

Stigma and restriction on the social life of families of children with intellectual disabilities in Vietnam

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INTRODUCTION Intellectual disabilities are as prevalent in East Asian countries as in the West (0.06%–1.3%). Widespread discrimination against intellectual disabilities in Asia may initiate stigma that places unfair restrictions on the social life of these individuals and their caregivers. We utilised established stigma frameworks to assess the extent to which a child's intellectual disability contributes to the social exclusion of caregivers in Vietnam.

METHODS A mixed quantitative and qualitative approach was employed to examine the experience of social life restriction among parents of children with intellectual disabilities. The child's disability level and restrictions on caregivers' social experiences were assessed among 70 mothers and fathers recruited from schools in Hue City, Vietnam. Qualitative responses describing social exclusion were also recorded.

RESULTS Caregivers reported elevated levels of social exclusion. As hypothesised, parents of children with greater intellectual disability experienced more restrictions on their social life (Beta = 0.79, 95% confidence interval 0.27–1.30, standard error = 0.26, $p < 0.01$). Qualitative analyses indicated that the threatening of core cultural norms (inability to be employed or married upsets community harmony) initiated labelling, social exclusion and efforts to keep the condition secret or withdraw from others.

CONCLUSION This study is among the first to demonstrate the impacts of intellectual disabilities on caregivers' social functioning in Asia. The findings illustrate how traditional Asian norms initiate stigma, which in turn restricts key social interactions among caregivers. Psycho-educational interventions may address the social domains in which caregivers are impacted and encourage sustained help-seeking among caregivers for their children.

Keywords: Asia, culture, disability, family, stigma
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INTRODUCTION

Estimates of intellectual disabilities (i.e. disorders that affect intellectual and learning abilities such as autism, Down syndrome and mental retardation) among East Asian countries indicate equal prevalence as reported in the West (at 0.06%–1.3%).⁽¹⁾ Due to widespread discrimination toward intellectual disabilities in Asia,⁽²⁾ the stigma might place unfair restrictions on the social life of these individuals and their primary caregivers.^(3–4) While stigma frameworks⁽⁵⁾ have been articulated for mental illness in Asia,^(6–8) a paucity of research has investigated the effects of stigma on families of children with intellectual disabilities in this context. Our study examines this crucial issue in the novel context of Vietnam, where such stigma might manifest in ways shaped by traditional Asian influences.

Studies of stigma among families of children with intellectual disabilities have focused on the resulting caregiver burden among caregivers. For example, studies in the West have indicated that stigma has predicted increased subjective burden,⁽³⁾ quality of life,⁽⁹⁾ social isolation and depression⁽⁴⁾ among caregivers. Studies of caregiver stigma in Asia also showed culture-specific findings. Contrary to findings in Western countries,^(10–11) one study in Taiwan demonstrated that caregivers of family members with

an intellectual disability reported a lower quality of life than caregivers of family members with mental illness.⁽¹²⁾ More severe stigma associated with intellectual disabilities in Asia may be associated with cultural dynamics indicating 'loss of face' (in Hong Kong)⁽¹³⁾ or being labelled by the community as an 'unsuccessful family' (in Taiwan).⁽¹⁴⁾ While research has focused on the impacts on caregiver burden, the potentially major role of stigma in restriction of the social life of caregivers has been neglected. Data on how such restriction on social life occurs might improve both the isolation and depressive symptoms⁽¹⁵⁾ among caregivers and help-seeking for the child.⁽¹⁶⁾ We address this issue by utilising stigma concepts from mental health literature and a measure specifically designed to assess restriction on the social life among caregivers.

