

ORIGINAL ARTICLE

Courtesy stigma of parents of children with Down syndrome: Adaptation process and transcendent stage

Motoko Watanabe^{1,2}  | Chieko Kibe³ | Masumi Sugawara⁴ | Hidehiko Miyake^{2,5}

¹Department of Clinical Genetics, Juntendo University Graduate School of Medicine, Tokyo, Japan

²Institute for Human Life Innovation, Ochanomizu University, Tokyo, Japan

³Center for Institutional Research, Educational Development, and Learning Support, Ochanomizu University, Tokyo, Japan

⁴Department of Developmental Psychology, Faculty of Human Studies, Shirayuri University, Tokyo, Japan

⁵Department of Genetic Counseling, Graduate School of Humanities and Sciences, Ochanomizu University, Tokyo, Japan

Correspondence

Motoko Watanabe, Department of Clinical Genetics, Juntendo University Graduate School of Medicine, 2-1-1 Hongo, Bunkyo-ku, Tokyo 113-8421, Japan.

Email: m.watanabe.is@juntendo.ac.jp

Funding information

JSPS KAKENHI, Grant/Award Number: 19K19384

Abstract

Courtesy stigma, which arises from close connections to people with stigmatized characteristics, negatively affects interpersonal relations. This study aimed to evaluate courtesy stigma and the adaptation process of parents of children with Down syndrome based on semi-structured interviews with 23 Japanese parents. The interview themes were (a) negatively perceived interpersonal experiences and coping strategies; (b) information disclosure and others' responses; and (c) positively perceived interpersonal experiences. The interview data were transcribed and analyzed based on a grounded theory approach. The results suggested that parents perceived and experienced multidimensional courtesy stigma, and they used various coping strategies categorized in combinations of passive-active and internal-external. All parents disclosed information about their child's diagnosis to others, and reverse disclosure (i.e., revealing own relations with people with disabilities) was characteristically observed thereafter. Through active interaction and reflection, the parents cultivated social relationships, compassion, world views, and community involvement, which led to the transcendent stage. However, internal conflict as a mediator between people with and without Down syndrome re-emerged even after achieving the transcendent stage. These findings could help to develop interventions in genetic counseling for parents to deal with interpersonal relationship difficulties.

KEYWORDS

coping, courtesy stigma, Down syndrome, genetic counseling, parents

1 | INTRODUCTION

Down syndrome is a well-known genetic condition characterized by certain common facial features, some physical complications, including congenital heart disease, and mild to moderate intellectual disability (Roizen & Patterson, 2003; Stoll et al., 2015). It is the most frequent chromosomal abnormality worldwide, affecting approximately 1 in 700 births (Canfield et al., 2006; Parker et al., 2010). Most people with Down syndrome have trisomy 21, which is caused by the

non-disjunction of chromosomes during meiosis, with the probability of its occurrence increasing with maternal aging (Loane et al., 2013; Yoon et al., 1996). Recently, non-invasive prenatal testing (NIPT) has been widely conducted to detect the possibility of a fetus having Down syndrome with the benefit of having high sensitivity and presenting no risk of miscarriage (Allyse et al., 2015; Palomaki et al., 2011; Samura et al., 2017). As the management of complications of Down syndrome has developed, so has life expectancy, which is currently over the age of 60 years (Bittles & Glasson, 2004; Glasson et al., 2002).

This is an open access article under the terms of the [Creative Commons Attribution-NonCommercial](https://creativecommons.org/licenses/by-nc/4.0/) License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

© 2021 The Authors. *Journal of Genetic Counseling* published by Wiley Periodicals LLC on behalf of National Society of Genetic Counselors.

Nevertheless, despite improvements in the medical environment involving people with Down syndrome, research has indicated that diagnosis of a child's condition has enormous negative psychosocial impacts on parents, such as distress, anxiety, and depression (Choi & Van Riper, 2017; Farkas et al., 2019; Marshak et al., 2019; Nelson Goff et al., 2013; Takataya et al., 2016). Furthermore, these negative psychological effects not only are observable at the time of a child's diagnosis, but also affect the broader psychosocial aspects of childbearing and subsequent childrearing. Therefore, in prenatal and pediatric genetic counseling, it is important to provide psychosocial support for parents in addition to information about the medical aspects of the condition (Ashtiani et al., 2014; Biesecker, 2001; Buyukavci et al., 2019; Sheets et al., 2011).

Among various negative psychosocial experiences, stigma involves detrimental effects in interpersonal relationships, and it has been reported that the mothers of children with disabilities, including Down syndrome, face courtesy stigma in their daily lives (Green, 2003). Stigma refers to an attribute that is devalued in social contexts, with negative effects, including stereotyping, emotional reactions, separation, discrimination experienced from others, and discrimination perceived by oneself (Corrigan & Watson, 2002; Goffman, 1963). Courtesy stigma refers to the stigma of individuals having close connections to people with a stigmatized characteristic (Angermeyer et al., 2003; Goffman, 1963; Gray, 1993; Mak & Cheung, 2008). Courtesy stigma affects parenting and the psychological health of parents (Ali et al., 2012; Cantwell et al., 2015; Green, 2003). In this sense, parents of children with genetic conditions are likely to perceive and experience courtesy stigma, since the conditions are reported to be associated with a stigmatized characteristic (Gaff & Clarke, 2007; Peters et al., 2005; Rozario, 2007; Sankar et al., 2006). Furthermore, it has been suggested that the expansion of NIPT could elevate social stigma regarding Down syndrome (Deem, 2016; Kellogg et al., 2014).

While courtesy stigma of parents of children with genetic conditions is very likely, it is also concealable, such as when the parent does not disclose information about the child's diagnosis to others. A concealable stigma becomes an issue in that people might have to determine whether to disclose the information, which poses another layer of pressure (Pachankis, 2007; Quinn & Chaudoir, 2009; Siegel et al., 1998). However, according to Goffman (1963), people with a concealable stigma reach a stage of no longer feeling the need to conceal their stigmatized characteristic, and this phase is deemed to be a final, mature, well-adjusted state of grace (Goffman, 1963, p. 102). Therefore, although the courtesy stigma might have negatively affected interpersonal relationships, it also could contribute to the individual's growth. Thus, it is crucial to assess and intervene in the courtesy stigma faced by parents of children with genetic conditions in genetic counseling sessions, to facilitate a positive adaptation of parents. Nonetheless, there are few empirical studies on the courtesy stigma of parents of children with genetic conditions (Green, 2003; Hamlington et al., 2015; Turner et al., 2007); and hence, little is known about how parents cope and the outcomes of their courtesy stigma.

What is known about this topic

Parents of children with Down syndrome face courtesy stigma in their daily lives, although there are few reports on coping and outcomes related to courtesy stigma. Courtesy stigma affects parenting and parents' psychological health, and thus, it is crucial to assess and intervene in the courtesy stigma faced by parents through genetic counseling sessions.

What this paper adds to the topic

Parents of children with Down syndrome in our study perceived and experienced multidimensional courtesy stigma, and they developed various coping strategies in combinations of passive-active and internal-external, as well as tactics of information disclosure. We developed a recurrent model of parents' adaptation process of courtesy stigma from the intermediate to the transcendent stage.

The present work aimed to evaluate the courtesy stigma of parents of children with Down syndrome by utilizing a qualitative study focused on their interpersonal relationships. Specifically, we investigated parents' experience of courtesy stigma, their coping strategies, and their tactics of information disclosure. Then, we developed a model of their adaptation processes with the aim of revealing useful insights to support parents in genetic counseling.

