Caregiving of Sibling with Autism: A Systematic Review on Typical Siblings' Perspective

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Abstract
This systematic review aims to synthesize the extant literature on typical siblings' perspectives on the current or future caregiving of their sibling with Autism Spectrum Disorder (ASD). The Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) guidelines were employed in screening qualitative research between 2010 and 2019. The findings from the eleven studies that met the inclusion and exclusion criteria revealed the typical siblings' perspectives on the forms of and their feelings towards caregiving, and their need for support from professionals and family members. By understanding the forms of caregiving that could take place, siblings can better prepare themselves for the future and not be overwhelmed when the time comes for them to take over caregiving responsibilities from their parents.
Keywords: Sibling with ASD, Typical Siblings, Autism Spectrum Disorder, Caregiving

Introduction
Sibling relationships generally span over many years, enabling the formation of a long-lasting and enduring bond. Siblings play an important role in families during childhood and adulthood (Ferraioli et al., 2012; McHale at el., 2012). The role of a sibling becomes even more significant when disability exists among them. In this instance, the acceptance and challenges faced in dealing with the circumstances affect family members (Ali & Sarullah, 2010). Typical siblings have been reported to willingly take on the role as caregivers toward the sibling with disability (Heller & Arnold, 2010). In the case where a sibling has been diagnosed with Autism Spectrum Disorder (ASD), the typical siblings often describe their experiences, feelings, and thoughts as being diverse (Turns et al., 2016). This could largely be due to the broad range of spectrum and characteristics of the disorder.

Individuals diagnosed with ASD display deficits at different degrees of severity that affects their social interaction and communication besides having restricted or repetitive patterns of behaviors, interests, or activities (American Psychiatric Association (APA), 2013). Some may need their parents' extra care to perform daily tasks due to the lack of adaptive functioning (Lee et al., 2017). They also may need life-long support from others to perform their daily activities due to these deficits. In many instances, caregiving responsibilities are taken up by their parents. However, in cases when the parents are gone or no longer able to carry out their duties, the caregiving responsibilities will then fall onto the shoulders of the typical siblings. These siblings are the most significant members in the families in terms of

providing lifelong care for their sibling with disability socially, emotionally, and financially (Banda, 2015).

Even though many typical siblings undertake the role as caregivers, they have largely been overlooked and ignored by parents, professionals, researchers, policy, and practice as the focus of researchers has always been on their sibling with ASD and their parents (Tozer et al., 2014). Typical siblings play an important role in informing decision-making processes and policy development (Arnold et al., 2012). Realizing the need to let their voices be heard, considerable studies involving typical siblings of individuals with ASD have been conducted in recent years. The existing literature revealed that the typical siblings wish to be more involved in the lives of their disabled siblings, especially when their parents can no longer carry out the caregiving responsibilities (Davys et al., 2016). Their involvement in the lives of their sibling with ASD has been shown to have positive effects whereby the typical siblings reported feeling a greater sense of empowerment (Pavlopoulou & Dimitriou, 2019). However, past research revealed that they are concerned about the future. Typical siblings who anticipate their roles as the future caregivers of their sibling with ASD worry about future planning and transitioning into their roles whilst current caregivers are frustrated with the difficulties obtaining information about formal services for adults with ASD (Burke et al., 2015). Some studies report that typical siblings want to lead an independent life without the added the responsibilities of caring for their sibling with ASD (Dansby et al., 2018). Moreover, the typical siblings are required to undertake different caregiving roles toward their sibling with ASD, their ageing parents, and children of their own (Tozer & Atkin, 2015).

Recently, qualitative studies have been central in providing valuable insights on the experiences and issues pertaining to future caregiving of the individual with ASD. Research using qualitative approach revealed factors influencing typical siblings' intention to provide care related to the characteristics of the individual with ASD and the typical siblings as well as their family dynamics (Lee & Burke, 2018). The display of aggression and limited social interaction skills affect typical siblings' relationship with their sibling with ASD (Rossetti & Hall, 2015). Furthermore, past studies have found the impact of an intimate sibling relationship toward typical siblings' future caregiving involvement (Burke et al., 2012; Hodapp & Urbano, 2007). Family dynamics such as cultural background also contribute to typical siblings' perception of caregiving (Sage & Jegatheesan, 2010) Other less reported factors are the number of siblings in the family, in which lone typical siblings who have no other siblings than the individual with intellectual and/or development disability, and typical siblings who reside at a closer proximity to their sibling with ASD have to assume more responsibilities (Burke et al., 2012). Some studies also highlighted the gendered nature of care in the case of sibling caregiving whereby sisters were found to be more likely to assume the role of a caregiver compared to brothers (Burke et al., 2012; Sonik et al., 2016). These studies shed light upon the nature of sibling caregiving and the importance of providing support for typical siblings that can relieve their concerns and worries about their caregiving responsibilities.

Caregiving of individuals with ASD by their typical siblings cover a variety of responsibilities. However, sibling caregiving has been differently defined in most studies (Lee & Burke, 2018). This is due to the differing objectives of these studies, which required caregiving to be viewed from different perspectives. The caregiving of individuals with intellectual and developmental disabilities by their typical siblings can be defined as responsibilities that cover aspects encompassing finance, residential arrangements, legal matters, interaction with the service providers and provision of companionship as well as emotional support (Burke et al., 2012). Financial support involve monetary aid given to the

individual with ASD in the form of, among others, inheritance, trusts, and funds (Post et al., 2017). Residential arrangements for the individual with ASD fall into two aspects namely, home residence and placement at formal care services (Ferraioli & Harris, 2009). Meanwhile, legal matters are issues on caregiving pertaining to law such as guardianship and power of attorney (Davys et al., 2015). Companionship is provided to the individual with ASD for assistance in daily tasks and emotional support (Keith, 1995). Typical siblings need to negotiate the complex service systems for their sibling with ASD (Tozer et al., 2013). Sibling caregiver is also defined as the head of the household (Sonik et al., 2016). In addition, caregiving responsibilities can also include coordinating daily activities and maintaining sibling relationship (Mauldin & Saxena, 2018). It is worth noting that these studies involve caregiving responsibilities by typical siblings toward individuals with intellectual and/or developmental disability that is not ASD-specific.

