

FAMILY QUALITY OF LIFE AMONG FAMILIES WITH A MEMBER DIAGNOSED WITH CLD – WHAT TO EXPECT?

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Abstract

Background and objectives. Health-related quality of life (HRQoL) is a very important outcome in patients with chronic liver disease. Thus, the present study attempts to assess the family quality of life of these patients, since it is well known that families have always represented the primary environment of most people.

Material and methods. A sample of 30 participants with a family member who had CLD were recruited to be interviewed through the Romanian adaptation of the Family Quality of Life Survey – general version 2006 (FQOLS-2006), an evaluation tool developed in Canada with the purpose of studying families' quality of life among. Primary caregivers completed the FQOL Survey. The data was analysed to describe population characteristics and to explore the relationship between the main domains and dimensions of QoL and the patients and caregivers characteristics.

Results. The findings showed highest domain scores for Support from services and Family relationships and lowest for Support from others. Dimension scores were highest for Importance and lowest for Stability. Overall FQOL approximated average (78.5±13.4). Younger patients scored lower rates of FQOL domains. Alcohol-related liver disease led to lower rates of all the domains, except from Support from others and Leisure and Recreation activities. Patients with liver cirrhosis or liver cancer negatively influence their caregiver's success in career. Also, families of liver cirrhosis patients reported the lowest level of satisfaction among all respondents.

Conclusions. The results of this study suggest that there are some significant areas of family life highly influenced by a chronic liver disease diagnosis in one of their members.

Keywords: family quality of life, chronic liver disease, burden, FQOL Survey.



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Rezumat

Introducere și obiective. Calitatea vieții în relație cu starea de sănătate reprezintă un parametru foarte important pentru evaluarea pacienților cu boli hepatice cronice. În acest sens, studiul de față urmărește evaluarea calității vieții familiilor în a căror componență există membri diagnosticați cu boli hepatice cronice, fiind bine cunoscut faptul că familia reprezintă cel mai important punct de sprijin al individului.

Material și metodă. Un grup de 30 persoane care au în componența familiei pacienți cu boli hepatice cronice a fost selectat pentru a completa un chestionar de evaluare a calității vieții familiei (FQOLS – 2006 varianta generală). Acest instrument de evaluare a fost elaborat de un grup de experți canadieni cu scopul măsurării calității vieții familiilor. Datele obținute au fost analizate cu scopul descrierii caracteristicilor acestor familii și pentru a compara scorurile obținute la fiecare domeniu de interes al QoL în funcție de caracteristicile pacienților și familiilor acestora.

Rezultate. Domeniile referitoare la sprijinul din partea serviciilor medicale și relațiile interfamiliale au obținut cele mai mari scoruri medii, iar cele mai mici valori au fost obținute de sprijinul oferit de alte persoane din afara familiei. Scorul cel mai mare a fost obținut de dimensiunea importantă, iar cel mai mic de stabilitate. Scorul mediu al chestionarului FQOL a fost 78.5 ± 13.4 . Cu cât vârsta pacientului a fost mai mică, cu atât scorurile domeniilor FQOL au fost mai mici. Etiologia alcoolică a bolii hepatice s-a corelat cu scoruri mai mici ale majorității domeniilor FQOL. Diagnosticul de ciroză hepatică și hepatocarcinom celular au determinat cele mai scăzute valori ale domeniului Carieră al aparținătorului. De asemenea, pacienții cu ciroză hepatică au determinat cel mai mic scor al satisfacției aparținătorilor.

Concluzii. Rezultatele acestui studiu indică influențarea semnificativă a anumitor domenii ale vieții de familie de către existența în componența familiei a unui membru diagnosticat cu boală hepatică cronică.