2 | MATERIALS AND METHODS

2.1 | Study population and recruitment

This study was conducted at Ochanomizu University and was approved by the Institutional Review Board (approval number: 2018-10). Parents with children with Down syndrome were eligible to participate in this study. The study population included 23 parents from 22 families: 18 parents were recruited through two Japanese family associations related to Down syndrome, and five parents were referred by participants (snowball recruitment strategy). CK and MS had no prior relationships with the study participants, while MW and HM had met two participants at a symposium related to Down syndrome. The participants were told about the study before the interviews, whose aims were to elucidate the experiences of parents in interpersonal relationships and to provide useful findings for genetic counseling. The participants were also informed that they had the right to withdraw from the study at any time, but no one dropped out. Written consent was obtained from each participant before the interview. All participants were Japanese. The surveillance period was from April to July 2019.

2.2 | Data collection

We conducted 23 semi-structured interviews (22 in-person and 1 telephone) according to an interview guide. It was designed to elicit the experiences in interpersonal relationships of parents with a child with Down syndrome. We focused on three themes: (a) negatively perceived interpersonal experiences and coping strategies; (b) information disclosure about a Down syndrome diagnosis and others' responses to the disclosure; and (c) positively perceived interpersonal experiences. We also asked for demographic information and rated the severity of the child's condition of Down syndrome on a scale of 0 (unaffected) to 10 (severely affected) in the interview. We did not use the term 'stigma' during the interviews, because it is not a general word in use in Japan, and it is preferable to avoid bias, as it might have implied that respondents should feel stigmatized (Sankar et al., 2006). Interviews were conducted by one investigator (MW), a genetic counselor with more than 5 years of experience. The average interview time was about 60 min (42–106 min) and all interviews were conducted in a private room. For one family, both parents participated in the study, and separate interviews were conducted for each parent. Data saturation was judged by richness and interpretability, and these were ascertained by constant comparison.

2.3 | Data analysis

Interviews were audiotaped and transcribed, and then analyzed based on a grounded theory approach (Corbin & Strauss, 1990; Saiki-Craighill, 2016). The data analysis consisted of three types of coding procedures: open coding, axial coding, and selective coding. First, we read the texts carefully; each section was extracted based on the meaning of the context and provided properties and dimensions. Then, we labeled each section using properties and dimensions, and organized labels into categories using comparisons. Second, a structural framework, composed by a set of conditions, actions/interactions, and consequences, was used to explore a phenomenon's structure. Then, the relationships between categories were determined by properties and dimensions to explore the flow of the process. Third, we created synthesized thematic diagrams, based on the categories, properties, and dimensions. Coding of five transcripts was performed in duplicate by two investigators (MW and CK, a psychologist) to check for coding inconsistencies and to validate the coding schemata. Coding discrepancies were rectified and adjusted accordingly. The other transcripts were analyzed by MW and checked by CK, after which we discussed the data analysis on a regular basis. For categorization, we referred to previous works on stigma (Goffman, 1963; Turner et al., 2007). Data were entered into MAXQDA 2018 (VERBI Software GmbH, Berlin, Germany), a qualitative analysis software package.

TABLE 1 Characteristics of participants ($n = 23$)

Participants	n (%) ^a
Female	19 (83)
Male	4 (17)
Age range (years)	35–63
35–39	3 (13)
40–49	10 (43)
50–59	9 (39)
≥ 60	1 (4)
Living place	
Japan (Tokyo and metropolitan region)	22 (96)
Other ^b	1 (4)
Children with Down syndrome	
Daughter	12 (52)
Son	11 (48)
Age range (years)	0–19
<1	4 (17)
1–6	4 (17)
7–11	6 (26)
>11	9 (39)
Diagnosis	
Prenatal	1 (4)
Prenatally suspected and postnatally diagnosed	3 (13)
Postnatal	19 (83)
Severity range reported by parents	3–7
Average	4.7
Number of children with siblings	13 (57)

^aPercentages are rounded off to the nearest whole number.

^bOne participant moved to the United States after having a child with Down syndrome.

3 | RESULTS

3.1 | Demographics

Table 1 shows the demographic characteristics of the parent-participants and their children with Down syndrome, including the parents' perceptions of the severity of their child's condition. The parents' average age was 47.9 years (35–63 years, $SD = 7.8$) and their child's average age was 9.7 years (0–19 years, $SD = 6.3$).

3.2 | Preconceptions about Down syndrome and perceived courtesy stigma

Parents recalled their past multiple preconceptions about Down syndrome before having a child ($n = 20$). For example, parents reported that they used to have vague negative images, such as 'all Down syndrome children have the same face' and 'it is hard to live with

Down syndrome'. Furthermore, parents recalled that they were ignorant and indifferent at that time.

Parents reported the following content categories of perceived courtesy stigma ($n = 20$). The first was their experience of negative emotions when their child was suspected of having and was then diagnosed with Down syndrome, including anxiety, disappointment, guilt, sadness, and anger. The second was a sense of suspicion and vigilance against others. That sense was derived from concerns about whether other people would notice that their child had Down syndrome from the child's appearance, which they then responded to negatively, or felt confused. The third was that they realized their own prejudice against Down syndrome when they had their own child.

3.3 | Experienced courtesy stigma

In the interviews, approximately half of the participants responded that they had not had obvious negative experiences in interpersonal relationships, at least until school-going age ($n = 11$; mother $n = 7$, father $n = 4$). However, the analysis extracted 10 types of courtesy stigma experience. Table 2 shows the 10 types of courtesy stigma experience and the examples reported by parents. The 10 types of courtesy stigma experience were furthermore divided into the categories of obvious, which was overt typical stigma experiences, and ambiguous.

As obvious experiences from strangers, respondents identified 'devaluing remarks and attitudes' and 'intrusive inquiries' mainly from other children when parents were present with their own child. However, some parents reported these experiences by adult strangers; their children were aged over 14 years, except for one (6-year-old). Meanwhile, stereotyping remarks and attitudes and overly concerned attitudes were mainly made by medical staff at hospital. Attributional ambiguous remarks that made parents unsure about the speaker's intention were mainly reported by parents with an infant or toddler. For example, parents felt difficulty in answering the question about their own child's age from adult strangers. Parents were uncertain whether they should answer honestly. One mother said that she changed her response depending on her mood (41-year-old mother, 5-year-old son).

3.4 | Coping strategies to deal with courtesy stigma

The participants used various coping strategies to deal with perceived and experienced courtesy stigma. These were categorized in combinations of passive-active and internal-external strategies (Table 3).

3.4.1 | Passive/internal coping strategies

This strategy was used mainly for perceived courtesy stigma. Parents concealed their child's diagnosis, or did not disclose any information

about their child's diagnosis to others, and this period lasted variously between 1 month and 2 years. One mother reported that she concealed her child's face in a sling. Attribution restoration was the feeling of wishing to get back to one's past own situation before having a child, involving the feeling of wishing away the existence of one's own child; for example: one mother recalled that, during her pregnancy, after suspecting the fetus had Down syndrome, '*I thought, just for a moment, that my baby and I might be happier if she was never born...*' (35-year-old mother, 10-month-old daughter); another mother reported '*I hate unusual situations...I hoped that she would get out of my life...*' (45-year-old mother, 9-year-old daughter). Attribution restoration included wishing to escape, focusing on a sibling without Down syndrome, and avoiding family association. In addition, parents socially withdrew by staying at home and not contacting others except for visits to hospital.

3.4.2 | Passive/external coping strategies

Ignoring was reported as a coping against courtesy stigma experiences. For example, in dealing with devaluing remarks, parents pretended as if they did not hear them. Similar strategies included offering tentative apologies or thanks.