We summarise three key conceptualisations of stigma that are especially applicable to how stigma manifests in Asia in Table I.^(17,18) In addition to stigma toward children with intellectual disabilities themselves, family members can experience 'courtesy' (or 'associative') stigma due to their close relationships with those stigmatised.^(19,20) From Jones et al's⁽¹⁷⁾ framework, we propose that intellectual disabilities—due to being less concealable and more disruptive, having a more stable and permanent course

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Table I. Dimensions of stigma

Source (year)	Dimensions of stigma
Goffman ⁽¹⁹⁾ (1963)	<ul style="list-style-type: none"> • Visibility • Discreditable: Possessing a concealable status, which if discovered, would lead to stigmatisation • Discredited: Having others discover a stigmatised condition that leads to negative stereotypes being attached to one's identity
Jones et al ⁽¹⁷⁾ (1984)	<ul style="list-style-type: none"> • Concealability: The degree to which the stigmatising condition can be hidden • Course: How much a stigmatising condition changes over time • Disruptiveness: The extent to which the stigmatised condition hampers social interaction • Aesthetics: Physical attractiveness and how much a person's appearance is affected • Origin: Aetiology of the stigmatised condition, whether it is congenital or acquired • Peril: The perceived danger to others associated with stigmatised conditions
Link et al ⁽¹⁸⁾ (2001)	<ul style="list-style-type: none"> • Labelling: When people distinguish a human difference as important and give it a label • Stereotyping: When beliefs of a cultural group connect labelled individuals to negative characteristics • Cognitive separation: When labelled persons are seen as so different from 'normal' people that a complete separation of 'us' (normal) from 'them' (deviant) is achieved. • Emotional responses: Includes the emotional responses to stigma felt by both the stigmatisers (e.g. fear) and those who are stigmatised • Status loss and discrimination: Where certain members of the society are deemed less capable than others, resulting in unfair treatment <ul style="list-style-type: none"> - Individual discrimination: Direct unfair treatment via person-to-person behaviour - Structural discrimination: When practices of larger institutions or laws disadvantage stigmatised groups • Power: The group who stigmatises must be higher in status (socially, economically, or politically) than the group who is stigmatised in order for the negative effects of stigma to occur

and typically being congenital in origin—may result in greater susceptibility to stigma among family members. In addition to Link and Phelan's⁽¹⁸⁾ seminal conceptualisation of stigma, Link et al⁽¹⁵⁾ also proposed a 'Modified Labelling Theory' that provides an important framework by which stigmatised individuals respond to anticipated stigma. Once a child is identified as having an intellectual disability, family members may anticipate discrimination through awareness of stereotypes (e.g. that other people will believe that family members are culpable in the genesis of the child's condition). Accordingly, two harmful ways that families may respond to anticipated rejection are secrecy or hiding the condition, and withdrawal from social activities. This model is particularly relevant to understanding stigma in Asia, where secrecy is used as a predominant coping mechanism,^(21,22) and has impacts upon social recovery⁽²³⁾ and reintegration.⁽²⁴⁾

In addition to these 'universal' stigma frameworks, Yang et al⁽⁶⁾ proposed that stigma is further shaped by local cultural values by threatening life domains that are most salient. This perspective aids the identification of precisely how stigma affects the stigmatised persons and their families within a given cultural setting. In Vietnam, shared Chinese cultural values, particularly those of Confucian teachings of self-cultivation, result in traditional attitudes toward disabilities that are manifested in Asia more generally⁽²⁵⁻²⁷⁾ First, widespread emphasis on academic achievement makes stigma of intellectual disabilities in Vietnam particularly debilitating.⁽²⁸⁾ Second, maintenance of harmony is threatened by individuals with disabilities, who often are perceived as disruptive, deviant or unpredictable.⁽²⁹⁾ Third, the traditional belief in karma causes disability to be viewed as a manifestation of ancestors' past moral failings.⁽³⁰⁾ Yet, another culture-specific value within Vietnamese culture may further exacerbate stigma of intellectual disabilities in children. Haines et al⁽³¹⁾ reported that

Vietnamese individuals have an obligation to contribute to the continued success of both kin and community, where the entire Vietnamese community is viewed as a continuous and harmonious network. Accordingly, the relatively permanent condition of intellectual disability implies that the child is unlikely to achieve educational success and get married, consequently destabilising this deeply prized harmony and amplifying the resulting stigma.