Nevertheless, there is still a dearth of studies that systematically reviewed and analyzed the extant literature on the perspectives of typical siblings of individuals with ASD about current or future caregiving and its related issues, namely the aspects of the caregiving responsibilities, typical siblings' feelings about caring for their sibling with ASD, and support pertaining to sibling caregiving. At the time of writing, existing reviews generally focus on typical siblings of individuals with intellectual and developmental disabilities not specific to ASD (e.g., Lee & Burke, 2018). Meanwhile, reviews that include studies on typical siblings of individual with ASD do not delve into the aspects and issues on sibling caregiving (Davys et al., 2011; Mandleco & Webb, 2015). While these reviews have provided information that illuminate the experiences of typical siblings of individuals with ASD, it is also important to educate typical siblings on the aspects and issues pertaining caregiving of their sibling with ASD to sustain the wellbeing of families affected by the conditions of the individuals with ASD. To understand the complexities of typical siblings' experiences as caregivers, this review will be analyzing qualitative studies on issues pertaining to care of their sibling with ASD by the typical siblings. It is the utmost significance that the typical siblings are furnished with the knowledge and support to ease their transition in becoming the caregivers of their sibling with ASD (Burke et al., 2015). Hence, the purpose of this systematic review is to synthesize the qualitative studies published over the past decade on typical siblings' perspectives of future or current caregiving responsibilities. This article was guided by these questions:

(1) How do typical siblings describe their caregiving responsibilities?
(2) How do typical siblings feel about caregiving?
(3) What is the support needed by the typical siblings to carry out their caregiving responsibilities?

Materials and Methods

The systematic review approach was adopted according to the Preferred Reporting Items for Systematic reviews and Meta-Analyses, PRISMA guidelines (Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009). The relevant items in the PRISMA checklist were used to gather information from the existing literature and synthesize the findings in a systematic way. The use of PRISMA guidelines also helped in assuring the quality and transparency of reporting. The processes involved were identifying resources to gather articles, screening of relevant articles, identifying eligible articles, and finalizing the articles to be included in the systematic review.

Information Sources

This review relied on resources taken from two electronic databases: Scopus and Web of Science (WoS). These two databases are renowned for being robust, covering a multitude of subject areas including special education, autism, and family care. These databases also provide a vast coverage of content consisting of peer-reviewed journals. A manual search was also performed using the reference lists of the articles obtained via the online search to identify other studies pertaining to the context of this review.

Eligibility and Exclusion Criteria

The studies included in this review met the inclusion criteria which were a) articles published between 2010 and the time the search was conducted, which was in March 2019, as this review is focused on finding how research evolved around this subject matter during the span of a recent decade; b) only articles written in English were selected to avoid misinterpretation; c) articles were derived from peer-reviewed journals; d) articles with empirical data, which meant review articles, books, chapters in books and conference proceedings were excluded; e) qualitative studies; f) articles focusing on typical siblings' caregiving; and g) caregiving of individual with ASD. Studies that did not meet the inclusion criteria were excluded such as studies about siblings' parentification roles.

Systematic Review Process

The review process was conducted in March 2019. In accordance with the PRISMA guidelines, the first stage, identification of articles was included in the review. Identification using electronic databases was performed using the databases from Scopus and Web of Science. A variety of keywords, obtained from reference of past studies and the use of thesaurus, related to siblings' caregiving of their sibling with ASD were used to identify articles. These keywords represent the key aspects of this review which were terms used to describe a) Autism Spectrum Disorder (ASD) (e.g., autis* OR ASD OR pervasive developmental disorder*), b) caregiving (e.g., future carer* OR future caregiving OR carer*), and c) siblings (e.g., sibling* brother(s), sister(s)). The search string that was used to identify the relevant articles for this review is shown in Table 1.

Table 1

The search string used for the systematic review process.

Databases	Keywords used
Scopus	TITLE-ABS-KEY (("ASD" OR autis* OR asperger* OR "pervasive developmental disorder*" OR "PDD?NOS" OR "rett") AND ("future carer" OR "future caregiver" OR "future care giver" OR caring OR caregiving OR carer) AND (sibling* OR brother* OR sister*)
Web of Sciences (WoS)	TS = (("ASD" OR autis* OR asperger* OR "pervasive developmental disorder*" OR "PDD?NOS" OR "rett") AND ("future carer" OR "future caregiver" OR "future care giver" OR caring OR caregiving OR carer) AND (sibling* OR brother* OR sister*))

The initial search from these databases resulted in 174 records. Subsequently, the reference lists of the articles recovered from the online search were manually searched to retrieve four additional articles. After obtaining the articles from the information sources, 26 duplicate records were removed in order to proceed to the next stage. During the second

stage, the remaining records' titles and abstracts were screened and 134 articles that did not meet the inclusion criteria were removed. In the eligibility stage, a full review on the remaining 18 articles was performed thoroughly and seven more records were excluded due to their irrelevance. The systematic review process is shown in Figure 1.