3.4.3 | Active/internal coping strategies

First, the most reported strategy was employing indifference. This strategy was used for both perceived and experienced courtesy stigma. For example, in response to staring, '*I said to myself that people can stare at us if they wish...*' (50-year-old mother, 9-year-old son); in response to a pitying remark, '*I think it is OK if you think so*' (63-year-old father, 9-year-old daughter). Two parents reported that they became better at dealing with others' negative attitudes, such as social distancing and devaluing remarks, and they developed their coping style over time: '*...I can talk with other parents even if they do not understand, I can handle better at social situations*' (44-year-old mother, 6-year-old daughter); '*I think I do not need to say anything to people who would never accept...I was trained [from others] not to care...*' (49-year-old mother, 15-year-old son). In addition, parents reported adopting an objectifying style; for example, in response to staring, one parent said, '*I thought it is the same as my old self*' (50-year-old mother, 8-year-old son); and in response to pitying remarks, one parent said, '*I understood that this is what society is like*' (57-year-old mother, 19-year-old son).

Second, assigning meaning to social exchanges against experienced courtesy stigma was reported. For example, one parent said about staring, '*... [they] just want to see, since they are not used to seeing...*' (50-year-old mother, 9-year-old son); another parent commented about intrusive inquiries as follows: '*I understood it was a pure response to something unfamiliar*' (45-year-old father, 10-year-old son). In addition, information gathering and preparing for courtesy stigma experiences were reported as ways of coping with perceived

TABLE 2 Ten types of courtesy stigma experiences

Category	n (% ^a)	Example
Obvious		
Devaluing remarks/ attitudes	17 (74)	When my child was around 3 years old...I was putting the child on a bicycle, when a boy came up and said 'strange face' (50F, 8M) ^b ; When I told my close friend that my child had Down syndrome, she said 'You did not undergo amniocentesis, did you?' (55F, 16M).
Social discrimination	16 (70)	Although I wanted to have my child enter a private kindergarten...many of them rejected us from the beginning... (44F, 6F); I hoped that my child could enter a mainstream elementary school...his friends all went there, it's just a short walk..., but we were refused... (55F, 16M).
Stereotyping remarks/ attitudes	13 (57)	The medical staff did not say 'congratulations' much to me, and I thought they should say it (54F, 15M); When I was an inpatient in the obstetric department, the nurse...elderly helper for cleaning was there... said 'such kids are really angels' ...even though the test results had not come back yet... (46F, 6F).
Staring	11 (48)	People often stared at us when we were on the train (53F, 19F).
Social/physical distancing	6 (26)	Some mothers avoid children with disability...they seem to believe that a disabled child would be born if such a child is near them (45F, 9F).
Intrusive inquiries	5 (22)	Other children of the same age living in the same apartment sometimes asked 'Why can't she speak well?' (44F, 6F).
Ambiguous		
Pitying remarks	13 (57)	The elder people who happened to sit next to each other on the bus, or who we met in the supermarket... said 'Poor thing, good luck' (49F, 15M); The boss said 'That's too bad' when I told him that my child has Down syndrome (50F, 8M).
Overly concerned attitudes	10 (43)	I felt (medical staff) tried not to touch the topic of my child in the obstetric clinic (44F, 6F); (Medical staff) really treated me with kid gloves...they deliberately isolated me in a room where there was no one else (45F, 9F).
Attributional ambiguous remarks	3 (13)	When others say that my child is pretty, I wonder whether they suspect (about the Down syndrome) ... (37F, 0M); I feel difficulty when strangers who I meet on the train or in the elevator...say 'Oh, he is pretty, how old is he?' because the child is small and cannot speak well (41F, 5M).
Excessive civil inattention	2 (9)	There were people on the train and bus who looked away as if they didn't notice us... (63M, 9F).

^aPercentages are rounded off to the nearest whole number.

^b(Parent's age and sex, child's age and sex); F: female (mother/daughter); M: male (father/son)

courtesy stigma. Parents reported that they felt relief through gathering useful information and selecting convenient information for themselves. Preparation included deciding how to respond to devaluing remarks. Other coping strategies to deal with social discrimination when entering kindergarten or school included asking for advice and exploring options, for example, selecting a nursery school other than a private kindergarten.

3.4.4 | Active/external coping strategies

This strategy was used for experienced courtesy stigma. Taking the offensive was mostly directed toward educators but sometimes also toward strangers. For example, in response to staring, 'I ask what... what are you looking at? ... I create expression... are you looking for a fight?' (50-year-old mother, 9-year-old son); 'I purposely show our close relationship with my son and how fun we are' (55-year-old mother, 19-year-old son).

Educating others was directed toward various groups of people, including strangers, friends, and educators. This coping strategy was also used to answer intrusive inquiries. One parent

reported that the aim of her explanations had morphed into getting others to understand about all children with intellectual and developmental disabilities: 'I explain properly to people who seem to misunderstand us now but might stand by our sides in the future... There are a lot of children like my child...' (49-year-old mother, 15-year-old son).

3.5 | Information disclosure

Information disclosure was categorized as proactive, reactive, intermediate, and one-way styles.

Parents used the proactive style, a type of active disclosure ($n = 22$), when they were used to people who would understand their child's diagnosis and when the disclosure was conventional, mostly to their own parents immediately after the diagnosis. Parents also actively disclosed the diagnosis to business associates as an excuse, because it affects their work operations. In addition, parents used it as a defense against other parents whose children attended the same nursery school. Meanwhile, parents used the reactive style ($n = 22$) when they considered the timing

TABLE 3 Passive–active and internal–external coping strategies to deal with courtesy stigma

Category	Types of coping strategies	n (% ^a)
Passive/internal	Concealing	8 (35)
	Attribution restoration	4 (17)
	Social withdrawal	2 (9)
Passive/external	Ignoring	9 (39)
Active/internal	Employing indifference	16 (70)
	Assigning meaning to social exchanges	13 (57)
	Information gathering	9 (39)
	Preparing for courtesy stigma experiences	3 (13)
	Asking advice	2 (9)
	Exploring options	2 (9)
	Active/external	Taking the offensive
	Educating others	10 (43)

^aPercentages are rounded off to the nearest whole number.

was right. Parents used this style mostly to their friends. Parents disclosed at the time of conversation about the child, when they were contacted for an unrelated matter, or when they met with friends together with their child. Some parents reported that they disclosed to friends who would understand and would maintain contact.

The intermediate style was used for disclosure to siblings of children with Down syndrome ($n = 11$). Parents disclosed to siblings when they noticed the developmental delay of the child with Down syndrome, were old enough to understand, or some life event triggered the disclosure. Some parents reported that they disclosed the diagnosis to siblings as early as possible. The ways to disclose included responding to the topic as presented on television or a corresponding tool, giving a related book, and attendance of activities concerning Down syndrome. During disclosure to siblings, some parents used the term 'Down syndrome' while others did not. One parent reported that they talked about Down syndrome repeatedly to the sibling.

Three parents reported a one-way style, mainly through social networking sites (SNS) ($n = 2$). By this style, parents could convey the information without knowing the reaction of others, although it is unclear whether others received the information or not. Another parent sent a picture of her child to friends in an e-mail, with the expectation that the friends would notice the child had Down syndrome from the facial appearance.

All parents reported that they disclosed information about the diagnosis of their child to someone, but nine parents reported that they sometimes selected non-disclosure. The reasons for non-disclosure were as follows: parents predicted that the responses of others would be negative and that others would notice from the appearance of their child without disclosure. Some parents planned to disclose the information depending on the necessity for it and who the person was.

3.6 | Responses of disclosure and connection with others

The responses after information disclosure were sometimes reported as courtesy stigma experiences, such as devaluing remarks and attitudes, stereotyping remarks and attitudes, and unwelcome pitying remarks by friends, their parents, and work acquaintances. However, many parents reported that others did not react so much immediately after disclosure ($n = 21$).