As one of the first investigations of this kind in Vietnam, we built on Shin et al's⁽³²⁾ study, which found that cognitive delays impacted the reported experience of stress among parents of intellectually disabled children in Vietnam. Our study further builds on prior studies by utilising the described stigma frameworks to directly assess the degree to which a child's intellectual disability contributes to the social exclusion of caregivers. First, we hypothesised that parents will experience greater exclusion from social life as their children manifest more severe cognitive impairments. As key sociodemographic variables have been found to correlate with increased familial stigma (e.g. lower education),⁽³³⁾ we also assess the relevant sociodemographic variables in the context of examining this first hypothesis. Second, we utilised qualitative methods to elucidate cultural dynamics surrounding the social exclusion of the primary caregivers to better describe how stigma is most acutely felt within the Vietnamese context.

METHODS

When this study was initiated in 2003, no early intervention programme for intellectual disabilities existed in Hue city, Vietnam (population 350,000). Since 85% of children aged 2–6 years attended kindergarten programmes, participant recruitment occurred in classrooms. In 2003, there were 47 kindergarten

Table II. Inclusion/exclusion criteria.

Type	Criteria
Inclusion	<ul style="list-style-type: none"> Teachers' identification of children's intellectual disabilities/delays from the Portage curriculum assessment, i.e. if they were at least one year behind their age level in terms of development Child's age 3–6 years Parents agreed for the child to be included into the early intervention programme
Exclusion	<ul style="list-style-type: none"> When the children were identified as beyond the capacity of the teachers to handle due to: <ul style="list-style-type: none"> overly severe or profound intellectual disabilities severe behavioural disorders

programmes in Hue. From these kindergarten programmes, 406 teachers served about 7,500 children in 284 classes.⁽³⁴⁾

Participants were administered our study assessments while being recruited to participate in a one-year intervention for children with intellectual disabilities in Vietnam.⁽³⁵⁾ This intervention was modelled upon teachers providing an early intervention, home-based education programme to parents during weekly home visits, 'The Portage curriculum for pre-schoolers'.⁽³⁶⁾ Since our study measures were administered at baseline of the intervention study⁽³⁵⁾ (i.e. prior to delivery of any intervention services), the intervention is not described here. Intervention funding was available to support about 40 children, which accounts for our sample size ($n = 37$). This study was approved by the Institutional Review Board at Hofstra University before subject recruitment.

The participants ($n = 37$) were recruited from two sources: (1) ten kindergarten programmes; and (2) from records of community health clinics in the city. Inclusion criteria for the children are listed in Table II. These children and their family members visited the assessment centre, where intervention teachers identified the children with intellectual disabilities/delays. Teacher's identification of children's intellectual disabilities/delays was based upon the Portage curriculum assessment.⁽³⁶⁾ The Portage curriculum is an intervention model, which was originally developed in the US and has been widely adopted internationally, especially in developing countries, where it has been translated into 36 languages. Its advantages include the availability of a previously developed curriculum, assessment materials and instruction manual. 11 teachers who had at least four years of experience working with children with intellectual and other developmental disabilities received three months of weekly training in this programme. A child was recognised as having intellectual disabilities/delays, recommended to receive intervention services and included into the current study if the child was at least one year behind his or her age level in terms of intellectual, social and motor development. Although reliability statistics were not kept, teachers were formally trained to apply this curriculum's standardised assessment as described above.

Through the aforementioned recruitment process, 37 children and 70 parents (37 mothers and 33 fathers) were included in the study after informed consent. There were 33 parental dyads, with

Table III. Patient demographics.

Variable	No. (%)
Caregiver's relation to patient	
Mother	37 (52.9)
Father	33 (47.1)
Gender of patient	
Male	22 (59.5)
Female	15 (40.5)
Household religious affiliation (n = 37)	
Buddhism	26 (70.3)
Catholicism	2 (5.4)
Others	9 (24.3)
Household economic status (n = 37)	
Very poor	3 (8.1)
Poor	11 (29.7)
Below average	12 (32.4)
Average	11 (29.7)
Rich	0 (0.0)
No. of children per household*	2.5 ± 1.2
Age*	
Mother	36.5 ± 6.7
Father	39.3 ± 6.0
Children	4.2 ± 1.4
Formal education*	
Mother	6.5 ± 1.4
Father	6.3 ± 1.2

*Data is expressed as mean ± standard deviation.

four mothers and four fathers participating without a partner. Participants' characteristics are summarised in Table III.

