The role of non-suicidal self-injury and binge-eating/purging behaviours in the caregiving experience among mothers and fathers of adolescents with eating disorders.

Lies Depestele[1,2,3], Gilbert MD Lemmens[3], Eva Dierckx[1,4], Imke Baetens[2,4], Katrien Schoevaerts[1], Laurence Claes[2,5]

[1] Eating Disorders Unit, Psychiatric Hospital Alexianen Tienen, Belgium
[2] Faculty of Psychology and Educational Sciences, University of Leuven, Belgium
[3] Department of Psychiatry and Medical Psychology, Ghent University, Belgium
[4] Department of Clinical & Life Span Psychology, Vrije Universiteit Brussel, Belgium
[5] Faculty of Medicine and Health Sciences (CAPRI), University of Antwerp, Belgium

Corresponding Author:
Lies Depestele
Eating Disorders Unit
Psychiatric Hospital Alexianen Tienen
Liefdestraat 10, 3300 Tienen, Belgium

Email: lies.depestele@fracarita.org

Abstract

This study investigated the caregiving experiences of mothers and fathers of restrictive and binge-eating/purging eating disordered (ED) inpatients with and without non-suicidal self-injury (NSSI). Sixty-five mothers and 65 fathers completed the Experience of Caregiving Inventory. All inpatients completed the Self-Injury Questionnaire-Treatment Related to assess NSSI and the Eating Disorder Evaluation Scale to assess eating disorder symptoms. Mothers reported significant more negative and more positive caregiving experiences compared to fathers. Mothers (but not fathers) of restrictive ED patients reported more positive caregiving experiences compared to mothers of binge-eating/purging patients. The presence of NSSI in ED patients was associated with more negative caregiving experiences of both parents. Mothers and fathers of ED inpatients differ in caregiving experiences and both binge-eating behaviours and NSSI negatively affect their caregiving experience. **Therefore supportive interventions for parents of ED patients are necessary, especially of those patients who engage in NSSI.**

Keywords: *experience of caregiving, burden of care, eating disorders, non-suicidal self-injury, binge-eating/purging behaviours*

Introduction

Eating disorders (ED) in adolescents have a major impact on parents' caregiving experiences due to **the early age of onset, the severity of the symptoms, the prolonged course of the illness and the high psychiatric and somatic co-morbidity.** Besides a worse quality of life and more psychological distress, carers of ED patients report more caregiving difficulties (e.g. experiencing shame or self-blame) compared to parents of healthy controls (Kyriacou, Treasure, & Schmidt, 2008). Carers of patients with anorexia nervosa **(AN) experience more** caregiving difficulties (e.g. feelings of 'loss') **than** carers of psychotic patients (Treasure et al., 2001). Nevertheless, how parents of ED patients experience their caregiving situation depends on several factors. Caregiving experiences are worse when parents have a higher need for information, have less social support, when illness duration is longer and when spending more time with their child (Whitney, Haigh, Weinman, & Treasure, 2007; Winn et al., 2007). Also gender of the parent plays a role in caregiving experiences. Mothers tend to experience the caregiving situation more negatively compared to fathers **(Anastasiadou, Medina-Pradas, Sepúlveda, & Treasure, 2014)**. **Mothers of AN inpatients also spent more time with caregiving and tend to experience a higher nutritional burden and guilt compared to fathers (Raenker et al., 2013).**

The role of specific eating and non-eating related symptoms in parental caregiving experiences is less investigated. Studies comparing the caregiving experiences between parents of **AN versus bulimia nervosa (BN)** patients found that carers of AN patients experience higher levels of subjective burden, have more concerns about the chronic course of the illness and the patient's future and express more need for professional support compared to parents of BN patients (Graap et al., 2008). **Sepúlveda et al. (2014)** found that binge-eating/purging behaviours (BP) across all ED diagnoses predict **more psychological distress** among caregivers. Although ED patients often engage in non-suicidal self-injury (NSSI), by our knowledge, no study investigated caregiving experiences of ED caregivers in presence/absence of NSSI. However, NSSI in ED patients with BP behaviours negatively

affects the family and NSSI in non-ED samples is associated with more parental burden and less parenting confidence (Arbuthnott & Lewis, in press; Depestele et al., 2015).