The overall responses of others after the information disclosure were mostly positive ($n = 20$), and they were categorized into remarks and attitudes that were understanding/accepting, supporting, and cherishing. Such positive experiences in interpersonal relationships were widely reported by all respondents, not only in response to their disclosure about their children's diagnosis, but also in their daily lives. For example, supporting remarks and attitudes were reported as the experience from medical staff in hospitals by 16 parents.

Furthermore, reverse disclosure as a reciprocal form of disclosure by friends, other parents, and work acquaintances was reported by eight parents. For example, one parent said, '*My friends said that...as a matter of fact, my cousin is...my relative is...also, I used to attend a special school for an illness for a while...they shared their own stories...I was relieved that I knew there are a lot of people like me...since I had felt like I lived in a different world up to that point...*' (37-year-old mother, 9-month-old son). In addition, three parents reported that they had received acknowledgement as a parent from their own mother or father. For example, one parent reported, '*My father said that maybe your daughter chose you [because you can raise her]*' (40-year-old father, 9-year-old daughter).

3.7 | Relationships with peers

Fifteen parents reported positive experiences in relationships with peers. Ten parents reported having encounters and connections with parents in the same situation, and changed their feelings and thoughts through these connections; for example, parents no longer felt it was necessary to conceal the diagnosis. Thirteen parents reported that they could talk with their peers more easily, and could feel their empathy. Seven parents reported that they received more information from their peers, and such information included prospects for the development of their own child. Two parents reported that peers cherished their child.

3.8 | Relationship with one's child

Most parents reported positive experiences in their relationships with their children ($n = 22$). Having a child with Down syndrome made nine parents realize the importance of life. For example, one parent said, '*I understood the most important thing is a life...I am grateful she is living...I am happy that she is here rather than minding that she has Down syndrome...*' (42-year-old mother, 7-month-old

daughter). Seven parents highlighted the cuteness of their children. Ten parents reported that childcare was enjoyable. Eight parents reported on the growth of their child, leading to changes in parents' feelings and thoughts, and increased confidence as parents. Three parents reported that caring for a child with Down syndrome was easy. Two parents reported that their own prejudice against Down syndrome reduced after having a child with Down syndrome.

3.9 | Adaptation process toward transcendent stage

As described above, parents encountered multiple types of courtesy stigma and used various coping strategies along with information disclosure tactics. Through those experiences they experienced personal changes as an outcome of having a child with Down syndrome with regard to interpersonal relationships ($n = 21$). In Figure 1, we illustrate a model of parents' adaptation process.

During the adaptation process, parents reported several personal changes: (a) enhanced interpersonal relations ($n = 13$); (b) enhanced compassion ($n = 10$); (c) expanded perspectives ($n = 21$); and (d) enhanced social connections ($n = 8$). The first change, enhanced interpersonal relations, included the expansion and deepening of interpersonal relationships. For example, one parent reported 'My social relationships have expanded explosively, such that I have encountered various people who I would not have met if I had a child with typical development' (55-year-old mother, 16-year-old son); another parent reported 'Only good people have come in contact with me...they have an interest in and understanding about my son. They are kind, loving, and honest' (54-year-old mother, 15-year-old son).

The second change, enhanced compassion, included feelings of increased warmth for people with disabilities. In addition, parents began to think about others' situations and developed an overwhelming need to serve others. For example, 'I came to think seriously how I could support people who actually need help' (63-year-old father, 9-year-old daughter); 'I became tolerant...whereas I had been inclined to think "why can't [they] do it, why don't [they] do it?" I came to understand that there are people who cannot do it. Now, I honestly think it is enough for each person to do within their own capacity...' (45-year-old mother, 9-year-old daughter).

The third change, expanded perspectives, included changes in views about people with disabilities. For example, one parent said, 'When I see someone with Down syndrome on the street, I feel like we are members of a fellow community...like coming from the same planet...' (50-year-old mother, 9-year-old son). Another parent said, 'I have gained different perspectives on children with disabilities, not only Down syndrome but also children with autism or those in a wheelchair, and I feel close to them' (37-year-old father, 10-month-old daughter). In addition, parents reported expanding their own world view, and developing views of diversification, inclusion, and globalization. One parent said, 'I realized that the world consists of diverse people and that makes our society [even more] interesting' (40-year-old father, 9-year-old daughter). Furthermore,

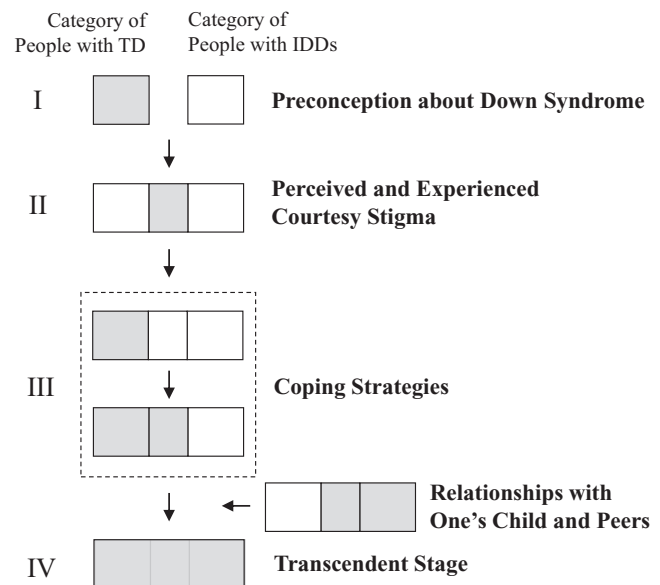


FIGURE 1 Hypothesis model of the adaptation process of individuals in the intermediate situation. Notes: Gray squares represent own standpoint, and white squares others' standpoint. The left square represents the category of people with typical development (TD); the right square the category of people with intellectual and developmental disabilities (IDDs), including Down syndrome; and the middle the category of people in the intermediate situation. Before having their own child, parents have preconceptions about Down syndrome and consciously or unconsciously consider their own category to differ (I). Upon diagnosis of their own child, parents are placed in an intermediate situation, in which there is perceived and experienced courtesy stigma (II). However, parents develop coping strategies and through interpersonal relationships with others (III), they reach the transcendent stage (IV). Note that a passive coping strategy (III, upper, showing 'passing') develops into an active coping strategy (III, bottom)

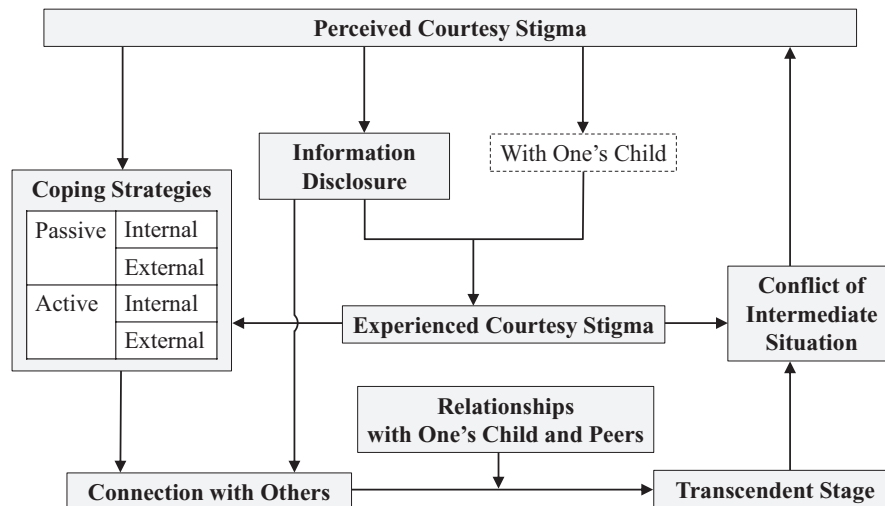
parents became interested in society and desired to make society better. For example, one parent reported, 'I think I used to be narrow minded before. I have come to notice various things more...I used to be unconcerned about incidents but now I have come to stop and think' (55-year-old mother, 16-year-old son).

