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Intellectual disabilities, Residential Care and Expressed Emotion: Functional Costs

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Abstract

A scheduled home-visit from a staff-supported, community-based facility was used to examine whether post-visit adjustment in a sample of adults (n=28) with mild intellectual disabilities is associated with pre-visit attributions of Expressed Emotion (EE) (i.e., criticism, hostility and/or over-protectiveness) to their primary residence counsellor. The findings suggest that participants who perceived their residence counsellor and/or a key family member as being a high EE individual were more likely to have post-visit increases on measures of behavioural dysfunction and subjective distress. Various implications of the findings are discussed.

The concept of expressed emotion (EE) was introduced over 40 years ago by Brown, Carstairs & Topping (1958) to explain why some individuals with schizophrenia who had been discharged to households characterized by criticism, hostility, and emotional over-involvement (i.e., high levels of EE) relapsed at significantly higher rates than those discharged to households that were not characterized by such attitudes (i.e., low EE families) (e.g., Brown, Birley & Wing, 1972; Brown, Monck, Carstairs & Wing, 1962; Leff & Vaughn, 1985; Vaughn & Leff, 1976a; 1981). Subsequent research has also made it clear that the construct of EE is not specific to schizophrenia (see Kavanagh, 1992 for a review). For example, high levels of family EE have been associated with poorer outcomes in eating disorders (Flanagan & Wagner, 1991; Van Furth, 1991), mood disorders (Priebe, Wildgrube & Muller-Oerlinghausen 1989), and even dementia (Bledin, MacCarthy, Kupiers & Woods 1990).

A growing number of researchers have also begun to explore the relationship between relapse and EE levels in non-familial support providers. For example, Moore, Kupiers and Ball (1992) found that among staff who were

responsible for the care of long-term mentally ill patients, high EE staff members were less tolerant and realistic in their expectations than their low EE counterparts. Similarly, in another study with a heterogeneous sample of chronically mentally ill patients, Moore and Kupiers (1992) found that high EE staff issued significantly fewer statements of support and more critical remarks than their low EE counterparts.

Given the fact that individuals with intellectual disabilities often reside in environments where there is extensive involvement with non-familial support providers, surprisingly little attention has been devoted to the role of EE in such environments. The present study is an attempt to address this oversight. Specifically, we were interested in examining the yet-to-be explored relationship between the EE levels of familial and non-familial support providers of individuals who are intellectually disabled (and residing in a community based residence) and changes in the functional status of the individuals who are the recipients of the support.

The study entailed measuring the EE levels of familial and non-familial support providers, and relating them to changes in functional status over a series of four measurements surrounding an extended family visit. Two of the measurements occurred before the visit, the other two, after the visit. The rationale for using the extended family visit as the vehicle for short-term change, and as the basis for assessing the impact of familial and non-familial EE was: 1. Given the relatively long-standing, on-going relationship with non-familial support providers in the community residence, it seemed unlikely that there would be a demonstrable change in adjustment unless the individual's accommodation to the high EE environment were temporarily disrupted (as would be the case with a home visit); 2. If the support recipient's expectations were confirmed (or at least not disconfirmed) during the home visit, those individuals who rated their familial support providers as high EE might show greater post-visit deficits than those who rated their familial support providers as low EE; and 3. Because it would take time to readapt to the high EE non-familial support relationship, we expected that those individuals who attributed high EE attitudes to their non-familial support-providers would also experience greater difficulties in transitioning back from a family visit.

Consequently, we predicted that perceived levels of elevated EE in either of the two types of support providers (i.e., familial or non-familial) would be related to negative pre-post visit changes in functional status after pre-visit functional status was taken into account.

Method

Participants

Thirty participants were recruited from a community-based residential facility in New York City that caters to adults with intellectual disabilities. The participants were eligible to participate in the study if they met the *Diagnostic and Statistical Manual of Mental Disorders (DSM IV)* (American Psychiatric Association, 1994) criteria for mild mental retardation. The exclusion criteria included suicidality, homicidality, psychiatric symptoms that required hospitalization and primary diagnoses of other developmental disorders. Of the 30 participants eligible to participate, two were not included in the study because they appeared to become too anxious when the study was explained to them. Demographic characteristics collected for the sample were as follows: 13 participants were male and 14 were female; they were primarily Caucasian (96.2%); their mean age was 36.8 years; and most completed most of their high school education (17.9% graduated from mainstream programs, 75.2% graduated from special education programs, and 7.1% did not graduate). In addition, of the five participants who were on psychotropic medications, two received medications on an as-needed basis.

