

Brief report: Family Networks of People with Mild Intellectual Disability with and without Challenging Behaviour

Rapport bref : réseaux familiaux des personnes ayant une déficience intellectuelle légère avec et sans comportements problématiques

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Abstract

Differences in perceived emotional support in family networks of people with mild intellectual disability with and without challenging behaviour were explored by using a self-report measure. One hundred and thirty-eight participants (78 men and 60 women, average age 28.2 years old) with mild intellectual disability were interviewed using the Family Network Method – Intellectual Disability to assess their emotionally supportive family relationships. The instrument maps the perceived emotional support among all the family members in the family networks of people with mild intellectual disability, with and without challenging behaviour. The results suggest that challenging behaviour may not be strongly associated with the family network characteristics and emotional support in family networks of people with mild intellectual disability. A few, and generally small, differences were found between the family networks of people with or without challenging behaviour. However, one moderate sized group difference was found: those with challenging behaviour reported less mutual support in their whole family network.

Résumé

Les différences dans le soutien émotionnel perçu au sein des réseaux familiaux de personnes ayant un déficit intellectuel léger avec et sans comportements problématiques ont été explorées au moyen de mesures auto-rapportées. Cent trente-huit participants (78 hommes et 60 femmes, âgée en moyenne de 28,2 ans) ayant un déficit intellectuel léger ont été interviewés à l'aide du Family Network Method – Intellectual Disability afin d'évaluer les relations familiales de soutien émotionnel. L'instrument cartographie le soutien émotionnel perçu au sein de tous les membres de la famille de personnes ayant un déficit intellectuel léger, avec ou sans comportements problématiques. Les résultats suggèrent que les comportements problématiques ne seraient pas associés aux caractéristiques ni au soutien émotionnel du réseau familial de personnes ayant un déficit intellectuel léger. Quelques différences, généralement petites, sont constatées entre le réseau familial de personnes avec ou sans comportements problématiques. Cependant, une différence de taille modérée entre les groupes a été trouvée : les participants ayant des comportements problématiques ont rapporté moins de soutien mutuel dans l'ensemble de leur réseau familial.

Mots-clés : déficit intellectuel léger, comportements problématiques, réseaux familiaux, soutien émotionnel

Introduction

The informal support networks of people with intellectual disability mainly consist of family members (Forrester-Jones et al., 2006; Lippold & Burns, 2009; Van Asselt-Goverts et al., 2013). Family members have a significant role in the lives of people with intellectual disability (Binnendyk et al., 2009). Family relationships are usually typified by emotional closeness, unconditional love, and a long-term perspective (Bigby & Fyffe, 2012), and can therefore be a potent source of meaning in life and contribute to a sense of belonging (Krause, 2007; Lambert et al., 2010).

Family relationships are also important specifically for people with intellectual disability and challenging behaviour. Positive family relationships can provide them a sense of belonging and valued roles and relationships, for example as a sister or an aunt (Clarke et al., 2019). Thus, there is no reason to imagine that family would be any less important to individuals with challenging behaviour. However, the assumption behind the present research is that the family networks of people with mild intellectual disability and challenging behaviour may be different to the family networks of people with mild intellectual disability without challenging behaviour. For example, people with intellectual disability and challenging behaviour are more likely to have live in services or secure accommodation that is distant from their family (Bigby, 2012; Robertson et al., 2001). Challenging behaviour of an individual with intellectual disability can also cause stress in family members (Hastings, 2002; Lecavalier et al., 2006), which might have impact on the quality of family relationships, and the family network (Greenberg et al., 2006; Orsmond et al., Hong, 2003). In addition, family members of individuals with challenging behaviour might avoid or reduce the time they spend engaged with the person with intellectual disability or engage in increased negative interactions (Floyd & Phillippe, 1993; Schuiringa et al., 2015), potentially leading to reduced relationship quality. Families of people with challenging

behaviour may also become more socially isolated from others, including family members, because they feel limited where they can go with their child (Fox et al., 2002).

To our knowledge, there has been no research examining the family networks of people with mild intellectual disability and challenging behaviour, and certainly none based on self-reports. Self-reports and active participation in research for people with intellectual disability have increased as they became more recognized as experts on their own lives, experiences and feelings (Lunsky & Benson, 1997; McDonald et al., 2013). In addition, there is a growing body of evidence that highlights the discrepancies between self- and proxy reports for subjective data (e.g., experienced stress or support) in the population of people with intellectual disability (Lunsky & Benson, 1997; Lunsky & Bramston, 2006; Scott & Haverkamp, 2018; Tournier et al., 2020). Therefore, it is important to use self-report measures to examine subjective themes such as emotional support in family networks.

