

PERCEIVED EXPRESSED EMOTION IN THE ILLNESS NARRATIVES OF INDIVIDUALS WITH CHRONIC GASTROINTESTINAL DISORDERS

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Received January 11, 2021; Revised April 8, 2021; Accepted May 2, 2021

Abstract. While expressed emotion has long been considered a valid predictor of a poor clinical outcome in individuals with mental and physical conditions, the present study marks the empirical investigation to assess specific communication patterns between family members and individuals with chronic gastrointestinal disorders. Following a rich tradition of studying illness narratives and a narrative approach to healing chronic illnesses, the present study examined illness narratives in a group of 40 mid-life adults with chronic gastrointestinal disorders. Two reliable, independent experts unfamiliar with the participants' research objectives and diagnostic status coded all narratives (ICC = .77). Self-narratives describing the illness and its impact on the family life were analyzed for a set of narrative elements, including agency, communion fulfilment, and narrative coherence. In addition, the study applies measures to assess expressed emotion, criticism towards family and perceived criticism towards individuals with a condition. The correlation analysis results indicate an association between agency and criticism (.33) and perceived criticism (.33). The main issue emerging from the multiple regression analysis findings is that agency of the narrative, criticism towards family and duration of disease taken together contribute to perceived criticism of the family towards the individual with a condition. However, a family's criticism towards the individual with a condition is the only independent

significant predictor of perceived criticism. One of the more significant findings from this study is that substantial autonomy from significant others and empowerment of individuals with a condition could worsen the family environment and have an unfavourable clinical outcome. More practical information on service users' autonomy and its impact on disease self-management would help us establish a greater accuracy.

Keywords: expressed emotion, illness narrative, narrative elements, perceived criticism, agency.

Пастрик Тетяна, Кирєєва Зоя, Кордунова Наталія, Лила Магдаліна. Сприйнята емоційна експресивність у наративах про хворобу в осіб із хронічними шлунково-кишковими розладами.

Анотація. Конструкт емоційної експресивності вважається значущим предиктором негативних клінічних наслідків в осіб із психічними та фізичними розладами рецидивів хвороби. Метою цього дослідження є емпіричне вивчення конкретних моделей спілкування між членами сім'ї та особами з шлунково-кишковими розладами. Слідуючи провідним ідеям наративного підходу та вивчення наративів про хвороби, ми досліджували наративи про хворобу 40 осіб середнього віку з хронічними шлунково-кишковими розладами. Двоє незалежних експертів, які не були знайомі з цілями дослідження та дослідницькими гіпотезами, здійснювали кодування наративів (ICC = 0,77). Аналіз наративів ґрунтувався на виділенні трьох провідних структурних компонентів наративів: суб'єктності, міжособової взаємодії, наративної когерентності. Наративна когерентність включає орієнтацію (наявність фонові інформації про особистий досвід), структуру (логічний й послідовний виклад подій), афекти (вираження емоцій і почуттів), інтегрованість (пояснення життєвих подій у контексті цілісного життєвого досвіду). Крім того, у дослідженні використовуються психометричні методики для вивчення ЕЕ (Health and Self-Management in Gastrointestinal Disorders, HASMGID, 2020), критичності стосовно членів сім'ї та й сприйнятої критичності особами із хронічною хворобою (Perceived Criticism Measure, 2019). Результати кореляційного аналізу вказують на зв'язок між змінними суб'єктності і критичності (0,33) та суб'єктності й сприйнятої критичності (0,33). Результати множинного регресійного аналізу свідчать про те, що наративна когерентність, критичність стосовно членів сім'ї та тривалість хвороби є предиктором сприйнятої критичності особами із хронічними захворюваннями. Водночас лише критичність стосовно членів сім'ї особи із захворюванням є єдиним незалежним значущим предиктором сприйнятої критичності. Одним із найбільш значущих висновків цього дослідження є те, що висока суб'єктність як інтенція контролювати хворобу та обставини, пов'язані із нею, мають зв'язок із підвищеною критичністю та сприйнятою критичністю, що зрештою погіршує сімейний клімат і може призвести до несприятливого клінічного результату. Подальше дослідження зв'язку суб'єктності та самоменеджменту хвороби й якості життя осіб із хронічними шлунково-кишковими захворюваннями дасть змогу розробити практичні рекомендації для клініцистів і розширити межі застосування наративного підходу у лікуванні осіб із хронічними захворюваннями.

