PRIMARY CARE STRATEGIES FOR SUPPORTING PARENTS OF CHILDREN WITH SUSPECTED AUTISM SPECTRUM DISORDER

by

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PROJECT SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF SCIENCE IN NURSING – FAMILY NURSE PRACTITIONER

UNIVERSITY OF NORTHERN BRITISH COLUMBIA

August 2018

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Abstract

ASD is a complex neurobiological disorder requiring early childhood intervention to mitigate effects on overall quality of life. Without early intervention, individuals and families are impacted socially, emotionally and economically. In BC, wait lists for a formal assessment and diagnosis are longer than a year. Parents of children with suspected ASD are often left in an anticipatory waiting phase once ASD is suspected. They require guidance on learning what ASD is, developing knowledge about treatment approaches, and determining what resources and supportive measures are available to them. The mainstay approach to assessment is initially via a primary care provider. As such, the primary care provider (PCP) is the first source of guidance when concerns about a child are raised, and is responsible for referring the child for diagnosis, and providing parents direction on where to obtain interventional therapies. However, there is limited guidance on how to support parents during the anticipatory period of time between suspicion of symptoms and diagnosis. The aim of this project is to explore strategies that enable PCPs when caring for parents of children with suspected ASD. An integrative literature review was conducted, which included ten carefully selected articles. Two major themes were identified, which focused on concepts of knowledge and communication. Knowledge linked to the PCP included the need for up-to-date developmental, clinical, communication understanding and tacit knowledge. Communication is essential during waiting and early diagnosis, and in aspects of PCP availability, multidisciplinary collaboration and supportive decision-making. These key aspects help to prepare families to flourish in their recreation of family life. Attention to parent health and wellbeing is critical, as is the need to discuss difficult topics such as emotional stress and service limitations. Patient and family centred care (PFCC) is reported as a health care model that illuminates the importance of respect, rapport and trust, while affording accord, equity and collaboration. Using the PFCC model as a polestar, the PCP can navigate care focusing on cocreating longer term relationships between primary care, parents, interventions teams and early education partners.

Keywords: autism spectrum disorder, parent-PCP relationship, primary care

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Glossary of Terms

Autism Spectrum Disorder: a neurodevelopmental disorder, defined as "persistent deficits in social communication and social interactions across multiple contexts" (American Psychiatric Association [APA], 2013a, p. 31)

Comorbidity: The co-occurrence of one or more diseases or disorders, concomitant or coinciding with a primary disease or disorder (Kessler, 1995)

Complementary Alternative Medicine: Health care practices and interventions that exist outside of conventional medicine (Zollman & Vickers, 1999)

Education: A formal process of learning experiences, designed to acquire knowledge (Merriam-Webster Online, n.d.).

Evidence-Based Practice: The conscientious, explicit and judicious use of current best evidence in making decisions about the care of the individual patient, integrating individual clinical expertise with the best available external clinical evidence from systematic research (Sackett, 1997)

Medical home: Defined as a philosophy of primary care that is patient centred, comprehensive, team-based, coordinated, accessible, and focused on quality and safety (Patient Centred Primary Care Collaborative, n.d., paragraph 1).

Primary Care Provider: The health care provider who operates at all levels of care, including prevention, pre-symptomatic detection of disease, early diagnosis, diagnosis of established disease, management of disease, management of disease complications, rehabilitation, palliative care and counselling (WHO, 2004)

Primary Care: first-contact care with a health care professional where the majority of non-acute health problems are treated. It is the principal point of continuing care and/or referral to specialist treatment (WHO, 2004).

Quality of Life: "An individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment." (WHO, n.d.-d)

Red flags: A concept of a warning symptom or clinical finding indicating the presence of a more extensive disease or disorder (Segen, 2002).

Self Efficacy: An individual's belief in their ability to perform a specific presenting or future task or skill (Bandura, 1977).

Screening: Targeted testing to identify individuals with specific infection, disease, disorder or health condition (WHO, n.d.-c).

Public Health Surveillance: Systematic, continuous data collection, analysis and interpretation to measure trends or outcomes in a population that requires further investigation or intervention if warranted (WHO, n.d.-b).

Acknowledgements

I would like to express my gratitude to my supervisors Dr. Caroline Sanders and Lauren Irving for believing in my scholarship, and tirelessly providing me with support and advice throughout this project. Thank you so much.

Thank you to my friends and family, who gave me much love and support throughout this program, witnessing my brightest and darkest moments.

Finally, thank you to my parents. Your trials and tribulations throughout life gave me perspective into the unmet needs of parents of children with autism. Your resilience and strength inspired me to support families facing similar challenges within my own professional practice. More importantly, thank you for inspiring me to face my own challenges with the same strength and resilience that I see in you. I am forever grateful.

Introduction

Autism spectrum disorder (ASD) is a lifelong complex neurodevelopmental disorder that results in a spectrum of developmental (dis)abilities (Weill, Zavody & Sounders, 2018). Caring for a child with ASD in the family setting is recognised as challenging and burdensome, resulting in caregiver vulnerability and stress (van Tongerloo et al., 2015). In Canada, the economic impact of caring for children with ASD over their lifetime is as high as \$5 million CAD, with an average cost of approximately \$75,000 CAD annually per child (Dudley & Emery, 2014; Lyall et al., 2006). Indirect costs can be attributed to decreased parental productivity and increased care needs (CDC, 2016).

Evidence-informed practice significantly improves the child's long-term developmental outcomes, and enhances the quality of life for children with ASD and their families (Weill, Zavody & Sounders, 2018). Early recognition of symptoms and referral for ASD assessment can promote early diagnosis, which is important for parents and their child with ASD in accessing appropriate resources and management interventions (Zwaigenbaum et al., 2015). Without early intervention, individuals frequently struggle with social acceptance, and are impacted emotionally and economically (Khowaja, Hazzard & Robins, 2015). Intervention itself includes a range of treatments, comprising of family education and behaviour intervention (CDC, 2016). However, as a result of various initial presentations, engagement, and service provision factors, children can experience a delay in receiving a diagnosis of ASD. Therefore, when ASD is suspected in young children, aged between 18-36 months, early referral for focused assessment and evaluation is considered best practice.

Within the context of primary care management of a child with suspected or diagnosed ASD, primary care providers (PCPs) play a pivotal role in care. As such, PCPs need to have knowledge of ASD, and the accompanying skills to sufficiently support the child and their family

(van Tongerloo et al., 2015). Knowledge of developmental surveillance, ASD red flags and screening tools increase earlier referral and diagnosis, improving the heavy costs attributed to later intervention (Ip et al., 2015). PCPs seeking educational opportunities on ASD enhance the patient care experience by becoming a supportive source of information to parents, and improve timely access to early intervention (Carbone, Behl & Azor, 2010; Garg et al., 2014).

In addition to increasing PCP knowledge, studies report that there is a need for collaboration between PCPs, parents, and the multidisciplinary team to effectively provide early intervention, assistance, and practical guidance for managing children with ASD (Carbone, Behl, Azor, & Murphy, 2009; van Tongerloo et al., 2015). Parents often report that PCPs do not elicit their presenting concerns about their child with suspected ASD, which can result in parent-PCP communication challenges (Bloch & Gardner, 2007; Mulligan et al., 2015). Barriers to establishing parent-PCP collaboration are further compounded in settings where populations experience low socio-demographic variables, such as poor maternal education (Fountain, King & Bearman, 2011). Challenges establishing partnerships at the parent-PCP level result in relationships that lack trust or respect (Khowaja et al., 2015).

Current literature, including clinical practice standards and pathways, support the importance of establishing and maintaining strong parent-PCP relationships via establishing good communication, partnership, and ongoing involvement to address ASD management (Dua, 2003; National Institute for Health and Care Excellence [NICE], 2017). However, ASD studies with younger children often focus on assessment, with little investigation in to focused evidence-informed strategies that promote relationships, establish, sustain, and reconcile communication in the partnership to foster ongoing engagement (Fewster & Gurayah, 2018; van Tongerloo et al., 2015; Weill, Zavodny & Souders, 2018). Of note, over the last few decades numerous models have been adopted that can help to foster professional-parent partnerships; for example, the

expert model, the transplant model, the consumer model (Cunningham & Davis, 1985), the social systems model (Appleton & Minchom, 1991) and patient and family centred care (PFCC) model (Bellin et al., 2011). Such models provide conceptual frameworks through which professionals can view, understand, and enhance their interaction with parents. Within the last eight years, a patient and family centred approach to care (PFCC) has being proffered as an ideal model of service delivery in children with ASD (Carbone, Behl & Azor, 2010). However, there are barriers to understanding how this model informs and guides practice i.e. how PCPs assess younger children in primary care with either suspected ASD or a new diagnosis (Carbone, Behl & Azor, 2010). Furthermore, such models are often viewed through the lens of a professional perspective, which can result in uncertainty about how accurately models explain, describe, or represent parent's perspectives. This project therefore seeks, in part, to understand how these models of care may facilitate the PCP role when working with young children aged 18-36 months with suspected ASD and their families in primary care settings.

While the interest in this capstone project was initially based upon personal experience, discussions with staff during clinical experiences consolidated thinking around the need for evidence-informed guidance in various areas linked to young children and ASD. Reflecting on these dialogues warranted further consideration for children aged 18 to 36 months with suspected ASD, specifically focusing on how PCPs approach difficult topics, engage parents, and support ongoing collaboration when concerns are raised. Public health nurses (PHNs) and PCPs provided anecdotal evidence of their experiences working with parents of young children suspected to have or with a new ASD diagnosis. These providers identified challenges when conveying concerns on child development, and were concerned if parents understood the intervention information provided, or if parents followed up on their appointments with specialists. Health providers voiced unfamiliarity on the availability of local social supports, and reported that once a child had

been referred for an ASD assessment they often did not receive follow-up from the referring provider. Such conversations supported the decision to focus on the issues identified within this review. Therefore, the question that this review aims to answer is as follows: "What are primary care strategies for supporting the parent(s) of children aged 18-36 months with suspected ASD?"

CHAPTER ONE: BACKGROUND

The following chapter provides a background understanding of this project's review question: "What are primary care strategies for supporting the parent(s) of children aged 18-36 months with suspected ASD?" This chapter will first examine the epidemiology and prevalence of ASD, and its pathophysiology and diagnostic criteria. The medical management for the condition, factors contributing to late diagnosis/interventions, followed by an exploration of the health impacts on the child and family will also be considered. Because the focus of this review is during a specific time in the diagnostic process of ASD, the timeline of symptom recognition, referral, assessment, diagnosis and intervention will be explained, along with an account of the PCP's role throughout the process, highlighting their role in early childhood development, ASD identification, referral, and parent support pre-and-post diagnosis. Finally, benefits of a health care model will be considered as an enhancing factor in communication and care between family and PCP.

Epidemiology and Prevalence

The prevalence and distribution of ASD is estimated to be at least 1.5% in developed countries (Baxter et al., 2015). Males are diagnosed at a higher rate than females, with four males diagnosed to every one female; of note, females diagnosed with ASD are likely to demonstrate more severe traits of ASD (Statistics Canada, 2015; Lyall et al., 2017). Prevalence of ASD diagnosis has been increasing over the last few decades, with a reported increase of 1:150 children in 2000 to 1:66 in 2015 (Centers for Disease Control and Prevention [CDC], 2016). This increased prevalence may be the result of various factors, such as changes to the diagnostic criteria and increased societal awareness of ASD resulting in earlier presentation for assessment and screening in primary care (Wright, 2017). Suggested biological and social factors of delayed

parenthood and viable premature births may also contribute to its increasing societal prevalence, which is further discussed in the next section (Wright, 2017).

There is a significant cost impact for families of children with ASD and the overall economy. These costs can be directly related to intervention, estimating up to \$40,000-\$75,000 CAD per child, or indirectly related to decreased parental productivity in the work force, and increased care needs (Lilly et al., 2006). As children age out of government funding and higher needs for caregiving are required, the costs to the family also increase. The caretaking costs for individuals over the age of 14 severely impacted with ASD can be upwards of \$150,000 CAD a year, or "\$5.5 million [CAD] above the costs of a neurotypical individual" over a lifetime (Dudley & Emery, 2014, p.1). It is difficult to determine if the cost of care is affected by a delayed ASD diagnosis (Horlin, Falkmer, Parsons, Albrecht & Falker, 2014). However, it is suggested "a delay in diagnosis could indirectly increase costs by neglecting symptoms that may respond to more immediate intervention" (Horlin et al., 2014, p.8). Therefore each additional reported symptom of ASD results in a higher cost of care to the family and economy (Dudley & Emery, 2014; Horlin et al., 2014). To better understand the pathophysiology of ASD, the following section will examine the diagnostic criteria of ASD and its impact on child development.

Autism Spectrum Disorder: Pathophysiology and Diagnostic Criteria

The pathophysiology behind ASD is complex, since there is no known cause and a wide variation in clinical presentation (Chaste, 2012). While various theories aim to explain and drive ASD pathophysiology research, this continues to be a developing area of study (Yenkoyan, Grigoryan, Fereshetyan & Yepremyan, 2017). There are more than 20 factors that may be linked with increased ASD risk (Lyall et al., 2017). Fully appreciating how these factors influence ASD pathophysiology is beyond the scope of this review, but key issues are briefly outlined below. ASD is associated with a strong genetic component, as well as epigenetic and environmental factors (Chaste, 2012). Genetically, ASD is caused not by an isolated gene, but by a combination of multiple genetic variants (Chaste, 2012). Given the sharing of genes across siblings, brothers or sisters of children with ASD are more likely to demonstrate ASD traits (Statistics Canada, 2015). A child born prematurely or having a father of older paternal age correlates with an increased risk for having ASD (Wright, 2017). Possible maternal factors that may affect risk of ASD include short inter-pregnancy intervals, and maternal hospitalization with infection during pregnancy (Lyall et al., 2017). Additionally, prenatal exposures to illicit substances, anti-epileptic medication such as valproate, or environmental toxins found in air pollution have also demonstrated increased risk of ASD or autistic traits (Karst & Vaughan Van Hecke, 2012; Lyall et al., 2017).

The American Psychiatric Association (APA, 2013b) describes ASD as a neurodevelopmental disorder that results in a spectrum of (dis)abilities for the child. The onset of symptoms is commonly seen in early childhood, typically before 3 years of age, with more recent studies suggesting symptoms can emerge from 6-18 months of age (Szatmari et al., 2016). ASD is defined as "persistent deficits in social communication and social interactions across multiple contexts" (APA, 2013a, p. 31). In 2013, the Diagnostic and Statistical Manual of Mental Disorders' (DSM-5) standard of diagnosis for ASD was updated and became an umbrella term to include four separate disorders: autistic disorder, Asperger's disorder, childhood disintegrative disorder, and pervasive developmental disorder (APA, 2013a). The changes aimed to simplify the diagnosis process, while also retaining its sensitivity (APA, 2013). The DSM-5 definition for ASD is the standard used in Canada, and is comprised of three criteria:

1) Social-emotional deficits in social, emotional or conversation interactions

2) Non-verbal communication behaviour deficits that are used in social interaction

3) Difficulty understanding, developing, and maintaining relationships

In addition to the three criteria, the criteria for diagnosis determines the severity levels of two other domains; these levels of severity reflect the level of support required to manage the limitations in an individual's life. Domains include:

- The level of severity of restricted, repetitive patterns of behaviour, demonstrated by preoccupation with parts of objects, rigid routines and rituals, and repetitive motor mannerisms, and
- The level of severity of social communication impairments, demonstrating an inability to develop relationships with peers at the appropriate developmental level.

Once demonstration of the three criteria and specified severity is established, the diagnosis may be accompanied by intellectual or language impairments and associated neurodevelopmental or medical conditions.

Along with the formal diagnosis and its level of severity, children with ASD can also experience co-morbid medical conditions and systemic difficulties linked to sensory impairments, gastrointestinal problems, sleep difficulties, and immunity problems (Lyall et al., 2017). Challenges with attention, anxiety, and depression can further affect sleep patterns, which in turn exacerbate attention capacity (APA, 2013b). The next section will discuss ASD intervention and medical management of its comorbidities, followed by a discussion of factors that may lead to delayed intervention, and its health impacts on the family.