Quality Assessment

The articles selected for this review were analyzed to appraise the quality of the research conducted. As all eligible articles were qualitative in nature, the Critical Appraisal Skills Programme for qualitative studies was used as a guide to evaluate the suitability of the articles included in this review (Critical Appraisal Skills & Programme, 2018). Discussions with the second and third authors were held to agree upon exclusion of records due to irrelevance (studies on siblings' parentification).
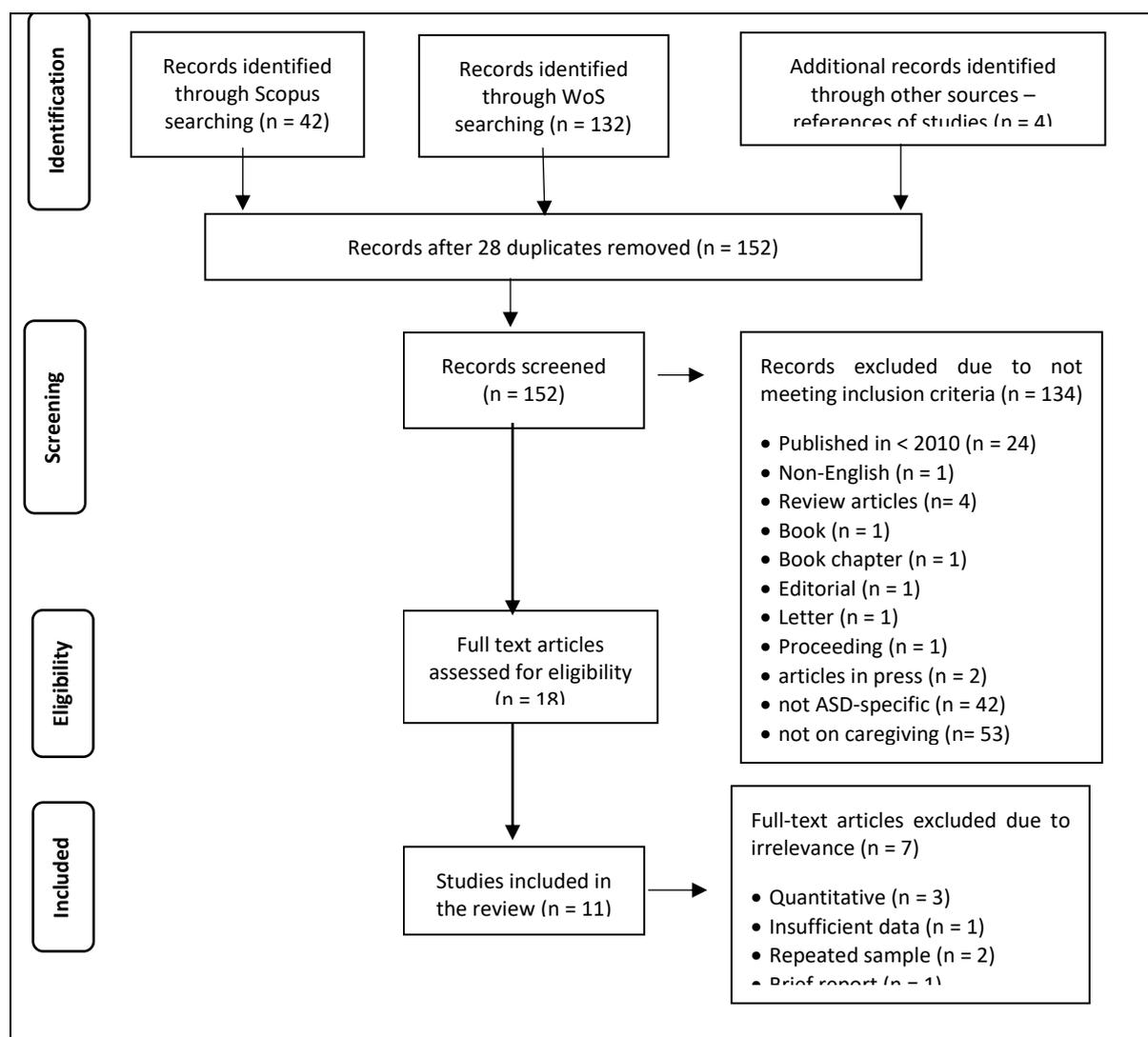

Figure 1. The flow diagram of this review (Adapted from Moher et al., 2009)

Data Extraction and Analysis

The 11 articles that met the inclusion criteria were analyzed in further detail to obtain data relating to the purpose of this review. Thematic synthesis was used to analyze the results and findings reported by the author(s) of the articles (Thomas & Harden, 2008). As mentioned by

Lee and Burke (2018), the definition of caregiving given by Burke *et al* (2012) is used to guide the authors in identifying the themes related to the aspects of siblings' caregiving due to the lack of a unified definition of the construct. Data analysis began with reading each article line by line to identify codes derived from significant words or statements, Codes from the articles were categorized into relevant descriptive themes which were then synthesized to produce analytical themes.

Results
Study Characteristics
A total of 193 typical siblings of sibling with ASD were included in these 11 studies. Two studies did not specify the genders of their participants. Out of the 117 siblings whose genders were specified, 41 were males and 76 were females. Although two studies did not specify the ages of the participants, they were predominantly reported to be older siblings. Nine out of the 11 studies employed semi-structured interviews, one visual ethnography and one phenomenological content analysis approaches. Three studies were from England {Formatting Citation}, two were from Ireland (Noonan et al., 2018), and one each from Australia Duignan & Connell (2015), France Sibeoni et al (2019), Italy Corsano et al (2016), South Korea Hwang & Charnley (2010), and Wales (Petalas et al., 2012). One study Dansby et al (2018) did not specify the country as data was derived from online postings in a forum, which can be made from anywhere in the world. Table 2 below illustrates the characteristics of the articles reviewed.

