

Adolescents who have siblings with intellectual or developmental disabilities (IDDs): A systematic review

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Abstract: Individuals with IDD face challenges and require lifelong support regarding to learning, social interaction, and self-care. Having siblings diagnosed with IDD tend to bring great impact on the typical developing (TD) siblings in the same family. Based on the special developmental characteristics of adolescents, the effect of having siblings with IDD tend to be different on them, compared with it on other age groups (e.g., children, adults). This study conducted a systematic review for literatures focusing on adolescents who had siblings with IDD, in terms of their daily life experience, adjustment behaviours, and relationship with their siblings. Twenty-seven studies were included, wherein the TD adolescents were interviewed or surveyed in various methods. The studies were summarized according to country, publication time, participant demographics, research methodology, study focus, and results. Results suggested that siblings with IDD brought warmth and challenges to the daily experience of TD adolescents. TD adolescents developed both positive and negative attitudes and adjustment behaviours toward their siblings with IDD. Adolescents' adjustment behaviours included their psychological well-being and strategies coping with the siblings' behaviours. This review further investigated relevant factors of adolescents' different performance and suggested the need of support from parents, peers, community, professions, and other TD adolescents who were in similar conditions. Given the existence of adjustment difficulties and insufficient support resources, this study come up with domains referential for practical support to the targeted population.

Keywords: Typical developing adolescents, Siblings, Intellectual or developmental disabilities

1. Introduction

Individuals with IDD face challenges and require lifelong support regarding to learning, social interaction, and self-care [1]. They have brought both positive and negative (e.g., sense of reward; stress) psychological impact on their siblings [2]. Adolescence is a distinct developmental stage. Compared with children, adolescents possess increased understanding and reasoning ability, independent thought (e.g., argue for their own position, criticize authority), consideration about future, and self-reflection [3]. The development of these abilities prompts adolescents' own perspectives and attitudes toward their siblings with IDD, rather than simply following adults. In addition, adolescents start to seek a sense of idealism and impartiality [4]. They can more easily detect of others' defects, but less sensitive of their own. They start to recognize the complexity of moral issues while their coping strategies are still "immature", which can result in the risk of being overwhelmed [3]. Such disadvantages increased the difficulty to face the stigma and even social exclusion for having siblings with IDD [5]. However, the already existed reviews included too broad of an age range of the TD siblings (i.e., children, adolescents, and adults). To obtain a well-directed understanding of adolescent siblings of individuals with ASD, this study conducted a systematic review specifically for adolescents who had sibling with IDD.

2. Methods

2.1 Inclusion Criteria

Studies must meet specific criteria to be included. First, studies should include individuals aged

between 10 to 19, who had at least one sibling diagnosed with IDD. To obtain a well-directed understanding, the studies should include only individuals fitting the age range (i.e., 10 to 19), or a wider range but with the results of adolescents reported separately. Thus, studies had adolescents involved but mixed with other age groups were not included. Second, this review only focuses on studies in relation with the psychological and behavioural characteristics of TD siblings. Studies related with physical, biological, or genetic characteristics were not involved (e.g., fMRI study; sensory processing). Third, there must exist some kinds of interaction between the adolescents and the siblings with IDDs. Parallel comparison was rejected (e.g., compare the likeability of being teased between TD adolescents and their siblings with IDDs).

Fourth, this review put its focus on life experiences of the TD adolescents (e.g., psychological functioning, sibling relationship). Thus, studies training adolescents to be interventionists for their siblings with IDDs were not included. Finally, studies could be involved only if they were published in English, empirical and peer-reviewed journals. There are no restrictions to the age, abilities, and comorbidities of the diagnosed siblings. There were also no criteria in terms of the publication time and location of the data collected.

2.2 Search Strategies

The whole search procedure consisted of the following phases: Database, journal, reference-list, and citation search. The databases contained PsycINFO, PubMed, and Web of Science. The researcher entered three search term groups into the databases (Table 1), screened the titles and abstracts of the outcomes, and read the full articles whose titles and abstracts satisfied the inclusion criteria.