This study investigates differences in negative and positive caregiving experiences between mothers and fathers of ED patients with or without NSSI or binge-eating/purging behaviours. Hereby, it was hypothesized that mothers would report worse caregiving experiences compared to fathers and that parents of restrictive patients and/or patients with NSSI **would appraise** the caregiving situation as more negative.

Method

Participants

This study included 65 female patients and their parents, **all living together**. The patients (age range: 14-25 years) **were** admitted to a specialized treatment unit for eating disorders.[1] As divorce is associated with worse caregiving experiences (Padierna et al., 2013), only intact families (N = 65) were included in this study. The mean age of the patients, the mothers and the fathers was respectively 18.3 years (SD = 2.31), 48.4 years (SD = 3.75) and 49.7 years (SD =3.33). Demographic characteristics of the fathers/mothers are described in **Table 1**.

Of the 65 patients, 51 % (N = 33) were diagnosed with AN restrictive type (AN-R), 31 % (N = 20) as AN binge-eating/purging type (AN-BP) and 18 % (N = 12) with BN using the Eating Disorder Evaluation Scale (EDES; Vandereycken, 1993). The mean BMI of the AN-R, the AN-BP and the BN patients was 14.7 (SD =1.53), 15.3 (SD = 1.43) and 22.3 (SD = 2.48) respectively. Patients were assigned to two subgroups: 51% restrictive patients (N=33) versus 49% binge-eating/purging patients (N = 32).

Sixty-six per-cent of the patients (N = 43) reported life-time presence of at least one type of NSSI, whereas 34% of the patients (N = 22) **never engaged** in NSSI. Presence of NSSI did not differ

[1] **Eating Disorders Unit, Psychiatric Hospital Alexianen Tienen, Belgium**

between binge-eating/purging patients (**75%**) and restrictive AN patients (**57.6%**) ($\chi^2_{(1)}$= 2.20, *ns*). Patients' age and illness duration did not differ between the two subgroups **(see Table 2).**

Procedure

All participants completed an online survey during the first 3 weeks of admission after **giving** an informed consent. The study was approved by the Ethical Committee of the hospital.

Measures

Parents completed the Dutch version of the *Experience of Caregiving Inventory* (ECI, Szmukler et al., 1996). The ECI measures the experiences of caring for an individual with a severe mental illness. It consists of 66 items to be scored on a 5-point rating scale (0 = *no difficulties* and 4 = *severe difficulties*). Items are grouped in two dimensions: Fifty-two items measure the negative appraisal of care ('total negative scale') and 14 items measure the positive appraisal of care ('total positive scale'). Higher scores on these scales indicate respectively more negative or positive caregiving experiences. In the present study, Cronbach's alphas of the ECI negative and positive scales were respectively 0.88 and 0.82.

The *Self-Injury Questionnaire-Treatment Related* (SIQ-TR) (Claes & Vandereycken, 2007) measures the presence of five specific NSSI behaviours: biting, scratching, bruising, cutting or burning oneself. A patient was assigned to the NSSI group when she answered to have engaged in at least one type of NSSI during life-time. Cronbach's alpha coefficient of the SIQ-TR behaviours in the present study was 0.70.

Data analyses

Differences in caregiving experiences between mothers and fathers were explored **by performing** a multivariate analysis of variance (MANOVA), using the ECI total scores as dependent variables and informant (mother vs. father) as independent variable. To explore the differences in parental caregiving experiences between restrictive and binge-eating/purging patients with or without NSSI a multivariate analysis of covariance (MANCOVA) was performed using the ECI total scores as

dependent variables, the presence/absence of NSSI, ED subgroup and their interaction (NSSI * ED subgroup) as independent variables and the patients' age as control variable because of its association with burden of caregiving (Martín et al., 2013). Finally, assuming that mothers and fathers significantly differ on the ECI total scores, the analyses were performed separately for mothers and fathers.

