International Journal of Science and Research (IJSR)
ISSN (Online): 2319-7064
Index Copernicus Value (2013): 6.14 | Impact Factor (2013): 4.438

Living with Cystic Fibrosis

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Abstract: ***Introduction**: Cystic fibrosis (CF) is a life-threatening, genetic disease that mostly damages the lungs and digestive system. It's a complex condition, with individual forms and severity of the symptoms. Various factors like age of diagnosis, number, type and control of infections, treatment options, comorbid conditions, etc. can affect individual's health, course of the disease and quality of life. Many CF patients will grow into adulthood, so quality of life is very important for the overall health and everyday living. **Aim of the study**: To screen the quality of life in CF patients in Republic of Macedonia. **Subjects and methods**: In the study we have enrolled67 CF patients. We have created questioners specially designed for this purpose, with questions related to their everyday living with CF. **Results**: Overall, majority of the patients with CF live normal life, have common and frequent social interactions, emotionally are stable but still the fear from the stigma in the society is present. **Conclusion**: despite the obstacles CF patients must overcome in the everyday life, they still can have full and meaningful lives, regardless of the severity of their condition.*

Keywords: cystic fibrosis, chronic illness, quality of life

1. Introduction

Cystic fibrosis (CF) is a complex, life-threatening, genetic and progressive disease that affects major organs in the body like respiratory and digestive systems and reproductive organs too. The treatment is life-long and includes special regime of everyday living, intake of various medications and increased calorie intake. Those treatments and way of living are complex, require serious amount of time each day as long as the patient is alive and often can cause difficulties for the families and patients. CF can be presented with the periods of worsening, stabilization and noticeable improvement. The impact that this disease, as any other chronic disease, has on the quality of life should be assessed periodically and monitored by the multidisciplinary team of professionals. The demand is even higher when CF is not properly controlled. Such conditions can lead to incapacity and limit the quality of life. It is now very well known that CF, like any other chronic diseases, has important psychological implications. The way in which the family and the patient come to terms with the disease and its treatment, will have a critical effect on the patient's survival and quality of life.

In the last several decades life expectancy for CF patients has increased dramatically due to earlier diagnosis and more advanced treatments. In the past, CF patients had much shorter life expectancy but in present time majority of them will reach adulthood [1].

Living with CF may cause fear, anxiety, depression and stress. Although CF requires daily care, most people who have the disease are able to attend school or work, have normal social and emotional life.

2. Aim of the Study

To screen the quality of life in CF patients in Republic of Macedonia.

3. Subjects and Methods

The study was conducted at the Cystic fibrosis center, University children's hospital in Skopje, Macedonia. A total of 67 CF patients from 7-32 years old were enrolled in the study. We have divided the subjects in two age groups-up to 14 and above 14 years of age. For each group we have created specially designed questioners. Questions were addressing demographic data, personal life, self-perception, daily CF treatments, interpersonal relations, economical status etc. Qualitative data from the questioners was analyzed.

4. Results

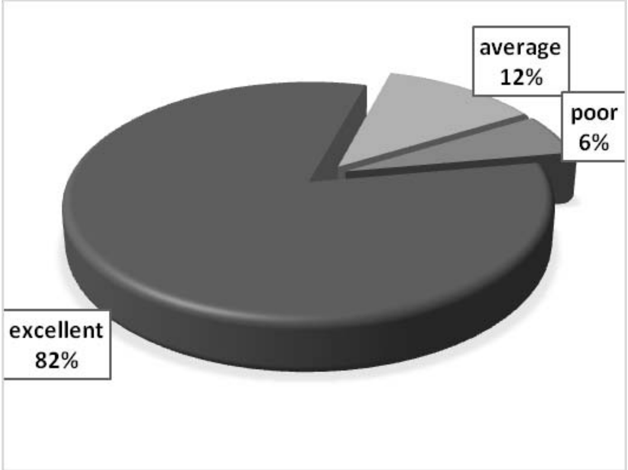
4.1 Results of the CF patients up to 14 years of age

In this group of CF patients we had 20 male and 9 female subjects, with mean age 9.3±3.14 for the girls and 8.89±4.76 (Table no. 1).