ASD Medical Management

The goal of interventions and treatments are to maximize the child's quality of life, improve family function and independence, and minimize the core features of ASD (Earles & Currie, 2011). Depending on a child's needs, intervention can include a single form of therapy, or a combination of multiple treatments. Generally, most interventions aim to address the impairments defined within the DSM-5, including social-emotional abilities, communication, and relationship skills (APA, 2013a). Using speech-language pathology and occupational therapy, communication interventions often focus on the nuance of language and interpretation, expression, or where possible, finding ways for the non-verbal child to effectively communicate (APA, 2013a). Behavioural interventional approaches also focus on developing body movement, exploring ways in which to promote attention capacity, and managing expressive outbursts (Earles & Currie, 2011). Social aspects of management build on drawing the physical, speech and language, and behavioral therapies together to help the child to build friendships and community (Earles & Currie, 2011). Complementary alternative medicine (CAM) such as music activities, arts or pet-based therapies are incorporated into treatment approaches (Earles & Currie, 2011; Hennel et al., 2011). Finally, cognitive skills are enhanced with tailored approaches to learning based on assessment of the child's learning capacity and capability (Earles & Currie, 2011). In supporting the child through various interventions, social and behavioural issues linked to physical wellbeing can be addressed; for example, aggression, self-injury, eating, sleeping, and toileting (Earles & Currie, 2011).

Children receiving intensive intervention during the early stages of childhood i.e. before the age of five, demonstrate better outcomes of treatment. Benefits include improved cognitive, language and adaptive behaviour (Elder, Kreider, Brasher & Ansell, 2017). Such improvements have a positive impact on the child's adaptive functioning in their daily living skills and social

behaviours (Elder et al., 2017). In contrast, later intervention correlates with decreased functioning and quality of life as children enter adulthood (Gardiner, 2014).

Children with ASD often need additional medical treatments aimed at managing associated physiological symptoms i.e. gastrointestinal (GI), sleep, and seizure (Earles & Currie, 2011). For children with ASD the combination of altered muscle tone, motor difficulties, sensory challenges, hyposensitivity to rectal sensations, and food selectivity commonly result in GI disturbances (Weill et al., 2018). Constipation can be a cumulative factor in changes to behaviour, toilet training, pain, and food intake, therefore it warrants early management. This brings additional burdens for parents, since the child with ASD may be reluctant to take medications or experience food and fluid aversions (Memari, Ziaee, Mirfazeli & Kordi, 2012). Disordered sleeping patterns and epilepsy are other possible comorbidities associated with ASD (Accardo & Malow, 2014). Current medical opinion offers that the association between ASD sleep and seizure activity relates to atypical neurodevelopment (Accardo & Malow, 2014). Insomnia, which is commonly seen in children with ASD, can have consequences on a child's learning, mood and behaviour, while also "lower[ing] the threshold for seizure in persons with epilepsy" (Accardo & Malow, 2014, p. 203). In addition to the child's sleep deprivation, parents often experience a lack of sleep as a result of needing to supervise their non-sleeping child (Accardo & Malow, 2014).

Holistic management of the child with ASD is complex. Treatments, both medically and behaviourally, have the capacity to enhance the child's long-term outcome and their families' quality of life. Access to services can be costly and limited with issues linked to rurality (O'Neill, Koehn, George & Shepard, 2016). In British Columbia (BC), government funding for interventional services is approved after a child receives an ASD diagnosis (Ministry of Children and Family Development [MCFD], 2017). However, funding for treatment decreases

dramatically after the age of six. Before six years old, families are provided \$22,000 CAD a year for intervention services, therapies, and parent respite. Funding goes towards a variety of services, depending on the child's individualized care plan and family decision-making. Services can include caregivers, therapists, specialty programs, or equipment. After the age of six, and until the age of 18, funding is reduced to \$6,000 a year. This funding cutback occurs when the child enters the education system, which becomes the expected primary source of interventional services. Children diagnosed at a later age therefore risk losing the funding that is imperative to early interventional treatment and therapy. The next section will discuss factors contributing to later diagnosis.

Factors Contributing to Late Diagnosis and/or Intervention

As a result of the complexities and length of time from first identifying concerns to diagnosing a child with suspected ASD, Canadian children typically receive a diagnose around the age of four (Zwaigenbaum et al., 2015). The current position behind understanding why there is variation behind delayed diagnosis is multifactorial (Mandell, Novak & Zubritsky, 2005; Roux et al., 2016; Siklos & Kern, 2007). For example, missed opportunities may be caused by gender expectation and distribution. With a higher prevalence of ASD in boys, symptoms in females are often not recognized, resulting in a delayed or even missed diagnosis (Siklos & Kern, 2007). In first time parents, children may receive a later diagnosis due to 'new parents' being unfamiliar with expected developmental milestones, remaining hopeful that their child will 'grow out' of the behaviours that they are witnessing, or not yet trusting their intuition (Bickel, Bridgemohan, Sideridis & Huntington, 2015; von Tongerloo et al., 2015).

Access to services can also be a confounding factor in timely diagnosis, since children

living in rural areas¹ may receive a diagnosis up to 0.4 years later than their urban counterparts, due to decreased resources or limited professional expertise in observing and identifying children with suspected ASD (Mandell, Novak & Zubritsky, 2005; Roux et al., 2016). A lower socioeconomic status is also noted in children who receive a later diagnosis than their more affluent counterparts (Fountain, King & Bearman, 2011; Mandell, Noval & Zubritsky, 2005).

Current ASD research may contribute to variation in evidence-based practice, and generate delays in ASD diagnosis. Most studies looking to identify at-risk children are retrospective (Zwaigenbaum et al., 2009). Retrospective studies include observing home videos of children diagnosed with ASD, and listening to parent historic reporting of their observations and experiences prior to their child's diagnosis (Zwaigenbaum et al., 2009). Retrospective studies provide a limited source of information, because of the potential inaccuracies from poor recall, misclassification of information, or biased selection of information (Sauerland, Lefering & Neugebauer, 2002). More recent research focusing on earlier identification of ASD in younger children is prospective, and includes surveillance of developmental delays, and closer monitoring of children with ASD siblings (Zwaigenbaum et al., 2009). At the time of this review, prospective research remains limited; therefore both retrospective and prospective studies continue to be used to guide clinician practice in early childhood ASD recognition. The ongoing gaps in research and its limitations are therefore reflected in the gaps in primary care that lead to delays in attaining earlier diagnosis and intervention.

¹ Rural communities can be defined as small populations spread over large distances (Smalley & Warren, 2012). Rural populations face challenges of geographical barriers and limited human resources, creating a barrier accessing primary care (Smalley & Warren, 2012)

The Health Impact of ASD on the Family

The impact of ASD affects both the child and their parents. 'Parents' is used to encompass all terms that describe the person(s) raising a child with ASD. Related terms include mother, father, family, or caregiver. Compared to caring for children other developmental disabilities such as Down Syndrome or Cerebral Palsy, parents of a child with ASD report lower quality of life scores (Gardiner, 2014). Brown, MacAdam, Crisp, Wang and Iarocci (2006) report that less than 50% of parents with children with ASD reported satisfaction with key aspects of quality of life linked to their careers, leisure time, and community engagement (as cited in Gardiner, 2014, p.21).

Parents first describe overwhelming negative emotional experiences beginning as soon as they sense something 'different' about their child (Bloch & Gardner, 2007). Parents describe confusion, fear and grief during and after the ASD diagnostic process (Bloch & Gardner, 2007; Mulligan et al., 2011). Physically and emotionally for parents the high demands of having a child with ASD can result in general physical and mental fatigue (Karst & Vaughan Van Hecke, 2012). Such a combination of factors results in parents of ASD children experiencing increased marital strain and increased rates of short- or longer-term clinical depression as compared to parents of children with any other developmental disability (Blackledge & Hayes, 2006; Gardiner, 2014; Karst & Vaughan Van Hecke, 2012). The impact of ASD on children and their parents can be further complicated by its associated comorbidities, such as obesity, anxiety disorders, sleep disorders, and Attention-Deficit Hyperactive Disorder (ADHD) (Memari, Ziaee, Mirfazeli & Kordi, 2012). In addition, any ongoing lifestyle presence of harmful factors such as substance abuse, linked to higher risks of having a child with ASD, may continue to negatively impact the physical and mental health of parents (Karst & Vaughan Van Hecke, 2012).

A key aspect of parental stress is linked to limited access to services as described by Gardiner (2014), reporting that families of children with ASD have both unmet service referral needs and unmet family support requirements. The financial burden associated with intervention cost is also exacerbated by the time parents have to take to attend appointments, distance to travel, and need for transport, which can result in loss of earnings (Cidav, Marcus & Mandell, 2012). For marginalized populations such as children and their families living in rural communities, care is compounded by poor accessibility to necessary resources, which includes rugged geographical landscapes affecting commutes to appointments, long distances, and unavailable human resources (Mandell, Novak & Zubritsky, 2005). The risk of health care isolation is also increased in families from different cultures, single parents, teen parents, low parent education, or parental depression, who may be unaware or underexposed to available resources (BC Ministry of Healthy Living and Sport, 2009).

Initially, many parents report low confidence in their knowledge of childhood development and cite the PCP as their primary source of information (Hennel et al., 2016). Conversely, some parents report that as they navigate the challenges of seeking a diagnosis or following a new ASD diagnosis, they feel dismissed or unsupported emotionally by their PCP, which contributes to their burnout (Bloch & Gardner, 2007; Gardiner, 2014). Following diagnosis, parents feel dissuaded when faced with either limited intervention resources within their community, or when primary care providers are unable to help them navigate and access timely treatment interventions (Mulligan et al., 2011).

As parents become experts in the care of their child, they report feeling that their capabilities go unrecognized by PCPs, which results in parents no longer seeking their PCP support, even during times of need (Carbone et al., 2010). Children with ASD are therefore less likely than other children with medical conditions to have a medical home (Brachlow, Ness,

McPheeters & Gurney, 2007). The medical home and robust relationships with health care providers are associated with better access to specialty services, improved patient outcomes and satisfaction, and decreased cost of care (Brachlow, Ness, McPheeters & Gurney, 2007). Therefore, a strained or fragile relationship between parents and health care providers can impact the overall health outcomes of the child, particularly if their care requires access to specialists, or specialty services. To better understand impacts on the parent-PCP relationship, the following sections will describe the PCP role during early childhood development and during ASD identification, referral and diagnosis.

The PCP Role in Early Childhood Development and Promoting Early ASD Identification

Early childhood is described as the first five years of a child's life and is valuable in children's cognitive and social skill development (WHO, n.d.-a). Many determinants influence a child's early development such as: environmental factors including housing, socioeconomic status, family education/literacy; biological factors such as gender, prenatal health, and nutrition; interpersonal relationships including social networks, parent styles, peer-to-peer interactions; and early childhood experiences including parent-responsiveness, trauma, and participation in physical and cognitive learning activities (Weins, 2014). Considering the value of early childhood the early recognition of ASD signs provides better opportunities to influence the child's neurodevelopment, and minimizing ASD's limiting impairments in social-emotional interaction, communication, and relationships. PCPs are therefore influential in early childhood development, as they have a role in general developmental surveillance, screening for ASD red flags, and completing regular health checks for all children under their care.

Both the Canadian Paediatric Society (CPS) and the BC Government guidelines recommend an enhanced assessment to identify concerns or promote positive health behaviours

that may enhance childhood development, and to look for specific milestones at 12, 18 and 24 months (Williams, Clinton & CPS, 2011; MCFD, 2017). The suggested visit at 18-months includes a health supervision guide such as the Rourke Baby Record, a developmental surveillance tool, screening for parental morbidities, promotion of early literacy activities, and information on community-based early childhood resources (Williams, Clinton & CPS, 2011). In Canada, children also expectantly encounter a health care provider or PCP at 18-months for scheduled immunizations (Williams, Clinton & CPS, 2011). However, children may not routinely see a PCP again until scheduled immunizations prior to beginning kindergarten at age five, which are often completed by public health nurses (PHNs) (Williams, Clinton & CPS, 2011). Within this gap, there is risk for missed opportunity in identifying or addressing developmental concerns. The onus is therefore often left on the parents to proactively call and book appointments for their children should they have concerns. However, the complexity of noting ASD signs remains difficult in the early years, and although symptoms can be recognised as early as 18 months, only 20% of children are identified before the age of 3 years (Guthrie, Swineford, Nottke & Wetherby, 2013). Therefore, current approaches to routine PCP 'development checks' are complex and varied, dependent on human resources and developmental knowledge of health care providers and parents.

Identifying young children in primary care, that either presents or are referred i.e. from public health nurse with suspected ASD, requires the PCP to be adept in a range of skills. The PCP needs to be competent in completing scheduled and timely developmental check-ups, reviewing antenatal and family history, eliciting, listening to, and appreciating parental concerns, and visually assessing the child in the clinic setting (Weill et al., 2018).

More recently, The Canadian Task Force on Preventive Services does not recommend universal screening for ASD (CTFPS, 2016); however, if ASD is suspected, focused screening is

advised. The PCP must be able to access and apply ASD-specific screening tools with skills, capacity, and confidence. There are numerous ASD screening tools; for example, the Modified Checklist for Autism in Toddlers, Revised (M-CHAT-R) (see Appendix A) is an efficient and evidence-based tool, commonly used in Canada that can be completed by both parent and PCP (Weill et al., 2018). Examining the sensitivity and specificity of such tools and knowing when to most effectively apply these in primary care practice is outside the scope of this paper. However, the PCP must have awareness and up-to-date training on how to use such tools to ensure that comprehensive surveillance and screening is completed in a timely manner, avoid jumping to conclusions, and link clinical impression with intuition and parent history (Anagnostou et al., 2014).

The PCP Role in Early Referral and Following an ASD Diagnosis

Once ASD is suspected, attaining a diagnosis follows a certain assessment protocol. The PCP's primary role is to facilitate the referral process, often to a pediatrician or a specialist multidisciplinary team. Once the PCP initiates a referral process, as well as an audiology evaluation, they are expected to provide parent direction towards early intervention (Earles & Currie, 2011). If the PCP has concerns that include global or neurological delays, appropriate referrals are made to the necessary specialists (neurology, etc.) (Earles & Currie, 2011). Once referral is received, a specialized multidisciplinary team completes a formal diagnosis for ASD. The assessment includes a formal psychological assessment, speech-language-communication assessment, and a medical evaluation (Dua, 2003). The multidisciplinary team may include a paediatrician, clinical psychologist, child psychiatrist, and speech-language pathologist and/or occupational therapist (Dua, 2003). Additional assessments may also include a comprehensive family assessment (Dua, 2003).

With the recent simplification via DSM-5 ASD diagnostic criteria, there has been a growing body of research dedicated to improving early diagnostic process and assessment policy (Penner, Anagnostou, Andoni & Ungar, 2018). However, the process still remains time-consuming and complex. In BC, the wait time for a formal assessment and diagnosis following PCP referral is over 55 weeks, often leaving parents in a "grey zone" of waiting and uncertainty (Provincial Health Services Authority [PHSA], 2018).

Following diagnosis, the CPS and BC guidelines recommend that the PCP provide parents with ASD information, help parents to network with their provider/peer community, and facilitate links between the education system, financial assistance, and diagnostic/treatment resources. The CPS further recommends PCPs become advocates for change by campaigning for improved early childhood resources in their community by using standard guidelines and fee codes in their province for the 18-month enhanced visit (Penner, Anagnostou & Ungar, 2018) promoting the well child visit to colleagues, and supporting research and pilot programs (Williams, Clinton & CPS, 2011). Finally, it is recommended the PCP collaborate with disciplines in the health and educational sectors to provide coordinated, comprehensive care for the child with ASD (Carbone, Behl & Azor, 2010). The following section aims to highlight the current PCP gaps and system challenges in light of the recommendations outlined by the Canadian Pediatric Society (Williams, Clinton & CPS, 2011).

Exploring the Gaps in the PCP Role

Despite guidelines being in place, there continues to be delay in obtaining ASD diagnosis for younger children in both urban and rural settings (Penner, Anagnostou & Ungar, 2018). The rationale for delays, difficulties, and barriers to care are complex and are highlighted in Table 1.

Table 1PCP causes for delay

- PCPs not feeling confident in voicing concerns about a child suspected of ASD to parents, which results in delayed referral (Unigwe et al., 2017).
- High healthcare environment contact can result in difficulties in the relationship between PCP and parent (Bultas, Johnson & Reinhold, 2015).
- PCPs reporting feelings of discomfort and unfamiliarity with the complexity of referral process (Anagnostou et al., 2014, Figure 1).
- Hesitancy to refer due to the long waitlists, which result in cumulative delay; in BC, the waitlist for evaluation is up to 54 weeks (PHSA, July 2018).
- Anxiety linked to understanding how to support young children and their parents during the 'waiting phase' for assessment and diagnosis. (Unigwe et al., 2017)
- Limited community resources, uncertainty linked to the quality of local, provincial and wider support networks (Unigwe et al., 2017).
- Other organizational factors (Penner, Anagnostou & Ungar, 2018).