Two measures, the ABILITIES Index⁽³⁷⁾ and the Restriction of Social Life Scale⁽³⁸⁾ were administered to parents. Both measures were translated into English and backtranslated into Vietnamese,⁽³²⁾ and were assessed for content and semantic equivalence according to a standardised procedure.⁽³⁹⁾ The ABILITIES Index was used to measure the functional ability of each child across nine major domains, including intelligence, communication, behaviour sensory level and muscle tone, motor skills and physical health.⁽³⁷⁾ For this study, only the rating of the intellectual functioning domain from the parent's ABILITIES Index was used in analyses with stigma. We solely utilised the intellectual functioning domain because our focus was on how the social experiences of parents were related to their perceptions of their children's intellectual ability. The Index consisted of 19 ratings subdivided across nine areas: hearing (left and right side), behaviour (inappropriate) and social skills, intellectual functioning, functioning of limbs (right and left hand, arm and leg), intentional communication (receptive and expressive), tonicity (hyper- and hypo-), integrity of physical status, eyes (left and right) and structural status (age-appropriate shape and form of the body). Each area was rated from 0 to 4, with a rating of 0 = normal functioning for age, 1 = suspected disability, 2 = mild disability, 3 = moderate disability, 4 = severe disability and 5 = profound disability. This scale has shown good inter-rater reliability,⁽⁴⁰⁾ with an alpha of 0.93 for mothers' and 0.93 for fathers' report. Further analyses of the ABILITIES Index domains indicated that 91.9% ($n = 34$) of children were perceived by parents as having both

cognitive and physical deficits, while only 8.1% (n = 3) were perceived as having cognitive deficits alone.

In rare cases (two out of 37), when both parents gave their child a '0' (i.e. 'Normal') on the Abilities Index and teachers rated the child as one year below his/her age level on the Portage assessment, the child was still included in the study (based on the teacher's assessment only). Thus, all enrolled children were evaluated as having an intellectual disability by the teacher. In these cases, the parents still agreed for their children to be included in the early intervention programme and acknowledged that their children need some form of intervention for their intellectual disability, even though their ratings on the ABILITIES Index did not reflect this.

The Restriction of Social Life Scale⁽³⁸⁾ was developed as a 12-item scale to assess the degree to which the stigma of having children with intellectual disabilities limits the social experiences of family members. Items were developed in collaboration with Vietnamese clinicians to reflect the types of social support that are available to Vietnamese families. Sample item domains consisted of caregivers' reluctance to take their child to public places, emotions of guilt and shame, degree to which 'social activities' are limited (e.g. "How often does your family including (child's name) attend social events?") and reduced quality of family life (e.g. "Do you think that the life of your family has been affected by your child's disability?"). Items included follow-up questions ("why" or "why not?") to elicit qualitative responses from participants. Open-ended responses were transcribed. Items were coded as 0 (stigma absent) or 1 (stigma present), with higher total scores (range 0–12; Cronbach's alpha 0.60) on the scale indicating greater stigma.⁽³²⁾

Qualitative responses were translated into English by a bilingual, bicultural translator. Subsequent initial content analysis (open coding) was done by a separate Vietnamese bilingual researcher who was well-versed in stigma following standard 'grounded theory' coding procedures.⁽⁴¹⁾ We developed initial codes with specific attention to varying descriptions of the particular stigmatising concerns among caregivers and the aspects in which the social life of caregivers is restricted. Qualitative responses with primary caregivers were analysed for these themes utilising the stigma frameworks described earlier. Five principal codes from these stigma frameworks were utilised, and these along with their frequencies are reported below.

RESULTS

As reported by mothers and fathers, the child's level of intellectual disability ranged from normal (0) to severe disability (4), with the mean rating falling between 'mild' and 'moderate' disability (mean 2.3 ± 1.1 ; median 3.0). No child in this sample was rated '5' (profound disability'). Scores on the Restriction of Social Life Scale indicated a range 4–12, with the average respondent reporting at the high end of the scale, indicating substantial restrictions on social life (mean of the entire sample 9.8 ± 2.8 ; median of the entire sample 10.0). Mothers reported slightly more social stigma

Table IV. GEE model results predicting family-level restrictions on social life with unstandardised beta scores.