Table 1: Gender distribution and age in CF patients up to 14 years of age

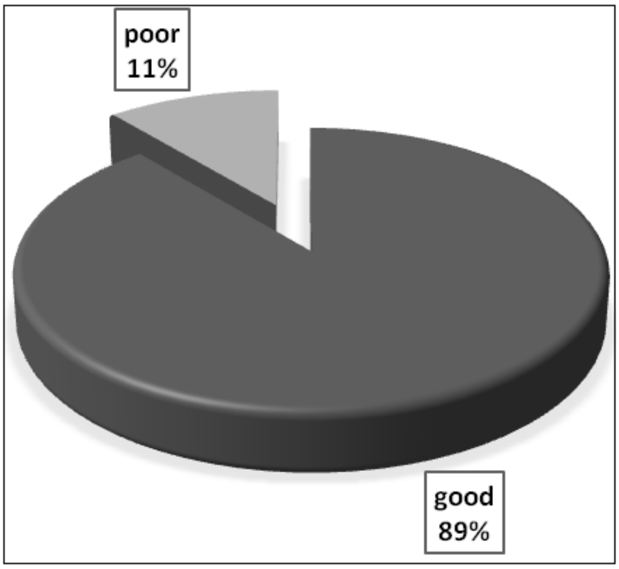
	Males	*Females*
No	20	9
Age	9.3±3.14	8.89±4.76

Concerning the overall health and body strength, in 82% of the cases, patients have stated that they feel in excellent health and level of energy, in 12.2% in average and in 5.8% in poor condition (Pie no. 1).



Pie no. 1: Self-stated condition of health and energy level

In 88.96% patients stated that most of the time, they feel happy, with good appetite, quality of sleep and level of physical activities. Only 11.04% stated that experience some problems concerning this issues (Pie no. 2).



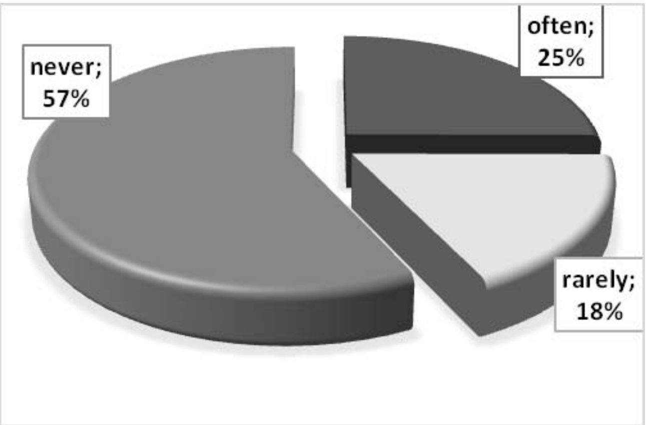
Pie no. 2: Self-stated condition on happiness, appetite, sleep and physical activities

In 78.57% CF patients stated that they are not feeling physically different in comparison with their peers and in 21.43% they do. In 89.65% they like to play with their peers, in 6.89% only sometimes and in 3.46% don't want to play with them. The frequency of socializing with friend is in 78.57% daily, in 10.7% every other day, in 3.55% twice per week and in 7.18% even rarely (Table no.2).

Table 2: Self-perception among the peers, desire and frequency of play

	Physically different		Desire to play with peers			Frequency of play			
	no	*yes*	*yes*	*sometimes*	*no*	*daily*	*Every two days*	*Twice per week*	*rare*
%	78.57	21.43	89.65	6.89	3.46	78.57	10.7	3.55	7.18

About sharingtheir health issues, in 25.1% patients with CF talk with their friends about the condition they have and the treatments they conduct everyday, in 17.85% rarely and even in 57.05% they never do (Pie no. 3).



Pie no. 3: Sharing with peers experiences about the health condition and treatment

However, the level of comfort to take pills in front of the peers is changing for the better. In 56% they don't hesitate to take the pills, in 40% only sometimes and just 4% very often. In family settings, majority of the children89.28%) don't hesitate to discuss about their illness or perform the daily therapy. Only 5.34% often have problems to discuss and perform it and5.38% always have difficulties.

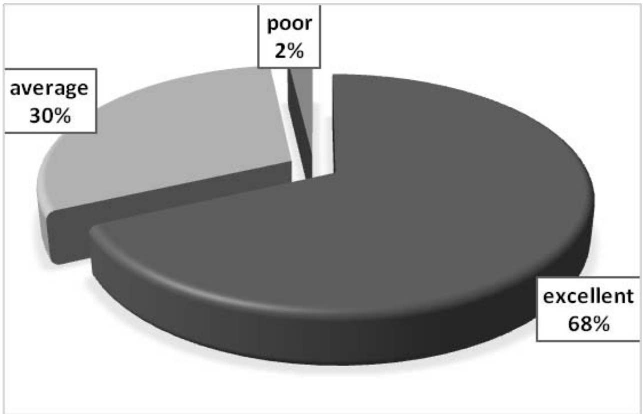
4.2 Results of the CF patients above 14 years of age

In this group of CF patients we had 22 male and 16female subjects, with mean age 19.62±5.98 for the girls and 19.72±9.88for the boys (Table no. 3).