In summary, available guidelines clearly describe the PCP role in surveillance, screening, and referral (Dua 2003; MCFD, 2017; CTFPS, 2016; Penner, Anagnostou & Ungar, 2018); however, the difficulty for the PCP lies in how to support young children and their families while awaiting diagnosis, and during the initial phase of a new diagnosis, when parents are still inexperienced, and the risk of delayed assessment and intervention is high. There remains little information, vague instruction, and contradictory advice for the PCP in this role (Mulligan et al., 2012). Considering the emotional turmoil that parents face during this time period, it is imperative that PCPs have a better understanding of their role and strategies that may support parents during this time period. Therefore, establishing a healthy relationship with parents early in the process of ASD diagnosis can positively benefit the child's future care and quality of life (Carbone et al., 2010).

Patient and Family Centered Care

A knowledge gap of how primary care providers can support the parents of children awaiting a diagnosis of ASD exists. How the PCP establishes a partnership with parents at this time of uncertainty can significantly impact future parent empowerment. An example of a health care model which can help to build a collaborative partnership between healthcare providers and parents of younger children with ASD is patient and family centred-care (PFCC) (Christon et al., 2015). PFCC² is described as a model of health care service delivery, grounded in a collaborative partnership between the family, patient, and provider (Arango, 2011). It is based on respect for family, and uses open, honest communication (Pelzang, 2010). The overarching objectives behind PFCC are to co-create a foundation of understanding, reciprocity, and engagement in all aspects of planning and providing safe informed care with children and their families. This collaborative model values respecting the strengths and abilities that each member brings to the relationship and encourages active participation in timely information sharing between the provider and family, to promote informed decision-making (Arango, 2011). For the purpose of this review, the principles of PFCC are adapted by Pelzang's (2010) model and are described in further detail in Table 4 (pg. 55).

Antecedents of PFCC include the willingness to be involved in client care from both the family and the provider (Hutchfield, 1999). In addition, PFCC requires adequate time to provide quality care; for example, creating time within an appointment for the provider to explain health conditions, and to listen effectively to family concerns (Hutchfield, 1999). Providing care through a PFCC lens offers positive outcomes for families with children suspected of ASD (Hutchfield, 1999). As previously noted, obtaining a diagnosis of ASD for a child is a very stressful experience (Bloch & Gardner, 2007; Hennel et al., 2016; Mulligan et al., 2012). Use of a PFCC model can help to address stressors by exploring and demonstrating empathy, and enabling communication in support of parents and their younger children. Parents of children with ASD

 $^{^{2}}$ For the context of this paper Patient and family centred care will be used to offer clarity. While discussion in the literature focuses on the merits of PFCC, FCC and CCC (child centred care), a detailed review of the theoretical positioning is outside the scope of this paper.

experience caregiver burnout, struggling with the decision-making and coordination involved in their child's care (Bloch & Gardner, 2007). At times, many parents describe frustration with complex health care systems, limited resource availability and location of services, and inconsistent information delivery (Carbone et al., 2010). The systematic approach that PFCC provides can address these challenges by building and sustaining stronger parent-PCP alliances, which enhance parent empowerment (Zajicek-Farber et al., 2015). The stresses that parents experience decreases as "family centered services improve resilience of families of children with autism" (Carbone et al., 2010, p.). Parents decision-making and decision-taking behaviours linked to intervention choice for their child can help to reduce stress. The PCP has a role in supporting parental decision-making by providing timely, transparent information to parents (Zajicek-Farber et al., 2015). However, for a PFCC approach to be successful it is important that both the parent and provider have a basic understanding of their respective roles in care (Pelzang, 2010). By aligning the perspectives of the PCP and parents, PFCC can increase the efficacy of professional time, improve family's overall satisfaction with care provided to their child, and can improve family functioning by strengthening protective factors (Zajicek-Farber et al., 2015).

Despite the benefits of patient centred models for PCP use with younger children suspected of ASD, there remains limited evidence of the translation of knowledge to practice. Regardless of model or framework, PCP strategies such as shared-decision making, supporting consistent approaches to management, and removing barriers to care, must be considered further in order to deliver quality care with younger children suspected with ASD. The PCP needs to have knowledge, skills, and be adept in their clinical judgement. When parents are in an anticipatory stage following identification of suspected ASD and newly confirmed diagnosis, PCPs are ideally positioned to support and guide these parents, while establishing rapport, affirming respect and dignity, and facilitating collaborative care for the child and family. As a result of reviewing the general literature linked to the challenges linked to understanding the PCP role in early childhood ASD, the following question was formulated within the context of this literature review: "What are primary care strategies for supporting the parent(s) of children aged 18-36 months with suspected ASD?" The following chapter will discuss the literature search methods used to explore this question. The following methods chapter will examine in detail the approach adopted to explore the topic area in greater depth.

CHAPTER TWO: METHODS

This chapter will discuss the literature search strategies used to select the final articles chosen for analysis. The purpose of this integrative review was to examine the primary care provider role (PCP) in supporting parents with young children suspected of ASD. The question that was formulated in order to answer this question was "What are primary care strategies for supporting the parent(s) of children aged 18-36 months with suspected ASD?" In order to explore this topic area, a review of the current literature was warranted. Since various methodological approaches have been used to explore these phenomena, an integrative literature review methodology was chosen, as this approach synthesizes literature from various research methodologies (Whittemore & Knafl, 2005). Study methods may include quantitative, qualitative and mixed methods (Whittemore & Knafl, 2005). The purpose of an integrative review is to provide a more comprehensive examination of the "phenomenon of concern", as it includes a variety of perspectives, concepts, theories and evidence that can more accurately portray the complexity of an issue (Whittemore & Knafl, 2005, p.547). Multiple approaches have been developed to guide the process of an integrative review, however the framework provided by Whittemore and Knafl (2005) is used to guide this review. Preceding chapters in this review have outlined the complexity of issues faced by both primary care providers and parents when ASD is suspected or newly diagnosed in a young child resulting in a focused question. This chapter will provide a comprehensive explanation of the methodology used in the literature search stage to acquire the articles for data analysis. As described by Whittemore and Knafl (2005), the literature search stage is led by a comprehensive examination of the themes that exist within the research question. The subsequent chapters will then address the next stages of the integrative review. "Chapter 3: Findings" will detail a data analysis of the chosen articles; "Chapter 4: Discussion" will provide an overall presentation of the data analysis, and "Chapter 5: Recommendations" will

provide detailed recommendations for practice, based on themes and discussion acquired with the data and its analysis.

Inclusion and Exclusion Criteria

Inclusion and exclusion criteria were created to provide a focused literature search. These criteria were created to include publications related to themes within the review question, such as targeted population age and health care setting, while excluding publications that were unlikely to provide relevant information related to this review's question. Sources from a 12-year period i.e. published from 2005 to 2017, were included for review. These dates were chosen to keep content relevant, while also capturing a sufficient breadth of material; moreover, increased interest in ASD research in the early 2000s is demonstrated in the increased quantity of research publications available after 2005 (Interagency Autism Coordinating Committee, 2012). Sources needed to be written in English, from America, Western Europe, and Australia. The rationale for English as the dominant language is that populations in these countries share similar health care culture and social demographics with Canada. All study populations with children between the ages of 18 to 36 months were included, as these ages reflect when ASD is earliest and most commonly suspected. Studies completed in acute or specialized care settings were excluded, as findings within these settings were less likely to apply to the primary care provider. Studies that focused on screening tools, school-related issues, ASD comorbidities or medical care were also excluded, as their studies were too broad for the scope of this review. Table 2 summarizes the inclusion and exclusion criteria of the literature search.

Table 2Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria	Rationale					
Written after 2005	Written before 2005	Keeps content relevant					
In English or translated to English From North America, western	In other languages From other countries	Able to understand Countries with similar health					
Europe or Australia		care culture					
Published in academic journals, peer reviewed or dissertations	Editorials, opinion pieces, unpublished, magazines	Sources are of evidence based research					
Inclusive of systematic reviews, integrative/literature reviews, quantitative and qualitative		research; covers multiple aspects of research topic					
Relevant abstract and title	Irrelevant abstract and title	Topic relevance					
Age: 18-36 months	Age: less than 18 months, older than 36 months	Recognition, assessment, referral and diagnosis typically happen around age of 2; very limited evidence available on younger than 18months					
Primary care setting	Acute care setting	Focus is in primary care					
Nurse practitioners, family physicians, primary care paediatricians	Acute care providers; educators/teachers, speech therapy, nurses	Health care focus: Any PCP practice is relevant to the FNP role					
Autism Spectrum Disorder, Asperger's	Cerebral palsy, FAS	May change based on research availability?					
Studies focused on role in referral, screening, diagnosis, red flags, suspected ASD, early management	Methods of treatment (screening tools), co- morbidities (insomnia, GI issues, ADHD), medical care for ASD children, school- related issues	Focus is on suspicion, recognition, assessment and referral					

Preliminary and Secondary Search

A preliminary search was conducted in September 2017 to provide a better understanding of the key words and ideas within the research question. Using a concept map, relevant ideas and terms were developed into keywords (see Appendix B). Keywords were then used within the selected search engines (see Appendix C). Final subject headings were chosen based on suggested MeSH terms that represented the themes of the research question. These databases organize sources based on these subject headings, subheadings and publication types; therefore, using these terms was more likely to generate a higher yield of relevant literature. The terms were searched in each database in a series of combinations using the Boolean operators "AND" and "OR". A summary of the key word search terms and Boolean combinations used are summarized in Table 3 and Appendix C, respectively.

Table 3

Seurch Terms. Mit	ajor Concepts, mes	in Terms und Subje	ci meuuings	
Autism	Provider or	Parent	Primary Care	Databases
	Setting		Strategies	
Autism	Primary care	Parent	Screening	PsycInfo
Spectrum				
Disorder	Nurse	Caregiver	Surveillance	Medline
	practitioner	-		
Autism	-	Family	Referral	CINAHL
	Family	-		
Autistic	physician		Diagnosis	
Disorder			-	
	Pediatrician		Intervention	
	Professional-			
	family relations			

Search Terms: Major Concepts, Mesh Terms and Subject Headings

Electronic databases selected from the University of Northern British Columbia library included: CINAHL, Medline, and PsycInfo. These databases were chosen because they were most likely to have content related to primary care, health care, and developmental health. The preliminary search from these databases yielded 240 results. The results were then handsearched. Five articles were chosen after applying inclusion and exclusion criteria and based on relevancy to the research question.

Following the preliminary search, eight additional search terms were added, to focus on the relationship between the parent and provider (see Appendix C for all search terms and combinations). Search terms related to screening and surveillance was removed. Following the same strategy detailed in the preliminary search, the databases yielded 454 results. After applying inclusion and exclusion criteria and hand-searching titles and abstracts for relevancy, another five articles were chosen for analysis. Figure 1 illustrates the full search in a flow diagram. References of the final ten articles were also examined. Three additional articles fulfilled the criteria review; however, after more detailed review, these three articles were excluded from final analysis and were used for providing supporting background information only. Therefore a total of ten articles were included for this review.

Figure 1. Search Results



Grey Literature and Supporting Literature

Cochrane, Clearinghouse, and Joanna Briggs electronic databases were searched within the same timeframe between November and December 2017, using only the search term "autism spectrum disorder". From these databases, only two guidelines were found that related to the population or themes of the research question (Canadian Task Force on Preventive Services [CTFPS], 2016; National Institute for Health and Care Excellence [NICE], 2017). Although these guidelines are used as supportive literature, they were not included in the total findings, as their information was too vague to apply to the primary care role. Additional grey literature and supportive literature were collected through a variety of databases including Google Scholar, and the Autism Community Training (ACT) Database. Finally, thesis completed by graduate students were found in the Open Access Theses and Dissertations (OATD) database, and were used as supporting references.

Data Analysis

After the review, the final sample included five (50%) qualitative studies, four (40%) quantitative studies and one (10%) mixed-methods survey. The articles were read and analyzed using a systematic tool, Critical Appraisal Skills Programme (see Appendix D) (February 2018). This tool, when applied, supports the reviewer to summarize each study, measure study quality and bias, consider overall relevance to the question, and identify recommended implications for practice. Although several studies contained bias in their method of study (i.e. parent interviews), all article data contributed equally to analysis, as personal experiences still provided applicable implications to PCP practice. Once the articles were measured for their quality and relevance, data extraction from the publications were added to a literature matrix (see Appendix E). Categories within the literature matrix included author and title, study design and summary, key

recommendations and implications to practice, and study gaps/limitations. Within recommendations and implications, definitions, antecedents, consequences and facilitators of parent-PCP relationships were considered. Once the matrix was completed, related terms in the matrix were extracted and grouped into common themes. For example, terms such as listening, approaching difficult topics, and emotional support were concepts grouped under the overarching theme of "communication". These themes were then reviewed with each primary source to ensure congruency. Throughout the data analysis, the Patient Family Centred Care (PFCC) model was identified as a conceptual framework that provided a logical structure for the themes to relate to one another, while also specifying concepts that addressed this review's question. A conceptual framework is "a structure of what has been learned to best explain the natural progression of a phenomenon that is being studied" (Grant & Osanloo, 2014, pg. 17). The themes were organized within the PFCC framework to better understand the relationships between the connected concepts. These themes will be explored within the PFCC framework in the following Chapter; Findings. The themes, and their implications on future practice, will be further explored in relation to each other through epistemological and ontological worldview perspectives in the final Chapter; Discussion (Grant & Osanloo, 2014).
CHAPTER THREE: FINDINGS

This integrative review examines the primary care provider role in supporting parents with young children suspected of ASD, using the formulated question: "What are primary care strategies for supporting the parent(s) of children aged 18-36 months with suspected ASD?" The previous chapter outlined the search process and data analysis used to answer this question. Once a search and review of the literature was completed, the common themes of the chosen studies were examined at a latent level (i.e. identifying underlying patterns, ideas, and assumptions (Braun & Clarke, 2006). This chapter will report the findings from the analysis of the themes and subthemes, including an examination of the underlying ideas, assumptions and concepts of each theme identified.

Ten articles fulfilled the criteria from the literature search to answer the research question. Appendix E provides a literature matrix that details the methodology, sample size, quality, key findings, gaps and limitations of each article. The literature eligible after review, synthesis and analysis included five (50%) qualitative studies (Bloch and Gardner, 2007; Carbone, Behl, Murphy and Azor, 2010; Hennel et al., 2016; Mulligan et al., 2012; Rhoades, Scarpa and Salley, 2007), four (40%) quantitative studies (Barbaro and Dissanayake, 2010; Carbone, Norlin and Young, 2016; Feinberg et al., 2016; Monteiro et al., 2015) and one (10%) mixed-methods study (Garg et al., 2014). All of the qualitative studies retrospectively interviewed parents on their experiences with primary care providers (PCPs) during their child's ASD diagnosis. The quantitative studies explored the benefits of additional ASD training for PCPs, as well as surveillance and routine monitoring for children suspected of ASD. The mixed-methods survey explored education for PCPs on ASD identification. Three studies were conducted in Australia (Barbaro and Dissanayake, 2010; Garg et al., 2014; Hennel et al., 2016), one study was conducted in Canada (Monteiro et al., 2015), and six studies were conducted in the USA (Bloch

and Gardner, 2007; Carbone, Behl, Murphy and Azor, 2010; Carbone, Norlin and Young, 2016; Feinberg et al., 2016; Mulligan et al., 2012; Rhoades, Scarpa and Salley, 2007).

As a result of following the thematic analysis approach outlined in Chapter two, two overarching themes were identified from the literature, and will be reported in this chapter (Braun & Clarke, 2006). The overarching themes and supporting subthemes are as follows:

a) Primary Care Provider Knowledge – three subthemes within this theme include acquiring information, personal factors, and team/model of care factors; at times, these subthemes may appear to overlap, however each subtheme brings a key element to supporting the complexity and significance of PCP knowledge as an overarching theme.

and

b) Communication – the concept communication is very broad; however, specific aspects surrounding communication were identified in the literature. Therefore, features of the theme are focused into four subthemes, including: Information sharing, listening, repeated interactions, and approaching difficult subjects.