Table 1: Search terms of adolescents whose siblings had IDDs.

Group 1	“intellectual or developmental disab*” OR “intellectual and developmental disab*” OR IDD* OR autis* OR ASD OR “autis* spectrum disorder” OR “high function* autis*” OR Asperger* OR Rett* OR “childhood disintegrative disorder” OR “pervasive developmental disorder not otherwise specified” OR “PDD NOS”
Group 2	brother* OR sister* or sibling*
Group 3	Adolescen* OR youth OR young OR teenager

The search terms refer to different content expected in the articles. The first group summarized a list of terms previously or currently used to describe people with ASD. The second group defined the inclusion of all kinds of siblings. Lastly, the third group further restricted the age of TD adolescents. As can be seen in Figure 1, the database search came out with 1080, 816, and 1146 articles in PsycINFO, PubMed, and Web of Science, respectively. After the removal of duplication, there were 1655 articles in total. The researcher screened the titles and abstracts of these 1655 results and retained 32 for further decision. The full texts of these articles were further reviewed and 25 were finally included in this systematic review.

The second search phase focused on the most frequently occurred journals in the first phase. The journal *Research in Developmental Disabilities* (RIDD) presented the highest number of related journals ($n = 5$) and the *Journal of Autism and Developmental Disorders* (JADD) involved the second most ($n = 3$). The number of studies published in other journals varies from one to two. The researcher screened the titles and abstracts of all the articles published in RIDD and JADD in a chronological order and retained six articles for further decision (date back to 1987 and 1971, when the journals were established). After going through the full-text articles, all the retained articles were rejected. Thus, this phase did not yield additional articles. The third phase is a reference-list search, the researcher went through the reference lists of the previously selected articles for more relevant resources, which resulted in two more studies. Lastly, articles who had cited the 27 aforementioned studies were reviewed and no study was found relevant (i.e., the citation search). Therefore, this review ends with 27 articles included.

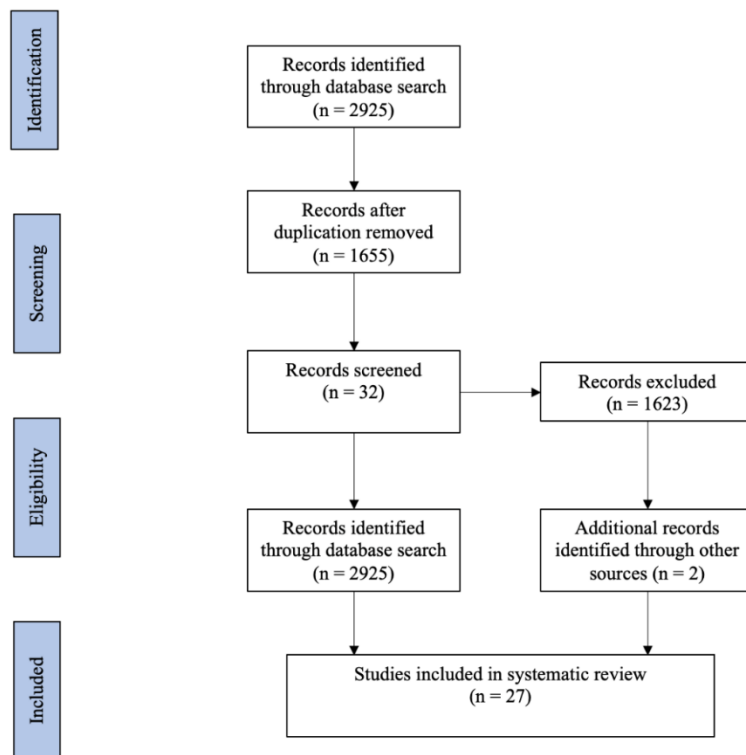


Figure 1: Search procedure and results in different phases.