The fourth change, enhanced social connections, included imparting information about Down syndrome to society, and improved awareness of others. This also included parents considering themselves to be interpreters for their children and advocates for the rights of children with Down syndrome. For example, one parent said, 'I have recently realized that people start to get to know about Down syndrome [if I explain to them]...I think I will be an evangelist...to let others know about positive aspects of Down syndrome' (45-year-old father, 10-year-old son).

3.10 | Conflict of intermediate situation

Participants reported continuous challenges in their daily lives as parents of children with Down syndrome ($n = 22$). The first challenge was ongoing prejudice from others and themselves ($n = 15$).

FIGURE 2 Association of main categories of parental adaptation process related to courtesy stigma. Note: Grey squares represent the main category extracted by the analysis. The figure explains the recurrent model of the adaptation process



Parents sometimes compared their children with other children with typical development, and then felt disappointment, needing to manage their feelings. For example, one parent reported, '...my prejudice was strong...[society] has excluded people with less ability...I admit that I also used to have the same thoughts. I deeply believe that the enemy was within me...and probably the enemy would have continued to be there... [things are] not all or nothing' (45-year-old father, 10-year-old son). Another parent reported, 'There is probably no such thing as 100% being bothered or burden free [about Down syndrome]. I get bothered [with my child having] Down syndrome when I interact with others [who have no disability]...I think it will never go away completely' (42-year-old mother, 7-month-old daughter).

The second challenge was difficulty in getting understanding from others ($n = 11$). Parents felt that others would never understand them, as they could not have understood families of children with disabilities before having their own child with Down syndrome. Parents felt a burden, as they had to explain repeatedly. Parents also reported that they needed to assess whether the others understood them or not, and they became sensitized to others' responses and values.

The third challenge was the perception of difficulty toward parent's own children ($n = 7$). Parents reported the perception that their children's lives were hard and they could not fully understand their own children. One parent said, 'I frequently think that perhaps I am the one who does not understand my son the most. I always underestimate him...I tend to think he will not be able to do this anyway...' (55-year-old mother, 19-year-old son). The fourth challenge was the physical and temporal burden as a parent ($n = 18$), including frequent visits to hospital and school. Parents also reported a lack of information, need for preparation for the future, and difficulty coordinating between siblings, where one had Down syndrome and another did not. Furthermore, five parents reported difficulties in getting along with peers.

Figure 2 depicts the recurrent model of the adaptation process of parents, which explains the association of category groups extracted in this study. For example, parents experience a recurrent intermediate situation and conflict, which necessitate a coping strategy that would lead to the transcendent stage.

4 | DISCUSSION

This study aimed to provide a comprehensive understanding of the experiences related to the courtesy stigma of parents of children with Down syndrome. The results from this qualitative study yielded three major findings on 1) perceived and experienced courtesy stigma, 2) coping strategies and information disclosure, and 3) transcendent stage and a recurrent model of adaptation process.

4.1 | Perceived and experienced courtesy stigma

Parents perceived courtesy stigma by a diagnosis of a child, since they were indifferent about Down syndrome before, and then they were concerned about discrimination from others. However, the findings showed that obvious courtesy stigma experiences in interpersonal relations were not common in the daily lives of parents of children with Down syndrome, contrary to our predictions. In addition, the experience of intrusive inquiries was reported to be less than in previous research that represented courtesy stigma experiences of parents of children with Proteus syndrome (22% versus 81%) (Turner et al., 2007). Instead, ambiguous discrimination experiences, such as excessive civil inattention and overly concerned attitudes, were characteristically observed in this study.

This finding is possibly due to the time differences among previous reports, coinciding with recent public perceptions that discrimination is reprehensible. In recent years, social discrimination has become an important public issue (Stein & Stein, 2007), and in Japan, a law prohibiting discrimination against individuals with disabilities was enacted in 2013 and executed in 2016. Our findings that obvious courtesy stigma experiences, such as devaluing remarks and attitudes and intrusive inquiries from adult strangers, were mainly reported by parents with older children, which would support this societal change.

The second possible cause of differences from previous studies is cultural differences. It has been reported that experiences of stigma differ by culture (Ali et al., 2012; Gaff & Clarke, 2007; Rozario, 2007). Japanese people tend to behave more passively in interpersonal

relationships, as shown by the fact that civil inattention is more common in Japan than in the United States (Patterson et al., 2007). In addition, since educational inclusion has not been developed in Japan yet (Kayama, 2010), most people do not understand how to form relationships with individuals who have Down syndrome. In our study, some participants reported experiencing opposition to their child with Down syndrome entering a private kindergarten or elementary school. Furthermore, many participants reported that immediately after information disclosure, others did not react much, suggesting that they did not know how to react at that moment.

4.2 | Coping strategies and information disclosure

Although there are few reports examining coping against courtesy stigma (Ali et al., 2012), the coping strategies extracted in this study are similar to those of a previous report (Turner et al., 2007). In addition, this study showed that the most selected style for parents was the internal way of employing indifference. The coping style probably differs according to the type of courtesy stigma experiences, because previous research has shown that parents reported the experience of intrusive inquiries being the most common, and that it was preferable to have the chance to educate others (Turner et al., 2007). In this study, ambiguous discrimination experiences were observed frequently; therefore, internal coping style was selected more by parents than any other style.

Second, the coping style was inferred to differ over time. A previous report suggested that parents' coping strategies against courtesy stigma experiences would develop over time and they became much better at employing indifference with time (Turner et al., 2007). In line with this finding, this study showed the possibility that coping style develops as time advances, as parents reported that they became better at dealing with others' negative attitudes. Accordingly, although the parents selected a passive way probably to avoid psychosocial effects to themselves and to protect their own children, it can be considered important to develop coping strategies in an active way. However, from the viewpoint of coping with stress, coping strategy is postulated to have psychological consequences (Penley et al., 2002; Van der Veek et al., 2009). For instance, emotion-oriented coping is a predictor of parental stress in parents of children with Down syndrome (Dabrowska & Pisula, 2010), suggesting that identifying the coping strategies of parents in genetic counseling would be beneficial for understanding parental psychosocial status.

Concerning information disclosure, various styles were used by parents according to the subjects, relationships, and aims of disclosure. Interestingly, the extent of disclosure was not always associated with adaptation level, since some parents used active disclosure as an excuse and defense against others, which is considered as a coping strategy against perceived courtesy stigma. In addition, extraction of the one-way style was a characteristic of this study, reflecting how SNS have become popular in modern society. As for the response of others after information disclosure, reverse

disclosure was characteristically observed as a reaction of friends and work acquaintances. Mutual disclosures have positive effects on interpersonal relationships (Sprecher et al., 2013), suggesting that information disclosure leads to good connections with others and psychological well-being for parents.

4.3 | Adaptation process and transcendent stage

Having a child with Down syndrome led to the outcome of connecting with others. The connections with and understanding from others were suggested to be caused by information disclosure and the active coping style of educating others. Enhanced relationships with peers and own child reduce parental prejudice and courtesy stigma perceptions (Green, 2003; Pyle et al., 2018), suggesting that these connections play an important role in the adaptation process for courtesy stigma.