Primary Care Provider Knowledge

To provide an overview of the theme PCP knowledge, there were various complexities and patterns that emerged on analysing the literature. Increasing PCP knowledge was the dominant focus across all studies as linked to various aspects of knowledge acquisition or enhancement. In the first subtheme, acquiring information, Bloch and Gardner (2007) and Carbone et al. (2010) identify the need for general early childhood development knowledge, through empirical training and education, in order to improve timely access to ASD diagnosis. Both Bloch & Gardner (2007) and Carbone et al., (2010) recognise the value of time needed for the PCP to learn about ASD presentation and management. However, for the PCP, time can be

limited, as a result of health care demands, yet it must be factored in organizationally when caring for children with suspected ASD to inform efficient, effective decision-making. In the second subtheme, personal factors, multiple studies identified personal factors of the PCP that contributed to increasing knowledge about ASD and its management. Personal factors include the PCP's willingness to learn and participate, and the impacts of their perceived self-efficacy on the child's continuity of care and the parents' perceptions of care (Carbone et al., 2010; Carbone Norlin & Young, 2016; Garg et al., 2014; Monteiro et al., 2015). In the final subtheme, team/model of care factors, Barbaro and Dissanayake (2010) and Feinberg et al. (2016) identify the value of increasing knowledge across the multidisciplinary team, within a health care model that provides focused training and better role clarity.

Acquiring information. Bloch and Gardner's (2007) exploratory survey primarily explored the parent burden experience. Their findings drew attention to the role PCP education had in facilitating parental caregiving capacity. Six mothers, recruited through purposive sampling, were informally interviewed and audiotaped, which was then analyzed with comparative analysis and triangulation. The authors found that parents believed that PCPs needed a general knowledge base about ASD in order to proactively guide clinical encounters and gather appropriate information resulting in timely referral and diagnosis (Bloch & Gardner, 2007). Parents reported that PCPs were not likely to have a comprehensive understanding of ASD deficits, and that "most of the practitioners gave advice that demonstrated little comprehension of the real problems faced by parents of a child with ASD" (Bloch & Gardner, 2007, p. 14). In addition to a PCP knowledge deficit of problems that parents may face, parents also pointed out that short appointment times limited the PCP's ability to acquire an in-depth understanding of the child, as well as missed opportunities to explain or teach child development check ups to parents. Such patterns of time limiting behaviours resulted in parents feeling rebuffed, as one mother

stated "Healthcare practitioners have limited contact time with the child. They don't understand the subtleties of why things are difficult." (Bloch & Gardner, 2007, p.13). This study provided an important opportunity to advance understanding of the impact PCP education has on facilitating and encouraging parent's engagement in consultations. The PCP is required to have a basic knowledge of ASD as well as detailed knowledge of normal developmental stages. Being able to draw these two aspects together in short appointment times can help parents to articulate developmental concerns about their child (Bloch & Gardner, 2007). PCP opportunities to attend quality training that promotes enhanced learning about ASD can result in heightened observational skills. Such skills can then be translated to clinical practice so that the PCP can make better use of the limited timeframe available during appointments spent with a child suspected of ASD (Bloch & Gardner, 2007).

Carbone, Behl, Azor and Murphy's (2010) used two separate focus groups to interview five parents and nine primary care providers to elicit their perspectives of how medical home setting are environments which can identify the unmet needs of a child with ASD. This qualitative study used an exploratory analysis. Similar to Bloch and Gardner (2007), this study highlighted that gaps in PCP knowledge impacted on ASD care. By missing opportunities to explore developmental concerns, indicate a need for service, or enhance parental knowledge, the PCP limited parent-PCP relational opportunities. In addition, Carbone et al. (2010) identified the responsibility of the PCP to have both insight and an understanding of how these factors influenced outcomes for the child and family. Furthermore, PCPs have a duty to parents to help them navigate access to local community services and resources available to the child and caregivers. Considering the study in a little more detail, Carbone et al. (2010) used purposive sampling to recruit five parents with children ranging from ages 2 to 14 from a school specialized in ASD. In parallel, the study team recruited nine providers from primary care clinics throughout

a metropolitan area in Utah. Although the providers in this study were paediatricians, their experiences can still be reflected in family PCP experiences³. Across both author-facilitated focus groups, participants were asked to answer open-ended questions concerning the role of the medical home in ASD care (Carbone et al., 2010). The small population and retrospective nature of the study provides limitations in applicability and bias, however their findings corroborate with other studies in similar population groups, and the information remains relevant to this review's topic of interest regarding provider and parent relationships.

Parents and providers both described the importance of the provider's general ASD knowledge and ability to discuss caregiver stress and complementary alternative medicine (CAM) treatments (Carbone et al., 2010). Some parents reflected on their experiences with their providers reporting that provider knowledge of child development, surveillance, and ASD screening tools, was foundational when setting up initial interactions with them. Such patterns of behaviour from the PCP, as an information resource and partner in their child's care, influenced how these parents perceived and trusted the information their PCP shared. These initial interactions reflected a deeper and sustainable level of parent trust in their provider, an integral aspect for providing future support and care (Carbone et al., 2010).

However, throughout the interviews with parents and providers both groups recognized provider knowledge gaps; for example, the providers identified their lack of awareness in evidence-based and complementary-alternative medicine (CAM) intervention options (Carbone et al., 2010). The study demonstrated when providers failed to develop a clear and comprehensive knowledge base, this resulted in a delay in ASD assessment, screening and diagnosis. As such, delays left caregivers frustrated and disempowered, leading to a loss of trust and confidence for

³ Pediatricians working within a medical care home context draw similarities to PCP settings within Canada, specifically within rural and primary care settings. Therefore while geographically different, the model of care used in this study has resonance within a PCP context and BC practice.

some parents in their provider. This was evidenced when caregivers reported switching providers, or expressed feelings of "lowered expectations" of their providers (Carbone et al., 2010, p.320). Such assumptions made by parents are difficult for providers to recognize and also recover from, since the risk in provider swapping does not eliminate the difficulties parents are likely to experience. There is no guarantee that new providers would have a greater knowledge unless they identify as having received additional education and training. As viewed through a wider lens, the need for providers to both access training and embed knowledge is critical if they are to promote provider-parent collaboration and communicate information well in ASD care with families.

In addition to the biomedical aspects of ASD, Carbone et al. (2010) identified providers needed to have an understanding of the social and political atmosphere in the community; this included recognition of allied health care providers, community resources or lack thereof, and specialists (Carbone et al, 2010). In their study, providers had little to no communication with the wider interdisciplinary team supporting children with ASD. Although not explicitly reported in the findings of this study, their limited knowledge of community resources highlighted an absence of an effective model of care as a result of a lack of information. Effectively applied models of care encourage the collaboration of multiple disciplines, recognizing the strengths of community partnerships, and how working together can improve services when gaps in care are identified. For example, all of the providers reported attempting to connect parents with community services, yet a lack of community information resulted in providers struggling with care coordination (Carbone et al., 2010). The PCPs interviewed by Carbone et al.'s (2010) described challenges obtaining community resource information, possibly linked to time, concluding that the parents were often more knowledgeable about ASD services than providers themselves. For example, one provider clearly reported "most families know more than I know about the resources in the state" (Carbone et al., 2010, p.320). The providers described their lack

of knowledge about community resources as a barrier in supporting children with ASD and their parents (Carbone et al., 2010). Such barriers can also result in a challenge to the confidence of providers. The historical power differential between health providers and care recipients has relied on providers to be the gateway to specialist referral as well as the knowledge broker (Forrest, 2003). This is significantly challenged when parents have a deeper knowledge than health care providers, and can challenge the partnership dynamic; however, it can also motivate PCPs to seek and acquire information proactively to enhance their skills when working with this patient population.

Providers were not without 'good ideas' about how to address their information deficits. An example was to propose the development of a local web-based resource to improve provider information and knowledge. However, the providers did not offer who would create this resource, or how it could be kept current which poses as a barrier to its development and sustainability long term (Carbone et al., 2010). The suggestions offered by the providers highlighted their reservations linked to investing time in learning more about this population, likely linked to personal factors, which is considered in the next subtheme. Additionally, these findings demonstrate a lack of leadership in creating resources, which may be a pattern of behaviour noted across many organizations, when time and cost are limited.

A significant strength of this study is in its parallel interviews with providers and parents (Carbone et al., 2010). The providers reported multiple knowledge gaps about ASD. When contrasted with the parents' experiences, it highlighted how the knowledge gaps affected not only the child's unmet needs, but also the parent perceptions in provider's competence. Although both Bloch and Gardner (2007) and Carbone et al. (2010) explore themes of educational needs for PCPs, both of the studies remain limited in that they do not discuss at what point in a PCP's career the training might occur, or how PCPs could remain informed of current ASD

nomenclature. When considering other implications, their findings propose that an absence of leadership in creating or acquiring resources on ASD affects PCPs and other health care providers, who may also find such resource availability beneficial in their own practice.

Personal factors. Personal attributes of the PCP can impact their knowledge base, and their ability to share information with parents. Garg et al.'s (2014) study support PCP education that extends beyond general knowledge of ASD features. In their mixed-methods study, the authors explored subjective and objective knowledge of PCPs (n=152) in New South Wales, Australia. The study employed a true/false survey on ASD, as well as narrative reporting to measure the relevance, perceptions and self-perceived educational needs for PCPs linked to ASD (Garg et al., 2014). Although a true/false survey provides low sensitivity and specificity, the information collected remains valuable, since it originated from the perspective of PCPs (Garg et al., 2014). The population for the survey was acquired on a voluntary basis, and while it received an overall low response rate in relation to the numbers of possible providers, over 100 participants warrants inclusion of the data in this review. Of note, female PCPs and PCPs with an interest in mental and or child health were more likely to respond to the survey (Garg et al., 2014). When comparing the results of the population demographics and accuracy of the true/false survey, knowledge of ASD was inversely related with the PCPs age and number of years in practice and was enhanced by personal involvement with children with ASD or awareness of community resources (Garg et al., 2014).

According to Garg et al., (2014), specialty resource and community resource awareness improved provider confidence and the overall ASD referral process. PCPs identified their educational needs included understanding their role within the multidisciplinary team, as well as knowledge of available community resources, reporting that increased awareness of community resources was "positively associated with self-perceived competence in developmental disorders"

(Garg et al., 2014, p.7). Across the data, a pattern emerged that demonstrated PCP self-interest and motivation as key facets that drove information seeking behaviours. For example, PCPs often drew on personal experiences, and identified key needs: "[I] need to know at a very basic level, recognition and referral pathways locally" (Garg et al., 2014, p.6). As such, Garg et al.'s (2014) study is a good example of the importance of self-awareness of knowledge gaps. PCPs have a responsibility in line with professional standards to be able to recognise their limitations and examine how to meet continuing education needs. Education is not solely focused on clinical aspects of care but must consider an appreciation of how to navigate community pathways and local nuisances to improve patient access. Working in teams is an important way in which PCPs can facilitate shared learning, and enhance their skill set while challenging thinking, which in turn helps providers recognise their knowledge gaps (Garg et al., 2014).

Garg et al.'s (2014) study also identified the settings and situations where by PCPs obtain their ASD training and information. PCPs reported varying sources of knowledge, including personal interactions with ASD patients, specialists and allied HCPs; self-directed reading on ASD; paediatric specific educational programs; and local community intervention programs and websites (Garg et al., 2014). This study's findings provide a new perspective when considering PCP knowledge; namely, Garg et al.'s (2014) findings "tak[e] into account GPs own beliefs, relevance and interest in these disorders" (Garg et al., 2014, p.7). It is evident in the findings that "an increased 'interest and concern' of practitioner accounted for a large proportion of variance in their ability to identify psychiatric illness" (Garg et al., 2014, p.7) which reiterates the need for the PCP to be self-directed and responsible in attaining, and subsequently maintaining, an ASD skill set. The PCP role in ASD care is therefore, in part, self-driven, and includes the personal facets as well as the need to find both time and resource to attend ASD training (Garg et al., 2014). Similarly to Carbone et al.'s (2010) study, experience matters, since this increases

confidence and provides opportunity for PCPs to learn from prior experiences through reflection. However, this also helps the PCP recognise their limitations, which is a critical aspect of reflection; for example, in Carbone et al.'s (2010) study, a provider states that "I can't see one autistic kid for hour and a half – I don't have enough patience" (p. 319). These remarks highlight that providers, even when willing, may not have the personal capacity to engage at the levels required, and therefore must know when, and how, to seek help in order to provide quality care.

Results from the survey by Garg et al. (2014) also demonstrated that part of the PCP's knowledge was inversely related to length of time and history of experience in clinical practice. The idea that longevity in a practice setting and local population needs can enhance skills when managing commonly seen health conditions is not new (Benner, 1982). When clinical experiences are uncommon in practice, there is a risk in losing the knowledge and skillset required to identify atypical behaviours or concerns brought forward by parents (Garg et al., 2014). Such findings are of note, since for PCPs to be able to become and remain knowledgeable about early childhood ASD, how this happens in clinical practices must be considered, particularly where populations of children are low, or where PCP burnout risk is present.

Carbone, Norlin and Young's (2016) intervention study demonstrates the benefits of PCP education on enhancing PCP self-efficacy which in turn enhances the PCP's capacity and capability, i.e. their knowledge and performance in ASD screening, referral, and early management. Self-efficacy is described as one's belief in their skills or ability to carry out specific tasks (Bandura, 1977). In their cohort study, n=43 PCPs from across 26 practices, spread across the Utah state, initially reported low levels of self-efficacy in their ability to provide adequate care for individuals with ASD (Carbone, Norlin & Young, 2016). The authors found that both in-person and three to six month webinar training provided to PCPs by a paediatrician-university partnership initiative increased the frequency of screening, and also improved PCP

perceived self-efficacy in delivering ASD care (Carbone, Norlin & Young, 2016). The authors measured the PCPs self-efficacy through pre and post-surveys of perceived knowledge on ASD. Carbone et al.'s (2010) findings demonstrated that improved self-efficacy fostered PCPs selfreported ability to address developmental and behavioural concerns in children presenting with suspected ASD. This pattern of improved self-efficacy influenced other significant areas, such as: appropriate referrals, parent guidance, and support in primary care settings during ASD treatment. While Carbone, Norlin and Young (2016) were not able to determine if the detection of ASD improved via universal screening approaches, this has relevance in Canadian clinical practice. Since the Canadian Task Force on Preventive Services (CTFPS, 2016) does not recommend that health care providers provide universal screening for ASD at any age, the key, for PCPs, is to identify those at risk earlier, and to complete appropriate ASD screening. The long-term benefits for ASD training and education illuminates that investment in education, coupled with motivation to learn, has a lasting impact on knowledge retention and recall. As demonstrated in Carbone, Norlin and Young's (2016) study, these factors impacted the care the PCPs provided, i.e. their practice and education on ASD continued to provide increased rates of screening.

Two further studies highlighted how the PCP's self-perceived confidence or self-efficacy in their knowledge on ASD influenced decision-making and enhanced communication capability (Carbone et al., 2010; Garg et al., 2014). While Garg et al. (2014) found that self-perceived confidence correlated with better knowledge of ASD, Carbone et al. (2010) found that the low or diminished confidence internalized by the PCP influenced their behaviours. PCPs did not prompt questions that may help them to recognise red flags in consultations with parents (Carbone et al., 2010). Comparing these findings demonstrates how the impact of low confidence levels, even

with good knowledge level, results in children with ASD experiencing delayed diagnosis and access to treatment.

Re-framing this through a positive lens to demonstrate how knowledge improved confidence and outcome, Monteiro et al. (2015) present a retrospective chart review that suggests the positive effects of PCP ASD knowledge. Their study aimed to determine if children received ASD intervention prior to a diagnosis (Monteiro et al., 2015). The children were all under the age of five, with a mean age of 44 months at the time of diagnosis (Monteiro et al., 2015). Out of n=561 children referred to the clinic, 64% received an ASD diagnosis, and all except 5 patients received a diagnosis involving a behavioural or developmental delay including ASD (Monteiro et al., 2015). Interestingly, 89% of patients were already receiving behavioural intervention prior to a diagnosis; this contradicted previous evidence suggesting delayed intervention as a consequence of delayed diagnosis, and highlighted that formal diagnosis is not necessary to initiate intervention. Due to the retrospective aspect of the study, it was difficult to determine why or how these children were able to receive early intervention (Monteiro et al., 2015).

Speculating from the study characteristics, it is feasible that the written information provided in the study empowered parents and improved PCP confidence to start or find early intervention opportunities (Monteiro et al., 2015). Monteiro et al.'s (2015) findings suggest that PCPs who are more informed about ASD are "less hesitant to … refer to early intervention and therapeutic services while their patients are awaiting diagnostic evaluation" (p. 17). Although the findings of this study are limited due to its retrospective nature, surrounding literature supports the authors' findings that PCP knowledge improves confidence in referral, and facilitates parents to seek out interventions while awaiting diagnosis (Carbone, Norlin & Young, 2016; Garg et al., 2014; Mulligan et al., 2012).