Family members were operationally defined as either a mother or father. In two cases, where the biological parents were deceased, the relative who assumed responsibility (an aunt in both cases) was counted. The demographic characteristics of the family members were as follows: primarily female (86.2%) and Caucasian (96.2%), a mean age of 60 years, and fairly well educated (7% had less than high school, 54% were high school graduates or had partial college, 39% had college or greater education).

Staff members (total of nine) were defined as the primary counsellors permanently assigned to specific clients.

Measures

Expressed emotion. The most commonly used method of assessing expressed emotion research is the *Camberwell Family Interview (CFI)* (Vaughn & Leff, 1976b). However, because the *CFI* takes approximately 1.5-2 hours to administer, and requires a considerable investment in training and other resources, it was deemed too impractical for use in the present study. Instead, the following two self- report measures of EE were used:

1. The *LEE Scale* (Cole & Kazarian, 1988), a 60 item, self-report, true/false questionnaire, is designed to assess characteristic attitudes or response styles of significant others. The scale was developed on the conceptual framework of expressed emotion and taps four dimensions: intrusiveness, emotional response, attitude toward illness, and tolerance/expectations. The reliability for the overall scale using the Kuder-Richardson (KR) Formula 20 is .95; the KR 20 values and test-retest correlations for the three subscales are comparable to those of the overall scale (Cole & Kazarian, 1988).

2. The *Influential Relationships Questionnaire (IRQ)* (Baker, Helmes, & Kazarian, 1984), a 37 item questionnaire developed from the *Parental Bonding Instrument* (Parker, Tulping & Brown, 1979), assesses perceived parental characteristics of care, overprotection, and criticism. The questionnaire uses a 4-point Likert-type scale ranging from "strongly agree" to "strongly disagree." Test-retest reliability ranges from .55 to .85, and internal consistency ranges from .76 to .91 (Baker et al., 1984). The correlation between the *LEE* and *IRQ* scales is high, hovering around .86 (Cole & Kazarian, 1988)

Functional status. The outcome dimension, functional status, was operationalized by using four measures that were designed to capture information about adaptive skills, activities of daily living, milieu participation, various clinical/psychiatric dimensions associated with subjective well-being and cognitive/perceptual functioning. The measures employed were: the *Symptom Checklist -90R (SCL-90R)* (Derogatis, 1993); the *Beck Depression Inventory, (BDI)* (Beck & Beamesderfer, 1974); the Maladaptive Behavior Domain on the *Vineland Adpative Behavior Scales (VABS)* (Sparrow, Balla, & Cichetti, 1984); and the behaviour problems section of the *Developmental Disabilities Profile (DDP)* (The State of New York, Office of Intellectual Disabilities and Developmental Disabilities, 1995).

With the exception of the *DDP*, all of the outcome variables are psychometrically sound. The *VABS – Maladaptive Behavior Domain* (Sparrow, Balla, & Cichetti, 1984) – is a two-part assessment of undesirable behaviours that may interfere with the individual's adaptive functioning. The authors report a split-half reliability coefficient of .86, test-retest reliability of .88, and inter-rater reliability of .73. The *SCL-90R* (Derogatis, 1983) is a 90 item self-report inventory designed primarily to reflect the psychological symptom patterns of psychiatric and medical patients. The internal consistency coefficients for the *SCL-90* range from .77 to .90, while the test-retest coefficients range from .78 to .90 (Derogatis, 1983). The *SCL-90-R*

compares favourably to other multidimensional measures of psychopathology such as the *Minnesota Multiphasic Personality Inventory* (Derogatis, 1983). The *BDI* (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961; Kendall, Hollon, Beck, Hammen, & Ingram, 1987) is a widely used 21-item instrument used to assess depression. Reliability coefficients for this measure are high and range from .79 to .88. Meta-analyses have yielded a mean correlation of .72 between clinical ratings of depression and the *BDI* for psychiatric patients, and a mean correlation of .60 between clinical ratings of depression and *BDI* scores for non-psychiatric participants (Beck & Beamesderfer, 1974). The *DDP* (The State of New York, Office of Intellectual Disabilities and Developmental Disabilities, 1995) is a screening instrument used by the New York State Office of Intellectual disabilities and Developmental Disabilities to classify an individual's level of disability. In the present study, only the Behavior Problems section (i.e., ratings of frequency of maladaptive behaviour on a six-point scale) of this measure was used. Unlike the other outcome measures, the *DDP* is not widely researched and its psychometric properties have not been established. However, since it is an instrument that is routinely administered in the residence, it was included among the outcome measures employed in the study.

