

“A Sickness with a Person in Tow”: The Experience of Healthcare for Adults with High-
Functioning Autism Spectrum Disorder

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A Thesis submitted to the Faculty of Graduate Studies at

The University of Manitoba in

partial fulfillment of the requirements of the degree of

MASTER OF ARTS

Department of Psychology

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Winnipeg

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Acknowledgements

First and foremost, I would like to acknowledge and thank all of the participants for taking the time to tell me about their experiences, and for their openness and insights which made this study possible. Second, I would like to express my gratitude to my committee for the endless support and encouragement. To my advisor, Dr. Maria Medved, thank you for all that you have done to support me and my research. I am grateful to have learned so much from you, and will always carry that with me. To Dr. Janine Montgomery, thank you not only for your support, but for your enthusiasm about my research. To Dr. Kerstin Roger, thank you for your insightful and thought provoking feedback, which has helped me grow as a researcher. Third, I would like to thank Ms. Amy Brown for her work in coding, checking and discussing participants' responses. Finally, I would like to acknowledge the research funding I have received from the University of Manitoba Graduate Fellowship, the Manitoba Graduate Scholarship, and the Susan Wright Bell Award for the Study of Developmental Disabilities.

Abstract

Patient-centred care positions patients as active participants, collaborators, and experts in their healthcare and healthcare relationships - a role that adults with High Functioning Autism Spectrum Disorder (HFASD) may find challenging. The purpose of this study was to better understand the perspective and experiences of adults with HFASD in healthcare and healthcare relationships. Twenty-eight North American adults with HFASD responded to four open-ended long-answer questions online, which were analyzed using constant comparison methods within the grounded theory framework. Participants' positive and negative experiences in healthcare were determined by their interactions with healthcare professionals who were portrayed as knowledgeable and empowering allies, or unknowledgeable and overpowering adversaries. Ultimately, these findings highlight the need for more education and knowledge about HFASD among healthcare professionals, and how it impacts these adults, as well as the need to develop evidence based interventions and tools to support adults with HFASD communication in healthcare.

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“A Sickness with a Person in Tow”: The Experience of Healthcare for Adults with High-Functioning Autism Spectrum Disorder

The modern western medical patient lives in an era of Patient-centred care (PCC) where patients contribute to and have agency in their own healthcare. This contribution and agency occurs within healthcare relationships, and therefore fostering these relationships has received much attention in the literature. However, agency and contribution is not merely an explicit option but an implicit responsibility (President and Fellows of Harvard College, 2007). Implicitly, those who want to get better put in the effort and engage in the process of collaboration and communication within healthcare relationships. However, communication can differ from person to person, and in some cases, groups of people may not engage as they are ‘expected’ to; not due to a lack of desire to engage and invest in their health, but rather due to differences in communication and social abilities. Adults with High-Functioning Autism Spectrum Disorder (HFASD) face challenges in communication and social abilities, and yet little is known about how they experience their healthcare. Although there has been extensive research on the importance of positive relationships and communication in healthcare in general, as well as research on the perspectives of parents and caregivers of those (often children) with lower functioning ASD, I could only find one study, published after my data collection that examined the experience of adults with ASD in healthcare (Nicolaidis et al., 2015). However this study included participants at various points on the spectrum, and also included caregivers as participants. I could find no research to date that has examined the perspectives of adults with *HFASD* who navigate healthcare independently (e.g., without a support person) in terms of their healthcare experiences.

Background

High-Functioning Autism Spectrum Disorder

HFASD (formerly known as Asperger's Syndrome) is characterized by 'deficits' in social interaction, but with intact cognitive abilities (Gutstein & Whitney, 2002; Holdnack, Goldstein, & Drozdick, 2011). This lack of what has been called "social competence" - defined in subsequent sections - is the hallmark of HFASD and results in difficulties in almost all aspects of their lives, including work, education, family and romantic relationships, and the day-to-day interactions required in independent living (Barnhill, 2007; Cederlund, Hagberg, & Gillberg, 2009; Gutstein & Whitney, 2002; Gray et al., 2014; Lawrence, Alleckson, & Bjorklund, 2010).

Another common challenge for those with HFASD relates to unusual sensory experiences in which there can be hyper-reactivity to social environmental stimuli including sights, sounds, touch and even smells (Elwin, Ek, Kjellin, & Schroder, 2013; Robertson & Simmons, 2015; Smith & Sharp, 2013). These unusual sensory experiences - whether distressing or pleasurable - can distract from a social situation, or lead the individual to want escape from the situation altogether. This additional challenge can further hamper social interaction in general.

Understanding persons with HFASD. These hallmark characteristics of HFASD are not physically visible to others, therefore people with this disorder are often perceived as odd, rude, narcissistic or uncooperative and are met with very little understanding (Bailey, 2011; Lawrence et al., 2010). Tantam (2003) described a case study of 'Hilda' – a woman with HFASD - who was perceived as strange, and whose physicians felt she was uncooperative, "believing she was simply unmotivated to change" (p. 148). These negative misperceptions are common, and based on other people ascribing meaning to the person's behaviour. Adults with HFASD are therefore often marginalized and suffer from the "constant pressure to fit in with the demands of the

society that fails to understand their needs or difficulties” (Howlin, 2000, p. 79). In more global terms, those with HFASD are often treated as having deficits and character flaws (i.e., rude) rather than differences. Therefore, the goal of society in general does not seem to be to accept and understand but rather to change and normalize their behaviour (Brownlow, 2010). This issue is not limited to adults with HFASD, but reflects a larger issue of how disability is viewed. Within the medical model of disability, disability is seen as being within the person, where as within the social model of disability, disability also arises from an environment that ‘disables’ people with impairments (Shakespeare, 2013).

HFASD and differences in social competence. Social competencies are “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). Individuals with HFASD may have difficulties with various skills and strategies that make-up social competencies.

First, those with HFASD often have difficulty with social competencies related to expressing and reading emotions (Lawrence et al., 2010; Tantam, 2003). In fact, “impaired interpretation of facial expressions is one of the most durable findings in research into autistic spectrum disorders” (Tantam, 2003, p.155). This can make social exchanges and relationships difficult because if a person cannot read emotion they cannot respond in a socially ‘conventional’ manner. For example, failing to console someone who displays distress may make an adult with HFASD appear uncaring. However, labelling them as uncaring is a result of ascribing a meaning to the behaviour that may not reflect the intended meaning. In fact, adults with HFASD often report feeling ‘baffled’ with other people’s reactions to their behaviour; attributing the cause as

external to themselves and not as a response to their own behaviour (Barnhill, 2007; Lawrence et al., 2010). In other words, they do not ascribe the same meaning to their own behaviour as do others, and therefore do not understand others reactions.

Second, it's not only the interpretation of others' emotions, but also a tendency to interpret language literally, and to have difficulty with metaphors, sarcasm and insinuation that can create challenges (Lawrence et al., 2010). Adults with HFASD have voiced the need to have others communicate in a direct and 'spell-it-out-for-me' manner (Muller, Schuller, & Yates, 2008). Furthermore, Gaus (2007) points out that adults with HFASD may have "unusual ways of expressing thoughts and emotions, including specific names for symptoms and experiences" that are not shared by others (as cited in Lawrence, 2010, p. 234). In addition, the 'pragmatics' of conversation such as speech prosody, turn-taking and responding in a timely manner, may also not fit conventional styles, and interfere with the ability to have a face-to-face conversation (Mitchell, 2008). Therefore, even when interpretation of emotion and facial expression is removed from social exchange (for example, a telephone conversation), there may still be difficulty with the verbal content and pragmatics of the exchange as well.

HFASD and social communication forums. Adults with HFASD may have difficulties with communication, to the point that it hampers them from achieving their 'real-life' potential that one would otherwise expect based on cognitive abilities (Saulnier & Klin, 2007). The problem is twofold because making oneself understood relies on the ability to communicate, and as one very eloquent writer – an adult with what was called Asperger Syndrome at the time – points out, "how do you communicate that you have a communication problem... when you have a communication problem?" (Shepherd, 2008, p. 54). The more difficult communication is, the more difficult it is to challenge the misperceptions of others. Online communication can help

level the communication playing-field for those with HFASD by allowing more confident and empowered communication (Brownlow, 2010; Mitchell, 2008; Smith & Sharp, 2013). Rather than having to deal with multiple ‘channels’ (i.e., eye contact, tone of voice, facial expression) or the unusual sensory experiences that come with more stimuli rich ‘in person’ environments, Mitchell (2008) argues that the internet offers “one channel communication” (p. 19), removing the in-person communication barriers and allowing for individuals to think about and respond at a pace that allows for well thought-out responses. It is for these reasons that some researchers have used the internet to conduct research with adults with HFASD, providing a data-collection method through which these participants report they can best make themselves understood (see Nicolaidis et al., 2012; Sciutto et al., 2012; Smith & Sharp, 2013). They rationalized that by removing these communication barriers, they would be better able to gain understanding of the unique perspectives of those with HFASD. This approach resulted in rich data about participants’ experiences with education and teachers.

HFASD and differences in relationships. Individuals with HFASD often value different aspects of friendships than do neurotypical individuals. Compared to friendships between neurotypical individuals, friendships for individuals with HFASD include a higher focus on a joint activity rather than the friend themselves, where abrupt behaviour may be seen by neurotypical individuals as intentionally avoidant or “stand-offish” behaviour (Lawrence et al., 2010). This can lead neurotypical individuals to believe that those with HFASD do not want friendships. However, this belief is once again based on ascribing a neurotypical meaning to the behaviour, when in fact individuals with HFASD often have feelings of loneliness and crave social interaction (Muller et al., 2008). Therefore, the meaning that neurotypical individuals

ascribe to the behaviour (i.e., stand-offish and therefore don't want interaction) is not the same as the meaning held by those with HFASD (i.e., they do crave social interaction).

Individuals with HFASD may also have difficulties in relationships that stem from difficulties with the expression of empathy, and the resultant label of unempathic (Rogers, Dziobek, Hassenstab, Wolf, & Convit, 2007). Interestingly, those with HFASD may feel more empathy than commonly thought. There is evidence that they very much experience feelings of compassion, warmth and concern for others – a notion that has already been asserted by family of those with HFASD - but that their expression of such may not reflect the expected neurotypical response (Rogers et al., 2007). More specifically, Rogers and colleagues (2007) examined empathy in those with HFASD and neurotypical controls, and found that those with HFASD have difficulties understanding the perspective of others. However, on the Empathic Concern Subscale - which measures “feelings of warmth, compassion and concern for others” (p. 711) - there were no significant differences between those with HFASD and controls. In general, the assumption that those with HFASD do not want friendships – in part due to behaviours that are misperceived as stand-offish, rude or uncaring - is commonly held (Lawrence et al., 2010). Unfortunately, it is due to social differences – not a lack of motivation - that serve as barriers to these relationships (Lawrence et al., 2010).

Research Including Adults with HFASD

Historically, research examining the *individual* with HFASD – their lives, challenges, difficulties and (rarely) their strengths – has been limited (Barnhill, 2007). Much research has focused on children with ASD; where parents, caregivers, childhood educators, and professionals have provided the bulk of the data. This important research may be more common due to the nature of children as participants, as well as the ability and desire of parents and professionals to

advocate on their child's behalf (Bailey, 2011). However, there is 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), combined with the 'invisibility' of the challenges in *High Functioning* ASD (i.e., why help someone who doesn't look like they need help), all of which contribute to a lack of research – or more to the point a lack of interest – in better understanding these adults.

This is not to say that there is no interest in adults with HFASD and their needs, however, most of the research is aimed at supporting those with HFASD often does not include these adults as participants, which is problematic. For example, research in social support for those with ASD has found that many interventions are designed and evaluated by caregivers and professionals without adequate (if any) consultation with adults with ASD. This exclusion explains why these interventions often *fail to meet the needs of adults with ASD* (Griffith, Totsika, Nash & Hastings, 2001). Put plainly, other people – even those committed to supporting and advocating for and with people with HFASD – are no substitution for consulting and understanding the individual with HFASD directly.

Promisingly, when research does consult adults with HFASD it often contributes to a better understanding of these individuals as *persons*. For example, Muller et al. (2008) found that those with HFASD can express themselves quite well in research interviews, which challenges the notion that those with HFASD are "socially aloof, deliberately self-isolating, affectively flat, and lacking consciousness of their social skills deficits" (p. 187). In fact, they conducted interviews to uncover themes of social challenges and support from the participants' perspectives, and uncovered meaningful themes surrounding the issue of support, as well as showing that those with HFASD can and will convey their experiences of social situations. In

terms of social support, those with HFASD revealed that “patient, caring, and non-judgemental attitudes [...] go a long way in alleviating persistent feelings of social estrangement” (p. 186). Other themes that emerged included, “longing for intimacy and social connectedness, and a desire to contribute to one’s own community” (p. 177). Themes such as these, that typically are not attributed to the HFASD experience, are important in understanding those with HFASD as persons. In addition to Muller et al. (2008) researchers are increasingly beginning to include adults with HFASD in various domains of research, examples being employment, education, social supports, independent living and relationships (for examples see Barnhill, 2007; Griffith et al., 2001; Luke, Clare, Ring, Redley & Peter, 2011; Punshon, Skirrow, & Murphy, 2009; Sciutto et al., 2012; Smith & Sharp, 2013). However, very few (for examples see Lum, Garnett & O’Connor, 2014; Nicolaidis et al., 2012; Nicolaidis et al., 2015), have consulted adults with HFASD with regards to their own *healthcare*.

