alone, a "longing for intimacy and social connectedness, and a desire to contribute to one's own community" (Muller et al., 2008, p. 177), and a whole host of experiences in a variety of settings (e.g., employment, education, social supports, independent living, relationships) that likely would not have emerged in research informed by non-autistic participants (Barnhill, 2007; Griffith et al., 2001; Luke et al., 2011; Lum et al., 2014; Punshon et al., 2009; Sciutto et al., 2012; Smith & Sharp, 2013; Wright, 2016). Autistic adults have been shown to have more autism knowledge and different views on autism (e.g., autism reflects 'differences' consistent with the neurodiversity movement and not merely 'deficits-deficiencies' as characterized by the typical medical model), in addition to lived experience which positions them as autism experts (Brownlow, 2010; Gillespie-Lynch et al., 2017).

Research related to healthcare and autistic adults has historically also been limited, often informed by non-autistic adults and/or relating to children. As an example, Kuhithau et al. (2014) conducted research to provide physicians with support for and recommendations about autistic patients as they age out of paediatric and into adult care. They included a range of participants (e.g., physicians, psychologists, social workers, and nurses), none of whom were autistic. Consequently, the results of this and other non-autistic informed studies (e.g., Hodgettes

et al., 2013) do not reflect needs as identified by autistic adults. Other research has examined how to 'manage' an encounter with an autistic individual (Green & Flanagan, 2008; Venkat et al., 2012) rather than understand the individuals themselves. Although invaluable in many ways, this research and the resultant recommendations have limited utility in terms of addressing the specific needs of autistic patients without intellectual disability who navigate healthcare independently as adults. Further, research needs to move beyond assessing and explaining 'deficiencies' and poor adult outcomes and move towards understanding and supporting the strengths of these highly pathologized adults (Howlin & Taylor, 2015).

Health and Healthcare for Autistic Adults

Autistic adults are significantly more likely to have chronic physical conditions (e.g., chronic pain, gastrointestinal disorders, compromised immune system) and mental health disorders (e.g., depression, anxiety, bipolar disorder, Tourette's syndrome) than the neurotypical population (Barnhill, 2007; Bishop-Fitzpatrick & Rubenstein, 2019: Lawrence, 2010; Lugo-Marin et al., 2019). They are also significantly more likely to have multiple co-occurring disorders, which leads to a greater need for multiple HCPs in multiple areas of specialty (Kuhithau et al., 2014; Nicolaidis et al., 2012). In sum, autistic adults have more health and healthcare needs than the general neurotypicalpopulation in general, needs that may not be adequately addressed. Nicolaidis and colleagues (2012) examined healthcare experiences for adults with and without autism in a community-based participatory study. They found that autistic adults were twice as likely to report visiting the emergency room, and had significantly lower rates of obtaining routine healthcare (such as vaccinations or pap-smears). In general, they found that autistic adults had higher unmet physical, mental, and pharmaceutical healthcare needs compared to the general population.

In addition to these unmet needs, autistic adults scored significantly lower on self-report measures of communication in healthcare (i.e., how they rate the quality of their communication with their HCP) and health self-efficacy (i.e., how they rate their ability to handle a specific healthcare condition, as well their healthcare in general [Nicolaidis et al., 2012]). In sum, autistic adults not only have more healthcare needs, but they are more likely not to have these needs met, and report lower quality and self-efficacy in addressing their healthcare needs either on their own or with their HCP.

Patient-Centered Care

PCC is a framework in healthcare in which patients are an active part of, rather than mere recipients of, healthcare. There are three main tenets in PCC, all of which have been shown to improve objective health outcomes and patient experiences of healthcare: (a) collaborative communication and decision-making between patient and HCP (Clayman et al., 2017; Cloninger, 2011; Stewart, 2001), (b) understanding individual patients wholistically (Clayman, et al., 2017; Cloninger, 2011; Stewart, 2001); (c) positive healthcare relationships (Bensing et al., 2013; Stewart, 2001).

Healthcare Communication

Strong communication is essential for the disclosure and exchange of medical information, the accurate identification of problems, and individualized treatment planning (Ha et al., 2010), and is positively linked with higher health and healthcare self-efficacy in individuals who are prone to lower self-efficacy, such as patients who have multiple chronic illnesses (Finney Rutten et al., 2016). Further, collaboration and shared decision-making—which requires strong communication—have also been found to be beneficial to the patient, with positive collaboration being linked to treatment adherence and health outcomes (Arbuthnott &

Sharpe, 2009; Ha et al., 2010). HCP training in PCC has largely focused on tools and strategies for improving patient-centred-communication and "interpersonal skills" (Ridd et al., 2009), perhaps because it is the factor of PCC that is most amenable to concrete strategies and training (Bensing et al, 2013). In their review of both the quantitative and qualitative research, Bensing and colleagues (2013) found that training was based on general guidelines of what constituted "good" communication skills, but that individual patients from various groups (e.g., different medical conditions, different SES status, individual levels of anxiety) have different communication needs and styles even when in similar situations. Consequently, diversity needs to be taken into account in patient-centered communication.

Understanding the Patient as a Person

Within PCC, HCPs must strive to understand the individual not merely as a patient with symptoms and conditions to be treated, but as a person with individual life experiences, personal definitions of health and illness, expertise and self-knowledge, all of which is situated in a unique context (Cloninger, 2011; Epstein, 2000; Kitson et al., 2013; Stewart, 2001). HCPs and patients who differ on subjective concepts such as personal definitions, causal attributions, and social construals of health and illness are more likely to disagree on treatments and goals, which in turn can hinder treatment adherence and objective medical outcomes (Goold & Lipkin, 1999; Ha et al., 2010). Consequently, both an understanding of the patient as a unique person *and* the acceptance of their views and beliefs contributes to better healthcare and health outcomes. Actively fostering this understanding is especially important in diverse populations with different backgrounds. This is perhaps best expressed by Epstein (2000) who wrote "given the diversity of patient needs and personalities […] we need to understand the patient as a person rather than cluster attributes."

Healthcare Relationships

Overall, the quality of healthcare relationships is linked with improved healthcare and health outcomes. Specifically, there are positive links between positive patient ratings of healthcare relationships and their 'buy-in' and adherence to treatment, satisfaction with treatment, improved quality of life reports, and both subjective and objective improvements in health outcomes (Bauman et al., 2003; Bennett et al., 2010; Fuertes et al., 2008; Fuertes et al., 2007). Even constructs as simple as trust and 'liking' (i.e., how much patients and healthcare practitioners rate that they 'like' one another) have been linked with better patient-perceived health outcomes, and therefore have value in healthcare (Bensing et al., 2013; Birkhauer et al., 2017; Fuertes et al., 2007; Hall et al., 2002; Ridd et al., 2009).

Although the components of PCC have been examined here as individual constructs, they are interdependent in practice. Strong communication is required to make one's self understood as a person, caring relationships foster trust when divulging potentially sensitive information, and hostile relationships may hamper open communication and prevent an individual from feeling accepted as a person. Therefore, HCPs must aim to address and foster all aspects of PCC in order to maximize its benefits. However, this may be challenging for HCPs working with patients who may have non-conventional conceptualizations of what constitutes a strong relationship, who vary greatly in social and communication skills, and who generally report feeling misunderstood by others in general, such as autistic adults.

PCC for Autistic Adults

The benefits of PCC are undeniable, with national and international agencies (e.g., WHO, NHS, Canadian Medical Association) promoting PCC not only as grounded in the best evidence for efficacious healthcare but also as a moral imperative (Clayman et al., 2017; Kitson et al.,

2013; Montague et al., 2017). At times, the promotion of PCC has crossed the line from merely being an evidence-based approach in which HCPs collaborate and engage with patients, to a moral responsibility on the part of the patient wherein it is implicit that patients who 'want' to get better will engage and contribute to their healthcare (President and Fellows of Harvard College, 2007). The perception that patients who 'want' to improve their health will actively engage in healthcare logically would not apply to those who are unable to engage in conventional ways (e.g., individuals with severe intellectual delay). However, autistic adults who have intact intellectual abilities are often misperceived as lacking competence, often struggle with social and conventional communication and relationships, and often struggle to feel understood as persons, and therefore it cannot be assumed that their experience of PCC is congruent with that of the general population. If we are to understand what makes for good PCC and overall healthcare for these adult patients, we must understand the components of PCC from *their* point of view.

Healthcare Communication and Autistic Adults

Research in healthcare for autistic adults has historically been aimed at HCPs in terms of recommendations to help facilitate the clinical encounter and communication (e.g., recommendations to create a quiet waiting environment, take the taste of medications into account when prescribing, and ask simple questions; Venkat et al., 2012), and often stem from paediatric research and research with parents (Kuhithau et al., 2014). Often, these recommendations are meant to respect and make the patient *feel* included in in healthcare communication (e.g., "'Charlie', I'm now going to ask your mom how we can talk together;" Venkat et al., 2012, p. 1477), however these recommendations would limit inclusion of a patient who is able and wanting to engage in healthcare communication directly.

Based on an emerging body of research, autistic adults often report that their strengths and challenges in healthcare communication are either helped or hampered by their HCPs poor understanding of ASD (e.g., misperceptions that communication challenges are indicative of intellectual challenges or a lack of 'desire' to engage in one's healthcare; a lack of recognition that communication support may be needed), their willingness to adjust their communication style (e.g., allow for extra time or accept written communication) and their willingness to work together (Bradshaw et al, 2019; Nicolaidis et al., 2015; Wright, 2016).

Although many autistic adults report a desire for increased inclusion in communication and collaboration in their healthcare, this desire may not be shared by all. Despite the benefits of PCC, some research suggests that it is more important for patient engagement to be in line with patient preferences and capacities than to universally promote engagement with all patients, and that patients deferring decision-making to an HCP or third party qualifies as an autonomous and patient-centered healthcare decision (Adams et al., 2012; Carlsen & Aakvik, 2006). In these instances, optimal health and healthcare outcomes—including positive relationships—are linked to congruency between a patient's desired and actual contribution to their healthcare (Jahng et al., 2005; Taber et al., 2011). Others take the position that maximal communication and collaboration are indeed essential, but that rather than 'push' patients beyond what they are comfortable with, the focus should be to adjust communication to bring it into line with the patient's comfort level. For example, an email, letter, phone call, or the use of a decision/communication support website, are all legitimate forms of communication that foster empowered collaboration (Elwyn et al., 2012). These positions notwithstanding, autistic adults have reported feeling dismissed in healthcare communication and relationships, and given they are a heterogenous group, it is important that HCPs have enough knowledge about ASD *and*

each patient individually to understand individual communication and collaboration needs and preferences.

Healthcare Relationships and Autistic Adults

Healthcare research related specifically to the qualities of healthcare relationships has been limited, with the historical focus being on the clinical encounter and communication rather than on the healthcare relationships of autistic patients. Given that autistic adults may struggle with relationships in general (e.g., may face biased views about not wanting relationships, may value different aspects of relationships than neurotypical peers, may face social and communication barriers to forging relationships, and may be perceived as rude, aloof, unemphatic and uncaring) it stands to reason that their healthcare relationships may be more strained than the neurotypical patient population. Given the importance of strong relationships in health and healthcare, it is important to understand their unique experiences and the role and impact of their healthcare relationships.

Understanding Autistic Adults Wholistically in Healthcare

When asked directly, autistic adults have consistently reported a lack of knowledge and a need for more training about ASD among healthcare professionals (Bradshaw et al., 2019; Chown et al. 2023; Ghaderi & Watson, 2018; Griffith et al., 2001; Kuhithau et al., 2014; Lum et al., 2014; Nicolaidis et al., 2015; Wright, 2016). These reports are consistent with reports by physicians that they often do not understand the needs or experiences of autistic adults, and often feel ill-equipped when treating them (Peter, 2009, as cited in Kuhithau et al., 2014; Zerbo et al., 2015).

Specific knowledge about ASD itself may not translate into meaningful understanding of the person with ASD or the development of confidence and competence for HCPs. In a study

with physicians from the United Kingdom, HCPs still held incorrect misperceptions about ASD (e.g., most autistic adults have an intellectual disability) even when ASD-specific knowledge (e.g., diagnostic criteria, common ASD behaviours) was over 85% accurate (Unigwe et al., 2017). This is in keeping with reports by some autistic adults that they feel dismissed as unintelligent or misperceived as not having much to contribute to their healthcare by HCPs (Wright, 2016). Similarly, in a study with U.S. physicians and specialists, ASD-specific knowledge was high (e.g., knowledge that sensory sensitivities, atypical communication, lack of eye contact, etc. were reasons to make an ASD referral). However, the majority of these physicians significantly underestimated how many patients with ASD they have on their caseload when compared to Health Maintenance Organization records, suggesting that knowledge of 'how to detect' ASD does not translate into real-world recognition of these patients. Consequently, there is recognition both among patients and HCPs that the latter lack the knowledge to work effectively with autistic adults, and that the knowledge required must extend beyond easily digestible one-size-fits-all facts and diagnostic criteria.

Current Tools and Accommodation Recommendations

Various tools exist to support autistic adults in healthcare, predominantly based on recommendations that accommodations should focus on communication and environmental/social factors (Chown et al., 2023: Nicolaidis et al., 2021). These include patient-level, provider-level, and system-level factors. For example, the National Institute of Health and Clinical Excellence guidelines make general recommendations including more training and awareness about ASD among professionals, targeting professional-level (e.g., HCPs need more training) and system-level (e.g., the training needs to be vetted and available) factors (National Collaborating Centre for Mental Health, 2012). This is consistent with calls for more training

from autistic adults, supporters, and HCPs. However, it is challenging to assess the feasibility of this recommendation. In the United States and Canada, medical doctors have limited time for continuing education (typically 20-25 hours per year with some province-to-province/state-to-state variation; Federation of State Medical Boards, 2023; Royal College of Physicians and Surgeons of Manitoba, 2023), with an endless number of areas in which HCP's need to remain current (e.g., specific medical conditions and treatments, research, administrative training), and HCPs have noted concerns related to having the time to specifically focus on ASD education and training as a priority (Chown et al., 2023; Coughlan et al., 2020). Further, HCPs have expressed concern over mandatory training, citing time constraints and the fear that mandatory training can feel like "box ticking" and does not garner the same level of engagement (Chown et al., 2023).

Given the limits of ASD-specific knowledge in improving overall HCP competence and self-efficacy in working with autistic adults, integrative and experiential modes of learning may be more appropriate. Higher levels of self-efficacy in working with autistic adults is linked to ASD knowledge and having more personal and professional 'real-life' experience with autistic adults (Corden et al., 2022). The Extension for Community Healthcare Outcomes (ECHO) was initially designed to address gaps in mental health service provision, and recently adapted as Project ECHO Autism to increase the self-efficacy and competence of mental health clinicians working with adults on the spectrum as part of their caseload (Dreiling et al., 2022). The model is similar to the process of group supervision in clinical psychology and specialty-specific rounds, with a "hub" (HCPs with experience and expertise providing mental health care to autistic adults, and a 'parent advocate/professional autism resource specialist') and "spokes" (mental health clinicians). There were a total of ten 90-minute sessions consisting of didactic training by hub members and case-presentation/consultation-seeking by clinicians, with high

levels of attendance (88% of clinicians attended 80% or more of sessions). Clinicians had higher self-efficacy, ASD knowledge, and clinical problem-solving at the end of the pilot. Unlike pure didactic or workshop training, these sessions allowed clinicians to discuss their current caseload and address challenges they were facing in their specific practices, which may have increased the immediate relevance of the training to the clinicians.

Another form of training that is increasingly being offered to healthcare professionals in general is implicit bias training (Cooper et al., 2022). Implicit bias refers to the negative and biased beliefs individuals hold irrespective of their explicit beliefs or personal commitment to equity for marginalized groups (Cooper et al., 2022). This is typically measured using the Implicit Association Test (Greenwald et al., 1998) which measures peoples' automatic associations between a target-stimuli (e.g., faces of individuals with different skin colour) and attributes (e.g., good, bad, safe, happy, dangerous). Given that marginalized and diverse communities frequently receive biased treatment based on these implicit biases, which has led to serious disparities (e.g., higher maternal morbidity among women of colour), negative implicit bias training is not only increasingly offered but increasingly mandated by professional governance bodies (Cooper et al., 2022). There is evidence that in the general population implicit bias negatively impacts autistic people (Jones et al., 2021) as well as the aforementioned bias due to negative myths and stereotypes (John et al., 2018; Lim et al., 2022). Efforts in autism acceptance training have been shown to decrease explicit bias but not implicit bias (Jones et al., 2021). Similar to the finding that higher levels of HCP lived-experience in working with people with ASD promotes confidence and competence (Corden et al., 2022), there is evidence in racial-bias research that a) explicit biases are more amenable to change based on knowledge and quality of contact with the minority group, but b) implicit biases are more amenable to change

based on quantity of contact with the group (Dasgupta & Rivera, 2008; Gardiner & Iarocci, 2014; Prestwich et al., 2008). These findings support the need to bring autistic adults into training and knowledge dissemination for target users (Concannon et al., 2014; Cooper et al., 2022; Dreiling et al., 2022).

Patient-Initiated Tools and Accommodations. Several tools and accommodations rely on the patient to initiate and introduce the tool into the healthcare encounter. With respect to specific accommodations for communication within healthcare, tools such as the "My Health Passport" (which patients can fill out and take to their HCP, providing the HCP with a range of personalized information about themselves and their communication preferences; The National Autistic Society, 2023), and the "Know Your Normal" (which individuals fill in to describe themselves under normal circumstances, which can in turn help them explain to others such as HCPs when something is 'not normal'; Ambitious About Autism, 2023) are tailored to each individual patient.

The most comprehensive North American source for personalized accommodations and general information I could locate is the Academic Autistic Spectrum Partnership in Research and Education (AASPIRE) healthcare toolkit, an online source for patients, supports, and HCPs to seek out information related to autism in healthcare (Academic Autistic Spectrum Partnership in Research and Education: AASPIRE Healthcare Toolkit, 2023; Nicolaidis et al., 2016). Perhaps the most unique feature within AASPIRE is the Autism Healthcare Accommodations Tool (AHAT), in which patients and/or their support person (where applicable) can complete an online questionnaire about their unique strengths, challenges and preferences, and the website will produce an individually tailored report about their personal healthcare and communication needs (and other relevant information such as who their support person is), with

recommendations to HCPs on how to make modifications and accommodation to foster more successful and empowered patient communication (Nicolaidis et al., 2016). Pilot and validation studies have shown that, when implemented, the report is generally helpful in reducing healthcare barriers and the perception of power imbalance between patient and HCP, and improving patient self-efficacy and patient provider communication (Kang et al., 2022; Nicolaidis, et al., 2016). Overall, the AHAT appears to be a strong tool in improving several autistic healthcare-relevant factors.

Despite the benefits of the AHAT tool among those that use it, it is important to note that there may be barriers to implementing this (and similar) tools. Some research participants did not want to share the report with their HCP because they did not want to disclose their ASD diagnosis to their HCP or were concerned that their HCP would react negatively (Nicolaidis et al., 2016). Furthermore, of the 88 HCPs who received the request for accommodations, only 47% completed the survey to participate in the study, making it impossible to assess why nearly half of HCPs did not participate (e.g., did they not want to read the report? Did they not want to implement accommodations? Did they not find the recommendations helpful, necessary or feasible? Did they find the report valuable but not participate in the study for other reasons? etc.). Further, not all HCPs welcome patient-introduced internet-based information and opinions (Dilliway & Maudsley, 2008). In fact, some HCPs view this type of patient-provided information as prolonging the appointment length, or—in instances where the HCP perceived the information as a challenge to their medical training and clinical judgement—as negatively impacting the healthcare relationship, the care quality, and health outcomes (Murray et al., 2003). Within my past research, some participants reported having written communication dismissed, with one reported instance of an HCP taking the papers from the patient's hand and discarding them,

stating “I’m the doctor here,” as well as a nutritionist questioning the written records of a patient due to how detailed and thorough they were, stating “this whole thing is a lie. I don't believe that this is what you are eating…You must be exaggerating, nobody keeps records like these. Where did you get this list?” (Wright, 2016). Although the nature of the study design did not allow for verification of other factors that may have impacted the successful introduction of these materials, it is important to note that from the perspective of the patient these were “not successful encounters” (Wright, 2016). Tools like the AHAT have the appearance of a medical professional’s report and contain information intended to help an HCP understand and work with autistic adults rather than challenge a medical opinion, both of which may make tools like the AHAT more acceptable to HCPs. Nonetheless, if patients identify barriers in introducing tools to their HCP—irrespective of HCPs ‘actual’ reaction—then these patient-identified barriers need to be understood.

