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Does type of disability make a difference in affiliate stigma among family caregivers of individuals with autism, intellectual disability or physical disability?

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Abstract

Background Studies have shown that beyond public and self stigma, stigma can also impact family members. Only scant research has examined the internalised aspects of stigma, known as affiliate stigma, among family caregivers of individuals with disabilities. This study examined affiliate stigma among family caregivers of individuals with developmental disabilities via a comparison between caregivers of individuals with intellectual disabilities (ID), autism spectrum disorders (ASD) and physical disabilities (PD) in Israel.
Methods Family caregivers (n = 171) of individuals with developmental disabilities, mainly ID (22.4%), ASD (32.9%) and PD (27.1%), completed a self-report structured questionnaire including the Affiliate Stigma Scale and background variables.
Results Results supported a one-factor structure for the Affiliate Stigma Scale. Overall, affiliate stigma was relatively low in this sample, but was found to be higher among caregivers of individuals with ASD when compared with caregivers of individuals with ID or PD.
Conclusion Findings from this study point to the importance of supporting caregivers of individuals with ASD to decrease their feelings of stigma. It is also important to further develop scales measuring affiliate stigma in order to capture the multidimensional nature of the concept.

Keywords Affiliate Stigma Scale, caregiving, developmental disabilities, stigma

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Introduction

Stigma is conceptualised as a set of prejudicial attitudes, stereotypes, discriminatory behaviours and biased social structures endorsed by a sizeable group about a discredited subgroup (Corrigan 2000). The first and best known type of stigma is public stigma, which focuses on the attitudes of the general population toward stigmatised persons (Link *et al.* 1997; Phelan *et al.* 1998). A second type of stigma is self-stigma, which focuses on individuals' internalisation of society's negative views toward themselves (Corrigan & Watson 2002). As stigma has been known to affect those surrounding the stigmatised individual (Goffman 1963), a third type of stigma is stigma by association. One example of this is family stigma, which relates to the stigma experienced by family members as a consequence of being associated with a stigmatised relative (Larson & Corrigan 2008).

Recently, Mak & Cheung (2008) differentiated between the stigmatic perceptions of the public about family caregivers (i.e. family stigma) and family members' internalisation of these views, which has been termed *affiliate stigma*. Affiliate stigma refers to the extent of self-stigmatisation as experienced by associates of targeted individuals and the corresponding psychological responses of these associates. The concept of affiliate stigma was developed on the basis of the theoretical understanding that stigma consists of cognitive (stereotypes), emotional (prejudice) and behavioural (discrimination) components (Mak & Cheung 2008). The concept has been examined lately in a small number of studies in the area of developmental disabilities (DD). The current study is an attempt to expand this narrow body of knowledge by examining affiliate stigma among family caregivers of individuals with various types of DD in Israel.

Developmental disabilities and stigma

Developmental disabilities refer to severe and chronic disabilities which originate at birth or during childhood. DD are attributable to a mental or physical impairment or a combination of both, are manifested before age 22 and they continue indefinitely, substantially restricting the individual's functioning in several major life activities (Developmental Disabilities Assistance and Bill of Rights Act 2000).

This study focuses on three broad types of DD. The first, intellectual disability (ID), is characterised by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18 (Schalock *et al.* 2010). The second, autism spectrum disorder (ASD), is a neurodevelopmental disorder characterised by a significant impairment in social communication, social interaction, and restricted and repetitive patterns of behaviour (American Psychiatric Association 2013). Finally, physical disability (PD) relates to a broad category of disabilities that typically involve the motor system and place some limitation on the person's ability to move about (Accardo & Whitman 2011).

