

## CHRONIC ILLNESS AND FAMILY: IMPACT OF SCHIZOPHRENIA AND CROHN'S DISEASE ON THE FAMILY QUALITY OF LIFE

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### SUMMARY

**Background:** Quality of life assessments are increasingly present in health research. Chronic and progressive illness of a family member unavoidably affects quality of life of a family as a whole. The goals of this study were to gain insight into the family burden of chronic disorders, especially possible differences in family quality of life (FQOL) in families that have members suffering from either schizophrenia or Crohn's disease, and families in which none of the members have chronic somatic or mental illness, as well as to pilot an instrument for this purpose.

**Subjects and methods:** The sample consisted of 53 families with a member suffering from schizophrenia, 50 families with a member suffering from Crohn's disease, and 45 families with no identifiable chronic illnesses. An informant from each family underwent a structured face to face interview, using a questionnaire specially adapted from Family Quality of Life Survey, an instrument widely used to assess FQOL in families with members with disabilities, and which addresses nine areas of family life.

**Results:** In the domain of health, both groups of families with chronic illnesses believe they have significantly different conditions when compared to members of the Control group. In the Crohn's disease group, families had a great deal more of challenges in accessing healthcare services; and see themselves at a disadvantage when compared to both other groups in the domain of finances. Control group offered lowest rating in the domain of support from others. Overall measures of FQOL show significant variation among the three groups, Crohn's disease group offering lowest ratings, followed by families of mental health service users.

**Conclusions:** Overall, FQOL seems to be lower in families that have members diagnosed with Crohn's disease than in families with members suffering from schizophrenia. Illness-specific studies are required, as well as instruments with stronger psychometric properties and studies of determinants of FQOL. Qualitative approach should be emphasised when studying FQOL related to chronic illnesses.

**Key words:** Family Quality of Life (FQOL) - schizophrenia - Crohn's disease - chronic mental illness - inflammatory bowel disease

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### INTRODUCTION

Clinical interest in the indicators of the quality of life dates back to the 1946, since the WHO definition of health as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" (World Health Organization 1948). In the decades following, there has been a slow but gradually increasing interest in professional literature and research in the aspects of quality of life as an indicator and/or outcome measure of the efficacy of particular services. In the area of mental health services, one of the ways to demonstrate improved quality of treatment or other forms of care is by demonstrating improved quality of life of the recipients of such care. Within the field of healthcare, quality of life is also often regarded in terms of how it is negatively affected, on an individual level, by disease. On the other hand, evaluation of patients'

quality of life can potentially serve as a feedback information source to guide specific areas of improvement of care.

The term "quality of life" is used to evaluate the general well-being of individuals and societies and it should not be confused with the concept of standard of living, which is based primarily on income (Carlsson et al. 2002). Instead, standard indicators of the quality of life include not only wealth and employment, but also the built environment, physical and mental health, education, recreation and leisure time, and social belonging.

Quality of life is a broad term that refers to the total well-being of the individual in terms of physical, psychological, emotional, mental and social well-being, which is influenced by many factors including age, gender, socioeconomic status, behavioral risk factors, environment in which the individual is living and the absence or

presence of the disease (Higginson & Carr 2001). Researchers at the University of Toronto's Quality of Life Research Unit define quality of life as "The degree to which a person enjoys the important possibilities of his or her life" (Renwick & Brown 1996).

In spite of several issues and problems outlined above, overall there can be little doubt that attention to quality of life rather than only symptoms and signs of disease can enable the health care provider to truly "add life to years and not only years to life".

Quality of life assessments are increasingly present in the research of mental health (Priebe et al. 1997). The results of these studies indicate the importance of interventions (medical, social, psychological, legal) for the quality of life in this group of mental health service users.

The illness, in terms of temporary or permanent disability of one family member unavoidably affects the quality of life of a family as a whole. This is particularly the case in chronic and progressive diseases or physical and intellectual disabilities where the unaffected family members take the role of caregivers. The "burden of care" does not only refer to emotional but also social, financial, spiritual burden.