These few examples notwithstanding, research in healthcare predominantly still focuses on ‘other’ people’s perspectives of patients that are a) generally children and b) generally *lower* in functioning than adults with HFASD. For example, Kuhithau, Warfield, Hurson, Delahaye, & Crossman (2014) recognized the need for physicians to have support, education and skills in treating *adult* patients with ASD (not necessarily HFASD) as they transition from pediatric to adult healthcare. They consulted physicians, psychologists, social workers and nurses, but did not consult adult patients with ASD. Other examples include managing the clinical encounter with patients with ASD (Green & Flanagan, 2008; Venkat, Jauch, Russel, Roman-Crist, & Farrell, 2012) and parents and professionals opinions on healthcare (Hodgettes, Nicholas, Zwaigenbaum, & McConnell, 2013). Research with caregivers, physicians and advocates has made inarguably valuable contributions to the literature, but ultimately is of tenuous value in

understanding the *perceptions of adults with HFASD regarding their challenges and needs while independently navigating healthcare and healthcare relationships.*

HFASD Health and Healthcare

HFASD: Healthcare utilization and medical conditions. I could find no data on healthcare utilization and costs for Canadians with HFASD. However, some data is available for American populations. By one estimation, the current annual healthcare cost for individuals with autism in America is 90 billion dollars, with an estimated 200 billion in the next decade (Venkat, et al., 2012). Individuals with ASD are more likely than neurotypical individuals to have serious and chronic physical conditions such as epilepsy, gastrointestinal abnormalities, impaired liver function, and compromised immune systems (Lawrence, 2010; Tantam, 2003). They are also more likely to have mental health conditions, including depression, anxiety disorders, bipolar disorder and Tourette's syndrome (Barnhill, 2007; Lawrence, 2010; Tantam, 2003). Not only do they have increased rates of physical and mental health conditions, but they are also more likely to have multiple co-morbid conditions and therefore more likely to require multiple and varied healthcare services (Kuhithau et al., 2014; Nicolaidis et al., 2012). In sum, this suggests that individuals with autism have higher need for healthcare than the general neurotypical population.

Healthcare disparities. In addition to the increased healthcare needs of adults with ASD as compared to the general population, there is also evidence that these needs are not as well met. Nicolaidis et al. (2012) noted that despite over 400 million dollars spent on autism research annually in the US alone, as well as previous research that has found adults with disabilities face various healthcare disparities, very few studies have examined either adults with autism or their healthcare. To begin addressing this paucity in the literature, Nicolaidis and colleagues (2012), carried out a community-based participatory study with both adults with ASD (mostly HFASD

or Asperger's Syndrome diagnosis) and neurotypical adults inquiring about their healthcare experiences. Results indicate that adults with ASD reported being more than twice as likely to have visited the ER, and significantly less likely to have routine healthcare (such as tetanus vaccination or pap-smears for women). Overall, those with ASD had higher rates of unmet needs in physical, mental, and pharmaceutical healthcare.

The adults with ASD reported significantly lower scores on measures of healthcare provider–patient communication (i.e., how they rate communication with their healthcare provider), health self-efficacy (i.e., how well they believe they can handle a specific health condition *and* general healthcare self-efficacy), and significantly higher scores on measures of unmet healthcare needs and higher healthcare utilization. Some specific responses – where adults with ASD scored significantly lower than neurotypical controls - worth noting include: a) my healthcare provider understood what I was trying to communicate; b) provider communicated in a way that I can understand; and c) I felt I could trust health professionals to take care of my health care needs. They concluded there is a significant disparity between adults with HFASD and the general population. The disparity exists in terms of having their healthcare needs met, as well as in their perception of communication and relationship with their healthcare provider.

Patient-Centred Care

Patient-centred care (PCC) has received much attention in the literature and is widely accepted as beneficial to the patient. The PCC framework is made up of three main tenets: (a) an understanding of the patient as a person, including holistic understanding of personality, emotional issues and life experiences (Cloninger, 2010; Stewart, 2001); (b) positive healthcare relationships (Stewart, 2001); and (c) communication and collaboration on identifying the problems and their treatment (Cloninger, 2010; Stewart, 2001). These will be elaborated below.

PCC: Understanding the patient as a person. In the first component of PCC, patients are considered experts on their lives, bodies and health conditions, and must be understood as people and not just a puzzle of symptoms to be solved through diagnosis (Cloninger, 2010; Stewart, 2001). This understanding inarguably requires social interaction. The sharing of history, of life-experiences that impact health, of concerns and fears that may influence treatment, and of emotions that establish the patient as a person - and not a mere diagnosis - all require skilled social exchanges.

Understanding how individuals explain or define their illnesses - and likewise how they uniquely define 'good health' - is being increasingly explored in the medical literature. Misunderstandings between physician and patient about the causes, behavioural factors, and social meanings of health and illness can lead to disagreement in treatment decisions and outcomes (Goold & Lipkin, 1999; Ha, Anat, & Longnecker, 2010). The importance of understanding these meanings for minority groups has also increasingly received attention. Developing such understandings of the patient as a person, including how they understand and perceive health and illness, is therefore of importance within the medical encounter.

PCC: Healthcare relationships. The second component of PCC – positive healthcare relationships – has been shown to have significant effects on health and healthcare. In neurotypical populations, a positive effect has been found between patients' *perceptions* of the healthcare relationships and the utility of treatment, patient adherence to treatment, and patient satisfaction with treatment results (Fuertes, Boylan, & Fontanella, 2008; Fuertes et al., 2007). Furthermore, healthcare relationships have been studied in samples that are unique from the general population (e.g., individuals with HIV, Lupus, Cardiac Disease, Cancer, etc.) and the results support that treatment adherence, patient satisfaction, quality of life self-reports and

health outcomes are indeed associated with quality relationships (see Bennett, Fuertes, Keitel & Phillips, 2010; Farin & Meder, 2010; Ong, Visser, Lammes & de Haes, 2000; Schneider, Kaplan, Greenfield, Li & Wilson, 2004).

One aspect that has been examined within healthcare relationships has been ‘liking’. Hall, Horgan, Stein, and Roter (2002) studied the presence of ‘liking’ (simply asking about how much patients and physicians liked each other) within established physician-patient relationships and the associations with outcomes. They reported several things of note. First, ‘liking’ on the part of the physician or the patient was associated not only being liked in return, but also in being able to accurately predict whether or not they were liked in return. Second, liking reported by patients within the relationship was associated with better health outcomes (self-report), greater satisfaction, and decreased likelihood of changing physicians over the following year. Furthermore, Fuertes et al. (2007) linked perceptions of relationship quality with outcomes like treatment adherence and satisfaction. They suggest that trust and ‘liking’ appear to have “real value” medically, and suggest this is because trust and liking may support “buying into” treatment.

PCC: Communication and collaboration. The third component of PCC - agreement and collaboration on the problem and its treatment – has also been well researched. In their meta-analytic review, Arbuthnott and Sharpe (2009) found that positive collaboration was linked with both treatment adherence and patient outcomes, and concluded that patient involvement in their own medical decisions is in their best interest and ought to be promoted. Overall, agreement is linked with better health-outcomes (Ha et al., 2010). This collaboration is intertwined with a good healthcare relationship, as agreement and collaboration requires patient involvement within a relationship with a physician who “cares enough and trusts the patient enough to seek his/her

thoughts and feelings about the medical problem and its treatment” (Fuertes et al., 2007, p. 35). Furthermore, Alexander, Hearld, Mittler, and Harvey (2011) conducted a large scale study examining the physician-patient relationship, including respect (perceived by the patient), and communication outside physicians’ offices, for chronically ill patients and found a significant positive association with increased patient engagement. However, even though collaboration and engagement are encouraged, they do not preclude power imbalances within healthcare relationships. Ultimately, doctors have the power – intentionally or otherwise – to act paternalistic (i.e., doctor makes decisions based on their own knowledge) and as-agents (i.e., doctor makes decisions based on what they believe their patient wants or needs), which can hamper true collaboration and understanding of the patient (Goodyear-Smith & Buetow, 2001).

Effective collaboration requires exchange of information and understanding of the persons involved. Therefore, effective communication is key in collaboration and agreement. In a review of the literature, Ha et al., (2010) highlight several benefits of effective communication in healthcare relationships. These include effective exchange of information for collaborative decision-making, earlier detection of problems, and the ability to individualize treatment to the patient’s needs. Additionally, they reported that good communication was associated with patients disclosing relevant information for accurate diagnosis, and increased treatment adherence (Ha et al., 2010).

PCC for Patients with HFASD

Although the components of PCC – positive relationships, communication and collaboration, and an understanding of the patient – are all linked to positive healthcare experiences and health outcomes, these components are areas in which adults with HFASD face challenges. Given the importance of healthcare relationships, communication, and an

understanding of the patient by HCPs, the perceptions of adults with HFASD are worth understanding.

Healthcare relationships and patients with HFASD. Research with physicians has focused on facilitating the clinical encounter rather than focus on the relationship with the patient with HFASD. For example, in order to respect and ease the patient with HFASD's hypersensitivity to certain stimuli, it has been recommended that physicians create a quiet and calm waiting area (or provide a separate waiting room if this is not possible), consider the adverse taste of certain medications before prescribing them, and ask single rather than multi-step questions (Venkat et al., 2012). Furthermore, these communication strategies including keeping conversation oriented towards the patient, even when addressing a caregiver (i.e., "‘Charlie’, I’m now going to ask your mom how we can talk together," [p. 1477]), avoiding idiomatic and non-literal language, and ensuring all staff involved understand these communication preferences. However, these recommendations are based on the needs of ASD patients in general (especially children or those with more intellectual challenges than HFASD), and may not accurately reflect best practice for adults with ‘Higher Functioning’ ASD.

Recent research suggests that the paediatric physician community is more proactive in researching and addressing the needs of child patients with an ASD in attempts to facilitate the clinical encounter than the adult physician community (Kuhithau et al., 2014). Recommendations made to adult physicians are similar to those made by Venkat et al. (2012). However, adults with HFASD have voiced a need for more training for professionals about ASD's (Griffith et al., 2001; Kuhithau et al., 2014; Lum et al., 2014; Nicolaidis et al., 2015). Furthermore, not only do those with HFASD feel there's a need for more training, but physicians themselves often report feeling ill-equipped in understanding and treating their adult patients

with ASD (Ousseney, Massolo, Qian, & Croen, 2015; Peter 2009 as cited in Kuhithau et al., 2014). Finally, given that adults with HFASD value aspects of relationships that typically are not valued by neurotypical individuals in general, it stands to reason that the focus of a good *healthcare* relationship may also be incongruent with what the neurotypical healthcare relationship looks like.

Healthcare communication and collaboration and patients with HFASD. The communication and collaboration that is promoted within PCC may also prove difficult for those with HFASD. Nicolaidis et al. (2015) asked adults with ASD (not HFASD specifically) and caregivers of these adults about their experiences in healthcare. They found that these participants felt HCPs lacked knowledge, and wanted more communication support in their healthcare.

If those with HFASD have difficulty with communication and collaboration in healthcare they are not alone. Some research has focused on patients' preferences, and challenged the idea that collaboration and agreement ought to be encouraged in all populations (Adams, Price, Tucker, Nguyen, & Wilson, 2012; Carlsen, & Aakvik, 2006). It may not be agreement on tasks and goals, but rather congruency between how much a person wants to and actually does contribute that is the key for more positive outcomes and development of the relationship bond (Taber, Leibert, & Agaskar, 2011; Jahng, Martin, Golin, & DiMatteo, 2005). Alternatively, some argue that collaboration is absolutely essential for good healthcare communication, but that it need not be face-to-face; "an email, letter or telephone call, or [a referral] to a decision support website," could all be effective alternatives to face-to-face interaction while still maintaining collaborative decision-making between patient and professional (Elwyn et al., 2012). Stewart (2001) points out that patient-centredness is not promoting engagement and collaboration per se,

but promoting what the patient wants in terms of engagement and collaboration. However, understanding what they want in terms of engagement and collaboration first and foremost requires effective patient-HCP communication

Understanding patients with HFASD as persons. Within PCC, patients are considered to be experts on their lives, bodies and health conditions, and must be understood as people and not just a puzzle of symptoms to be solved through diagnosis. However, adults with HFASD generally express difficulty being and feeling understood by others. This lack of understanding stems from everything from challenges in communication, misperceptions by others about their intentions (e.g., rude, ‘stand-offish’, unempathic), and valuing different aspects of relationships than do neurotypical individuals.

Part of understanding these adults requires asking them about their experiences directly. Although the input of others (e.g., parent, spouse, caregiver) is important in terms of identifying areas of need (e.g., the need for communication supports), these others cannot always speak to the experience of these adults (e.g., they cannot speak to whether patients feel saddened, frustrated, discriminated against during communication, or if they feel patronized or empowered by communication supports, etc.). Although it may not always be the case, it is not unreasonable to assume that individuals with HFASD who have a third party involved in their healthcare interactions may do so because they rely on the third party to perform all social functions on their behalf (e.g., communication) and therefore they may construct and attribute different meanings in their healthcare experiences. Not only would there be differences between those with and without a third party present, but also differences depending on who the third party is (i.e., parent, spouse, support worker, etc.). Furthermore, an understanding of what these adults experience in healthcare requires that they have had actual experiences in the *adult* healthcare

system. The experiences of 18-year-old adults would likely reflect their experiences with paediatric rather than adult healthcare practitioners. Although Nicolaidis et al. (2015) examined the experiences of adults with ASD (age 18 years and older), and their caregivers, their study is fundamentally different from mine because my sample was made up of adults who navigate healthcare independently, and who are age 20 or older to ensure they had at least two years of experience with *adult* healthcare. Although their findings were the first of their kind and provide valuable insight into these adults' experiences, the experiences of adults with *HFASD* who navigate adult healthcare independently cannot be understood from their sample.

Grounded Theory

Grounded Theory [GT] has established itself firmly within health research (Charmaz, 2006; Hall & Callery, 2001). GT can be used to understand the experiences of those with HFASD in a way unique to other methods. In *The Discovery of Grounded Theory* (1967) Glaser and Strauss propagated developing theory from data – or ‘grounding’ theory in data – rather than testing hypothesis derived from pre-existing theory. At its most basic, they put forth several defining components by which researchers could construct theory from data, including a) developing codes and categories from the data itself and not from the pre-conceived hypotheses of the researcher, b) using a constant comparison method whereby new data is constantly compared to previously coded data and categories, and c) simultaneously collecting and analysing data (Bryant & Charmaz, 2007; Charmaz, 2006; Glaser & Strauss, 1967).