Table 2
Study Characteristics

Author(s)	Country	Method	Participants	Findings
**Corsano *et al*. (2018)	Italy	Qualitative (semi-structured interviews) Content analysis	14 typical adolescents (nine males and five females, aged between 12-20) with a brother with an ASD (aged between 12-20), and their mothers (n=13, aged between 40–52). Eight out of the nine brothers and three out of the five sisters were older siblings.	Typical siblings describe their experiences including mixed feelings about their sibling with ASD, a precocious sense of responsibility, concern about the future, difficulties in relationships with friends, and finding it hard to talk about their sibling with ASD.
*Dansby *et al*. (2018)	Not specified	Qualitative (phenomenological content analysis)	65 typical siblings (aged between 17-31) who made blog entries, comments, or replied to original posts relating to their	Typical siblings describe their experiences as (1) having unique relationships with their sibling with

Author(s)	Country	Method	Participants	Findings
			sibling with ASD. Age and gender of siblings not specified, but from context, most bloggers/commenters were older than their sibling with ASD.	ASD, (2) feelings of a complex range of emotions, (3) having an effect on their personal and future lives, and (4) ways of coping with the stress.
**Duignan and Connell (2015)	Australia	Qualitative (semi-structured interviews)	40 carers, who were attending carers support groups, consisting of three fathers, three typical adult brothers, eight typical adult sisters and 26 mothers aged between 18–91, caring for ASD individuals aged between 2-57. Age of siblings not specified.	The demands caring for sibling with ASD affect typical siblings in a way that they have to make adaptation to home spaces, change pattern of employment and socialization, home avoidance, and altering intra-family relationships.
Hwang and Charnley (2010)	South Korea	Qualitative (visual ethnographic 76 daily video diary entries and 110 home movies).	Nine typical siblings of ASD individuals (four males and five females) aged between 7-15.Three out of the four brothers and two out of the five sisters; were older siblings.	The Confucian values heavily affects the typical siblings' lived experiences in which sacrifice is important in achieving family harmony.
Noonan *et al* (2018)	Ireland	Qualitative (semi-structured interviews) Interpretative Phenomenological Analysis	Eight typical siblings (three males and five females) of adults with ASD and co-occurring intellectual disability; aged 18 to 37 years old.	Typical siblings describe the complex experience explained by the overarching theme "engaging with and navigating limbo", which was characterized by commitment to the sibling

Author(s)	Country	Method	Participants	Findings
				relationship, power tensions in the family, uncertainty about the future and negotiating the tension between relational closeness and distance.
Pavlopoulou and Dimitriou (2019)	England	Qualitative (semi-structured interviews) Interpretative Phenomenological Analysis	Nine typical sisters aged between 10-14. Seven out of the nine sisters were older siblings.	Sisters describe their interactions with their sibling with ASD and parents, struggles of caring, and perceived needs.
Petalas et al (2012)	Wales	Qualitative (semi-structured interviews). Thematic analysis	12 typical adolescents with a brother with an ASD aged between 14–17 (six males, six females). Nine older siblings, but their genders were not specified. Interpretative Phenomenological Analysis	Typical siblings expressed their perspectives of growing up with their sibling with ASD. One of the themes describe their' thoughts and worries about the future.
Rawson (2010)	England	Qualitative (semi-structured interviews) Thematic analysis	13 typical siblings aged between 17–23 (two males, 11 females) of boys and girls who attend/had attended a residential school for young people with complex needs, majority of the student population are ASD individuals Both brothers and nine out of the 11 sisters were older siblings.	Typical siblings felt unprepared and concerned due to their lack of knowledge pertaining to the future responsibilities, transitioning to adult services, being held responsible for their sibling with ASD, and their welfare.
Sibeoni et al (2019)	France	Qualitative (semi-structured interviews)	20 typically developing boys or girls aged between	Older typical siblings describe the relationship

Author(s)	Country	Method	Participants	Findings
		Thematic analysis.	12-18 (seven males and 13 females) with a younger sister or brother attending sessions in two-day hospitals for at least one year for severe ASD. All participants were older siblings.	they have with their sibling with ASD as (1) a classic sibling relationship in which they share moments and pleasures and (2) a helper and a care giver in the present or future.
**Tozer and Atkin (2015)	England	Qualitative (semi-structured interviews)	21 typical adult siblings (Seven males and 14 females, aged between 24-67), 12 of their siblings with ASD, 12 health and social care professionals. Four out of the seven brothers and 12 out of the 14 sisters were older siblings.	Typical siblings reported willingness to care for their sibling with ASD but faced marginalization from service providers, who lack engagement with typical siblings.
*Yacoub *et al* (2018)	Ireland	Qualitative (structured interviews) Thematic analysis	11 typical adult siblings of service users who have ASD and ID as well as a history of challenging behaviour. Age of siblings not specified.	Challenging behaviour can cause emotional losses and can impact upbringing and the sibling relationship. Despite the siblings making adjustments, they continue to have concerns for the future.

ASD = Autism Spectrum Disorder, * = Gender and age of participants not specified, ** = Participants include parents, sibling with ASD Spectrum Disorder and/or professionals. Only typical siblings' accounts were analyzed.

Thematic Synthesis

Themes were generated using a method introduced by Thomas and Harden (2008) called thematic synthesis. Using this method, each article was read thoroughly to identify codes from statements of participants or the author. The codes from all the articles were then grouped into their respective descriptive themes. Finally, analytical themes were created to group together descriptive themes. The example of this process is the identification of codes

(1) 'arranging accommodation' and (2) 'interaction with professionals' from the statement in Tozer and Atkin (2015): "*Some siblings described how they had to negotiate moving their brother or sister to alternative accommodation, despite reassurances from social care professionals that he or she had a 'home for life.'*" Meanwhile, code (3) 'power of attorney' was identified from the quote in Dansby *et al.* (2018), *"(My parents) were going to give me power of attorney over my siblings in case something ever happened to my parents."* Each code was grouped into its respective subtheme. In the example given, code (1) was placed under the subtheme 'residential arrangements ' and code (2) was placed under the subtheme 'interaction with services'. Meanwhile, code (3) was placed under the subtheme 'legal matters'. These subthemes were grouped into the analytical theme 'caregiving responsibilities'.

Guided by the aims of this research, three main themes and ten subthemes were derived from the findings this review (Table 3). The first theme was the typical siblings' description on the forms of caregiving responsibilities (n=11 articles) and were categorized into five subthemes; the second theme was the typical siblings' feelings about caregiving (n=10 articles) which were categorized into three subthemes; and the third theme was the support needed by siblings (n=9 articles) and categorized into two subthemes.