Cuvinte cheie: calitatea vieții familiei, boli hepatice cronice, povară, FQOLS

Introduction

Chronic liver disease (CLD) is related to important morbidity and mortality and it represents one of the major burdens for health care systems around the world. Although, in the past decades, there has been major progress regarding the knowledge and management of chronic liver disease, there are still approximately 30 million persons estimated to suffer from CLD only in Europe⁽¹⁾. United States statistics indicate that liver cirrhosis accounts for nearly 60.000 deaths each year, being referred as the 12th leading cause of death among Americans and as the 3rd or the 4th leading cause of death among persons aged 45-64 years old⁽²⁾.

According to WHO (World Health Organization), in terms of alcohol consumption, the heaviest drinking occurs in Europe, where the mortality rate from alcohol-related disease is as high as 47 per 100.000 persons^(3,4). Given these circumstances, there is an urgent need to implement prevention programs by governments in order to lower the substantial burden of alcohol-associated liver disease morbidity and mortality worldwide.

Also, patient-reported outcomes are nowadays considered more and more important in the assessment of health outcomes. Determining global satisfaction and overall quality of life (QoL) from the patient's perspective is of utmost importance^(5,6). Furthermore, in order to achieve a greater scoring of patients' QoL as to improve chronic disease management, the concept of family quality of life (FQOL) has been developed.

Aim of the present study

The aim of this study was to describe the FQOL of families having a member with chronic liver disease who reside in south-eastern Romania

that were being followed in an Internal Medicine service in Bucharest. We hypothesized that FQOL ratings would be affected by sociodemographic and etiological factors. More specifically, we examined whether FQOL would be lower in those residing outside of a major urban area and would differ between families of different age, economic and etiology of CLD background.

Method. Participants

The participants comprised a convenience sample of family members who identified themselves as the main caregivers of individuals with CLD, who received medical services from Bucharest Emergency University Hospital during 2018.

Subjects were included if they:

- Families with a member over 18 years of age diagnosed with CLD defined when there was evidence of alcoholic or non-alcoholic liver disease, chronic hepatitis B virus (HBV) or hepatitis C virus (HCV) infection by reviewing serologic markers and history, serologic and/or radiologic evidence of liver cirrhosis of different etiologies and radiologic and/or histopathologic examination of hepatocellular carcinoma.
- Knowledge of Romanian native language.
- Out of free will to participate to the study.
- Written informed consent.

Information about the patient sample

A total of 30 family members participated in the study, including 13 wives, 6 husbands, 5 daughters, 4 mothers, 1 father and 1 sister, representing the main caregivers of the individual with chronic liver disease included. Three quarters of them were females, with a mean age of 49.9 ± 13.8 years (range 29-83). Most of them described their



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family as a two-parent family (76.7%), indicating the “mother” as the most involved member of the family (43.3%), followed by “both of the parents equally” involved in day to day life of their families (26.7%).

More than a half of the respondents believed that the responsibility for day to day affairs of the family accounts for the amount they like, but the main concern was regarding the responsibility related to caregiving. Most of them, rated this item with 1 or 2 out of 5 on a Likert scale (from 1 to 5, lowest to highest), which means “much more responsibility than I would like” or “more responsibility than I would like” (see **Table 1**).

Regarding the individuals with CLD, almost three quarters were male (73.33%) and their mean age was 51.3 years (SD = 14.1 years; range 26-79). 3 families lived in the countryside, while the other 27 families lived in the city (90%). 30% of patients included had alcohol related liver disease (see **Table 2**).

Instrument

The instrument used in this study was the FQOLS-2006 (Brown et al. 2006), a questionnaire containing 54 items that examine nine core quality of life domains. The first section includes background information (gender, age, diagnoses, etc.) on the family and its members. The assessed domains are health of the family, financial well-being, family relationships, support

from other people, support from medical related services, influence of values, careers and planning for careers, leisure and recreation activities and community interaction.