Although I could find no research on the impact of requesting accommodations from HCPs, findings from research with adults with disabilities who request accommodations within higher education and employment settings have been mixed. Although adults with disabilities who seek accommodations earlier in their academic training objectively perform better academically (Lightner et al., 2012), students face social barriers disclosing their diagnosis and requesting accommodations. Some students have reported that accommodations requests lead faculty members to view them as less competent or that they are not suitable for the class, that some faculty members are unwilling to make accommodations. Some students link requests for accommodation with perceived discrimination (Cawthon & Cole, 2010), and have a desire to enter college without a ‘disability-focused identity’ (Lightner et al., 2012). Similarly, some autistic adults who request accommodations in the workplace have reported being supported and

accepted, while others report stigma and discrimination (Lindsay et al., 2021). Research in these contexts as well as the aforementioned patient-level barriers in introducing tools does not call into question the value of the accommodation or the tool itself, but rather highlights that for some users, tool implementation is a barrier. If patients in medical settings have similar experiences or apprehensions about perceived competence and discrimination, it stands to reason that there would be tension between disclosing a need for accommodation and protecting one's identity as competent in the eyes of others.

PCC and Third-Party Engagement

The issue of third-party engagement (e.g., the presence of a third-party such as a parent, adult child, spouse, or support worker) in adult healthcare encounters is complex. A meta-analysis examining the presence of third-party engagement in healthcare with older adults found that HCPs spoke for the same amount of time whether or not there was a third-party present, and that the time used by the third-party came out of the time the patient would have spent talking had they been alone with the HCP (Wolff & Roter, 2011a). More specifically, patients were less engaged in terms of providing information relevant to PCC (e.g., the sharing of psychosocial information), partnership building, and question asking. Furthermore, physicians have mixed views on whether or not the presence of a family member was helpful or detrimental (Wolff & Rotter, 2011b). Part of the reason why physicians' opinions are mixed is likely due to the fact that each individual patient and their chosen third-party has a unique combination of goals, attitudes, abilities, and interpersonal dynamics that would lead to an endless variety of outcomes.

Within my previous research (Wright, 2016), data were obtained from participants who did not regularly have a third-party with them as they navigated healthcare. However, in relating their experiences about interacting with HCPs, a subtheme emerged among participants about the

presence of a third-party. Some individuals reported feeling resentful and dismissed by HCPs and felt that they gave more authority to the words of a third-party than to the patient themselves, including instances of asking the third-party to speak to the 'veracity' of what the adult patient was reporting. Consequently, these participants viewed the need to have a third-party present as evidence of discrimination as opposed to support. Other participants felt that it was a relief to have a third-party present to share some of the communication burden. Given that a) the impact of third-party engagement in healthcare is highly variable in general, b) there is preliminary evidence that autistic adults have a variety of experiences with third-party communication, and c) autistic adults often report feeling dismissed in healthcare communication, it is important to examine the experience of third-party engagement from the perspective of autistic adults themselves.

Purpose

The purpose of the current study was to better understand the unique experiences of autistic adults in their healthcare communication and relationships. This was achieved by asking open-ended long-answer questions about communication and relationship experiences in healthcare, with the goal of not only understanding their priorities, challenges and strengths, but also of understanding the meaning they ascribe to their experiences. I utilized Grounded Theory (GT; Glaser & Strauss, 1967) and worked within a knowledge translation (KT) framework. These methods were carefully selected to meet my study goals, while ensuring participants retained control over the direction of the findings by allowing them to identify and define what was most important from their point of view. Below, I provide background information regarding the research methods followed, which supports my decision to use these approaches.

Grounded Theory

GT is well established in the health and healthcare literature (Charmaz, 2006; Hall & Callery, 2001). GT is an ideal framework within which to understand the unique experiences and perspectives of autistic adults, and ensure they are able to inform research solely on their own behalf. At its inception, GT was created as a method to develop or generate theory from data, or 'ground' the theory in data, rather than examine an existing theory with hypothesis testing (Glaser & Strauss, 1967). The defining components included a) generating codes and categories from the data, rather than using pre-conceived researcher developed codes and categories, b) using constant comparison analysis to compare previous and newly coded data and categories in an iterative process, and c) collecting and analysing data simultaneously (Bryant & Charmaz, 2007; Charmaz, 2006; Glaser & Strauss, 1967).

The initial theory put forth by Glaser and Strauss (1967) was an attempt to 'legitimize' a qualitative approach within the dominant positivist-quantitative climate of the mid 1900's (Charmaz, 2006). However, it can be argued that the GT framework initially proposed by Glaser (coming from a positivist-quantitative background) and Strauss (coming from a pragmatist background) gained acceptance for its positivist components, which in essence did not help 'legitimize' qualitative research by challenging positivist ideology, but rather by becoming part of it (Bryant & Charmaz, 2007). Consequently, this initial framework of GT has faced multiple criticisms within the qualitative theoretical and methodological literature, which in turn has led to the multiple theoretical and methodological changes that make up the many iterations of GT frameworks we see today. One of these iterations, often used in health and healthcare research, stems from a social-constructivist worldview (see Charmaz, 2006). The social constructivist paradigm purports that there is no objective or discoverable 'reality', but rather the unique meaning that individuals create from and ascribe to their experiences are what matter—

experiences that are lived and constructed within and in relation to one's social world (Charmaz, 2006; Warmoth, 2000).

In *Constructing Grounded Theory* (2006) Charmaz outlines a constructivist GT framework, which she describes as "a container into which different contents can be poured" (p. 9) where the practices applied to the data (e.g., coding) are neutral, but the way in which researchers use these practices and guidelines are not (i.e., researchers do not code for reality but for underlying meaning). From a constructivist point of view, the goal of GT is to uncover the specific meanings that people construct in relation to their respective worlds, and to use these meanings to either construct theory, or develop a rich description and understanding of the constructed phenomena. Within this framework, theory does not need to be defined as a positivist accounting of explanatory and predictive variables, but rather can be interpretive in nature. Interpretive theory "calls for the imaginative understanding of the studied phenomenon" (Charmaz, 2006, p. 126), in which the theorist accepts that there may be multiple emerging and evolving realities within diverse populations, with an emphasis on the processes and creation of meaning.

The social constructivist GT framework put forth by Charmaz (2006) was best suited for my specific research goal of understanding the unique experiences and perspectives of autistic adults, informed by these adults themselves. This is essential for multiple reasons. First, autistic adults are often faced with the negative misperceptions of others in terms of their intentions and abilities, both of which can lead to their marginalization. The use of GT methods within the constructivist paradigm allows me to stay close to *their* data, and focus on the intended message within *their* responses, while removing the potential for the misperceptions of non-autistic others in the data.

Second, social constructivist GT allows for the development of interpretive rather than conventional theory. My goal was not a positivist determination of the 'objective reality' of what occurs within healthcare between the multiple parties. For example, if an individual believes that their doctor kept them waiting because they do not care about them as a person, I was not interested in whether the doctor actually kept them waiting or if waiting was 'truly' a reflection of a doctor's lack of caring. I was solely interested in how the patients' experiences impact their healthcare. Therefore, interpretive theory in which multiple realities are viewed as co-existing rather than contradictory is in keeping with the goals of my study.

Third, the basic premise of GT – irrespective of worldview – is that the findings emerge from the participants' data itself. Within constant comparison, codes and categories are dictated by the data and, by extension, are created by the participants. The codes and categories are not pre-determined by the researcher or other non-participants (e.g., not created in consultation with the HCP literature). This approach was crucial within my study because autistic adults historically have had 'others' inform research on their own behalf. Focusing solely on what their data dictates positioned them and not others as the experts of their own experience.

Finally, GT is a qualitative method well suited for the analysis of documents. Given that autistic adults have reported feeling most comfortable in online communication formats, without time constraints or the need to navigate body language and the conventions of in-person communication, it was important to allow for online data collection.

Knowledge Translation and Diversity

There are several models for knowledge translation (KT), with the main commonalities being that research findings and resultant recommendations need to be: deemed useful by all users in the implementation context for successful uptake, be readily usable (e.g., jargon free,

easily digestible, low burden on the end user), and implemented in a timely manner (e.g., the 7P's Framework for Stakeholder Engagement, Concannon et al., 2014; the Knowledge to Action Framework, see Graham et al., 2006; the User Context Framework, see Jacobsen et al., 2003; the Interactive Systems Framework, see Wandersman et al., 2008). Consensus between these frameworks includes the presumption that knowledge in and of itself is of limited value without stakeholder engagement, and a full understanding of all parties involved, their lived experience, the multiple contexts in which they exist, and the different views that diverse users have on these contexts is essential. This understanding is especially relevant when working with diverse groups who historically have been missing in research (Camden et al., 2015; Dew & Boydell, 2017; Elsabagh et al., 2014; Woolf et al., 2016b). Within the KT literature, the term 'diverse' appears to refer predominantly to intergroups diversity (e.g., 'disability' vs 'non-disability' populations, minority vs majority populations, etc.), and sometimes positioning 'diverse' groups as homogeneous. This is changing, however, with increasing focus in intersectionality in diversity, which emphasizes that marginalization and discrimination is not single-factored, but that "systems of inequality based on gender, race, ethnicity, sexual orientation, gender identity, disability, class and other forms of discrimination 'intersect' to create unique dynamics and effects" (The Centre for Intersectional Justice, 2023), and emerging recommendations for addressing intersectionality within IKT research (see The Knowledge Translation Program's [2023] 'Intersectionality & Knowledge Translation: Intersectionality Guide').

Within the ASD community there is also significant intra-group diversity or heterogeneity. This diversity extends beyond the heterogeneity of ASD 'traits' and into social implications as well. This is perhaps best seen in the shift from person-first to identity-first language among autistic adults consistent with the neurodiversity movement (Kenny et al., 2016;

Taboas et el., 2023). However, healthcare professionals still tend to prefer person-first language (adult with ASD) which may reflect their conceptualization of the deficit-focused medical-model of autism (Kenny et al., 2016; Taboas et al., 2023). Within the autism literature and community, there is tension between a) clinical/behavioural research that seeks to classify individuals with, or traits of, autism in order to intervene, and b) the neurodiversity movement which emphasizes neuro-differences over deficiencies, and calls on society to change how it positions these differences (Fletcher-Watson, 2022; Gyawali & Patra, 2019; Shuck et al., 2022).

Although in many respects the neurodiversity movement is in line with the human rights of autistic adults and fostering acceptance in their communities, there are also concerns that the neurodiversity movement best serves individuals who have fewer challenges that interfere with everyday "functioning" (Gyawali & Patra, 2019). Fletcher-Watson (2022) notes that some danger lies in assuming that the neurodiversity model is by definition a strengths-based model, which may leave significant numbers of autistic adults with unmet needs because "importantly, while not all neurodivergent people will also identify as disabled, neurodivergence does not deny disability" (p. 419). Therefore, even within a neurodiversity model, individual differences need to be fully explored and understood prior to making recommendations on behalf of said group. Due to this heterogeneity, the KT goals at the outset of this study were to be determined by the data itself, with the priority to fully understand diversity in autism, and the diverse contexts in which they exist and potential implementation barriers rather than focus on the development of an easily digestible "one size fits all" set of recommendations or tools if they came at the expense of reflecting diversity.

Method

Participants

Participants were 28 Canadian and American adults who self-reported as having received a formal ASD diagnosis (including those previously diagnosed with Asperger's Syndrome, Pervasive Developmental Disorder–Not Otherwise Specified, or High Functioning Autism Spectrum Disorder). They must have been able to answer study questions in English. Furthermore, they were at least 20 years old to ensure they had at least 2 years of experience in the adult healthcare system. As per the goals of the study, they must also have been able to navigate healthcare independently, irrespective of their choice to include a third-party support person in any or all aspects of care (see Table 1 for sample characteristics).

Participants were recruited online via recruitment posters and announcements placed on social media and webpages that cater to autistic adults across Canada and the United States (see Appendix A). Recruitment postings informed potential participants of the opportunity to participate in a study that would ask them about their experiences in healthcare. Recruitment numbers were not pre-determined, but rather recruitment continued until the coding of the data reached a point of saturation, wherein including additional participants no longer led to the identification of new themes, experiences, and meanings, and the emerging codes reached a point of stasis (Gaskell, 2000).

Data Collection Procedure

Upon choosing to participate, individuals were sent an email with the link to Qualtrics (online survey software) where they found the letter of informed consent (Appendix B). Those who provided informed consent electronically gained access to the first phase of the study consisting of a basic demographic questionnaire, as well as the *Autism Spectrum Quotient* 10-item scale (AQ-10, Allison et al., 2012; Autism Research Centre, 2015; Appendix C). The demographic questionnaire served to gather basic demographic information (e.g., gender, major

health conditions, types of HCPs encountered) and confirm eligibility (e.g., can comfortably respond in written English, is at least 20 years old). Furthermore, the demographic questionnaire asked questions about the individual's ASD diagnosis, when the diagnosis was conferred, and who provided the diagnosis. The AQ-10, a brief measure designed to screen adults for ASD, was administered to help provide support to participants' self-report of diagnosis (Allison et al., 2012). A cut-off score of 4 or higher (Sensitivity 0.96; Specificity 0.70) was chosen as supporting self-reported ASD diagnosis, in addition to responses in the demographic questionnaire (e.g., whether or not the person who conferred the diagnosis was a professional capable of doing so, such as a psychologist). All participants scored above the cut score of 4 (average score 7.2; range 4-10).

Participants who met the eligibility criteria received an email with a link to the five main study questions (Appendix D). Three questions were designed to examine the participants' experience in healthcare communication in general, one question explicitly referred to communication with a third-party, and one explicitly referred to relationships. Recruitment began in the Summer of 2020, following the emergence of the COVID-19 pandemic. A question pertaining to how the pandemic had impacted healthcare was included as an optional sixth question. These questions were open-ended in order to meet the goal of understanding the participants' unique experience from their point of view, with the freedom to discuss the priorities that they identify (e.g., "If you could tell your doctors and other healthcare professionals about your individual communication needs, what would you tell them?" as opposed to a leading question such as "what don't doctors understand about how you need to communicate?"). Although relatively vague by design, prompts were provided to help participants who may need more guidance or structure in answering these questions (see

Appendix E for an example). Questions were presented to participants in an alternating order to ensure the order of the questions did not consistently bias responses. Participants were free to leave and return to Qualtrics to answer at their own pace. As per the consent form, participants who did not complete the study questions within two weeks of beginning it were contacted by email to remind them that they had study questions in progress. Any individual who did not complete the study after this reminder was considered to have withdrawn from the study and not contacted further.

Responses were highly varied in length and detail. Previous research has found that both interview and online data collection with autistic adults has been informative despite a wide range of response lengths, and that online data can result in rich, long-answer responses typically attributed to in-person interviews (Muller et al., 2008; Sciutto et al., 2012; Wright, 2016). In order to be inclusive of all participants irrespective of their communication style and abilities, responses were coded for both content and meaning (as described below), rather than excluding responses that may otherwise be deemed 'too short' for inclusion.

Once the data reached a point of saturation, preliminary findings were written up and disseminated to the participants via an emailed link to Qualtrics. Participants were given the opportunity to confirm or clarify whether I had captured their intended meaning, and comment on the preliminary findings in general. Twenty of the 28 participants opened the link to review the findings, but only one individual chose to make a comment ("I think a lot of this applies to doctors for the general population as well"). It is worth noting that due to COVID-19 and recruitment delays, some individuals were contacted up to 18 months after their initial participation, which may have contributed to low investment in responding.

Analysis

Constant Comparison Analysis

Upon removing all potentially identifying information and assigning pseudonyms, the written responses became the documents for analysis. Analysis was conducted through constant comparison analysis—a coding and analytic GT method that transcends the different iterations of GT frameworks (Bryant & Charmaz 2007; Charmaz 2006; Corbin & Strauss 2008; Glaser & Strauss 1967) —wherein data are coded as they are collected, newly coded data is constantly compared to previously coded data, and the categories emerge, expand, collapse and/or otherwise change as dictated by the addition of newly coded data.

Initial Coding. Initial coding occurred in two phases. First, line-by-line coding of a participant's entire response for what I refer to as 'content' was done to get a general picture of what participants conveyed, while still remaining vague enough to remain open to multiple possible interpretations and meanings (Bryant & Charmaz 2007; Charmaz 2006). These codes were simple and captured initial impressions. As a fictitious example, some participants may provide responses such as "I don't talk because my doctor rushes me," while others may write out multiple paragraphs about their experiences with being rushed and how they were impacted by those experiences. At this initial stage, both would be coded for the content "rushing limits communication." Although these codes do not speak to meaning, I included them in order to ensure that all participants, including those whose communications preferences or abilities do not lead to the rich data typically favoured in qualitative analysis, were valued and their contributions included (rather than discarding data that was deemed 'too short' for more in-depth analysis).

Second, the longer and more in-depth responses were coded for what I refer to as meaning. Continuing with the example of rushing, one individual may state, "my doctor rushes

through our appointments, quick and to the point without me having to say much. It is such a relief that my doctor knows to end the appointment quickly before my anxiety becomes unbearable." Another may state, "I am about to give up on my doctor. She rushes me through so quickly I don't have time to tell her anything." Although the content of both could be coded as "rushing limits communication," the meaning of the former could be coded as feeling cared for and understood within communication, whereas the latter coded as feeling hopeless and dismissed within communication. In both content coding and meaning coding, constant comparison began immediately, with new data from new participants continuously informing the dynamic and evolving sets of codes and categories, rather than initial codes and categories remaining static throughout the analysis.

Focused coding. In the second phase of coding, focused codes were applied to documents that had previously been coded for meaning. Focused coding involves a more in-depth examination of the initial codes (Bryant & Charmaz 2007; Charmaz 2006). This includes focusing on the most common or significant codes and drawing links and comparisons between participants' data, condensing the initial codes into more conceptual categories and themes. However, initial and focused coding are not entirely sequential, and as initial codes change during the process of constant comparison, so do the focused codes, and therefore going back and forth between the two is required throughout.

Memo writing. Memo writing, a process by which researchers document their thought process during analysis, can help researchers move from codes to conceptual categories, highlighting connections between processes and concepts, the condition in place for these processes or changes to occur, and how these concepts ultimately support an argument or finding (Charmaz, 2006). I wrote memos throughout the coding process.

Analysis was considered complete once the constant comparison of all data (including codes, memos, categories, participant feedback, and member checks with other coders) reached a point of stasis. At that point, resultant overarching themes from within and between participants data became the findings of the study.

Rigour

Credibility

Similar to internal validity, credibility reflects how accurately the findings capture the participants intended meaning (Houghton et al., 2013). Credibility checks consisted of having participants review preliminary findings and confirm, correct, or otherwise comment on their accuracy. Member checks with other researchers (i.e., faculty member and post-doctoral researcher) also occurred to ensure they agreed that the findings were indeed grounded in the participants' data.

Theoretical Sensitivity

Study questions were developed with theoretical sensitivity (Giles et al., 2013). Although it is important that questions are open-ended in order to allow participants to explore the issues that *they* rather than the researchers prioritize, it is also necessary to base questions on experiences and phenomenon that are important to the participants. The choice to ask questions about communication, relationships, and third-party engagement in healthcare was sensitive to limited but emerging prior research that autistic adults often feel misunderstood by others and have communication challenges in general, all of which can impact the quality of PCC. Furthermore, questions were adapted from similarly formatted questions that have led to rich data in the past with the same population (Sciutto et al., 2012; Wright, 2016), giving me

theoretically sound reason to believe that the format of the questions in the current study would also be successful.

Furthermore, questions were carefully crafted to avoid bias in terms of predicting what participants may say. For example, the assumption that autistic adults have negative communication experiences in healthcare would be theoretically sound (e.g., Nicolaidis et al., 2015; Nicolaidis et al., 2012; Wright, 2016). However, I made no such assumptions about what participants would report, and therefore used neutral language and phrasing (e.g., "What do you think is important for HCPs to know about how you communicate?" not "Why do you think communication with HCPs is so challenging?"). Although one of the questions related to negative experiences, another one purposefully related to positive experiences, ensuring I was not 'pulling for' negative experiences in a biased way. In sum, although I crafted the questions, I did not contradict the goal of having the participants define the direction of the data and findings. In the words of Giles and colleagues (2013), GT researchers need an "open mind [not] an empty head" (p. E29).

Transferability

Similar to generalizability, transferability is the degree to which the research findings may be relevant or 'transferable' to contexts beyond the study sample (Houghton et al., 2013). Similar to my previous study, to capture the diversity of the autism population and the breadth of possible unique healthcare experiences, the sample was relatively large (compared to other qualitative studies) in order to reach saturation. This increased the chances of diversity within the sample. Consequently, common, consistent or repeated themes that transcend this diversity are more likely to apply to diverse contexts. However, this idiographic approach was specifically designed to delve into a deeper understanding of individual experience, allowing for a depth

often missed by nomothetic approaches. Rich description of the contexts, conditions, and perspectives related to individual experiences can help give understanding as to how individuals experience specific contexts, and providing these rich descriptions within the findings allows readers an understanding of the specificity of the experience context.