All analyses were performed by means of SPSS version 22. A type one error of .05 was used throughout all analyses.

Results

Both the negative and positive ECI total scores significantly differed between mothers and fathers [Wilks' $\lambda = 0.89$, $F(2, 127) = 7.71$, $p < 0.01$]. Mothers reported more negative as well as more positive caregiving experiences compared to fathers (see **Table 3**).

The MANCOVA with the mothers' ECI total scores as dependent variables and NSSI and ED subgroup as independent variables showed a main effect of ED subgroup [Wilks' $\lambda = 0.88$, $F(2, 59) = 4.15$, $p < 0.05$] on the positive ECI total score: the mothers of restrictive patients reported significant more positive caregiving experiences compared to the mothers of binge-eating/purging patients. The effect of the presence/absence of NSSI was not significant but approached a significant trend [Wilks' $\lambda = 0.90$, $F(2, 59) = 3.04$, $p = 0.055$]: mothers tended to report more negative caregiving experiences when their daughter engaged in NSSI compared to those without NSSI. No interaction between ED subgroup and NSSI emerged [Wilks' $\lambda = 0.98$, $F(2, 59) = 0.74$, *ns*] (see **Table 4**).

The MANCOVA with the fathers' total ECI scores as dependent variables and NSSI and ED subgroup as independent variables showed no main effect of ED subgroup [Wilks' $\lambda = 0.99$, $F(2, 59) = 0.37$, *ns*] nor an interaction **effect** between ED subgroup and NSSI emerged [Wilks' $\lambda = 0.94$, $F(2, 59) = 1.83$, *ns*]. A significant main effect of NSSI was found for the ECI negative total score [Wilks' $\lambda = 0.89$, $F(2, 59) = 3.74$, $p < 0.05$]: fathers reported more negative caregiving experiences if their daughter engaged in NSSI compared to those without NSSI (see **Table 5**).

For mothers and fathers, the patients' age was a significant covariate on the positive ECI total score ($p < 0.05$): more positive caregiving experiences are reported as the patients' age decreased.

Discussion

This study confirms that mothers of ED patients have more negative caregiving experiences but also report more positive caregiving experiences compared to fathers (Martín et al., 2013; Sepúlveda et al., 2012). Several explanations can be put forward: Mothers, **who are** more frequently involved in the nutritional caregiving of children (e.g. preparing meals), might be more exposed to their daughters' illness than fathers and might be more negatively affected by their daughters' illness. But spending more time with their daughter may also involve more emotional closeness, which may explain the more positive caregiving experiences of mothers (**Raenker et al., 2013**). Further, gender differences in coping strategies might play a role: Males/fathers tend to **respond** with conflict or avoidance/withdrawal ('fight-or-flight') to interpersonal stressors (e.g. relationships and health of relatives) whereas females/mothers tend to respond to these stressors with caring for the children and seeking support with other people ('tend-and-befriend') (Tamres, Janicki, & Helgeson, 2002). The latter may also explain why mothers also report more positive personal experiences (e.g. having become closer to friends) compared to fathers.

Secondly, no differences were found between the negative caregiving experiences of parents of restrictive versus binge-eating/purging patients. However, mothers (but not fathers) of restrictive patients reported significant more positive caregiving experiences compared to mothers of binge-eating/purging patients. **This leans towards** the finding of Vidović et al. (2005) that the mother-daughter communication was better in restrictive patients versus binge-eating/purging patients, which might be explained by the restrictive patients' tendency for conflict avoidance and sense of duty contributing to the quality of the mother-daughter relationship.