Their work served to ‘legitimize’ qualitative research which was generally greeted with hostility within the positivist-quantitative climate that dominated the mid 1900’s (Charmaz, 2006). However, the GT proposed by Glaser (who brought a positivist and quantitative background) and Strauss (who brought a pragmatist background) may have ironically gained

acceptance for its positivist components rather than its pragmatist components; ‘legitimizing’ qualitative research not by challenging the positivist ideology but rather by becoming part of it (Bryant & Charmaz, 2007). Criticisms of this early form of GT have been manifold, and changes to the methodology have occurred leading to the multiple iterations of GT today. One of these iterations – commonly found in health research – embraces a social-constructivist worldview (see Charmaz, 2006). Unlike the positivist paradigm, the social-constructivist paradigm purports that there is no discoverable ‘reality’, but that the meanings individuals create from and ascribe to their experiences are what matter and that these meanings are constructed within social contexts and in relation to one’s social world (Charmaz, 2006; Warmoth, 2000).

Given the differences between the positivist and constructivist worldview, the GT practiced by both differ as well. In *Constructing Grounded Theory* (2006) Charmaz likens GT to “a container into which different content can be poured” (p. 9) where the practices are applied neutrally to data (e.g., coding), but *how* researchers use these practices and guidelines is not neutral (i.e., the belief that you are coding to uncover reality versus to uncover meaning). The goal of GT from a constructionist point of view is to discover the meanings people construct and to use these meanings to generate theory, or rich description and understanding, of the phenomena under study. In fact, theory need not be viewed as a positivist explanation that links variables, explains or predicts, but rather theory can be interpretive. Interpretive theory “calls for the imaginative understanding of the studied phenomenon” where the theorist assumes multiple ‘realities’ that are emergent and evolving, placing and importance on the processes and creation of meaning (Charmaz, 2006, p. 126).

Grounded Theory within the social-constructionist framework outlined by Charmaz (2006) was best suited to my research goals of understanding the experiences and perspectives of

adults with Autism. First, those with HFASD generally live within a society that ascribes negative and erroneous meanings; meanings that contribute to their exclusion and marginalization. Therefore, I want a method that allows for an understanding of *meaning*. By following GT methods within the constructionist paradigm, I will stay close to *their* data, focusing on the meaning *they* ascribe to their own experiences.

Second, GT within the constructivist paradigm does not strictly call for theory to be built from data to explain the phenomenon under study. Equally valuable is rich and detailed description of the experiences to better understand the phenomenon, or interpretive theory in which multiple explanations can exist. Detailed, in-depth description and understanding – especially given the historical lack of understanding – has strong merits in-and-of itself within my study.

Third, irrespective of world view, the basic techniques of GT – the ‘container’ Charmaz (2006) referred to, apply. At its most basic, findings in GT (theory or interpretation) emerge from the data itself. Data is coded through constant comparison, so that findings are always ‘close to the data’, and are not categorized or coded based on pre-existing notions of the researcher. This is crucially important in my study because adults with HFASD have often had others inform research on their behalf, and consequently some of the resulting support and programming has failed to meet their needs. Focusing on their data without imposing pre-conceived concepts positioned them as the experts, and not others (including myself).

Fourth, GT allows for analysis of documents. Although multiple methods are suited to a better understanding of meaning (i.e., narrative, discursive) they are generally suited to an interview format where meaning and understanding is negotiated within the interview itself. Given that adults with HFASD feel most empowered communicating online without the time

pressures or social cues of in-person, it is necessary to choose data collection procedure that respects their preferences and strengths (i.e., online responses) and a method that coincides (i.e., GT and document analysis). The open ended questions posed to the participants required an interaction of sorts (i.e., the question itself, the performative aspect of knowing who will read the document, etc.) but did not have the in-vivo back and forth of an interview.

Purpose

The purpose my research was to ask adults with HFASD who navigate healthcare independently about their healthcare and healthcare relationships, with the goal of understanding* their experiences, as well as the meaning they ascribe to these experiences. This included understanding and ‘defining’ the issues as *they* see them, identifying their wants and needs, and most importantly describing their experiences in-depth in order to sketch the best understanding possible of these predominantly misunderstood adults. My methods were carefully selected to meet this purpose, from the use of online data collection (which reflects how adults with HFASD reported being best able to communicate and make themselves understood), open-ended questions which allowed *participants* to communicate the experiences that they felt were most important, constant comparison analysis which kept analysis grounded in *participant’s* data, and follow up theoretical sampling questions that allowed participants to comment on my preliminary analysis and confirm I had accurately understood what they intended to communicate.

Method

Participants

Participants were 28 North American adults who self-reported as being formally diagnosed with HFASD (or diagnosed with either Asperger's Syndrome [AS] or Pervasive Developmental Disorder Not Otherwise Specified [PDD-NOS]). (See Table 1 for detailed demographic information).

Participants were recruited online through postings on social media sites that cater to those with HFASD in their membership, and through the websites of North American agencies represent the autism community. Through these venues, participants were informed of the opportunity to participate in a research study in which they would be asked about their experiences with healthcare and healthcare professionals. My contact information was included for those who were interested in either receiving more information or participating. Recruitment continued until coding reached 'meaning saturation' in which participants continued to present new experiences and events, but the meaning of these as they relate to the phenomena became stable (Gaskell, 2000). For example, participants reported experiences with healthcare professionals (HCPs) who accepted written forms of communication, accepted communication outside of the clinical encounter (e.g., email), and who understood that often they needed extra time to communicate clearly. The overarching meaning of these events was that these participants felt supported and empowered by these HCPs accommodation of their communication strengths and challenges.

In order to meet inclusion criteria, participants were 20 years of age or older and identified as having a diagnosis of HFASD (or AS). Participants had to be able to attend some of their medical appointments independently. Finally, participants required access to the internet as

Table 1

Sample Characteristics

Variable	% of Sample	Variable	% of Sample
Sex		Living Situation	
Male	46.4	Alone	28.6
Female	53.6	Parents	50.0
Age (years)		Partner/Spouse	10.7
20-29	67.9	Other**	10.7
30-39	3.6	Relationship Status	
40-49	10.7	Single	53.6
50-59	3.6	Partner/Married	28.6
60+	14.3	Divorced/Widowed	7.2
Ethnicity		PNS*	3.6
Caucasian	67.9	Sexual Orientation	
Asian	21.4	Heterosexual	82.1
Aboriginal/Metis	3.6	Homosexual	7.1
Other**	7.1	Other**	10.7
Province/State		Employment	
BC	17.9	Full-Time	17.9
MB	7.1	Part-Time	39.3
NB	3.6	Unemployed	39.3
ON	14.3	PNS*	3.5
QC	17.9	Highest Level of Education	
CA	3.6	High-School	7.1
CT	3.6	Some College	46.4
MA	7.1	Bachelor/Assoc.	32.1
MN	3.6	Masters/PhD	3.6
PNS	21.4	Other**	10.7
Residence			
House	64.3		
Apartment	28.6		
Other	7.1		

*PNS = Responded by endorsing the option 'Prefer not to say', or did not respond;

**Other = Responded by endorsing the option 'Other'

the study was entirely online. Exclusion criteria included poor English language skills and inability to provide informed consent. Third party consent was not sought as participants were on the 'High Functioning' end of the Autism Spectrum with sufficient cognitive abilities to independently navigate healthcare, and therefore sufficient cognitive abilities to provide free and informed consent. Participants were able to withdraw at any point during the study. A link to the study webpage was emailed to individuals who indicated interest in participating and who met inclusion criteria.

Data Collection Procedure

Upon signing up for the study, participants were sent an email with a link to the study page on Qualtrics (online survey software). The first page consisted of the letter of informed consent (Appendix A) which included the option to electronically provide or decline informed consent. Only those who provided informed consent gained access to the study. Informed consent included options to consent to be re-contacted for follow up questions, as well as consenting to have their future email correspondences with me included as data (i.e., field notes). The letter of informed consent also included an explanation of inclusion criteria; specifically, that upon filling out the demographic and screening questions, some participants may not qualify for the main part of the study. The components of the study were presented sequentially as follows, a) demographic questionnaire (Appendix B) b) the *Autism Spectrum Quotient* 10-item scale ([AQ-10], Allison, Auyeung, & Baron-Cohen, 2012) (Appendix C) c) the four open-ended research questions (Appendix D) and d) theoretical sampling questions in which participants were asked to comment on the initial findings (Appendix E).

The demographic questionnaire provided basic information about the individual participating, such as gender, age, employment status, diagnosed physical/psychological

conditions, etc. (See Appendix B). The questionnaire also included questions related to inclusion criteria, such as ‘how often do you see a health professional in a year?’ and ‘how many different health professionals do you see in a year?’ The demographic questionnaire preceded the AQ-10 so that participant’s first impression of the study was not a diagnostic tool, which would not be in keeping with my position that they are experts informing on their own behalf, rather than ‘subjects to be studied.’ (Further issues related to relationality – the nature and balance of power between researcher and participant – will be discussed in subsequent sections).

Because recruitment was entirely online, I used the AQ-10 - a brief screen designed to screen adults for HFASD – in order to support participants self-report of diagnosis (Allison et al., 2012; ARC Autism Research Centre Cambridge University, 2014). I used a cut-point lower than 4 (Sensitivity 0.96; Specificity 0.70) in order to support an HFASD/Asperger Syndrome diagnosis. Only two individuals who completed the first phase of the study did not qualify (due to not having a formal diagnosis). This left 39 potential participants who qualified for the study based on the demographic questionnaire and the AQ-10. These 39 individuals were invited to participate and sent a link to the four study questions through email, which was completed by 28 participants.

The four study questions (Appendix D) were in an open-ended long-answer response format. These questions were designed to get at the experience unique to participants by being open-ended (i.e., what are some of the things you wish HCPs better understood about you? What has been the most significant challenge while interacting with doctors and other healthcare professionals? What has been your biggest strength while interacting with doctors and other healthcare professionals? What has been most helpful in dealing with your health and healthcare, while interacting with doctors and other healthcare professionals?). This allowed participants to

guide the focus and direction of the data. This was especially important for adult with HFASD because they so often report feeling and being misunderstood; these questions did not assume I understood, but rather they helped me gain understanding. The four questions were presented in alternating order between participants, to reduce any impact the sequencing of the questions may have on responses. Participants were free to leave Qualtrics and return to the study at a later time to complete their responses, with the hopes of reducing the challenges adults with HFASD often report having when trying to communicate under time restraints. They were also able to type up their responses in their own word processors and ‘cut-and-paste’ their responses into Qualtrics when they were ready to submit them. These written responses were the documents that served as the data for the analysis. Participants were asked to complete the four study questions within 2 weeks, after which I emailed non-responsive participants to confirm their continued consent and interest in the study. I considered those who did not respond to have rescinded consent and they were removed from the study. Upon completion of the four study questions, participants were redirected to a Qualtrics page in which they could select a \$30 Canadian or \$25 USD gift card (e.g., amazon, iTunes, Tim Hortons, Starbucks, Subway, Cineplex Odeon, and more).

As expected, I received varied lengths of responses from the participants. Similar to Muller et al. (2008) who found that even interviews with adults with HFASD that were only 9 minutes long were still valuable, and Sciutto et al. (2012) who found that with online questions they were able to get rich, long-answer data, the majority of responses were informative irrespective of their length. Two participants had one of their responses excluded because the response was so brief that it was not comprehensible (e.g., “the overall advice I get from all walks of the medical system is the key to good communication when it comes to my health concerns. I can understand exactly what I want and not need”). Although it may be tempting to

assume that these responses provided information about the way these participants communicate and the way in which this may have impacted their healthcare communication, this was not part of the analysis. If a neurotypical participant had provided such responses, they would have had their responses excluded, and perhaps attributed to lacking effort (e.g., rushing through the motions simply to receive their gift card). To make the assumption that an adult with HFASD provided such short and ineffective answers due to a lack of ‘ability’ would be a marginalizing assumption. Data collection continued until saturation was reached, resulting in a total of 28 participants completing the four open-ended questions.

Those that provided responses and continued consent to be contacted were invited to participate in a second set of open-ended study questions that emerged from the initial data, including a presentation of the preliminary findings and asking participants for their feedback (Appendix E). Fifteen of the 28 participants responded, all of whom either agreed that the preliminary findings accurately reflected their experiences, or left responses blank. No participant responded that the preliminary findings did not speak to their experience.

Analysis

Constant comparison analysis. The written responses had all potentially identifying information removed, at which point they became the documents for analysis. The documents were analysed using Constant Comparison Analysis [CCA] - the form of analysis that transcends GT irrespective of paradigm (Bryant & Charmaz 2007; Charmaz 2006; Corbin & Strauss 2008; Glaser & Strauss 1967) – in which each piece of coded data is constantly compared to previously coded data and any resulting categories.

Initial coding. Initial coding occurred in two ways. First, I used line-by-line coding to get a general picture of what participants wanted to convey, while remaining open to the possibility

of multiple meanings (Bryant & Charmaz 2007; Charmaz 2006). As recommended by Charmaz (2006), codes at this level were simple and precise, applied quickly for initial impressions. This coding was applied to all documents irrespective of their depth or length. During this phase, short responses such as ‘my doctor doesn’t listen to me’ and longer responses that were rich and detailed accounts of a time that a doctor did not listen to them were both coded as ‘doctors do not listen.’ Second, longer and more detailed responses were re-coded for an understanding of the participant’s experience and the meaning they attributed to this experience. For example, a participant’s story of not being listened to, feeling condescended towards as intellectually inferior, arguing with the doctor to be heard, and then being proven right would have been assigned codes such as ‘feeling dismissed,’ ‘self-empowered/overcoming,’ and ‘vindication.’ In both forms of coding, CCA began immediately in the coding process, where new data was constantly compared to previously coded data to look for similarities and differences. This allowed for codes to expand or collapse, emerge and disappear over the course of analysis rather than have the first few codes and data become static categories that subsequent data was forced into.

Focused coding. As the name implies, focused coding involves a more focused look at the initial coding (Bryant & Charmaz 2007; Charmaz 2006). At this stage I combed over the initial codes, focusing on the most frequent or significant in order to begin to condense the massive amounts of initial coding data. These codes were more conceptual in nature, and involved thinking about what was going on theoretically. Initial and focused coding is not linear, and therefore I went back and forth between the two, staying true to the constant comparison method.