Stigma is considered to be a major problem for individuals with DD and their families, who frequently experience negative attitudes and responses from the public (Ali *et al.* 2012). Our review of the literature on family and affiliate stigma in DD as well as a recent comprehensive systematic review specific to ID (Ali *et al.* 2012) show that most studies in the DD field have examined the more general construct of family stigma, and only three have focused specifically on affiliate stigma (Mak & Cheung 2008; Mak & Kwok 2010; Chiu *et al.* 2013). Overall, studies assessing family stigma – although not specifically affiliate stigma – showed consistently that families of persons with DD reported feelings of shame, embarrassment and distress (e.g. Baxter & Cummins 1992; Chang 2009; Green 2004, 2007; Ntswane & van Rhyn 2007; Perkins *et al.* 2002; Shin *et al.* 2006), and felt marginalised by their community and their families. These studies found stigma to be associated with negative outcomes, such as parental stress (Baxter & Cummins 1992; Shin *et al.* 2006), burden (Green 2004, 2007; Mak & Cheung 2008) and decreased quality of life (Chou *et al.* 2009). For example, in the fields of both PD (Green 2003) and ID (Shin *et al.* 2006) parental distress has been found to be associated with the burden of caring for the child, and especially with the perception of negative public attitudes towards the child with the disability, including public reactions of ignoring the child, staring at him or her and feeling uncomfortable when the child is present (Baxter 1989).

Family stigma was reported especially with regard to ASD (Gray 1993, 2002), probably as a results of the unique characteristics of this type of DD, which is often characterised by extremely disruptive behavioural symptoms. Further, a study examining the stigmatic experiences of 16 parents of children with ASD found that they attempted to resist feeling stigmatised by providing medical knowledge and engaging in a reconstruction of normality (Farrugia 2009).

Despite the importance of these studies, it should be noted that most have used qualitative methodologies (e.g. Gray 1993, 2002) and did not examine the specific concept of affiliate stigma which allows us to better concentrate on and understand the internalised feelings of the family caregivers.

As mentioned above, only three studies have specifically examined affiliate stigma in DD: one concentrated on family caregivers of individuals with ID or mental illness (Mak & Cheung 2008), the second on family members of persons with ASD

(Mak & Kwok 2010), and the last on family members of persons with ID (Chiu *et al.* 2013). All the studies relied on quantitative methodology and used the Affiliate Stigma Scale (Mak & Cheung 2008) to assess affiliate stigma. Overall, these studies showed that affiliate stigma was below the mid-point of the scale for most items, reflecting a low to moderate level of this type of stigma. However, they also consistently showed positive associations between affiliate stigma and caregiver stress and burden, as well as negative associations to psychological well-being (Mak & Kwok 2010), mental health (Chiu *et al.* 2013) and positive perceptions in caregiving, such as happiness and fulfilment, strength and family closeness, and personal growth (Mak & Cheung 2008).

In terms of the association between affiliate stigma in the area of DD and socio-demographic variables, the scant research available shows inconsistent findings, with most background variables not found to be related to affiliate stigma. Specifically, no differences were found in affiliate stigma according to caregivers' gender (Mak & Cheung 2008) or caregivers' educational level (Chiu *et al.* 2013). While Mak & Cheung (2008) found caregivers' age and children's age to be unrelated to affiliate stigma, Chiu *et al.* (2013) found higher levels of stigma on the behavioural dimension among older caregivers (Chiu *et al.* 2013) and among caregivers of older children (Mak & Kwok 2010; Chiu *et al.* 2013). Contrary to the lack of relationships with most demographic variables, in terms of the child's diagnosis, affiliate stigma was found to be significantly higher among children who had dual diagnoses, such as ID and ASD, as compared with only ID (Mak & Cheung 2008) or only ASD (Mak & Kwok 2010).

In sum, although it is clear that families of individuals with DD are exposed to stigmatic experiences, there is a surprisingly limited body of research in the area of family stigma and almost none in the area of affiliate stigma. Moreover, all existing studies assessing affiliate stigma were conducted solely in Hong Kong or mainland China. Because it has been established that stigma is culturally related (Chiu *et al.* 2013), it is important to examine this topic in a different cultural setting. Furthermore, to the best of our knowledge, no studies have compared affiliate stigma among the aforementioned DD groups. Studies assessing the lay public's perceptions found a hierarchy of preferences among disabilities held by individuals in the lay public (Tringo 1970), with more positive attitudes found towards people with PD than towards individuals with mental disabilities (Wong *et al.* 2004). The present study examines whether these preferences are also internalised among caregivers and translated into affiliate stigma.

Thus, the overall aim of the current study was to expand the narrow body of knowledge in the area of affiliate stigma and DD. Our specific goals were to: (1) examine the extent and characteristics of affiliate stigma within an Israeli sample of caregivers of individuals with DD; and (2) examine the association between affiliate stigma and caregiver's and child's background characteristics, with special attention to DD groups.