Thirdly, consistent with findings in community samples, it was found that the presence of NSSI in ED patients is associated with more negative parental caregiving experiences (Arbuthnott & Lewis, 2015). The confrontation with NSSI increases negative feelings in parents (e.g. shame, self-

blame) probably resulting in increased parental feelings of failure and burden. Further, poor emotion regulation skills, typical for adolescents engaging in NSSI, might contribute to emotional escalations between parents and child and increase parents' burden of care (Arbuthnott & Lewis, 2015; Baetens et al., 2011).

Finally, it was found that parents had more positive caregiving experiences as the patients' age decreases. Shorter illness duration could explain why the illness not yet affected the parent-child relationship in a negative way.

Some limitations to the present study must be addressed. The absence of a control group and a small sample size **of only female patients diminish** the generalizability of the results. Next, the ECI, initially developed for families of people with psychosis, might fail in examining specific caregiving experiences of ED caregivers. Other questionnaires (e.g. Eating Disorders Impact Scale; Sepúlveda et al., 2008) **have been** developed to address these failures and should be used in future research. Finally, time **spent** with their child **and overall quality of the parent-child relationship were** not measured in this study, which prevents us from drawing conclusions about the underlying parent-child dynamic. However, this study, the first to examine the role of NSSI in parental caregiving experiences among ED patients, **shows the importance of exploring NSSI in ED families and offering supportive interventions for parents of ED patients, certainly of those patients who engage in NSSI.**

Conclusion

Our findings suggest that mothers of ED patients suffer more than fathers under the caregiving situation but that mothers also experience more positive aspects in the caregiving for their daughter. Furthermore, presence of binge-eating/purging behaviours and/or NSSI in ED patients might negatively affect the parents' caregiving experiences.

References

Anastasiadou, D., Medina-Pradas, C., Sepulveda, A. R., & Treasure, J. (2014). A systematic review of family caregiving in eating disorders. *Eating Behaviors*, *15*, 464-477. doi:10.1016/j.eatbeh.2014.06.001

Arbuthnott, A. E., & Lewis, S. P. (2015). Parents of youth who self-injure: a review of the literature and implications for mental health professionals. *Child and adolescent psychiatry and mental health*, *9*, 1-20. doi:10.1186/s13034-015-0066-3

Baetens, I., Claes, L., Willem, L., Muehlenkamp, J., & Bijttebier, P. (2011). The relationship between non-suicidal self-injury and temperament in male and female adolescents based on child-and parent-report. *Personality and Individual Differences*, *50*, 527-530. doi:10.1016/j.paid.2010.11.015

Claes, L., & Vandereycken, W. (2007). Self-injurious behaviour: differential diagnosis and functional differentiation. *Comprehensive Psychiatry*, *48*, 137-144. doi:10.1016/j.comppsych.2006.10.009

Depestele, L., Claes, L., Dierckx, E., Baetens, I., Schoevaerts, K., & Lemmens, G. (2015). The role of non-suicidal self-injury and binge-eating/purging behaviours in family functioning in eating disorders. *European Eating Disorders Review*. doi: 10.1002/erv.2371

Graap, H., Bleich, S., Herbst, F., Trostmann, Y., Wancata, J., & de Zwann, M. (2008). The needs of carers of patients with anorexia and bulimia nervosa. *European Eating Disorders Review, 16*, 21–29. doi:10.1002/erv.804

Kyriacou, O., Treasure, J., & Schmidt, U. (2008). Expressed emotion in eating disorders assessed via self-report: An examination of factors associated with expressed emotion in carers of people with anorexia nervosa in comparison to control families. *International Journal of Eating Disorders, 41*, 37-46.doi:10.1002/eat.20469

Padierna, A., Martín, J., Aguirre, U., González, N., Muñoz, P., & Quintana, J. (2013) Burden of caregiving amongst family caregivers of patients with eating disorders. *Social Psychiatry and Psychiatric Epidemiology, 48*, 151-161. doi:10.1007/s00127-012-0525-6