Similar to previous studies that showed that parents perceived they had grown themselves by having a child with Down syndrome (Marshak et al., 2019; Skotko et al., 2011), our study, which focused on courtesy stigma, revealed growth in parents. For example, parents became advocates for intellectual and developmental disabilities, which was also indicated as being the result of discrimination in a previous report (Krueger et al., 2019). Interestingly, our findings showed that the change could be considered from the intermediate situation to the transcendent stage, as shown by enhanced interpersonal relationships, compassion for people with and without Down syndrome, views of diversification or globalization, and social involvement, and these changes indicate that the barrier between people with and without Down syndrome has disappeared. Meanwhile, the conflict of the intermediate situation re-emerged, suggesting that the transcendent stage is not the goal, but is an important process for life as a parent of a child with Down syndrome. Therefore, even if parents experience the transcendent stage, it is necessary to provide continuous appropriate support for them.

Finally, we should consider the ability of our model to apply to other genetic conditions. For parents of children with Down syndrome, it is relatively easy to connect to social support, including family associations, because of high birth frequency and it is widely known in society. It has been reported that parents experience positive aspects to have a child with Down syndrome and adapt well (Choi & Van Riper, 2017; Hodapp, 2007; Lenhard et al., 2005; Skotko et al., 2011); this is sometimes referred to as the 'Down syndrome advantage'. In addition, it has been suggested that the families of children with Down syndrome have lower stress and higher well-being than the families of children with other genetic conditions (Abbeduto et al., 2004; Lanfranchi & Vianello, 2012). Therefore, it is important to consider the characteristics of the condition to deal with the courtesy stigma of parents of children with other genetic conditions in genetic counseling and to support connections with peers, especially for parents of children with rare conditions.

4.4 | Implications for practice

This study showed various experiences of parents with medical staff in hospitals. Many positive experiences, including attitudes and remarks of support, were reported by participants, but at the same time, parents also reported negatively perceived experiences, including overly concerned attitudes and stereotyping assessment. For medical staff, the assessment of the family of children with Down syndrome is an important task to consider in supporting the family, but they should carefully avoid stereotyping assessment. In addition, the overly concerned attitudes may be derived from trying to conceal one's own prejudice; therefore, medical staff need to acknowledge their own stigma and perceptions of Down syndrome.

Our findings could be used to understand and intervene in situations of parents of children with genetic conditions in genetic counseling. For example, if parents are in an avoidance state wishing away the existence of their own child, it may involve the process of attribution restoration. In such cases, it would be beneficial for support providers to show empathy and understanding for parents, helping to reduce their feelings of guilt. If parents adopt a passive coping style, such as concealing or ignoring, it should be respected as a process of adaptation, and parental psychological status needs to be considered carefully. In addition, genetic counseling providers could offer information on active coping styles, various approaches to disclosure, and their potential outcomes, which could then be discussed with parents. In prenatal genetic counseling, information could be provided to show that obvious negative experiences are not common, and parents could develop coping strategies as a result. Furthermore, genetic counseling providers should make effort to provide continuous support to ease the burden of childcare and to promote connections with peers.

4.5 | Limitations

The study's participants were all Japanese. Thus, the results may be affected by cultural characteristics. Furthermore, the parents participated in this study actively by themselves, and thus, they may have the characteristic of tending to connect with others actively. In addition, this study was an exploratory study on a small scale; while we developed one empirical model, there may be other potential models for different cases. Therefore, it is necessary to validate the findings, including the process of adaptation on a large scale. It would be useful to apply our model to various other genetic conditions through further research.

5 | CONCLUSIONS

This study revealed the experiences of parents of children with Down syndrome in interpersonal relationships. Obvious negative experiences were not common in their lives. However, 10 categories were extracted as courtesy stigma experiences, and parents developed

passive-active and internal-external coping strategies to deal with perceived and experienced courtesy stigma. Through active interpersonal relationships, parents reached the transcendent stage, which no longer acts as a barrier between people with and without Down syndrome. Nevertheless, the transcendent stage was not the goal. Our adaptation model could enhance understanding of parents of children with Down syndrome, encourage empathetic responses to them, promote parents' adaptation, leading to enhanced support in interpersonal difficulties for parents in genetic counseling.

AUTHOR CONTRIBUTIONS

Motoko Watanabe contributed to study design, survey development, data collection, data analysis, and manuscript editing. Chieko Kibe contributed to data analysis and manuscript editing. Masumi Sugawara contributed to study design. Hidehiko Miyake contributed to study design, survey development, and manuscript editing. Motoko Watanabe and Chieko Kibe confirm that they had full access to all the data in the study and take responsibility for the integrity of the data as well as the accuracy of the data analysis. All authors gave final approval for this version to be published and agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

ACKNOWLEDGMENTS

This work was supported by JSPS KAKENHI Grant Number 19K19384. We thank F. Yamada for her support during the interview, and N. Sato, X. Wang, and N. Tsuji for their support in transcribing the interview data. We are most grateful to Acceptions (<https://acceptions.org/>) and the Yokohama Project (<https://yokohamaj.org/en/>) for their support in recruiting participants, and to the parents of children with Down syndrome who participated in this study.

COMPLIANCE WITH ETHICAL STANDARDS

CONFLICT OF INTEREST

All authors, Motoko Watanabe, Chieko Kibe, Masumi Sugawara, and Hidehiko Miyake, declare that they have no conflict of interest.

HUMAN STUDIES AND INFORMED CONSENT

All procedures were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all participants.

ANIMAL STUDIES

No non-human animal studies were carried out by the authors for this study.

DATA AVAILABILITY STATEMENT

The data are not publicly available due to privacy or ethical restrictions.