Table 3
Summary of Findings

First author and year	Caregiving responsibilities					Feelings			Support	
	FS	RA	LM	IS	CE	R	C	W	SS	PS
Corsano (2016)		✓					✓	✓	✓	✓
Dansby (2018)	✓	✓	✓		✓	✓	✓		✓	✓
Duignan (2015)		✓			✓		✓			
Hwang (2010)	✓	✓			✓		✓			
Noonan (2018)		✓		✓	✓		✓	✓	✓	✓
Pavlopoulou (2019)		✓		✓	✓	✓	✓			✓
Petalas (2012)		✓			✓		✓		✓	✓
Rawson (2010)	✓	✓	✓	✓	✓		✓	✓		✓
Sibeoni (2019)		✓			✓		✓			✓
Tozer (2015)		✓	✓	✓	✓	✓	✓	✓	✓	✓
Yacoub *2018)		✓					✓		✓	✓

FS = Financial Support, RA = Residential Arrangements, LM = Legal Matters, IS = Interaction with Services, CE = Companionship and Emotional Support, R = (Sense of) Responsibility, C = Challenging, W = Worry, SS = Social Support and PS = Professional Support.

Typical siblings' description of the forms of caregiving responsibilities
Five subthemes were derived from all 11 articles describing the forms of caregiving responsibilities toward sibling with ASD undertaken by typical siblings. These were in line with those described by Burke *et al* (2012) which were related to financial support, residential arrangements, legal matters, interaction with services, and provision of companionship and emotional support.
Financial support. In three studies, the typical siblings were aware of their eventual involvement in the financial aspects of caregiving toward their sibling with ASD once their parents pass away (Dansby et al., 2018; Hwang & Charnley, 2010; Rawson, 2010). However, this responsibility was met with different reactions. According to some cultures, typical

female siblings are not expected to provide financial support to their sibling with ASD (Hwang & Charnley, 2010). This cultural role expectation placed the responsibility of providing financial aid to the individual with ASD on the shoulders of the typical brothers. Additionally, financial support for the individual with ASD also include aspects such as Wills, trusts, and funds, which are aspects that are interrelated with legal matters (Rawson, 2010).

Residential arrangement. The residential arrangements for the sibling with ASD is a theme that emerged in all 11 studies included in this review. One of the arrangements was to place the sibling with ASD at residential facilities providing full time care (Corsano et al., 2016; Dansby et al., 2018; Duignan & Connell, 2015; Noonan et al., 2018; Pavlopoulou & Dimitriou, 2019; Petalas et al., 2012; Rawson, 2010; Tozer & Atkin, 2015; Yacoub et al., 2018). Typically, the sibling with ASD is placed at a residential facility due to the inability of his or her family members to manage aggressive behaviors that risk the safety of everyone living in that house. Typical siblings also decided to place their sibling with ASD at a care facility if they could not manage the added responsibilities of sibling caregiving due to life commitments (Dansby et al., 2018; Rawson, 2010; Tozer & Atkin, 2015). The placement of ASD sibling at formal care facilities were decided by their parents (Duignan & Connell, 2015; Noonan et al., 2018; Petalas et al., 2012). Some of the typical siblings were not keen with the idea of their parents to send their ASD sibling to a full-time care (Noonan et al., 2018). Typical siblings also wished for their sibling with ASD to live independently, albeit with some form of support (Corsano et al., 2016; Hwang & Charnley, 2010; Petalas et al., 2012; Tozer & Atkin, 2015). Another preferred residential arrangement for the sibling with ASD is to live with or close to his or her parents or typical siblings (Corsano et al., 2016; Duignan & Connell, 2015; Hwang & Charnley, 2010; Noonan et al., 2018; Petalas et al., 2012; Sibeoni et al., 2019; Tozer & Atkin, 2015). Typical siblings needed to find partners who would be able to live with the rules that existed due to their sibling with ASD, such as the need to stick to a set routine (Duignan & Connell, 2015). Their partner also should not mind taking on added responsibilities (Hwang & Charnley, 2010). These placements are done either permanently or temporarily until a suitable service is identified. Additionally, the typical siblings who participated in Hwang and Charnley's (2010) research reported the care of the individual with ASD by other than family members were deemed implausible.

Legal matters. Typical siblings also oversee the aspect of legal matters that are involved in sibling caregiving. Legal matters pertain to the rights of the typical siblings as guardians of their sibling with ASD and aspects related to Power of Attorney, wills, and trusts (Rawson, 2010). Legal matter are mentioned in three studies (Dansby et al., 2018; Rawson, 2010; Tozer & Atkin, 2015). Some parents made plans to hand over the power of attorney to the typical siblings in the event of the parents' sudden incapacitation (Dansby et al., 2018). Typical siblings were uncertain about their rights as caregivers to impose changes to the care received by their sibling with ASD (Tozer & Atkin, 2015). The uncertainties appeared as typical siblings were not equipped with sufficient information regarding legal matters (Rawson, 2010). Hence, Rawson (2010) developed an information pack containing information that will help typical siblings' transition to their role as caregiver.

Interaction with services. Typical siblings' involvement in the transitioning of their sibling with ASD to adult services was one of the areas of caregiving discussed in four of the studies in this review (Noonan et al., 2018; Pavlopoulou & Dimitriou, 2019; Rawson, 2010; Tozer & Atkin, 2015). The interactions between typical siblings and service providers were based on discussions of matters pertaining to support programs for their adult sibling with ASD. Typical siblings concentrated their efforts to look for information on services that can assist smooth

transition of their sibling with ASD to adult services (Rawson, 2010). They were particularly concerned with finding suitable services that would provide quality long-term care for their disabled siblings (Pavlopoulou & Dimitriou, 2019; Rawson, 2010). Typical siblings who are older and are at the stage in their lives where they have lesser commitments toward their own families were more involved in sibling caregiving and had more interactions with service providers (Tozer & Atkin, 2015). Typical siblings also want information regarding the availability of services that provide a holistic approach to the long-term care of the adult sibling with ASD, training on employment skills so as to prepare the ASD siblings for employment, and enjoyable social activities for their sibling with ASD (Pavlopoulou & Dimitriou, 2019). Occasionally, typical siblings would disagree with the approach used by the service provider, however they expressed gratitude to the service provider for their tireless effort and time spent working with their sibling with ASD (Noonan et al., 2018).