Raenker, S., Hibbs, R., Goddard, E., Naumann, U., Arcelus, J., Ayton, A., ... & Treasure, J. (2013). Caregiving and coping in carers of people with anorexia nervosa admitted for intensive hospital care. *International Journal of Eating Disorders*, *46*, 346-354. doi:10.1002/eat.22068

Sepúlveda, A. R., Anastasiadou, D., Pellegrin, Y., Andrés, P., Graell, M., Carrobles, J. A., & Morandé, G. (2014). Impact of caregiving experience on mental health among caregivers: a comparison of eating disorder patients with purging and non-purging behaviors. Eating and Weight Disorders-Studies on Anorexia, Bulimia and Obesity, *19*, 31-39. doi: 10.1007/s40519-013-0064-5

Sepúlveda, A.R., Graell, M., Berbel, E., Anastasiadou, D., Botella, J., Carrobles, J.A. & Morandé, G. (2012). Factors associated with emotional well-being in primary and secondary caregivers of patients with eating disorders. *European Eating Disorders Review, 20*, e78-e84. doi:10.1002/erv.1118

Sepúlveda, A. R., Whitney, J., Hankins, M., & Treasure, J. (2008). Development and validation of an Eating Disorders Symptom Impact Scale (EDSIS) for carers of people with eating disorders. *Health and Quality of Life Outcomes*, *6*, 28. doi:10.1186/1477-7525-6-28

Tamres, L.K., Janicki, D., & Helgeson, V.S. (2002). Sex differences in coping behavior: A meta-analytic review and an examination of relative coping. *Personality and Social Psychology Review*, *6*, 2-30. doi:10.1207/S15327957PSPR0601_1

Treasure, J., Murphy, T., Szmukler, T., Todd, G., Gavan, K. & Joyce J. (2001). The experience of caregiving for severe mental illness: A comparison between anorexia nervosa and psychosis. *Social Psychiatry and Psychiatric Epidemiology, 36*, 343–347.

Vandereycken, W. (1993). The eating disorder evaluation scale (EDES). *Eating Disorders*, *1*, 115-122. doi:10.1080/10640269308248279

Vidović, V., Jureša, V., Begovac, I., Mahnik, M., & Tocilj, G. (2005). Perceived family cohesion, adaptability and communication in eating disorders. *European Eating Disorders Review*, *13*, 19-28. doi:10.1002/erv.615

Whitney, J., Haigh, R., Weinman, J., & Treasure, J. (2007). Caring for people with eating disorders: Factors associated with psychological distress and negative caregiving appraisals in carers of people with eating disorders. *British Journal of Clinical Psychology, 46*, 413–428. doi:10.1348/014466507X173781

Winn, S., Perkins, S., Walwyn, R., Schmidt, U., Eisler, I., Treasure, J.,…Yi, I. (2007). Predictors of mental health problems and negative caregiving experiences in carers of adolescents with bulimia nervosa. *International Journal of Eating Disorders, 40*, 171-178. doi:10.1002/eat.20347

Table 1. Demographic characteristics of the mothers (N=65) and the fathers (N=65)

	Mothers (*N*=65)		**Fathers (N=65)**	
	M	***(SD)***	***M***	***(SD)***
Age mean (SD)	**48.44**	**(3.75)**	**49.67**	**(3.33)**
	N	***(%)***	***N***	***(%)***
Education				
Primary	**1**	**(1.5)**	**0**	**(0)**
Secondary	**15**	**(23.1)**	**15**	**(23.1)**
Higher education	**32**	**(49.2)**	**24**	**(36.9)**
University	**11**	**(16.9)**	**20**	**(30.8)**
Missing values	**6**	**(9.2)**	**6**	**(9.2)**
Employment				
Paid employed	**51**	**(78.5)**	**59**	**(90.8)**
Unemployed/homemaker/ sick/retired	**10**	**(15.4)**	**1**	**(1.5)**
Missing values	**4**	**(6.1)**	**5**	**(7.7)**