2.3 Coding

The authors read all the included articles from the beginning to the end and took notes for various information. A data extraction table was then established (see appendix), where the previously collected information were classified under the following topics: (a) country of the studies, (b) participant information for TD adolescents and their siblings with IDD, (c) study methods (e.g., qualitative and quantitative studies, standardized and non-standardized measurement scales, self-report and parent-report studies), (d) study focus (e.g., sibling relationship, perspectives, caretaking roles, well-being), and (e) common themes related with the TD adolescents.

2.4 Inter-Rater Agreement (IRA)

IRA was examined for article inclusion. A PhD researcher in education was introduced as an extra rater. The researcher was trained by the inclusion and exclusion criteria and provided with 300 articles, which were selected from the outcomes of the first (database) phase search randomly (18.12% of the total articles after duplication). The rater reviewed the titles and abstracts, sometimes the whole articles if necessary, to determine whether each article satisfies the inclusion criteria. The IRA value was reported by the ratio of agreed articles (i.e., both agreed to meet the criteria or not) to the total number (n = 300). The articles considered to meet the inclusion criteria by the author and rater were exactly the same (n=7). Thus, the inter-rater agreement was 100%.

3. Results

3.1 Participant Information.

A review of all the involved studies is available upon request. This section includes some demographic information for the involved TD adolescents and their siblings with IDD, including the age and gender distribution for the TD adolescents, and the age, gender and diagnoses of their siblings. A total of 1414 TD adolescents and 1425 siblings were contained from the 27 involved studies. The numbers of both TD adolescents and siblings with IDD involved in different studies varied from 1 to

231. Although parents sometimes were the reporters, the characteristics were not introduced since the study interest were the TD adolescents. Twenty-six of the 27 studies reported the age for 1365 of the 1414 TD adolescents, with an average of 14.17 years. The gender was presented in 25 studies for 1132 adolescents, including 519 males and 613 females. The age of sibling with IDD was reported in 25 studies for 1121 of the 1425 participants, with an average of 13.39 years. Twenty-four studies reported the gender for 1274 the siblings, including 966 males and 310 females.

All of the studies had at least some description of the diagnosis of the siblings. The diagnosis included: (a) ASD (n = 1034), (b) PDD-NOS (n = 73), (c) non-specified IDDs (n = 69), (d) DS (n = 115), (e) ASD and IDs and attention deficit hyperactivity disorder (ADHD, n = 2), (f) ASD and ADHD (n = 1), (g) mental retardation (n = 22), (h) IDDs and mental illness (n = 9), (g) developmental delay (n = 2), (h) speech disorder and learning disabilities (n = 4), (i) non-specified physical and cognitive disabilities (n = 31), (j) closed head injury (n = 1), and (k) cerebral-related syndromes (calcifying leukodystrophy, cerebral atrophy, cerebral epilepsy, cerebral palsy, n = 10).

3.2 Research Outcomes

3.2.1 Attitudes

TD adolescents developed both positive and negative attitudes toward their siblings with IDDs. Positively, they reflected love, acceptance, empathy, sense of togetherness, positive interactions, and enjoyment of the shared time [6]. In addition, some adolescents presented positive view on the difference of their siblings, including sensory processing (e.g., eat too much pepper), idiosyncratic behaviour, and personality traits [7]. Distinctions existed between adolescents with different age, gender, and having siblings with different diagnosis. For example, an increase of positive emotions (e.g., love, affection) and similar level of positive behaviours (e.g., spend time together) was presented from childhood to adolescence [8]. In addition, an absence of significant difference amongst early adolescent (12 to 14 years), adolescents (15 to 18 years), and young adults (19 to 26 years) for attachment and caregiving behaviours can be detected in previous studies [9]. Some studies presented no difference in empathy of different disability group [10]. However, it was highlighted that female adolescents displayed higher empathy than male toward their siblings with IDDs [10]. Adolescents whose siblings had ASD were reported with more problems and less warmth in sibling relationship than whose siblings had DS [11].