Within each domain, six dimensions are assessed by one item each: Importance – importance of each domain to the family, Opportunities – the perceived opportunity to increase attainment of the domain, Initiative – the efforts made by the family to increase attainment, Attainment – the amount of achievement in each domain, Stability – the stability of attainment over time, and Satisfaction – the level of satisfaction of the family with attainment. Some examples of the items are: “How important is your family's health to your family's QOL?”; “All things considered, how satisfied are you with the financial well-being of your family?”.

FQOLS-2006 was found superior above other tools that examine families and their QoL in several previous studies (Werner et al. 2009, Schertz et al. 2016)^(7,8). The instrument has several major strengths which make it useful for clinical research. For example, the questions are worded similarly and all the responses are rated on a similar 5-point scale which enables an easier comparison between the results. Also, another favorable feature of FQOLS-2006 is that it incorporates both quantitative and qualitative data, providing a more comprehensive

Characteristics	N (%)
Gender	
Male	7 (23.3)
Female	23 (76.7)
Age (mean±SD) (years)	49.9±13.8
SF-36 scoring (mean±SD)	77.1±8.7
Family structure	
One-parent	7 (23.3)
Two-parent	23 (76.7)
Most involved in day to day life of the family	
Mother	13 (43.3)
Father	4 (13.3)
Both of the parents equally	8 (26.7)
Brothers or sisters	2 (6.7)
Others	3 (10)
Responsibility in day to day affairs of the family	
More responsibility than I would like	12 (40.0)
About the amount of responsibility I like	16 (53.3)
Less responsibility than I would like	2 (6.7)
Responsibility related to caregiving	
More responsibility than I would like	17 (56.7)
About the amount of responsibility I like	12 (40.0)
Less responsibility than I would like	1 (3.3)

Table 1. Family characteristics of those having a member with CLD



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Patients characteristics	N (%)
Gender	
Male	22 (73.3)
Female	8 (26.7)
Age (mean $\pm$ SD) (years)	51.3 $\pm$ 14.1
Residency	
City	27 (90.0)
Rural areas	3 (10.0)
Type of CLD	
Fatty liver disease	9 (30.0)
Viral hepatitis	8 (26.7)
Liver cirrhosis	8 (26.7)
Liver cancer	5 (16.7)
Etiology	
Alcoholic	9 (30.0)
Non-alcoholic	21 (70.0)
Treatment	
Under treatment	18 (60.0)
Supportive treatment	10 (33.3)
Specific antiviral therapy	8 (26.6)
Without treatment	12 (40.0)
SF-36 scoring (mean $\pm$ SD)	69.1 $\pm$ 20.8
LDQOL scoring (mean $\pm$ SD)	78.5 $\pm$ 13.4

Table 2. Characteristics of the patients with chronic liver disease (CLD)

representation of family life⁽⁷⁾. It is a very adaptive tool and it can be used for a wide range of clinical research.

Procedures

Caregivers of patients with CLD, who met the research inclusion criteria, were approached by us and were provided an explanation regarding the research study. 93% of those approached agreed to participate on the study. Of the 30 family members questioned, 83% were interviewed face-to-face in the clinic, 13% self-administrated the survey and 4% were interviewed by the phone. In all cases, the respondents were asked to focus on and consider the QOL of their entire family, rather than just their individual QOL. Demographic information was verified and data regarding the patient's significant history, diagnostic and treatment was obtained from their medical record.

Data analysis

Statistical analyses were carried out using SPSS 23.0 software. Analyses were conducted on the group of patients to establish profiles of FQOL for families with a member diagnosed with chronic liver disease. Furthermore, analyses included relationship of FQOL results, domains and dimensions to family characteristics (age, gender, location of residency, family type) and patient characteristics (age, gender, diagnosis, etiology of CLD, method of treatment).

The population was described using numbers and frequencies for the qualitative variable and the average and standard deviations for the quantitative variables. Spearman correlation coefficient was used for evaluating the relationship between the quality of family life dimensions/domains and family or patients characteristics. Each

time, the p value less than 0.05 was considered statistically significant.