Memo writing. Memo writing is the documentation of thought processes within the analysis. Writing memo's helps the researcher go from codes to conceptual categories, noting links between processes and concepts, the conditions under which processes occur or change, and how they support or refute a specific assertion or argument (Charmaz, 2006). Along with codes and categories, memos are also subject to constant comparison and evolve over time.

Analysis concluded once the constant comparison of codes, memos, and conceptual categories reached a level of 'stasis' that provided a rich and detailed explanation of the participant's experiences and meanings. This 'stasis' was supported by feedback from participants (e.g., follow-up on preliminary findings) and a graduate student who independently coded the participants' documents and subsequently agreed that our coding was consistent (i.e., member checks). The few inconsistencies that did exist were resolved through discussion and reaching agreement.

Rigour

Credibility. Similar to internal validity – credibility reflects how 'believable' the findings are and how accurately the findings represent the participants intended meaning (Houghton, Shaw, & Murphy, 2001). I felt this was of paramount importance due to previous findings that adults with HFASD often feel misunderstood and are poorly represented in the literature. Therefore, credibility checks occurred with participants at several points throughout the study. Throughout analysis, member checks with other researchers (i.e., faculty members and a graduate student) occurred to ensure the findings were grounded in the data, and that I had integrated participant credibility checks without bias towards the preliminary findings (i.e., ensuring that I was not committed to 'my' initial findings if credibility checks had suggested that these findings were not accurate).

Integrated knowledge translation. In addition to being supported by the literature (Mitchel, 2008; Sciutto et al., 2012; Smith & Sharp, 2013), the use of online data collection methods was supported by stakeholders. I consulted with adult stakeholders who self-identified as having HFASD – or as having Asperger syndrome - in order to ‘check-in’ with individuals with HFASD and get their perspective of online versus in-vivo methods. A professor who conducts research in the autism community – and who is a member of an online social media group for adults with HFASD –posted the following question to the group on my behalf:

I have been asked by a grad student to check with adults with autism on their opinion on how best to get meaningful information from adults with AS. Many researchers suggest face to face is best (for NTs maybe?), however, some adults have mentioned this is the least comfortable method for them. The topic she will be researching is experiences with healthcare and health systems. Personally, do you feel you could best express yourself in a face-to-face interview, over the phone, or even by typing your answers and submitting them online?

The responses were categorized and tallied, resulting in 75% of respondents indicating a preference for online methods. Therefore, not only has the use of online methods been successfully used in previous research, and was also the preference of the adults with HFASD that I polled.

Within my study I conducted a theoretical sampling phase, in which participants were not only asked follow up questions, but provided with preliminary analysis, and asked to comment on how accurately this analysis represents what they had intended to communicate. This allowed these adults with HFASD to comment on my *interpretation* of what they had told me, helping

ensure that they were indeed understood not only for what they had said, but also for their intended meaning.

Theoretical sensitivity. Study questions were developed with theoretical sensitivity, where the literature was used to guide the questions content and format (Giles, King and Lacey, 2013). They were loosely adapted from questions asked by Sciutto et al. (2012), and therefore I had theoretical reason to believe that structuring my questions in a similar manner, and using similar online data collection methods, would also be successful.

Second, although there were no assumptions as to what the experiences of these individuals were, the assumption that there were barriers in healthcare for these individuals is theoretically sound (Nicolaidis et al., 2012). Given this phenomena, these questions were developed to ask about healthcare and healthcare relationships, but also designed to be neutral and not suggest that these experiences are necessarily problematic (e.g., “what would you tell your physician” not “what could your physician do better”; as well as asking about *both* difficult and helpful experiences).

Transferability. Transferability is the extent to which the data and findings could transfer to contexts outside the study (Houghton et al., 2013). This was achieved in several ways. First, the sample of participants was fairly large for a qualitative study of this nature (n=28), and although it was somewhat skewed towards young Caucasian adults, there was representation by diverse segments of the population (e.g., various ethnicities, sexual orientations, education levels, employment status’, living situations, and ages ranging from as young as 20 to 60 years and older). As such, the consistency of the themes from their responses seems to transcend some aspects of the *participants’* diversity, which speaks to an element of universality to the HFASD experience. However, the findings also speak to individuality, where participants had different

strengths and challenges, and had varied experiences with HCPs in contexts that could not be assessed within this study (e.g., do these findings hold true with HCPs that have had short versus long term relationships with patients?). Further research is required to examine how these findings may generalize to specific healthcare situations, until which time it would be premature to take these findings and turn them into concrete recommendations.

Finally, although not directly related to the transferability findings themselves, the participants provided valuable and well-written responses. This is worth noting because adults with HFASD have not consistently been included in informing research on their own behalf (Bailey, 2011). The participants' responses and the insights gained from their unique perspectives led to valuable understanding of their experiences and what *they* find most important in their own healthcare. This builds on a small but growing body of research that shows these adults can valuably inform others on their own behalf, and this inclusion is certainly transferable to other contexts, research or otherwise

Reflexivity. I consistently reflected on how the interaction between myself and the participants may influence the research process (Hall & Callery, 2001).

The nature of the responses. I originally designed the study to allow participants to be able to provide written responses without the challenges of in person communication. Within the analysis, I wanted to stay as close to the *content* of the responses as possible to ensure that my interpretation of their responses was not just another instance of someone misunderstanding their meaning and intention. I received a range of responses. Some were short, and literal or hard to follow. Most were five to ten sentences in length, describing what they wish HCPs understood, their strengths and challenges in full sentences or list form. These responses included some important statements of how healthcare was experienced, but at a surface level (e.g., naming how

they felt with a single adjective). However, in some cases participants wrote out long answers that were rich with detail and context, and conveyed how participants felt about their experiences. This occurred in two ways. First, when participants wrote as though they were addressing HCPs directly, ‘this is what you need to know’ and ‘this is how you make me feel’. Second, when participants wrote out long, rich stories of their experiences, describing their interactions with HCPs and the meaning they ascribed to them. However, there was a clear difference in how these responses could be analysed. All responses could be analysed for their content, but only some could be analysed for the meaning they ascribed to the content. What I found surprising, was that despite the responses being written documents and not transcribed conversations, these longer responses read somewhat like narratives, and could have been analysed as such.

Exclusion of the undiagnosed. For my inclusion criteria, I required that participants be formally diagnosed. However, I was surprised by the number of emails I received from individuals who wanted to participate but who were not formally diagnosed. These individuals often reported believing that they had autism, based on family history, ‘classic’ symptoms, and/or HCPs suggesting the diagnosis as a possibility. Similar to participants, these individuals reported struggling to communicate with HCPs, and being given misinformation about HFASD by HCPs (e.g., HFASD is mainly a male condition, is a childhood condition, etc.). These individuals expressed that these challenges made it difficult to pursue a diagnosis and navigate healthcare. In addition, they reported facing other challenges such as the cost of an ASD assessment with a psychologist, and long wait times. Because HFASD is lifelong, diagnosis occurs when the condition is formally recognized, not at the onset of the condition. The many people who are pre-diagnosis face the same challenges as adults who are diagnosed, but would

not yet receive some of the supports a diagnosis may afford them. Therefore, I think it is important to find a way to include adults who are pre-diagnosis in future research, and perhaps examine the process of obtaining a diagnosis.

Advocacy versus 'objectivity'. At times, it was hard to read some of the participant responses without feeling ill-will towards uninvested and adversarial HCPs. Furthermore, while sending out requests for various agencies to post my recruitment poster on their website, I heard back from one agency that provided support for the families of adults with an ASD. I was taken aback by this person's response that 'adults with autism do not care about their health', and the 'burden falls upon the families' to get these adults to take care of themselves. She further stated that adults with and ASD 'will not tell you about their healthcare' and that if I wanted 'useful' information I would have to ask their families. My initial response to this was one of disgust and anger, that a person running an ASD related agency would have such dismissive and disparaging views of these adults. I had to consider this carefully, and check myself to ensure my interpretation was not affected by an initial desire to 'prove her wrong'. As time passed I was able to re-evaluate her response, and think of it in the same way I experience participants' responses. I believe that some participants feel bullied and discriminated against by HCPs that they perceive as adversarial. I believe that their perception of this is important to understand, and that it is in fact their experience. This does not mean that I believe HCPs are behaving in aggressive or intimidating manners, or that they are aware of how patients experience them. These HCPs are likely at a loss as to what to do when interacting with these patients, and therefore may be unintentionally handling their interactions in ways that these adults perceive negatively. I have (slowly) come around to viewing the woman's response the same way. Her perception is one of working tirelessly to help someone take care of their health, who she

perceives as not caring about their own health or healthcare. This task is likely frustrating, and exhausting, and therefore feels burdensome. I think that being able to view her comments, and reports of HCPs comments in this way has helped me stay more neutral and balanced, and less inclined to code the data in a way that prematurely advocates on the participants' behalf.

Relationality. Power and trust within the relationship I have with participants – or relationality - was also of concern (Hall & Callery, 2001). In the planning of the study, I made significant efforts to balance power between myself and the participants. For example, given that adults with HFASD have difficulties with many aspects of conventional social exchange, I had to question whether face-to-face or phone interviews – with which I am quite comfortable – put me in a position of power over participants. Research has highlighted that adults with HFASD seek online interaction in part because they feel more confident and empowered than in face-to-face interactions (Brownlow, 2010; Mitchell, 2008; Smith & Sharp, 2013) and the preference for online communication was indeed supported by responses from stakeholders (described above). In sum, I chose online data collection methods to create a space where participants can interact with me in a way they feel most confident and competent.

Relationality was also built into the analysis of the study through the lens I have adopted; that of 'mutual difference,' in which I do not believe autism is different' but that 'there are differences between NTs and those with autism. As a neurotypical individual I acknowledge that it is not just a matter of those with autism having differences and difficulties making themselves understood, but I – as a researcher – also have difficulty and shortcomings in understanding. They are experts not subjects.

'Validity'. For the purposes of this study, 'validity' was defined as "the accurate representation of a phenomenon that an account is *intended* to describe, explain, or theorize."

(Hammersley 1987 as cited in Hall & Callery, 2001). By this definition of validity, because I used online methods (through which they reported feeling most confident) as well as credibility checks (where they were able to confirm or deny that I had captured what they intended to describe), I hope to have gathered what the participants would endorse as the ‘most valid’ responses.

Audit Trail/Code Mapping: In order to be transparent about my analysis and interpretations, I maintained records of how the data led to the categories and overall findings through a ‘code map’ (Anfara, Brown, & Mengione, 2002). This documents my analysis (e.g., *how* data led to initial codes, initial codes to focused codes, etc.), and provides a transparent ‘audit trail’ (Lincoln & Guba 1985 as cited in Anfara et al., 2002) for other researcher to see how I went from initial data to findings.

Ethics

Ethical approval was obtained from the University of Manitoba Psychology Sociology Research Ethics Board (PREB 2015:056), and any modifications (e.g., the offer of gift cards, expanding recruitment to include Americans, etc.) were implemented after approval through official PREB amendments. All ethical guidelines were strictly adhered to.

Findings

Participants provided responses to the questions that varied in length and depth. Some participants provided short, straightforward and concrete responses without elaboration or interpretation. As such, the content of these responses neither included nor allowed the interpretation of how these participants felt about their healthcare or their healthcare professionals (HCPs). Other participants wrote out longer, in-depth responses, in which they conveyed how they experienced their healthcare, and how they attributed their overall

experiences in healthcare as either positive or negative to their interactions with HCPs.

Therefore, the findings are reported in two sections. The first section includes findings that resulted from the shorter and more concrete responses, such as the personal strengths and challenges they identified, and the things they felt HCPs needed to better understand about HFASD. The second section includes the findings that emerged from the longer, more in-depth responses, within which their healthcare experiences were attributed to interactions - which frequently included their strengths weaknesses and HCP knowledge - with their HCPs who were portrayed as allied, well-intentioned, uninvested and adversarial. (Note: The term participant refers to their interactions with me, where as the term patient refers to their experiences with their HCPs. For example, several *participants* reported (to me) that their intelligence was a strength. *Patients* felt dismissed when they perceived their HCP as uncaring).

Section 1: What They Wished HCPs Better Understood

Basic knowledge about HFASD. Many participants believed that HCPs often lacked basic information about HFASD, including reports of misinformation about how to identify HFASD. Participants repeatedly made comments pertaining to HCPs perceived lack of knowledge about the physical ramifications of HFASD, including general statements such as, “[I wish they understood] autism is a physical illness and not just a mental one,” (Meghan) and more specific statements such as, “many, if not most, autistic individuals have some type of digestive dysfunction or chronic immune system disorders” (Elaine). In addition, participants repeatedly called for more awareness that HFASD is not an intellectual delay. For example, Sarah stated, “I wish they understood that having an ASD label does not mean one is LD [learning disabled] as well.” Finally, participants discussed a need for better understanding of how to identify HFASD, and the diversity in HFASD presentations. For example, Elaine recounted, “I have been told

many times that I did not ‘look’ autistic, therefore I must not be.” In some cases, participants attributed a lack of understanding about HFASD not only to HCPs poor ability to identify HFASD, but also to a misunderstanding about relevant available services. For example, throughout years of pursuing a diagnosis Kate recalled several experiences with HCPs that she portrayed as misinformed:

[The psychologist] thought that mainly it was a male disease and that I didn't act autistic which he described as stiff and fixated on weird topics. [... I asked my GP] “can't you recommend somebody who does know something about this that I could see?” He said “No. We only have services for autistic children. You don't have any problems like that.” (Kate)

Kate, not only experienced difficulty receiving her diagnosis, but she felt her HCP's lack of knowledge about adult HFASD, prevented her from being properly referred to someone who did have knowledge about HFASD. Within all of the excerpts above, there was an underlying theme of a need for better awareness about HFASD without blame of the HCPs for lacking this awareness. Several participants echoed opinions like Amy, who said, “I think GPs need more support in terms of time resources and education on adults with spectrum disorders.”