Team and model of care factors. Barbaro and Dissanayake (2010) provide the only prospective study from the literature search. Their study provided ASD training using a developmental surveillance approach focusing on social and communication behaviours at ages 8, 12, and 24 months, to n=241 public health nurses (PHNs). These nurses were already familiar with expected childhood developmental stages since they often undertook general developmental surveillance with children in their clinics (Barbaro & Dissanayake, 2010). Training on early developmental milestones related to ASD was delivered and then applied to their routine surveillance, screening and assessment charting. Children could be directly referred to a specialized Social Attention and Communication team for comprehensive ASD assessment by the PHN if a child was deemed at-risk, with atypical signs of development after 12 months of age (Barbaro & Dissanayake, 2010). Compared to the average number of children with ASD to the general population, more children were referred and diagnosed with ASD, demonstrating improved rates of identification and referral as a result of education on early identification signs of ASD (Barbaro & Dissanayake, 2010). The authors of the study followed up on the sample population in 2017 and reported that the children referred at an early age either retained an ASD diagnosis, or continued to demonstrate delays in social and communication abilities (Barbaro & Dissanayake, 2017).

The true sensitivity and specificity of the tool used in the study could not be calculated because the entire cohort was not followed, however it was estimated as 84% and 99%, respectively (Barbaro & Dissanayake, 2010). Although this study specifically focused on the validity of a prospective tool in screening for children with ASD, it brings forth questions regarding its overall value in consideration of time, cost and education requirements for implementation, as well as its relevance to the PCP role when identifying younger children with suspected ASD. Findings of the study demonstrate that the focused education on early age

development appeared to enhance knowledge in PHNs over the course of the study. Based on these results, the enhanced knowledge acquired through the added time, cost and education on early child development, surveillance tools and screening can assist the PCP role when identifying younger children with suspected ASD (Barbaro & Dissanayake, 2010).

Of note, the referral process in many countries, including Canada, is medically directed, which means via a PCP. In Barbaro and Dissanayake's (2010) study, nurses were able to directly refer children for an ASD assessment. Within BC, only a PCP or specialist (i.e. pediatrician) can refer a child for an ASD assessment (PHSA, 2018). Therefore, within the BC health care system, it would be necessary to have interprofessional collaboration between PCPs and PHNs visits. In light of the findings, the education to enhance knowledge across and between those working in primary care settings (PCP and PHN) is key to strengthening knowledge and opening dialogue between such partners, should they be working in teams, which results in timely referral for younger children with ASD.

Feinberg et al.'s (2016) pilot randomized control trial (RCT) examined if "family navigation" (FN) could improve timeliness to ASD diagnosis (p. 913). Through a sample of 39 families, Feinberg et al.'s (2016) pilot RCT compared families (n=20) who received FN with a control group receiving usual care (n=19). Participants in the study were chosen based on criteria that increased likelihood of an assessment delay which included the following factors; living below the poverty line, coming from a racial or ethnic minority group, and/or having mothers less than 24 years old (Feinberg et al., 2016). The study demonstrated that nineteen out of twenty families provided with FN received an assessment within a year, versus the control group where eleven out of nineteen families received an assessment within the same timeframe (Feinberg et al., 2016).

Patient, or family, navigation (FN) is a health care model based on principles of costeffective patient-centred care (Freeman, 2013). Its core function is to have a navigator, other than the provider, with a defined role to eliminate barriers to care for the child and family (Freeman, 2013). In Feinberg et al.'s (2016) study, the navigator role included working with the family of a child referred for an ASD assessment, by providing explanations of the referral, assessment process, and documentation requirements, as well as ensuring family understanding for the reason for referral and assessment. These goals were achieved over an average of four appointments between the navigator and family leading up to the child's ASD assessment (Feinberg et al., 2016). The navigators in the study were bilingual, and received training on "navigation competencies, completing an online course...on Autism Spectrum Disorder, and observing three ASD diagnostic assessment" (p. 913). One of the principles of family navigation is that the navigator is an individual other than the PCP (Freeman 2013). However, in situations where there is no additional navigational support, additional PCP training on ASD and the referral process may be a cost-effective option to enable the PCP within their existing portfolio to support family navigation, from the time of referral to the assessment. Feinberg et al.'s (2016) findings support the positive impact of additional training for the PCP and the multidisciplinary team. Their study highlights the benefits of additional training when it is provided through a specific model of care, which results in the delivery of focused information and clear role identification. Therefore, when the PCP seeks knowledge, it is advantageous to acquire training through a focused model of care.

Communication

Communication is the second overarching theme that emerged from the analysis of data. Effective communication is one of the core principles of patient-family centred care (PFCC), and is cited as vital to resilience, education and successful management of ASD (Carbone et al., 2010). Respect, dignity and effective communication within the PFCC model provides support for the child, and for parents, who are typically the primary care coordinators for their children. A key aspect in their ability to provide effective care coordination is dependent on being able to both form and sustain trusting relationships with the PCP (Carbone, Norlin & Young, 2016).

Parents identify the need to be seen, by their PCP, as partners in the decision-making aspects of their child's care (Carbone et al., 2010). As such, PCP knowledge deficits linked to ASD can be barriers to forming trusting relationships, resulting in communication breakdown and a perceived lack of parent support, whereby parents disengage, leading to suboptimal health outcomes for the child with ASD (Carbone et al., 2010).

This theme explores four subthemes that were identified in the literature as influential in the parent-PCP communication dyad: The first subtheme exploring PCP strategies when working with children with suspected ASD is information sharing. Parents of children with ASD eventually become experts in the management of their children's ASD needs (Carbone et al., 2010; Mulligan et al., 2012). Parents therefore require significant levels of ASD quality and evidence-informed information (Mulligan et al., 2012). In the second subtheme, multiple authors highlight listening as an essential factor in effective communication, and identify the risk and difficulties created by the PCP when parents believe their concerns or expertise are rebuffed or dismissed (Bloch & Gardner, 2007; Carbone et al., 2010; Hennel et al., 2015; Mulligan et al., 2012). Studies by Mulligan et al. (2012) and Rhoades, Scarpa and Salley (2007) identify the importance of repeated interactions in establishing rapport with parents, the space in which

professional familiarity builds collaboration. Finally, the findings from Mulligan et al. (2012) and Bloch and Gardner (2007) consider the significance of the PCP approaching difficult topics to establishing trust and a sense of hope in the parent.

Information sharing. In addition to PCP confidence in their knowledge of ASD and local resources, sharing information of services or peer support groups may influence how PCPs guide parents towards earlier ASD intervention opportunities. In Monteiro et al.'s (2015) study, once a referral was sent and the child was placed on the assessment waiting list, the specialist assessment team mailed parents with written information encouraging parents to initiate early ASD therapy. Additionally, parents were provided with information on funding sources, and had access to a social worker while they waited. With this information, parents were able to initiate intervention and start the process of seeking financial support, as care of a child with ASD is known to be costly (Monteiro et al., 2015). These findings highlight the diversity needed for PCPs to actively promote communication strategies. For example, using different forms of information sharing such as written and verbal information enhanced communications. The twoway nature of information should not be neglected. Often, once a referral is in 'situ', the PCP can be left waiting to hear from the specialist service. PCPs will therefore act as the focal point to reach out for updates and receive specialist service communications. The PCP then has the responsibility of disseminating this information to the parents, answering any new questions or concerns (Monteiro et al., 2015).

Rhoades, Scarpa and Salley (2007) completed an online retrospective, author-designed survey to determine the experiences of parent interactions with their providers around the time of their child's ASD diagnosis. The study presented three hypotheses: Respondents would report having received a diagnosis for their child between 3-4 years old; the majority of respondents would report receiving little to no information about ASD from a diagnosing professional, and

that respondents would report using sources of information on ASD other than their PCP (Rhoades, Scarpa & Salley, 2007). The participants (n=146) were asked, specifically in the second section of the survey, if they received information at the time of diagnosis on a variety of topics including; available ASD resources, general ASD information, referrals to ASD specialists, or support groups (Rhoades, Scarpa & Salley, 2007). Within their findings, most of the parents (82%) received information on ASD from their PCP at the time of diagnosis (Rhoades, Scarpa & Salley, 2007). However, only 20% of parents described receiving most of their ASD information from a healthcare professional versus other sources (Rhoades, Scarpa & Salley, 2007). Parents reported that the majority of information was obtained from media sources (including the Internet and books), conferences/workshops, and other parents (Rhoades, Scarpa & Salley, 2007).

The authors identified that "although the majority of physicians are giving parents information about ASD, this avenue of support [could] be significantly strengthened." (Rhoades, Scarpa & Salley, 2007, p.7). While there was no provider that had a "lack of knowledge" (p. 7) on ASD treatment, subsequent explanations and follow-up dialogues related to the information provided to parents was weak, leaving the authors questioning the rationale for provider hesitancy in explaining information to parents (Rhoades, Scarpa & Salley, 2007). In addition, Rhoades, Scarpa and Salley (2007) highlighted that some parents felt overwhelmed by the volume of information available, and looked to their PCPs as a trusted resource to help them filter information, suggesting that PCPs were "in a perfect role to guide families toward information with empirical support" (p.8). The voluntary nature of an online survey distributed via a support group network in America within this study provided a biased viewpoint (i.e. selfselected participants), however, the findings align with themes found in other studies, i.e. the need for the PCP to strengthen parent understanding (Hennel et al, 2015; Mulligan, 2012). To

summarize, the study identifies that the PCP needs to be 'ASD' knowledgeable in order to appraise what is both quality and safe ASD information. The PCP must then provide and use this information to meaningfully support parents promoting their understanding of what ASD means for their child.

In addition, Hennel et al.'s (2015) retrospectively surveyed n= 404 parents through a postal mail survey about their experiences when their child received an ASD diagnosis. This study also included the perspectives of paediatricians (n=43), enquiring as to the type and utility of the information they provided to the parents during the process of reaching an ASD diagnosis. Through a national research network in Australia, the authors designed a questionnaire and surveyed both the families and pediatricians between 2010-2012 with key questions focusing towards both participant groups on their perceptions of information received or provided at the time of diagnosis. Overall, Hennel et al. (2015) identified that parents perceived that they did not receive enough information at the time of diagnosis. Specifically, parents focused on a lack of information linked to the following: ASD prognosis, allied HCP support, educational support, parent support groups, early intervention and complementary alternative treatment (CAM). Hennel et al.'s (2015) results revealed that parents expressed greater satisfaction with the information provided at time of diagnosis when a support person was present. In contrast to Rhoades, Scarpa and Salley's (2007) parent reported findings, paediatricians in Hennel et al.'s (2015) study perceived that they did provide adequate information on ASD topics at the time of the child's diagnosis. These findings suggest that information may be lost in translation during these emotional experiences (Hennel et al., 2015). The findings from Hennel et al. (2015) and Rhoades, Scarpa and Salley (2007) highlight that providers with additional training in the area of ASD (i.e. developmental pediatricians) were more likely to provide additional ASD information to parents. When parents were able to easily access useful information delivered by providers,

they were satisfied, and expressed feeling supported; this is reassuring, since only 18% of providers failed to provide additional information following diagnosis (Rhoades, Scarpa and Salley, 2007). It can be concluded therefore that failure to attend to parents ASD-informational needs has a lasting impact on the parent-PCP relationship. Limited PCP provision of information, and their hesitancy, remains with parents many years after diagnosis, and is internalized by parents through questioning PCP knowledge of ASD in early childhood, and hence their confidence to engage in meaningful future care provision.

Mulligan et al. (2012) provide the final study contributing to the information-sharing theme. In their phenomenological narrative study, Mulligan et al. (2012) used parent interviews to explore ten parent experiences of their child's ASD diagnosis. Their study resonates with Hennel et al.'s (2015) findings in describing the abandonment that parents felt as a result of PCP limited knowledge, fearfulness, or low confidence levels which limited supportive management of ASD following diagnosis (Mulligan et al., 2012). Parents in the study described searching for information prior to a diagnosis from the Internet or friends and feeling overwhelmed with information after a diagnosis. After receiving a diagnosis for their child, parents also described feeling powerless and frustrated with resource limitations, describing "long waiting lists, rigid admission criteria, and limited resources, amid little professional guidance and continuity across service providers" (Mulligan et al., 2012, p. 321). Drawing from the findings the significance of PCP attitude was linked to transparency when discussing new information (Mulligan et al., 2012). There is need to be cognizant that in order for the PCP to be able to do this they have to be knowledgeable, confident and competent in the areas of care of ASD in younger children. If PCPs are to support parental autonomy and raise awareness of ASD choice, they must be respectful, and inclusive in decision-making with parents. PCPs also need a sound knowledge base and confidence to act in engaging ways that foster and champion parental empowerment.

Parental empowerment was defined within the study as a "process of gaining personal power and control" within the health care setting (Mulligan et al., 2012) and something to be supported when working with parents. When sharing information with the intent of empowering parents, the PCP needs to be prepared to discuss topics including: diagnostic criteria, prognosis, system care, next steps in intervention, and the parent role (Mulligan et al., 2012).

Listening. Three studies demonstrated parental frustration at feeling dismissed for raising their initial concerns about their child's behaviours with a PCP (Bloch & Gardner, 2007; Carbone et al., 2010; Mulligan et al., 2012). In Bloch & Gardner's (2007) explorative interviews with caregivers, they described frustration when their PCP did not have compassion for the challenges they faced. The ability of the PCP to listen with empathy was highly valued (Bloch & Gardner, 2007). Carbone et al. (2010) recognized the impact listening had on caregivers as a 'protective factor', since it allowed parents to express frustrations and stressors in a safe space. Of note, parents desired simple questions that sought out how they were coping and how the family as a whole was doing (Carbone et al., 2010). Conversely, providers in the study commented on their "lack of skill" in alleviating parent stress, recognizing their failure in providing support (Carbone et al., 2010, p. 321). Both perspectives demonstrate that parents expect emotional support from their providers, although providers may not know how to initiate these conversations, thus creating barriers to communication.

Parents from Carbone et al.'s (2010) study described how they viewed themselves as the primary care coordinators in their child's care, and as such, expected recognition from their providers. The providers in the study corroborated with this perspective, describing parents as better experts than themselves on ASD and local resources. However, the authors noted that "early negative experiences [with providers] strongly influenced [future] interactions" (Carbone et al., 2010, p.320). This sentiment demonstrates that when parents feel dismissed or their

expertise is not recognized, parents will change providers, or alternatively avoid seeking out support (Carbone et al., 2010).

Parents also described losing confidence in their own expertise when the PCP dismissed their opinion or concerns, serving as a barrier to a family-centred care approach (Carbone et al., 2010). Trust was further impeded when parents brought forward information they acquired from other sources and were met with a negative response from their provider (Carbone et al., 2010). For example, Carbone et al. (2010) discussed how parents experienced negative responses from their provider when discussing CAM, creating a barrier to consultation and provider input. Providers in the study had mixed feelings about the scientific integrity of CAM, although younger providers seemed more open to discussing it (Carbone et al., 2010). Conversely, Hennel et al. (2016) stated that up to 95% of parents use CAM with their children. These reports demonstrate the need to establish respect between the PCP and parent, and that a lack of PCP sensitivity to parent-perspectives creates a significant divide in their relationship.

The final study by Carbone, Norlin and Young (2016) that contributes to the listening subtheme highlights a positive perspective on listening. In Carbone, Norlin and Young's (2016) study, the authors specifically included parents in practice teams as part of the learning collaborative, proposing "parents are considered essential team members because they assist practices in creating family-centred changes" (p.2). The study demographic included both urban (60%) and rural (40%) practices (n=26), with over 80% of the provider cohort having been in practice for more than five years, and more than a third caring for children with ASD for over a decade. During this time, providers had had the opportunity to reflect, refine, and reflexively apply their ASD knowledge, as well as their communication skills, i.e. listening. Although not stated in the study, Carbone, Norlin and Young (2016) have dual roles as providers of care for children with ASD and their families within their own clinical practices. While likely informed

by their clinical knowledge, their research methodology may be open to bias, since they hoped to demonstrate the positive impact on the relationship between PCPs and parents. However, the practice teams in their study were not their clinical partners, and the learning collaborative approach used retrospective chart audit to see changes in provider screening and support for toddlers with ASD.