Companionship and emotional support. The companionship and emotional support were discussed in nine studies in this review (Dansby et al., 2018; Duignan & Connell, 2015; Hwang & Charnley, 2010; Noonan et al., 2018; Pavlopoulou & Dimitriou, 2019; Petalas et al., 2012; Rawson, 2010; Sibeoni et al., 2019; Tozer & Atkin, 2015). The majority of the typical siblings in Hwang and Charnley (2010) expressed their intention to provide care for their sibling with ASD that was built upon the strong connection both physically and emotionally. The emotional bond shared between the siblings was the driving force for the typical siblings to take on the caregiving responsibilities as they wished for a more intimate relationship with their sibling with ASD (Petalas et al., 2012; Tozer & Atkin, 2015). Some typical siblings appreciate the companionship provided by their sibling with ASD and really enjoyed spending some alone time together (Duignan & Connell, 2015; Noonan et al., 2018; Pavlopoulou & Dimitriou, 2019). Companionship of typical siblings also include the provision of direct care toward their sibling with ASD (Dansby et al., 2018; Sibeoni et al., 2019). Some of the typical siblings were not involved in any caring responsibility toward their sibling with ASD due to fear of overburdening (Rawson, 2010). However, they claimed to be very involved in providing emotional support to their sibling with ASD. Additionally, typical siblings felt responsible to provide emotional support to their sibling with ASD upon the passing of their parents (Hwang & Charnley, 2010; Tozer & Atkin, 2015).

Typical siblings' feelings about caregiving

All 11 articles in this review described the mixed feelings experienced by typical siblings in undertaking caregiving responsibilities and how these feelings further influenced their desire to be caregivers. Three subthemes derived were sense of responsibility, challenge and burden, and worry.

Sense of responsibility. Eight studies discussed the typical siblings' desire to become caregivers which was found to be driven by their strong sense of responsibility toward their sibling with ASD (Corsano et al., 2016; Dansby et al., 2018; Hwang & Charnley, 2010; Pavlopoulou & Dimitriou, 2019; Petalas et al., 2012; Rawson, 2010; Sibeoni et al., 2019; Tozer & Atkin, 2015). They were committed to the cause of becoming primary caregivers for their sibling with ASD and taking over that responsibility from their parents (Corsano et al., 2016; Dansby et al., 2018; Hwang & Charnley, 2010; Rawson, 2010; Tozer & Atkin, 2015). Typical siblings assumed the duties as caregivers of their sibling with ASD which was borne out of their sense of responsibility toward the family (Hwang & Charnley, 2010; Pavlopoulou & Dimitriou, 2019). Meanwhile, while some just acknowledged and naturally assumed the responsibility (Petalas et al., 2012; Sibeoni et al., 2019). Typical adolescent siblings have the

ability to reflect upon previous experiences and are used to taking on responsibilities for their sibling with ASD (Petalas et al., 2012; Sibeoni et al., 2019). Petalas *et al* (2012) reported the adolescent siblings becoming more involved in the lives of their sibling with ASD and have better coping skills compared to when they were younger. Furthermore, adolescent siblings are more aware of the implications of the ASD sibling's condition in terms of future caregiving (Sibeoni et al., 2019).

Challenging and burdensome. All 11 articles reported the challenges faced by the typical siblings in providing care for their sibling with ASD. The challenging aspect of caregiving is due to the atypical characteristics of the sibling with ASD and typical siblings' commitment to other life responsibilities. Typical siblings found the added responsibility of caring for their sibling with ASD to be burdensome (Corsano et al., 2016; Dansby et al., 2018). Furthermore, they also find their responsibilities toward their sibling with ASD very challenging (Duignan & Connell, 2015; Noonan et al., 2018; Petalas et al., 2012; Rawson, 2010; Tozer & Atkin, 2015; Yacoub et al., 2018). The difficulties faced by the typical siblings were due to the aggression of their sibling with ASD and their incapability managing the behaviors (Duignan & Connell, 2015; Yacoub et al., 2018) They were also aware of the challenges in care due to their sibling's inability to perform self-care tasks independently (Sibeoni et al., 2019). Meanwhile, the sisters in Pavlopoulou and Dimitriou (2019) did not specifically mention the challenges in the future caregiving of their sibling with ASD, however, they hoped to find more information on ways to improve the communication of their sibling with ASD and ways to manage the sibling's sensory processing issues. Typical siblings' inability to manage challenging behaviors could be detrimental to the special needs siblings' wellbeing (Dansby et al., 2018; Duignan & Connell, 2015; Rawson, 2010).

Additionally, typical siblings must shoulder more responsibilities as they grow older. These siblings felt conflicted with the need to juggle commitments between their sibling with ASD and their relationships with their partners, children, parents, and friends (Duignan & Connell, 2015; Hwang & Charnley, 2010; Tozer & Atkin, 2015). Moreover, the challenges faced by the typical siblings in the study conducted by Hwang and Charnley (2010) were due to the public's stigma about disabilities and the embarrassment they felt due to the ASD sibling's condition. The typical siblings who made the commitment to care for their sibling with ASD described their choice in partners as those who could willingly accept the condition of their sibling with ASD (Duignan & Connell, 2015; Hwang & Charnley, 2010). The challenges in sibling caregiving were also attributed by the lack of information dissemination to guide their decision-making of the caregiving of their sibling with ASD (Rawson, 2010). Due to these challenges, some typical siblings decided to not partake in the caregiving of their sibling with ASD in the future (Corsano et al., 2016; Dansby et al., 2018).