Ключові слова: емоційна експресивність, наративи про хворобу, структурні компоненти наративу, сприйнята критичність, суб'єктність.

Introduction

The prognostic value of factors enhancing the health-related quality of life in individuals with chronic gastrointestinal (GI) disease has renewed the interest in the family environment as a robust predictor of chronic disease outcome (Ludvigsson et al., 2017; Sandler et al., 2002). In addition, recent developments in the family environment in disease management have heightened the role of Expressed Emotion (EE). EE is a well-validated measure of the familial emotional climate of individuals

with mental and physical conditions that examines carers' critical, hostile and emotionally over-involved attitudes towards a family member with a condition (Brown et al., 1972). Notwithstanding that most studies on EE have focused on family settings of service users with psychotic disorders, recent findings indicate a poor impact of EE on disease management in individuals with a medical condition (Wearden et al., 2000). Recently, considerable literature has grown up around the theme of life-long adhering to a diet and its negative effect on family relationships (Sandler et al., 2002). More specifically, preoccupation with food might reduce the quality of life of the entire family of a service user with chronic GI disease.

Explanatory models for EE

Previous research has established three explanatory models for EE, namely cause attributional model, vulnerability- or diathesis-stress model, and personality trait model.

The causal attribution model posits that high attributions of service users' controllability, responsibility, and blame concerning their illness might predict EE, families' high criticism towards service users in particular (Brewin et al., 1991). Family members with the high attributions of controllability consider that their family members with a condition can control their symptoms and express critical remarks when the service users, in their opinion, do not manage their condition. Blame/guilty attributions predict carers' belief in service users' responsibility for disease outcomes. The diathesis-stress model explains life-long disease as service users' specific vulnerability to experiencing stress (Hooley & Gotlib, 2000). Finally, the personality trait model points out that high EE-carers are more intolerant, inflexible, and intrusive than low-EE cares (Leff & Vaughn, 1985).

A narrative approach to perceived EE as a family communicative pattern

Unlike previous research, the current study aims to apply the narrative approach to examine EE as family communicative patterns. Evidence consistently suggests an association between EE and the speech style of family members towards individuals with a condition, namely high-EE carers who express more critical statements and fewer support statements than low-EE parents (Hooley & Parker, 2006). Leff and Vaughn (1985) point out four characteristics of high EE as a family communicative pattern, intrusiveness (verbal attempts to control service user's behaviour totally; emotional response (verbal expression of negative emotions, namely anger and emotional distress); unacceptance of service user's disease (verbally expressed blaming service user for symptoms and being ill); intolerant attitude towards service user (impatient and critical remarks). One significant way for service users to cope with chronic disease is to construct meaning of long-term sufferings and significant others attitudes towards them. Therefore, the perceived EE from the service users' perspective is essential (Medina-Pradas et al., 2011). In addition, it has been suggested that there is a reciprocal character of carers-service users' relationships.

One unanticipated finding was that the match between carers and service users, namely low service users' EE – low carers' EE or high service users' EE – high carers' EE is more important than the actual level of EE (Rienecke & Richmond, 2017). Considering this finding, the subjectively perceived family climate rather than the actual EE could explain the family communication and atmosphere and construct the meaning of health-related quality of life and favourable family environment. Despite the importance of perceived EE, there remains a paucity of evidence on illness narrative as a service user's way of constructing the meaning of family attitudes towards the individual with chronic GI disease. This paper shows that constructing illness self-narrative through distinct narrative elements is associated with the perceived EE and family environment of the individual with chronic GI disease.