Adolescents also generated some negative feelings, including jealousy for typical sibling relationship, guilt for controlling the siblings in crude ways (e.g., hitting), annoyance, unacceptance, and shame [6]. Compared with adolescents whose siblings did not have IDDs, they expressed more wishes related with their siblings, rather than themselves [12]. Some adolescents felt frustrated when making social comparison. They tended to exhibit an egocentrism that they were the only ones having such atypical experience and wished for normal sibling interaction [13]. Comparisons were also conducted for negative attitudes amongst TD adolescents with different characteristics. Those whose siblings had ASD and DS did not show significant difference in hostility toward and conflicts with them [12]. In terms of age, early adolescents reported more engagement in negative behaviours than adolescents and young adults [9]. Moreover, an over-time loss of closeness and connectedness can be detected (without specific age reported) [13].

3.2.2 Adjustment behaviours

Having siblings with IDDs, adolescents established both positive and negative adjustment behaviours, including different psychological well-being and coping strategies. From psychological perspective, the self-perception was overall positive. TD adolescents rated themselves as being kind, patient, helpful, and responsible (sometimes even precocious, [14]). Compared with TD adolescents without siblings with IDDs, they developed increased understanding of IDDs, which enhanced their perspective-taking, positive meaning making, and normalization of the behaviour problems their siblings. They enjoyed being able to provide help for people with IDDs directly and elevate others' understanding of IDDs [15]. TD adolescents of siblings with IDDs displayed a sense of responsibility, which could sometimes be accompanied with different feelings. Some adolescents felt being pride and stronger, while others complained about caretaking burden, unfairness (e.g., more housework), unwanted pressure, and excessive worry about the present and future [16]. Furthermore, some adolescents mentioned their sacrifice for the benefit of their siblings and the whole family [14]. Adolescents did value autonomy and individuality, while at the same time, they also recognize the necessity to make a balance between duty and freedom [13].

Coping behaviours were also examined. To deal with depressive emotions, the adolescents sought support from family members and close friends [15]. Moreover, they changed their behaviours to cater the ability and behaviour problems of their siblings with IDD. Adolescents' behaviours related to the communication skills of their siblings with IDD was measured [18]. It was suggested that the adolescents tailored their communication complexity and inclusion of word account according to their siblings' ability level. Adjustment behaviours of different age and gender group were compared [19]. Conclusions were drawn that the adolescents engaged in more shared activities with their siblings, perceived more support from others, and adopted more strategies focusing on emotions and less on problem-solving than TD adults of siblings with IDD [19]. In addition, if the siblings with IDD were females, female TD adolescents tended to develop more shared activities than males [19]. However, such difference was not shown when the siblings with IDD were males. The TD adolescents engaged in negative adjustment behaviours as well. They presented overall higher psychological and behavioural syndromes, compared with those whose siblings did not have IDD. They developed more dysphoria, including anxiety, stress, hyperactivity, and external behaviour problems [20]. A lower level of school-belonging and academic self-concept was also indicated [6]. In addition, some studies compared the behaviours reported by the TD adolescents themselves and their parents [21]. Parents evaluated the adolescents with more problems in hyperactivities, ordinary behaviours, and interaction with their peers. However, problems related to emotions and prosocial behaviours were rated with a similar level.

Some studies compared the adjustment behaviours of adolescents with different characteristics, including age, gender, and specific diagnoses of their siblings with IDD. Some studies investigated the depressive symptoms of adolescents and adults of siblings with IDD and concluded an absence of significant difference [19]. Regarding to the gender of TD adolescents, females reported more stress than males. Furthermore, adolescents whose siblings with IDD were males presented more stress than whose siblings were females. Compared with those whose siblings did not have IDD, TD adolescents whose siblings had ASD presented higher level of dysphoria, while whose siblings had other IDD (e.g., ID) did not [17]. Some potential stressors for TD adolescents of siblings with different syndromes were detected [12]. Those whose siblings had ASD were more likely to get stressed because of their siblings. However, the stressors for TD adolescents whose siblings had DS were similar as adolescents who had siblings without IDD. IDD could be complicated with mental illness. It was highlighted in that TD adolescents whose siblings had both IDD and mental illness engaged in higher dysphoria than those solely with IDD [18]. Some studies reported a similar level of self-efficacy, self-concept, social competence, and behaviour adjustment of TD adolescents who had siblings with and without IDD [22]. For adolescents of siblings without IDD, self-efficacy was only related to interpersonal competence. For adolescents whose siblings had IDD, the correlating factors contained interpersonal competence, maternal attitudes, and modelling of others.