Family quality of life (FQOL) is a dynamic sense of well-being of the family, collectively and subjectively defined and informed by its members, in which individual and family-level needs interact. FQOL is an interactive process in which individual family member demographics, characteristics, and beliefs interact with family-unit dynamics and characteristics within the context of individual and family-level supports, services, and practices.

The findings of quality of life studies may translate to policy level (Oliva-Moreno et al. 2010). This takes place through identifying impacts of current policies or policy changes on QOL, comparing them before and after policy changes were implemented, and using domains and indicators to craft new policies designed specifically to address respective domain(s). On the agency and community level it provides a basis for decision making, staff training and for meeting accountability/reporting requirements. And finally, on the individual level it helps identifying the priority areas, assists in communication and self evaluation; e.g. assess own opportunities, initiatives, attainment, and satisfaction with their overall family quality of life (Schalock et al. 2007).

The study has several aims. The first aim of this paper is to provide insight into the family burden of a chronic mental disorder and the impact of a chronic somatic disorder on FQOL in a country recovering from war and destruction that is going through a painful process of social and economic transition and recession. The rationale for this choice of subjects was the assumption that Quality of Life assessment (in general) may reflect the efficacy of services for chronic diseases (Barry & Zissi 1997). The second aim of this study was

to determine possible differences in family quality of life (FQOL) in families that have members suffering from schizophrenia, those with members diagnosed with Crohn's disease, and families in which none of the members have chronic somatic or mental illness. The main difficulties that may impact the quality of life of families with members suffering from schizophrenia or Crohn's disease, may stem not only from the need to care and to compensate for the decreased functioning of the ill member of the family, but also from stigmatizing views of others. The third aim of the study was to pilot an instrument "Family Quality of Life Survey" (Brown et al. 2006) for this population.

## SUBJECTS AND METHODS

### Subjects

The study was transversal, randomized, descriptive and comparative. The study subjects were informants from three groups. Group 1 consisted of the families of the outpatients treated for schizophrenia (Group 1) at the outpatient Unit of the Department of Psychiatry of the Clinical Center of the University of Sarajevo, and the outpatient Unit of the Cantonal Psychiatric Hospital Sarajevo. Outpatients on the two study locations were randomized with the use of sequentially numbered, opaque, sealed envelopes – SNOSE (Schulz & Grimes 2002). Group 1 – Inclusion criteria: The families whose informants agreed to sign the Informed consent to participate in the study. The families who have a member who has been diagnosed with schizophrenia: more than 3 years ago, both genders, age between 21 and 45. Exclusion criteria: the families that have a member who has comorbid alcohol and psychoactive substance abuse, more than one family member diagnosed with schizophrenia, family member diagnosed with other chronic somatic disease including Crohn's Disease.

The informants from the families of the members of the Association of Patients with Crohn's Disease comprised Group 2. The same procedure of randomization was used for the members of the Association of Patients with Crohn's Disease. The inclusion criteria for Group 2 (Crohn's) were that the families whose informants agreed to sign the Informed consent to participate in the study. The families who have a member who has been diagnosed with Crohn's Disease: more than 3 years ago, both genders, age between 21 and 45. Exclusion criteria for Group 2 (Crohn's) – family has more than one family member diagnosed with Crohn's Disease, or has a member diagnosed with other chronic somatic or mental disease including schizophrenia. The informants in both groups were individuals who usually took most care of communication with the medical staff regarding the health of their relative.

The families from the community sample (Group 3, control) were approached with the use of Random Walk

Technique – RWT (Priebe et al. 2010). Families were excluded from entering the control group if they had a member diagnosed with chronic somatic or mental diseases.

The design of the study was approved by the Ethical committee of the Sarajevo Canton Medical Chamber.