Methods

Participants

Participants were a convenience sample of 171 family caregivers of individuals with DD. One participant was removed due to a large amount of missing data, and thus data analyses were based on data collected from 170 caregivers.

Instruments

The study utilised the Affiliate Stigma Scale as well as a background data form that were distributed to caregivers as part of a larger study (Werner & Shulman 2013).

1 *Affiliate Stigma Scale*: Nineteen of the original 22 items in Mak & Cheung's (2008) scale were utilised to measure caregivers' internalisation of stigma. Items were adapted to fit all DD by replacing the term 'family member with mental illness/intellectual disability' to 'child with a disability'. All items in the Affiliate Stigma Scale are worded negatively. For example, 'Having a child with a disability makes me feel that I am lesser to others'. Caregivers in a pilot study reported having difficulty answering a scale that included only negative items. Thus, three items that had the lowest factor loadings according to Mak & Cheung (2008) were dropped, specifically: 'I avoid communicating with my family member with a disability'; 'I've cut down the contacts with my family member with a disability'; and 'I dare not participate in activities related to disability lest other people would suspect that I have a family member with a disability.' Each item was rated on a 4-point Likert scale ranging from 1 = *strongly disagree* to 4 = *strongly agree*. The scale was translated into Hebrew and back-translated by the authors using the Brislin technique (Brislin 1980). The internal consistency for this scale was high in the original study ($\alpha = 0.94$; Mak & Cheung 2008) as well as in the current study ($\alpha = 0.93$).

2 *Background data form* included information on the caregiver's age, gender, years of education, income and religious affiliation, as well as the child's age, gender, type of day setting and diagnosis. If a child was reported to have more than one diagnosis, caregivers were asked to report which was the primary diagnosis or had most impact on the child. Primary diagnoses were re-coded into three categories (ID, ASD and PD).

Procedure

Since the Affiliate Stigma Scale has not been previously validated in Israel, several steps were taken to check its validity and reliability. First, the face validity of the questionnaire was examined by eight experts in the disability field. Next, a pre-test was conducted among eight family caregivers who were asked to provide comments on the clarity and appropriateness of each of the items. Several changes were made in item wording after this phase in order to increase clarity and three items were dropped as described above.

Finally, we contacted the heads of national associations providing support to individuals with ID, ASD and PD and their families; described the study, its aims, importance and procedures; and asked for their help in recruitment of family caregivers. Questionnaires were placed in an envelope along with an explanatory letter and a stamped return envelope. A contact person in each of the associations was responsible for sending out the questionnaires to a random selection of parents on their member list. Using a similar procedure, questionnaires were also sent out to caregivers through four special education schools for children with ID, ASD and PD. Finally, an Internet version of the questionnaire was made available through an e-mail newsletter via a national organisation which provides support to families of individuals with disabilities. The use of multiple samples has been found to be adequate for research on rare populations (Holaday *et al.* 1991).

Ethical considerations

The study's protocol was approved by the Ethics Committee of the School of Social Work and Social Welfare at the Hebrew University of Jerusalem.

Statistical analyses

First, factor structure of the Affiliate Stigma Scale was examined using a Principal Component Factor Analysis with varimax rotation. Second, the association between affiliate stigma and demographic background variables was examined using an independent *t*-test for binary variables, one-way ANOVAS for categorical variables and Pearson correlations for continuous variables. Third, differences in affiliate stigma between DD groups were examined via a Kruskal–Wallis test for each of the affiliate stigma items. This test was selected because the three groups were of unequal size and because each separate scale item is not an interval scale.

Results

Participant demographic characteristics

The distribution of participants' demographic characteristics is found in Table 1. As can be observed, most participants were female (79%), with a mean age of 43 years. Most caregivers were the mothers (79%) or fathers (20%) of the individual with a DD.