3.2.3 Relevant factors

The correlating factors of sibling relationship and adjustment behaviours were investigated in a number of studies, including family factors, social support, coping abilities, and characteristics of siblings with IDD. Family factors contained adolescents' satisfaction toward families, their personal space (time and physical room), and parents' mental well-being [9]. Specific illustration of family satisfaction was made, which were positively contributed by family cohesion, communication amongst family members, and problem-solving flexibility of parents [9]. Contrarily, it was suggested to drop with higher criticism, antagonism, and conflict within family. Although adolescents regarded it reasonable that parents need to take more over their siblings with IDD, parental attention was still desired, especially one-on-one time [16]. A possible explanation for the importance of one-on-one time was that the family time with both parents and siblings with IDD was influenced by the interests, activity difficulty, and moods of the siblings, which was sometimes even considered ruined by the TD children [15]. Moreover, adolescents valued family time even as they were aging [15].

Sufficient and pertinent support was considered as essential for positive sibling relationship and adjustment behaviours [23]. TD adolescents reported the needs to talk with friends, other siblings with IDD, and related professional [14]. Moreover, researchers compared the perceived social support of the adolescents who had siblings with different diagnosis and concluded that there was no difference between the ASD and DS group [12]. An insufficiency of social support can be detected in the included studies. Moreover, the attached importance and actual availability of social support could make a difference interactively. For example, it was highlighted that adolescents who rated social support as important and frequent exhibited few behaviour problems [23]. However, those who rated it as important but infrequent suffered from emotional and behavioural difficulties, especially when the IDD

symptoms of their siblings were severe.

Adolescents' coping abilities can be noticed when dealing with negative emotions and helping their siblings with IDD. There was examination of adolescents' sense of coherence (SOC), which was the ability to deal with life stressors and could therefore, enhance positive sibling relationship and adjustment behaviours [2]. It was noticed that adolescents' stress-dealing ability can be weakened by high level of behaviour problems and diagnostic severity of their siblings. In addition, positive relationship could be contributed by effective coping strategies of TD adolescents, including skills to prevent inappropriate behaviours, increase desired behaviours, and teach skills [16]. Some characteristics of the siblings with IDD were presented to influence sibling relationship and the adjustment behaviours of TD adolescents. Positive sibling relationship and adjustment behaviours were related with their older age, higher communication ability, and lower diagnostic severity [17]. When the siblings with IDD were older, adolescents presented higher family satisfaction and less negative sibling interactions [9]. As reported by the siblings with IDD, having higher communication ability was related with their status and power in their relationship with the TD adolescents [2]. Nevertheless, communication ability did not make significant difference on warmth, conflict, or rivalry amongst siblings [2].

The adjustment behaviours can be influenced by the interaction of various factors. For example, the relation between more dysphoria had the following combinations: (a) having female siblings and family history of IDD, (b) having and living together with female siblings with IDD, (c) having broad autism phenotype on themselves and stressful life events, and (d) having mother with broad autism phenotype and stressful life events. Moreover, the amount of shared activity among siblings (i.e., sibling engagement) was correlated with behaviour problems of the siblings with IDD and problem-solving ability of TD adolescents [19]. If the level of behaviour problems was low, the adolescents' ability to solve problems did not have an effect. However, when the level of behaviour problems was high, the amount of shared activity had a positive relation with the problem-solving ability of TD adolescents.