Results

Results showed that most of the families feel that the lack of knowledge regarding the treatment for some of their health concerns are the greatest barriers to accessing health care services. Mostly, the families with a member diagnosed with viral hepatitis B or cancer responded this way (see **Figure 1**).

Secondly, some complained about the lack of transportation to the hospital and, third, the absence of specific health services in the residency area. These two barriers were more frequently mentioned by the families who resided in the countryside, rather than those who lived in an urban area (**Figure 1**).

The overall means of the nine domains are shown in Fig. 2. As seen, the highest means were those referring to Support from special services (3.89), followed by Family relationships and Leisure and Recreation activities. The lowest mean domain scores was Support from other people (3.11).

The overall means of the six dimensions are shown in Fig. 3. As the figure illustrates, Importance was rated the highest (4.11), while Stability was rated the lowest (3.09). Opportunities, Initiative and Satisfaction scored average rates, with slight differences in between (3.61 vs 3.57 vs 3.56).

No statistically significant correlations were found between the studied family characteristics (age and gender of the main caregiver of the family, residency area and family type) and FQOL domains and dimensions (see **Table 3a** and **Table 3b**).

We found positive statistic correlations between the age of the patient and all FQOL domains, except from the Influence of Values domain. Therefore, the younger the patient,



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the lower the FQOL score domains were. Patients with alcohol-related chronic liver disease scored lower rates for almost all FQOL domains, besides Support from other people and Leisure and Recreational activities domains.

The patient's diagnosis was found to negatively influence the caregiver's Career domain as follows – liver cirrhosis patients, followed by hepatocellular carcinoma patients determined the lowest values for their main caregiver's Career domain. The strongest statistically significant correlation between FQOL domains and patient characteristics was found between the alcohol-related causes of CLD and the Community domain ($p < 0.001$).

The age of the patient also statistically positively correlated with all FQOL dimensions without exception, meaning that a younger patient determined lower rates of all FQOL dimensions. The mean score of Satisfaction was significantly influenced by the patient's diagnosis. In our studied group, liver cirrhosis patients caused the lowest Satisfaction rates for their main caregivers.

A statistically significant correlation was also found between the etiology of chronic liver disease and all the FQOL dimensions. Thereby, patients with alcohol-related liver disease were associated with the lowest FQOL dimensions rates among all patients in the studied sample. (see **Table 3b**)

Discussion

The current study examined FQOL by using the revised FQOLS (Brown et al. 2006). The interrelationships between the nine life domains, their six dimensions and the overall score of FQOLS, alongside family and patients characteristics were explored.

The mean age of the patients diagnosed with CLD in our group was 51.3 ± 14.1 (mean $\pm$ SD), similar to other liver disease patients cohorts reported in literature⁽⁹⁾. Also, most patients in our group were male (73.3%), results which are consistent with the latest literature reviews regarding age-gender medicine, which is a relatively recent developed and used concept⁽¹⁰⁾.

In terms of amount of involvement in day to day life of the family, most of the respondents designated the “mother”, as the most involved person, for the two-parent type of family, as these represented 76.7% of the total. Regarding the personal amount of responsibility in day to day family life, 53.3% of the respondents reported an average score (“about the amount of responsibility I like”), on contrast with only 40% with the same answer regarding the responsibility related to caregiving for the family member with CLD. In this case, the majority of answers (56.7%) were “more responsibility than I would like”, suggesting that the family member with CLD signifies a burden for the