Validity

For the present study, I used Hammersley's (1987) definition of validity, meaning "the accurate representation of a phenomenon that an account is *intended* to describe, explain, or theorize" (Hammersley 1987 as cited in Hall & Callery, 2001, p. 258). Validity was promoted through the use of online methods (in which autistic adults have reported feeling understood), as well as credibility checks (where participants were given the opportunity to directly confirm that I either captured their intended meaning or provide correction).

Audit Trail

I kept transparent records pertaining to the analysis and interpretations (Anfara et al., 2002), providing a clear and stepwise trail that other researchers can follow to see how codes led to categories, and subsequently to findings, allowing for an audit of my analysis (Lincoln & Guba 1985 as cited in Anfara et al., 2002).

Reflexivity and Relationality

As a part of memo writing, I intentionally noted and reflected on my influence on the research (reflexivity) and the power and trust within the participant-researcher relationship (relationality) as a non-autistic adult conducting research with autistic adults (Hall & Callery, 2001). I attempted to design the study in a way that created a balance of power, such as choosing an online method which many autistic adults feel empowers them in communication (Brownlow,

2010; Mitchell, 2008; Smith & Sharp, 2013; Wright, 2016), leaving the priorities in the data for the participants to define through GT methodology, and ensuring credibility.

Similar to past research (Wright, 2016), participants provided responses that varied in depth and length. Although richer responses allowed for more in-depth analysis of meaning, all responses were given equal weight through the coding of content. This meant that those who may have struggled to provide in depth responses did not have their responses minimized or marginalized either by myself (i.e., I did not exclude short or surface level responses) or other participants (i.e., the *content* of responses provided by participants who provided more context, meaning, and detail did not overshadow the content of participants who may have struggled to elaborate in their responses).

Ethics

Ethical approval was obtained through the University of Manitoba Psychology Sociology Ethics Board (P2020:049), and that approved protocol was strictly adhered to throughout the study.

Findings

Participant's responses were diverse in terms of content, style and depth. Some responses were very direct (e.g., single themed responses, point form, concrete, minimal elaboration) and others were more elaborate (e.g., multi-themed responses, long paragraphs with real life examples, full of context and their emotional experience of events). Some participants had a consistent response style across questions, others varied across questions and provided longer and richer responses depending on the question they were responding to. Many responses were multi-themed and attempts to tease apart themes as independent constructs did not do the complexity of participants' experience justice. Findings below are presented in a quasi-

cumulative order, with each section increasing in complexity by way of integrating the previous section's findings where applicable. Note that this structure was imposed as an editorial decision to provide clarity to the reader and is not a reflection of any one given theme being more relevant than another. Preliminary discussion is embedded by way of summary after each major findings section.

Healthcare Relationships

Participants discussed multiple factors that contributed to a positive relationship with their HCP. Although participants varied in terms of what they wanted or needed from their HCP, they generally reported that the quality of the healthcare relationship in and of itself was an important factor in their health and healthcare.

Interest in the Patient as an Individual

Participants reported having positive relationships with HCPs who were invested in them and took an interest in them as a person. For example, Sonia described what makes her relationship with her HCP so successful, and stated:

> *I do think my PCP* [primary care physician] *cares a lot about me. He remembers details of my life and my story. He told me a few years ago that I should be very proud of myself. He said that, when I was in high school, he really had doubts that I would be able to be successful and finish college and get a job. He said that I've made incredible progress. Much of that progress was finding the right medication and being correctly diagnosed to learn about my problems properly.*

Similarly, when discussing the strong relationship he has with his HCP, Nicholas wrote:

> *He is definitely a caring person. He asks about my well-being and seems to clearly remember what we talked about the last time. He even remembers things I mention about*

> *my personal life and follows up with them to see how they are going…I can no longer worry about health issues I have at the moment because I know he will take the time to come up with what is best for me.*

Participants like Sonia and Nicholas not only appreciated that their HCPs took an interest in them as people, but also drew a link between the HCP taking that personal interest and making progress with their health and healthcare concerns. Participants also reported that HCPs can convey personal interest in the patient through their actions, including following up with the patient, ensuring the patient books future appointments, taking time to understand the patient, and providing alternatives when they do not have the time. For example, "*my psychiatrist absolutely cares for me. She's very nice and makes sure I come back to see her soon (otherwise I'll wait too long to book an appointment)"* [Yvette], and "*I like him because in most cases he calls me to ensure that I am okay and to follow up to see if I am taking the prescribed medication on time"* [Moe]. Some participants noted that having a positive relationship with their HCP was more nuanced than their HCP simply being nice, friendly, polite, or otherwise having positive bedside manner, but that positive relationships depended on the HCP's *genuine interest* in them as a person. This is best described by Paula, who wrote "*my biggest struggle with healthcare providers is when I can tell they are not genuinely curious about me or my concerns. They may be nice and polite, but still dismissive. The worst are explicitly dismissive."*

Conversely, participants reported having negative relationships with HCPs who did not take a personal interest in them. For example:

> *My first doctor was unsuccessful since he was not understanding and he could not make an effort to understand me. When I attended for a healthcare appointment he pretended being so busy and he attended to me as the last person even when I arrived earl* [Jason],

and "s*he is not total [sic] interested to me during a healthcare appointment and when she writes a note to me she writes in a handwriting that I could not read"* [Olivia]. For participants like Jason and Olivia, feeling not only that they were poorly understood but that their HCP was not invested enough in them to make the effort to understand contributed to a negative healthcare relationship.

Caring, Accepting, and Supportive

Participants reported having positive relationships with HCPs who they perceived as caring and supportive of them and their needs. For example, when describing why she had such a good relationship with a specialist, Fran stated, "*the endo specialist moves her chair to sit beside me and reassure me if I get scared and start to cry during an in-person appointment."* For participants like Fran, having HCPs recognize that they were struggling and offering support led to stronger healthcare relationships. Similarly, when participants had needs that may not be typical of most patients, participants expressed that having these unique needs met in a caring manner was important. For example:

> *When I am having a conversation with him and I happen to fall asleep he wakes me up in the most gentle way. Due to his willingness and caring nature, my health status has greatly improved and I really appreciate it* [Moe],

and "*he helps me in all aspects of my health life and also encourages me when I am depressed"* [Aisha]. For participants like Moe and Aisha, having an HCP who treated them in a caring manner to support them in engaging in the appointments and encouraging them in general contributed to their health and healthcare experiences.

Trust and Safety

Several participants noted a connection between feeling trust and safety in their healthcare relationships and their health and healthcare. For some participants, low trust was explicitly linked to disengaging from healthcare and healthcare advice. For example, "*I didn't trust a doctor who prescribed me meds without explaining what they would do so I didn't take them...which obviously didn't end well...but it isn't something I do intentionally in the moment"* [Claire]. Similarly, Wendy stated *"trust is key, and as I feel that isn't there, I tend to avoid healthcare interactions and this has caused me to suffer worse than I could have."* For participants like Claire and Wendy, a lack of trust in the HCP was linked to a lack of trust in the healthcare treatment being provided, and in turn had a negative impact on health outcome (i.e., not "ending well").

Conversely, trust was linked to feelings of safety and confidence in healthcare. For example:

> *I feel like I'm allowed to cry and be scared with her without risking her becoming dismissive of my physical pain and deciding it's 'just emotional'. She takes both my physical and mental health seriously…I feel safe with her. Patients should be allowed to express vulnerability without being treated as incompetent* [Fran],

and, *"he is easy to trust. This relationship puts me more at ease knowing I have a quality doctor to go to"* [Nicholas]. For participants like Fran and Nicholas, perceiving HCPs as trustworthy led to feelings of safety and reassurance in their relationship and their healthcare. Overall, the relationships that were perceived as the most positive and most beneficial were those that included a personal and genuine interest in the patient, made one feel cared for and supported, and built trust. Some participants, however, were either unable or chose not to provide specific reasons as to what made for a negative healthcare relationship, but nonetheless identified that

negative healthcare relationships were a barrier to healthcare. For example, "*I had a very poor relationship with my healthcare provider and I don't like her because she was inhuman. I quited* [sic] *from my healthcare appointment with her"* [Natasha].

Relationship Summary

Overall participants' responses highlight the importance of positive healthcare relationships, and the consequences of negative healthcare relationships, on their health and healthcare. Specifically, participants perceived their healthcare relationships positively when they felt that their HCP was genuinely interested in them as a person, and that they cared and were supportive. These factors in turn fostered trust and safety, which participants noted were essential to positive relationships.

Communication with HCP

Participants identified a variety of ways in which communication with their HCP either facilitated or hindered their health and healthcare experiences.

Conveying Information

Participants were highly varied in terms of the level of information that they wanted, with some wanting simple information, finding too much information confusing and overwhelming, and others wanting complex information, feeling that simplified information was insufficient. Irrespective of the type of information preferred, information exchange was linked with how participants perceived their healthcare relationship.

Wanting Simple Information. With respect to how and what information is conveyed, participants had a wide range of preferences and needs. Some participants focused their responses on *what* they wanted in terms of information from their HCPs. For example, Rhoda was specific in wanting her HCP to "*highlight abnormal results, new meds, new diagnoses, and*

[include] follow-up contacts on the pages." However, most participants focused on *how* they wanted information conveyed by their HCP. Some participants identified the need for simple and concrete information with clear language. For example:

> *My other communication need is that I like things being explained to me in a simple and easy way so that I don't spend so much time trying to think what exactly people mean. The doctor has to asks [sic] me a question me in a simple way to avoid confusion. We prefer not to use difficult language with a lot of vocabularies* [Aisha].

and

> *[My HCP] uses a precise statements [sic] when giving instructions and in some occasions he repeats the statement two to three times until I understand what he was saying. I felt grateful because of his effort to make me understand him* [George].

For participants like Aisha and George, simple information is key in terms of avoiding confusion and being understood. Furthermore, participants like George drew a clear link between the HCPs effort to tailor communication with patient needs and their positive feelings towards their HCP (e.g., gratitude). Some participants also noted the importance of providing only essential information. For example: "*provide a better environment if I cannot listen or understand them. Do not overload on details in one blow. Divide them into sections. Refer me to someone else who can communicate more effectively"* [Yuri]. For participants like Yuri, it was not solely about the type of information, but implicit within his response is that the onus is on the HCP to be able to manage the environment and facilitate effective communication (i.e., if not, then find someone who can).

Wanting Detailed and In-Depth information. In contrast to the participants quoted above, some participants wanted detailed and complex information about their health and healthcare needs. For example:

> *What helps me is being able to have all the information possible before making a decision or understanding something. I may dive deeper into some subjects than feels typical for [my HCP], and it's both because I'm a compulsory seeker of knowledge about things I'm learning about and because I want to find ways to treat my untreated pain and fatigue. So I'm going to ask a lot of questions that she may not know answers to and I may even present information to her that I've found from reputable sources she's not aware of because she treats 100s of diseases—so there's no way she can know exactly everything about mine…I appreciate that she's knowledgeable and cares about both my desire for knowledge and engaging like an equal, and that she also presents information I didn't already know* [Lee].

and

> *Knowing that a professional is using accurate terminology helps me to understand the situation, is more stimulating because I usually learn something new, and it makes me feel more comfortable because I know I can trust them* [Claire].

For participants like Claire and Lee, fully detailed and complex information was important not only to satisfy their desire for knowledge about their healthcare, but also had implications for their relationship with their HCP (e.g., shows that HCP cares, contributes to trust). Some participants were more explicit in linking the provision of information with a positive HCP relationship. For example, Thomas wrote, *"I have a strong relationship with my healthcare*

provider…This relationship impact [sic] *me in a positive way because he gives me all the information about autism and I am able to know more about my health status."*

Conversely, some participants commented on a lack of detailed information. For example: "*I don't like when doctors dumb down their explanations to me or hide things that would frighten most other people"* [Sonia],

and

> *As for help with medical conditions, I wish doctors would take the time to connect the dots of all of my disorders and find a link, [and] explain the pattern to me. I'm the type of patient who wants to know why this is happening and how X and Y diagnosis are related* [Yvette].

Overall, participants were very clear about the ways in which they wanted information communicated to them by their HCPs, as well as the type of information they wanted. Participants' needs and preferences were unique and varied in terms of simplicity/complexity, and level of detail. However, whether implicit or explicit, most participants referenced that the successful communication of information was related to a positive healthcare relationship.

Rushing Communication and Providing Too Much Information at Once. One of the most common themes that emerged with respect to communication was the negative impact of HCPs providing information too quickly and rushing communication. For example:

> *I have been facing a very hard time during the time I was having a conversation with a healthcare provider. He was speaking to me very fast and in long sentences and in most time I could not understand his full information…I have known him since I started anxiety diagnosis and behavioral therapy with him. His impatience* [sic] *nature made me feel very irritated* [Victor].

For participants like Victor, the amount of information and the pace at which it was being provided impeded their understanding of what was being communicated. Other participants brought up that even when information is fully understood, time is needed to formulate a response. For example:

> *What I would tell my doctor about my communication needs is that sometimes I take time to respond to a question or a statement and they should allow me to respond even though it takes time. If I would share my experience with a previous doctor I can say that things were not that good…She did not give me time to respond, most of the time she kept asking my partner to answer some questions that I could simply answer and this made me feel annoyed* [Moe].

For participants like Moe, not having enough time to respond, and not being granted the opportunity to respond on their own behalf when wanting to do so[3], contributed to poorer communication. Whether time constraints impacted taking in, processing, or responding to what their HCP was saying, in all instances participants linked inadequate time with negative healthcare experiences.

Participants who reported that they did have sufficient time for communication with their HCP also reported better healthcare experiences such as a good HCP relationship, liking their HCP, trust, and better health outcomes. For example: "*[In contrast to my former HCP,] my relationship with [my current] healthcare provider has been very good. He spends as much time as possible with me during care encounters and explains medical concepts clearly and in lay terms"* [Moe], and "*what I like about the doctor is that she was providing a long time for me to*

[3] As opposed to participants who explicitly preferred that support persons play a role in communication, see "Support Persons" section below

process the information" [Olivia]. Although participants like Moe and Olivia reported positive experiences related to having enough time, the majority of responses emphasized feeling rushed, and the negative consequences on understanding, processing information, and responding during healthcare encounters. Recommendations such as *"I would tell them also to give me time to process things and that might take time"* [Lynne], *"the doctor has to schedule a longer period during the appointment"* [Aisha], *"allow me to respond even though it takes time"* [Moe], and *"healthcare providers should schedule enough time for health appointments"* [Victor] were made repeatedly. In sum, a lack of adequate time was identified as one of the most prevalent concerns by participants.

Structuring Communication

Several participants noted challenges with knowing what to bring up in their healthcare appointments or feeling comfortable enough to bring up what they wanted to focus on. In some instances, this related to challenges starting discussions in general. For example: "*It is also sometimes better if the psychologist asks questions to help me get started talking. Sometimes I don't know where to start and executive functioning issues get in the way of initiating a conversation"* [Fran], and "*unless a professional notes I'm not doing well, I won't be able to express it"* [Yvette]. For participants like Yvette and Fran, it was important that their HCP ask specific questions and bring up specific topics and issues. However, not all participants needed this from their HCP. For example:

> *I don't really have a lot of communication issues. I am highly verbal (I'm the type of Aspie who talks TOO much), and I am very articulate about my opinions and feelings…I would say that the biggest communication issue I've faced would be that doctors tend to not believe me* [Sonia].

and, "*when I ask questions or try to dialogue…I get interrupted quite a lot, and then she answers a question I wasn't asking as she assumes she knows what I will ask, and/or she will get condescending"* [Wendy]. Participants like Sonia and Wendy felt able to express themselves but reported barriers in terms of HCPs 'allowing' patients to express themselves and believing what patients say.

Listening Versus Interrupting. Participants reported having communication challenges with HCPs who do not listen to what they are trying to communicate. Some participants specifically cited being interrupted as the cause of feeling as though they were not being listened to. For example: *"I would tell them to speak to me in an understanding way and take time to listen to what I say instead of interrupting in between my conversation, more of turn taking conversation"* [Lynne] and:

> *I finally see the Doctor and because her charting and everything is paperless and done on the computer, it makes me feel as if I'm not properly listened to, which seems to be the usually the case as I'm asked to repeat myself regularly or am misunderstood* [Wendy].

Some participants listed ways in which HCPs could improve their listening. Some of these were general recommendations such as "show us we are being heard" [Paula], and some were specific recommendations, such as "I would like my caregiver to listen to me and respond with language that shows they are listening. Example: using the words from my questions to answer me" [Beth]. These were in addition to the general recommendation of not interrupting or rushing the patient.

Written Communication. Whether it be in in response to feeling rushed, feeling comfortable or able to initiate conversation, to manage the amount and type of information being provided, or to support challenges related to verbal and non-verbal communication, participants

consistently referenced written communication as supporting better communication. In some instances, participants wanted HCPs to provide them with information in written format (e.g., providing lists of information and instructions, summaries of discussions; having a list of 'feeling words' on hand that patients could use to help them describe what they are feeling). For example, *"provide follow-up information in a clear list, with all information on one or at the most 2 pages*" [Rhoda]. Participants like Rhoda wanted written information to be provided to them by their HCP. For others, writing down notes helped facilitate the communication interaction itself. For example:

> *Sometimes [my HCP] communicates to me very fast and she uses many word in a single statement. I usually finds it hard to process the information so I started carrying a note book during the next appointment* [Olivia],
>
> *I struggle to find words to describe my emotions and bodily feelings so maybe ask for help with a list of words that indicate bodily feelings* [Adam],

and

> *Communication with my second doctor was very good and there was not much struggle in understanding one another. She preferred me to write down a statement other than having verbal communication with her. My health status have improved [even] though I still stammer* [Jason].

Challenges with Non-Verbal Communication

Participants listed that they had challenges with non-verbal communication that negatively impacted their healthcare. Participants cited body language, hand gestures, facial expressions, and tone of voice as confusing and complicating communication. Some participants reported that misunderstandings related to non-verbal communication led to feeling stereotyped

or misunderstood by HCPs. This was particularly true with respect to a lack of eye contact. Participants noted that meeting the expectation of maintaining eye-contact made it more difficult to understand what was being communicated. For example:

> *I would tell them that presence or absence of eye contact is not a reliable indicator of how much attention I'm paying. Sometimes I default to eye contact if I don't feel that the provider will listen to me if I don't make it (autistic camouflaging). With people I feel comfortable with, I might make eye contact, but I also might not because I trust that they won't take it as a sign that I'm being rude or not listening* [Fran].

For participants like Fran, eye contact was not a natural facilitator of communication, but rather something that she felt was necessary to avoid being perceived as not paying attention or being rude. Others noted that a lack of eye contact may be sign of other challenges (e.g., anxiety) and that not making eye contact may be a way of improving understanding of verbal information or managing anxiety, rather than evidence that they are trying to avoid communication. In addition, some participants noted that when they fail to understand non-verbal communication, they feel that they are dismissed by HCPs because of it. Either for not "paying attention" or out of poor understanding/frustration on the part of the HCP. For example:

> *Sometimes she could only speak to me with body language and she expects that I could understand what she is saying. On such occasions when I don't respond to her body language as she expects she orders me to leave the room on a high tone* [Natasha].

Communication Summary

Participants noted both strengths and challenges related to communication. Participants' reports were unique and varied in terms of their needs and preferences related to how much information they wanted from their HCP, the type of information they wanted, and whether they

wanted their HCP to take the lead in structuring communication as opposed to having the freedom to lead the conversation. Within these varied responses, participants were generally consistent in identifying being interrupted, not feeling listened to, and feeling rushed as barriers to communication, and incorporating written communication and having adequate time as facilitators to communication. Finally, participants who reported nonverbal communication challenges not only noted the challenges posed to communication in general, but noted feeling that nonverbal challenges were not well understood by HCPs (e.g., lack of eye contact being mistaken for not paying attention, not picking up on nonverbal cues being met with frustration/dismissal). Overall, irrespective of the diversity and commonalities in responses, participants were able to clearly communicate within their responses what their strengths, challenges, preferences, and needs in healthcare communication were.

Support Persons

Participants were highly individualized in terms of what they wanted from support persons who may accompany them in their healthcare and the role they believe support persons should play. Participants provided responses ranging from wanting support persons to attend appointments on the participant's behalf all the way to not wanting support persons at all as that violated their privacy and autonomy. However, most participants wanted support persons to fulfill a role somewhere within these two extremes.

Who are Support Persons?

Some participants reported that they did not have a support person with them because they did not feel it was necessary. Others reported that it felt like a violation of their privacy. For example, "*I sometimes need rides to access care, but I still want and deserve privacy. I want to be alone when I meet with my doctor*" [Beth], and "*though it is nice having company, I cannot be*

completely honest when a family member is there. I used to smoke cigarettes but would always lie about it when my mum was in attendance" [Yvette]. The vast majority of participants reported that they were accompanied to their healthcare appointments by a family member (a parent or spouse), with only one person indicating a non-family member (a friend) accompanied them, and one person stating they wanted support but did not have anyone in their life who could fill that role. When discussing support persons, participants' responses focused on support persons' level of knowledge about ASD and the patient, as well as knowing the role that they are expected to play during the healthcare encounter.