Independent variable	Model 1		Model 2	
	Beta	SE	Beta	SE
Level of disability				
STEP 1	0.79*	0.26		
STEP 2			1.07**	0.20
Parents' age			-0.01	0.06
Religion				
Buddhism			0.66	1.47
Catholicism			-1.74	2.45
Others			0.00	0.00
Parents' education			-0.77*	0.26
Family SES			0.91***	0.50
No. of children			0.17	0.40
Parent's gender				
Male			-0.12	0.54
Female			0.00	0.00

*p < 0.01 **p < 0.001, ***p < 0.07

SE: standard error; SES: socioeconomic status

(mean 10.0 ± 3.1 ; median 11.0) than fathers (mean 9.6 ± 2.5 ; median 9.0), but this difference was not significant.

To test our first hypothesis, we examined whether the mothers' and fathers' exclusion from social life was positively associated with their reports of the child's level of intellectual disability. As parents providing information about their child were members of the same family and thus non-independent observers, we utilised a series of Generalised Estimating Equations (GEE) Models for our analyses.⁽⁴²⁾ GEE was appropriate as it could take into account the correlated nature of the mothers' and fathers' responses and because it could use all information from the parents to maximise power. GEE provides re-estimation of the standardised effect measures (i.e. with a 'parent' term representing mothers and fathers) via an adjusted multiple linear regression model. All data was analysed using the Statistical Analysis System version 9.2 (SAS Institute Inc, Cary, NC, USA).

Supporting our first hypothesis, the GEE Model (Table IV, Model 1) showed that restriction on social life, when entered singly, was significantly predicted by the child's level of intellectual disability. Specifically, stigma increased by 0.79 units for every 1 unit of increase in the child's level of intellectual disability (95% confidence interval [CI] 0.27–1.30, standard error [SE] 0.26, p < 0.01). We next examined if this relationship endured even after controlling for sociodemographic variables (Table IV, Model 2). In order to rigorously examine this, we entered all relevant sociodemographic variables simultaneously into the model as covariates. When adjusting for all measured sociodemographic variables (i.e. parents' age, gender, religion, education, socioeconomic status, child's age, child's gender and the total number of children in the household), the analysis showed an even greater effect of restriction on social life; restriction on social life increased by 1.07 units for every 1 unit increase in the child's level of intellectual disability (95% CI 0.68–1.47, SE 0.20, p < 0.001).

Table V. Qualitative responses by caregivers (n = 70).

Coded theme	No.	Example from responses
Core lived values	30	“He can’t care for himself and his job in the future is affected.” “He cannot get married.”
Stigma: discredited	25	“They [community] know and stare at the child.”
Individual-level discrimination	24	“They [neighbours] don’t want us to come to their house.” “They don’t let our child play with their child.”
Emotional reactions of caregiver	22	“I feel sad and don’t want to talk about it again.”
Coping strategy: secrecy/ withdrawal/ avoidance	18	“Don’t want to take my child outside [of home] or go to ceremonies.”

As we were also interested in the relationship between sociodemographic variables and caregivers’ experience of social exclusion, we examined the relationship between these two sets of variables after accounting for effects of the child’s intellectual disability (Table IV, Model 2). When all variables were entered, only the parents’ educational level was significantly and negatively related to social exclusion; for every one year of increase in the parents’ level of education, restriction on social life decreased by 0.77 units (95% CI –1.28 to –0.25, SE 0.26, $p < 0.01$). Further, higher family socioeconomic status (SES) emerged as a trend finding, and was positively related to social exclusion; for every 1 unit increase in family SES, restriction in social life increased by 0.91 units (95% CI –0.07 to 1.89, SE 0.50, $p < 0.07$).