Examining the patterns across these studies (Bloch & Gardner, 2007; Carbone et al., 2010; Carbone, Norlin and Young, 2016; Hennel et al., 2016; Mulligan et al., 2012) there is evidence that when providers listen to their patients, and use reflexivity, they influence parent-PCP interaction, and act as role models to other providers and stakeholders. Through active attentive listening, the PCP's ability to hear parent concerns influences their ability to advocate for children with ASD in the community, and even champion for new services. Furthermore, PCPs can incorporate what they learn about the patient experience into new research initiatives, influencing future clinical practice. Listening to parents therefore improves the parent-PCP relationship, and also influences the PCP's ability to effect system-wide practices within primary care.

Repeated interactions. The parents in Mulligan et al.'s (2012) study describe how a significant part of the ASD referral and diagnosis process is emotional. Parents therefore require time to come to terms with the diagnosis (Mulligan et al., 2012). Their findings highlight the need for extended time during appointments, timely follow-up appointments for parents to receive thorough information, as well as time for parents to ask questions (Mulligan et al., 2012). In support of these factors, Hennel et al.'s (2016) study compared parent and provider perspectives on the amount of time to discuss a new diagnosis and found that only half of the providers felt they had enough time to provide adequate information to parents. Rhoades, Scarpa and Salley's (2007) online survey further highlights the gap in repeated interactions in parent-

PCP relationship by identifying that only 18% of parents sought out follow-up information from their PCP. For PCPs, the discordance indicates the need to share small sections of information at a time during appointments, preferably with a support person present; repeating information in both written and verbal methods and taking the time to check in on the parent's understanding (Hennel et al., 2015; Mulligan, 2012; Rhoades, Scarpa & Salley, 2007). Providing information with such techniques allows parents to fully understand the information they are receiving, thereby empowering their decision-making abilities, and increasing likelihood of respectful, productive dialogue between parent and PCP.

Approaching difficult topics. Compassionate listening to a parent's concerns extends to communicating to parents during times of distress (Mulligan et al., 2012). Several studies describe the importance of considering what, how and when to deliver professional and well-delivered information, along with opportunities to ask questions on a regular basis (Bloch & Gardner, 2007; Carbone et al., 2010; Hennel et al., 2016; Mulligan et al., 2012). This open-door form of communication opens up dialogue, and empowers parents (Mulligan et al., 2012).

Mulligan et al. (2012) discuss how initial concerns are brought up by the PCP or other health care providers, but are dismissed in an attempt to decrease parent worry. Bloch and Gardner (2007) further add to the concept of 'difficult conversations', detailing how caregivers describe providers as afraid to "upset" caregivers by suggesting their child has ASD. Although for some parents, the suggestion posed by the PCP that the child may have ASD can be a welcome relief, allaying their own doubts and confusion. The PCP is therefore able to validate their concerns that something is not "quite right" with their child (Mulligan et al., 2012).

When considering communication during and after diagnosis, Mulligan et al. (2012) examine how communicating difficult information is most appreciated when coming from a place of hope. Within parent interviews, parents describe a need for information that is transparent and

honest, while also offering a sense of hope and compassion (Bloch & Gardner, 2007; Carbone et al., 2010; Hennel et al., 2016; Mulligan et al., 2012). Parents further describe feeling overwhelmed with information during the time of referral and diagnosis (Carbone et al., 2010; Hennel et al., 2016; Mulligan et al., 2012). Therefore, once a diagnosis has occurred, conversations around stress and coping become invaluable to the parent (Bloch & Gardner, 2007; Mulligan, et al., 2012). Conversely, several studies demonstrate how a lack of transparency or skill in navigating these conversations can be destructive in parent-PCP rapport (Bloch & Gardner, 2007; Carbone et al., 2010; Hennel et al., 2016; Mulligan et al., 2012).

Finally, Hennel et al. (2016) also explore the topic of satisfaction of information provided at the time of diagnosis and afterwards, comparing parent and pediatrician perspectives on the adequacy of meeting these expectations. Their study demonstrated that although many parents were satisfied with information provided at the time of delivery, most information was received from allied health care providers after the diagnosis (Hennel et al., 2016). This suggests that the PCP may not be the primary source of support, but can still support the parents emotionally through honest, transparent communication and providing information to services such as parent support groups or social workers (Hennel et al., 2016).

To summarize this chapter, both the overarching themes and subthemes share elements linked to knowledge and communication. The aim in trying to fragment the primary care providers role in order to answer the question "What are primary care strategies for supporting the parent(s) of children aged 18-36 months with suspected ASD?" was challenging. However, core themes that draw together elements linked to practice complexities are discussed in Chapter Four.

CHAPTER FOUR: DISCUSSION, IMPLICATIONS FOR PRACTICE, AND RECOMMENDATIONS

This review sought to answer the question, "What are primary care strategies for supporting the parent(s) of children aged 18-36 months with suspected ASD?" The previous chapters in this review identified ASD in children as a complex, multifaceted condition that affects the child and their family. This final chapter considers these findings and how they relate to a patient and family centred care (PFCC) model and its use within primary care settings. Furthermore, this chapter proposes several recommendations for practice, which build upon the analysis conducted in prior chapters. Through thematic analysis, the previous chapter identified two overarching themes with subsequent subthemes; Primary Care Provider (PCP) Knowledge and Communication were identified as the key themes that influence PCP strategies to support parents of children with suspected ASD.

PCP Knowledge encompassed subthemes of acquiring information, personal factors that influence the PCP's ability to acquire knowledge, and team factors that influence knowledge. Findings demonstrated that this theme and its subthemes significantly influence the PCP's functional ability to provide competent, comprehensive care.

The second theme Communication, within the context of primary care strategies, included listening to, information sharing, broaching challenging subjects, and continuing interactions with parents and family after the initial suspicion of ASD until the initial diagnosis. Communication, and its subthemes' significance to the PCP role, is demonstrated through the use of openness, honesty, and compassionate communication when establishing relationships with parents, thus strengthening the parent-PCP partnership and collaborative decision-making process. To help organize the two themes for further discussion, this paper adopted the use of the PFCC model. Both the PFCC model and its principles were identified in several of the studies and supporting literature, and reflect the values and themes portrayed in this review. A PFCC model developed by Pelzang (2010) was adapted to organize this chapter and frame the discussion of further details and findings. Table 4 outlines the structural components of the specific PFCC model originally created by Pelzang (2010), which provides a visual interpretation of where the themes and subthemes of this review fit into an already existing framework for patient-centred care. It should be noted that several terms described in the original model differ from terms used in the findings, however, many of these concepts are related or overlap.

Table 4

Patient and Family Centred Care Model (Adapted from Pelzang, 2010)				
	Project Key Findings	PFCC Model Factors		
Outcomes	Strong PCP-parent	Parent Satisfaction		
	alliance	Involvement		
	Parent empowerment	Improved health		
	Improved Parent-	Well-being		
	functioning	Therapeutic culture		
	Timeliness/efficacy			
Process	Collaborative	Engagement, shared decision making		
	partnership	Work with patient beliefs and values		
	Work with family	Sympathetic presence		
	values with dignity and	Providing for all needs		
	respect			
	Open, honest,			
	compassionate			
	communication			
Foundational		PCP attributes	Organizational	Patient
Structure of			attributes	attributes
PFCC	Acquiring Information	Competence	Time	Perception
			Skill diversity	Participation
	Communication	Communication	Supportive	Perspective of
		skills	organization	care
			Shared power &	Cooperation
	Personal Factors	Commitment	decision making	Culture
			Innovation/creativity	
	Team Factors	Interpersonal	Team relationships	
		skills	Role clarity	

Looking at the adapted model, PFCC is visualized as a hierarchy, with a foundational 'structure' to create the optimal patient-centred environment (Pelzang, 2010). This 'foundation' is divided into three components, or pillars: Personal professional attributes, Organizational attributes, and Parent attributes. These pillars create the foundation required for the PFCC process and its intended outcomes.

The themes and subthemes from this review primarily fall under the first pillar, 'Personal and professional attributes.' However, each structural component has a nexus affect on the other. PCP attributes influence organizational and parent attributes, and vice versa. This is evident in several of the subthemes from this review, which identified organizational or parent attributes that influenced or were influenced by the PCP role. This chapter discusses these themes and subthemes, using the three foundational structural components of PFCC to organize and better understand how each theme and pillar may influence the other. Following a discussion, this chapter will present recommendations for practice, the limitations of this integrative review, and future directions in research.

Personal and Professional Attributes

'Personal and professional attributes' is the first pillar in the PFCC foundational framework and is the most relevant pillar to the findings of this review. Personal professional attributes are special characteristics that the PCP must embody in order to create an environment conducive to patient-centred care. Personal professional attributes are divided into three factors, including PCP commitment, PCP competence, and PCP communication skills. The themes and subthemes from this review align with these three factors. Commitment, competence, and communication skills align, respectively, with the subthemes from PCP Knowledge – personal factors and acquiring information, and the overarching theme Communication.

Commitment. In this review, PCP willingness was identified as essential to providing quality care (Carbone et al., 2010; Garg et al., 2014). 'Willingness' aligns with the PFCC concept of 'commitment', which motivates the PCP to provide care for the patient, engage in shared decision-making, and develop working relationships based on mutual respect and shared values (Pelzang, 2010).

Factors that contribute to PCP commitment to learning about ASD and providing better care for this population include a personal interest or involvement with children with ASD, mental health, or related conditions (Garg et al., 2014). This willingness and commitment to provide optimal care also serves as a motivator for the PCP to seek out training, and address their personal gaps in knowledge. PCPs may have a vested interest in training if they frequently see patients with ASD in their own practice, or if concerns regarding gaps in care are often identified in the clinical practice setting. Focusing strategies on the PCPs with a personal interest, whose commitment and willingness to learn make them receptive to innovation, creates PCPs that are agents of change in the ASD domain. Strategies should focus on learning across a range of diverse platforms, including alternative approaches to care, new research, and innovations aimed at effective delivery of care. Successful learning strategies can provide direction for committed PCPs, resulting in individuals becoming champions in ASD care, encouraging leadership and influencing future practice (see: Recommendations).

Demonstrating commitment to optimal care is the PCP's internal constituent required to meet both PFCC attributes as well as regulatory body standards of duty to provide care. Professional standards that determine the expected level of provider performance typically include professional responsibility as part of its mandate. For example, the regulatory body for

NPs, the British Columbia College of Nursing Professionals (BCCNP), states that they are "accountable and take responsibility for [their] own nursing actions and professional conduct" in clinical practice, education, administration and research, in order to "promote provision of safe, appropriate and ethical care" and "develop policies, practices and education consistent with standards of the profession" (BCCNP, 2018, p.8). Therefore, the concept of commitment relates to the PCP's expected professional duty and responsibility to provide competent patient care.

Competence. The studies in this review demonstrate that PCP competence correlates to their acquired knowledge, and perceived self-efficacy (Carbone, Norlin & Young, 2016; Garg et al., 2014; Monteiro et al., 2015).

PFCC uses the term 'competence' to indicate the PCP's ability to provide entry-level care. Similarly, professional regulatory bodies such as the BCCNP define "competence" as the ability to apply acquired knowledge, skill and judgment with the appropriate indication, to make context-appropriate decisions (BCCNP, 2018). Although competence cannot be measured, a PCP's 'competence' is determined by a series of measurable indicators, or 'competencies', which are based on the individual's knowledge, skills and abilities. These 'competencies' can be used to determine the PCP's entry-level capability to practice, and once acquired, are maintained through continuing professional development (BCCNP, 2018).

For the PCP, acquiring knowledge serves to maintain competence and continue professional development, for the purpose of supporting patients and their families. Studies suggest that delayed ASD referrals may be related to PCP uncertainty or lack of familiarity with the topic (Carbone, Norlin & Young, 2010; Garg et al., 2014; Hennel et al., 2016; Monteiro et al., 2015). This review therefore suggests that PCPs need to be aware of their own gaps in knowledge, and must be able to both seek and apply knowledge to practice in order to care for individuals with ASD and their families. Knowledge acquisition involves the ability to

disseminate, implement and retain information on ASD, and is demonstrated by the use of evidence-informed protocols, examining individual understanding, and determining the utility of each aspect into practice.

Throughout the literature, providers gain knowledge of ASD from both experience and education (Bloch & Gardner, 2007; Feinberg et al. 2016, Garg et al., 2014). Education involves a variety of opportunities, including research, training, community involvement and clinical practice. Examples of educational opportunities from the studies include training on general early childhood development, ASD red flags, and reaching out into the community to learn about available services (Bloch & Gardner, 2007; Mulligan et al., 2014). The PCP must be cognizant of atypical development (i.e. be skilled in using ASD screening tools), understand the family experience, and be able to facilitate parent decision-making. The knowledge that PCPs acquire during their training, as well as through observation in clinical practice, must then be contextualized in order to translate evidence and experience to practice. This synthesis of knowledge, experience, and context must occur to create higher levels of change at meso and macro levels.

Studies also identified that self-efficacy contributes to PCP competence (Bloch & Gardner, 2007; Carbone et al., 2010; Garg et al., 2014; Monteiro et al., 2015). A comprehensive understanding of self-efficacy is beyond the scope of this review; however, one theory of "self-efficacy" is defined as a person's belief in their ability to perform a presenting or future task or skill (Bandura, 1977). This review suggests that low self-efficacy as perceived by the PCP can be used as a prompt to consider gaps in knowledge, and motivate the PCP to seek ways to address their learning needs. Several of the studies demonstrated that low self-efficacy and confidence, despite adequate knowledge, negatively influenced competent care (Carbone et al., 2010; Carbone, Norlin & Young, 2016; Monteiro et al., 2015). Although self-efficacy is not a

measurable indicator of competence, it can be used to recognize personal level of comfort in providing care for children of ASD. Therefore, as self-regulating professions in BC, the PCP must have the ability to rate self-efficacy in skills demonstrates the ability to reflect on practice and competence in care, and to seek professional development.

Several barriers are highlighted to maintaining professional development. Firstly, acquiring additional training is time consuming, and costly (See: Time and Timeliness) (Carbone et al., 2010). Secondly, additional training on ASD can be exceptionally broad (Garg et al., 2014). For example, training can vary from learning about community service availability and the political atmosphere, to general ASD pathophysiology. These barriers may prevent or intimidate the PCP from seeking new information, or investing individual time or resources. In light of these barriers, Lindsay et al. (2016) suggests that PCPs "benefit by a more specific 'fit' between personal learning needs and the activities pursued to address these needs" (p.43). Recommendations for the PCP therefore include the creation of individually determined learning strategies based on each PCP's learning needs, and seeking out focused avenues of knowledge, through personal experience, journal articles, workshops, or traditional classroom settings that are ASD-focused.

Communication skills. Communication skills are the third component of personal professional attributes in the adapted PFCC model. 'Communication' is a complex concept, linked to relationships and role clarity with members of the multidisciplinary team and the family, and its impact is highlighted further in Organizational and Parent Attributes.

Communication skills are an important requirement to building trust, and facilitating reciprocal family engagement. Considering a PFCC approach, the PCP's communication skills empower the family to make informed decisions (Pelzang, 2010). The ability to communicate and share information encourages talking about positive and negative experiences in order to

change, improve, and develop practices and policies (Pelzang, 2010). Several studies focusing on communication demonstrated the value of the nature of language, active and compassionate listening, and the PCP's ability to approach difficult topics (Bloch & Gardner, 2007; Carbone et al., 2010; Mulligan et al., 2014).

Risks of poor communication skills include the inability to articulate initial concerns when ASD is suspected, the loss of information relevant to referral or intervention, and exacerbation of parent confusion and isolation. Reflecting on the studies that did not explicitly use a PFCC model also support this review's conclusions in that the value and impact of good communication, identifying the need to share information from a place of hope, and using varying forms of communication such as combined verbal and written information, all enhance care.

Consistent and transparent communication is a key aspect that demonstrates principles of dignity and mutual respect between patient and provider. PCPs who attend to their information sharing and communication styles ensure that families feel heard and empowered during clinical consultations. Communication therefore enhances the overall health care experience for the family, which is critical in developing and sustaining the parent-PCP relationship.

Organizational and Parent Attributes

This section considers aspects of the second and third pillars necessary for the implementation of successful PFCC; namely, the PCP's role and influence on Organizational Attributes and Parent Attributes. Two specific organizational components are discussed in the context of this review's findings: the multidisciplinary team and timeliness. The multidisciplinary team fits into the subtheme of 'team/organizational factors' from this review's theme Knowledge. Factors from both overarching themes relate to the concept of timeliness and parent attributes.