Support Persons Need to be Knowledgeable

Participants reported that good support persons are knowledgeable about ASD and know them very well as an individual. Some participants were very clear that they needed the support of someone who knew them well but did not provide details as to what that support looked like. For example: *"It is also important to get educated on the characters and behaviors of people with autism"* [Moe], *"he should have knowledge on how to care for an autistic person"* [Victor], *"since I cannot communicate effectively, he should understand my challenges in communicating and he should find a way to understand me"* [Jason] *"they should understand challenges of an autistic person and treat them with care and respect"* [Natasha], and:

> *People who help and accompany me during my healthcare appointment should understand and know how to take care of an autistic person. They should have knowledge of how to communicate effectively to a person with autism and be educated on how to handle and care for an autistic person* [George].

These participants emphasized *that* support persons 'should' know but did not convey *what* they should know beyond having a knowledge of ASD or that they 'should understand' how to

communicate. However, themes of care, respect and understanding did emerge repeatedly within these responses. It may be that the very challenges these participants face in communicating with their HCP also make it challenging for them to express what specific role they would like their support to fill. Some participants noted the importance of a support person knowing them well, and not just having knowledge about ASD. For example:

> *I've chosen my parent to accompany me because they know first hand how I went through life under ASD. But they don't forget that the one who knows most about my ASD is me. [In general, it's important for a support person to know about] ASD so they do not miss the point, and know me so they don't stereotype. That all probably sounds too much wishful thinking because the only way for someone [who is not family] to understand my case is to keep in touch with me regularly, and that is just too taxing* [Yuri].

Participants like Yuri explicitly highlighted the importance of having a support person know them very well in terms of respecting their autonomy and preventing being stereotyped, as opposed to a mere knowledge of ASD itself. For others, the importance of having a support person know them well was more nuanced, and emerged through participants' highly diverse and unique responses regarding what role they as individuals wanted their support person to fill.

Support Persons Should Understand Their Role

Speak on Patients' Behalf. Some participants discussed that they want supports to communicate and perform other functions (e.g., make appointments, fill prescriptions) on their behalf. When asked about what makes for a good support person, responses included:

> *My mother speaks with the doctor on my behalf in some instances, When we get in the appointment venue, she was leaving me in the car then she go to speak with the healthcare provider before she requests to see me in-person"* [Olivia],

and, "*when my doctor doesn't require my physical appearance, she (mother) goes on my behalf for my medical consultation"* [Natasha]. Participants like Olivia and Natasha wanted their support to quite literally attend appointments on their behalf. In some cases, participants also opted to have their support person make decisions on their behalf. For example, Xavier wrote, "*I let my mother and the healthcare [provider make] decisions when needed. I still have my part when it comes to medication.*"

Speak only when needed. Some participants discussed that they have communication challenges that they wanted support persons to actively support, especially with respect to what details are relevant to mention, clarifying what the patient means when speaking to the HCP, clarifying/rephrasing what the HCP is saying, fostering personal insight, and knowing what questions to ask. For example:

> *My wife participated in my diagnosis and was apparently crucial to convincing the psychologist that I had ASD. My wife didn't actually think I had ASD, so that was interesting. She provided responses to questions that gave the psychologist an outside view of what I'm like. The psychologist had told me that she was about 80% sure I was autistic prior to talking to my wife but the personal interview made it pretty clear. I've been with my wife for about 14 years. Her participation did seem to be helpful as I suspect that I don't see myself the way that others see me, and she knows me well. She can answer questions that I may be less aware of* [Bert],

and

> *The only other person I can remember who has attended doctor's appointments with me in recent years is my mother. As my mother, of course she has always known about my aspergers and has seen how I interact and manage most of the time. She knows that I*

> *don't always explain things fully and may not ask enough questions to clarify things. She is a person who is usually very talkative and wants to know things, so she has been very helpful in doctor's appointments with me* [Nicholas].

Responses from participants like Bert and Nicholas contained the implicit message that supports fill in communication gaps based on how well they know the patient as a person and what their specific needs and communication style are. So it is not so much a specific task that they want their support to complete (e.g., make decisions, take notes) but rather to address communication needs as they arise in the moment (e.g., answer questions about which the patient may be "less aware", ask "enough" questions, etc., but it is up to the *support person* in those moments to identify what the patient may be unaware of or what questions need to be asked). Knowing the person well will facilitate this.

Support Persons and Patient Autonomy. Some participants stated that they wanted a support person there to speak up in the face of marginalization. This theme was less related to wanting the support person there for their own communication challenges, and more to fight perceived discrimination from HCPs. For example:

> *People who might help me need to understand that I don't want them to talk over me or instead of me, but to amplify and reiterate what I am saying if the healthcare provider doesn't believe me…I need her to help keep me calm but also because her communication about me sometimes gets listened to more than mine. Since I'm autistic with anxiety disorders, I am not seen as a reliable narrator of my own experiences. I wish this were not so, but in the meantime, providers need to not send her out of the room without even asking me* [Fran].

Although the phenomenon of not feeling believed will be explored further (see Feeling Dismissed section below), it is important to note here that for participants like Fran the support person did not need to speak up to address communication challenges on the patients' part, but rather to overcome the barrier of feeling dismissed by the HCP. In some cases, however, support involvement was in and of itself seen as having their autonomy dismissed. For example:

> *If I would share my experience with a previous doctor I can say that things were not that good. First, I did not know her since it was my first time there and she did not give me time to respond, most of the time she kept asking my partner to answer some questions that I could simply answer and this made me feel annoyed* [Moe].

and

> *If someone were to come with me I would probably let them know to not answer the health care staff if they ask them questions if they are questions that could be asked directly to me. I have had experiences in the past where physicians would ask my friend a question about me that I could answer myself. I worry that people will underestimate my independence and doubt my ability for autonomy* [Peter].

For participants like Fran, it was helpful for their support to speak up to reinforce what they as patients were saying, but for other participants like Moe and Peter, the support person speaking up or answering questions undermined their autonomy. Further, it would appear that in some instances this practice of the HCP consulting the support person directly may be related to previous discussed communication challenges (e.g., Moe feeling able to respond *if* he were provided more time to respond). This suggests that asking the support person questions directly may be how some HCPs attempt to get around (rather than support) communication challenges, and in doing so they dismiss the patient's voice and autonomy.

Supports Should be a Calming Presence. Some participants reported that the role of a support is to help them remain calm and feel emotionally supported, while remaining a relatively silent presence. For example, "*understanding that I can often get stressed at a doctor's office. Help me by being calm and stuff. I'd really only bring someone whose presence is itself calming"* [Adam], and:

> *It would be really helpful to just have a calm and supportive presence. To not ask too many questions, just understand what may be going on and hold space for that. If there are other small things you can do to help me get ready, that is a big help* [Paula].

and

> *Usually, I just like to have someone else there with me. If I can have someone who I know and trust it makes the situation a million times easier. The best situation is when I can just focus on their breathing or something, but, for that to work, they have to be completely normal, not freaking out because I am freaking out. The most annoying thing someone could do would be speaking for me or trying to make small talk to "keep my mind off of it." It is okay if I get overwhelmed. I know how to deal with it* [Claire].

For participants like Paula and Claire, just having the person in the room was in and of itself helpful, and they did not want the support to take any specific action.

Support Summary

Most participants reported having a family member accompany them to their healthcare appointments to provide communication and moral support. Participants were highly varied in terms of what they wanted from their support person, ranging from wanting a support person to speak on their behalf (sometimes without them even being present) all the way to wanting a support person to remain largely silent and provide more passive emotional support. Within this

range, some participants felt the need for supports to speak up in order to prevent the patient from being dismissed, while others felt that supports speaking up in this way contributed directly to having their autonomy dismissed. This speaks to the participants' need to have a support person who knows them well enough to understand their specific needs and preferences, in addition to having someone who has strong knowledge of ASD itself. Some participants did not have a support present as they felt it was unnecessary or it violated their privacy. Overall, those who preferred or felt the need to have a support person present reported that having a support person made their healthcare experience better.

Impact of the Healthcare Interaction

When discussing the overall impact of their healthcare interactions, participants tended to provide richer and more detailed responses and personal accounts, including the context and consequences of their encounters. These responses were often multi-themed, drawing connections between relationships, communication, and support persons, and conveying a wholistic understanding of their experience.

Feeling Dismissed

The most consistent and common theme that emerged from the participant's responses about healthcare interactions related to feeling dismissed. They attributed this to not being believed, the invisibility of their struggles, the perceived demeaning attitudes of others, and the perceived disrespect within healthcare encounters.

Not Being Believed. The theme of not being believed emerged previously within participant responses about support persons (e.g., wanting a support person to reiterate what the patient was saying to support the patient being believed), but emerged more consistently within participants responses about their interactions with HCPs. This was attributed in part to HCPs

not listening or not understanding what they were saying, but also to HCPs not believing what they were saying. Some participants stated this outright. For example, *"doctors tend to not believe me about my mental health issues if they don't know me well"* [Sonia]. Sonia recounted an instance in which her HCP told her and her mother that her "meltdowns" were a form of manipulation to get out of going to school, rather than true distress, resulting in what she refers to as a 'meltdown' in front of him.

> *It was heavily implied that I was being manipulative, something that I am NOT. My OCD centers around "moral scrupulosity" and issues of right and wrong. So, when my PCP* [primary care physician] *thought that I was faking and manipulating my mother, that really upset me. As soon as he said that, I started tearing up and said to my mom, "Okay, NOW I'm going to get upset..." And my mom said, "Good! Show him what's going on!" My PCP got very quiet and serious after that. And he never doubted my mental health issues after that, either. The point of this is that I shouldn't have had to get visibly upset for him to understand* [Sonia].

Although this was one specific example, Sonia's experience of not being understood or believed was not an isolated incident.

> *It's like doctors don't believe me when I tell them things. They have to see me get upset to believe me. My verbal explanations should be enough. I shouldn't have to PROVE myself. This is why I fell through the cracks for so many years. Since then, my PCP really and truly listens to what I have to say. It took me getting upset for him to understand, but he knows now that if I say I'm upset about something, it's real…He takes my concerns seriously and listens to my ideas* [Sonia].

Sonia's account highlights what several other participants conveyed in their responses: that it was not only a matter of being able to clearly communicate to HCPs about their experiences, it was a matter of being believed and somehow being able to prove that they were being honest in what they were reporting. Other participants, however, recounted stories in which doctors did not question their honesty, but rather the accuracy of the patient's report on their experience. For example, Claire recounted a time in which she was in severe pain after having an IUD put in place.

> *I have also had pretty severe issues with professionals not listening to me. The IUD somehow shifted and I didn't know it at the time but I started getting completely unbearable cramps all the time. I told the doctor and he asked me if I was sure I wanted it out probably ten times and kept trying to convince me not to get it removed. He specifically told me it was normal if I felt cramps because I am more sensitive since I am autistic. Well, I stuck to my guns and when it was removed it took a chunk out of my cervix because it had turned sideways and implanted itself into the top of my cervix* [Claire].

Claire's story highlights that she knew something was wrong and abnormal, but she was not believed and her experience was "normalized" as being on the spectrum. Within Claire's story is a sense of vindication, she was right, something was wrong, and the HCP's lack of belief in her experience led to further pain and damage. Implicit in both Claire's and Sonia's stories is a sense of vindication, both participants were able to prove that their experience was 'valid' either by having the doctor bear witness to the distress (Sonia) or having a medical explanation to account for her reported experience (Claire).

Impact of Invisibility. Some participants spoke to the experience of feeling dismissed because of the invisibility of their challenges. For example, Paula cited the fear of feeling dismissed as being a barrier to open communication with her HCP. In discussing what she wished her HCP understood about her, she stated:

> *I may appear to be very open and engaged, but I am anxious and self-conscious. I will likely not bring up topics I am curious about because I feel too anxious or I feel rushed or like I wouldn't be able to articulate myself. I am also very concerned about what your response may be. Even if you are nice, I still worry your response may make me feel ashamed or dismissed* [Paula].

For participants like Paula, the fear of being dismissed is strong, to the extent that it impacts how she interacts with her HCP, whether or not they are actively being dismissive. Unlike Sonia and Claire, she may struggle to advocate and speak up against feeling as though she will not be believed, but instead remains silent to avoid the painful experience of potentially being dismissed. Paula's experience also speaks to a common phenomenon reported by many participants, which is that their challenges may not be visible. For some participants, this invisibility is what led to feeling dismissed.

Some participants reported a mismatch between how they present within a healthcare encounter and how they feel. For example:

> *Primarily, my issue with health care professionals, both physical and mental, is that because I tend to present a very calm exterior, they are at risk of assuming that I'm "Ok". If I raise a mental health concern, for example depression, my demeanour does not match that of a typically depressed person. I am able to work and can get out of bed in the mornings etc. I believe that some people on the spectrum simply don't display the*

> *common signs that professionals are looking for…Mostly, things are good, but I think it is difficult for him to judge my internal state and I am not so very good at expressing it. So when I say I think I may be depressed, my body language doesn't really match expectations. This mostly applies to psychological issues. I don't seem to display emotions the way that most people do. I've become more aware of this over time. I think this creates misunderstanding between my doctor and I* [Bert].

Other individuals discussed the impact of camouflaging on their interactions with their doctors and having their challenges dismissed.

> *I'm quite serious all the time, and I have learned to mask and perform how to act or react like a neurotypical, but I don't do it well all the time (and I don't believe I should have to). So I'm really good at showing what's not really going on inside and it's sometimes difficult for me to verbalize what really is going on because I don't know how to truly show what I'm really feeling*, *I've had 33 years to untrain myself from showing that accurately. So please, bear with me and help me get out what I'm feeling*, *and believe me when I say I'm in pain even if I don't look like I'm in pain* [Lee].

For individuals like Bert and Lee, there is a struggle to explain and convey how they are feeling because they do not express or present themselves in socially conventional ways, however the onus is not entirely on them to create this understanding. Bert points out that the way in which he presents himself is not consistent with "the common signs professionals are looking for" in assessing depression. For Lee, camouflaging and appearing "neurotypical" has helped them hide their challenges, but it does not mean that they are truly able to express themselves, and they need their HCP to recognize this, so that they can support them conveying what they are feeling.

Alternatively, some individuals felt that either way, these experiences are underpinned by being dismissed and not being believed.

Feeling Demeaned. Numerous participants gave responses that either implicitly or explicitly spoke to feeling demeaned or marginalized within their healthcare. Often, this was due to the perceived negative misperception by HCPs about an individual's intellectual abilities. Several participants reported feeling condescended towards or made to feel as though they lacked intelligence. For example, "*it makes me so annoyed thinking about how small and incapable they made me feel. Stereotypes about autism kinda ruin my chances before I can even talk to anyone"* [Claire], and "*I would tell them take what I say seriously including answering questions. Presume competence even though I am a woman, have a label, and am over 60"* [Rhoda].

Feeling demeaned was a common theme that led to negative healthcare experiences in general. However, responses like Claire and Rhoda's highlight that feeling demeaned negatively impacted communication. Several participants provided in-depth and specific examples of ways in which HCPs made them feel demeaned or condescended towards. For example:

> *I am a graduate student in a program [related to mental health], so I know a lot about psychology and mental health, but I have noticed that my new therapist since I received my diagnosis feels compelled to explain different behavioral and psychological concepts to me more than my previous therapists, despite knowing I have a degree and am in a […] grad program. It feels like the mental health worker to mental health worker equivalent of mansplaining. I have reminded them multiple times of my in-depth knowledge of psychology and that they should ask if I know about it before going into a long explanation, but most of the time they just go into this long explanation of a*

> *psychological theory or concept that I already know about or sometimes know more about than them. Interrupting people is something I hate to do so I just sit there irritated and remind them when they are done* [Peter].

Peter quite clearly outlines feeling as though he was deemed incompetent or intellectually inferior once his HCP discovered he is on the spectrum. Notably, he reported that these attitudes became an issue *after* an HCP discovers that he has ASD, leading to repeatedly demeaning experiences that do not meet his needs. In addition to demeaning attitudes about his intellectual abilities, Peter went on to discuss an extremely marginalizing and disparaging experience as a transgender male seeking a hysterectomy. He recounted:

> *During my hysterectomy consult I had to assure that I know I don't want children. And the gynecologist said that that made sense with the autism and other health problems. I don't want biological children for many reasons (the biggest being the gender dysphoria of the whole possibility). I felt like it was unnecessary for her to say that. It feels like she was saying I shouldn't have biological kids because I'm autistic which is not something you should say to someone. It had a strong eugenics feel to it. It is okay for me to decide I don't want to have bio children because of the risk of passing on some of the negative components of my neurotypicality and mental health struggles, but I don't think it is appropriate for a physician to suggest my autism is something so horrible that I shouldn't have kids to avoid passing it on. I struggle but my autism does not mean I should have been avoided from existing. Regardless of the fact that I never want to have biological children she should not have said that* [Peter].

In this instance, the HCP's comment conveyed demeaning attitudes about what it meant to be a person with ASD, as though she assumed she was correct about Peter's reasons for not wanting

to start a biological family. Similarly, other participants reported hearing demeaning comments about them as individuals with ASD. For example:

> *I went to the ER a few years ago and the nurse and doctor were literally talking bad about me on the other side of the curtain, as if being autistic means I can't hear if I can't see you. It was horrible and I didn't trust her or follow up with her after the fact* [Claire].

Feeling Disrespected. The final way in which participants reported feeling dismissed in their healthcare was through feeling as though their HCP engaged with them in disrespectful ways. For example:

> *There were even times she would just ignore some of the things I mentioned and did not pay attention to what I felt and I stayed silent because I did not want to make her angry as she already seemed upset. She did not speak to me in a respectful manner as a fellow adult* [Moe].

Similarly, when George spoke about his experiences, he reported that his HCP's moods impact how respectfully he is treated.

> *He offered treatment services to me depending on his moods of that day. During the day when his moods was not good we never had a successful communication with him. There was a time I went for my healthcare appointment and found him as he was looking very irritated. I sited* [sic] *down on the patient's seat waiting for him to diagnose me and after some minutes he abused me and complained that I entered in the treatment room and I didn't speak to him, yet during the previous healthcare appointment he warned me that I should keep quite* [sic] *until he asks for my health expressions* [George].

George's experience was one of feeling abused and criticized for how he engaged as a patient. With both Moe and George, there is some implicit uncertainty about the situation; for Moe it was

not wanting to make the HCP angry based on her already "seeming" upset, for George it was uncertainty around his HCP's expectations around when he should speak. However, irrespective of George's or Moe's potential uncertainty about the situation, they both had the experience of feeling disrespected by their HCP.

In sum, participants wrote at length and provided multiple rich and detailed examples about experiencing feeling dismissed, including feeling as though they are not believed or seen, and that they are demeaned and disrespected. Although subthemes of vindication and 'proving oneself' did emerge, the majority of experiences included subthemes of marginalization such as having invisible challenges dismissed, feeling ashamed, remaining silent, feeling stereotyped, and feeling labeled as less capable. These themes and subthemes both explicitly and implicitly speak to the power imbalance in the healthcare relationship.

Advocacy, Knowledge, and Power

The power imbalance within relationships has been alluded to throughout the participants' responses thus far. HCPs have the power to dismiss, interrupt, make decisions about patient accuracy and believability, and control the pace and duration of communication, and are in a position to allow or accept attempts for accommodation (e.g., written communication, inclusion of supports, etc.). Participants also explicitly referenced power when asked what they wished their HCP understood. For example:

> *You wield a great deal of power over us and our lives when our health is in your hands. Please understand and internalize our pain and fears and how you may contribute to that. Please work to ensure our comfort. Don't make fun of us. Don't dismiss us. Don't joke with us. Believe us* [Paula].

Responses like Paula's explicitly point out the power HCP's hold in terms of making patients feel dismissed, demeaned (e.g., made fun of), or believed within the relationship. Similarly, some participants noted the need to advocate within their healthcare relationships. For example.

> *Here is an example of a fail: years ago I had a doctor who said I could not be a patient unless I agreed to following whatever meds they thought was necessary. I threw the form in the trash, walked out and never went back. A patient/doctor relationship is not a relationship at all if the patient is not a participant in that relationship. It has taken a long time to advocate for myself and many doctors I moved on from* [Dana],

and

> *The doctor was unwilling to investigate a new health condition diagnosis with me despite my best efforts to advocate for myself. I eventually shut down, because in that position I had no ultimate power over what could happen. The only way I see to address this would be to request a different doctor or return to the specialist who treats my main condition to see if he could advocate for me behind the scenes, but above all I simply don't feel safe returning to the same doctor who was unwilling to communicate with me on the same level and understand my complex medical needs. He shut me down a lot and that is how doctors lose my trust, which means I either shut down completely or fight back even harder to try to engage as an equal* [Lee].