3.2.4 Challenges in daily experience

Some studies reported the challenges faced by the TD adolescents in their daily life, including burdened caretaking roles, bully involvement, daily routines, friendship difficulty, behaviour problems, and prejudice from others. They took various roles in their daily life, including caretaking, protecting their siblings from bullies, advocating for their siblings, educating others with the knowledge of IDD, and passing message between teachers and parents [6]. Additionally, one mother mentioned that TD adolescents stopped their protective role when staying at home. She further supposed the reason that home was safer than outside environments and adolescents got tired with protecting their siblings at school [15]. Adolescents' suffering from sleep (shortened time, frequent awakenings), meals (limited types of food), and homework (limited space, lower requirement for quality, destroyed paper, limited support from parents) were reported as well [16]. There were interviews involving questions related to friendship and most of the adolescents reported the existence of at least one good friend. Among these adolescents, some presented confidence that they were considered as good friends by others and even admired for coping with issues to their siblings with IDD. However, some were uncertain about how their peers actually view them. Moreover, TD adolescents reflected difficulties in maintaining friendship, including destroyed social events at home, less time to spend with friends, limited access to activities, and embarrassment of having siblings with IDD [14].

TD adolescents felt it challenging to face behaviour problems of their siblings with IDD, including disobedience of social conventions (e.g., speech volume), lack of flexibility, aggression, unpredictable behaviours, and incompletion when adolescents were trying to provide a caretaking role [15]. They also reported their wishes to approach ordinary activities without making additional preparation, such as calling on relatives and entering restaurants [6]. Witnessing siblings receiving hospitalization was reported to be a painful experience (e.g., blood tests, MRI scans, treatment for the consequence of self-injurious behaviours). Moreover, that the siblings with IDD failed to understand death caused sadness for the TD adolescents [13]. However, the influence of behaviour problems was not reported to be significant some studies [15]. The prejudice, tease, ignorance, and bully from others tended to cause the feeling of loneliness and isolation for both TD adolescents and their siblings with IDD, which would further bring a distance between the sibling dyads. Some siblings even reported the difficulty of explaining IDD to others. In addition, as a consequence of lacking related knowledge and effective coping strategies, the help from others was not always helpful. Even worse, inappropriate interference could evoke anger, frustration, and disappointment of the TD adolescents [19].

Some studies recruited the siblings with IDD as reporters. In terms of bully involvement, some siblings reflected that both themselves and the TD adolescents were involved as perpetrator and victim [24]. The level of sibling bully was generally higher than ordinary sibling dyads, while presented a reduction from age 11 to 14. They further indicated that more bully involvement was related with higher behaviour problems and lower social skills of siblings with IDDs. Specifically, their relationship with the TD adolescents was described with more conflict, criticism, antagonism, and less support than with friends. In the relationship with other TD peers (except their siblings), individuals with IDDs reported their emphasis on the feelings of safety and companion. Moreover, the siblings with IDDs reported more accident hurt and less trustfulness, acceptance, shared interest, and shared preference with their TD siblings, compared with sibling dyads of TD individuals [19].

3.2.5 Behaviours of parents

Parents were reported to treat TD adolescents and their siblings with IDDs in different manners. For specific issues, [25] focused their study on parents' management strategies for television and videogame use. It was suggested that parents adopted more social and active strategies in managing television and videogame use for TD adolescents and more restrictive for the siblings with IDDs. Adolescents reflected the excessive expectation of their parents, which was particularly related to their current and future caretaking roles [6]. Nevertheless, some parents showed changes in such expectations overtime. For example, there were interviews for parents in China, where social support for the population with IDDs was severely insufficient (e.g., governmental nursing institution) [26]. Results suggested that the involved parents gradually realized the necessity of TD adolescents to have their own life [26].

4. Conclusion

This review provides reference to practical support for these adolescents. It indicated various domains where supports are required, including family environment, social support, coping strategies of the TD adolescents, and ability and behaviour problems of the siblings with IDDs. Family environment consisted of family coherence, communication amongst family members, personal space (physical room and time), parents' problem-solving abilities, and parents' mental health. Improvement could be made in these areas to help with these TD adolescents, including family coherence, social support from different professions and institutions, and interactions with peers under similar situations.

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