Illness narrative and its elements

Chronic GI disease is a condition that considerably impacts service users' quality of life. Brokerhof et al. (2020) define chronic illnesses as prolonged illnesses, do not resolve spontaneously and are rarely cured completely. Every fourth individual in the world, four suffer from functional gastrointestinal disorders of varying severity. In addition, digestive diseases necessitate 25% of all surgical operations. Wearden et al. (2000) argue that in the case of chronic illnesses with diet adherence, EE refers instead to the course of illness than its outcome. Nevertheless, pointing out the outcome of the illness, other essential aspects emerge, namely "psychosocial adjustment, coping, and the burden of the family" amongst others (Wearden et al., 2000, p. 656). One of the most well-known approaches to examine all these aspects in individuals with a medical condition is illness narrative.

Shapiro (2020) argues that illness narrative is the conscious and unconscious representation of intricate personal motives and personal relations in micro-and macro-environments; therefore, illness narrative expresses family communicative patterns, considering disease and service user's behaviour. Thus, illness narratives and narrating elements could be an additional measure to assess perceived EE. Therefore, research of EE in illness narratives offers excellent potential for understanding the family environment in people with chronic GI disease.

Adler et al. (2012) suggest that agency, communion and narrative coherence are the fundamental elements in illness narratives in patients with a borderline personality disorder. We assume that these elements also play a crucial role in constructing the meaning of the family environment of a service user with the chronic disease since agency, community and narrative coherence express the subjective view of disease and its impact on relations with significant others. Furthermore, elements of agency and communion might express service users' perceived EE. Agency is a narrating element, expressing service users as the initiators of their family's experiences related to the chronic disease. Community regards the intimacy between the service user and significant others. While agency considers service users' motivation to overcome circumstances, communion expresses the individual's

motivation for attachment, affiliation, love, friendship, and nurturance (Adler et al., 2012, p. 501). Considering that agency and communion are two principal dimensions of thematic content, narration coherence is one of the fundamental structural components of illness narratives. Adler et al. (2012) suggest that low narrative coherence is associated with poor mental health. However, the association between low narrative coherence and chronic medical conditions remains unclear. The present study explores the specific manifestation of agency, community and narrative coherence of the illness narratives of individuals with chronic gastrointestinal disorders. The research question is relevant to the current research project: Is there any association between perceived EE and agency, community and narrative coherence as markers of constructing meaning in the illness narratives?

In light of the research question, the following is hypothesised for the current study:

H1: There is an association between EE, PC and criticism and structural components of illness narrative (agency, community and narrative coherence).

H2: There is a reciprocal character of carers-service users' relationships, which is embodied in a match of high PC towards service users and high service users' criticism towards carers.

H3: There is an association between narrative coherence and health and self-management in chronic disease.

H4: Duration of disease, criticism and agency will predict PC in individuals with chronic GI disorders.

Methods

Before the current study, we have got approval from Lesya Ukrainka Volyn National University Ethical Committee. Therefore, the inclusion criteria for recruiting participants are the clinical diagnosis of chronic with chronic GI study recruited 40 patients of Gastroenterology and Proctology Departments of Volyn Oblast Clinical Hospital (Lutsk, Ukraine), females (n=24), males (n=16), mean age was 44.90 ± 2.22 (see Table 1).