## Methods

In each family one of the members (informant) who signed the informed consent to participate in the study underwent a structured face to face interview lasting between 30 and 60 minutes. The questionnaire for the interview was specially adapted from Family Quality of Life Survey (Brown et al. 2006). This instrument had already been translated for the purposes of a study involving families with children with special needs (Švraka et al. 2011) and it was this existing translation that was adapted for this study. The adaptation meant rephrasing or removing those items that would be specific for families with an ill child instead of an adult. The general outline of the FQOL Survey which has several parts has been retained. The first part covers basic demographic data about the family. The following 9 parts address specific areas of family life: health, financial well-being, family relationships, support from others, support from services, influence of values, careers, leisure and recreation, and community integration. Each of these 9 parts has 2 sections. Section A contains questions that gather some general information and provide context. Section B contains questions related to six key concepts: two outcome measures (attainment and satisfaction), and four explanatory measures (importance, opportunities, initiative, and stability). Section B is basically repeated for each of the nine different areas (domains) of life. The final short part of the FQOL Survey asks for overall impressions of family quality of life.

## Statistical analyses

Descriptive statistical procedures were used with relevant variables. As quality of life measures rarely provide data that meet the criteria for the use of parametric statistical procedures (Beaumont et al. 2006), so was the case with the data in this study. In cases where only two groups were compared (Schizophrenia and Crohn's disease), differences were tested using the Mann-Whitney test. Differences among all three groups were tested using the Kruskal-Wallis test with Mann-Whitney test as post hoc procedure. Two-tailed tests were used. The threshold of statistical significance was set at  $p < 0.05$ .

## RESULTS

### Sociodemographic properties of the sample

Group 1 (Schizophrenia) consisted of 53 families, Group 2 (Crohn's) of 50, and Group 3 (the control

group) consisted of 45 families. The average number of years of formal education achieved by the informants in all three groups was 12 (high school education). Most of the families surveyed were domicile and stayed in Sarajevo during the war, with eight families in the Control group and 5 in Crohn's disease group having returned to Sarajevo after the war. Only few other families had a status of either refugee family or of internally displaced persons (within the country). Age and gender of informants from these families is shown in Table 1.

Kruskal-Wallis test shows that the groups differ significantly in age of informants ( $p < 0.01$ ). Informants from Schizophrenia group deviate in age from both Control and Crohn's disease group, according to post-hoc procedures (Mann-Whitney test,  $p < 0.0167$ ).

The distribution of family sizes (numbers of family members) does not differ significantly among groups (Kruskal-Wallis test,  $p > 0.05$ ).

Average age of all family members does not differ among groups (Control:  $36.37 \pm 10.62$ , Schizophrenia:  $39.68 \pm 10.37$ , Crohn's disease:  $35.36 \pm 9.14$ ), with a total of  $37.21 \pm 10.22$ . 24 families (53.3%) of the Control group have underage members, while that is the case with 21 (39.6%) and 16 (32%) in the Schizophrenia and Crohn's disease group, respectively. Least number of families with members over 65 years of age were in the Crohn's disease group (9, or 18%), while 21 family (39.6%) of the Schizophrenia group had senior members. Again, the Control group had most of families with members over 65: 23, or 51.3%.

### Issues related to services received and required

In terms of social care and healthcare services required and received, only Schizophrenia and Crohn's disease groups were compared. While 21 family or 40.4% in the Schizophrenia group claimed that they were not getting the needed services in full extent according to their perception, that was the case with 46 (93.9%) of the families in the Crohn's disease group. The services they list include disability allowance, disability attendance allowance or respite care, paid nursing care, paid caregiver; in eight families of the Schizophrenia group, but 23 of the Crohn's disease group. Crohn's disease group informants state also services that are specifically indicated for that disease, namely medical rehabilitation (12 families) and nutritionist treatments (13 families). Interestingly, while informants from the Schizophrenia group listed socialization or support groups in five cases, seven families in the Crohn's disease claimed they would benefit from some kind of psychotherapy. Frequencies of families responding to offered options through which they can describe the barriers in accessing health care are shown in Table 2, and the relative cost of treatment in Table 3.