The individuals with DD had a mean age of 12 years and were mostly (62%) male. Based on caregivers' report, 31 children had ID, 51 had ASD, 44 had PD, 7 had sensory disabilities, 4 had other disabilities (e.g. attention deficit hyperactivity disorder or emotional difficulties), 2 were reported to have developmental delays affecting many areas and 31 children had more than one diagnosis. Among children with more than one diagnosis, parents' report of the primary diagnosis allowed recoding of 2

Table 1 Distribution of demographic variables ($n = 170$)

	n (%)	
Caregiver demographic variables:		
Gender		
Male	36 (21.2)	
Female	134 (78.8)	
Main caregiver		
Mother	129 (75.9)	
Father	13 (7.6)	
Both parents	11 (6.5)	
Other	11 (6.5)	
Religious affiliation		
Secular	98 (57.6)	
Traditional	37 (21.8)	
Religious	23 (13.5)	
Very religious/orthodox	11 (6.5)	
Income		
Lower than average	39 (22.9)	
Average	52 (30.6)	
Higher than average	79 (46.5)	
		M, SD, range
Age		M = 43.15, SD = 7.64, range = 23–63
Education		M = 15.11, SD = 2.52, range = 9–25
Child demographic variables:		
Gender		
Male	105 (61.8)	
Female	65 (38.2)	
Main diagnosis		
Intellectual disability	38 (22.4)	
Autism spectrum disorder	56 (32.9)	
Physical disability	46 (27.1)	
Sensory disorder	7 (4.1)	
Other (attention deficit hyperactivity disorder, emotional difficulties)	4 (2.4)	
More than one diagnosis	19 (11.2)	
Daily setting		
Special education kindergarten/school	108 (63.5)	
Small class within mainstream setting	21 (12.4)	
Mainstream kindergarten/school	32 (18.8)	
Other	6 (3.5)	
		M, SD, range
Age		M = 11.86, SD = 5.86, range = 1–27

children into the PD group, 5 into the ASD group and 7 into the ID group. The remaining 17 children could not be allocated into one of the discrete categorical groups, as parents reported several diagnoses as equally dominant. The two children mentioned above with developmental delays in many areas were also classified as belonging to this last group. Thus, overall (as shown in Table 1), 38 (22.4%) children were classified with ID, 56 (32.9%) with ASD, 46 (27.1%) with PD, 7 (4.1%) with sensory disability, 4 (2.4%) with other diagnoses and 19 (11.2%) with more than one dominant diagnoses.

Reports of more than one diagnosis were more frequent among girls (63.2%) than among boys (36.8%). An association was found between child's gender and diagnosis [$\chi^2_{(5)} = 26.30$, $P < 0.001$]. Specifically, more boys were found in the ASD group (87.5% boys vs. 12.5% girls), while the percentage of boys was only slightly higher than girls in the other two disability groups (57.9% boys vs. 42.1% girls in the ID group; 57.1% boys and 42.9% girls in the PD group). In terms of their day setting, most participants (63.5%) studied in special education settings.

Affiliate stigma of caregivers of children with DD

As can be observed in Table 2, the mean level of affiliate stigma reported by the participants was relatively low in all the individual items comprising the Affiliate Stigma Scale. The highest level of affiliate stigma was reported in the items reflecting negative internalised emotions related to everyday difficulties of having a child with DD. The lowest level of affiliate stigma was reported in the items reflecting interpersonal relationships and feelings of decreased self-esteem in relation to others.

Next, we examined whether the items in the Affiliate Stigma Scale reflect underlying dimensions of stigma. Factor analysis elicited a three-factor solution with eigenvalues > 1. However, 11 of the items loaded onto two factors, indicating that the suggested three-factor solution was not independent. Another indication of the misfit of the three-factor structure was the scree plot drawn which suggested a one-factor solution. Finally, item–total correlations of the 19 items ranged between 0.43 and 0.76, suggesting an overlap between the items. Taken together, these indications led to a preference for a one-factor solution (Table 2) explaining 45.59% of the variance in affiliate stigma with factor loadings between 0.47 and 0.80. Following these

Table 2 Means, SD, factor loadings and item–total correlation of 19-item affiliate stigma scale among caregivers of individuals with developmental disabilities