The multidisciplinary team. Studies in this review found that quality care for children with ASD and their families involves a multidisciplinary approach (Barbaro & Dissanayake, 2010; Carbone, Norlin & Young, 2016; Garg et al., 2014). When the multidisciplinary team is able to collaborate effectively, the perspective and strength of multiple disciplines can promote optimal care for family support and ASD intervention (Barbaro & Dissanayake, 2010; Feinberg et al., 2016). This review suggests that effective multidisciplinary team functionality is dependent on role clarity, a team approach to understanding collaboration, and advocacy of resource availability. As such, PCPs must be flexible and adaptable, possessing skills that allow them to navigate the multidisciplinary team and local community resources.

This review identifies clear role identification as a necessary tenet within the multidisciplinary team supporting families in a PFCC model (Pelzang, 2010). Despite these findings, PCPs and other health care professionals may still not understand how to identify or express their roles in daily practice. Risks of role confusion include miscommunication, and missed opportunities to provide optimal care. For example, PCPs who do not understand their role in the multidisciplinary team may not understand their role in referral for ASD assessment, leading to delays in care. The PCP role should therefore be considered alongside other professions in order to optimize care. Clear role boundaries and shared responsibilities must be navigated within the team in order to optimize care for the young patient suspected of ASD.

Despite the reported benefits of role clarity, parents and PCPs alike reported that PCPs have limited exposure and understanding of their role in collaborating with other professions, including educators, speech language pathology, or subspecialists (Carbone et al., 2010). Collaboration may prove challenging if other disciplines are not available as a local resource, or if disciplines are working in isolation. PCPs in Carbone et al.'s (2010) study demonstrate that they are often at the limit of personal capacity and unable to take on more responsibility within

their workload. With the PCP having to direct clinical practice time and delegation of tasks, finding time to collaborate with other disciplines proves challenging if no formal informationsharing system has been set in place. Furthermore, each discipline is likely to have their own 'philosophy' of care, and there may be tensions that could impact care to the child and family. These tensions and gaps in care therefore need to be acknowledged and addressed in thoughtful ways.

Other risks to working in isolation include family expectations that the PCP will provide many services, while also being a source of the latest information on ASD. However, the PCP loses collateral information on children that other disciplines have opportunity to observe more frequently. For example, it is often public health nurses (PHNs) or early childhood educators who identify children who may have ASD. These barriers result in missed opportunities for the child and family in respect to access, education, and early intervention. Moreover, families do not receive the full scope and complementary services that a multidisciplinary team can provide. If the PCP can follow up and delegate tasks to someone who is competent and confident in ASD, they need to be clear about which tasks they are holding on to. Multidisciplinary team patterns of working allow the parents to form connections with those they feel more comfortable with. While this may or may not be the PCP, the PCP continues to have a role in supporting the families, as they are often still the first health care professional that parents seek out, and therefore serve as gatekeepers, system navigators, and a source of emotional support.

In conclusion, the PCP must actively and meaningfully engage in forming and sustaining professional relationships with other key providers through innovative and dynamic approaches to overcome disconnects between the multidisciplinary team (e.g. speech and language pathologists, early childhood educators). Like many providers, the PCP's time is limited; therefore, creative approaches to connecting with providers may be necessary when resources are

scarce, or services are not co-located in the same geography. Effective multidisciplinary teams have the potential to liberate the talents for all partners, each having the opportunity to learn from a different discipline, thereby sharing knowledge and learning new skills in supporting families during the latent stage while awaiting a diagnosis. Partial onus to improve the multidisciplinary team approaches depends on the health care authority or governmental ability to perceive and act upon gaps in service. The PCP must therefore demonstrate leadership skills and advocate for their patients to health authorities and higher levels of government to increase awareness of service gaps (Pelzang, 2010). Finally, approaches that maximize technology, as well as formal information- sharing networks are ways in which PCPs can stay connected to others and aware of timeliness.

Time and timeliness. In addition to the multidisciplinary team, time is a valuable resource required within Organizational Attributes for successful PFCC implementation. PCP skills and competence can affect outcomes in time management. The foundational attributes of PFCC encourage effective time spent between provider and family, thus providing an upstream approach to time management. However, the ability to successfully apply PFCC principles requires initial time spent determining patient issues, adopting strategic leadership, and incorporating patient-PCP collaboration.

According to PFCC principles, PCPs require adequate knowledge of patients, clinical skills to care for patients, and proficient communication and relational skills. With time, the dynamic between the provider and the family changes, therefore helping relationships grow. Time is therefore also considered in relation to the skill of being with the patient and gaining rapport, applying knowledge, and developing an interest in the research. Ongoing PCP time for learning and skill application is significant. Inadequate time can create a barrier to PFCC
implementation, and ultimately to the development of meaningful relationships with parents and families, with the risk of patient disengagement.

In this review, factors within the two overarching themes are associated with the concept of timeliness, and are often linked to the perception of satisfactory or unsatisfactory family care. First, acquiring knowledge was often dependent on time (Carbone et al., 2010). PCPs reported they did not have enough time to seek out specific information on ASD, and found appointment times too short to sufficiently assess a child or listen to parent concerns. Inadequate time impeded the PCP's ability to share comprehensive information with parents about ASD during and after diagnosis. Moreover, time was imperative to achieving the benefits associated with repeated interactions between parents and PCPs (Mulligan et al., 2012; Rhoades, Scarpa & Salley, 2007). Secondly, following an ASD diagnosis, finding time for quality care was also difficult in the studied clinical settings (Hennel et al., 2016; Rhoades, Scarpa & Salley, 2007), suggesting that many PCPs face clinical cultures that expect brief visits and high patient visit numbers. Such organizational barriers to time availability can be dependent on the biomedical model, which encourages short amounts of time spent with patients, and not enough time to reflect on listening, information sharing or shared decision-making. The findings in this review illuminate that PCPs involved in the care of children with ASD face challenges similar to many PCPs attempting to implement PFCC into general primary care, "often report[ing] that they know what to do clinically, but system related issues such as time constraints or access to community referral resources of diagnostic testing create barriers to applying their clinical knowledge" (Lindsay et al., 2016, p.39). This suggests that PCPs involved in the care of populations with ASD must have time allocated to both learning, as well as to implementation and evaluation of practice changes.

One approach that has been favoured for improved timeliness is the creation of a registry of children with possible ASD in order to improve follow-up and monitoring (Carbone, Norlin &

Young, 2016). Such an organizational strategy could identify children with suspected ASD, and in turn prompt the PCP to prepare for these visits, follow up in a timely manner, and consider longer appointments when necessary. It could also ensure that future interactions address child development and prioritize conversations on child development with parents, therefore improving efficiency and effectiveness within each appointment. Further recommendations for acquiring quality time to implement effective PFCC include PCP advocacy for professional cultural shifts away from a limited disease-focused, biomedical model, to a model that allows the PCP to spend more time in quality patient interactions. The PCP can also advocate for continuing professional development in avenues outside of the typical understanding of disease and its management such as other necessary structural components supporting PFCC; these may include interprofessional collaboration, supportive administration, and scheduling.

The parent role. The findings in this review identify that clear role identification is necessary in the parent-PCP relationship. Oftentimes, families and providers will assume roles, rather than openly and explicitly discussing them. These assumptions can potentially lead to misunderstandings in communication, relationships, and patient care.

Within this integrative review's findings, parents reported feeling alone, overwhelmed and unaware of whom to turn to for help while waiting for or after receiving an ASD diagnosis (Carbone et al., 2010; Hennel et al., 2016; Mulligan et al., 2012). These feelings of isolation may, in part, demonstrate lack of communication from their initial contact with the PCP regarding role expectations in their child's ongoing care. Eventually, parents often learn to adopt the care coordinator role for their child and become experts in their own field. The initial emotional turmoil associated with role confusion can be lessened with the use of a health care model such as PFCC since clear role identification is an integral part of its structural organization. In addition to openly discussing and clarifying these roles and expectations in a child's care, the PCP also has a duty to recognize and respect the role that the parent plays in their child's care. Consequences of a PCP's dismissal of parent knowledge or overlooking parent expertise in their child's behaviour and management can result in low parent regard for the PCP's competence, feelings of distress or lack of buy-in, or avoidance of future interactions with the PCP (Carbone et al., 2010; Hennel et al., 2016; Rhoades, Scarpa & Salley, 2007). According to the findings of this review and the PFCC model, active participation and recognition of PCP and parent roles is necessary and integral to negotiating patient care and collaborative decision-making.

Recommendations

This final section will summarize the recommendations for PCP practice based on the findings and discussion of this review. There is a significant knowledge deficit in regards to ASD among providers in health care. The complex nature of ASD, and recent changes to its diagnostic criteria, create challenges in understanding the needs of these children. Specifically, this review provides recommendations for PCP practice during the waiting period of time that occurs between recognizing ASD symptoms in a young child, to their formal assessment and diagnosis.

Interventional support strategies for these children often focus on educational and behavioural needs, and less so on the supportive role of the PCP. It is important to understand that families of children with suspected and newly diagnosed ASD have distinct needs that require support from many different systems of care, including educational systems, allied health and primary care. Results from this review support the need for complex systemic changes to address their needs. The recommendations presented here therefore seek to address issues from front-line delivery to system-wide restructuring. Based on the focus of this review, the strategies recommended here are tailored to the PCP role. These recommendations were developed from the findings of studies that explored the experiences of other health care professionals such as

nurses, social workers, and medical specialists and therefore can be applied to any person caring for families of children with suspected ASD. Furthermore, although most of the studies in this review observed populations in urban demographics, it is possible to utilize these recommendations in rural or other settings, albeit likely with some modification, depending on human and other resource availability. Table 5 provides a summary of this review's recommendations; following the table, these recommendations are briefly summarized.

Theme One: Knowledge		
Recommendations	Level of Change	Strategies
Additional Training	Micro	 Create individually determined learning plan, where possible negotiating managerial support. Explore becoming a practice champion, developing updates and sharing new practice standards and policy. Take courses/seek information on ASD, general development, referral process and ASD management
	Meso	 Seek information on local community services, interventions, and referral pathways, create recommendations to share with other local PCPs Propose ways in which to address information and knowledge deficits within local teams by exploring collaborations with research teams. Seek information on local support groups and advocacy groups Appraise existing resources that local populations are utilizing within a systematic approach, and share this with networks, peer support groups and families
Personal Factors	Micro/Meso	 Demonstrate willingness to engage in parent-PCP relationship Be willing to engage in communication development
Restructuring team and health care models	Macro	 Advocate for and adopt a health care model that is patient and family centred embed within clinic, community, or health authority Seek support and information-input from allied health professionals, educational professionals, and local member of the legislative assembly Seek out community services i.e. schools, childcare programs, OT/SLP, rec centres to gain knowledge in availability and utility Engage with other allies in health authorities and local government to improve local services and resource availability
Theme Two: Communic	ation	

Table 5Primary Care Provider Strategy Recommendations

Recommendations	Level of Change	Strategies
Information Sharing	Micro/Meso	 Provide verbal and written information at appointments Plan for follow-up following referral or new diagnosis to assess family well-being Once referred, encourage family to bring support person to appointments and assessments for better information retention Discuss scheduling with administration/MOA to set up longer appointment times or repeated interactions for developmental assessments
Approaching difficult topics	Micro/Meso	 Discuss difficult topics from a place of hope; normalize concerns, fears, and introduce available resources of support Create surveillance list within primary care clinic for children with suspected ASD and to initiate/follow-up on concerns or conversations about child's development, using existing technology i.e. electronic medical records
Listening	Micro	 Develop therapeutic relationship Listen to and validate parent concerns Listen to complementary alternative medicine (CAM) ideas, encourage empowerment on how to choose CAM and how to do research for informed decision- making Find a champion for CAM-related therapies, ask to work in partnership with them to explore how to advocate for this with families
	Macro	• Listening to parent/team concerns on resource availability or challenges accessing services; advocate for policy and procedure changes within health authorities or within current government standards

Additional training and personal factors. Create an individualized learning plan and be willing to seek out information on ASD. PCPs that have a personal interest and willingness to learn more about ASD can take on a role as leaders for change. Seeking sources of information can include personal experiences, research journals, workshops, and courses.

Parent-PCP relationships. Develop positive parent-PCP relationships. Enter relationship with positive regard of parents as experts in their child's behaviours and issues. Take time to listen to parent initial concerns and during waiting period pending diagnosis, and validate and normalize the stress of the referral and diagnosis process. Encourage conversations to promote informed parent decision-making, and provide opportunity for additional appointments to allow for follow-up questions and concerns. Additionally, use parent expertise to evaluate resource needs within the community.

Multidisciplinary team relationships and organizational changes. Develop relationships with local services and allies. Developing these relationships can inform parents of existing service availability and limitations. These relationships can encourage earlier PCP referrals regarding concerns about a child from health and non-health care providers more quickly. Seeking out community stakeholders can also lead to collaboration development and lobbying opportunities for community resources.

Within the clinic setting, recommendations include administrative changes to accomodate for parents of children with suspected ASD. Barbaro and Dissanayake (2009) and Carbone, Norlin and Young (2016) utilized a registry for identifying at-risk children to ensure proper follow up, evaluation and if deemed necessary referral for ASD diagnosis. Registries can also improve time management, as next appointments can be made longer to focus specifically on developmental milestones. Registries can encourage repeated interactions with families, and providing parents with information on development at these appointments can also provide opportunity for PCPs to initiate conversations around child development early, improving the ability to approach difficult topics if the child is not meeting expected milestones.

Limitations and Recommendations for Future Research

Several limitations and biases in this project potentially influence the use of the literature in the clinical setting and context of this review's question, and will be discussed in this section.

Personal limitations. The author of this review completed this project with limited primary care experience. This may have provided a more objective perspective on determining effective PCP strategies; however, factors may have been interpreted differently or missed due to limited exposure to this type of setting.

Study limitations. A major limitation of the findings is in the limited number of locally based studies relevant to the topic. Most studies were completed by USA and Australian researchers, which affects the ability to directly explain or provide strategies for PCPs in BC. Several of the studies were based on small, homogenous population sizes, affecting the applicability to the general population. Additionally, several of the studies were retrospective or exploratory in nature. This may have led to a biased interpretation of situations, which would have been based on personal memories, and cannot be used in isolation to determine traits for the general population, or all families of children with suspected ASD. Additionally, parents of children with ASD in these interviews were chosen in a voluntary manner, and it is possible that this population have certain qualities or perspectives on PCPs and the health care system that do not reflect the views of the wider population. The interviews done in several of the studies were often parent-focused, and did not provide PCP insight into factors. These studies may not have considered situations where PCPs may initiate concerns, but are dismissed by parents. It is therefore difficult to assess which scenario may be more common, or how to assist these parents when PCPs find themselves in these situations.

Future directions in research. In consideration of the limitations of this review, several recommendations for future directions in research are proposed. Future directions for research include:

- Repeating studies on larger population sizes with wider demographics
- Encouragement of Canadian research initiatives on these populations
- Developing research that is focused on the PCP experience when ASD is suspected
- Developing research methodology that explores the efficacy of PFCC for children with suspected ASD and their families within a framework of patient-oriented research
- Determining prospective studies of more specific strategies and educational interventions that appropriately address parent issues during the waiting period of their child's ASD diagnosis

Conclusion

This integrative review sought to answer the question: "What are primary care strategies for supporting the parent(s) of children aged 18-36 months with suspected ASD?" An integrative review using Whittemore and Knafl's (2005) methodological rigour identified ten studies. Two overarching themes were highlighted. Knowledge on ASD and communication were the key themes identified in supporting parents and children.

This study provides insight for PCPs on the service provision challenges and facilitators that parents experience when their child is suspected of ASD and awaiting diagnosis. Parents often experience feelings of fear, isolation and frustration during this waiting period of time. These feelings continue after diagnosis as parents are overwhelmed by new information and service limitations, and poor communication with their PCP can influence future care for their child. PCPs that engage with parents of children with suspected or newly diagnosed ASD form collaborative, positive, and long-lasting relationships that can positively influence the child's access to services and care.

In consideration of the many demands of daily clinical practice, the PCP is not expected to be an expert or primary care coordinator in ASD management. However, this review calls upon PCPs with vested interests in this population to be alert to the experiences of parents during the anticipatory waiting period of their child's suspected ASD diagnosis, and to serve as a source of emotional and educational support. As parents become the experts in their child's care, the PCP can act as a translator of information for parents following diagnosis, and provide navigation for community resources. Furthermore, the PCP can maintain connection between fellow multidisciplinary team members, act as advocate for system-wide and organizational changes, and finally promote the provision of equitable PFCC practices. These strategies improve the parent-PCP relationship, and may eventually influence the improvement of early referral,

diagnosis or intervention for ASD, in effect improving the quality of life for children with ASD and their families.