ORCID

Motoko Watanabe  <https://orcid.org/0000-0001-6779-7059>

REFERENCES

- Abbeduto, L., Seltzer, M. M., Shattuck, P., Krauss, M. W., Orsmond, G., & Murphy, M. M. (2004). Psychological well-being and coping in mothers of youths with autism, Down syndrome, or fragile X syndrome. *American Journal of Mental Retardation*, 109(3), 237–254. [https://doi.org/10.1352/0895-8017\(2004\)109<237:PWACIM>2.0.CO;2](https://doi.org/10.1352/0895-8017(2004)109<237:PWACIM>2.0.CO;2)
- Ali, A., Hassiotis, A., Strydom, A., & King, M. (2012). Self stigma in people with intellectual disabilities and courtesy stigma in family carers: A systematic review. *Research in Developmental Disabilities*, 33(6), 2122–2140. <https://doi.org/10.1016/j.ridd.2012.06.013>
- Allyse, M., Minear, M. A., Berson, E., Sridhar, S., Rote, M., Hung, A., & Chandrasekharan, S. (2015). Non-invasive prenatal testing: A review of international implementation and challenges. *International Journal of Women's Health*, 7, 113–126. <https://doi.org/10.2147/IJWH.S67124>
- Angermeyer, M. C., Schulze, B., & Dietrich, S. (2003). Courtesy stigma—A focus group study of relatives of schizophrenia patients. *Social Psychiatry and Psychiatric Epidemiology*, 38(10), 593–602. <https://doi.org/10.1007/s00127-003-0680-x>
- Ashtiani, S., Makela, N., Carrion, P., & Austin, J. (2014). Parents' experiences of receiving their child's genetic diagnosis: A qualitative study to inform clinical genetics practice. *American Journal of Medical Genetics Part A*, 164A(6), 1496–1502. <https://doi.org/10.1002/ajmg.a.36525>
- Biesecker, B. B. (2001). Goals of genetic counseling. *Clinical Genetics*, 60(5), 323–330. <https://doi.org/10.1034/j.1399-0004.2001.600501.x>
- Bittles, A. H., & Glasson, E. J. (2004). Clinical, social, and ethical implications of changing life expectancy in Down syndrome. *Developmental Medicine & Child Neurology*, 46(4), 282–286. <https://doi.org/10.1017/s0012162204000441>
- Buyukavci, M. A., Dogan, D. G., Canaloglu, S. K., & Kivilcim, M. (2019). Experience of mothers with Down syndrome children at the time of diagnosis. *Archivos Argentinos De Pediatría*, 117(2), 114–119. <https://doi.org/10.5546/aap.2019.eng.114>
- Canfield, M. A., Honein, M. A., Yuskiv, N., Xing, J., Mai, C. T., Collins, J. S., & Kirby, R. S. (2006). National estimates and race/ethnic-specific variation of selected birth defects in the United States, 1999–2001. *Birth Defects Research Part A—Clinical and Molecular Teratology*, 76(11), 747–756. <https://doi.org/10.1002/bdra.20294>
- Cantwell, J., Muldoon, O., & Gallagher, S. (2015). The influence of self-esteem and social support on the relationship between stigma and depressive symptomology in parents caring for children with intellectual disabilities. *Journal of Intellectual Disability Research*, 59(10), 948–957. <https://doi.org/10.1111/jir.12205>
- Choi, H., & Van Riper, M. (2017). Adaptation in families of children with Down syndrome in East Asian countries: An integrative review. *Journal of Advanced Nursing*, 73(8), 1792–1806. <https://doi.org/10.1111/jan.13235>
- Corbin, J. M., & Strauss, A. (1990). Grounded theory research: Procedures, canons and evaluative criteria. *Qualitative Sociology*, 13, 3–21. <https://doi.org/10.1007/BF00988593>
- Corrigan, P. W., & Watson, A. C. (2002). The paradox of self-stigma and mental illness. *Clinical Psychology: Science and Practice*, 9(1), 35–53. <https://doi.org/10.1093/clipsy/9.1.35>
- Dabrowska, A., & Pisula, E. (2010). Parenting stress and coping styles in mothers and fathers of pre-school children with autism and Down syndrome. *Journal of Intellectual Disability Research*, 54(3), 266–280. <https://doi.org/10.1111/j.1365-2788.2010.01258.x>
- Deem, M. J. (2016). Whole-genome sequencing and disability in the NICU: Exploring practical and ethical challenges. *Pediatrics*, 137(Suppl 1), S47–55. <https://doi.org/10.1542/peds.2015-3731>
- Farkas, L., Cless, J. D., Cless, A. W., Goff, B. S. N., Bodine, E., & Edelman, A. (2019). The ups and downs of Down syndrome: A qualitative study of positive and negative parenting experiences. *Journal of Family Issues*, 40(4), 518–539. <https://doi.org/10.1177/0192513x18812192>
- Gaff, C. L., & Clarke, A. (2007). Stigmatization, culture and counseling a commentary on growing up and living with NF1: A UK–Bangladeshi case study—by Santi Rozario. *Journal of Genetic Counseling*, 16(5), 561–565. <https://doi.org/10.1007/s10897-007-9098-z>
- Glasson, E. J., Sullivan, S. G., Hussain, R., Petterson, B. A., Montgomery, P. D., & Bittles, A. H. (2002). The changing survival profile of people with Down's syndrome: Implications for genetic counselling. *Clinical Genetics*, 62(5), 390–393. <https://doi.org/10.1034/j.1399-0004.2002.620506.x>
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Touchstone.
- Gray, D. E. (1993). Perceptions of stigma—The parents of autistic children. *Sociology of Health & Illness*, 15(1), 102–120. <https://doi.org/10.1111/1467-9566.ep11343802>
- Green, S. E. (2003). What do you mean 'what's wrong with her?': Stigma and the lives of families of children with disabilities. *Social Science & Medicine*, 57(8), 1361–1374. [https://doi.org/10.1016/s0277-9536\(02\)00511-7](https://doi.org/10.1016/s0277-9536(02)00511-7)
- Hamlington, B., Ivey, L. E., Brenna, E., Biesecker, L. G., Biesecker, B. B., & Sapp, J. C. (2015). Characterization of courtesy stigma perceived by parents of overweight children with Bardet-Biedl syndrome. *PLoS One*, 10(10), e0140705. <https://doi.org/10.1371/journal.pone.0140705>
- Hodapp, R. M. (2007). Families of persons with Down syndrome: New perspectives, findings, and research and service needs. *Mental Retardation and Developmental Disabilities Research Reviews*, 13(3), 279–287. <https://doi.org/10.1002/mrdd.20160>
- Kayama, M. (2010). Parental experiences of children's disabilities and special education in the United States and Japan: Implications for school social work. *Social Work*, 55(2), 117–125. <https://doi.org/10.1093/sw/55.2.117>
- Kellogg, G., Slattery, L., Hudgins, L., & Ormond, K. (2014). Attitudes of mothers of children with Down syndrome towards noninvasive prenatal testing. *Journal of Genetic Counseling*, 23(5), 805–813. <https://doi.org/10.1007/s10897-014-9694-7>
- Krueger, K., Cless, J. D., Dyster, M., Reves, M., Steele, R., & Nelson Goff, B. S. (2019). Understanding the systems, contexts, behaviors, and strategies of parents advocating for their children with Down syndrome. *Intellectual and Developmental Disabilities*, 57(2), 146–157. <https://doi.org/10.1352/1934-9556-57.2.146>
- Lanfranchi, S., & Vianello, R. (2012). Stress, locus of control, and family cohesion and adaptability in parents of children with Down, Williams, Fragile X, and Prader-Willi syndromes. *American Journal on Intellectual and Developmental Disabilities*, 117(3), 207–224. <https://doi.org/10.1352/1944-7558-117.3.207>
- Lenhard, W., Breitenbach, E., Ebert, H., Schindelhauer-Deutscher, H. J., & Henn, W. (2005). Psychological benefit of diagnostic certainty for mothers of children with disabilities: Lessons from Down syndrome. *American Journal of Medical Genetics Part A*, 133A(2), 170–175. <https://doi.org/10.1002/ajmg.a.30571>
- Loane, M., Morris, J. K., Addor, M. C., Arriola, L., Budd, J., Doray, B., Garne, E., Gatt, M., Haeusler, M., Khoshnood, B., Klungsøyr Melve, K., Latos-Bielenska, A., McDonnell, B., Mullaney, C., O'Mahony, M., Queißer-Wahrendorf, A., Rankin, J., Rissmann, A., Rounding, C., ... Dolk, H. (2013). Twenty-year trends in the prevalence of Down syndrome and other trisomies in Europe: Impact of maternal age and prenatal screening. *European Journal of Human Genetics*, 21(1), 27–33. <https://doi.org/10.1038/ejhg.2012.94>