For participants like Dana and Lee, advocacy to be included as an equal, to effectively communicate, and to have medical needs met, was an important theme. Furthermore, the majority of participants who conveyed a need for advocacy were similar to Dana and Lee in that when the power imbalance was too large to overcome, they often did not return to that HCP. Others include a support person to help them advocate, but often at the expense of their

autonomy as a patient (as previously discussed). Other participants noted that the negative impact of healthcare interactions presented further challenges to advocacy.

Challenges with Advocacy. Participants discussed ways in which advocacy was difficult due to challenges with social comprehension and a lack of confidence that they could advocate in ways that did not upset or frustrate their HCP. For example:

> *I honestly don't know if this is a complaint or a cry for help. My fear is rubbing things the wrong way and make others annoyed just because I asked for accommodations. I wanted to talk to someone to CAN talk clearly AND able to understand what I'm explaining. But the least I wanted to happen is for them to take it the wrong way and make it into a discrimination issue. With all of my conditions becoming an inconvenience on them, the level of frustration starts to rise on them. I cannot tell by face but I can tell by tone when that person is getting mad. When that tone sounds threatening, I ether get defensive or anxious - depending on the day I'm having* [Yuri].

For participants like Yuri, the very act of asking for accommodations, especially in the presence of social challenges, feels like a burden and puts him at risk of angering his HCP, leading to feeling defensive and anxious. Multiple participants mentioned anxiety, worry, and fear about how that would impact their healthcare relationship and how their HCP would respond. For example:

> *It has worried me because I feel she will be annoyed if she thinks I'm telling her how to do her job, but I don't want to get put back on a medication that hasn't worked for me, so I have to say something* [Fran],

and

> *I am also reluctant to push too hard in expressing my concerns because I have had negative experiences with mental health professionals in the past…Thus, I hesitate to be too forceful in pressing my concerns. With physical issues, we are all good but my mood disorder is more of a challenge to discuss…I feel he does a good job on the physical side and I don't want psychological issues to sour that productive relationship. I suspect GPs are not as well equipped for that side of things* [Bert].

Unfortunately, fear of HCP reaction and negative self-concept (e.g., feeling like a burden) presented an additional barrier to patient advocacy, which often left patients remaining silent about their communication and healthcare needs. Therefore, it is not merely a matter of challenges with feeling rushed, the exchange of information, and knowing what to bring up within healthcare interactions, but also a fear of upsetting the HCP and the negative impact on self-concept (e.g., feeling like a burden) that create barriers to advocacy and communication in general.

Advocacy through disclosure. One way in which participants advocated for their needs was by disclosing their diagnosis. Some participants discussed the impact disclosing their diagnosis had on their healthcare. Ostensibly, participants who want their HCPs to modify their approach to support patients with ASD (e.g, provide more time, not mistake a lack of eye contact for lack of engagement, etc.), need their HCPs to be aware that they have ASD. For some individuals, this disclosure was helpful. For example, *"after he knew [that I was autistic], I can remember that he was generally more patient with me and probed me for questions and answers if I was not giving enough information"* [Nicholas]. Participants like Nicholas felt that telling their HCP led to changes that fostered better communication, better understanding, and did not increase marginalization. However, this was not always the case, as other participants noted

feeling that the act of disclosing increased marginalization, largely through stereotyping. For example:

> *Autism does not equal dumb. My official autism diagnosis is recent and since I have received it I have observed some change in pitch and slower speaking from physicians. I noticed that after my HCP looked at my chart which has my autism diagnosis in it she slowed her speed of talking and tone of voice to that cheesy way adults talk to children for some reason. I am not intellectually disabled and get really annoyed when people treat me like I am after learning I am autistic. Intellectually disabled people should be talked to like normal people too just with more patience if they need processing time. It feels infantilizing* [Peter].

Consequently, it would appear that receiving support and accommodation from an HCP did not depend on the disclosure by the patient, but rather the HCP's understanding of how that disclosure should impact the interaction. In essence, the power resided with the HCP to use the disclosure in ways that were helpful, which requires knowledge about ASD and how it impacts the individual patient.

HCP Knowledge. The most consistent theme that emerged with respect to healthcare relationships, communication, and feeling understood as a person was the impact of HCP knowledge about ASD. Lack of HCP knowledge (or incorrect and 'stereotypical' knowledge) contributed to the experiences of feeling dismissed and made consistent calls for HCPs to better understand how ASD impacted them as patients. For example:

> *I think the big thing my doctor and I struggle with is his lack of understanding of my disability. Regardless of the situation, that ignorance mixed with outdated information is a huge problem* [Katherine],

and

> *I feel that education would help, even if just calling on colleagues who have experience with ASD. People often use their instincts when dealing with others but this can be misleading when dealing with a person who has ASD* [Bert].

Participants like Katherine and Bert cited a lack of knowledge as problematic. However, implicit within Bert's response is that it is not just knowledge about ASD itself but that working with adults with autism requires *experience* and an understanding of the patient as an individual because relying on conventional "instincts" may not work. Participants noted that this was a challenge not only in terms of HCPs who lack knowledge, but also those who have just enough knowledge to stereotype without realizing how diverse autistic adults are. For example:

> *Consider our autism but ask us about our specific needs and don't assume all autistic people have the same needs. I need to be talked to like an adult and need to be treated like an intelligent person, because I am* [Peter].

and

> *Autism is a "hidden disability" for a reason. Just because I have a college degree and can hold down a job doesn't mean that I don't struggle in lots of areas. I wish that doctors would ask more questions about a person's autism diagnosis, give us a chance to explain how it affects us individually* [Sonia].

For participants like Peter and Sonia, it is not so much a lack of knowledge on the part of the HCP, but the HCPs' lack of awareness about the diversity in ASD (e.g., relying on assumptions, not working to understand the patient as an individual) that prevents them understanding their patient as a wholistic person and consequently prevents them from fully meeting their needs in relationships, communication and healthcare.

Impact of the Healthcare Interaction Summary

Participants noted the healthcare interaction, including the relationship, communication and being (mis)understood, could either empower and support the individual or demean, dismiss, and otherwise disempower the individual in healthcare. Those who felt demeaned and dismissed attributed perceived negative attitudes from HCP as being due to bias and stereotyping, lack of knowledge, lack of understanding the patient as a person, and invisibility. Some participants tried to advocate against this perceived marginalization, although the power imbalance was difficult to overcome.

The Impact of COVID-19 Pandemic on Healthcare

Few participants chose to respond to the optional question about the impact of COVID-19 on healthcare. Of those who did respond (10 of the 28 participants) some participants noted that (at the time of participation) they had not had any healthcare interactions or that they did not note a difference in their healthcare since the outset of COVID-19. Two participants commented that masks were an issue (e.g., impact on sensory sensitivity and communication) within healthcare. Four participants commented on telehealth, with two participants preferring it to in-person healthcare and two participants preferring in-person. Overall, due to the timing of the study (recruitment began Summer 2020, which was early in the pandemic), the low response rate to the optional question, and the brevity of responses by the few who did comment, the impact of COVID-19 was not adequately captured and will not be further discussed below.

Discussion

The present study explored the experiences of 28 Canadian and American autistic adults in healthcare, with the specific goal of understanding their priorities, challenges and strengths, as well as the meaning they make of their experiences. Grounded Theory methods were used to

ensure participants retained control over the direction of the findings, allowing them to prioritize and define what was most important from their point of view. Implications for recommendations and knowledge translation are discussed below.

The Three Factors of PCC

This study supports that, as is the case with members of the non-autistic population, a) healthcare relationships, b) healthcare communication and collaboration, and c) feeling understood as a wholistic person (hereinafter referred to as the factors of PCC) are important factors for autistic adults in healthcare, and work together to promote a wholistic healthcare experience. Feeling known and understood as a person was perceived as promoting understanding of their unique communication preferences. Likewise, effective communication about oneself and one's needs fostered better understanding. Good relationships stemmed from feeling that HCPs have a genuine interest, understanding, and care for them as individuals, which contributes to the trust and safety that allows for open communication. Participants identified all factors as important, which is noteworthy given the current focus of recommendations being on communication (and other more pragmatic concerns such as controlling the environment)– recommendations that for many in this study would fall short in the absence of a strong, safe healthcare relationship or feeling understood. Findings of this study reflect core categories related to high levels of diversity, as well as a great deal of tension between main themes (e.g., tension between wanting support versus feeling marginalized, being invisible versus disclosing a diagnosis, and knowledge about ASD versus understanding the person with ASD, and the role of support persons versus the right for autonomy/privacy), all of which played important roles and defined the complex context in which PCC takes place. Consequently, rather than discuss

communication, relationships and understanding as separate constructs, the following discussion is structured around this core categories of diversity and tension.

Tension Between Accommodation/Support and Disclosure/Marginalization

The most consistent theme that emerged across participants was the need for more time to take in, process, and respond to information during healthcare interactions, which is consistent with previous findings with autistic adults both within and outside of healthcare (Haigh et al., 2018; Mitchell, 2008; Nicolaidis et al., 2015; Wright, 2016). Of note, participants wanted and needed more time irrespective of the amount of information that was being conveyed. For example, some participants wanted more time for processing by way of their HCP speaking more slowly, using simpler terms, and paring down communication to essential information only. In some cases, participants opted to designate a support person to communicate entirely on their behalf. For those individuals, having too much or too complex information to process, being required to process and respond under time constraints, or being required to speak on their own behalf when they are facing too many challenges in doing so (e.g., anxiety, processing, comprehension, expression, environmental overwhelm, fear of HCP response) created a barrier to engaging in healthcare communication and was therefore marginalizing. However, many patients who wanted additional time for processing *did not* want the resultant accommodation to be for HCPs to speak more slowly, for information to be minimized and simplified, or for support persons to engage on their behalf as they found these to be demeaning and condescending practices that they believed reflected a presumed lack of competence. For these participants, anything less than complete and complex information was viewed as impeding their ability to make informed decisions and take control of their health and healthcare. Although some participants welcomed accommodations made by HCPs, other participants explicitly stated

they felt the need for accommodations was perceived by others as a corresponding lack of competence, consistent with the mixed findings in the accommodation literature in other contexts (Cawthon & Cole, 2010; Lindsay et al., 2021; Lightner et al., 2012). For the latter participants, despite wanting more processing time, misplaced or unwelcome attempts at accommodation were seen as demeaning and dismissive and led to negative healthcare experiences and barriers (e.g., staying silent, giving up, not returning to that HCP) and thus, was another form of marginalization in healthcare. In sum, although there was consistency in wanting more time to take in, digest, and respond to information, there was diversity in how these autistic adults wanted this to be facilitated or accommodated.

The issue of how communication and the clinical conversation is structured was another theme that blurred the line between accommodation and marginalization for participants. Some autistic adults noted challenges with initiating conversation and certain topics due to a range of issues. Some participants wanted the support of their HCP (and in some cases their support person) to direct the conversation and ask the 'relevant' questions. However, some participants felt silenced by HCPs interrupting, redirecting, and otherwise not listening, which in turn felt dismissive. Some participants noted significant strengths in communication but felt that this communication (e.g., written communication, communication that is not under time constraints) was dismissed outright or led to negative views about competence, again consistent with past findings that alternate forms of communication have been dismissed (Wright, 2016) or that some patients fear they would be dismissed (Nicolaidis et al., 2016). In these instances, it is not a matter of challenges with communication itself, but challenges with the communication options that are permitted by the HCP. To be clear, many participants noted appreciation for HCPs who made accommodations, and that these accommodations were appropriate and empowering.

However, equally as many participants within this study reported that when HCP reactions to accommodations were perceived as demeaning or dismissive, these reactions negatively impacted all three factors of PCC.

Tension in Disclosing Diagnosis

Participants reports were highly diverse in terms of whether disclosing a diagnosis was helpful. Some reported that disclosing their diagnosis (or having HCPs who otherwise knew that they were autistic) made things better, and that some HCPs naturally modified their approach in ways that were helpful (e.g., providing extra time, using clearer language, providing emotional support, etc.). However, consistent with other areas of research (Thompson-Hodgetts, 2020) including healthcare (Lum et al., 2014; Nicolaidis et al., 2016, Wright, 2016) some participants experienced fear and hesitancy in disclosing their diagnosis. Participants noted instances of HCPs reacting in ways that they found demeaning and condescending (e.g., speaking to them like a child, assuming lack of competence, making negative assumptions about what they want from their healthcare, dismissing their disclosure altogether) upon disclosing their diagnosis. In some ways, this is consistent with findings in the implicit bias literature, where knowledge about ASD itself may reduce explicit bias and thus allow HCPs to make conscious modifications (e.g., simplify communication, allow more time), but they may still hold implicit biases (e.g., the disclosure leads to negative assumptions about competence in general). This places patients who are hesitant to disclose in a tension-filled catch-22: disclose their diagnosis in hopes of receiving understanding, support, and accommodation at the risk of being dismissed and lacking competence, *or* hide their diagnosis and forego potential understanding, support, and accommodation in the hopes that their credibility and competence will be preserved. More robust exploration of this phenomenon, including a better understanding of what other knowledge users

'actually' think about autism and accommodations is essential before making recommendations or requesting accommodations that inherently require disclosure. Put plainly, it is insufficient to make recommendations to address the fear of a negative response from HCPs as a patient-level factor when there is evidence that these negative reactions from HCPs exist.

Further complicating matters related to the impact of support and accommodation, and the pros and cons of disclosing diagnosis to obtain support and accommodations, is that participants were open to multiple possibilities as to *why* support and potential accommodations may not be in line with their needs. Many participants felt a lack of knowledge on the part of HCPs about ASD, negative biases, and condescending attitudes were highly problematic. However, several autistic adults took the perspective of HCPs and noted that bias is not the only factor as HCPs cannot always rely on their conventional knowledge to help guide their interactions. First, the phenomena of social camouflaging, which may prevent HCPs from picking up on conventional signs of socio-emotional and communication challenges (see Lai et al., 2011) was identified as hampering HCP understanding, but not something that participants could simply 'turn off'. Second, challenges with alexithymia traits and unconventional self-reporting style (e.g., a mismatch between emotional/facial expression and the level of distress they were feeling, challenges perceiving and thus navigating HCP 'mood', challenges with expression related to self-report and personal experience) were also reported as interfering with HCP understanding. HCPs who do not fully understand the impact and presentation of individuals with alexithymia traits may fail to pick up on the presence and severity of reports of medical and mental health conditions that rely on observation and self-report. Third, the impact of 'self-silencing' despite adequate time (e.g., due to anxiety, past negative experience) can contribute to HCPs' poor understanding of the patient, both in terms of their medical needs and

in understanding of them as a person. All of these factors beg the question as to which challenges in gaining meaningful support are linked with explicit disclosure, and which may be due to a lack of 'implicit' disclosure through behaviours, statements and presentations that HCPs may not realize are attributable to autism. These factors did not just lead to 'invisible' needs, but they led to examples of negative HCP responses, such as perceiving autistic adults as deceptive, difficult and aloof, un-insightful, incompetent, and deliberately disengaged within their healthcare relationships, consistent with other common biases about autistic adults (John et al., 2018; Lim, et al., 2022). Therefore, these factors not only make it challenging to address needs and provide support but can lead to a fundamental and negative misunderstanding of the patient as a person and strain relationships. Whether marginalized by invisibility (i.e., HCP lack of awareness that they are struggling resulting in a lack of awareness that support is required) or negative misperceptions, participants identified the mismatch between HCP perceptions of their needs versus actual needs as a factor preventing otherwise knowledgeable and well-intentioned HCPs from fully understanding and making appropriate modifications to their interactions.

Tension Between Knowledge About ASD and Understanding Autistic Individuals

Consistent with previous research, participants expressed a need for HCPs to have more knowledge about ASD as well as how autism impacts them uniquely as an individual (Bradshaw et al., 2019; Ghaderi & Watson, 2018; Griffith et al., 2001; Nicolaidis et al., 2015; Wright, 2016). Specific knowledge was deemed necessary to support the factors of PCC (e.g., realize that autistic adults may need support with communication, may be misunderstood in relationships, may experience environmental overwhelm) as well as to dispel potential stereotypes (e.g., communication challenges are *not* indicative of intellectual disability, lack of eye contact does not always indicate a lack of interest) and common biases (e.g., autistic adults do want

relationships, are credible self-reporters) that may be held by HCPs. However, understanding each patient as an individual remains essential because specific knowledge about ASD does not address diversity of needs. This understanding is fostered through patient, trustworthy, and caring relationships, and it grows over time. The importance of these relationships and 'knowledge' are highlighted by research on HCP training, which has found that experience and familiarity with autistic adults (e.g., more direct experience with autistic patients, more interaction with autistic adults in their personal lives) and not mere 'knowledge' about ASD itself leads to higher levels of self-efficacy and competence in HCPs with respect to autistic patients (Corden et al., 2022; Dreiling et al., 2022). In sum, it is important to expand some of the focus from predominantly communication-related knowledge and tools to include supporting patients and HCPs in forging relationships in which both 'ASD specific knowledge' and understanding of the person can work together.

HCPs who held specific or 'cursory' knowledge about ASD emerged as problematic not only because this knowledge is not representative of the heterogeneity in ASD, but also in terms of managing health and medical treatments. To cite a specific example as illustration, an HCP acknowledging that a patient was in pain and remarking that it is "normal" for someone on the spectrum to be more sensitive to pain. While it is potentially helpful that the HCP has this cursory piece of knowledge, that does not make it a forgone conclusion that pain sensitivity is an issue for any given patient (indeed, some autistic adults are *hypo-sensitive* to pain), that enduring pain is just a natural and acceptable part of ASD, or that the complaint is due to inaccurate self-report and low pain tolerance. It would appear based on the participant's report that the HCP did not have an in-depth understanding of what to do with this piece of information and how it could inform clinical practice. Continuing with this example, a medically informed and ethical

response would be to acknowledge that indeed the individual may be experiencing more pain than generally expected due to their autism, but that does not make accepting this pain a foregone conclusion or preclude the need for alternate treatment options or more adequate pain management protocols. Consequently, education about ASD itself cannot be equated with learning easily deliverable and digestible 'facts' without a richer understanding of the implications of these facts in practice.

Impact of Healthcare Interactions on Autistic Patients

The participants in this study described social and emotional impacts stemming from healthcare interactions which in turn affected their healthcare. These factors went beyond the impacts of challenges with communication and explore phenomena such as negative self-concept and a desire to preserve healthcare relationships. Negative self-concept related to feeling (and efforts to avoid feeling) like a burden within healthcare relationships (e.g., challenges expressing mental health concerns and the fear that trying to explain would frustrate the HCP and jeopardize the relationship, fear that they would contribute to an HCPs 'bad mood'), the fear of angry or dismissive reactions from HCPs (often based on past negative experience), and the fear of not being believed or taken seriously when reporting one's own lived experience. Contrary to commonly held biases about ASD and relationships (Fennell & Johnson, 2022; Muller et al., 2008), these participants had a strong desire to foster a strong relationship with HCPs, which speaks to the need to address the relationship within healthcare. Further, the self-silencing that occurs due to these negative impacts is a prime example of how relationships and being misunderstood impact communication in ways that are not necessarily helped through communication-specific tools, but may be more adequately addressed through strong, supportive, caring and understanding relationships that foster trust and safety.

The Role of Support Persons

The majority of participants chose to have a support person accompany them to their healthcare appointments. Support persons were largely reported as contributing to more positive healthcare experiences in terms of all three factors of PCC. Support persons held value in multiple areas, including more pragmatic concerns such as facilitating communication and scheduling (e.g., taking notes, booking appointments, speaking on patient's behalf when appropriate, filling prescriptions, clarifying communication, etc.). Support persons were also uniquely positioned by way of their close relationship to the patient to provide emotional support and reduce barriers related to the impacts of healthcare interactions (e.g., reduce anxiety, provide moral support, be a calming presence, help with advocacy when appropriate) and bring their understanding of the patient as a person into healthcare encounters.

Emphasis was also placed on support persons knowing their role, with tension arising when participants either felt that support persons overstepped their role (e.g., contradicting the patient) or that HCPs deferred to support persons at the expense of patient autonomy (e.g., asking questions to the support person directly, verifying with a support person, or seemingly only taking a statement seriously when echoed by a support person). Some participants resented the need to have a support person but felt that the support person was necessary to overcome the power held by HCPs (e.g., HCPs who do not listen or dismiss the patient's independent contributions). Finally, challenges were reported with respect to support persons and patient privacy, however the option to have a confidential (i.e., non-family member/non-acquaintance) support person did not seem feasible. Essentially, challenges with role violations and privacy notwithstanding, the support person had to be someone with whom patients have a strong relationship and shared understanding.

There was an intangible quality that emerged as to what HCPs and supports 'should know' about patients or autism in general. The idea that others "should know how to treat patients with autism" is problematic given there is no singular way to treat highly diverse autistic adults. Aside from a few overarching themes that were common to most participants (discussed below) there was no clear message about *what specifically* HCPs "should know" about any given autistic adult. The knowledge held by support persons was not clearly defined; support persons are positioned to implicitly 'get' the people they support in ways that HCPs do not due to the nature of their relationships and in-depth understanding of the person.