Table 3: Gender distribution and age in CF patients up to 14 years of age

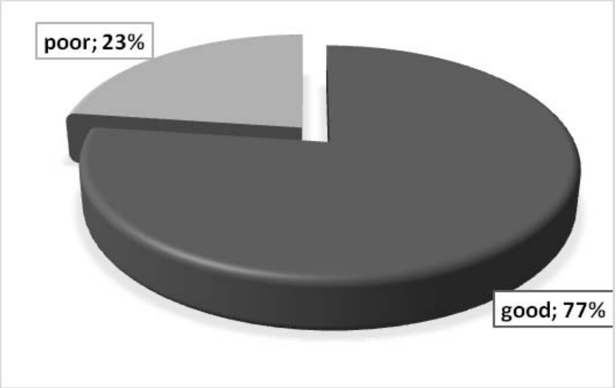
	males	**females**
No	22	16
Age	19.72±9.88	19.62±5.98

Concerning the overall health and body strength, in 68.04% of the cases patients stated that they feel they are in excellent health and with a good level of energy, in30.12% in average and in 1.84% in poor condition (Pie no. 4).



Pie no. 4: Self-stated condition of health and energy level

In 77.16% patients stated that they are feeling happy, with good appetite and physical activities. Only 22.84% stated that experience some problems concerning this issues (Pie no. 5).



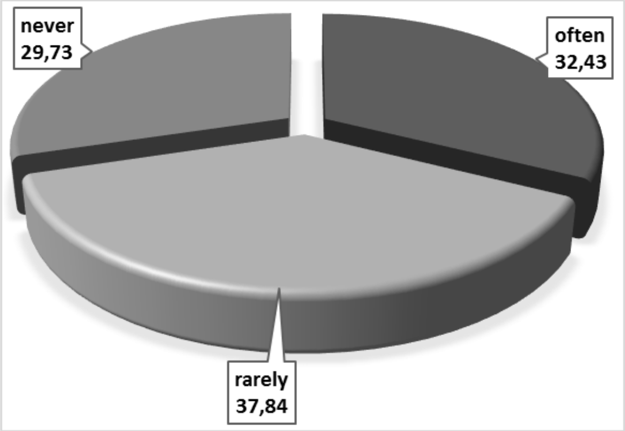
Pie no. 5: Self-stated condition on happiness, appetite and physical activities

It's interesting that in much higher percentage, this group of CF patients feel different from their peers than the younger ones (56.76% versus 43.24%). 86.84% like to interact with their peers, 7.89% only sometimes and 5.27% rarely do it. The frequency of socializing with friend is 71.05% daily, 10.53% every other day, 7.89% twice per week and 10.53% even rarely (Table no. 4).

Table 4: Self-perception among the peers, desire and frequency of interaction

	Physically different		Interaction with peers			Frequency of interaction			
	no	*yes*	*yes*	*sometimes*	*rarely*	*daily*	*every other day*	*Twice per week*	*rare*
%	43.24	56.76	89.84	7.89	5.27	71.05	10.53	7.89	10.53

Concerning sharing experiences of health issues with others, 32.43% patients with CF talk with their friends about the condition they have and the treatment they conduct every day, 37.84% rarely and 29.73% they never share (Pie no. 6).



Pie no. 6: Sharing with peers about the health condition and treatment

Again, the level of comfort to take pills in front of the friends is satisfying. 50% don't hesitate to take the pills, 26.31% only sometimes and 23.69% very often. In family settings most of the patients (85.15%) don't hesitate to discuss about the illness or perform the daily therapy. Only 13.1% often have problems to discuss and perform it and in 1.75% always have difficulties. Concerning the effect that illness has on everyday living, 35.13% have been declared no negative effect on daily functioning, 29.73% said it does affect a bit, 24.32% moderate impact and 10.82% severe effects onto their daily life.

5. Conclusion

Generally, chronic illnesses are slowly progressing and lasting in long periods. All chronic illnesses are potentially limiting the level of functionality, productivity and overall quality of life of the patients. Chronic illnesses might change the way of living, the way of seeing and experiencing ourselves and relate to others.

Despite the obstacles chronic patients must overcome in the everyday life, they still can have full and meaningful lives, regardless of the severity of their condition.

Regardless of the problems CF patients in Republic of Macedonia have to face daily, in the end they experience to have productive lives. But still the fear from the stigma in the society is present and makes them less open to share experiences and to talk about their condition.

References

[1] Cystic Fibrosis Foundation (2002). Patient Registry 2001 Annual Report. Bethesda, MD: Author.