Communication style. Many participants stated that they wished HCPs understood their communication style and how difficult communication can be. In some cases, this emerged through comments about how communication could be tailored to meet their needs. For example, Sarah stated, “I wish they understood that it is often helpful to provide information in writing in addition to speech,” which was echoed by many participants who appreciated - or stated they would appreciate - written forms of communication. Other participants wanted to convey that

their communication style may be more concrete and literal than typical patients, and that HCPs need to take this into account.

The first thing [HCPs] would need to understand is that all their questions would be taken literally and answered in the shortest possible way (single word, if it can be answered yes or no, that's what they're going to get) and that it will be the question they asked, maybe not the one they meant to ask.

(Mason)

Furthermore, many participants wanted HCPs to understand how much of a challenge communication can be, how hard they try to overcome these challenges, and the impact it has on how they feel. Clint stated, “I wish they can understand how difficult it is for me to put things into words. I get frustrated when I cannot use the right words or convey my message accurately, and it also depresses me.”

Anxiety is a significant challenge. Participants wanted to make clear the extent to which they struggle with anxiety, and how it impacted the way they communicated with and related to their HCPs.

My family doctor observing me is nerve-wracking. I am nervous when people look at me and stare at me when I am talking. I wish [my HCP] could accommodate that for me. [...] I cannot always fully explain how I feel other than saying I just don't feel comfortable ... its hard. (Wendy)

Wendy is one of many who cited struggling with anxiety, its impact on communication, and how hard this is for her. Several participants identified anxiety as a barrier to healthcare. Comments such as, “anxiety can be a significant issue for me. [...] This anxiety can lead me to not make appointments, postpone or cancel them,” (Meghan) and, “I usually have to be pushed real hard

and to last resort to seek medical attention. Not because of the prejudice but because of the anxiety and frustration that is triggered when I have to see a doctor,” (Edwin) were common. Therefore, whether it be a challenge within healthcare encounters, or a barrier to these encounters, anxiety was a significant and prevalent struggle for these participants.

Many strengths in healthcare. Participants reported multiples strengths that they considered assets in their healthcare. When discussing strengths, participants repeatedly made statements such as “my biggest strength is that I'm intelligent,” (Francois) and “I am exceedingly well informed about my own health and well being and always want to be listened to when it comes to my health care issues” (Kate). Overall, intelligence was the most frequently discussed strength.

Participants also discussed some of their personality traits as strengths in healthcare. “My biggest strength is that I am not a quitter. I keep going to the same counsellor and try to make progress despite the circumstances,” (Edwin) and “the most helpful thing in dealing with my health in the healthcare system is taking on the responsibility to ensure I take care of ME first. I could tell that the professionals I dealt with respected that position,” (Amy) are representative of statements made by many participants about their perseverance and self-empowerment in healthcare being a strength. Another common strength that participants discussed was their honesty and openness. “I am honest with my feelings. I am able to tell with honesty my symptoms and how I feel when interacting with others. [...] However, it [is still] difficult for me to connect with doctors” (Jason). Like Jason, many participants reported that their honesty and openness was a strength, but still something that was difficult and that they had to work hard at.

Section 2: Experiences in Healthcare

In addition to the content of the responses above, several participants elaborated on their responses and provided rich, detailed examples of their experiences in healthcare, including the meaning they attributed to their HCPs actions. Although participants discussed many strengths and challenges in healthcare, positive and negative experiences were largely determined by the healthcare relationships within which these strengths and challenges occurred.

Positive experiences: HCPs who are allied. Several participants wrote about positive experiences in healthcare, which they largely attributed to positive relationships and interactions with HCPs who were portrayed as allied. These allies were praised for being collaborative, valuing patients input and knowledge, empowering patients, advocating on patients' behalf, and caring for their patients' as persons.

HCPs who are empowering and advocates. In some cases, these allies were described as advocates. For example:

I am fortunate to have a great GP, and two great orthopedists. I feel at home talking to them. I feel like I am talking to someone who really cares.

Sometimes, my doctor will go over our scheduled appointment time, if we are talking about something important. He won't just rush me out. He gives a shit.

My orthopedists are God-sent, they work tirelessly fighting the government, trying to provide services though the government's steadfast obstinacy to cover these services [...] I'm forever indebted to them. (Francois)

Francois praised his HCPs for their care and concern, and their efforts to advocate on his behalf.

In many cases, allies acted as knowledgeable and collaborative supporters, who encouraged patients towards feeling self-empowered. For example:

My psychiatrist has a good understanding of Asperger's and that is helpful. I feel like she provides me a safe and confidential space to let out difficult feelings. She gives me advice on effective ways to handle those situations. [...] I feel that she will never give up on me. She is accepting and not judgemental. I gain confidence from her kind words saying that it is not a big deal, that I can manage, that I can handle. (Hannah)

For Hannah, her psychiatrist is an ally with whom she feels safe and supported, and as someone who 'will never give up', empowering her to feel confident and capable to handle her struggles.

HCPs who are accepting. Overall, HCPs who listen, care, understand and are not judgemental were cited as the best HCPs. For example:

My current counselor is very good. [...] Whenever I go to see her, she KNOWS and UNDERSTANDS [[emphasis by participant]] that I am not always up for talking. [...] She shows warmth and acceptance and makes me feel like I can trust her, rather than me being investigated with questions, as some counsellors do. (Anne)

These understanding and caring HCPs had varied approaches. In cases like Anne's, they did not push for communication when patients were struggling, and in other cases they pushed for communication in a way that was interpreted as an act of caring.

While I am not one for small talk, my general practitioner starts each appointment asking me about how things are going with me since my last visit. I'm certain it's a way for him to monitor me about my depression, but for him to take the time to ask me questions about how school goes and how

my volunteer work goes shows me that he has a genuine interest in my well being. (Emanuel)

Overall, good HCP's were described as understanding of how their patients felt, demonstrating genuine care for their patients, and providing support, acceptance, and encouragement.

HCPs who listen and value patients' knowledge. Allies were praised for listening in general. In many cases, they were specifically praised for listening to the information that patients provided, and valuing the insight and knowledge of their patients. This included accepting patients' communication strengths, such as written communication.

I have an excellent chiropractor who motivates and encourages me. He also lets me send him research articles that I find over the internet. Not only does he adjust me, but I look forward to my visits at his office. (Meghan)

Meghan appreciated her HCPs willingness to accept her research, and listed it among the reasons that she views him positively. Others discussed how their HCPs acceptance of written communication allowed them to directly impact their healthcare.

I recently suspected that I had a thyroid imbalance [...] I wrote a report of my symptoms and concerns and emailed it to my PCP. My primary care doctor immediately responded and sent me for testing. Testing proved that I was right. My test results showed that I did not have enough of the thyroid hormone in my system and that I need certain supplements. (Kate)

For Kate, written communication was a strength that helped her navigate healthcare, and having a collaborative HCP that accepted this communication led to positive outcomes. Accepting patients input was not restricted to patients reports of their symptoms and concerns, but also included a willingness to listen to information patients brought forth about HFASD itself.

Several participants stated that the process of receiving their diagnosis and subsequent support was put into motion based on information that they brought to their HCP.

In the case of my autism diagnosis, I had enough information with me to direct my doctor to look for resources that would best help me. That took a lot of time, but his efforts paid off. In the end, I think that part of why I was able to get good health care experiences is because I have done my part to assist the doctor, whoever it might be; after all, my well being is my priority to take care of. (Emanuel)

Overall, HCPs who accepted written communication and valued patients input and knowledge contributed to positive healthcare experiences. These relationships were collaborative, where patients' strengths in written communication, research, and knowledge were accepted and therefore these strengths could be realized.

Positive experiences: HCPs who are well-intentioned. HCP's were not always successful in fully providing the kind of care patients either wanted or needed. Their efforts, nonetheless, were appreciated by patients, and these HCPs were portrayed as well-intentioned. For example, Elaine – who previously cited honesty as a strength - described an experience with an HCP who listened to her concerns and had an empathic, well-intentioned response:

What I find is most helpful is to be honest and explain to the health care professional I encounter what my challenges are. For example, recently, I had to go through a very invasive test for which I was very anxious about. [...] I explained to the doctor that I was autistic, overwhelmed and anxious and that my brain was shutting down, unable to take any more. The assistant then

lowered the light and talked to me gently, allowing me the time to process everything and calm down.

Elaine appreciated this HCPs well-intentioned response, even though the HCP was not entirely successful in meeting her needs:

((continued)) It would have been better if they knew a little more about the condition and not treat me and talked to me like I was mentally challenged instead of just overwhelmed, but at least it gave me a little reprieve and the meltdown that followed was not as intense as it would have been had I not expressed my challenge. (Elaine)

Similarly, Wendy described an encounter in which her HCP was somewhat but not entirely understanding of what she was going through:

I told my psychiatrist about depression and anxiety and bad thoughts that I had. She was understanding. But she asked me to share my feelings with my close acquaintances, (parents and friends). I know it is good to tell people but it is hard for me to just share these things. I wish she could understand that it is not easy for us to reach out to others, although I do agree with her, we need help. (Wendy)

Although Wendy described her psychiatrist as understanding, and making recommendations that she knows would be good for her, she feels her psychiatrist doesn't fully understand the extent of her struggles, as evidenced by her psychiatrist's recommendation to 'reach out to others' which is indeed part of her struggle to begin with.

HCPs who are accepting of patients who tailor their communication. Other participants discussed how their HCP did not fully understand how they communicate, and the onus was on

the patient to communicate in a way that HCPs would be more likely to respond to. For Diana, written communication was a strength, but she felt communication needed to be tailored in a way that HCPs found acceptable.

Making a list IS a strength. [...] I learned instead of rote recital, [to] throw in feeling words such as, "this is no way to live. My quality of life is getting me down." I may not feel for this method of talking, but expressing emotion with [my HCP] helped get me to a rheumatologist. Why was she less inclined to listen to the SAME laundry list of symptoms, but when I expressed how the symptoms made me feel, THEN she referred me to proper care? Go figure people!!!! [[all emphasis by participant]] (Diana)

Diana emphasized her strength in making a list and in clear communication of her symptoms, but found that her HCP did not act on this information until Diana figured out how to present that same information in a way that her HCP valued. In some ways, this speaks to a power difference, in which her HCP was able to determine what styles of communication are legitimate and thus are responded to.

My biggest strengths, after I realized that I needed strengths in dealing with people that were supposed to help me.... are my enthusiasm, friendliness and complete stubbornness. I know what I want and I have learned how to communicate what I want. When they finally started listening, I proved that I can be insightful. It's just a matter of cajoling them into noticing that I'm a person, not a file or a condition. (Francois)

Both Diana and Francois ultimately received what they needed from their HCP, however they both also question why they should have to tailor their communication. Diana points out the that

content of the information she was conveying did not change, and that although she ‘figured out’ how to present the information in a way that she HCP would pay more attention, she questions why she should have to this, stating “go figure people!!” Francois more subtly calls into question the logic of needing to tailor how he communicates in order to get HCPs to listen to him, pointing out the irony of needing strengths in dealing with people who are supposed to help him. Ultimately, both Diana and Francois found a way to change their communication style, which then allowed for positive interactions.

Patients wanting support without discrimination. Positive interactions with HCPs occurred when HCPs respected their patients’ strengths, knowledge, and input. However, this does not mean that participants wanted HCPs to focus on their strengths to the exclusion of their challenges. Some participants pointed out this dichotomy, and urged balance rather than exclusive focus on strengths.

I’ve felt I’m treated the same as any other patients. While there are some advantages, especially to deter discrimination against those with ASD, there are some important points that [...] people with an ASD find challenging. Those points are what doctors NEED to know and it is not and should not be considered discrimination or bigotry. It would make me feel more at ease and hopeful if they know more about ASD and take some necessary procedures or precautions when handling patients with that disorder. (Clint).

Overall, positive experiences in healthcare were within positive healthcare relationships with HCPs who listened to, valued and cared for their patients as persons, while remaining aware of their challenges. Even when healthcare experiences were not entirely successful, HCPs who were perceived as well intentioned in their actions were appreciated.

Negative experiences in healthcare: HCP's who were perceived as adversarial.

Although many participants reported some positive healthcare experiences and interactions, the majority either also or exclusively reported negative healthcare experiences. Many participants wrote about negative interactions with HCP's who were adversarial and dismissive. Patients felt as though these HCPs were actively discriminating against them. For example, Kate expressed that although she struggled with communication in general, she felt it was especially difficult when interacting with HCPs who did not value what she was saying.

I need to feel like the professional is prepared to listen to me. If I feel that I am being rushed, or if the person is rude or impatient, I have trouble communicating. Because I know that this is often the case [...] I write out my concerns, symptoms, etc.

Kate previously reported that her written communication skills were a strength that helped her obtain a diagnosis. However, in this instance her strength did not help her in her healthcare because she felt her HCPs invalidated these strengths. She recalled two instances of providing written communication:

Both those times the specialist refused to even look at the information or drawing. In one instance the papers were grabbed from my hand and discarded, and I was told, "I am the doctor here." [...] On another occasion, a nutritionist asked me to keep a food diary. I did so meticulously. At the next appointment she looked over my records and announced, "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?"

As you can imagine these were not successful encounters. (Kate)

Within these experiences, Kate's strength in written communication did not translate into an asset in healthcare, and she portrayed her HCPs as adversarial. Similarly, Stephanie stated interactions in which the veracity of her reports was questioned within what she described as an adversarial interaction. She recalled following a strict diet and exercise regime, which required great effort due to her chronic pain and fatigue. When she spoke with her HCP about not having lost any weight, she recounted the following:

The doctor harshly accused me of first eating too much oil, then too much fruit, then of not really exercising enough, then of doing too much strength training and not enough cardio. By then I was getting loud and defensive with my responses because he was outright yelling at me and that's when he said I was either lying or stupid. I just started bawling my eyes out and ran out to the parking lot where I collapsed on the pavement and sobbed until I began to hyperventilate and it was one of the worst experiences of my adult life.

(Stephanie)

These interactions were adversarial in that Kate's strengths in communication were rejected (written communication was literally thrown in the garbage), and both Kate and Stephanie had their honesty questioned and the veracity of their reports dismissed.