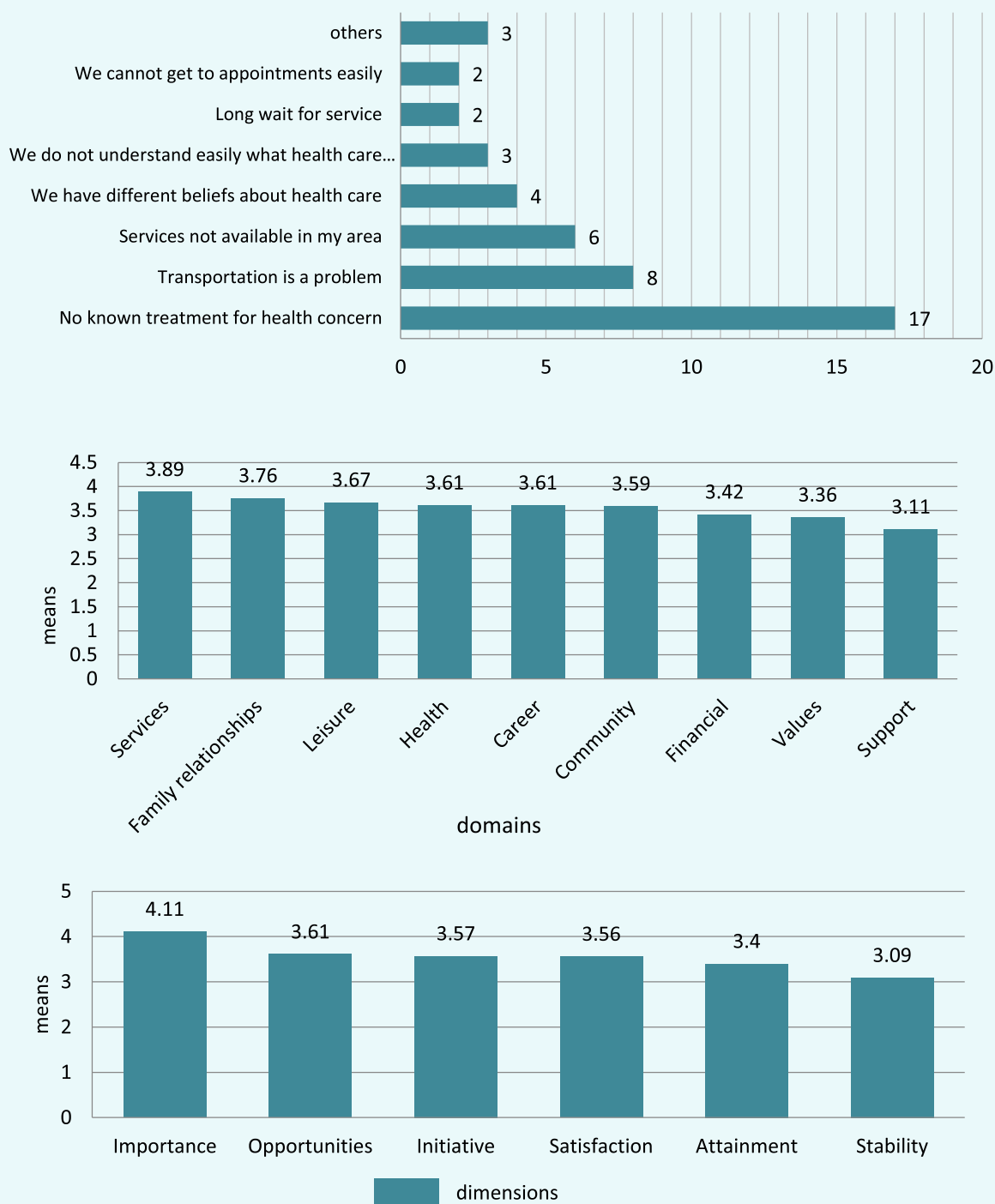


Figure 3. Means of dimensions scores of FQOLS



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main caregiver of the family and the rest of its members.