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APPENDIX A: MODIFIED CHECKLIST FOR AUTISM IN TODDLERS, REVISED

MCHAT			
	www.m-chat.org		
Child's name	Date		
Age	Relationship to child		
M-CHAT-R [™] (Modifi	ied Checklist for Autism in Toddlers Revised)		
Please answer these questions about your child. Keep in mi she does not usually do it, then please answer no . Please c	nd how your child <u>usually</u> behaves. If you have seen your child do the beha ircle yes <u>or</u> no for every question. Thank you very much.	vior a few tin	nes, but he or
1. If you point at something across the room (FOR EXAMPLE, if you point at a toy or	m, does your child look at it? an animal, does your child look at the toy or animal?)	Yes	No
2. Have you ever wondered if your child m	ight be deaf?	Yes	No
 Does your child play pretend or make-be from an empty cup, pretend to talk on a p 	elieve? (For ExAMPLE, pretend to drink phone, or pretend to feed a doll or stuffed animal?)	Yes	No
Does your child like climbing on things? equipment, or stairs)	(FOR EXAMPLE, furniture, playground	Yes	No
5. Does your child make <u>unusual</u> finger mo (For EXAMPLE, does your child wiggle his	ovements near his or her eyes? s or her fingers close to his or her eyes?)	Yes	No
 Does your child point with one finger to (FOR EXAMPLE, pointing to a snack or toy) 	ask for something or to get help? / that is out of reach)	Yes	No
7. Does your child point with one finger to (FOR EXAMPLE, pointing to an airplane in	show you something interesting? the sky or a big truck in the road)	Yes	No
8. Is your child interested in other children' other children, smile at them, or go to the	? (FOR EXAMPLE, does your child watch m?)	Yes	No
 Does your child show you things by brin see – not to get help, but just to share? (animal, or a toy truck) 	ging them to you or holding them up for you to FOR EXAMPLE, showing you a flower, a stuffed	Yes	No
10. Does your child respond when you call I look up, talk or babble, or stop what he o	nis or her name? (FOR EXAMPLE, does he or she r she is doing when you call his or her name?)	Yes	No
11. When you smile at your child, does he c	r she smile back at you?	Yes	No
12. Does your child get upset by everyday r child scream or cry to noise such as a va	noises? (FOR EXAMPLE, does your cuum cleaner or loud music?)	Yes	No
13. Does your child walk?		Yes	No
14. Does your child look you in the eye whe or her, or dressing him or her?	n you are talking to him or her, playing with him	Yes	No
15. Does your child try to copy what you do' make a funny noise when you do)	? (For Example, wave bye-bye, clap, or	Yes	No
16. If you turn your head to look at somethin are looking at?	ng, does your child look around to see what you	Yes	No
17. Does your child try to get you to watch h look at you for praise, or say "look" or "wa	<pre>im or her? (For Example, does your child atch me"?)</pre>	Yes	No
18. Does your child understand when you te (For EXAMPLE, if you don't point, can you on the chair" or "bring me the blanket"?)	ell him or her to do something? ur child understand "put the book	Yes	No
 If something new happens, does your cl (For EXAMPLE, if he or she hears a stran he or she look at your face?) 	nild look at your face to see how you feel about it? ge or funny noise, or sees a new toy, will	Yes	No
20. Does your child like movement activities (For EXAMPLE, being swung or bounced	? on your knee)	Yes	No

2009 Diana Robins, Deborah Fein, & Marianne Barton

APPENDIX B: CONCEPT MAP



APPENDIX C: LITERATURE SEARCH BOOLEAN COMBINATIONS

Search Combinations Search #1: November 24, 2017 (Primary Care OR family physician OR nurse practitioner) AND Autism Spectrum Disorders AND (Screening or Surveillance) = 240 results ==> used 5 articles - (Barbaro, Carbone & N, Garg, Monteiro, Rhoades) Search #2: December 26, 2017 (Primary care OR family physician OR nurse practitioner OR paediatrician OR professionalfamily relations) AND Autism Spectrum Disorders AND (Referral OR Diagnosis OR Intervention) AND (Parent or family or caregiver) = 454 results ==> used 5 articles (Carbone &B, Bloch, Hennel, Feinberg, Mulligan) Other engines searched December 8, 2017: Cochrane: 28 = 0Clearinghouse: 2 guidelines; Canada Task Force and NICE = 0 used (neither really discuss parent/PCP relationship or strategies) Joanna Briggs: 0 Grey Literature searched December 8, 2017: **BC** Guidelines Support websites: Autism Information Services BC Autism Society of BC Autism Support Network BC Autism Assessment Network (BCAAN) Children and teens with special needs Family Support Institute Pacific Autism Family Center Provincial Outreach Program for Autism and Related Disorders --> for schools SET BC \rightarrow for schools American Academy of Pediatrics and Canadian Pediatric Society Patient education & Counselling Journal

APPENDIX D: CRITICAL APPRAISAL SKILLS PROGRAMME CHECKLISTS

Cohort Study	Randomized Control Trial	Qualitative Study
Section A: Are the results of the study	Section A: Are the results of the study	Section A: Are the results of the
valid?	valid?	study valid?
1. Did the study address a clearly focused	1. Did the study address a clearly focused	1. Was there a clear statement of the
issue?	issue?	aims of the research?
2. Was the cohort recruited in an acceptable	2. Was assignment of patients to	2. Is a qualitative methodology
way?	treatments randomized?	appropriate?
Is it worth continuing?	3. Were all of the patients who entered the	Is it worth continuing?
3. Was the exposure accurately measured to	trial properly accounted for at its	3. Was the research design appropriate
minimize bias?	conclusion?	to address the aims of the research?
4. Was the outcome accurately measured to	Is it worth continuing?	4. Was the recruitment strategy
minimize bias?	4. Were patients, health workers and study	appropriate to the aims of the research?
5. a) Have the authors identified all important	personnel 'blind' to treatment?	5. Was the data collected in a way that
confounding factors?	5. Were the groups similar at the start of	addressed the research issue?
b) Have they taken account of the confounding	the trial?	6. Has the relationship between the
factors in the design and/or analysis?	6. Aside from the experimental	research and participants been
6. a) Was the follow up of subjects complete	intervention, were the groups treated	adequately considered?
enough?	equally?	Section B: What are the results?
b) Was the follow up of subjects complete	Section B: What are the results?	7. Have ethical issues been taken into
enough?	7. How large was the treatment effect?	consideration?
Section B: What are the results?	8. How precise was the estimate of the	8. Was the data analysis sufficiently
7. What are the results of the study?	treatment effect?	rigorous?
8. How precise are the results?	Section C: Will the results help locally?	9. Is there a clear statement of
9. Do you believe the results?	9. Can the results be applied to the local	findings?
Section C: Will the results help locally?	population, or in your context?	Section C: Will the results help
10. Can the results be applied to the local	10. Were all clinically important outcomes	locally?
population?	considered?	10. How valuable is the research?
11. Do the results of this study fit with other	11. Are the benefits worth the harms and	
available evidence?	costs?	
12. What are the implications of this study for		
practice?		

APPENDIX E: LITERATURE MATRIX

Author, Year, Country, Title	Study Design and Summary	Key Recommendations & Implications for PCP Role	Limitations
(Barbaro & Dissanayake, 2009)	Prospective cohort study	Additional training on ASD using a health care model for	Public health nurses were
		providers across multidisciplinary team with previous	participants in study; consider
Victoria, Australia	Nurses with previous	child development knowledge effective in improved	feasibility on PCP practice
	knowledge of developmental	surveillance	
Prospective identification of	milestones trained in ASD and		Australia-based healthcare
autism spectrum disorders in	at well-child visits put at-risk	Repeated surveillance increased accuracy of identifying	system, potentially different
infancy and toddlerhood using	kids into closer surveillance	ASD at 18 or 24 months	variables than Canada
developmental surveillance: The			
social attention and	Participants: 22,168 children,	Registry effective for closer monitoring children who have	
communication study.	241 nurses	missing or atypical developmental milestones	
(Bloch & Gardner, 2007)	Exploratory descriptive	Parents feel dismissed regarding initial concerns regarding	Homogenous, small sample
	qualitative study	their child's symptoms	size
USA			
	Looks at burdens caregivers of	Parents feel emotional distress when not heard and when	Retrospective study, may
Accessing a diagnosis for a child	new ASD dx face and how	feeling PCP unaware of the challenges they face with ASD	result in recall bias
with an autism spectrum disorder:	NPs/PCPs can help	within family	
the burden is on the caregiver			Older article, greater than 10
	Participants: 6 mothers of	Parents feel there is not enough time during appointments	years old
	children with ASD	to properly assess their child or listen to all concerns	
			US-based healthcare system,
			potentially different variables
			than Canada

Author, Year, Country, Title	Study Design and Summary	Key Recommendations & Implications for PCP Role	Limitations
(Carbone, Behl, Azor & Murphy, 2010)	Qualitative focus group Looks at gaps perceived by	Parents want PCPs to have knowledge on red flags, specialist referrals, medications, and be open to complementary alternative medicine discussions	Retrospective study, may result in recall bias
Salt Lake City, Utah The medical home for children with autism spectrum disorders: parent and pediatrician perspectives	both parents and physicians of children with ASD in a metropolitan population Participants: 5 parents, 9 pediatricians	For parents, early negative experiencesstrongly influenced future interactions; parents will change providers based on initial experiences regarding their child's diagnosis Parents wish providers conversation around stress and coping, often experiencing financial strain and information overload Parents likely to seek out informal parent-parent support rather than PCP support Parents are not aware of what a medical home can offer. Pediatricians found it beneficial to have an in-office care coordinator, or some form of a health care model improving multidisciplinary collaboration and coordination	Small sample size, homogenous group from specialized ASD school US-based healthcare system, potentially different variables than Canada
(Carbone, Norlin & Young, 2016) Utah, USA Improving early identification and ongoing care of children with autism spectrum disorder	Quantitative: quasi- experimental (cohort) Strategies implemented with aim to increase screening for ASD and providing care for children with ASD in rural and urban multidisciplinary clinic settings Participants: 20 pediatric and 6 family practice teams: at least 1 physician, nurse/MOA, office manager & parent of child with ASD	Learning collaborative strategies over 3-6 months increased PCP knowledge of ASD needs and associated conditions Creation of a registry of patients requiring follow up evaluation streamlined scheduling/appt set up specifically for children with special needs Such learning strategies with the multidisciplinary team effective in team collaboration and community service connection Educational opportunity improved use of screening tools as well as perceived PCP self-efficacy even up to 4 years later	Strategies may fall short if community resources are unavailable Doesn't describe what the role of each participant is? Post-surveys only include physicians US-based healthcare system, potentially different variables than Canada

Author, Year, Country, Title	Study Design and Summary	Key Recommendations & Implications for PCP Role	Limitations
(Feinberg et al., 2016)	Quantitative: Randomized control trial	Children within family navigation (FN) program more likely than children who receive routine clinic care to	FN strategies not clearly detailed
USA Reducing disparities in timely autism diagnosis through family navigation: Results from a randomized pilot trial	Feasibility of family navigation (FN) to improve timely diagnosis of ASD in low-income families from racial-ehnic minority groups Participants: 39 children suspected of ASD	 complete an ASD diagnostic assessment FN addressed structural and family barriers that impeded timely diagnosis FN focused on the needs of the family, including a broader scope of addressing navigating the medical system, community and educational barriers FN explored understanding of ASD, identifies barriers & community resources, and completing necessary documentation 	FN may not be a feasible role expectation of the PCP or if resources are limited US-based healthcare system, potentially different variables than Canada
		FN required the addition of other multidisciplinary team members, however addressed issues of role clarity within a focused model of care	
(Garg, Lillystone, Dossetor,	Mixed methods Study	There was more response from female GPs, Australian	Low specificity/sensitivity in
Ketford & Chong, 2014)	Survey for understanding	and/or child health.	a true/false survey
New South Wales, Australia An exploratory survey for understanding perceptions, knowledge and educational needs of general practitioners regarding autistic disorders in New South Wales (NSW), Australia	perceptions, knowledge and educational needs of general practitioners regarding autistic disorders Participants: 1185 GPs; 734 urban, 237 regional, 214 rural/remote	Variability was noted in how GPs perceived their competence and knowledge of autistic disorders. Self-directed learning was considered paramount in obtaining ASD knowledge Knowledge was inversely related to the number of years in practice and enhanced by personal involvement with children of these disorders and awareness of community	Australia-based healthcare system, potentially different variables than Canada
		resources. GP concerns include lack of role and pathway clarity, long wait times, and lack of adequate services in rural areas	

Author, Year, Country, Title	Study Design and Summary	Key Recommendations & Implications for PCP Role	Limitations
(Hennel et al., 2016)	Descriptive/Cross-Sectional	Pediatricians do not feel they have enough time to provide	Retrospective study, may
	Study	information on ASD at time of diagnosis	result in recall bias
Australia	D. DOD		
Diagnosing autism: Contemporaneous surveys of parent needs and paediatric practice: Parent needs at autism diagnosis	experience/preference/importa nce of diagnosis delivery, information at delivery and information after delivery	of diagnosis; particularly information on the education system, support groups, funding or allied health professionals	system, potentially different variables than Canada
liagnosis		time of and after diagnosis	
	43 pediatricians	Parents find allied health providers more helpful in providing information on ASD	
		Majority of families use CAM therapy with their child, yet do not receive information on this at time of diagnosis	
		Parents had a better experience receiving information at the time of diagnosis with a support person present or with written & spoken information	
(Monteiro et al., 2015)	Retrospective cohort study/Chart review	PCPs who are informed about ASD are more confident in referring children for early intervention and therapeutic	US-based healthcare system, potentially different variables
USA	Determining the prevalence of	services while awaiting diagnosis – formal diagnosis is therefore not necessary to initiate intervention	than Canada
Early intervention before autism	receipt of early intervention		Higher than average socio-
diagnosis in children referred to a	and therapeutic services in	Supporting appointments with written information may	demographics among patient
regional autism clinic	children before their ASD	empower parents to start early intervention	participants, potential for bias
	Participants: 561 children		Causes for early intervention suggested but no obvious correlation; challenging to repeat study findings

Author, Year, Country, Title	Study Design and Summary	Key Recommendations & Implications for PCP Role	Limitations
(Mulligan, MacCulloch, Good &	Phenomenological study	Parents experience a number of emotions from the time of	SW perspective (not PCP)-
Nicholas, 2012)		initial concern up to and following diagnosis. These	
	Experiences of parents	include:	Retrospective study, may
Ontario, Canada	experiencing ASD diagnosis	- Fear and helplessness prior to diagnosis	result in recall bias
	of their child, with a	- Relief with diagnosis, especially if given prognosis	
Transparency, hope, and	protocol/clinical guidelines for	through a hopeful lens	Other participant bias:
empowerment: A model for	providers to support them	- Feeling overwhelmed with information, desiring follow-	Parents in survey had pre-
partnering with parents of a child	throughout the experience	up for questions after initial conversation	existing knowledge or high
with autism spectrum disorder at	(what to share, how to share,	- Frustration with lack of resources, waitlists, and	levels of education
diagnosis and beyond	when to share)	dismissal of their own expertise	
	Participants: 10 parents (8 mothers, 2 fathers)	Parents require information on ASD through biomedical and sociopolitical spheres, inclduing: Service availability, their role in their child's care, timeliness of intervention, and available funding	
		Parents benefit from written and spoken information as well as repeated interactions to allow for follow-up questions and continuing dialogue into their child's care	
(Rhoades, Scarpa & Salley, 2007)	Descriptive/Cross-Sectional	Most parents say they receive information on ASD or	US-based healthcare system,
		resources at time of diagnosis, however most turn to media	potentially different variables
Virginia, USA	Online survey of parents	(internet, books, videos), conference/workshops or other	than Canada
	observing age of diagnosis,	parents for primary sources of information	
The importance of physician	information received at		Convenience sample: Self-
knowledge of autism spectrum	diagnosis, and sources that	Often resources are very limited, leaving little for PCPs to	selecting for online survey,
disorder: Results of a parent	parents use to seek ASD	refer to – however identification is better than nothing, and	possibility that populations
survey	information	the PCP can act as a lobbying advocate	accessing website have
	Destisionentes 146 menerates 6		similar blases
	children with ASD	runderstanding the chundeness of information on ASD and	No information on loval of
	children with ASD	can support parents to choose interventions that are evidence-based or empirically supported	training of professionals.
		criticitie custa of empiricary supported	