Implications for Knowledge Translation

Tension Between Intergroup and Intragroup Diversity

The findings of this study highlight the tension between understanding ASD itself and autistic adults as a group versus understanding the heterogeneity within said group. Autistic adults share some common traits by way of definition (i.e., if they qualified for diagnosis then, by definition, they met certain group criteria including challenges with social competencies and communication, both of which were reported by these participants), and therefore there is value in having some general knowledge about autistic adults as a group. In addition, autistic adults face marginalization as a group due to the biases and misperceptions of others (Fennel & Johnson, 2022; John et al., 2018; Lawrence, 2010; Lim et al., 2022), which includes explicit and implicit negative biases (Cooper et al., 2022; Harder, 2009; Jones et al., 2021; McClure, 2011); they also have a condition that categorizes them based on their 'deficiencies', despite many autistic adults not equating being autistic with being disabled (Fletcher-Watson, 2022; Gyawali & Patra, 2019; Kenny et al., 2016; Shuck et al., 2022; Taboas et al., 2023). Therefore, there is

value in discussing and understanding more about autism and autistic adults, both in terms of gaining accurate knowledge and combating biases, among HCPs.

These biases and negative misperceptions notwithstanding, it would be equally inaccurate based on the findings of this study to mistake advocacy against negative misperceptions and biases for promoting a strengths-based only lens. Participants in this study were highly aware of challenges and wanted support and understanding of these challenges, not denial of these challenges. Themes of gratitude towards patient, caring, knowledgeable, and accommodating HCPs and support persons were shared by many participants. While diversity research and intersectionality importantly focus on how different factors (e.g., race, gender, the label of disability) need to be understood in terms of the intersecting discrimination that results, autistic adults face a more complicated need for understanding than some other marginalized groups (e.g., a female person of colour who faces gender and racial discrimination would not say that they have within-person challenges related to skills and competencies that are attributable to their race or gender). The nuance between the fight against bias and the need to understand real challenges and needs of autistic adults, which for some significantly impact the ability to function in daily life, cannot be overlooked.

Further, many identified factors that went beyond ‘ASD knowledge’ and ‘communication strategies’ emerged from participants, such as the importance of the relationship, trust, safety, feeling understood and respected, and being treated as a capable, credible, and autonomous human being. These factors were again diverse (e.g., HCP speaking more slowly could help communication and the relationship, or lead to feelings of marginalization and hurt the relationship, depending on the person). KT in terms of recommendations, tools, accommodations, and HCP training must take into account the intergroup diversity that

categorizes autistic adults as a unique group, but must not rush into implementation that fails to account for intragroup diversity.

KT at the Patient Level. The participants identified the need to be understood as a unique individual, including specific needs and preferences related to communication, social comprehension, the clinical environment, and the unique role that they wanted supports to play (and the need for HCPs to be aware of this role). Although no tools or accommodations were assessed in this study, these findings give face-validity to tools that allow an individual to explain their individualized needs and preferences directly to their HCP, such as "My Healthcare Passport" (The National Autistic Society, 2023) and the AHAT report (Academic Autistic Spectrum Partnership in Research and Education, 2023). Several participants listed wanting the types of accommodations that are already included in the AHAT report. However, several participants struggled with barriers in disclosing their diagnosis, including the fear that HCPs' reactions to disclosure or accommodation requests will lead to marginalization or negatively impact the healthcare relationship. This issue needs to be further understood prior to making patient-level recommendations. In other words, it is not appropriate to make recommendations on how autistic adults may reduce their anxiety about HCP reactions without sufficient evidence that HCPs are indeed not responding in marginalizing ways.

KT at the Provider Level. Although HCP knowledge was not assessed in this study, the literature on HCPs' lack of self-efficacy and competence in working with autistic adults is well established (Kuhitau et al., 2014; Zerbo et al., 2015). The findings of this study are consistent with calls among autistic adults and advocates for HCPs to have more autism related knowledge. However, it was not general 'ASD specific' knowledge but rather knowledge about how each individual was impacted by autism, their specific autism related strengths and challenges, and the

biases and stereotyping that may stem from 'ASD specific' knowledge that was the bigger issue for these participants. This is consistent with findings that HCPs with high knowledge about ASD still hold incorrect misperceptions and do not necessarily have increased self-efficacy or competence working with autistic adults (Unigwe et al., 2017), and that real-life experience knowing and working with autistic adults does lead to greater competence (Corden et al., 2022). Despite HCPs' priorities for simple, easily disseminated, easily digestible fact sheets and low burden resources as part of 'feasible' continuing education, these types of knowledge resources would fall short in addressing the types of complexity and diversity that emerged in this study. Within the context of KT, the findings of this study suggest that more robust, in-depth, and experiential KT activities may be required.

To address this, autism training may want to be modelled on training regarding other marginalized groups and include explicit and implicit bias training, breaking down negative misconceptions about autism, and dispelling the notion that a readily available fact sheet or diagnostic criteria capture the knowledge required. Myths surrounding homogeneity, prevalence of intellectual disability, processing time being a comprehension issue, relationships, and that camouflaging reflects an absence of challenges need to be addressed (without undermining the needs of individuals with intellectual disability, comprehension challenges, etc.). Furthermore, higher contact with autism could be achieved through involving autistic adults in training as experts and providing networks for consultation with colleagues who have more experience with autistic patients (either through supporting informal consultation networks or more formal training programs similar to the ECHO model). This would allow HCPs who lack self-efficacy to gain confidence *while* working with patients on their very own caseload.

Transferrable Findings for HCPs

The emphasis up to this point on the challenges of generalized recommendations notwithstanding, a few specific themes emerged repeatedly across participants. Given the heterogeneity of this large qualitative sample, the fact that these findings emerged repeatedly across participants speaks to the transferability of the findings below as general recommendations for HCPs:

1. Autistic adults without intellectual disability who choose to engage in healthcare independently often need more time during appointments to take in and process information and generate a response. This may be due to slower processing speeds, anxiety, alexithymia traits, or environmental overwhelm. However, this finding has limitations, specifically among patients who convey that they would like to minimize interaction time, or who *choose* to defer to a support person.
2. Autistic adults have many communication strengths. Allow for and provide alternate communication formats, such as written communication, when possible.
3. Despite common myths, and the potentially non-conventional ways some autistic adults interact with others, autistic adults want strong relationships, including with their HCPs. Convey genuine interest, care, and support. Strong relationships in healthcare not only have an impact on health and healthcare directly, but they also help foster strong communication through trust and safety.
4. Having knowledge about autism is important. But do not mistake knowledge about autism as a condition with an understanding of the *person* themselves. What works for one autistic patient may not work for another. Be curious and get to know the individual.

Strengths and Limitations

Strengths

Based on an extensive review of the literature, this study is the first in which autistic adults conveyed in-depth experiences about all three factors of PCC, highlighting the importance of all three and how they work together. This provides additional context to the literature and KT activities, which have tended to focus on the important but more narrow aspect of communication. Although improved communication does positively impact understanding and relationships, understanding and relationships have separate contributions to communication, self-concept, and overall healthcare experience that are worthy of independent attention in research and practice. This is also the first study to my knowledge that captures the views and experiences autistic adults have towards support persons, the importance of which is twofold: it captures the many benefits and some of the challenges that arise when support persons are involved in healthcare from the perspective of autistic adults, and it provides some balance to the literature that historically has been informed by—not about—support persons.

Second, the design of this study was a strength in ensuring accuracy when capturing participants intended meaning. The use of online and written data collection methods increased the chances that participants' responses captured their intended meaning, including consulting stakeholders to inform the use of online methods, and making preliminary findings available for participant review and comment on.

Third, the sample represented the diversity of autistic adults without an intellectual disability in terms of age, gender, ethnicity, level of educational attainment, and living arrangement. However, diversity was lacking in certain areas (e.g., adults over the age of 60 years old, certain ethnicities, individuals who are not fluent in English). Within this ideographic approach, the goal was not to generalize to the larger population. However, the relatively large

and diverse sample strengthens the likelihood that these themes reflect a common experience among the autistic population and are not limited to a select few.

Limitations

The findings of this study need to be understood within a few limitations. First, participants self-selected to participate based on interest in the recruitment poster, which may have led to higher inclusion of participants with more healthcare challenges and, therefore, a stronger desire to be heard. Further, despite the strengths of online and written methods, the online format may have been less appealing to participants who struggle with written communication and prefer face-to-face, which may have implications for individuals who prefer in-vivo communication in healthcare.

Second, some participants responded with richer, narrative-like stories. The online method precluded a more dynamic interaction that is possible in in-vivo interviews, and therefore analysis of narrative and discursive elements was limited. Although several studies successfully use in-vivo and real-time interviews, such studies often allow for a support person to be present, if the autistic participants chooses to have one. This would be problematic in this study given that I wanted autistic adults' perspective *on* support persons, and certain themes may not have emerged if supports were involved in participation. Therefore, the decision to use online and written data collection methods without time constraints at the expense of more interactive methods was consistent with stakeholder-identified strengths for independent participation and the overall goals of the study. Future studies may benefit from an 'instant messaging' option, which allows for some back and forth but still provides the opportunity for participants to engage in 'one-channel communication' (Mitchell, 2008) and to write out and reflect on responses without time constraints.

Third, while not a limitation based on the goals of this study, the lack of HCP input limits the extent to which findings can be implemented (see future directions below). The goal of this study was to gain an understanding autistic adults' experiences, and the 'verification' of their experiences through HCP reports was not relevant to meet this goal. For example, if participants state that an HCP speaking more slowly makes them feel demeaned and therefore marginalized, we do not need to 'verify' with HCPs whether or not they are 'actually' being/intending to be demeaning and marginalizing. The fact that such interactions can make some autistic adults feel demeaned is a problem from the participants' view, making it valuable information about these recipients of healthcare and the complex context in which they receive care. Having said this, not obtaining HCP input does limit the extent to which specific recommendations can be made that HCPs will find implementable.

Finally, autism diagnosis was based on self-report. All participants completed the AQ-10 (Allison et al., 2012; ARC Autism Research Centre, 2014), and scored at or above the chosen cut point of 4 (M=7.2). Furthermore, all participant reported that their diagnosis was conferred by diagnostic professional (e.g., paediatrician, psychiatrist, psychologist), which lends further support to a verified diagnosis. However, these measures do not fully confirm their self-report of diagnosis. This limitation was a construct of the otherwise strong online method, the benefits of which outweighed the need for the diagnostic verification that would require in-person data collection.

Future Directions

Because HCPs were not participants, the assumptions made in this discussion about a lack of knowledge and understanding, as well as potential HCP implicit and explicit bias cannot be verified, although they are consistent with the literature (Jones et al., 2021; John et al., 2018;

Lim et al., 2022). If meaningful training and recommendations are to be made, future research needs to examine what knowledge and biases HCPs hold. One area in particular, for example, may be HCP attitudes towards accommodation (i.e., do they equate the need for accommodation with a lack of competence), and whether or not they see value in implementing accommodations with individuals who do not appear to be struggling (e.g., camouflaging). Current feedback from HCPs tends to come from HCPs who may be predisposed to valuing autism related training, tools, and accommodations. For example, in Chown et al. (2023), HCP participants were recruited from "Autistic Doctors International, from the personal and professional networks of the medical doctor members of the project's Steering Group, and via Twitter" (p.6), which likely heavily over-represents HCPs with interest and dedication to autism related training. Similarly, there was only a 47% HCP response rate in Nicolaidis et al. (2016), and it cannot be ruled out that this subgroup was motivated to participate, in part, due to a commitment to autism advocacy. Although challenging in terms of research recruitment, it is important to assess how HCPs in general perceive and value autistic adults, training, and accommodations. These are important factors in the implementation context that need to be understood for implementation success, especially when the burden is largely on the patient to introduce these tools in healthcare.

Second, although there are social tensions with respect to classification of subgroups of autistic adults, there may be high value in delving further into how specific autism related factors impact PCC. Participants in this study identified barriers related to alexithymia traits and camouflaging (e.g., their affect not matching their distress, challenges reading their HCP's mood, challenges describing their mental health, and their challenges not being visible). These factors are highly complex and are not amenable to easily disseminated and quick 'facts' (i.e., even highly trained clinicians often miss camouflaging unless brought up by the patient). Therefore,

potential recommendations from these and other potential 'specific' factors may be too burdensome for HCPs to fully incorporate into practice. Further research is needed to understand these specific factors, and to develop and pilot training and deliverables that are both comprehensive enough to address the complexity of these factors as well as simple enough to be implementable.

Third, to the extent that the complexities of need (including the potential impact of the aforementioned 'specific factors') in autistic adults belie simple and straightforward recommendations and training, it may be prudent to create autism-specific clinics and specialists with in-depth knowledge and experience to fill healthcare gaps rather than focus on having all HCPs develop general skills and competence. Given that experience working with autistic patients builds HCP self-efficacy and competence, offering HCPs the opportunity to train and work in autism focused practices that allow them to build in-depth experience and appreciation for autistic diversity may be warranted. These HCPs with more in-depth understanding and training could in turn become the consultants and 'hubs' that are needed within the larger system. This would require systems-level implementation and advocacy, beginning with an assessment of interest among HCPs.

Conclusion

As a group, autistic adults have higher health and healthcare needs than the neurotypical population in general, and face healthcare disparities. The PCC framework, the model of healthcare currently promoted in Canada and the United States, is well established as contributing to better healthcare experiences and better healthcare outcomes. The findings of this study highlight autistic adults' experiences in healthcare related to the three factors of PCC: healthcare communication, relationships, and being understood. Some describe strong

relationships with HCPs who are caring, supportive, trustworthy, safe, and sensitive to their individual needs, including being willing to modify communication in ways that fosters their inclusion and contribution. Others experience negative relationships in which they feel demeaned, dismissed, and misunderstood, and face significant communication challenges with HCPs who lack knowledge, all of which contribute to feelings of marginalization. Recommendations and accommodations that support communication are emerging, however the findings of this study highlight that negative relationships and poor understanding of the patient as a wholistic person—which may stem from HCP biases and lack of understanding about diversity in autism—create barriers and negative experiences in healthcare for autistic adults. Consequently, individually customizable tools, training for HCP's that extends beyond 'facts' about ASD, and an emphasis that these patients do want strong relationships with HCPs who understand them as an individual, are all important factors pieces in fostering healthcare that is truly *patient* centered.

References

Academic Autistic Spectrum Partnership in Research and Education. (2023). *AASPIRE Healthcare Toolkit.* Retrieved April 20, 2023, from https://autismandhealth.org

Adams, R., Price, K., Tucker, G., Nguyen, A. M., & Wilson, D. (2012). The doctor and the patient--how is a clinical encounter perceived? *Patient Education and Counseling*, *86*(1), 127–133. https://doi.org/10.1016/j.pec.2011.04.002

Allison C., Auyeung B., and Baron-Cohen S., (2012). Toward brief "red flags" for autism screening: The short Autism Spectrum Quotient and the Short Quantitative Checklist in 1,000 cases and 3,000 controls. *Journal of the American Academy of Child and Adolescent Psychiatry,* 51(2), 202-212. https://doi.org/10.1016/j.jaac.2011.11.003

Ambitious About Autism. (2023). *Know Your Normal.* Retrieved April 28, 2023, from https://www.ambitiousaboutautism.org.uk/what-we-do/connecting-young-people/youth-led-toolkits/know-your-normal

American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: Authors. https://doi-org.uml.idm.oclc/10/1176/appi.books.9780890425596

Anfara, V., Brown, K., & Mangione, T. (2002). Qualitative analysis stage: making the research process more public. *Educational Researcher, 31*, 28-38. https://doi.org/10.3102/0013189X031007028

Arbuthnott, A., & Sharpe, D. (2009). The effect of physician–patient collaboration on patient adherence in non-psychiatric medicine. *Patient Education and Counseling, 77*(1), 60-67. https://doi.org/10.1016/j.pec.2009.03.022

Autism Research Centre. (2015). *The Autism Spectrum Quotient (AQ-10).* https://www.autismresearchcentre.com/arc_tests

Bailey, A. (2011). Autism in adults. *Autism Research, 5*(1), 1-2. https://doi.org/10.1002/aur.233

Barnhill, G. (2007). Outcome in adults with aspergers syndrome. *Focus on Autism and other Developmental Disabilities, 22,* 116-126. https://doi.org/0.1177/10883576070220020301

Bauman, A. E., Fardy, H. J., & Harris, P. G. (2003). Getting it right: Why bother with patient-centred care? *The Medical Journal of Australia*, *179*(5), 253-256. https://doi.org/10.5694/j.1326-5377.2003.tb05532.x

Bennett, J. K., Fuertes, J. N., Keitel, M., & Phillips, R. (2011). The role of patient attachment and working alliance on patient adherence, satisfaction, and health-related quality of life in lupus treatment. *Patient Education and Counseling*, *85*(1), 53-59. https://doi.org/10.1016/j.pec.2010.08.005

Bensing, J., Rimondini, M., & Visser, A. (2013). What patients want. *Patient Education and Counseling*, *90*(3), 287-290. https://doi.org/10.1016/j.pec.2013.01.005

Bird, G., & Cook, R. (2013). Mixed emotions: The contribution of alexithymia to the emotional symptoms of autism. *Translational Psychiatry*, *3*(7), e285. https://doi.org/10.1038/tp.2013.61

Birkhäuer, J., Gaab, J., Kossowsky, J., Hasler, S., Krummenacher, P., Werner, C., & Gerger, H. (2017). Trust in the health care professional and health outcome: A meta-analysis. *PloS one*, *12*(2), e0170988. https://doi.org/10.1371/journal.pone.0170988

Bishop-Fitzpatrick, L., & Rubenstein, E. (2019). The physical and mental health of middle aged and older adults on the autism spectrum and the impact of intellectual

disability. *Research in Autism Spectrum Disorders*, *63*, 34-41. https://doi.org/10.1016/j.rasd.2019.01.001

Bradshaw, P., Pellicano, E., van Driel, M., & Urbanowicz, A. (2019). How can we support the health care needs of autistic adults without intellectual disability? *Current Developmental Disorders Reports, 6*, 45-56. https://doi.org.10.1007/s40474-019-00159-9

Brownlow, C. (2010). Presenting the self: Negotiating a label of autism. *Journal of Intellectual & Developmental Disability*, *35*(1), 14-21. https://doi.org/10.3109/13668250903496336

Bryant, A., & Charmaz, K. (2007). The SAGE Handbook of Grounded Theory. SAGE publications, London.

Camden, C., Shikako-Thomas, K., Nguyen, T., Graham, E., Thomas, A., Sprung, J., & Russell, D. (2015). Engaging stakeholders in rehabilitation research: A scoping review of strategies used in partnerships and evaluation of impacts. *Disability and Rehabilitation, 37*(15), 1390-1400. https://doi.org/10.3109/09638288.2014.963705

Carlsen, B., & Aakvik, A. (2006). Patient involvement in clinical decision-making: The effect of GP attitude on patient satisfaction. *Health Expectations, 9*, 148-157. https://doi.org/10.1111/j.1369-7625.2006.00385.x

Cawthon, S. W., & Cole, E. V. (2010). Postsecondary students who have a learning disability: Student perspectives on accommodations access and obstacles. *Journal of Postsecondary Education and Disability*, *23*(2), 112-128.

Cederlund, M., Hagberg, B., & Gillberg, C. (2009). Asperger syndrome in adolescent and young adult males. Interview, self - and parent assessment of social, emotional, and cognitive problems. *Research in Developmental Disabilities, 31*(2), 287-298. Https://doi.org/10.1016/j.ridd.2009.09.006

Charmaz, K. (2006). Constructing Grounded Theory: A Practical Guide through Qualitative Analysis. SAGE publications, London.

Chown, N., Shaw, S., Doherty, M., Johnson, M., Krupa, J., Martin, N., & Brooker-Corcoran, M. (2023). General practitioner autism training and mandatory medical training: A cross-sectional study of GPs' knowledge, attitudes and practices. *Canadian Journal of Educational and Social Studies, 3*(1), 1-16. https://doi.org/10.53103/CJESS.V3IL.99

Clayman, M. L., Gulbrandson, P., & Morris, M. A. (2017). A patient in the clinic; a person in the world: Why shared decision making needs to center on the person rather than the medical encounter. *Patient Education and Counselling, 100*(3), 600-604. http://dx.doi.org/10.1016/j.pec.2016.10.016

Cloninger, C. R. (2011). Person-centred integrative care. *Journal of Evaluation in Clinical Practice, 17*(2), 371-372. https://doi.org/10.1111/j.1365-2753.2010.01583.x

Concannon, T. W., Fuster, M., Saunders, T., Patel, K., Wong, J. B., Leslie, L. K., & Lau, J. (2014). A systematic review of stakeholder engagement in comparative effectiveness and patient-centred outcomes research. *Journal of General Internal Medicine, 26*(12), 1692-1701. https://doi.org/10.1007/s11606-014-2878-x

Cook, R., Brewer, R., Shah, P., & Bird, G. (2013). Alexithymia, not autism, predicts poor recognition of emotional facial expressions. *Psychological Science*, *24*(5), 723–732. https://doi.org/10.1177/0956797612463582

Cooper, L., Saha, S., & van Ryn, M. (2022). Mandated implicit bias training for health professionals: A step toward equity in healthcare. *JAMA Health Forum, 3*(8), 1-3. https://doi.org/10.1001/JAMAhealthforum.2022.3250

Corden, K., Brewer, R., & Cage, E. (2022). A systematic review of health care professionals' knowledge, self-efficacy and attitudes towards working with autistic people. *Review Journal of Autism and Developmental Disorders, 9*, 386-399. https://doi.org/10.1007/S40489-021-00263-w

Corbin, J., & Strauss, A. (2008). *The basics of qualitative research: Techniques and procedures for developing grounded theory (3rd ed)*. SAGE publications, Thousand Oaks.