Researchers in the field of intellectual disability have mainly focused on the effects of singular aspects of social (including family) networks, such as total network size (Lippold & Burns, 2009), or the amount of perceived support (Forrester-Jones et al., 2006). However, social networks are a significant source of social capital (Furstenberg & Kaplan, 2004). The social capital theory defines the possession of a durable social network as a source of socially supportive relationships (Bourdieu, 1986). From this theoretical perspective, when focusing only on singular dimensions of networks, one will fail to capture the multi-dimensional nature of networks (e.g., a dense network with many reciprocal supports (Fiori et al., 2006).

A social capital perspective can also be applied to family networks. An instrument that measures the multi-dimensional nature of family networks is the Family Network Method (FNM; Widmer et al., 2013). The FNM maps who participants consider to be their family members and assesses how they perceive the relationships between these family members (Widmer et al., 2013). To ensure the instrument was accessible for the use in the population of individuals who have a mild intellectual disability, the method was adapted by Giesbers et al. (2019) as the Family Network Method-Intellectual Disability (FNM-ID).

Therefore, the aim of the present study was to assess whether people with mild intellectual disability who have challenging behaviour perceive their family networks differently than those without challenging behaviour. We used the FNM-ID to gather data about the properties of family networks.

Materials and Method

Participants and Procedure

Participants were recruited for a large study to examine people with mild intellectual disabilities' perceptions of their family networks (Giesbers et al., 2020). A stratified sampling procedure was used to recruit eligible participants from within five service providers in the Netherlands. Inclusion criteria for participation in the study were: 1) age between 18 and 40 years; 2) mild intellectual disability (IQ 50-70 according to records); and 3) support at least once a week by paid support staff for at least 6 months. For each service facility, the total number of people with mild intellectual disability who met these inclusion criteria was determined. Then, per service provider, a sample of 10% of the population was selected for the study. In total, 138 participants

(78 men and 60 women), with an average age of 28.2 years old (range: 18-40; $SD = 6.2$) participated in the study. The majority of the participants lived more independently in the community ($n = 116$) in group homes or clusters of apartments with support for a part of each day, or where support staff were available at other times if necessary. The remaining participants ($n = 22$) lived in residential facilities (i.e., a site with multiple group homes for people with intellectual disability, and where support staff were present all the time).

Approval for the study was obtained by the Ethics Committee of Tilburg University (EC-2015.46). Data were collected by face-to-face interviews at the participants' homes, or at the service providers' offices. First, two WAIS-IV subtests (matrix reasoning and vocabulary) and a demographic information questionnaire were administered. The Family Network Method – Intellectual Disability (FNM-ID; Giesbers et al., 2019) was used to obtain the participants' descriptions of their family networks. Finally, demographic information was obtained. With the participants' consent, the researcher also completed the Behaviour Problem Inventory-01 (BPI-01; Rojahn et al., 2001) with their key worker (i.e., an appointed support worker who takes care of personal matters for the person with an intellectual disability, such as contact with family, organising an annual care review).

Measures

Family Networks. To measure the perception of people with mild intellectual disability about the support in their family networks, the Family Network Method – Intellectual Disability (FNM-ID; Giesbers et al., 2019) was used. The FNM-ID maps the family network and relationships among all the family members in terms of (reciprocal) emotional support and a variety of social network variables can be coded. The instrument was adapted based on thorough piloting, involving 19 participants with mild intellectual disability, and the FNM-ID was adjusted to meet the cognitive and linguistic needs of people with mild intellectual disability (Giesbers et al., 2019). The FNM-ID adopts a broader concept of family, that is, whom do people with mild intellectual disability themselves consider as family? Moreover, the measure maps the relationships among all family members (e.g., father – mother; mother – sister; grandpa – aunt). As a result, a broader understanding of the family context of structural interdependencies is obtained, which gives insight into how the relationships between people with mild intellectual disability and their family members are embedded (Widmer, 2016).

Challenging Behaviour. The Behaviour Problems Inventory-01 (BPI-01) is a questionnaire that was designed to assess challenging behaviours in individuals with intellectual disability. The items fall into one of three sub-scales: Self-Injurious Behaviour (SIB), Stereotyped Behaviour (SB), and Aggressive/Destructive Behaviour (ADB). Each item is rated on a frequency scale (0 = never to 4 = hourly), and a severity scale (0 = no problem to 3 = severe problem; Rojahn, et al., 2001). To operationalize the definition of the presence of challenging behaviour during the preceding two months, we used the working definition from a recent population-based study of challenging behaviour (Bowring et al., 2017). This working definition can be used to code challenging behaviour measured by the BPI-01. SIB is considered “challenging” when it is either rated as severe and occurs at least weekly, or when it is rated as moderate but occurs at least daily. ADB is “challenging” when it is either rated as severe and occurs at least weekly, or when it is rated as moderate but occurs at least daily. SB is considered “challenging” when it occurs at the highest rated frequency. Overall, challenging behaviour is present if at least one behaviour is defined as challenging according to these three definitions