Table V illustrates the five principal characteristics of restriction on social life among caregivers based on open coding. The five codes are listed in order of frequency of occurrence, ranging from 24.7% (Coping strategy) to 42.8% (Core lived values), indicating that a substantial proportion of parents reported having experienced these forms of stigma. The five codes reflected both potential concerns about stigma and actual restrictions on social life experienced by caregivers. In many cases, the social exclusion faced by a child with intellectual disability carried over to the family member. We utilised the prior stigma conceptualisations to organise reported qualitative instances of stigma via the following framework. The genesis of many concerns regarding restriction on social life occurred due to a stigmatised condition threatening the core cultural norms;⁽⁴³⁾ for instance, respondents stated that a child with an intellectual disability “will not be able to get a job in the future” or “get married”. We viewed this threat to ‘full status’ as leading the individual to be labelled and ‘discredited’.⁽⁴⁴⁾ For example, one participant, in response to whether others knew about his child’s condition, stated that community members stare at the child (thus marking the child as a ‘social other’). Caregivers’ knowledge of others’ awareness of the child’s condition may then subsequently lead to limitations on social activities (i.e. individual-level discrimination) of the child with the intellectual disability and his/her family. Examples included the child not being allowed to socialise with other ‘normal’ children.

For the caregivers, this included the family not receiving an invitation to banquets or everyday social gatherings at others’ homes (which frequently marks inclusion within one’s social network in Asian groups).⁽⁷⁾ As a fourth potential process, concerns of future discrimination may result in the caregivers harbouring negative emotional reactions (e.g. feeling sad or ashamed). As a consequence of the preceding processes, families may decide to socially isolate themselves or withdraw from community activities.⁽¹⁵⁾ For instance, caregivers reported not wanting to take the child outside of their homes or to community activities. Hence, restriction on the social life of caregivers manifested as an intersection of stigma concerns and processes, which was observed among a substantial proportion of respondents.

DISCUSSION

Our study is the first of its kind in Vietnam and is among the first to demonstrate a direct relationship between intellectual disabilities and its impacts on caregivers’ social functioning in Asia. The elevated level of perceived stigma reported by the caregivers in our study appears relatively high even when compared to the moderately high stigma reported by caregivers in Taiwan and Hong Kong.^(13,14) Our trend finding that positively links higher socioeconomic status with perceptions of social stigma has been reported in other studies in the West.^(45,46) Yet, our finding that higher education of the parent was associated with less perceived restriction on social life among caregivers in Vietnam contradicts findings that are typically reported in Western cultures.⁽³³⁾ This may be attributed to prominent lay beliefs of karma and past sins in Vietnam implicating the caregivers in the genesis of the child’s condition.⁽³⁰⁾ Caregivers exposed to higher education may not readily subscribe to these beliefs, thus reducing the impact of stigma on their social activities. More research is needed to clarify these potential mechanisms.

While the quantitative findings documented the effect of the child’s intellectual disability on limiting caregivers’ social experiences, the qualitative analyses illustrated key features of how these negative social life concerns and experiences are manifested. The frequency of occurrence of these stigma themes (ranging from 24.7% to 42.8%) indicated that these aspects of stigma were fairly common among caregivers. Corroborating our reported findings of negative emotional reactions (e.g. sadness or embarrassment), prior research has shown that shame and guilt are common experiences cross-culturally in families of children with developmental disabilities.^(4,25,26) Other studies in Asia have also found similar coping mechanisms among parents of children with intellectual disabilities (i.e. secrecy and withdrawal from others) and cultural factors that lead to these coping responses. For example, in Hong Kong, Lam and MacKenzie⁽²⁶⁾ examined the coping strategies of mothers of children with Down Syndrome and found that these mothers avoided taking their children to public places due to fear of rejection, criticism and disgrace in the community. These stressors were further exacerbated by the competitive nature of Hong Kong culture, where socioeconomic

status and the child's academic achievements were the subjects of comparison among families.