	Overall sample (n = 170)		
	Mean (SD)	**Factor loading**	**Item–total correlation**
1. I feel sad because I have a child with a disability.	2.41 (1.01)	0.59	0.55
2. I feel under great pressure as I have a child with a disability.	2.38 (1.06)	0.61	0.58
3. I feel emotionally hurt because I have a child with a disability.	2.17 (1.02)	0.67	0.64
4. Other people would discriminate against me if I am with my child with a disability.	2.08 (0.86)	0.47	0.43
5. The behaviour of my child with a disability makes me feel embarrassed.	1.99 (0.97)	0.63	0.57
6. I feel helpless for having a child with a disability.	1.81 (0.87)	0.75	0.71
7. Given that I have a child with a disability, I've cut down the contact with my friends and relatives.	1.81 (0.97)	0.75	0.71
8. Being a parent of a child with a disability imposes a negative impact on me.	1.77 (0.96)	0.75	0.71
9. I feel inferior because I have a child with a disability.	1.73 (0.87)	0.51	0.47
10. When I am with my child with a disability, I keep an especially low profile.	1.71 (0.90)	0.80	0.76
11. Having a child with a disability makes me feel that I am incompetent compared with other people.	1.70 (0.85)	0.67	0.61
12. I dare not tell others that I have a child with a disability.	1.58 (0.86)	0.59	0.52
13. I reduce going out with my child with a disability.	1.54 (0.80)	0.68	0.64
14. People's attitude towards me turns bad when I am with my child with a disability.	1.50 (0.75)	0.65	0.60
15. Given that I have a child with a disability, I've cut down the contacts with my neighbours.	1.49 (0.77)	0.72	0.66
16. My reputation is damaged because I have a child with a disability at home.	1.36 (0.61)	0.64	0.59
17. I worry that others would know I have a child with a disability.	1.33 (0.64)	0.73	0.66
18. Having a child with a disability makes me feel that I am lesser than others.	1.31 (0.58)	0.76	0.70
19. Having a child with a disability makes me lose face.	1.29 (0.58)	0.77	0.72

results, an overall index of affiliate stigma was derived by calculating the mean of the items. The overall mean caregiver's affiliate stigma was found to be relatively low (M = 1.72, SD = 0.57).

Association between affiliate stigma and background variables

Table 3 shows the results of independent *t*-tests and one-way ANOVAs conducted to examine relationships between the overall index of affiliate stigma and caregiver's and child's background variables. No statistically significant differences were found in the participants' reported level of affiliate stigma according to any of the caregivers' background characteristics (age, years of education, gender, income and religious affiliation).

Similarly, no statistically significant differences were found in reported levels of affiliate stigma according to the child's age and his or her day setting. However, our results showed a statistically significant difference in affiliate stigma according to the diagnosis of DD, with higher levels of affiliate stigma reported by caregivers of children with ASD (M = 1.88, SD = 0.61), followed by caregivers of children with ID (M = 1.71, SD = 0.63) and finally PD (M = 1.57, SD = 0.40). Further, mean affiliate stigma was higher among caregivers of boys (M = 1.78, SD = 0.63) than of girls (M = 1.62, SD = 0.43). However, given that more boys than girls had ASD, while similar proportions of boys and girls had ID or PD, it is likely that the difference in stigma between boys and girls was actually a confounding variable of diagnosis. Thus, a linear regression was carried out to determine the contribution of both gender and diagnosis to explaining stigma. Child's diagnosis significantly predicted affiliate stigma ($\beta = 0.24$; $R^2 = 0.06$, $P < 0.05$) while gender did not predict stigma ($\beta = -0.00$).

Table 3 Association between affiliate stigma and background variables

	Mean (SD)	*T*-score or *F*-score
Caregiver demographic variables:		
Gender		0.64
Male (*n* = 36)	1.67 (0.61)	
Female (*n* = 134)	1.74 (0.56)	
Income		0.44
Lower than average (*n* = 39)	1.79 (0.64)	
Average (*n* = 52)	1.67 (0.52)	
Higher than average (*n* = 79)	1.72 (0.56)	
Religious affiliation		0.99
Secular (*n* = 98)	1.69 (0.48)	
Traditional (*n* = 37)	1.84 (0.70)	
Religious (*n* = 23)	1.73 (0.57)	
Very religious (orthodox) (*n* = 11)	1.55 (0.77)	
		Pearson *R*
Age		0.03
Years of education		−0.06
		***T*-score or *F*-score**
Child demographic variables:		
Gender		2.03*
Male (*n* = 105)	1.78 (0.63)	
Female (*n* = 65)	1.62 (0.43)	
Diagnostic group		4.07*
Intellectual disability (*n* = 38)	1.71 (0.63)	
Autism (*n* = 56)	1.88 (0.61)	
Physical disability (*n* = 46)	1.57 (0.40)	
Daily setting		2.17
Special education setting (*n* = 108)	1.73 (0.57)	
Small class within mainstream setting (*n* = 21)	1.94 (0.69)	
Mainstream setting (*n* = 32)	1.54 (0.40)	
Other (*n* = 6)	1.72 (0.57)	
		Pearson *R*
Age		0.04

* $P < 0.05$.