- Mak, W. W. S., & Cheung, R. Y. M. (2008). Affiliate stigma among caregivers of people with intellectual disability or mental illness. *Journal of Applied Research in Intellectual Disabilities*, 21(6), 532–545. <https://doi.org/10.1111/j.1468-3148.2008.00426.x>
- Marshak, L. E., Lasinsky, E. E., & Williams, C. (2019). Listening to fathers: Personal impacts of raising children with Down syndrome. *Journal of Intellectual Disabilities*, 23(3), 310–326. <https://doi.org/10.1177/1744629518801112>
- Nelson Goff, B. S., Springer, N., Foote, L. C., Frantz, C., Peak, M., Tracy, C., Veh, T., Bentley, G. E., & Cross, K. A. (2013). Receiving the initial Down syndrome diagnosis: A comparison of prenatal and postnatal parent group experiences. *Intellectual and Developmental Disabilities*, 51(6), 446–457. <https://doi.org/10.1352/1934-9556-51.6.446>
- Pachankis, J. E. (2007). The psychological implications of concealing a stigma: A cognitive-affective-behavioral model. *Psychological Bulletin*, 133(2), 328–345. <https://doi.org/10.1037/0033-2909.133.2.328>
- Palomaki, G. E., Kloza, E. M., Lambert-Messerlian, G. M., Haddow, J. E., Neveux, L. M., Ehrich, M., van den Boom, D., Bombard, A. T., Deciu, C., Grody, W. W., Nelson, S. F., & Canick, J. A. (2011). DNA sequencing of maternal plasma to detect Down syndrome: An international clinical validation study. *Genetics in Medicine*, 13(11), 913–920. <https://doi.org/10.1097/GIM.0b013e3182368a0e>
- Parker, S. E., Mai, C. T., Canfield, M. A., Rickard, R., Wang, Y., Meyer, R. E., Anderson, P., Mason, C. A., Collins, J. S., Kirby, R. S., & Correa, A. (2010). Updated national birth prevalence estimates for selected birth defects in the United States, 2004–2006. *Birth Defects Research Part A: Clinical and Molecular Teratology*, 88(12), 1008–1016. <https://doi.org/10.1002/bdra.20735>
- Patterson, M. L., Iizuka, Y., Tubbs, M. E., Ansel, J., Tsutsumi, M., & Anson, J. (2007). Passing encounters east and west: Comparing Japanese and American pedestrian interactions. *Journal of Nonverbal Behavior*, 31(3), 155–166. <https://doi.org/10.1007/s10919-007-0028-4>
- Penley, J. A., Tomaka, J., & Wiebe, J. S. (2002). The association of coping to physical and psychological health outcomes: A meta-analytic review. *Journal of Behavioral Medicine*, 25(6), 551–603. <https://doi.org/10.1023/a:1020641400589>
- Peters, K., Apse, K., Blackford, A., McHugh, B., Michalic, D., & Biesecker, B. (2005). Living with Marfan syndrome: Coping with stigma. *Clinical Genetics*, 68(1), 6–14. <https://doi.org/10.1111/j.1399-0004.2005.00446.x>
- Pyle, M., Pilling, S., Machin, K., Allende-Cullen, G., & Morrison, A. P. (2018). Peer support for internalised stigma experienced by people with psychosis: Rationale and recommendations. *Psychosis: Psychological Social and Integrative Approaches*, 10(2), 146–152. <https://doi.org/10.1080/17522439.2018.1437212>
- Quinn, D. M., & Chaudoir, S. R. (2009). Living with a concealable stigmatized identity: The impact of anticipated stigma, centrality, salience, and cultural stigma on psychological distress and health. *Journal of Personality and Social Psychology*, 97(4), 634–651. <https://doi.org/10.1037/a0015815>
- Roizen, N. J., & Patterson, D. (2003). Down's syndrome. *The Lancet*, 361(9365), 1281–1289. [https://doi.org/10.1016/S0140-6736\(03\)12987-X](https://doi.org/10.1016/S0140-6736(03)12987-X)
- Rozario, S. (2007). Growing up and living with neurofibromatosis1 (NF1): A British Bangladeshi case-study. *Journal of Genetic Counseling*, 16(5), 551–559. <https://doi.org/10.1007/s10897-007-9097-0>
- Saiki-Craighill, S. (2016). *Grounded theory approach: Riron wo Umidasu made* [Grounded theory approach: Toward the development of theory], Revised ed. Shinyosha.
- Samura, O., Sekizawa, A., Suzumori, N., Sasaki, A., Wada, S., Hamanoue, H., Hirahara, F., Sawai, H., Nakamura, H., Yamada, T., Miura, K., Masuzaki, H., Nakayama, S., Okai, T., Kamei, Y., Namba, A., Murotsuki, J., Tanemoto, T., Fukushima, A., ... Sago, H. (2017). Current status of non-invasive prenatal testing in Japan. *Journal of Obstetrics and Gynaecology Research*, 43(8), 1245–1255. <https://doi.org/10.1111/jog.13373>
- Sankar, P., Cho, M. K., Wolpe, P. R., & Schairer, C. (2006). What is in a cause? Exploring the relationship between genetic cause and felt stigma. *Genetics in Medicine*, 8(1), 33–42. <https://doi.org/10.1097/01.gim.0000195894.67756.8b>
- Sheets, K. B., Crissman, B. G., Feist, C. D., Sell, S. L., Johnson, L. R., Donahue, K. C., Masser-Frye, D., Brookshire, G. S., Carre, A. M., LaGrave, D., & Brasington, C. K. (2011). Practice guidelines for communicating a prenatal or postnatal diagnosis of Down syndrome: Recommendations of the National Society of Genetic Counselors. *Journal of Genetic Counseling*, 20(5), 432–441. <https://doi.org/10.1007/s10897-011-9375-8>
- Siegel, K., Lune, H., & Meyer, I. H. (1998). Stigma management among gay/bisexual men with HIV/AIDS. *Qualitative Sociology*, 21(1), 3–24. <https://doi.org/10.1023/A:1022102825016>
- Skotko, B. G., Levine, S. P., & Goldstein, R. (2011). Having a son or daughter with Down syndrome: Perspectives from mothers and fathers. *American Journal of Medical Genetics Part A*, 155A(10), 2335–2347. <https://doi.org/10.1002/ajmg.a.34293>
- Sprecher, S., Treger, S., Wondra, J. D., Hilaire, N., & Wallpe, K. (2013). Taking turns: Reciprocal self-disclosure promotes liking in initial interactions. *Journal of Experimental Social Psychology*, 49(5), 860–866. <https://doi.org/10.1016/j.jesp.2013.03.017>
- Stein, M. A., & Stein, P. J. S. (2007). Beyond disability civil rights. *Hastings Law Journal*, 58(6), 1203–1240. <https://doi.org/10.2139/ssrn.1552010>
- Stoll, C., Dott, B., Alembik, Y., & Roth, M. P. (2015). Associated congenital anomalies among cases with Down syndrome. *European Journal of Medical Genetics*, 58(12), 674–680. <https://doi.org/10.1016/j.ejmg.2015.11.003>
- Takataya, K., Yamazaki, Y., & Mizuno, E. (2016). Perceptions and feelings of fathers of children with Down syndrome. *Archives of Psychiatric Nursing*, 30(5), 544–551. <https://doi.org/10.1016/j.apnu.2016.04.006>
- Turner, J., Biesecker, B., Leib, J., Biesecker, L., & Peters, K. F. (2007). Parenting children with Proteus syndrome: Experiences with, and adaptation to, courtesy stigma. *American Journal of Medical Genetics Part A*, 143A(18), 2089–2097. <https://doi.org/10.1002/ajmg.a.31904>
- Van der Veek, S. M. C., Kraaij, V., & Garnefski, N. (2009). Down or up? Explaining positive and negative emotions in parents of children with Down's syndrome: Goals, cognitive coping, and resources. *Journal of Intellectual and Developmental Disability*, 34(3), 216–229. <https://doi.org/10.1080/13668250903093133>
- Yoon, P. W., Freeman, S. B., Sherman, S. L., Taft, L. F., Gu, Y. C., Pettay, D., Flanders, W. D., Khoury, M. J., & Hassold, T. J. (1996). Advanced maternal age and the risk of Down syndrome characterized by the meiotic stage of the chromosomal furor: A population-based study. *American Journal of Human Genetics*, 58(3), 628–633.

How to cite this article: Watanabe, M., Kibe, C., Sugawara, M., & Miyake, H. (2022). Courtesy stigma of parents of children with Down syndrome: Adaptation process and transcendent stage. *Journal of Genetic Counseling*, 31, 746–757. <https://doi.org/10.1002/jgc4.1541>