HCPs who were perceived as a non-collaborative authority. Participant difficulties with communication and feeling intimidated appeared to compound the negative experience, making it difficult to provide a counter-argument in these adversarial interactions. Some participants explicitly referred to feeling intimidated by an HCP in a position of power. Stephanie stated, "don't be so arrogant that you can't admit when you don't know the answer to something. Don't

take advantage of your position of power to threaten or intimidate patients” (Stephanie). In other instances, participants felt that HCPs had the power to mislabel patients.

The biggest thing that irks me is that people see me as a sickness with a person in tow, not the proper way round as how others are seen. I’m very observant, and a lot of the time doctors have assumed I was an idiot or worse, even though I’m actually closer to a genius level intellect. (Lucas)

These examples highlight that there is a power difference, in which patients may feel they cannot combat being intimidated, or mislabelled as ‘an idiot’. In addition, within these excerpts the legitimacy of the HCPs power is questioned. Stephanie pointed out that they do not know all the answers, and Lucas stated that despite feeling dismissed he is extremely intelligent, perhaps more so than the HCPs themselves.

HCPs who were perceived as discriminatory. Some participants discussed the power difference in terms of how they countered being dismissed and condescended towards.

I’m not just a goddamn case study. So many healthcare professionals will treat people in a way that is totally detached, and totally condescending. They consider themselves the bigshots with the framed papers on the walls, and we are just lowly peasants on disability. So they stereotype us, and stereotype themselves in the process, and end up treating us not like we’re people, but like we’re some random case study in a textbook. (Francois)

Although Francois is often able to counter this discrimination, he realizes that many others may not.

((continued)) In my own regard, I can usually present myself in a way which minimizes my being treated like this, for reasons previously mentioned

((referring to cajoling others into seeing him as a person)), but many people can't, and they just sit there being stigmatized. (Francois)

Similarly, Sarah also felt as though she had to counter discrimination, by challenging what she perceived as HCPs pre-conceived notions about autism and intelligence.

The most significant challenge has been their thinking they know about autistic people and their condescension as a group. [...] Frankly, being treated as if I am inferior really pisses me off. [...] I am quite knowledgeable in the basics, having worked in biomedical research and spent 2 years in medical school before leaving to pursue a degree in law. [...] If they start condescending, I point out my academic background. (Sarah)

Some individuals felt that despite being capable, they needed a third party in order to lend credibility to what they wanted to communicate.

Telling them that a parent or friend has suggested a certain test or treatment or possible diagnosis will get monumentally better results than saying it was your own idea. [...] Bonus points for bringing someone else to the appointment and having them say it for you. [...] I've asked others and been told they discovered the same pattern. (Stephanie)

Whether it be finding ways to 'cajole' or convince HCP of their value, having to 'prove' intelligence by citing academic backgrounds, or requiring a third party to lend legitimacy to what they are saying, many participants cited needing to combat condescension and stigmatization.

Negative experiences in healthcare: HCPs who were perceived as uninvested. Many participants recounted interactions with doctors who were very similar to adversarial HCPs, but who were perceived more as dismissive than as actively adversarial within their interactions.

This dismissal was a result of HCPs not listening, not valuing knowledge and input, not caring, and not taking time with the patient. This dismissal was also attributed to HCPs perceived general lack of knowledge about what HFASD is and how it affects the patients they are interacting with.

Doctors and healthcare professionals do not understand Asperger's and the challenges we have to overcome on a daily basis. I wish they would take the time to listen as we try to explain, and realize that most of the physical symptoms and issues we are experiencing are basically the result of what is going on in our brain. (Elaine)

Elaine, like others, emphasized that HFASD is not simply a mental condition, but a physical illness. However, it's not just that HCPs lack awareness about HFASD and its ramification, but they do not 'take the time to listen' or accept patient knowledge and their reports about their symptoms.

((continued)) For example, I was experiencing excruciating muscle pain and spasms, insomnia and extreme fatigue. I had to insist and try to convince [my HCP] that I was not depressed and asked to be referred to a rheumatologist for further examination. He hesitated and argued with me for a while, finally to end up giving me the referral to get me out of his office because he didn't want to admit that he was wrong. Why listen to someone who's living in her body 24/7 when he has all the answers to everything, right? (Elaine)

For Elaine, both the impact of HFASD on the body, and her reports of excruciating pain were dismissed. Unlike Kate, who described adversarial and unsuccessful encounters with doctors, Elaine ultimately did receive the referral to the rheumatologist that she requested. However, she

believed that she received the referral not because she was listened to and respected, but because it was the easiest way for her doctor get her out of his office without ‘admitting he was wrong’. Elaine’s story shows her empowerment as a self-advocate in getting the referral. Ultimately, her story was also one of vindication in which she stated, “I was diagnosed with fibromyalgia,” lending credibility to her argument initial argument that she felt she was unjustly dismissed by the referring HCP.

HCPs who were perceived as dismissive. Many participants discussed feeling dismissed by HCPs who they often felt did not listen to them.

The whole incident about not listening to us as patients is very common.

[...] Very often, "so-called" specialists brush off symptoms. This needs to change. Pay more attention please! (Edwin)

Feeling dismissed was not limited to the content of what they were saying, but also dismissing them and their experiences as persons.

In general, they should listen more to the patients. Sometimes they just come into the room with their own agenda and don't take the time to find out my expectations for treatment/medications. They don't take effort to see eye to eye on where I am coming from. I feel like we don't understand each other. [...] It is difficult as it is. I feel socially isolated [in general] and the last thing I want is a "distant" doctor. (Jason)

These excerpts come from two of many participants that believed their HCP neither listens nor tries to engage and connect with their patients. In some cases, participants message to HCPs was not only that they did not want to be seen as symptoms, but they did not want to be dismissed

because they were defined by their ‘symptoms’. For example, when addressing HCPs, Diana stated, “don’t see my gaze aversion or flat monotone as annoying. Or as disinterest. I matter!”

HCPs who focus on the HFASD, not on the person. Some participants more explicitly linked this dismissal to HCPs treating them as a set of stereotypical HFASD symptoms, without showing care for them as persons, or consideration for their struggles. For example:

[My biggest challenge is] definitely communication and interaction with the healthcare professionals. I feel that they do not understand what I am going through because they are simply busy jotting down notes about how I look, how I am speaking not loud enough, how I am looking nervous, how I am not making eye contact etc. I find that seeing doctors is extremely nerve-wrecking and I can barely speak well in that setting. And obviously, I cannot express myself very well like that. (Marta)

Unlike allies and well-intentioned HCPs, these HCPs were perceived as dismissive and uncaring, because rather than feeling understood and empathy for their struggles, they felt they were treated as a diagnosis.

((Continued)) Before "examining" me as if I was an object, I wish they were more personal and understanding that I may already be disliked or judged upon by the society before coming to see them. How I get bullied by others, get looked at, etc. etc. So in other words I guess, show more empathy? Just care about me more... more than just a patient with AS that comes every now and then. (Marta)

Several others echoed feeling this way, including Peter:

Everything is left on my own for me to deal and cope with. [...] Doctors shouldn't treat the time as just a few minutes just calculating what I say and matching that with their notes from the previous visit. Why wouldn't they want to show more care and sympathy? They always say that I have a problem connecting to peoples' emotion but doctors do not show initiative either to show emotion with me. Quite ironic!

Several participants echoed what people said, pointing out that although they were the ones with the 'communication disorder', HCPs seemed to make very little effort to foster communication or connection.

In some instances, participants did not feel treated like symptoms or a mere condition, but still felt as though their HCPs did not understand them and the extent of their struggles and efforts, which seemed so easily dismissed.

I always get nervous when I see the doctor. [...] It takes me a large dose of sugar in Starbucks frappuccino or latte before going into the doctor's appointment. However, I find that he would sit there and write down on his notepad and let me go out in 10 minutes. Sometimes I feel helpless. (Louise)

Here, Louise felt dismissed due to being 'let go' so quickly in contrast to how long and hard she had to work herself up to get to the appointment. Whether it be the stress imposed by 'society' in general, the anxiety during their interactions with HCPs, or HCPs focus on their behaviours rather than on them as persons, many participants provided examples like these where they felt fundamentally misunderstood, dehumanized, and helpless.

Overall, negative healthcare experiences stemmed from negative interactions with HCPs who were adversarial and uninvested. These HCPs were characterized as arguing against

patients, dismissing their reports, being condescending and discriminatory, not understanding their struggles, not caring about them, and neither connecting nor trying to connect with their patients.

Discussion

The findings of this study highlight that the experiences of adults with HFASD who navigate healthcare independently were largely determined by their interactions with and perceptions of their HCP. Participant experiences of their HCPs and their healthcare relationships laid on a continuum, with knowledgeable and empowering allied HCPs at one end of the continuum, and unknowledgeable and overpowering adversarial HCPs at the other. These interactions determined the extent to which participants benefitted from their strengths or were hampered by their challenges.

Participants discussed multiple personal strengths and challenges that they brought to their healthcare. The most commonly cited strength was intelligence, and many participants made the distinction between having intelligence and being able to convey their intelligence in a way that either fought perceived discrimination or contributed to more positive healthcare relationships. Similar to Nicolaidis et al., (2015) communication skills, especially written communication – such as preparing written questions and concerns in advance of appointments, and keeping detailed records – were also cited as strengths. Participants also felt that their personality factors, such as perseverance and honesty, and behaviours such as taking ownership of their health and engaging in self-care were significant strengths.

Similar to the challenges they face in other social interactions (Gutstein & Whitney, 2002; Lawrence et al., 2010; Mitchell, 2008; Shepherd, 2008; Tantam, 2003), the personal challenges most frequently cited by participants were with verbal communication, making

themselves understood, and extreme anxiety, all of which made it difficult for them to engage in healthcare. Participants also discussed challenges that stemmed from HCPs, whom they felt lacked knowledge about HFASD and its impact of them as persons, resulting in feeling stigmatized, dismissed, and misunderstood.

PCC with Allied, Well-Intentioned, Uninvested and Adversarial HCPs

Within the PCC framework, positive and effective healthcare results from, a) positive, caring healthcare relationships from the patient's perspective; b) effective communication and collaboration between the patient and HCP; and c) a holistic understanding of the patient not only in terms of their health conditions, but as a person overall, including their struggles, strengths, and life experiences (Cloninger, 2010; Stewart, 2001). Using the PCC framework as the model for positive and effective healthcare, we can explain why adults with HFASD have positive and negative experiences based on their allied and well-intentioned HCPs success in these three tenets of PCC, or their uninvested and adversarial HCPs failure in these three tenets. Throughout this discussion, it is important to note that these descriptions and categorizations are participants' experiences and perceptions of HCPs, and are meant neither as a comment on how HCPs are 'actually' behaving, nor as a reflection of HCPs intention to behave in the way they are perceived.

HCPs who are Allied: Patients experienced positive relationships with HCPs whom they portrayed as allies. Allies were praised as ideal HCPs, and were described as fostering strong, caring relationships in which patients felt safe from judgement and unconditionally accepted. Allies were described as never 'giving up' on their patient, either encouraging them in the face of challenges or advocating on their behalf. Allies accepted communication differences, and fostered communication that was in line with their patient's communication strengths. This

inclusive communication allowed for effective collaboration between patient and HCP, where patient's felt they could inform HCPs and their healthcare on their own behalf. Therefore, allies succeeded in all three areas of PCC from their patients point of view.

Allies were portrayed as understanding the impact HFASD had on their patient, and as understanding their patient holistically as a person, which may have stemmed from having knowledge about HFASD that would serve to dispel misperceptions and foster empathy. In some cases, patients felt they were not able to express themselves, but they still had positive experiences with allies who 'never give up on' them. Therefore, even when a patient could not make themselves fully understood, they still felt accepted by their HCP whom they portrayed as an ally.

HCPs who were Well-intentioned: Well-intentioned HCPs were similar to allies, but generally had a less complete knowledge about HFASD. For example, in terms of understanding the patient as a person, they may know enough to realize that their patient is struggling, but not know how to provide effective support (e.g., how to provide support that is not condescending). In terms of communication, they may realize that adults with HFASD can be highly intelligent, but be unaware that that specific patient may share their knowledge through non-conventional communication styles (e.g., information provided through concrete and 'unemotional' speech may not be given the same weight as emotionally expressive speech). These HCPs shortcomings were attributed to being ill-equipped, or being unaware that they were not quite 'getting it right', and not attributed to being ill-intentioned. Ultimately, being well-intentioned went a long way in creating positive healthcare experience, even though they did not fully succeed in all areas of PCC.

HCPs who were Uninvested: HCPs who were uninvested were characterized as lacking knowledge about HFASD, not caring about their patient, and as being dismissive of their patient's communication, intelligence and concerns. This dismissal of communication and input led to clinical encounters with agendas that did not take their patient's concerns and expectations into account, and was linked to the patient feeling like a collection of symptoms or as a 'sickness with a person in tow,' leaving them feeling dehumanized and poorly understood. Overall, these uninvested HCPs were portrayed as failing in all three areas of PCC, as well as lacking knowledge about HFASD and the impact it has on these adults.

HCPs who were Adversarial: HCPs who were portrayed as adversarial were characterized as a much harsher and hostile version of uninvested HCPs, portrayed as more than just dismissive, but as actively adversarial. Patients described being yelled at and criticised, being accused of lying or 'stupidity', and being aggressively dismissed (e.g., having their written communication taken from them and thrown away). These 'aggressive' interactions often lead to patients leaving their medical appointments in a state of distress, and describing these interactions as 'not successful encounters' and 'one of the worst experiences of my adult life'.

Patients also perceived adversaries as being sure of themselves and condescending, despite lacking knowledge about HFASD. Furthermore, they were perceived as 'arrogant' about their knowledge, and as unwilling to have their knowledge or perceptions challenged, especially by someone whom they treated as intellectually inferior. Patients experienced feeling discrimination – being excluded from engaging in and informing their own healthcare by HCPs who misperceived them as lacking intelligence, credibility, and communication abilities – and being unable to combat this discrimination. Therefore, adversaries were portrayed as failing at all aspects of PCC.