**Table 1.** Age and gender of informants

Informants	Control (N=45)	Schizophrenia (N=53)	Crohn's disease (N=50)	Total (N=148)
Age (min. 21 – max. 75)	41.60±8.99	51.19±12.67	44.42±13.54	45.99±12.59
Gender	M=16; F=25	M=22; F=31	M=27; F=23	M=65; F=83

**Table 2.** Number of families reporting barriers in accessing healthcare

Barrier	Schizophrenia	Crohn's disease
Long wait for service	6	37
Not known treatment for health problem	3	20
Services not available in my area	3	3
Transportation is a problem	3	0
We cannot make appointments easily, we have trouble getting a service	3	12
We do not know where to go for health care services	1	4
We do not understand easily what health care professionals say to us	1	8
Poor treatment by health care professionals	0	30
We do not share same beliefs about health care	9	14
Other	7	3
Total	36	131

### Key descriptors of FQOL

Table 4 shows mean rank comparison of key descriptors of family quality of life in each area by family condition.

With regard to the domain “Services support”, since the healthy members of the Control group are not assumed to be regular users of health services, the difference was explored only between the Schizophrenia group and the Crohn's disease group, using the Mann-Whitney test. Significant differences among these two groups are shown in the measures of opportunities ( $U=502.5$ ,  $z=-5.46$ ,  $r=-0.55$ ), attainment ( $U=241.5$ ,  $z=-7.2$ ,  $r=-0.72$ ), stability ( $U=863.0$ ,  $z=-3.75$ ,  $r=-0.38$ ), and satisfaction ( $U=168.0$ ,  $z=-7.72$ ,  $r=-0.77$ ) with services support.

Finally, two overall measures of FQOL are compared among the three groups (Table 5).

Both overall measures of FQOL show significant variation among the three groups ( $p<0.05$ ). Pairwise differences are not manifest between the Schizophrenia group and the Crohn's disease group when it comes to overall rating of FQOL.

**Table 3.** Percentage of total income spent for treatment and related costs

%	Schizophrenia (N=53)	Crohn's disease (N=50)
≥51%	0	32 (64%)
26–50%	5 (9.4%)	12 (24%)
10–25%	16 (30.2%)	2 (4%)
<10%	28 (52.8%)	0
0	3 (5.7%)	4 (8%)
No answer	1 (1.9%)	0

Numbers indicate frequency of families in each group

### DISCUSSION

This study provides preliminary evidence about the family burden of chronic mental or somatic illness, but also in the context of Bosnian-Herzegovinian health and mental health services particularly so by identifying the unmet needs of both groups of patients and their families. The role of research is to inform treatment and policy guidelines and the family QOL approach provides data that are perhaps more relevant to this topic than the clinical outcome studies.

Both from their free description of services they require, including psychotherapy, and from the list in Table 2, it was obvious that families with members that suffer from Crohn's disease had a great deal more of challenges they have to face in accessing healthcare services. This probably stems from the fact that Crohn's disease is significantly less prevalent in the general population (Caprilli et al. 2006), so the healthcare system reflects the respective lack of adequate response. Also, the mental health system is undergoing continuous changes and is receiving substantial funding from foreign sources as well (Kucukalic et al. 2005). Still, the responses also demonstrate the fact that the needs in both groups also overlap, mental health problems in the families with Crohn's disease being very clearly stated. Since seven families in the Crohn's disease claimed they would benefit from some kind of psychotherapy, this clearly reflects this dimension of the burden. The fact that so many informants in the Crohn's disease group state that the patients are poorly treated by professionals might stem from the fact that their physicians neglect this aspect of their pathology, although the informants claim there is also lack of expertise among gastroenterologists. Additionally, the relative cost of services also reflects these challenges, as evident from Table 3.