The main complaints of the families with respect to the barriers in accessing health care services were the absence of a known treatment for the liver disease, the lack of transportation and the inexistence of medical services in the residency areas. These last two complaints were more consistent with the group of people living in the countryside. The least barriers families reported were regarding the difficulty in accessing medical appointments and the amount of time needed for this to take place. Support from services and Family relationships were rated highest overall, demonstrating that these domains are prominent in the lives of families that have a member with chronic liver disease. The constant upgrade of the health care services in our country, particularly in terms of diagnosis and treatment for liver disease would explain the high level of confidence that patients reported regarding the support from special services. New updates upon the attainability for patients with Hepatitis C to receive interferon-free therapies were issued recently by our National Health System in a press release.⁽¹¹⁾ Also, the most recent data about The Romanian National Program for Liver Transplantation for patients with end-stage liver disease describes a continuous evolution including 852 procedures in 815

patients over a period of 17 Years (2000-2017)⁽¹²⁾. The fact that the liver transplantation program has constantly evolved over time may be associated with the results described in our study regarding the support families with CLD reported having from health care services.

Support from other people (relatives, friends, neighbors and others) was rated lowest across all dimensions. This finding is consistent with previous findings from the original survey of lack of practical support from relatives, friends and neighbors (Brown et al. 2003). An explanation for this fact could be that families with members with CLD, especially alcohol-related liver disease or viral disease do not feel comfortable asking for help in the community. Also, patients with viral hepatitis assuredly feel anxious about possible apprehension or rejection from other people, aside from their closest family members.

On the positive side, family relationships were rated second high across other domains. This showing places family as the main caregiver of the patient with CLD, especially because for this kind of patients long-term follow-ups and extended treatments are required. Moreover, this finding is likely indicative of a primary reliance on the close family unit, which may lead to higher levels of patient's compliance regarding suggested treatments for their

		Overall FQOL	Health	Financial well being	Family relationships	Support from others	Support from services	Values	Career	Leisure	Community
Family characteristics	Gender	0.165	0.164	0.205	0.408	0.943	0.395	0.847	0.234	0.833	0.728
	Age	0.804	0.995	0.682	0.145	0.979	0.876	0.554	0.513	0.194	0.874
	Residency	0.441	0.289	0.684	0.733	0.866	0.101	0.391	0.230	0.699	0.176
	Family type	0.980	0.596	0.962	0.153	0.792	0.866	0.408	0.500	0.255	0.960
Patient characteristics	Gender	0.270	0.343	0.297	0.729	0.927	0.547	0.835	0.393	0.783	0.924
	Age	0.003	0.015	0.002	0.030	0.016	0.004	0.319	0.005	0.002	0.006
	Diagnosis	0.369	0.101	0.169	0.923	0.231	0.653	0.325	0.029	0.846	0.719
	Etiology	0.003	0.001	0.010	0.001	0.184	0.007	0.011	0.001	0.137	<0.001
	treatment	0.614	0.223	0.369	0.835	0.901	0.967	0.645	0.561	0.982	1.00

Table 3a. Overview of correlations between FQOL domains and family and patient characteristics

		Importance	Opportunities	Initiative	Attainment	Stability	Satisfaction
Family characteristics	Gender	0.596	0.737	0.321	0.136	0.621	0.195
	Age	0.924	0.542	0.363	0.922	0.966	0.519
	Residency	0.587	0.259	0.519	0.611	0.326	0.474
	Family type	0.683	0.755	0.810	0.810	0.674	0.700
Patient characteristics	Gender	0.890	0.891	0.447	0.246	0.705	0.488
	Age	0.005	0.008	0.036	0.003	0.010	0.004
	Diagnosis	0.079	0.910	0.827	0.273	0.098	0.040
	Etiology	0.003	0.039	0.001	0.001	0.005	0.002
	Treatment	0.983	0.772	0.836	0.216	0.403	0.755

Table 3b. Overview of correlations between FQOL dimensions and family and patient characteristics



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disease and long-term care. Concerning the mean FQOL dimensions scores, Importance was rated highest, with a remarkable rate beside the second highest, which was Opportunities (mean score 4.11 versus 3.61). This suggests that families of patients with CLD understand which are the key elements to attaining quality of life and admit the importance of the domains which make up QoL. In addition to this, Opportunities and Initiative were also rated high among other dimensions, which demonstrate that families are willing to make effort to improve some areas in life and that they see the current situation as in full career.