Next, differences between DD groups were examined separately for each of the affiliate stigma items (see Table 4). Affiliate stigma was significantly higher among caregivers of individuals with ASD on five items, specifically: 'The behaviour of my child with a disability makes me feel embarrassed', 'I reduce going out with my child with a disability', 'Given that I have a child with a disability, I've cut down the contact with my friends and relatives', 'Being a parent of a child with a disability imposes a negative impact on me', and 'I dare not tell others that I have a child with a disability'. No significant differences were found on any of the other items.

Discussion

The current study enriches the limited existing literature on affiliate stigma and DD by examining this topic among family caregivers of individuals with ID, ASD and PD. Our results provide interesting insights related to: (1) the factor structure of affiliate stigma; (2) the level of affiliate stigma regarding DD in Israel, and its comparison to similar findings in other cultures; and (3) correlates of affiliate stigma, with special attention to diagnosis group.

Level and factor structure of affiliate stigma

Similar to previous studies (Mak & Cheung 2008; Mak & Kwok 2010), the level of affiliate stigma reported by our participants was relatively low. A straightforward explanation may be that indeed these families are not suffering deeply from internalised stigma. An alternative hypothesis may be supported by a study among family caregivers of individuals with mental illness that found greater levels of stigma when parents reported on other families and lower stigma when reporting on themselves (Shetruch *et al.* 2007). It could be hypothesised that in order to decrease their pain families preferred to report lower stigma levels. This hypothesis is especially relevant to the Affiliate Stigma Scale in which all items are worded negatively. It is quite possible that in order for families to be able to protect their emotional status they underreported negative experiences and feelings. Further, parents' coping mechanisms, which were not examined in

Table 4 Means and standard deviations of affiliate stigma items among caregivers of children with intellectual disability (ID), autism spectrum disorders (ASD) and physical disabilities (PD)

	ASD	ID	PD	Kruskal–Wallis Test
1. I feel sad because I have a child with a disability.	2.61 (0.98)	2.29 (1.06)	2.27 (0.99)	3.74
2. I feel under great pressure as I have a child with a disability.	2.61 (1.12)	2.08 (1.02)	2.35 (0.97)	5.72
3. I feel emotionally hurt because I have a child with a disability.	2.39 (1.14)	2.18 (1.04)	1.89 (0.80)	4.96
4. Other people would discriminate against me if I am with my child with a disability.	2.11 (0.93)	1.95 (0.80)	2.15 (0.82)	1.20
5. The behaviour of my child with a disability makes me feel embarrassed.	2.25[†] (0.92)	2.13[§] (1.10)	1.54[†§] (0.78)	15.10***
6. I feel helpless for having a child with a disability.	1.93 (0.93)	1.74 (0.86)	1.72 (0.81)	1.58
7. Given that I have a child with a disability, I've cut down the contact with my friends and relatives.	2.13[†] (1.05)	1.66 (0.97)	1.57[†] (0.78)	9.61**
8. Being a parent of a child with a disability imposes a negative impact on me.	2.05 (1.04)[†]	1.71 (1.01)	1.45[†] (0.66)	8.86*
9. I feel inferior because I have a child with a disability.	1.88 (0.92)	1.58 (0.76)	1.67 (0.90)	2.85
10. When I am with my child with a disability, I keep an especially low profile.	1.86 (0.96)	1.76 (1.00)	1.49 (0.66)	3.16
11. Having a child with a disability makes me feel that I am incompetent compared with other people.	1.75 (0.88)	1.71 (0.93)	1.63 (0.77)	0.30
12. I dare not tell others that I have a child with a disability.	1.73[†] (0.82)	1.66 (1.05)	1.31[†] (0.67)	8.67*
13. I reduce going out with my child with a disability.	1.79[†] (0.91)	1.53 (0.80)	1.26[†] (0.54)	10.30**
14. People's attitude towards me turns bad when I am with my child with a disability.	1.56 (0.81)	1.58 (0.79)	1.35 (0.60)	2.62
15. Given that I have a child with a disability, I've cut down the contacts with my neighbours.	1.54 (0.74)	1.53 (0.86)	1.41 (0.75)	1.16
16. My reputation is damaged because I have a child with a disability at home.	1.45 (0.63)	1.42 (0.72)	1.20 (0.46)	4.85
17. I worry that others would know I have a child with a disability.	1.45 (0.74)	1.32 (0.66)	1.20 (0.45)	3.86
18. Having a child with a disability makes me feel that I am lesser than others.	1.35 (0.62)	1.37 (0.63)	1.22 (0.47)	1.65
19. Having a child with a disability makes me lose face.	1.36 (0.62)	1.37 (0.71)	1.15 (0.36)	3.49