**Table 4.** Mean rank comparison of selected key descriptors of FQOL in each area by family condition

Area	Key	Control		Schizophrenia		Crohn's disease		H
		M (SD)	Mean rank	M (SD)	Mean rank	M (SD)	Mean rank	
Health	Importance	4.78 (0.85)	73.29	4.92 (0.33)	74.44	4.94 (0.24)	75.65	0.30
	Opportunity	4.18 (0.74) <sup>a</sup>	86.34	4.00 (0.77)	77.66	3.44 (1.23) <sup>b</sup>	59.08	11.84
	Initiative	4.11 (0.71)	63.18	4.50 (0.73)	85.90	4.20 (0.86)	71.36	8.75
	Attainment	4.16 (0.86) <sup>a</sup>	96.70	3.58 (0.89) <sup>b</sup>	70.32	3.18 (1.11) <sup>b</sup>	56.10	24.40
	Stability	3.20 (0.51) <sup>a</sup>	80.14	3.25 (0.76) <sup>a</sup>	83.90	2.80 (0.46) <sup>b</sup>	57.65	15.86
	Satisfaction	4.02 (0.69) <sup>a</sup>	104.52	3.34 (0.94) <sup>b</sup>	75.92	2.72 (0.64) <sup>c</sup>	45.98	48.97
Financial	Importance	4.16 (0.80) <sup>a</sup>	59.92	4.31 (0.51) <sup>a</sup>	63.70	4.78 (0.55) <sup>b</sup>	97.38	29.03
	Opportunity	3.09 (1.08) <sup>a</sup>	92.08	2.79 (1.09) <sup>a</sup>	79.37	2.10 (0.97) <sup>b</sup>	52.15	23.72
	Initiative	3.96 (0.95)	65.61	4.45 (0.67) <sup>a</sup>	87.28	3.73 (1.28) <sup>b</sup>	63.25	11.64
	Attainment	3.36 (1.03) <sup>a</sup>	91.16	3.06 (1.09) <sup>a</sup>	81.34	2.22 (1.06) <sup>b</sup>	49.61	27.46
	Stability	3.38 (0.61) <sup>a</sup>	87.08	3.18 (0.74) <sup>a</sup>	77.47	2.84 (0.47) <sup>b</sup>	57.23	17.91
	Satisfaction	3.42 (0.94) <sup>a</sup>	95.46	3.00 (1.05) <sup>a</sup>	78.92	2.20 (0.97) <sup>b</sup>	49.57	30.68
Family	Importance	4.76 (0.57)	76.44	4.75 (0.43)	74.34	4.72 (0.50)	72.92	0.28
	Opportunity	4.31 (0.63)	81.72	4.06 (0.73)	69.95	3.84 (1.28)	71.26	2.72
	Initiative	4.51 (0.66)	76.71	4.28 (0.86)	68.40	4.54 (0.61)	78.98	2.19
	Attainment	4.56 (0.62) <sup>a</sup>	84.08	4.17 (0.19) <sup>b</sup>	67.23	4.40 (0.54)	73.59	4.69
	Satisfaction	4.38 (0.75) <sup>a</sup>	86.47	3.94 (0.94) <sup>b</sup>	66.96	4.06 (0.82)	70.10	6.68
Support (others)	Opportunity	3.40 (0.89) <sup>a</sup>	91.94	2.60 (1.31) <sup>b</sup>	65.49	2.63 (1.33) <sup>b</sup>	66.72	12.25
	Attainment	3.18 (1.01) <sup>a</sup>	87.54	2.53 (1.31) <sup>b</sup>	67.67	2.57 (1.32) <sup>b</sup>	68.41	7.02
	Stability	3.16 (0.42) <sup>a</sup>	81.37	3.00 (0.40)	73.38	2.88 (0.44) <sup>b</sup>	66.41	10.58
	Satisfaction	3.60 (0.81) <sup>a</sup>	92.00	3.06 (1.05) <sup>b</sup>	71.29	2.78 (1.12) <sup>b</sup>	60.40	14.54
Values	Importance	4.07 (0.94)	79.38	3.89 (1.01)	72.15	3.98 (0.74)	72.60	1.00
	Opportunity	3.82 (0.94)	83.22	3.58 (0.87)	70.75	3.46 (1.18)	70.63	3.14
	Initiative	3.82 (0.91)	72.21	3.91 (1.01)	77.72	3.90 (0.71)	73.15	0.58
	Attainment	3.89 (0.98)	74.21	4.09 (0.82)	82.10	3.84 (0.71)	66.70	4.18
	Satisfaction	3.96 (0.67) <sup>a</sup>	87.82	3.77 (0.85) <sup>a</sup>	79.03	3.22 (1.04) <sup>b</sup>	57.71	14.81
Careers	Importance	3.91 (1.74)	83.97	2.92 (2.17)	63.41	3.98 (1.32)	76.46	6.61
	Opportunity	3.38 (1.48) <sup>a</sup>	89.89	2.32 (1.94) <sup>b</sup>	65.25	2.92 (1.18)	70.45	9.37
	Initiative	3.62 (1.60)	84.34	2.75 (2.09)	67.12	3.58 (1.09)	73.46	4.35
Leisure	Importance	4.33 (0.88)	78.88	4.23 (0.61)	67.58	4.36 (0.75)	77.90	2.61
	Opportunity	3.69 (0.95) <sup>a</sup>	84.92	3.55 (0.85)	79.51	3.04 (1.18) <sup>b</sup>	59.81	10.38
	Initiative	3.76 (0.86)	75.20	3.70 (0.89)	72.71	3.80 (0.73)	75.77	0.18
	Attainment	3.53 (0.79)	77.94	3.58 (0.87)	83.04	3.20 (0.95)	62.35	7.30
	Satisfaction	3.20 (0.46) <sup>a</sup>	79.90	3.19 (0.48) <sup>a</sup>	78.11	2.98 (0.25) <sup>b</sup>	65.81	9.33
Community	Satisfaction	3.69 (0.73) <sup>a</sup>	89.34	3.58 (0.84) <sup>a</sup>	86.71	2.54 (1.09) <sup>b</sup>	48.20	31.69
	Opportunity	3.71 (0.84) <sup>a</sup>	87.48	3.08 (1.00) <sup>b</sup>	59.18	3.42 (0.90)	75.53	12.53
	Initiative	3.78 (0.74)	86.91	3.17 (1.08)	62.78	3.47 (0.92)	74.05	8.76
	Attainment	3.53 (0.87) <sup>a</sup>	84.31	3.02 (1.09) <sup>b</sup>	63.93	3.29 (0.97)	75.19	6.27
	Satisfaction	3.76 (0.65) <sup>a</sup>	95.06	3.27 (0.82) <sup>b</sup>	70.39	3.34 (0.77) <sup>b</sup>	58.80	20.73