Coughlan B., Duschinsky R., O'Connor M. E., & Woolgar M. (2019). Identifying and managing care for children with autism spectrum disorders in general practice: A systematic review and narrative synthesis. *Health and Social Care in the Community, 28*(6), 1928-1941. https://doi.org/10.1111/hsc.13098

Dasgupta, N., & Rivera, L. M. (2008). When social context matters: The influence of long-term contact and short-term exposure to admired outgroup members on implicit attitudes and behavioral intentions. *Social Cognition, 26*(1), 112-123. https://doi.org/10.1521/soco.2008.26.1.112

Dew, A., & Boydell, K. (2017). Knowledge translation: Bridging the disability research-to-practice gap. *Research and Practice in Intellectual and Developmental Disabilities, 4*(2) 142-157. http://dx.doi.org/10.1080/23297018.2017.1315610

Dilliway, G., & Maudsley, G. (2008). Patients bringing information to primary care consultations: A cross-sectional (questionnaire) study of doctors' and nurses' views of its impact. *Journal of Evaluation in Clinical Practice, 14*(4), 545-547. https://doi.org/10.1111/j.1365-2753.2007.00911.x

Dreiling, N. G., Cook, M. L., Lamarche, E., & Klinger, L. G. (2022). Mental health Project ECHO Autism: Increasing access to community mental health services for autistic

individuals. *Autism: The International Journal of Research and Practice*, *26*(2), 434-445. https://doi.org/10.1177/13623613211028000

Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A., Kinnersley, P., Cording, E., Tomson, D., Dodd, C., Rollnick, S., Edwards, A., & Barry, M. (2012). Shared decision making: a model for clinical practice. *Journal of General Internal Medicine, 27*(10), 1361-1367. Https://doi.org/10.1007/s11606-012-2077-6

Elsabbagh, M., Yusuf, A., Prasanna, S., Shikako-Thomas, K., Ruff, C., & Fehlings, G. (2014). Community engagement and knowledge translation: Progress and challenge in autism research. *Autism, 18*(7), 1-11. https://doi.org/10.1177/1362361314546561

Epstein, R. M. (2000). The science of patient-centred care. *The Journal of Family Practice, 49*(9), 805-807.

Federation of State Medical Boards. (2023). *Continuing medical education board-by-board overview.* Retrieved May 14, 2023, from https://www.fsmb.org/siteassets/advocacy/key-issues/continuing-medical-education-by-state.pdf

Fennell, L. C. P., & Johnson, S. A. (2022). Examination of professional biases about autism: How can we do better? *The Clinical Neuropsychologist, 36*(5), 1094-1115. https://doi.org/10.1080/13854046.2021.1958922

Finney Rutten, L. J., Hesse, B. W., St. Sauver, J. L., Wilson, P., Chawla, N., Hartigan, D. B., Moser, R. P., Taplin, S., Glasgow, R., & Arora, N. K. (2016). Health self-efficacy among populations with multiple chronic conditions: The value of patient-centered communication. *Advances in Therapy, 33,* 1440-1451. https://doi.org/10.1007/s12325-016-0369-7

Fletcher-Watson S. (2022). Transdiagnostic research and the neurodiversity paradigm: Commentary on the transdiagnostic revolution in neurodevelopmental disorders by Astle et al. *The Journal of Child Psychology and Psychiatry*, 63(4), 418-420. https://doi.org/10.1111/jcpp.13589

Fletcher-Watson, S., & Bird, G. (2020). Autism and empathy: What are the real links? *Autism: The International Journal of Research and Practice, 24*(1), 3-6. https://doi.org/10.1177/1362361319883506

Frye-Cox, N. E., & Hesse, C. R. (2013). Alexithymia and marital quality: The mediating roles of loneliness and intimate communication. *Journal of Family Psychology, 27*(2), 203-211. https://doi.org/10.1037/a0031961

Fuertes, J., Boylan, L., & Fontanella, J. (2008). Behavioural indices in medical care outcome: The working alliance, adherence, and related factors. *Journal of General Internal Medicine, 24*(1), 80-85. https://doi.org/10.1007/s11606-008-0841-4

Fuertes, J., Mislowack, A., Bennett, J., Paul, L., Gilbert, T., Fontan, G., & Boylan, L. (2007). The physician-patient working alliance. *Patient Education and Counseling, 66*(1), 29-36. https://doi.org/10.1016/j.pec.2006.09.013

Gardiner, E., & Iarocci, G. (2014). Students with autism spectrum disorder in the university context: Peer acceptance predicts intention to volunteer. *Journal of Autism and Developmental Disorders*, *44*(5), 1008-1017. https://doi.org/10.1007/s10803-013-1950-4

Gaskell, G. (2000). Individual and group interviewing. In Bauer, M. and Gaskell, G. (eds), *Qualitative researching with text, image and sound*. Sage, London.

Ghaderi, G., & Watson, S. L. (2019). Autism spectrum disorder knowledge, training and experience: Ontario physicians' perspectives about what helps and what does not. *Journal on Developmental Disabilities, 24*(2), 51–60.

Giles, T., King, L., de Lacey, S., (2013). The timing of the literature review in grounded theory research: An open mind versus an empty head. *Advances in Nursing Science, 36*(2), 29-40. https://doi.org/10.1097/ANS.0b013e3182902035

Gillespie-Lynch, K., Kapp, S. K., Brooks, P. J., Pickens, J., & Schwartzman, B. (2017). Whose expertise is it? Evidence for autistic adults as critical autism experts. *Frontiers in Psychology, 8*, 438. https://doi.org/10.3389/fpsyg.2017.00438

Glaser, B. G., & Strauss, A. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago.

Goold, S. & Lipkin, M. (1999). The Doctor-Patient Relationship: Challenges, opportunities, and strategies. *Journal of General Internal Medicine, 14*(1), s26-s33. https://doi.org/10.1046/j.1525-1497.1999.00267.x

Gould, J. (2017). Toward understanding the under recognition of girls and women on the autism spectrum. *Autism, 21*(6), 703-705. https://doi.org/10.1177/1362361317706174

Graham, I. D., Logan, J., Harrison, M. B., Straus, S., Tetroe, J., Caswell, W., & Robinson, N. (2006). Lost in knowledge translation: Time for a map? *The Journal for Continuing Education in the Health Professions, 26*(1), 13-24. https://doi.org/10.1002/chp.47

Gray, K., Keating, C., Taffe, J., Brereton, A., Einfeld, S., Reardon, T., & Tonge, B. (2014). Adults outcomes in autism: Inclusion and living skills. *Journal of Autism and Developmental Disorders,44,* 3006-3015. https://doi.org/10.1007/s10803-014-2159-x

Green, R.M., Travers, A.M., Howe, Y., & McDougle, C.J. (2019). Women and autism spectrum disorder: Diagnosis and implications for treatment of adolescents and adults. *Current Psychiatry Reports, 21*(22), 1-8, https://doi.org/10.1007/s11920-019-1006-3

Green, D. & Flanagan, D. (2008). Understanding the autistic dental patient. *General Dentistry, 56*(2), 167-71.

Greenwald, A. G., McGhee, D. E., & Schwartz, J. L. (1998). Measuring individual differences in implicit cognition: The implicit association test. *Journal of Personality and Social Psychology*, *74*(6), 1464-1480. https://doi.org/10.1037//0022-3514.74.6.1464

Griffith, G., Totsika, V., Nash, S., & Hastings, R. (2001). 'I just don't fit in anywhere': Support experiences and future support needs of individuals with Asperger syndrome in middle adulthood. *Autism, 16*(5), 532-546. https://doi.org/10.1177/1362361311405223

Gyawali, S., & Patra, B. N. (2019). Trends in concept and nosology of autism spectrum disorder: A review. *Asian Journal of Psychiatry, 40*, 92-99. https://doi.org/10.1016/j.ajp.2019.01.021

Gutstein, S., & Whitney, T. (2002). Aspergers syndrome and the development of social competence. *Focus on Autism and other Developmental Disabilities, 17*(3), 161-171. https://doi.org/10.1177/10883576020170030601

Ha, J., Anat, D., & Longnecker, N. (2010). Doctor-patient communication: A review. *The Ochsner Journal, 10,* 38-43. https://doi.org/10.1046/j.1525-1497.1999.00267.x

Haigh, S. M., Walsh, J. A., Mazefsky, C. A., Minshew, N. J., & Eack, S. M. (2018). Processing speed is impaired in adults with autism spectrum disorder, and relates to social communication abilities. *Journal of Autism and Developmental Disorders*, *48*(8), 2653-2662. https://doi.org/10.1007/s10803-018-3515-z

Hall, W. & Callery, P. (2001). Enhancing the rigor of grounded theory: Incorporating reflexivity and relationality. *Qualitative Health Research, 11*(2), 257-272. https://doi.org/10.1177/104973201129119082

Hall, J., Horgan, T., Stein, T., & Roter, D. (2002). Liking in the physician-patient relationship. *Patient Education and Counselling, 48,* 69-77. https://doi.org/10.1016/s0738-3991(02)00071-x

Harder, H. (2009). Invisible disabilities. *The International Journal of Disability Management Research, 4*(1), 1. https://doi.org/10.1375/jdmr.4.1.ii

Hodgetts, S., Nicholas, D., Zwaigenbaum, L., & McConnell, D. (2013). Parents' and professionals' perceptions of family-centred care for children with autism spectrum disorder across service sectors. *Social Science and Medicine, 96*, 138-146. https://doi.org/10.1016/j.socscimed.2013.07.012

Holdnack, J., Goldstein, G., & Drozdick, L. (2011). Social perception and WAIS-IV performance in adolescents and adults diagnosed with Asperger's Syndrome and Autism. *Assessment, 18*(2), 192-200. https://doi.org/10.1177/1073191110394771

Houghton, C., Casey, D., Shaw, D., & Murphy, K. (2013). Rigour in qualitative case-study research. *Nurse Researcher, 20*(4), 12-17. https://doi.org/10.7748/nr2013.03.20.4.12.e326

Howlin, P. (2000). Outcome in adult life for more able individuals with autism or Asperger syndrome. *Journal of Autism, 4*(1), 63-83. https://doi.org/10.1177/1362361300004001005

Howlin, P., & Taylor, J. L. (2015). Addressing the need for high quality research on autism in adulthood. *Autism: The International Journal of Research and Practice*, *19*(7), 771-773. https://doi.org/10.1177/1362361315595582

Jacobson, N., Butterill, D., & Goering, P. (2003). Development of a framework for knowledge translation: Understanding user context. *Journal of Health Research Services, 8*(2), 94-99. https://doi.org/10.1258/135581903321466067

Jahng, K., Martin, L., Golin, C., & DiMatteo, M. (2005). Preferences for medical collaboration: Patient-physician congruence and patient outcomes. *Patient Education and Counseling, 57*(3), 308-314. https://doi.org/10.1016/j.pec.2004.08.006

John, R. P., Knott, F. J., & Harvey, K. N. (2018). Myths about autism: An exploratory study using focus groups. *Autism: The International Journal of Research and Practice, 22*(7), 845-854. https://doi.org/10.1177/1362361317714990

Jones, D. R., DeBrabander, K.M., & Sasson, N.J. (2021). Effects of autism acceptance training on explicit and implicit biases towards autism. *Autism, 25*(5), 1246-1261. https://doi.org/10.1177/1362361320984896

Kang, L. R. J., Barlott, T., Turpin, M., & Urbanowicz, A. (2022). A trial of the AASPIRE healthcare toolkit with Australian adults on the autism spectrum. *Australian Journal of Primary Health*, *28*(4), 350-356. https://doi.org/10.1071/PY21134

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism, 20*(4), 442-462. https://doi-org.uml.idm.oclc.org/10.1177/1362361315588200wio

Kitson, A., Marshall, A., Bassett, K., & Zeitz, K. (2013). What are the core elements of patient-centred care? A narrative review and synthesis of the literature from health policy, medicine and nursing. *Journal of Advanced Nursing, 69*(1), 4-15. https://doi.org/10.1111/j.1365-2648.2012.06064.x

Kuhithau, K., Warfield, M., Hurson, J., Delahaye, J. & Crossman, M. (2014). Pediatric providers perspectives on the transition to adult healthcare for use with autism spectrum disorder: current strategies and promising new directions. *Autism, 19*(3), 1-10. https://doi.org/10.1177/1362361313518125

Lai, M-C., Lombardo, M. V., Pasco, C., Ruigrok, A., Wheelwright, S., Sadek, S. A., Chakrabarti, B., Medical Research Council Autism Imaging Multicentre Study Consortium, Baron-Cohen, S. (2011). A behavioural comparison of male and female adults with high functioning autism spectrum conditions. *PLoS ONE, 6*(6), 1-10. https://doi.org/10.1371/journal.pone.0020835

Lawrence, D., Alleckson, D. & Bjorklund, P. (2010). Beyond the roadblocks: Transition to adulthood with Asperger's disorder. *Archives of Psychiatric Nursing, 24(*4), 227-238. https://doi.org/10.1016/j.apnu.2009.07.004

Lightner, K. L., Kipps-Vaughan, D., Schulte, T., & Trice, A. D. (2012). Reasons university students with a learning disability wait to seek disability services. *Journal of Postsecondary Education and Disability*, *25*(2), 145-159.

Lim, A., Young, R.L., & Brewer, N. (2021). Autistic adults may be erroneously perceived as deceptive and lacking credibility. *Journal of Autism and Developmental Disorders, 52,* 490-507. https://doi.org/10.1007/s10803-021-04963-4

Lindsay, S., Osten, V., Rezai, M., & Bui, S. (2021). Disclosure and workplace accommodations for people with autism: A systematic review. *Disability and Rehabilitation, 43*(5), 597-610. https://doi.org/10.1080/09638288.2019.1635658

Lugo-Marín, J., Magán-Maganto, M., Rivero-Santana, A., Cuellar-Pompa, L., Alviani, M., Jenaro-Rio, C., Díez, E., & Canal-Bedia, R. (2019). Prevalence of psychiatric disorders in

adults with autism spectrum disorder: A systematic review and meta-analysis. *Research in Autism Spectrum Disorders, 59*, 22-33. https://doi.org/10.1016/j.rasd.2018.12.004

Luke, L., Clare, I., Ring, H., Redley, M. & Peter W. (2011). Decision-making difficulties experienced by adults with autism spectrum conditions. *Autism, 16*(6), 612-621. https://doi.org/10.1177/1362361311415876

Lum, M., Garnett, M., & O'Connor, E. (2014). Health communication: A pilot study comparing perceptions of women with and without high functioning autism spectrum disorder. *Research in Autism Spectrum Disorders, 8*(12), 1712-1721. https://doi.org/10.1016/j.rasd.2014.09.009

Mazurek M. O. (2014). Loneliness, friendship, and well-being in adults with autism spectrum disorders. *Autism: The International Journal of Research and Practice*, *18*(3), 223-232. https://doi.org/10.1177/1362361312474121

McClure, J. (2011). The role of causal attributions in public misconceptions about brain injury. *Rehabilitation Psychology*, *56*(2), 85-93. https://doi.org/10.1037/a0023354

Milton, D. (2012). The ontological status of autism: The 'double empathy problem'. *Disability and Society, 27*(6) 883-887. https://doi.org/10.1080/09687599.2012.710008

Mitchell, C. (2008) One-Channel Communication: Developing Social Relations Online. in Edmonds, Genevieve, Beardon, & Luke (Eds.). *Asperger syndrome and social relationships: Adults speak out about Asperger syndrome*, (pp 19-26). Jessica Kingsley Publishing. London, England.

Mitchell, P., Sheppard, E., & Cassidy, S. (2021). Autism and the double empathy problem: Implications for development and mental health. *The British Journal of Developmental Psychology*, *39*(1), 1-18. https://doi.org/10.1111/bjdp.12350

Montague, T., Gogovor, A., Aylen, J., Ashley, L., Ahmed, S., Martin, L., Cochrane, B., Adams, O., & Nemis-White, J. (2017). Patient-centred care in Canada: Key components and the path forward. *Healthcare Quarterly, 20*(1), 50-56. https://doi.org/10.12927/hcq.2017.25136

Muller, E., Schuler, A., & Yates, G. (2008). Social challenges and supports from the perspective of individuals with Asperger syndrome and other autism spectrum disabilities. *Autism, 12*(2), 173-190, https://doi.org/10.1177/1362361307086664

Murray, E., Lo, B., Pollack, L., Donelan, K., Catania, J., White, M., Zapert, K., & Turner, R. (2003). The impact of health information on the internet on the physician-patient relationship: patient perceptions. *Archives of Internal Medicine*, *163*(14), 1727-1734. https://doi.org/10.1001/archinte.163.14.1727

National Autistic Society. (2023). *My health passport for autistic people.* Retrieved on April 28, 2023, from https://dy55nndrxke1w.cloudfront.net/file/24/.ZuLn47.Z3Oq7eJ.ZkJp.0QsoHD/Health_Passport_A4_Editable_2022.pdf

National Collaborating Centre for Mental Health (UK). (2012). *Autism: Recognition, referral, Diagnosis and Management of Adults on the Autism Spectrum*. British Psychological Society.

Nicolaidis, C., Raymaker, D., Ashkenazy, E., McDonald, K., Dern, S., Baggs, A., Kapp, S., Weiner, M., Boisclair, W.C., (2015). "Respect the way I need to communicate with you": Healthcare experiences of adults on the autism spectrum. *Autism, 19*(7), 824-31. https://doi.org/10.1177/1362361315576221

Nicolaidis, C., Raymaker, D., McDonald, K., Dern, S., Boisclair, W., Ashkenazy, E., & Baggs, A. (2012). Comparison of healthcare experiences in autistic and non-autistic adults: A

cross-sectional online survey facilitated by an academic-community partnership. *Journal of General Internal Medicine, 28*(6), 2761-2769. https://doi.org/10.1007/s11606-012-2262-7

Nicolaidis, C., Raymaker, D., McDonald, K., Kapp, S., Weiner, M., Ashkenazy, E., Gerrity, M., Kripke, C., Platt, L., & Baggs, A. (2016). The development and evaluation of an online healthcare toolkit for autistic adults and their primary care providers. *Journal of General Internal Medicine*, *31*(10), 1180-1189. https://doi.org/10.1007/s11606-016-3763-6

Nicolaidis, C., Schnider, G., Lee, J., Raymaker, D. M., Kapp, S. K., Croen, L. A., Urbanowicz, A., & Maslak, J. (2021). Development and psychometric testing of the AASPIRE Adult Autism Healthcare Provider Self-Efficacy Scale. *Autism: The International Journal of Research and Practice*, *25*(3), 767-773. https://doi.org/10.1177/1362361320949734

Oakley, B. F. M., Jones, E. J. H., Crawley, D., Charman, T., Buitelaar, J., Tillmann, J., Murphy, D. G., Loth, E., & EU-AIMS LEAP Group (2022). Alexithymia in autism: Cross-sectional and longitudinal associations with social-communication difficulties, anxiety and depression symptoms. *Psychological Medicine*, *52*(8), 1458-1470. https://doi.org/10.1017/S0033291720003244

Punshon, C., Skirrow, P., & Murphy, G. (2009). The 'not guilty verdict': Psychological reactions to a diagnosis of Asperger syndrome in adulthood. *Autism, 13*(3), 265-283. https://doi.org/10.1177/1362361309103795

President and Fellows of Harvard College (2007). Doctor-patient communication: A shared responsibility. *Harvard Men's Health Watch, 12*(1), 6-7.