To consider the heterogeneity of the population with CD, we have applied a maximum variation sampling strategy regarding age, gender, marital status, occupational status, and disease duration. *Health and Self-Management in Gastrointestinal Disorders (HASMIGID)* as adopted version of *Health and Self-Management in Diabetes*. The measure provides an assessment of self-management in diabetes (Carlton et al., 2020). The questionnaire consists of 8 attributes, four about quality of life (mood, disease relapse, social limitations, energy), and four about self-management (control, hassle, stress, support), and shows a high and constructed validity. The internal consistency for the adopted Ukrainian version of the entire questionnaire HASMIGID is 0.72. Since the questionnaire includes health quality of life items in individuals with medical conditions, the current study applies this questionnaire to substitute item 2 of hypoglycemic attacks for disease relapse. The questionnaire assessed the individuals with a medical condition with eight items

anchored from 0 = not at all to 3 = a great deal. Scores are additive from 0 to 24. This measure has an inverse scoring, indicating that the higher score, the worse health self-management.

Perceived Criticism Measure. Masland et al. (2019) suggest that PC is an independent construct aligned with poor outcomes and relapses. Assessing the service users' views could lead to a deeper understanding of relatives' roles in the transactional process of family caregiving and illness. Considering criticism as a most significant component of EE, Hooley and Teasdale (2006) instructed the service users to rate how critical they thought their relative was of them using a 10-point Likert-type scale. In addition, they asked patients how critical they thought they were of their relative using the same scale. Therefore, the service users' responses to the two questions, namely "When your relative criticises you, how upset do you get" and "When you criticise your relative how upset does he or she get?" (Hooley & Teasdale, 2006, p. 391). Findings of assessing individuals with depression indicate an association between service users' scores, spouses' and overall EE ($r = .51$) when measured by the Camberwell Family Interview (CFI).

Narration coherence. The study examines illness self-narratives through narrative structural components: agency, community, and narrative coherence (Adler et al., 2012). We instructed the individuals with a medical condition to write the self-narrative about their disease and its impact on their life. Illness narratives were scored separately for the agency and community using a 0–3 scale. Narrative coherence includes four dimensions, namely *orientation* (essential background information to understand the context of the illness narrative), *structure* (logical and consistent narrating), *affect* (expressing emotions and feelings in the illness narrative), *integration* (relation of separate episodes to the entire personal story). The study assesses each dimension independently using a 0 to 3 scale, from 0 = not at all to 3 = a great deal. Here are two excerpts from the illness narratives and different scoring:

- (1) When I got known my diagnosis, my relatives began to take care of me and support me in everyday activities. They do not overload me with work. I am thankful to God that I have my family.
- (2) Everything seemed to be good before I felt ill. However, my disease made me feel angry all time. I often quarrel with my family members for any reason. I often cry at my wife and children because they do not understand me and my condition. They also are not satisfied with my behaviour and often criticise me. They are not aware that I can work as much as earlier. In addition, I cannot work at my previous job.

The first excerpt expresses positive family environments, and the second expresses a hostile atmosphere. All narrative structural components are embodied in distinct language units. For example, the first excerpt received score 3 on the agency ("I got known", "I am thankful") and communion ("they take care of me", "they support me"); score 1 on orientation (there is no background and personal experience before being diagnosed), score 1 on affect (there are no categories expressing feeling

and emotions except thankful), score 3 on structure (logical and consistent thoughts), score 1 (there is no concrete life episodes confirming narrator's experience).

The second example received score 3 on the agency (fully expressed narrator's stand and behaviour), score 0 on communion (there is no intimacy and family support and understanding the health-related issues), score 1 on orientation dimension (there a brief introduction and background), score 3 on structure dimension (the narration is logical and consistent), score 3 on affect dimension (there are categories indicating emotions and feelings: feeling angry, being not satisfied), score 1 on integration dimension (there is only one life episode describing the previous pace of occupation).

Two reliable experts, blinded to the objective and hypothesis of the current research examined all structural components of illness narrative (Agency ICC = .77, Communion ICC = .80, Orientation ICC = .80, Structure ICC = .79, Affect ICC = .82, Integration ICC = .79).