Table 2. Clinical characteristics of the patients (N = 65)

	Restrictive group (AN-R) (*N*= 33)		Binge-eating/purging group (BP-ED) (*N*= 32)		
	M	***(SD)***	***M***	***(SD)***	**t-test AN-R vs BP-ED**
Age	**17.9**	**(2.09)**	**18.6**	**(2.51)**	**1.20**
BMI	**14.7**	**(1.53)**	**17.9**	**(3.88)**	**4.48******
Illness duration (years)	**2.8**	**(1.84)**	**3.2**	**(2.53)**	**0.79**
	N	**(%)**	***N***	**(%)**	**$\chi^2_{(1)}$ AN-R vs BP-ED**
Lifetime presence of NSSI	**19**	**(57.6)**	**24**	**(75.0)**	**2.20**
Scratching	**13**	**(39.4)**	**14**	**(43.8)**	**0.13**
Biting	**4**	**(12.1)**	**6**	**(18.8)**	**0.55**
Bruising	**10**	**(31.3)**	**8**	**(25.0)**	**0.31**
Cutting	**12**	**(36.4)**	**15**	**(46.9)**	**0.74**
Burning	**2**	**(6.1)**	**1**	**(3.1)**	**0.32**

****** $p < .0001$**

Table 3

Means (standard deviations) of the total ECI scores of mothers (N=65) and fathers (N=65) of ED patients

	Mothers (*N*=65)		Fathers (*N*=65)		*F*-test
ECI total score	*M*	*(SD)*	*M*	*(SD)*	
ECI negative	100.2	(23.00)	86.80	(27.25)	9.18**
ECI positive	29.18	(7.16)	24.98	(7.18)	11.15**

**$p < .01$

Table 4

Means (standard deviations) of the ECI total scores of mothers of ED patients with and without NSSI, controlled for the patients' age (N = 65)

	Restrictive group (AN-R)						Binge-eating / purging group (BP –ED)						*F*-test		
	No NSSI N = 14		NSSI N= 19		Total N = 33		No NSSI N= 8		NSSI N= 24		Total N= 32				
ECI total score	*M*	*(SD)*	M	(SD)	*M*	*(SD)*	*M*	*(SD)*	*M*	*(SD)*	*M*	*SD)*	AN-R vs BP-ED	NSSI vs no NSSI	Interaction ED subgroup /NSSI
ECI negative	92.71	(17.49)	106.31	(27.11)	100.54	(24.17)	92.00	(15.25)	102.46	(23.64)	99.84	(22.10)	0.17	3.81	0.12
ECI positive	32.78	(4.74)	30.95	(8.74)	31.73	(7.28)	26.62	(7.27)	25.54	(5.82)	26.56	(6.09)	7.75**	0.33	0.85

** $p < .01$

Table 5

Means (standard deviations) of the ECI total scores of fathers of ED patients with and without NSSI, controlled for the patients' age (N = 65)

	Restrictive group (AN-R)						Binge-eating / purging group (BP –ED)						*F*-test		
	No NSSI N = 14		NSSI N= 19		Total N = 33		No NSSI N= 8		NSSI N= 24		Total N= 32				
ECI total score	*M*	*(SD)*	M	(SD)	*M*	*(SD)*	*M*	*(SD)*	*M*	*(SD)*	*M*	*(SD)*	AN-R vs BP-ED	NSSI vs no NSSI	Interaction ED subgroup /NSSI
ECI negative	76.00	(27.32)	95.37	(20.49)	87.15	(25.17)	74.50	(34.07)	90.42	(27.66)	86.44	(29.64)	0.21	6.00*	0.08
ECI positive	24.57	(8.50)	25.74	(7.05)	25.24	(7.59)	20.25	(6.27)	26.21	(6.47)	24.72	(6.84)	0.70	3.63	3.08

* $p < .05$