Worry. Nine studies reported that the typical siblings have worries and concerns for what the future might hold for them and their sibling with ASD. Typical siblings raised concerns regarding the future in which they would have to negotiate the services and supports for their sibling with ASD (Noonan et al., 2018; Pavlopoulou & Dimitriou, 2019; Petalas et al., 2012; Rawson, 2010; Tozer & Atkin, 2015; Yacoub et al., 2018). Typical siblings were unsure about the availability of services for their sibling with ASD once they become adults (Pavlopoulou & Dimitriou, 2019; Rawson, 2010). The quality of services received by their sibling with ASD is one of the reasons for concern for typical siblings They regard the quality of care by offered by formal services would not compare to theirs (Hwang & Charnley, 2010). Additionally, the sudden changes in the structure of service (Tozer & Atkin, 2015) and the termination of service showed the volatile nature of services and caused problems for the typical siblings

(Noonan et al., 2018; Yacoub et al., 2018). Typical siblings also faced difficulties engaging with service providers who did not value the importance of the role typical siblings play in the lives of the individuals with ASD, especially after the parents are gone (Noonan et al., 2018; Tozer & Atkin, 2015). The typical siblings were also unsure of the role they play in caring for their sibling with ASD after their parents have passed away (Corsano et al., 2016; Dansby et al., 2018; Petalas et al., 2012). Typical siblings were worried that the caregiving they provide for their sibling with ASD is incomparable to the care provided by their parents (Rawson, 2010). Moreover, they were also apprehensive over the responsibilities and major decisions that they had to undertake on behalf of their sibling with ASD. Additionally, typical siblings were concerned with the care of their sibling with ASD once they become older and have poorer health (Rawson, 2010; Yacoub et al., 2018).

Typical siblings' need for support

Different supports were needed by the typical siblings to provide future caregiving of their sibling with ASD. Social support and professional support are two subthemes regarding the support needed by the typical siblings in carrying out their caregiving responsibilities.

Social support. Typical siblings mentioned the need for social support in five articles (Dansby et al., 2018; Noonan et al., 2018; Petalas et al., 2012; Tozer & Atkin, 2015; Yacoub et al., 2018). The social support needed by typical siblings was not the assistance in caring for their sibling with ASD, but more of the provision of moral and emotional support for them as caregivers for their sibling with ASD. The opportunity to have open discussions with their parents and the rest of their family to address future concerns would help lessen their worries about the future (Noonan et al., 2018; Petalas et al., 2012; Tozer & Atkin, 2015; Yacoub et al., 2018). However, typical siblings were reluctant to initiate discussions with their parents as thinking about something far ahead may cause discomfort (Noonan et al., 2018). Typical siblings wanted an opportunity to share their experiences with siblings who were facing the same situation as they were and at the same time gain knowledge from the information shared. Some typical siblings sought support offered by sibling support group (Corsano et al., 2016), while others through online community (Dansby et al., 2018). Typical siblings hoped to gain social support from their community through societal reform that can be achieved through educating the public about ASD to avoid stigmatization (Yacoub et al., 2018).

Professional support. Apart from social support, nine of the studies in this review highlighted the typical siblings seeking information and support from the service providers to appease their concern about their future responsibilities (Corsano et al., 2016; Dansby et al., 2018; Noonan et al., 2018; Pavlopoulou & Dimitriou, 2019; Petalas et al., 2012; Rawson, 2010; Sibeoni et al., 2019; Tozer & Atkin, 2015; Yacoub et al., 2018). Professional support is the aid provided to typical siblings by practitioners, professionals, and/or service providers. Typical siblings hoped to be included in planning for the future and wished for services and information to be more accessible (Pavlopoulou & Dimitriou, 2019; Petalas et al., 2012; Rawson, 2010; Sibeoni et al., 2019; Tozer & Atkin, 2015). Information should be easily available during the transition to adult services as it is often a very stressful period for families affected by ASD (Rawson, 2010). Rawson (2010) also outlined ways for information to be shared with typical siblings such as disseminating information pack containing information regarding future care, testimonials of other siblings who have gone through successful transitioning with their ASD sibling, website development dedicated to typical siblings, and regular communication with service providers. Typical siblings who were aware of their role as the future caregiver to their sibling with ASD began to attend reviews to familiarize

themselves with the services and attain knowledge (Noonan et al., 2018). Additionally, typical siblings hoped practitioners were aware of their struggles in trying to maintain involvement due to other life commitments, especially for typical siblings with young families (Tozer & Atkin, 2015). Despite their struggles, the siblings wanted a more collaborative relationship with practitioners and would like to be involved in more discussions and planning (Tozer & Atkin, 2015). However, some of the siblings rejected the idea of getting long-term care services for their sibling with ASD, and preferred hiring domestic helpers to look after their sibling with ASD in times of need (Hwang & Charnley, 2010). Typical siblings also acquired professional help by attending therapy and/or counseling to cope with their burden (Corsano et al., 2016; Dansby et al., 2018; Tozer & Atkin, 2015). Lastly, typical siblings also called for a policy enactment to improve services that will increase public knowledge about ASD (Yacoub et al., 2018).

Discussion

This paper aimed to systematically synthesize the existing literature over the last decade on the typical siblings' perspectives of the current or future caregiving of their sibling with ASD and its related issues, namely feelings and support associated with the responsibility. This review analyzed the articles for descriptions of caretaking that took the forms of finance, residential arrangements, legal matters, interaction with services as well as provision of companionship and emotional support based on the definition set by (Burke *et al*., 2012). Overall, the results from the analysis showed the typical siblings' acceptance of the responsibility as primary caregivers to their special sibling with ASD. This could be due to the predominantly female participants, as shown by past studies in which typical sisters have higher inclination toward undertaking caregiving responsibilities (Cridland et al., 2016). The typical siblings' degree of involvement differed depending on their current life stage in terms of their commitment and responsibilities (Tozer et al., 2013). Most of the typical siblings in the studies were older siblings; nevertheless, research has shown that birth order is not a determining factor on the siblings' caregiving intent (Tudor & Lerner, 2015).