Results

Table 1

Descriptive Information for the Individuals with Chronic GI Disease Sample (n=40)

	Patients	
	Frequency	Percentage
Gender	24/16	60.0/40.0
Female/male		
Marital status		
Single	7	17.5
Married	33	82.5
Occupational status		
Full-time worked	22	55.0
Part-time worked	2	5.0
Retired	15	37.5
Unemployed	1	2.5
Partner	24	60.00
Other relatives	16	40.00
Duration of disease		
1-5 years	13	32.5
6 years and more	17	42.5
	Mean (SD)	Min-Max
Age	44.90 (2.22)	18-69
Duration of disease (years)	7.20 (.93)	1-20

H₁, H₂ and H₃ assume that there is an association between EE, PC and criticism and structural components of illness narrative; there is a reciprocal character of

carers-service users' relationships, embodies in the match of high PC towards service users – high service users' criticism towards carers; there is an association between narrative coherence and health and self-management in chronic GI disease.

The sample size meets the requirements of the Central Limit Theorem ($n=40>30$). Therefore, Pearson product-moment correlation was used.

Table 2 illustrates significant correlations between variables.

Table 2

Correlations (2-tailed Pearson r) Between HASMGID, EE, Perceived Criticism, Criticism and Structural Components of Illness Narrative ($n = 40$)

Variables	HASMGID	EE	PC	C	Ag	Cm	NC
HASMGID	-	-.26	.49**	.44**	.09	.04	.02
EE	-.26	-	-.20	-.04	.07	-.22	-.08
PC	.49**	-.20	-	.90**	.33*	.09	.06
C	.44**	-.39*	.90**	-	.33*	.24	.11
Ag	.09	.07	.33*	.33*	-	.15	.03
Cm	.04	-.22	.09	.24	.15	-	.59**
NC	.02	-.08	.06	.11	.03	.59**	-
Mean	10.45	5.75	7.23	6.70	3.19	1.52	5.35
(SD)	(3.52)	(4.02)	(7.65)	(6.27)	(.99)	(1.47)	(4.86)

Note. EE = Expressed emotion, PC = perceived criticism, C = criticism, Ag = agency, Cm= communion, A = affect, C = communion, NC = narrative coherence, * $p < .05$., ** $p < .01$

Multiple regression analysis has been used to predict the value of continuous variable PC based on other independent continuous variables, namely duration of disease, criticism and agency. The assumptions of linear relationship, homoscedasticity, independence of residuals (Durbin Watson $d=1.99$), multicollinearity (average Tolerance=.97>.1, and average VIF=1.33, thus $1 < VIF < 10$) were met. Finally, the sample size is above the number required by Central Limit Theorem ($n=40>30$). Therefore, the assumptions regarding the normal distribution of data are also met.

The results of the regression with a forced enter method show that three variables (duration of disease, criticism and agency) explained 81.3 % of PC in service users, $R^2 = .813$, $F(3,36) = 57.56$, $p < .001$. The results also show that criticism significantly predict the perceived criticism, $b = .87$, $t(39) = 11.56$, $p < .001$. Duration of disease, $b = -16.03$, $t(39) = -1.58$, $p = .12$ and agency, $b = .13$, $t(39) = 1.24$, $p = .22$ do not significantly predict the PC in individuals with chronic GI disease (see Table 3).

Table 3

Summary of Multiple Regression Analyses for Variables Predicting PC for All Subjects with Chronic GI Disease (n = 40)

Variables	B	SEB	β	t	p
DD	-16.03	.10	-1.13	-1.58	1.24
Ag	.13	.10	.11	1.24	.22
C	.87	.08	.87	11.56	.001