The Role of Knowledge about HFASD and Power in Healthcare Relationships

Similar to the general population (Arbuthnott & Sharpe, 2009), the findings of this study suggest that adults with HFASD were invested in and wanted to be engaged in their own healthcare through collaboration. Engaging in healthcare was perceived as a lottery of sorts, where their contribution and collaboration was dependent upon their HCPs who either empowered or overpowered their patient's communication and collaboration. HCPs who possessed more knowledge about HFASD were portrayed as being more empowering of their patients, while those with less knowledge were portrayed as overpowering. This may be due to the role of knowledge in dispelling misperceptions about these adults' intentions, abilities and experiences.

Within the literature, it has been established that there are many *negative* misperceptions about adults with HFASD. Their social and communication challenges can lead them to be misperceived as rude and narcissistic rather than as well-intentioned but struggling (Bailey, 2011), not interested in relationships and 'stand-offish' rather than feeling socially isolated and wanting relationships (Lawrence et al., 2010; Muller et al., 2008), and unempathic and unemotional, rather than caring and wanting to be cared for in return (Rogers et al., 2007), all of which contributes to their behaviours being met with very little understanding (Bailey, 2011; Howlin, 2000; Lawrence et al., 2010). HCPs who lack knowledge would likely hold these misperceptions, which may explain why they are perceived as reacting to their patient's behaviours harshly, and in ways that their patient felt intimidated and thus overpowered in their communication. Participants also perceived discrimination, which was vicious cycle in which they could not counteract these misperceptions about their lack of intelligence or lack of communication abilities, because HCPs held the power to nullify their communication (e.g.,

unwilling to accept written communication, not allowing extra time for verbal communication, etc.), leading to feelings of frustration, anger, and helplessness. Conversely, HCPs who were portrayed as knowledgeable about HFASD were portrayed as empowering, valuing their patient's intelligence and supporting communication and collaboration.

Cursory understanding of HFASD itself goes beyond misattributing patient behaviours to their character (e.g., rude, uncooperative, etc.) and overlooking their abilities (e.g., intelligence, written communication), but these misattributions may further lead HCPs to fundamentally misunderstand their patient's experience. In general, challenges with social competency skills can lead to perceptions that these adults lack emotions and empathy, lack effort or desire for connection, and lack intelligence or the ability to communicate. Therefore, misperceptions surrounding HFASD define these adults by what they are perceived to be *lacking*, which leaves HCPs who hold these misperceptions with very little to understand and interact with other than their patient's visible symptoms, which in turn would contribute to patients feeling dehumanized as a collection of symptoms rather than as a person.

Knowledge dispels many of the negative misperceptions about adults with HFASD that may otherwise prevent positive relationships, communication and collaboration. For example, understanding that a patient struggles with social conventions and communication, but is intelligent and wants to inform their healthcare, would encourage HCPs to help patients overcome their struggles, fostering relationships and communication. Conversely, misperceptions that a patient is uncooperative, rude, unable to communicate, unintelligent or uninterested in interacting with others would hamper an HCPs understanding that positive relationships and communication, and their patient's ability to intelligently inform their healthcare is something that they are either capable of or interested in doing. This would lead to

patients feeling dismissed, discriminated against and overpowered – dismissed as either not wanting or not being able to communicate or collaborate. Therefore, HCP knowledge – and it's impact on power within healthcare relationships –appears to determine the difference between HCPs who are allies, well-intentioned, uninvested and adversarial in terms of their role in positive or negative healthcare experiences. (See Figure 1)

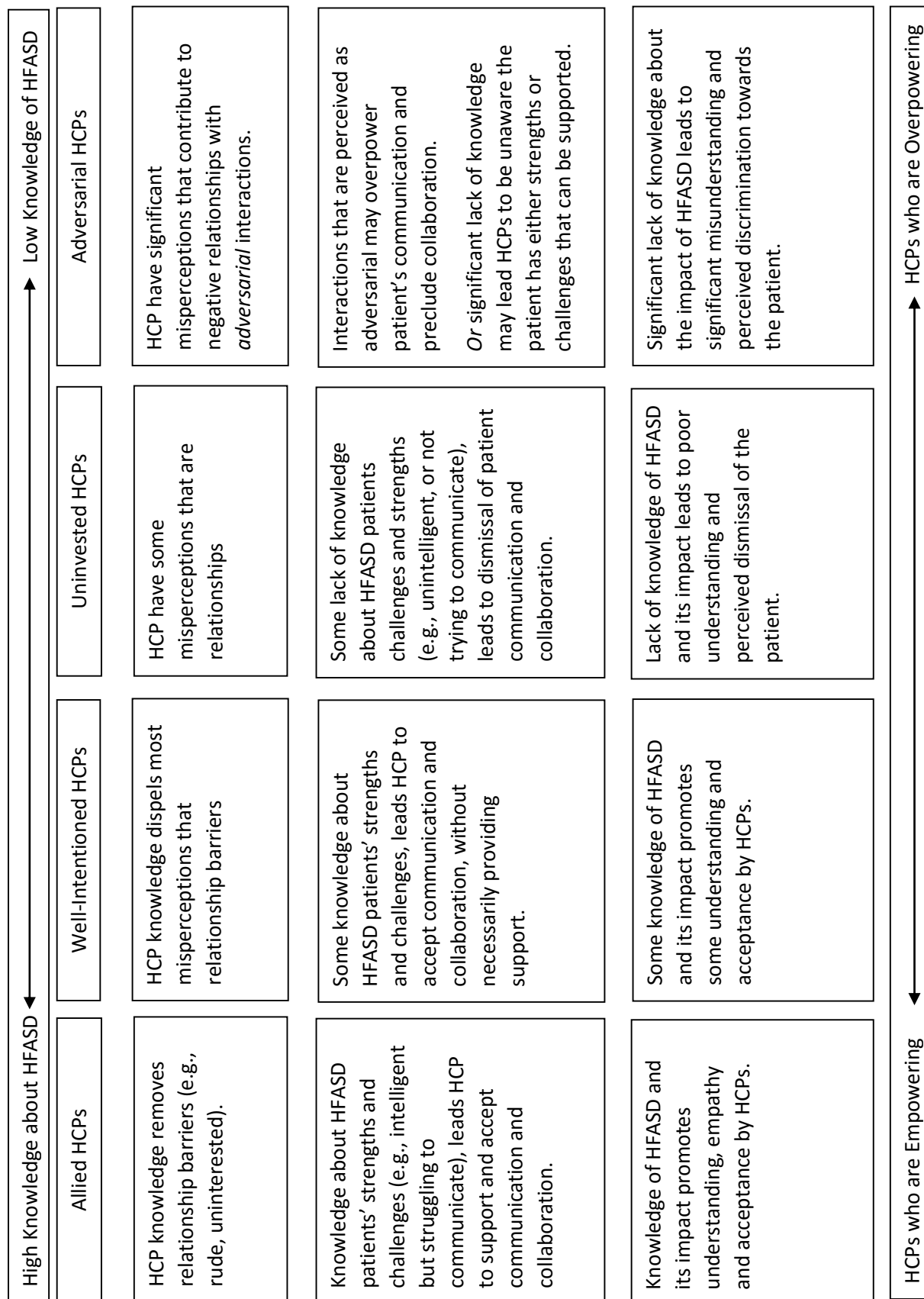


Figure 1: HCPs' Knowledge about HFASD and Patients' Experience of Healthcare

Strengths and Limitations

Strengths. The strengths of this study are manifold. First, based on extensive search of the literature, this is the first study in which adults with HFASD – who navigate healthcare independently and without the support of third party - directly informed research on their own behalf about their overall experiences in healthcare. Although some of these findings echo those of Nicolaidis et al. (2015), this study goes beyond the identification of a need for more knowledge among HCPs and more communication supports, and speaks to a larger experience where the role of the HCP can be one of ally or adversary. Two studies that have included adults with HFASD with respect to their healthcare have established that they face disparities in healthcare, but did not address what they attributed these disparities to (Lum, et al., 2014; Nicolaidis et al. 2012). In general, previous research has often been informed by others, and usually with respect to patients who are ‘lower-functioning’ and/or children (Bailey, 2011; Barnhill, 2007). The use of open ended questions allowed participants to highlight their experiences and the concerns that were most pertinent to them, and identify not only that they had positive or negative experiences, but what they perceived as contributing to these experiences.

Second, adults with HFASD often report being misunderstood, and having difficulty making themselves understood (Barnhill, 2007; Lawrence, 2010; Shepherd, 2008). The design of this study helped ensure that my understanding of the participants’ responses reflected their intended meaning, including consulting stakeholders about communication strengths prior to choosing online methods, and providing participants with preliminary findings allowing them to comment on whether or not I had captured their intended meaning.

Third, the sample represented the diversity of the HFASD population in terms of age, gender, cultural backgrounds, educational level and living situations. Within this ideographic approach, generalization to the larger population is not necessarily the goal. However, it is worth noting that the themes that emerged from this diverse sample speaks to an experience common to adults with HFASD, suggesting these challenges are not limited a select few (e.g., these struggles are not limited to those with less education, or who live alone, etc.).

Limitations. The findings of this study need to be understood within a few limitations. First, there may have been a bias in recruitment in which adults who have experienced frustration and dismissal within healthcare had a higher motivation to sign up for the study. In addition, although online data collection was in keeping with the communication strengths and preferences of many adults with HFASD, individuals who are more comfortable with face-to-face communication may have been deterred from participating. Therefore, this sample may represent individuals who prefer written communication over in-person conversation, which would likely lead to a difference in the experiences of interactions with HCPs than those who prefer in person communication. Second, several participants provided rich, narrative-like stories as their responses. This data collection method did not allow for the sorts of dialogue and follow-up that occurs in an in-vivo interview, and as such missed the opportunity to gather more data that would have allowed for even more understanding of narrative and discursive elements. To address these limitations of potentially over selecting participants who prefer written communication, and potentially losing rich data due to the response format, future studies should provide the option of online data collection, and telephone or in-vivo interviews. Furthermore, using methods such as instant messaging may allow participants who prefer written communication to still engage in the back-and-forth of a dialogue.

Third, participants discussed a range of healthcare professionals, including general practitioners, specialists such as rheumatologists, neurologists, psychiatrists (or sometimes simply referred to as a ‘specialist’), psychologists, ‘therapists’, chiropractors, a nutritionist, a dentist, and a medical assistant. In some cases, it was unclear to whom they were referring when they provided these responses. Therefore, it is not possible to assess if or how experiences vary based on these professions. Furthermore, factors such as the length of time a participant had known their HCP varied, (e.g., a one time consult or a family physician whom they have seen all of their life), which prevented an understanding of how these factors may impact their experiences.

Finally, there was no way to confirm a participant’s self-report of having been diagnosed with HFASD (or with AS or PDD-NOS). All participants scored at or above the chosen cut point of 4 ($M=7.64$) on the AQ-10 (Allison et al., 2012; ARC Autism Research Centre, 2014), and all reported receiving their diagnosis from a diagnostic professional, which supports but does not confirm their self-report of diagnosis. There was also no way to confirm that participants did not seek the support of a third party in providing their responses. Although the support of a third party may be beneficial for some participants to express themselves clearly, it could also result in the responses reflecting the third party’s interpretation of the participant’s experiences. Despite this limitation, the opportunity to include the diverse sample obtained online – as opposed to a sample from one specific community association – and to use online data collection in keeping with participants reported communication strength outweighed the need for absolute confirmation of diagnosis that could only come through in person data collection.

Implications

These findings reflect the experiences of adults with HFASD in healthcare, an understanding of which are crucial in terms of understanding what makes for positive experiences and effective healthcare, and making recommendations for healthcare that is meaningful from their perspective and is therefore *patient* centred. However, these findings do not reflect the perspectives of HCPs and other third parties, and are not intended to speak to what is ‘actually’ taking place in healthcare interactions, or suggest that HCPs are ‘actually’ being adversarial, dismissive, or discriminatory, intentionally or otherwise. However, it is important for HCPs to know that they are at times perceived in these ways so that they can understand the impact they have on their patient’s healthcare experiences.

Overall, there is a need for HCPs to have more knowledge about HFASD and its impact on these adult patients. Although the findings of this study can only speak to the perspective of adults with HFASD, previous reports have highlighted that HCPs feel ill-equipped in interacting with and treating adults with HFASD (Ousseney et al., 2015; Peter 2009 as cited in Kuhitau et al., 2014), suggesting that both patients and HCPs recognized this need. Participants cited a lack of knowledge and awareness on the part of HCPs ranging from diagnostic criteria, diversity in symptom presentation and comorbid illnesses to misperceptions about their intelligence, how they communicate, and their experiences. Awareness campaigns and the dissemination of information needs to be done through approaches that are evidence based in their effectiveness. For example, if patients who are alone on the ‘front lines’ of communications with their HCPs are having difficulty in communicating with HCPs it would be naïve to believe that arming them with a pamphlet or brochure will address the problem. Information also needs to be disseminated

by advocacy groups, through healthcare professionals' colleges, and through academic conferences and journals.

Based on these findings, awareness needs to be raised surrounding the diversity of adults with HFASD, and their strengths and challenges, and dispel any notion that HFASD is a uniform experience. The overall message needs to first and foremost be one that dispels the misperceptions that lead to these adults being misperceived as rude, uncooperative, narcissistic, unintelligent, uncommunicative and unempathic. All of these misperceptions hamper relationships, communication, and understanding, and therefore should be targeted so that other efforts – such as supporting patient communication – are not quashed by these poor relationships. Next, there needs to be a balance between information that highlights that many adults with HFASD have strengths that may be easily overlooked, and that these strengths vary from person to person. Furthermore, when it comes to strengths and challenges, the message must clearly combat any suggestion that strengths preclude the need for support, or that needing supports implies a lack of strengths.