Financial and legal issues are the important aspects of sibling caregiving for smooth transitioning of care from parents to the typical siblings (Arnold et al., 2012). However, these were the least discussed aspects of caregiving mentioned by the typical siblings in the studies included in this review. Most of the time, parents tend to overlook their children in issues pertaining to the financial and legal aspects of care as they considered it as unnecessary burden to the typical siblings (Rawson, 2010). Failure in seeing the importance of planning the financial and legal aspects of sibling caregiving can lead to future uncertainties and worries for the typical siblings. In addition, the siblings' interactions with services were infrequent and labeled unreliable by the practitioners due the inconsistent involvement of the typical siblings in the care of their sibling with ASD (Tozer & Atkin, 2015). However, some of the typical siblings mentioned the lack of understanding by service providers and practitioners regarding the nature of caregiving that they provide (Mansell & Wilson, 2010). This in turn causes strained relationship between the siblings and professionals (Davys et al., 2015). The last aspect of caregiving provided by typical siblings is companionship and emotional support. This include providing direct care, such as bathing and getting dressed, and planning activities to spend time together (Mauldin & Saxena, 2018). However, the atypical characteristics of the sibling with ASD such as, behavioral issues and problems with social interaction, affect the sibling relationship quality (Kaminsky & Dewey, 2001). Meanwhile, the existing literature reported that typical siblings' intention to provide future

care is related to the relationship quality with their sibling with ASD (Burke et al., 2012). As such, typical sibling might face difficulties in providing their sibling with ASD with companionship and emotional support.

Existing studies highlight the typical siblings' feelings toward their sibling with ASD in relation to their experiences growing up with added responsibilities due to the limitations of the ASD sibling (Cridland et al., 2016; Petalas et al., 2009). However, this review attempts to analyze the feelings described by typical siblings when discussing their caregiving responsibilities after the passing of their parents. Although most of the typical siblings were receptive to the idea of becoming primary caregiver to their sibling with ASD, some reported feeling burdened and were worried about the challenges associated with the caregiving of their sibling with ASD. Feeling concerned were caused by the typical siblings' lack of understanding of the adult services for their sibling with ASD (Rawson, 2010). Adult services are interventions, services, or supports that aim to assist intellectually and/or developmentally disabled adults with independent living, post-secondary education, work, and social participation (Shattuck et al., 2012). Typical siblings also faced difficulties to be more involved in the care of their sibling with ASD while balancing their commitments toward their own families, work, and their parents. As a result, typical siblings are more involved in the caregiving of their sibling with ASD after their retirement and/or children have grown up.(Rossetti & Hall, 2015). However, this caused service providers and practitioners to judge the typical siblings as lackadaisical toward their sibling with ASD (Tozer et al., 2013). Vice versa, when the typical siblings felt a strong sense of responsibility toward their sibling with ASD, caregiving responsibility was undertaken with a sense of commitment (Sibeoni et al., 2019). Furthermore, cultural values seemed to influence the typical siblings' view of their responsibilities as caregivers (Hwang & Charnley, 2010). These mixed emotions show the complexities of the experience being a sibling to an individual with ASD.

The typical siblings also discussed the supports and services they needed to carry out the caregiving responsibilities more efficiently. They hoped for a better provision of services by the professionals, be it from government or non-governmental organizations (Abdullah et al., 2019; Isa et al., 2017). The supports required were mostly related to information regarding future care and planning. This constant occurrence of the need for information, indicate a lack of dissemination of information regarding adult services and typical siblings' role as caregivers (Rawson, 2010). There was also a lack of the siblings' involvement in discussions with the professionals regarding care of their sibling with ASD (Tozer & Atkin, 2015). Additionally, typical siblings lacked confidence when dealing with professionals (Atkin & Tozer, 2014). This may be due to their difficulty in trusting others to take care of their special needs siblings. Aside from professionals' aid, typical siblings found it helpful to receive support from their families, friends, and communities. The form of support they wished to receive from the people around them were a listening ear to share experiences, knowledge, and information, rather than assistance on caretaking. Similarly, the lack of social support is also reported by parents due to the stigma associated with disability (Tsai et al., 2018). The demand for supports from the typical siblings show the challenging nature of their responsibilities as caregivers. Support should be provided to future or current sibling caregivers to sustain the wellbeing and livelihood of the individuals with ASD as well as the caregivers.

This review had its limitations whereby the articles that were included after the screening process were mostly studies conducted in the Western countries which is not adequate to discuss sibling caregiving with regards to cultural influence.]. Second, the aspects

of caregiving were limited to those discussed by Burke *et al.* (2012) and may not include other perspectives that could be important to the understanding the nature of sibling caregiving. Third, the studies included in this review revealed more female participants which may have favored gender's impact on the findings on siblings' willingness to undertake the caregiving responsibilities. Finally, the studies included in this review are subjected to the inclusion criteria which limits generalization to the general population of typical siblings.

Conclusions

This review has summarized the forms of caregiving undertaken by the typical siblings, their feelings toward being a caregiver to the sibling with ASD and the supports they would like to receive to perform their caregiving responsibilities. The lack of information provided to the typical siblings showed a need for proper dissemination of information regarding future care and planning. It is also important to ensure a collaborative relationship between typical siblings and service providers so that the typical siblings are kept up to speed with matters pertaining to their ASD sibling's care and wellbeing. By understanding the forms of caregiving that could take place, the typical siblings can better prepare themselves for the future and not be overwhelmed when the time comes for them to take over caregiving responsibilities from their parents. Future research could be done to fill this gap especially in terms of including studies from other parts of the world to give greater and more in-depth perspective on siblings of differing cultures. Areas of caregiving could be expanded to include other aspects of caretaking that may have been missing from this review. Future research could also benefit from including more male siblings to give a balanced view of sibling caregiving from both genders.

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