Our findings extended these studies on caregivers' social stigma experiences by illustrating how culture initiates stigma that is expressed via restriction in key social interactions among parent caregivers. Based on Yang et al's⁽⁴³⁾ conceptualisation of how fundamental cultural values impact stigma, we located themes of activities that are potentially central to 'full adult status' (e.g. work, marriage, education) among the Vietnamese participants, and thus central to stigma. While the core concern that children with an intellectual disability in Vietnam would not be able to fulfil their responsibilities by getting married and achieving academic success are cross-cultural in nature, we propose that it is further intensified by the disturbance in harmony that such children pose to Vietnamese families and communities.⁽³¹⁾ The inability to pursue education further disrupts the achievement of Confucian self-cultivation, which is common to many Asian cultures.⁽⁷⁾ We propose that the core concern that individuals with intellectual disability cannot fulfil these obligations causes both the children and their family members to be labelled and potentially 'discredited'.⁽¹⁹⁾ Being discredited may further initiate fears of anticipated or actual social discrimination (e.g. both the child and family members being excluded from social gatherings). As noted above, caregivers also frequently experience negative emotional reactions (e.g. feeling sad or embarrassed) as a result of anticipating or experiencing actual devaluation. A common strategy to avoid social rejection and negative emotions is for caregivers to conceal the child's condition or withdraw from social interactions with community members who might further discriminate against them. Our findings thus illustrate that stigma originating from culturally-specific values could have significant consequences on the social life of individuals with intellectual disability and their family members.

This study has several limitations. First, resource constraints faced by teachers resulted in excluding the most cognitively disabled or severely behaviourally disordered children from the study. This may have underestimated the degree of social stigma that caregivers experience in Vietnam. Further, since there are few special education teacher training programmes established in Vietnam and no standardised diagnostic system to identify children with intellectual disabilities,⁽⁴⁷⁾ it is quite possible that children with mild intellectual disabilities were not detected. However, our use of a standardised assessment protocol from a widely adopted curriculum (i.e. the Portage curriculum assessment);⁽³⁶⁾ that identified children at one year behind their age group intellectually somewhat mitigates this concern. Second, because our sample consisted predominantly of children who had both cognitive and physical disabilities, our results should not be generalised to children who might have cognitive disabilities alone. Third, as this the first use of the Restriction of Social Life Scale, there is no other reliability data on it. This scale's internal consistency may be improved upon with further development and testing. However, to our knowledge, our scale is the first to

specifically assess restrictions on social life among caregivers of children with intellectual disabilities and may be especially suited for use in Vietnam and other countries in Southeast Asia. Further, our study—and its confirmed hypotheses—offer initial construct validity for this scale. We plan in future studies to utilise larger sample sizes with our measure in order to allow for advanced analyses, including factor analysis. Fourth, although the causal pathway of greater intellectual disability leading to increased restriction on social life intuitively appears much more plausible than the reverse, the correlational design of our study does not allow us to definitively test for causality. Further, because both measures of intellectual disability and caregivers' restriction on social life were based on parents' reports, it is possible that some unidentified parent variable (e.g. overall perceptiveness of the child's functioning and environment) may account for our findings. Future studies may also identify culture-specific constructs in Vietnam that have not been measured in this study (e.g. belief in karma) that could affect the parents' social life restriction. Additionally, responses to the qualitative probes were not as elaborated as might be desired, as Vietnamese informants might not be accustomed to providing open-ended responses in a research setting.

In conclusion, expanding our knowledge concerning how intellectual disabilities limit caregivers' social functioning illuminates a critical domain that adversely impacts caregivers' social and psychological experiences.^(9,16,48) These results also have important ramifications for the implementation of anti-stigma interventions, which might address the specific social domains in which caregivers are impacted. These programmes may help caregivers to cope with the forms of interpersonal discrimination encountered from the community. Such psychoeducation may also encourage caregivers to break patterns of secrecy and withdrawal by confiding in trusted family members or health providers. Such a strategy is indirectly supported by our finding that increased education among caregivers appears to result in less restriction on social life. Psychoeducation may additionally encourage sustained help-seeking among caregivers, who might hold alternative conceptions of their child's condition, which then influence treatment-seeking.^(49,50) We hope to spur future research to examine the mechanisms underlying the stigma of intellectual disabilities and interventions to reduce their impact on caregivers' social functioning in Vietnam and other Asian countries.

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