Procedures

Level of *Expressed Emotion*, for each of family members and staff, was assessed two weeks before the family visit using the *LEE* and the *IRQ*. Thus, there were four measures of EE: *LEE Family* (*LEE F*), *LEE Staff* (*LEE S*), *IRQ Family* (*IRQF*), and *IRQ Staff* (*IRQ S*).

Four successive measurements of functional status were taken: Two measurements were taken prior to the scheduled family visit, two weeks apart; the other two measurements, also two weeks apart, were made after the family visit.

The two measures for expressed emotion and the four measures for functional status were administered as follows:

Week 1:	*DDP, BDI, SCL-90R,* and *VABS* (functional status)
Week 3:	*DDP, BDI, SCL-90R,* and *VABS*(functional status)
	LEE-F/S and *IRQ-F/S* (expressed emotion)
Week 5:	Family visit (approximately 2-3 days)
Week 7:	*DDP, BDI, SCL-90R,* and *VABS* (functional status)
Week 9:	*DDP, BDI, SCL-90R,* and *VABS* (functional status)

The *LEE*, the *IRQ*, the *BDI* and the *SCL-90R* were scored by one of the investigators (JS), whereas the *DDP* and *VABS*, both of which required knowledge of day-to-day functioning in the milieu, were scored by the primary counsellors. However, the primary counsellors remained blind to the goals of the study.

Analysis

A correlational design was used to assess the relationship between two measures of EE and four indices of functional status across two EE environments (pre-family visit environment vs. post-family visit environment).

Results and Discussion

As might be expected, there is a high degree of inter-correlation among the dependent measures (see Table 1). Also not surprising is the robust correlation between the measures of EE (*IRQ F* and *LEE F*: r=.82, p>.0001; *IRQ S* and *LEE S*: r=.89, p>.0001). Interestingly, family and staff EE scores on the *LEE* (but not on the *IRQ*) were also found to be correlated (r=.54, p<.01), suggesting that certain support recipients had a greater tendency to either: 1) elicit high EE behaviours from their support providers (Kavanagh, 1992; Strachan, Feingold & Goldstein,1989); or 2) misconstrue the behaviours of their support providers as being overly critical or overly protective.

With one exception, EE scores on both EE measures, for both staff and family members, were found to be statistically independent of pre-visit scores on the dependent measures of functional status (see Table 2). It is particularly notable that the *DDP*, which is the only pre-visit measure to show a significant relationship with any of the EE measures (i.e., *IRQ staff*), is also one of the two measures that primary counsellors were asked to complete. This suggests that to some extent, the negative expectations of the primary counsellors (i.e., higher frequencies of maladaptive behaviour) for their clients may have existed in a reciprocal relationship with the negative expectations of their clients (i.e., high EE). Moreover, this notion of reciprocity is not inconsistent with the aforementioned relationship between family and staff EE scores on the *LEE*.

Table 1. Intercorrelations Between Pre- and Post-Scores on the Dependent Measures

Measure	*SCLPre*	*SCLPost*	*BDIPre*	*BDIPost*	*VABSPre*	*VABSPost*	*DPPre*
SCLPre	.--						
SCLPost	.93****	.--					
BDIPre	.68****	.65****	.--				
BDIPost	.56**	.78****	.61***	.--			
VABSPre	.04	.07	.61***	.33*	.--		
VABSPost	.18	.43**	.43**	.81****	.65****	--	
DDPPre	-0.02	.06	.24	.38	.46**	.52**	--
DDPPost	.14	.40*	.32*	.76****	.42*	.84****	.79****

**p<.05, **p<.01, ***p<.001, ****p<.0001, all two-tailed*
Note: n=28, SCL Pre = Symptom Checklist 90R, pre-visit; SCL Post = Symptom Checklist 90R, post-visit; BDI Pre = Beck Depression Inventory, pre-visit; BDI Post = Beck Depression Inventory, post-visit; VABS Pre = Maladaptive behavior section of the Vineland, pre-visit; VABS Post = Maladaptive behavior section of the Vineland, post-visit; DDP Pre = Behavior problems section of the Developmental Disabilities Profile, pre-visit; DDP Post = Behavior problems section of the Developmental Disabilities Profile, post-visit.