* $P < 0.05$, ** $P < 0.01$, *** $P < 0.001$.

[†] Significant differences between ASD and PD.

[§] Significant differences between ID and PD.

the current study, could potentially explain these results. It is possible that parents distance themselves from individuals who hold negative attitudes towards them in order to protect themselves and, thus, do not internalise stigma. In addition, it is possible that perhaps carers who felt the most stigmatised did not return the questionnaire or have even refused input from services that are associated with the stigmatised group.

Although the Affiliate Stigma Scale was constructed to reflect cognitive, emotional and behavioural components of internalised family stigma (Mak & Cheung 2008), the results of the current study, similarly to those of the scale's developers, confirmed a one-factor solution. The explanation suggested by the scale's developers was that the three components are highly inter-connected, resulting in a single dimension (Mak & Cheung 2008). However, several alternative hypotheses can be offered to explain the one-factor solution.

First, the Affiliate Stigma Scale was developed based on existing literature. Although the authors did not specify which literature guided their scale construction, our review of the literature on courtesy and affiliate stigma may offer an explanation for the one-factor solution. Most literature in the field has focused on two aspects, parents' experience of marginalisation and parents' psychological wellbeing. The first aspect, experience of marginalisation, seems to relate to the wider construct of family stigma. The second aspect of psychological wellbeing relates more specifically to the affiliate stigma concept. This literature focuses on internalised emotional underpinnings of the perceptions and feelings experienced by family members (e.g. Green 2004, 2007; Chou *et al*. 2009; Ali *et al*. 2012). Thus, it seems that the cognitive and behavioural dimensions of affiliate stigma are under-represented in both the literature and in the scale.

The above hypotheses may be strengthened by looking at methodological issues within the Affiliate Stigma Scale. Although Mak & Cheung (2008) did not provide sufficient information as to the process that led to their categorisation of scale items into each of the three components, a careful examination of the content of each scale item suggests that there is no clear differentiation between the components. Specifically, several items selected by the authors to represent the cognitive component may actually be measuring an emotional aspect. For example, 'having a family member with ID makes me lose face', 'my reputation is damaged because I have a child with a disability at home' and 'having a family member with ID imposes a negative impact on me' all have attached an emotional dimension and could arguably represent the affective component.

This argument should be examined carefully, especially since this unclear differentiation between the components may be associated with translation issues. Despite the fact that in our study we adhered to a strict methodology of translation and back translation, we cannot disregard the possibility that the rewording of several items in the translation process affected the differentiation of the cognitive and affective components. Specifically, in two items 'Having a family member with ID makes me think that I am incompetent compared with other people' and 'having a family member with a disability makes me think that I am less than others' the word 'think' was replaced by 'feel' in order to better fit the Hebrew language.

Differences in affiliate stigma between Israel and Hong Kong

It has been established that stigma may be influenced by culture (Chiu *et al*. 2013). Since the present study is the first conducted outside of China and Hong Kong, it is of great interest to compare our results to previous results from Hong Kong.