Kruskal-Wallis test statistic is denoted by H; variables where differences are found to be significant at  $p < 0.05$  are printed in *italic type*; significant ( $p < 0.05$ ) pairwise differences, using Mann-Whitney test, were found among means with differing superscripts

**Table 5.** Comparison of overall descriptors of FQOL by Family Condition

Variable	Control		Schizophrenia		Crohn's disease		H
	M (SD)	Mean rank	M (SD)	Mean rank	M (SD)	Mean rank	
Overall rating of FQOL	3.60 (0.96) <sup>a</sup>	98.19	2.67 (1.18) <sup>b</sup>	66.58	2.30 (0.84) <sup>b</sup>	50.85	33.57
Overall satisfaction with FQOL	3.82 (1.01) <sup>a</sup>	90.28	3.40 (0.93) <sup>b</sup>	72.58	2.94 (0.90) <sup>c</sup>	52.37	22.16

Kruskal-Wallis test statistic is denoted by H; significant ( $p < 0.0167$  with Bonferonni correction) pairwise differences, using Mann-Whitney test, were found among means with differing superscripts

Not surprisingly, the comparisons shown in Table 4 indicate that in the domain of health, both families of patients with schizophrenia and those with Crohn's disease believe they have significantly different attainment, stability, and satisfaction when it comes to this aspect of functioning when compared to members of the Control group. It is interesting, however, that when it comes to how these groups see the opportunities they have in maintaining their overall health, families with a member suffering from schizophrenia do not differ significantly from either of the two remaining groups. The comparison is similar in the domain of support from others, where both groups with chronic conditions have significantly lower perception of quality of life in this domain when compared to members of the Control group, but not among each other. Since the Control group objectively does not require support from others compared to the other two groups, this finding would neither be surprising nor interesting if there were not for the fact that the overall rating in these descriptors by the Control group is lowest in this domain. This perhaps reflects the complex changes in the Bosnian-Herzegovinian society related to post-war transition (Filipović 2011, Žiga 2011), alienation of individuals as a response to complex stresses and challenges (cf. Raphael & Wilson 2003), and the speedy Westernisation of the style of life. In the domain of community, informants from the Crohn's disease group were usually half way between the two other groups, indicating that people do appraise the close layers of the community that they might expect some support from, in a way considerably different than they do with the community as a whole.