The moderate Satisfaction score (3.56) suggests that there was no domain in which families were satisfied to a high degree and that there is need for additional services in order to achieve a greater score for Satisfaction in most areas of family life. Also, this finding is similar to Cummins' finding in 2001, indicating that the "gold standard" for QoL is a maximum satisfaction index of 75%⁽¹³⁾.

Stability was rated lowest among all dimensions (3.09). This indicator measures perceived change over time, rather than the current situation, like the other dimensions. Questions of the survey referring to Stability include the phrase "in the near future", which suggest that families of patients with CLD have low expectations regarding the

improvement of QoL among time. This fact is in contrast with the high rates achieved by Opportunities and Initiative, which may indicate that families are willing to make an effort but there is a lack of confidence regarding the success of these efforts in the near future or that they are hindered by various obstacles in achieving a higher quality of life.

We found significant positive correlations between the age of the patient and FQOL, with the exception of the Values domain. Therefore, younger patients scored lower rates of FQOL domains. Also, the same significant correlation was obtained between the alcohol-related liver disease and most of FQOL domains, except from Support from other people and Leisure and Recreation activities. Previous studies (Nguyen et al. 2015) have demonstrated that alcoholic cirrhosis led to increased caregiver burden compared to other causes of cirrhosis, which is similar to our findings⁽¹⁴⁾.

In addition to this, the strongest statistically significant correlation ($p < 0.001$) was found between the alcoholic etiology of CLD and the Community domain. This finding suggests that individuals known for heavy alcohol consumption are not well seen in their community and they might be rejected by people around them because of this reason. Moreover, this domain also takes into consideration not only the individual's

connection with people or places around, but also the family as a whole community interaction, which appears to be negatively influenced by the drinking habit of one of its members.

The presence of the chronic liver disease in the family statistically correlates with the caregiver's Career domain. Thus, the families of patients with liver cirrhosis and hepatocellular carcinoma scored the lowest rates in Career domain of FQOL. This fact could be explained by the larger amount of time needed by the caregiver to support the patient with CLD, as it requires more assistance, follow-up visits and emotional and, in some cases physical support from the family. Moreover, another explanation could be that the poorer long-term prognosis of cirrhosis and liver cancer determines higher levels of anxiety and distress for the patient's family. In the same direction, mean scores of Satisfaction in the caregivers were rated the lowest among other FQOL dimensions for patients with liver cirrhosis, as there is a significantly statistic correlation between the Satisfaction dimension and patient's diagnosis, found in our study.

Limitations

The results of the current study must be interpreted with caution in light of a few limitations. First, the respondent population was small and comprised of people who volunteered, which may have biased the data. The relatively small sample size had clearly affected our ability to examine different subgroups of families in a more intense manner, for example according to the liver disease severity. The size of the sample could be explained by the challenges we encountered in having some of the families complete the FQOL Survey, given

the amount of time needed to complete this action (approximately one hour per filling).

Conclusions

This study contributed to advancing the FQOLS-2006 as a useful tool in examining FQOL among families with a member who has CLD, as in the present there is no specific tool for that. Determining the individual quality of life for a patient with liver disease tends not to be enough for a thorough evaluation of QoL. Families play a very important role in the patient's life. Clearly, many aspects that are important to individual well-being are also important to the family system. In order to determine that, it is necessary to compare perceptions between different family members because some domains might be achieved at the individual level and not at the family lever or vice versa.

Also, the findings point to the usefulness of examining both life domains and dimensions in the process of studying FQOL. Correlations between these indicators need to be done for a deeper understanding of their meanings and interrelationships. FQOL is mediated by both patient and family factors that should be given into consideration when developing a treatment and follow-up plan for patients with CLD. These types of studies can be of great value in the process of resource allocation for policy makers and service providers in our country

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