As we did not specifically analyse differences between the current results and previous studies, the discussion regarding these differences should be approached with caution. Nevertheless, several interesting differences appear. First, in terms of the level of affiliate stigma, caregivers in the current study reported lower levels of affiliate stigma than caregivers from Hong Kong. This finding is in line with two recent systematic reviews (Ali *et al*. 2012; Werner *et al*. 2012), showing that family members in non-Western countries are particularly subjected to negative treatment by members of the community and the family (Ali *et al*. 2012). This difference might stem from the fact that while many Western countries seemed to show interest in issues of public stigma, Asian countries focused mainly on family stigma research (Werner *et al*. 2012), probably as a consequence of cultural variations in the social representation of disability in both cultures. Specifically, the Chinese culture is characterised by collectivism, or having close linkages between individuals and a greater sense of obligation to the group than to the individual. Further, Chinese people may tend to emphasise the biological roots of ID (Kung 2001) and may be more prone to considering children with disabilities as 'bad seeds' and disgraces to their families (Sue & Sue 1987). Given these beliefs, these families may be exposed to a greater experience of family stigma (Mak & Cheung 2008).

Nevertheless, similar items in the two countries were rated as associated with lower or higher levels of stigma. In both countries higher levels of affiliate stigma were related to feeling sad, burdened and emotionally hurt by having a child with a disability and feeling embarrassed by the child's behaviour. It seems that these items are associated with negative internalised emotions related to the everyday difficulties of having a child with a DD. Items of lowest affiliate stigma in both studies were related to worrying that others would know of the child, feeling less than others and losing face. These items seem to relate to inter-personal relationships and feelings of decreased self-esteem. Thus, greater internalised stigma in both cultures seems to relate more to the everyday strain of caregiving.

Correlates of affiliate stigma

Results showed that affiliate stigma was not related to any of the caregiver background variables, which is in line with most previous research (Chiu *et al.* 2013; Mak & Cheung 2008). In relation to child-related variables, affiliate stigma was found to be higher among caregivers of individuals with ASD as compared with PD or ID. Greater stigma among caregivers of individuals with ASD was related to feeling embarrassed by the child's behaviour, feeling a negative impact on the parent, reducing going out with the child, reducing contact with friends and relatives and not telling others that the child has ASD. These findings support previous studies reporting that parents of children with ASD experience discrimination and feel shame and worthlessness (Gray 1993, 2002). These feelings might be related to the problematic behaviours that characterise many individuals with ASD and the relative lack of public knowledge and understanding regarding ASD (Gray 1993, 2002). Consequently, this may lead to parents seeking to distance themselves from others.

Study limitations

Several limitations of this study should be kept in mind. First, the sample was small and non-random. Further, given the various data collection methods utilised, it was not possible for us to calculate the response rate. Second, although an attempt was made to distinguish between disability groups, it should be noted that some individuals had more than one primary diagnosis. In addition, diagnosis was based on caregivers' reports rather than representing an objective diagnosis. Further, in interpreting the results one should keep in mind that Israel is an immigrant society while Hong Kong is quite homogeneous in terms of its population.

Conclusions and implications

Despite the above limitations, this study has important theoretical and practical implications. Theoretically, the study showed that affiliate stigma has differing impacts on caregivers according to the nature of the child's disability. It is important to be aware of this and recognise that disability is not one general concept. Rather, it is important to look at disability groups separately.

In addition, the study supported a one-factor solution to the Affiliate Stigma Scale. In order to truly represent the multidimensional theoretical construct, it is important to be able to differentiate between the affiliate stigma components. To achieve this, we suggest that future studies need to further explore the meaning of internalised stigma within qualitative studies with parents as well as other family members. Following qualitative studies, additional research with large random samples is needed in order to continue development of this evolving concept. It would be desirable to reword several of the items so that the scale will not be negatively skewed, and in order to deal with issues of social desirability and the tendency of some individuals to underreport negative feelings. Another way to deal with this issue may be through the development of an implicit attitude measure, which may be useful in revealing attitudes of individuals who prefer not to express them by measuring underlying automatic evaluation (Greenwald *et al.* 1998). Further, in order to measure the behavioural dimension, it may be useful to examine real-world behaviours rather than employ self-report questionnaires.

It terms of practical implications, it is important to increase knowledge and awareness and to reduce stigma in the community toward DD, and especially to ASD. Deeper knowledge and more positive community attitudes may reduce family internalised stigma, especially among families of individuals with ASD. Along with this, families should be supported in dealing with their everyday strain and burden which most negatively influence their internalised stigma.

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