Prestwich, A., Kenworthy, J. B., Wilson, M., & Kwan-Tat, N. (2008). Differential relations between two types of contact and implicit and explicit racial attitudes. *British Journal of Social Psychology, 47*(4), 575-588. https://doi.org/10.1348/014466607X267470

Ridd, M., Shaw, A., Lewis, G., & Salisbury, C. (2009). The patient-doctor relationship: A synthesis of the qualitative literature on patients' perspectives. *The British Journal of General Practice: The Journal of the Royal College of General Practitioners*, *59*(561), e116–e133. https://doi.org/10.3399/bjgp09X420248

Rogers, K., Dziobek, I., Hassenstab, J., Wolf, O., & Convit, A. (2007). Who cares? Revisiting empathy in Asperger Syndrome. *Journal of Autism and Developmental Disorders, 37,* 709-715. https://doi.org/10.1007/s10803-006-0197-8

Royal College of Physicians and Surgeons of Manitoba. (2023). *Continuing and professional development.* Retrieved on May 17, 2023, from http://www.cpsm.mb.ca/standards/continuing-professionaldevelopment#:~:text=continuing%20professional%20development%20activities.,College%20of%20Surgeons%20of%20Canada

Samur, D., Tops, M., Schlinkert, C., Quirin, M., Cuijpers, P., & Koole, S. L. (2013). Four decades of research on alexithymia: Moving toward clinical applications. *Frontiers in Psychology*, *4*, 1-4. https://doi.org/10.3389/fpsyg.2013.00861

Saulnier, C. & Klin, A. (2007). Brief report: Social and communication abilities and disabilities in higher functioning individuals with autism and asperger syndrome. *Journal of Autism and Developmental Disorders, 37,* 788-793, https://doi.org/10.1007/s10803-006-0288-6

Scheerer, N. E., Boucher, T. Q., & Iarocci, G. (2021). Alexithymia is related to poor social competence in autistic and nonautistic children. *Autism Research: Official Journal of the*

International Society for Autism Research, *14*(6), 1252-1259. https://doi.org/10.1002/aur.2485

Sciutto, M., Richwine, S., Mentrikoski, J. & Niedswiecki, K. (2012). A qualitative analysis of the school experiences of students with aspergers syndrome. *Focus on Autism and Other Developmental Disabilities, 27*(3), 177-188. https://doi.org/10.1177/1088357612450511

Shakespeare, T. (2013). The Social Model of Disability. In Davis, L. (Ed.), *The Disability Reader* (214-221). London: Routledge.

Shepherd, N. (2008). 'How do you communicate that you have a communication problem... When you have a communication problem?'. In Edmonds, G. & Beardon, L., (Eds.), *Asperger syndrome and employment: Adults speak out about Asperger syndrome,* (54-66). London, England: Jessica Kingsley Publishers.

Sheppard, E., Pillai, D., Wong, G. T. L., Ropar, D., & Mitchell, P. (2016). How easy is it to read the minds of people with Autism Spectrum Disorder? *Journal of Autism and Developmental Disorders, 46*, 1247-1254. https://doi.org/10.1007/s10803-015-2662-8

Schuck, R. K., Tagavi, D. M., Baiden, K. M. P., Dwyer, P., Williams, Z. J., Osuna, A., Ferguson, E. F., Jimenez Muñoz, M., Poyser, S. K., Johnson, J. F., & Vernon, T. W. (2022). Neurodiversity and autism intervention: Reconciling perspectives through a naturalistic developmental behavioral intervention framework. *Journal of Autism and Developmental Disorders*, *52*(10), 4625-4645. https://doi.org/10.1007/s10803-021-05316-x

Smith, R. & Sharp, J. (2013). Fascination and isolation: A grounded theory exploration of unusual sensory experiences in adults with Asperger Syndrome. *Journal of Autism and Developmental Disorders, 43,* 891-910. https://doi.org/10.1007/s10803-012-1633-6

Spitzer, C., Siebel-Jurges, U., Barnow, S., Grabe, H. J., & Freyberger, H. J. (2005). Alexithymia and interpersonal problems. *Psychotherapy and Psychosomatics*, *74*(4), 240-246. https://doi.org/10.1159/000085148

Stewart, M. (2001). Towards a global definition of patient centred care: The patient should be the judge of patient centred care. *British Medical Journal*, 323, 444-445. https://doi.org/10.1136/bmj.322.7284.444

Strömberg, M., Liman, L., Bang, P., & Igelström, K. (2022). Experiences of sensory overload and communication barriers by autistic adults in health care settings. *Autism in Adulthood: Challenges and Management*, *4*(1), 66-75. https://doi.org/10.1089/aut.2020.0074

Taber, B.J., Leibert, T.W., & Agaskar, V.R. (2011). Relationships among client-therapist personality congruence, working alliance, and therapeutic outcome. *Psychotherapy, 48*(4), 376-380. https://doi.org/10.1037/a0022066

Taboas, A., Doepke, K., & Zimmerman, C. (2023). Preferences for identity-first versus person-first language in a US sample of autism stakeholders. *Autism, 27*(2), 565-570. https://doi-org.uml.idm.oclc.org/10.1177/13623613221130845

Tantam, D. (2003). The challenge of adolescents and adults with Asperger Syndrome. *Child and Adolescent Psychiatric Clinics of North America, 12*(1), 143-153. https://doi.org/10.1016/s1056-4993(02)00053-6

The Centre for Intersectional Justice. (2023). Retrieved on April 17, 2023, from https://www.intersectionaljustice.org

The Knowledge Translation Program. (2023) *Intersectionality and knowledge translation: Intersectionality guide.* Retrieved on April 17, 2023, from https://knowledgetranslation.net/portfolios/intersectionality-and-kt/

Thompson-Hodgetts, S., Labonte, C., Mazumder, R., & Phelan, S. (2020). Helpful or harmful? A scoping review of perceptions and outcomes of autism diagnostic disclosure to others. *Research in Autism Spectrum Disorders, 77,* https://doi.org/10.1016/j.rasd.2020.101598

Unigwe, S., Buckley, C., Crane, L., Kenny, L., Remington, A., & Pellicano, E. (2017). GPs' confidence in caring for their patients on the autism spectrum. *British Journal of General Practice, 67*(659), e445-e452. https://doi.org/10.3399/bjgp17X690449

Venkat, A., Jauch, E., Russel, W., Roman-Crist, C., & Farrell, R. (2012). Care of the patient with an autism spectrum disorder by the general physician. *Postgraduate Medical Journal, 88*(1042), 472-481. https://doi.org/10.1136/postgradmedj-2011-130727

Wandersman, A., Duffy, J., Flaspohler, P., Noonan, R., Lubell, K., Stillman, L., Blachman, M., Dunville, R., & Saul, J. (2008). Bridging the gap between prevention research and practice: The interactive systems framework for dissemination and implementation. *American Journal of Community Psychology*, *41*(3-4), 171-181. https://doi.org/10.1007/s10464-008-9174-z

Warmoth, A. (2000). Social Constructionist Epistomology. Sonoma State University. http://www.sonoma.edu/users/w/warmotha/epistemology.html

Wolff, J.L., & Roter, D.L. (2011a). Family presence in routine medical visits: A meta-analytical review. *Social Science and Medicine, 72*(6), 826-831. https://doi.org/10.1016/j.socscimed.2011.01.015

Wolff, J.L., & Roter, D.L. (2011b). Older adults' mental health function and patient-centred care: does the presence of a family companion help or hinder communication? *Journal of General Internal Medicine, 27*(6), https://doi.org/10.1007/s11606-011-1957-5

Wright, M., (2016). "A sickness with a person in tow": The experience of healthcare for adults with high-functioning autism spectrum disorder. (Unpublished Master's thesis). University of Manitoba, Winnipeg, Canada.

Zerbo, O., Massolo, M., Qian, Y., & Croen, L. (2015). A study of physician knowledge and experience with autism in adults in a large integrated healthcare system. *Journal of Autism and Developmental Disorders, 45,* 4002-4014. https://doi.org/10.1007/s10803-015-2579-2

Tab1e 1

Sample Characteristics

Sample Characteristics

Variable	% of Sample
Sex	
Female	53.6
Male	42.9
Other[a]	3.6
Age (years)	
20-29	42.9
30-39	39.3
40-49	14.3
50-59	3.6
60+	0.0
Ethnicity	
White	64.3
Black	17.9
Hispanic	7.1
Other[a]	7.1
PNS[b]	3.6
Country[c]	
Canada	35.7
United States	53.6
PNS[b]	10.7
Residence	
House	57.1
Apartment	39.3
Other	3.6

Variable	% of Sample
Living Situation	
Alone	35.7
Parents	28.6
Partner/Spouse	28.6
Other[a]	7.1
Relationship Status	
Single	53.6
Partner/Married	39.3
Divorced/Widowed	7.2
Sexual Orientation	
Heterosexual	71.4
Homosexual	3.6
Other[a]	21.4
PNS[b]	3.6
Highest Level of Education	
High-School	14.3
Some College	10.7
Bachelor/Assoc.	53.6
Master's Degree	17.9
Other[a]	3.6

Other[a] = Responded by endorsing the option 'Other';
PNS[b] = Responded by endorsing the option 'Prefer not to say' or did not respond;
Country[c] =(Canada was represented by AB, MB, ON, QC; United States was represented by CA, CT, GA, MD, MI, MN, NY, OR, PA, TX, VA, WI)

Appendix A

Research Opportunity:
The Experience of Healthcare for Adults with Autism Spectrum Disorder
An Online Study

This study will gather feedback from adults diagnosed with Autism Spectrum Disorder (including those diagnosed with Asperger's Syndrome, HFASD, and PDD- NOS) about their experiences in healthcare. This will include asking these adults what they perceive as helpful and challenging in interacting with healthcare professionals, the role of a family member or support person in their healthcare (if applicable), as well as what they wish healthcare professionals better understood about them. Participation is up to three phases and completely online. All three phases can be completed in 1-2 hours, however if participants prefer to take more time to respond, they will have up to 2 weeks.

Participants completing the first phase of the study will be entered into a *draw* for one $20 CAD ($15 USD) gift card.

Participants completing the second phase of the study will *receive* a $40 CAD ($30 USD) gift card (e.g., amazon, Tim Horton's, Starbucks).

Participants must be Canadian or American, age 20 or older, and able to attend at least some of their medical appointments independently and able to make their own medical decisions.

If you are interested in participating, know someone who may be interested, or would like further information, please contact the primary investigator:

Michelle Wright, umwrig28@myumanitoba.ca

This study is being conducted as part of Michelle Wright's PhD Dissertation at the University of Manitoba, Department of Psychology, with the assistance of Research Manitoba/Manitoba Mental Health Foundation PhD Studentship, and the approval of the University of Manitoba Psychology/Sociology Research Ethics Board



UNIVERSITY OF MANITOBA

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Appendix B

Information and Consent Form

Study Name: The Experience of Patient-Centered Care and Communication for Adults with Autism Spectrum Disorder

Principal Investigator: M Michelle Wright, PhD Student, Psychology, umwrig28@myumanitoba.ca

Research Supervisor: Dr. Janine Montgomery, Associate Professor, Psychology, Janine.Montgomery@umanitoba.ca

This consent form, a copy of which you may save or print for your records and reference at this time (it will not be available later), is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to contact us. Please take the time to read this carefully and to understand any accompanying information.

Purpose of Study

Michelle Wright is conducting this study as her PhD dissertation, under the supervision of Dr. Janine Montgomery. The purpose of this research is to examine how Canadian and American adults with Autism Spectrum Disorder (including those formerly diagnosed with Asperger Syndrome and High Functioning Autism Spectrum Disorder). In the first phase, participants in this study will be asked to complete a questionnaire – including demographic questions such as age, gender, ethnicity, as well as the nature and frequency of contact with healthcare and healthcare providers. This will be followed by a brief 10-item screening questionnaire. These questions will help determine individual's eligibility for the study.

Individuals who are eligible will then be asked to participate in the second and third phases of the study. In the second phase, participants will be emailed a link to the survey website with five to six long-answer questions about their healthcare. They will be free to take up to two weeks to complete their responses. Individuals with incomplete responses will be reminded at the end of the two-week period that their participation is in progress. These

questions will ask participants to write about their healthcare experiences and their healthcare.

relationships. Some participants may experience distress during the study, because some of what participants choose to write about may include negative experiences, but we do not expect this distress to be long-lasting. If you choose to participate, and your recall of these events creates significant or long-lasting distress, please contact your local crisis line or your healthcare professional. In the third phase, participants may be emailed links to additional follow-up questions to help clarify the original responses provided. This may include a summary of our interpretation of participants' responses in which participants will be asked to comment on this interpretation, and give feedback on whether or not we captured what they intended to communicate.

In addition, any and all email correspondences participants have with the primary research may be included as research data along with the survey responses. This means that by clicking "I consent" participants agree to have all future emails with the researcher included in their data. The researcher will take notes about these emails without using any of your identifying information, after which the emails will be deleted. If at any time you wish to communicate with the researcher and not have that specific email correspondence kept as data, you can indicate this in the subject line or body of the email.

We estimate that the time it will take participants to complete the study will vary from participant to participant. We anticipate that the first phase of the study – comprised of the letter of informed consent and a short questionnaire – will take approximately 20 minutes. Upon completion of the first phase, participants will be redirected to a webpage in which they will provide their email (for electronic gift card) or mailing address (for physical gift cards) in order to be entered into the draw for one $20 CAD ($15 USD) gift card. Due to each individual's unique experiences in healthcare, we expect that the content and length of the responses for phase 2 will also vary. Participants will be free to leave and return to the website over the course of the two-week period, allowing time to think about and edit their responses. As a rough estimate, total participation time may take between 1 and 2 hours. Upon completing phase 2, participants will be redirected to a webpage in

which they will provide their email (for electronic gift card) or mailing address (for physical gift cards) and choose which $40 CAD ($30 USD) gift card they would like to receive. This information will be kept separate from your data, and destroyed as soon as the gift card is mailed. The only information that will be kept is your first and last initial and the date the card was mailed. This gift card should be received within 2-3 weeks of completing this phase.

Confidentiality

Your participation in this study is completely voluntary. Should you choose to withdraw from the study at any point or feel that you would rather leave some question(s) you may do so.

All of the answers you provide will be kept confidential. Any information you provide will be stored on the encrypted and password protected site, Qualtrics, and your anonymized responses (i.e., your written responses after all possible identifying information) will be saved in a password protected document. Only the primary researcher, her supervisor, and other authorized lab personnel (e.g., research assistants) will have access to your anonymized data. We need to keep your contact information (your initials and email) with the data until the end of the third phase of the study in order to link your responses for each phase. However, we will keep your identifying information confidential. Once you have completed the third phase of the study and we have had a chance to pair your responses, we will delete all identifying information from our data, thus rendering it anonymized; we estimate we will do this by within 2 weeks the participant's completion of phase three, or within 2 weeks of participants withdrawing from the study. Your name and email address or mailing address will be collected in in a separate survey in order to send you your gift card, and will not be stored with your responses. Partial and incomplete responses will be included in the data unless you contact me to let me know you would like to withdraw and would like your data excluded from the study. Once all the data are collected and analyzed for this project, we plan to share this information with the research community through the final written dissertation, conferences, presentations, journal articles and the Social Cognition Lab website. When presenting the results of this research, we will use direct quotes from your responses, but we will in no way use any identifying information when discussing the findings. All anonymized data will be deleted no later than December 2025.

Findings

The results of this study should be available by December 2023. You will be able to see the research summary posted on the Social Cognition Lab website once they become available (see https://janinemontgomery.wixsite.com/socialcoglab- mb). Alternatively, if you would like to receive a summary, please contact Michelle Wright at umwrig28@myumanitoba.ca, provide her with your email address and inform her you would like to be on the email list to receive a summary once it is available. You only need to provide this information if you wish to receive a summary of the results; you are not required to provide this information.

Voluntary Participation/Withdrawal from the Study

Clicking “I agree” at the bottom of this page indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. If you wish to withdraw, simply email Michelle Wright at umwrig28@myumanitoba.ca to inform her that you no longer wish to participate. If you do choose to withdraw from this study, you will have the choice of submitting partial responses or no responses at all for the second phase, and we will destroy any data that you have provided and not include it in the analysis. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way.

This research has been approved by the Psychology/Sociology Research Ethics Board. If you have any concerns or complaints about this project you may
contact any of the above-named persons or the Human Ethics Secretariat at 204- 474-7122.

If you have read the information presented in this form and do not have any questions about this study, please click “I agree” when you are ready to

begin. You should only click “I agree” if you agree to participate with full knowledge of the study presented to you in this information and consent form and of your own free will. We strongly encourage you to save or print a copy of this consent form now for your records, as it will not be available later.

Thank you for considering participating in this study.

Michelle Wright – Primary Investigator
MA, PhD Candidate
Department of Psychology
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Appendix C

AQ-10

Please tick one option per question only:		***Definitely Agree***	***Slightly Agree***	***Slightly Disagree***	***Definitely Disagree***
1	I often notice small sounds when others do not				
2	I usually concentrate more on the whole picture, rather than the small details				
3	I find it easy to do more than one thing at once				
4	If there is an interruption, I can switch back to what I was doing very quickly				
5	I find it easy to 'read between the lines' when someone is talking to me				
6	I know how to tell if someone listening to me is getting bored				
7	When I'm reading a story I find it difficult to work out the characters' intentions				
8	I like to collect information about categories of things (e.g. types of car, types of bird, types of train, types of plant etc)				
9	I find it easy to work out what someone is thinking or feeling just by looking at their face				
10	I find it difficult to work out people's intentions				

Reproduced from Autism Research Centre (ARC), University of Cambridge.

Appendix D

Study Questions

1) If you could tell your doctors and other healthcare providers about your individual communication needs, what would you tell them?
2) What do you think is important for other people (e.g., parents, friends, support people) who may accompany you and help you during your healthcare appointments to understand?
3) Describe what you and/or your healthcare provider do to make communication successful. If possible, please describe a real-life example in detail, including what happened, how you felt about it, and how you feel it impacted your healthcare.
4) Describe what you and/or your healthcare provider struggle with that contributes to unsuccessful communication. If possible, please describe a real-life example in detail, including what happened, how you felt about it, how you feel it impacted your healthcare and what you think could be done to address it?
5) Do you have a good relationship with your healthcare provider? Please describe your relationship. How does this relationship impact your health?
6) The previous questions referred to your healthcare experiences in general, not specifically to COVID-19. If there is anything you would like to discuss about your healthcare experience since the onset of COVID-19 (for example, if you have experiences with how it has impacted communication with your healthcare providers, or your healthcare in general), please feel free to leave a response below. This question is optional.

Appendix E

Example of Prompts for Questions

1) If you could tell your healthcare providers about your individual communication needs, what would you tell them?

   If you are having difficulty coming up with a full and detailed answer, you may find following suggestions helpful.

   - Describe a real-life communication experience you've had with a healthcare provider. Include as much detail as possible, including:
     - who the healthcare provider was and how long you've known them
     - what you discussed
     - how it made you feel
   - Write your answer as though it were a 'report card' for the healthcare provider.
     - Did they do anything well? If so, what?
     - Did they do anything poorly? If so what could they do better?
     - How did the communication make you feel?

Appendix F

Preliminary Findings Sent to Participants

1. Positive Healthcare Providers are described as:
    a. take a personal interest and know the patient well
    b. take extra time, don't rush
    c. follow up with the patient after appointments
    d. are trustworthy, supportive, and understanding
    e. tailor communication to patient's strengths and preferences
2. Negative Healthcare Providers are described as:
    a. low knowledge about ASD
    b. dismissive
    c. demeaning/condescending
    d. not believing the patient
    e. have negative misperceptions about
3. Some participants reported that they do not have a support person (someone who accompanies them to their healthcare appointments). Their reasons included:
    a. because they felt it invaded their privacy
    b. they didn't feel it was necessary
    c. they didn't have anyone in their life who would accompany them
4. Most participants reported that they have support person (someone accompany them to their healthcare appointments. Their reasons included:
    a. supporting communication
    b. taking notes
    c. helping with advocacy
    d. helping with decision making
    e. providing a calming presence to reduce anxiety
    f. tasks outside of the appointment (e.g., transportation, booking appointments, filling prescriptions)
5. Participants had a wide range of definitions as to what made for a good support person:
    a. some participants wanted the support to speak on their behalf, others wanted the support person to help the patient speak, wanted the support person to say nothing
    b. some participants wanted the support person to make decisions for them, others wanted the support person to help with decision making, others wanted the support person to stay out of decision making
    c. some participants wanted support persons to act solely as a calming presence and not have any direct involvement in communication, advocacy, or decision making
6. Overall participants tended to agree on challenges in healthcare, but they had very individual ways in which they wanted to address those challenges.
    a. The relationship with healthcare providers and good communication are linked. Good relationships make good communication easier *and* better communication makes better relationships. Both are important.
    b. Healthcare providers and supports need to have good knowledge about ASD *and* good knowledge about the individual patients in order to foster good relationships and good communication.

c. Healthcare providers and support persons need to make sure they are meeting the patient's expectations and not overpowering patient autonomy.
d. Healthcare providers need to respect their patients' knowledge about themselves, and not confuse potential communication or social challenges with low overall abilities. Healthcare providers need to be aware of their patients' strengths – of which there are many.

(n.b. within the Qualtrics software, there was space to provide open ended comment after each of the six major findings).