These findings support the need for communication tools and aids for adults with HFASD (Nicolaidis et al., 2015). Although participants who had negative experiences often felt that their communication strengths were dismissed, it cannot be determined from these findings the nature of the communication they were providing to their HCPs. Although it would be ideal if HCPs would recognize and accept communication strengths, further research would be required to ensure that adults with HFASD are communicating in ways that HCPs can make use of. For example, if a patient identifies that they have strengths in written communication, this communication may still need to be tailored in a way makes it effective in healthcare. This may require the development of dynamic tools, such as a smartphone application, within which the

software, the HCP, or a third party can help guide and strengthen patient communication (e.g., set parameters to hone the communication of patients who may provide overwhelmingly excessive detail, add prompts to elicit more information from patients who may be very brief, provide templates of how to discuss various concerns with their HCP, etc.). Tools such as these would take the onus off of patients to adapt to socially-conventional healthcare communication and begin to remove barriers cited within the social model of disability by adapting the healthcare environment as a whole. Effective communication – and the resultant collaboration – is key in PCC and positive healthcare outcomes (Ha, et al., 2010), and therefore supporting healthcare specific communication needs to be a priority. Overall, tools need to be developed with stakeholders and well researched to ensure their effectiveness is evidence based. Furthermore, participants frequently reported experiencing anxiety, which acted as a barrier to scheduling and attending their healthcare appointments, and hampered their ability to communicate. Therefore, HCPs need to be aware of and help address this anxiety, not only to help create more positive experiences, but as part of supporting communication.

Finally, these findings support the idea that warm and caring attitudes go a long way in reducing feelings of ‘social estrangement’ in general (Muller et al., 2008), and help patients feel accepted and understood in healthcare. Although more knowledge and awareness among HCPs about HFASD is needed, they do not need to be ‘experts’ in order to foster positive healthcare experiences. Allies were described as being ‘non-judgemental’ and ‘never giving up’, qualities that do not required HFASD specific knowledge. Furthermore, well-intentioned HCPs did not always ‘get it right’, but they were perceived as having their patient’s best interests at heart and therefore they contributed to positive healthcare experiences. Although there are many things that HCPs need to better understand about HFASD, perhaps most importantly they need to

convey that – despite having shortcomings or gaps in knowledge – they value and care about these adults not as patients with HFASD, but as persons.

Dissemination of Findings. I will present my findings within journals and conferences that target healthcare professionals in general. Tools and materials that increase knowledge and awareness about HFASD among HCPs and communication supports that are result from these findings will be disseminated once developed with stakeholders.

Conclusion

Within this study, adults with HFASD wrote about their healthcare strengths, challenges, and their relationships and interactions with their HCPs. Irrespective of these patients' many strengths and challenges, their experiences in healthcare were largely determined by their HCPs – whom they portrayed as allied, well-intentioned, uninvested, or adversarial. The fundamental difference between these classification of HCPs was their level of knowledge about HFASD and its impact on these adults – knowledge that dispels the many negative misperceptions about adults with HFASD. Positive experiences were ones in which patients felt empowered, valued, understood, accepted, and in which their communication was supported. Negative experiences – which were more prevalent than positive ones – were ones in which patients felt misperceived as unintelligent, uninterested in or unable to communicate, and treated dismissively or adversarially within their interactions. There is a need for a) more knowledge and awareness among HCPs about HFASD to create more understanding and supportive relationships, and b) supports that facilitate communication within these relationships. Furthermore, these findings highlight the desire of adults with HFASD to meaningfully engage in and inform their healthcare, and work with HCPs to create care that is truly *patient* centred.

Appendix A

Information and Consent Form

Study Name: The experience of healthcare for adults with Asperger's Syndrome or High-Functioning Autism Spectrum Disorder

Principal Investigator: M Michelle Wright, MA Student, Psychology, 204-474-6982,
umwrig28@myumanitoba.ca

Research Supervisor: Dr. Maria Medved, Associate Professor, Psychology,
maria.medved@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 Master's thesis, under the supervision of Dr. Maria Medved. The purpose of this research is to examine how Canadian adults with Asperger's Syndrome or High-Functioning Autism Spectrum Disorder experience their healthcare. 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 four long-answer questions about their healthcare. They will be free to take up to two weeks to complete their responses. 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 sent a link to a second set of 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. Due to each individual's unique experiences in healthcare, we expect that the content and length of the responses 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 3 and 6 hours.

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 on password-protected computers affiliated with Dr. Medved's lab. Only the primary researcher, her supervisor, and other authorized lab personnel (e.g., research assistants) will have access to your data. We need to keep your contact information (name and email) with the data until the end of the third phase of the study, so that we can send you the link to the second part. However, we will keep your identifying information confidential. Once the third phase of the study is completed and we have had a chance to pair responses, we will delete all identifying information from our data, thus rendering it anonymous; 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. Once all the data are collected and analyzed for this project, we plan to share this information with the research community through seminars, conferences, presentations, and journal articles. When presenting the results of this research, we will in no way use any identifying information and when discussing the findings.

Findings

The results of this study should be available by December 2016. If you would like to receive a summary, please contact Michelle Wright at umwrig28@umanitoba.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. This summary may not be available until as late as 06/16. 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 as a subject. 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@umanitoba.ca to inform her that you no longer wish to participate. If you do choose to withdraw from this study, 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.

< I agree > (proceed to survey) <I do not agree> (exit)

Appendix B

Demographic Questionnaire

Age?

Gender?

What is your occupation?

What is the highest level of education you've attained?

Where do you live (House, apartment, etc.)?

Who do you live with?

Do you have a regular and consistent family physician (as opposed to seeing different physicians from visit to visit, like at a walk in clinic)?

How often have you seen a family doctor/general physician in the last year? If you are unsure, please make your best guess.

Have you seen a medical specialist(s) in the last year? If so, what kind of specialist(s) and how often? If you are unsure of how often, please make your best guess.

How often have you been to the pharmacy in the last year? If you are unsure, please make your best guess.

In the last year have you been to an emergency room?

Does someone accompany you to your doctor appointments?

Please list all chronic health conditions you have.

Please list all medical diagnoses you have (including physical and mental health conditions).

Does anyone help you with your healthcare and appointments (for example, calling and making the appointments on your behalf, picking up your prescriptions, helping make decisions about healthcare, etc.). If yes, who are they? What tasks do they help with?

Appendix C

AQ-10

Please tick one option per question only:

		<i>Definitely Agree</i>	<i>Slightly Agree</i>	<i>Slightly Disagree</i>	<i>Definitely Disagree</i>
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				

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Appendix D

Study Questions

- 1) Imagine you are discussing your healthcare experiences with an audience of doctors and other healthcare professionals. In a few paragraphs, please tell me what are some of the things you wish they understood better about you?

If you are having trouble thinking of how to provide enough detail, you may want to try the following. These are only suggestions if you are having trouble writing long answers. You are free to respond to the initial question above however you choose.

- a. Write out a detailed real-life example of a time that you wished a doctor better understood something about you. Include details such as what type of doctor, how you got along with them, how you felt during your interaction, whether it was a single doctors visit or multiple visits, and other details you feel are important about that real-life example.
 - b. Include full descriptions and details about what you wish they better understood about you, and write out everything you think you would need to tell a doctor to get them to better understand.
 - c. If doctors did better understand what you wish they better understood, what do you think the impact would be? How would you feel? How would your healthcare change?
- 2) What has been the most significant challenge while interacting with doctors and other healthcare professionals? (For example, tell me about your experiences with this challenge, including why it's a challenge, and how it has affected you. Feel free to include any other

information that you think is important for me to know about your biggest challenge in healthcare.)

If you are having trouble thinking of how to provide enough detail, you may want to try the following. These are only suggestions if you are having trouble writing long answers. You are free to respond to the initial question above however you choose.

- a. Write out a detailed real-life example of a time that you experienced this challenge.

Include details such as what type of doctor, how you got along with them, how you felt during your interaction, whether it was a single doctors visit or multiple visits, and other details you feel are important about that real-life example.

- b. Include full descriptions and details about this challenge, and write out the things that you think would help reduce this challenge.

- 3) What has been your biggest strength while interacting with doctors and other healthcare professionals? (For example, tell me about this strength in your healthcare experiences, including why it is a strength, and how it has affected you. Feel free to include any other information that you think is important for me to know about your strengths in healthcare.)

If you are having trouble thinking of how to provide enough detail, you may want to try the following. These are only suggestions if you are having trouble writing long answers. You are free to respond to the initial question above however you choose.

- a. Write out a detailed real-life example of a time you used or demonstrated this

strength. Include details such as what type of doctor, how you got along with them, how you felt during your interaction, whether it was a single doctors visit or multiple visits, and other details you feel are important about that real-life example.

- b. Include full descriptions and details about what this strength means to you, and write out the ways you think strength helps you.
- 4) What has been most helpful in dealing with your health and healthcare, while interacting with doctors and other healthcare professionals? This could be describing something that you do that makes for good healthcare, something that someone else does (healthcare professionals) that makes for good healthcare, or something you both do together that makes for good healthcare.

If you are having trouble thinking of how to provide enough detail, you may want to try the following. These are only suggestions if you are having trouble writing long answers. You are free to respond to the initial question above however you choose.

- a. Write out a detailed real-life example of a time that you did or experienced something helpful. Include details such as what type of doctor, how you got along with them, how you felt during your interaction, whether it was a single doctors visit or multiple visits, and other details you feel are important about that real-life example.
 - b. Include full descriptions and details about when this most helpful thing in dealing with your health and healthcare occurred. Is it in all situations or only some situations?
 - c. Is there anything that you have not experienced, but that you think would be helpful?

Appendix E

Preliminary Findings/Theoretical Sampling

Thank you for choosing to participate in this study. Your participation is voluntary, and you can choose not to answer some or any of the questions. As indicated in the consent form, if you have questions about the study or your continued participation, please email me, Michelle Wright at umwrig28@umanitoba.ca, or call 204-474-6952.

This is the third and final phase of the study. On the following pages you will find a preliminary summary of the responses that all participants submitted. Please read them over. There is space for you to comment on these preliminary findings if you would like to. If you do not wish to comment, you may leave the space blank.

.....

Before reviewing the preliminary results, please take the time to respond to the following question.

Many individuals have very strong beliefs about how they do and do not want to be referred to. I would like to respect each individual's wishes. When the final results are formally written up, please indicate how you would like to be referred.

- ☐ a woman/man with Autism (ASD)
 - ☐ a woman/man with Asperger's Syndrome (AS)
 - ☐ a woman/man with High-Functioning Autism (HFASD)
 - ☐ an autistic woman/man
-

- Many individuals expressed that there needs to be more awareness of ASD/AS among doctors and other healthcare professionals, so that they can better identify and recognize ASD/AS in their patients. Some people reported that it was months or years before a doctor suggested that ASD/AS may be a potential diagnosis.
- Many individuals expressed the following needs:
 - 1) *Better support* and availability of information for healthcare professionals (mainly General Physicians, Specialists, Psychologists).
 - 2) *More effort* on the part of these healthcare professionals to seek out the available information about AS/ASD and the types of support that are available.
 - 3) *More willingness to refer* to (or consult with) another healthcare professional when a patient suspects they may have AS/ASD. Also, more willingness to listen to a patient who suspects they may have AS/ASD.
 - 4) *Better understanding* that ASD/AS has physical medical ramifications (in addition to cognitive/psychological ramifications)
- This is a preliminary overview. The final findings will contain much more detail and context. If you would like to comment on the finding above please do so in the space below. For example, you may agree/disagree with the finding above, or have something you would like to add.

.....
- Another common theme that emerged was that many (not all) healthcare professionals did not understand the *challenges* of ASD. In addition, many participants stated that healthcare professionals did not understand or value their strengths.

- Participants expressed a need for the following:
 - 1) More empathy and understanding from healthcare professionals. Patients need to be treated as human beings, not as a list of symptoms.
 - 2) More respect for the intelligence and knowledge of patients. Patients should not be dismissed; they are a valuable resource in their own healthcare.
 - 3) A better understanding of how ASD/AS affects interactions in the doctor's office. For example, if a doctor knows that adults with ASD/AS can create challenges in communication, then they should 'know better' than to rush their patient or dismiss written communication that the patient has prepared.
 - This is a preliminary overview. The final findings will contain much more detail and context. If you would like to comment on the finding above please do so in the space below. For example, you may agree/disagree with the finding above, or have something you would like to add. This is optional.
-

- Many participants discussed being empowered, and taking initiative in their own health care and self-care. This was presented as an important strength.
 - 1) Some participants reported feeling encouraged and supported by a good doctor which helped them take charge of their health and self-care.
 - 2) Some participants reported feeling unsupported and alone, and therefore took initiative over their own health and self-care out of necessity.
 - 3) Some participants reported taking an active role in their health and self-care regardless of the type of doctor or support they had in their life.

- This is a preliminary overview. The final findings will contain much more detail and context. If you would like to comment on the finding above please do so in the space below. For example, you may agree/disagree with the finding above, or have something you would like to add. This is optional.

.....

- 1) Doctors who are adversaries: These doctors were perceived very negatively, and were associated with very negative experiences in healthcare (e.g., causing anxiety), as well as negative healthcare outcomes (e.g., not providing correct diagnoses or treatment). These doctors were described as actively fighting against patients. They were also described as dismissive, condescending, rushing, not believing patients, and actively opposing their patients' requests for referrals, tests, and support.
- 2) Doctors who are not invested in their patients: These doctors were perceived negatively, and were associated with very negative experiences in healthcare (e.g., causing anxiety), as well as negative healthcare outcomes (e.g., not providing correct diagnoses or treatment). These doctors were described as not taking the initiative to support patients (although they were not described as actively fighting against patients). These doctors were also described as not caring about patients as individuals, and as seeing patients as a 'list of symptoms to be solved' rather than as not as a human being
- 3) Doctors who are ill-equipped: These doctors are portrayed somewhat positively. They are described as caring, doing their best and having good intentions. However, they are not often successful in providing help that patients find beneficial or meaningful.
- 4) Doctors who are allies: These doctors were praised and perceived very positively. They care about their patients and work hard to find effective solutions. Patients feel

understood and valued as a human being, not just as a ‘patient’. These doctors are described good listeners, not rushing, valuing the patient’s knowledge and input, advocating with/for patient, and working collaboratively with their patients.

- Do you feel that one (or more) of these preliminary categories adequately describes the different doctors and healthcare professionals you have experienced? If you would like to comment please do so below.

.....
If there is anything else you want to comment on before submitting your responses please do so in the space below.

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