(Bowring et al., 2017). The Dutch version of the BPI-01 has good internal consistency reliability (Dumont et al., 2014). The internal consistency for the total BPI-01 scale was .89, and for the subscales Self-Injurious Behaviour .63; Stereotyped Behaviour .85; and Aggressive/Destructive Behaviour .88 (Dumont et al., 2014). The instrument has good intra-class correlations for the total scale as well as the subscales of the Dutch version of the BPI-01. The total scale was .93 ($p < .05$), intra-class correlations for the subscales were: Self-Injurious Behaviour .86 ($p < .05$), Stereotyped Behaviour .90 ($p < .05$), and Aggressive/Destructive behaviour .93 ($p < .05$) (Dumont et al., 2014).

Data Analysis

The UCINET software package (version 6.623) was used to analyse the family network data (Borgatti et al., 2002). Several social network measures were derived, based on the social capital theoretical framework, see Table 1 (Sapin et al., 2016; Widmer et al., 2010).

Table 1. Overview of the Computed Social Network Measures (Tournier et al., 2021; Table is reproduced with permission from Wiley)

Total family network measures	Size	Number of family members within the network of the participant with intellectual disability
	Density	An indicator of how close a network is, so on average how many network members support each other? Density is defined as the ratio between the number of existing supportive relationships between the family members divided by the total number of possible supportive relationships between the family members
	Arc reciprocity	Proportion of supportive relationships between family members that are reciprocal. The focus of this measure is on the number of supportive relationships that are involved in reciprocal relations, relative to the total number of actual relations
Individual family network measures	In-degree	Number of relationships in which the person with intellectual disability receives support
	Out-degree	Number of relationships in which the person with intellectual disability provides support
	Dyad reciprocity	Number of dyads (in which the person with intellectual disability is an actor) with reciprocal relationships, divided by the total number of adjacent dyads (in which the person with intellectual disability is an actor)
	One step outreach centrality	Number of distinct family members within one link of a given person (i.e., with how many people is the person connected)

Network measures were exported to SPSS-24 and independent samples *t*-tests were conducted to examine differences in the characteristics of the family networks perceived by the participants with mild intellectual disability with and without challenging behaviour. The Cohen's *d* effect size was calculated using $(M_1 - M_2)/[S^2_{pooled}]$ (Cohen, 1988).

Results

Thirty-six participants (26.3%) met the definition for having challenging behaviour. Table 2 presents the demographic characteristics per subgroup.

Table 2. *Demographics of Participants per Subgroup*

Variable		Individuals without challenging behaviour (<i>n</i> = 102)		Individuals with challenging behaviour (<i>n</i> = 36)	
		<i>n</i> (%)	<i>M</i> (<i>SD</i>)	<i>n</i> (%)	<i>M</i> (<i>SD</i>)
Sex	Male	59 (57.8)		19 (52.8)	
	Female	43 (42.2)		17 (47.2)	
Living situation	Community	90 (88.2)		26 (72.2)	
	Residential	12 (11.8)		10 (27.8)	
Cultural background	Dutch	93 (91.2)		34 (94.4)	
	Other	9 (8.8)		2 (5.6)	
Age in years			28.6 (6.1)		27.2 (6.3)

Table 3 summarises group differences and the results of independent samples *t*-tests comparing FNM-ID scores. Participants with challenging behaviour had lower scores on all network variables, though all differences, bar one, were non-significant and the effect sizes were negligible to small. One statistically significant difference did emerge: reciprocal emotional support in the whole family network of participants with challenging behaviour (arc reciprocity) was lower compared to participants without challenging behaviour with a moderate effect size ($M = .39$, $SD = .34$, $p = .013$, $d = 0.47$).

Table 3. Mean Scores for the Network Measures

	Variable	Mean (SD)		<i>t</i>	<i>p</i>	Cohen's <i>d</i>
		Individuals without challenging behaviour (<i>n</i> = 102)	Individuals with challenging behaviour (<i>n</i> = 36)			
Network measures - Full network	Size	10.30 (6.51)	9.06 (5.56)	1.03	.307	0.20
Network measures – Significant network	Size	7.42 (4.87)	6.50 (4.84)	0.98	.330	0.19
	Arc reciprocity	.54 (.29)	.39 (.34)	2.50	.013*	0.47
	Density	.37 (.24)	.34 (.23)	.57	.568	0.13
Individual measures - full network	In-degree	2.45 (1.66)	2.03 (1.38)	1.37	.174	0.28
	Out-degree	2.60 (3.87)	1.72 (2.25)	1.28	.202	0.28
	Dyad reciprocity	.29 (.32)	.26 (.34)	0.49	.627	0.09
Individual measures - significant network	One step outreach centrality	.37 (.38)	.29 (.36)	1.14	.258	0.22