Note. Ag = agency, C = criticism, DD = duration of disease

Discussion

It was hypothesised that individuals with chronic GI disease with PC represent structural peculiarities in their illness narratives. Concerning the first research question, it was found that there is a positive correlation between the structural narrative component of the agency and service users' criticism towards carers ($r=.33$, $p<.05$), PC towards service users ($r=.33$, $p<.05$). In addition, there is a medium positive correlation between HASMGID and PC ($r=.49$, $p<.01$). These results corroborate the recent findings of Rienecke and Richmond (2017), suggesting that the subjectively perceived family climate rather than the actual EE could explain the family communication and atmosphere. In addition, our findings are in line with the results of other research of Masland et al. (2019), suggesting that PC is an independent construct aligned with frequent relapses. Therefore, examining PC will shed light on the effect of family environment on health and self-management in individuals with chronic GI disease. Considering adhering to a life-long diet by service users with chronic GI disease, family support and understanding seems to be of great value. Another important finding was a moderate correlation between service users' criticism towards carers and PC by service users. This result reflects those of Rienecke and Richmond (2017), who also found that the match of carers and service users' EE is more critical than the actual level of EE. Contrary to expectations, this study did not find a significant difference between EE and HASMGID. However, these findings demand further investigation with a larger sample of participants.

One unexpected result is that there is a positive correlation between agency and perceived criticism ($r=.33$, $p<.05$) and criticism ($r=.33$, $p<.05$). A possible explanation for this might be that. In contrast, the agency is concerned with the individuals' motivation to achieve and exert some influence over their circumstances. It also relates to the motivation of control over the family environment and family members. This control could result in critical settings in the family, which has a poor impact on disease outcomes. This explanation supports other findings reported by Cherry et al. (2018), postulating that EE results from beliefs about the controllability of health-related difficulties. However, previous findings relate controllability as a

robust predictor of EE in carers. There are many unanswered questions about controllability as a predictor of service users' EE and perceived EE in health and self-management of chronic GI disease. This is an important issue for future research. Another unexpected finding is no significant negative correlation between communion and EE. This result may be explained by how communion relates to the individual's motivation for attachment and love.

By contrast, EE includes criticism, hostility and emotional over-involvement, which are not directly associated with attachment avoidance. This result corroborates the other findings, suggesting no associations were between emotional over-involvement as an EE component and attachment anxiety. However, further research is needed to clarify the association between criticism, PC and attachment. Considering the association between the fundamental role of PC and criticism and HASMGID, another important finding was that duration of disease, criticism, and agency have taken together are predictors of perceived criticism. In addition, actual criticism is a significant independent predictor of PC. Because the current study measures actual criticism as service users' critical attitudes towards carers. This result may be explained by hyper-controllability of disease, expressed by service users' agency, which might predict the critical family environment. However, these data must be interpreted with caution because high agency as a motivation to achieve and control health-related conditions could positively impact the health and self-management of chronic GI diseases. Further studies, which take variables of agency, criticism and PC, and HASMGID into account, will need to be undertaken.

Conclusions

This paper has argued an association between perceived EE in service users with chronic GI disease and agency, community and narrative coherence of the illness narratives. This study has identified that criticism and perceived criticism play a fundamental role in developing EE as a hostile family climate for service users' with chronic GI disease. The research has also shown a match of service users' criticism towards carers and PC by service users, confirming a reciprocal nature of EE. In addition, service users' high motivation to control health-related circumstances might predict high PC and criticism in the family environment. The findings will be of interest to clinicians to consider beliefs of disease controllability in both groups of service users with chronic GI disease and carers. However, considering the possible significant role of service users' controllability for efficient self-management of GI disease, further research is needed to clarify the degree of possible correlation the direction of effect of agency on PC and HASMGID before convincing conclusions can be drawn.

Focusing on GI, this study lacks PC, agency, and HASMGID in service users with other medical conditions. Notwithstanding these limitations, the study suggests that the association of PC, criticism, HASMGID and disease duration indicate the significance of psychological interventions for enhancing family climate. In addition, more information on the association between agency as a motivation to control

medical conditions and criticism and PC and the impact of agency on HASMGID in service users with GI would help us establish a greater degree of accuracy on this matter.

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