Table 2. Correlation Coefficients for Staff EE and Pre-Visit Dependent Variables

Measure	*IRQ S*	*LEE S*	*IRQ F*	*LEE F*
SCL Pre	-.06	.15	.12	.17
BDI Pre	-.02	.16	.10	.23
VABS Pre	-.08	.01	-.06	.18
DDP Pre	.32*	.30	.22	.26

**p<. 05, two-tailed. ***p<.0001, two-tailed*
Note: n= 28, IRQ S=Influential Relationships Questionnaire, Staff; LEE S= Level of Expressed Emotion Scale, Staff; SCL Pre= Symptom Checklist 90R, pre-visit; BDI Pre= Beck Depression Inventory, pre-visit; VABS Pre= Maladaptive Behavior Section of the Vineland, pre-visit; DDP Pre= Behavior problems section of the Developmental Disabilities Profile, pre-visit.

In addressing the critical question of whether post-visit functional status might be related to staff and family EE, a series of partial correlations were computed between staff EE and post-visit scores, and between family EE and post-visit scores, controlling for pre-visit scores. In contrast to the findings with pre-visits scores, post-visit scores were found, as predicted, to be significantly correlated with both staff- and family-EE levels, on both measures (i.e., *IRQ S*, *LEE S*, *IRQ F* & *LEE F*) (see Table 3). When considered in the context of the aforementioned inability to find a similar relationship with the pre-visit scores (except in the case of the *DDP*), this latter finding is consistent with the notion that at least some support

recipients were capable of adapting to their high EE pre-visit interpersonal relationships. For example, some residents may have adopted the strategy of simply minimizing the amount of contact that they had with their high EE residential counsellor.

Table 3. Correlation Coefficients for EE and Functional Status Controlling for Respective Pre-Scores

Measure	*IRQ F*	*IRQ S*	*LEE F*	*LEE S*
SCLPost	.59***	.60***	.88****	.70****
BDI Post	.64****	.52**	.80****	.65****
VABS Post	.66****	.59***	.76****	.67****
DDP Post	.56**	.51**	.77****	.58***

**p<.05, **p<.01, ***p<.001, ****p<.0001, all two-tailed*

Note: n=28, SCL Post (ctrl) = Symptom Checklist 90R, post visit, controlling for SCL pre-visit scores; BDI Post (ctrl) = Beck Depression Inventory, post-visit, controlling for BDI pre-visit scores; VABS Post (ctrl) = Maladaptive behavior section of the Vineland, post-visit, controlling for VABS pre-visit scores; DDP Post (ctrl) = Behavior problems section of the Developmental Disabilities Profile, post-visit, controlling for DDP pre-visit scores.

In sum, the results of the present study, despite an admittedly small sample, suggest that the attitudes of support providers for individuals with intellectual disabilities can and do affect the functioning of the support recipients. Moreover, the relative absence of a strong relationship between pre-visit functioning and EE levels indicates that EE is not a proxy for current levels of adjustment. Indeed, as is the case with other conditions and disorders that are known to be affected by EE, EE's true worth with respect to MR appears to lie in its predictive value.

Many of the limitations of this study are methodological. For example, (and in keeping with a point that has been made earlier) it is possible that high EE counsellors may have come to expect negative behaviours from their support recipients, and therefore were more inclined to rate the *DDP* and *VABS* in that direction. Even so, this hypothesis does not account for the significant correlations that were obtained between Staff EE levels and the post-visit measures that were not scored by the counsellors. Future studies might also strengthen the methodology by using larger samples and including a control group that had not participated in an extended family visit.

Finally, we chose to limit the EE-relevant assessments of the participants' attitudes toward their primary counsellor at the residence and the family

member with the most support-related contact. Consequently, it is possible, if not probable, that we failed to account for all of the sources of high EE in the social environments of the participants. However, it is important to bear in mind that including high EE relationships in families that had been identified as low EE in this study might have made it more difficult to examine the overall relationship between outcomes and EE level.

These limitations notwithstanding, the results of the present study offer a reasonable amount of support for the guiding hypothesis of the study. We have been able to demonstrate that individuals with mild intellectual disabilities can be adversely affected by relationships that are characterized by high levels of EE, and that both familial and non-familial sources of EE are capable of having an impact on functional status. Equally important is the fact that by using self-report measures, rather than the *CFI*, we have been able to confirm that the support-recipients perceptions of high EE, even those with intellectual disabilities, is a practical and effective method for assessing the EE liability of important support-provider-support-recipient relationships.

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