In the domain of finances, however, the situation is completely different, where families from the Crohn's disease group see themselves at a disadvantage when compared to both Control group and the families with members suffering from schizophrenia, in virtually all the tested descriptors. The latter two groups do not differ significantly in any of those.

In the domain of family, it is indicative that only Control and Schizophrenia group differ significantly, and only in one aspect, informants with mental health service users in the family not being as satisfied as the other two groups.

It is interesting that the two overall measures of FQOL (Table 5) seem to yield results that are so different from one another. Perhaps rating, unlike satisfaction, implies a sort of comparison with some intuitive standards of "average".

### **Limitations of the study and suggestions for further research**

There are obvious difficulties in comparing the domains of family functioning across groups of different chronic illnesses, especially between somatic and mental illnesses, since they have distinctive features as to what kind of involvement is needed within the

family, and what aspects of family functioning are most damaged.

The study used a relatively small sample, and to a certain degree it can even be seen as somewhat biased in the two clinical groups, since the data were obtained directly by clinicians working with mental health service users, or by the staff of a patient association gathering people diagnosed with Crohn's disease. However, this can hardly affect variables other than those pertaining to services received.

In addition, it appears that information obtained from qualitative research will provide further important data that may help us in trying to reach an in-depth understanding of the determinants of family quality of life. The instrument used seems by its structure to downgrade the importance of some determinants of FQOL that may prove to be of particular importance in some conditions. The informants are given the opportunity to offer their free comments on various issues, but usually fail to do so, probably partly due to the taxing duration of the interview. For instance, it is well known that the demand for information and knowledge about their condition and its treatment is high in people with inflammatory bowel disease (Wilson & Greco 2012) and information-seeking is a well-known coping strategy in health-related conditions. On the individual level, intraindividual coping skills certainly help in improving quality of life, and that is bound to reflect on the family level. Similar to the allegorical example of the "shirt of a happy man" for the individual level (Jakovljević 2010, Krmpotić 1989), the essence and nature of FQOL remains elusive. After all, quality of life is an emergent property of the sum total of processes that we go through and experience as live, interacting, and sentient beings (Šošić 2010), and the same applies to FQOL.

The surge of popular books on maintaining good relationships in the family testifies to the importance of FQOL. Health arguably includes "social wellbeing", as evident also from the definition of health itself. Not only does the family contribute to the quality of life of an individual, but also it has long been known that e.g. social isolation can be treated as a predictor of adverse health outcomes (e.g. Ruberman et al. 1984).

However, in spite of the global trends in which cultures increasingly resemble the Western model, various aspects of family functioning can be of varied importance in various cultures. Therefore, mere description according to a unified model does not necessarily contribute to our understanding of the key determinants of FQOL. Adversities, such as chronic illness in the family, may shift the emphasis to other aspects, making an individual family more prone to value (or perhaps even to overrate) the good health of other family members in comparison to e.g. the socio-economic status of the family. Also, individuals in the family may resort to other contexts in the ecology of contexts, such as school or work.

## CONCLUSION

Overall, FQOL seems to be lower in families that have members diagnosed with Crohn's disease than in families with members suffering from schizophrenia. Not surprisingly, FQOL is highest in families in which none of the members have chronic somatic or mental illness, which testifies to the importance of health in general as a determinant of family quality of life.

For future studies we recommend that the qualitative approach should be emphasized when studying FQOL in groups of people with chronic illnesses, to uncover possible new domains of functioning worth exploring as important for overall family functioning. The stigma associated with both schizophrenia and Crohn's disease could be particularly well explored using the qualitative approach as it affects families in different cultures. As far as the quantitative studies are concerned, it is known that instruments most commonly used to assess FQOL have varying degrees of limitations and strengths (Hu et al. 2011), so instruments with stronger psychometric properties are needed to reach more reliable conclusions, and enabling the study of causal determinants of FQOL. What is required are both studies specific for each illness, and those trying to pinpoint general determinants of FQOL.

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