Note. * $p < .05$

Legend

The *full network* measure (in this case one measure: size of the total network) represents all the listed family members by the participant. The measures about the *significant network* are calculated for a subset of family members who are considered to be significant. The results of this study indicate that there are no significant differences between the two groups on this level, except for reciprocal emotional support (arc reciprocity) in the significant family network of participants with challenging behaviour. The emotional support within their significant family network was significantly lower compared to participants without challenging behaviour.

Individual measures are calculated specifically for the persons with intellectual disability themselves (e.g., how many family members are they supporting (out-degree)). Again, a distinction was made for the full network and the significant family network. These social network measures show that there are no significant differences between the two groups.

Discussion

In contrast to our initial expectations, the results suggest that there are only small differences between the family networks of people with mild intellectual disability with and without challenging behaviour. The impact of challenging behaviour on the quality of family relationships may not have substantial effect on the structure of family networks and emotional support within the family network as perceived by individuals with intellectual disability themselves. However, caution is needed in interpreting these findings due to the small sample size of participants with challenging behaviour, and the fact that all participants (with and without challenging behaviour) resided in a health care service supported by professionals and not in their family home. Future research should include a larger sample of people with intellectual disability and challenging behaviour, who also live with their family to investigate if our preliminary results are replicated.

One network measure differed significantly between the two groups, with a moderate effect size. Arc reciprocity, the mutual support between all the family members in the network, was reported as higher in the family networks of people with intellectual disability without challenging behaviour. This suggests that in the family networks of people with intellectual disability and challenging behaviour there is less reciprocal support. A potential reason for this difference might be that people with mild intellectual disability and challenging behaviour who live in a health care service are less aware about the emotional support family members provide to each other. They may be spending less time at their family home compared to people without challenging behaviour and therefore have less opportunity to witness the support between their family members. Widmer et al. (2010) suggested that witnessing broader family relationships affects the perceptions of people with intellectual disability. Relationships that were not directly connected to the participant with intellectual disability were not typically recognized by them. Another possible explanation for the finding is that less emotionally supportive wider family contexts may be associated with increased risks for challenging behaviour (McPherson et al., 2014). Without replication and further exploration, these competing explanations cannot be reconciled.

Whatever the direction of association, maintaining positive family relationships is likely to be beneficial for the quality of life of people with intellectual disability and challenging behaviour (Clarke et al., 2019). Therefore, it can be valuable for support staff to assist people with intellectual disability and challenging behaviour with developing, maintaining, and enhancing their family relationships. Providing emotional support to others might also be valuable for people with intellectual disability and challenging behaviour; it may enhance feelings of self-worth and self-esteem (Forrester-Jones & Barnes, 2008; Liang et al., 2001). Finally, a better balance between given and received emotional support might be beneficial for people with intellectual disability and challenging behaviour. Earlier research outside of the field of intellectual disability showed that an over-benefited position (with more received than given support) may lead to a less positive outcome in terms of mental health and well-being than an under-benefited position (Fyrand, 2010; Thomas, 2010).

Key Messages from this Article

People with Disabilities. Whatever your support needs, staff in services should help you to have the positive relationships with your family members that you want to. It is good to be able to help people in your family as much as they help you.

Professionals. People with mild intellectual disability and challenging behaviour perceive that the quality of their family relationships is quite similar to those of people without challenging behaviour. It is important not to assume that challenging behaviour always makes life worse for people with intellectual disability.

Policymakers. Given the importance of increasing social capital to support everyone's well-being, it is likely to be important to promote mutually supportive family relationships for people with challenging behaviour.

Messages clés de cet article

Personnes ayant une incapacité. Quels que soient vos besoins de soutien, le personnel des services devrait vous aider à avoir les relations positives que vous souhaitez avec les membres de votre famille. Il est bien de pouvoir aider les personnes de votre famille autant qu'elles vous aident.

Professionnels. Les personnes ayant une déficience intellectuelle légère et des comportements problématiques perçoivent que la qualité de leurs relations familiales est plutôt semblable à celles de personnes sans comportements problématiques. Il est important de ne pas présupposer que les comportements problématiques rendent nécessairement la vie de personnes ayant une déficience intellectuelle plus difficile.

Décideurs. Étant donné l'importance d'accroître le capital social afin de soutenir le bien-être de tous, il est probablement important de promouvoir des relations familiales de soutien mutuel pour les personnes ayant des comportements problématiques.

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