

QUALITY OF LIFE AND SELF-EFFICACY AMONG PARENTS OF CHILDREN AFTER TRANSPLANTATION: A PILOT STUDY

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A – study design, B – data collection, C – statistical analysis, D – interpretation of data, E – manuscript preparation, F – literature review, G – sourcing of funding

ABSTRACT

Background: Organ transplantation often proves to be the only way to save a young patient's life. However, it is associated with a long-term stay in the hospital and the need to change the lifestyle of not only the patients but also their entire family. This largely affects the child's family situation as well as the relationships between their relatives. Therefore, it is important to determine the factors that have the greatest impact on the quality of life (QoL) of the parents after transplantation and their self-efficacy assessment. This will facilitate providing parents in need with help and showing them support.

Aim of the study: This research aimed to assess the QoL and self-efficacy among parents of children after organ transplantation, as well as the correlation between QoL and self-efficacy.

Material and methods: The study was conducted using a shortened version of the Quality of Life Questionnaire (WHOQOL BREF), the Satisfaction with Life Scale (SWLS), and the General Self-Efficacy Scale (GSES), as well as a self-designed questionnaire. The research group consisted of 54 people, of which 49 questionnaires were subject to statistical analysis.

Results: The sten score for the level of satisfaction with life in the research group was 5.88. QoL in the physical and mental domains was on average (M=12.93 and M=13.04, respectively), and in the social and environmental domains (M=16.40 and M=15.09, respectively). The sten score for the level of self-efficacy assessed by the respondents was 7.09. A relationship between the level of perceived self-efficacy and QoL was observed.

Conclusions: This study indicates an average level of satisfaction with life, average to high results in terms of QoL, and a fairly high level of self-efficacy, which had an impact on the QoL of parents of children after transplantation.

KEYWORDS: organ transplantation, quality of life, self-efficacy, parents

BACKGROUND

Organ transplants, which are often the only treatment for organ failure, have been considered almost routine for several years now. The survival statistics of patients after transplantation are currently very satisfactory, with the 5-year survival rate being

80% [1]. Transplantation is not, however, a definitive treatment, but an ongoing chronic disease process [2]. This is associated with the need to use daily immunosuppression [3,4], the fear of transplant rejection [5], and the possible occurrence of complications [6,7,8,9]. A long-term illness, a prolonged stay with the child in the hospital, and stress related to

the surgery can affect family relations, both between the patient and their parents, as well as among other family members. It is estimated that it may take up to 5 years for parents to adapt to the new situation that is their child's illness. The illness also affects the development of the child. Frequent and long-term stays in the hospital may lead to a deterioration in the child's school performance and intellectual level, reduced physical fitness, worse self-perception, uncertainty, and internal inhibitions [10]. The disease limits the child's mental and social activities.

Studies indicate a reduced quality of life for parents of children with chronic diseases [11,12,13]. It is assumed that quality of life is a multidimensional concept [14] concerning a number of important aspects of human life, including health [15]. It involves functioning in physical, mental, and social areas, which can be affected by the illness or the treatment, or both. Quality of life can be assessed either objectively or subjectively, and various factors should be taken into account in this assessment [14].

The concept of self-efficacy is defined as the level of self-esteem and respect for one's own competence in the face of life challenges [16]. It allows a person to accurately assess the situation in looking for the right ways to deal with possible life adversities [17]. People who show a higher sense of self-efficacy are more motivated to act, which translates into better results in their activities as well as self-development [16]. Such people may have relatively stable emotions despite the pressure [18]. People with low self-efficacy, in turn, more often feel helpless in difficult life situations [16]. In addition, self-efficacy allows a person to assess their own involvement and degree of perseverance in pursuing a goal [16], and to increase their concentration and self-control [19,20].

Therefore, it is important to determine the factors that have the greatest impact on the quality of life of the parents of children after transplantation and their self-efficacy assessment. These problems should not be ignored in the therapeutic process of a young patient. It will then be possible to provide parents in need with help and support.

AIM OF THE STUDY

This research aimed to assess the quality of life and self-efficacy among parents of children after organ transplantation, as well as the correlation between the quality of life and self-efficacy.

MATERIAL AND METHODS

Study design and setting

This was a cross-sectional observational study, carried out at the Children's Memorial Health Institute,

in the General Surgery and Organ Transplantation Clinic, at the Organ Transplantation Department, where kidney and liver transplants are performed in children.

Participants

Fifty-four people were asked to participate in the study, of which 4 refused to participate after reading the questions, and one failed to complete the questionnaire in full. Ultimately, 49 parents of children after kidney and liver transplantation participated in the study. Due to the epidemic situation prevailing during the study and the related ban on visits, reaching a larger number of respondents proved difficult. Throughout the study period, only one guardian was allowed to stay with each child. In addition, carrying out this type of study directly at the Organ Transplantation Department is associated with a limited possibility of reaching respondents due to the number of transplants performed.

Data sources

The consent of the Deputy Director for Nursing, the Head of the Clinic, and the Ward Nurse was obtained for the study. The research was conducted from October 2021 to April 2022. Before completing the questionnaire, the respondents were informed about the purpose of the study and asked for their consent to participate in it. They were further informed that the collected data is confidential and will be used for scientific purposes only. Participation in the study was voluntary, conscious, and anonymous. Each participant could withdraw from the study at any time without giving a reason.

Measurement

The survey questionnaire consisted of 4 parts:

The first part of the study was an original questionnaire containing questions about socio-demographic details such as age, gender, place of residence, level of education, marital status, professional and social status, partner support, and number of children. Questions regarding the communication of the respondents with the medical staff and the psychological help received were also included.

The second part was a shortened version of the World Health Organization Quality of Life (WHOQOL BREF) [21] in the Polish adaptation by Wołowicka & Jaracz [22]. The questionnaire was designed to assess the quality of life of both healthy and sick people. It consists of 26 questions concerning four domains of life such as physical (DOM₁), mental (DOM₂), social (DOM₃), and environmental (DOM₄). In addition, the WHOQOL-BREF contains two questions that are an-

alyzed separately. Question 1, is the individual's general perception of the quality of life, and question 2, is the individual's general perception of their own health. The scores ranged from 1 to 5 points. A maximum of 20 points could be obtained in each domain. The higher the score, the higher the quality of life. The areas assessed by respondents included everyday life activities, ability to work, self-esteem, spirituality, social support, financial resources, healthcare, transportation, etc.

The third part of the questionnaire was the Satisfaction With Life Scale (SWLS) by Diener et al. [23] in the Polish adaptation by Juczyński [24]. This is a short method that consists of 5 statements. Subjects are asked to respond to each of the given statements by selecting an answer from "strongly disagree" (1 point) to "strongly agree" (7 points). The total SWLS score ranges from 5 to 35 points, with higher scores reflecting greater satisfaction with life. Then, the scores were converted into a standardized sten scale. The interpretation of the results is as follows: 1–4 sten scores are low, 5–6 sten scores are average, and 7–10 sten scores are high [25]. The Cronbach's *alpha* SWLS reliability index was established in a study of 371 people and turned out to be satisfactory (0.81). For the original version, the reliability index (Cronbach's *alpha*) is 0.87.

The fourth part of the questionnaire concerns the sense of self-efficacy of the parents of children after transplantation. The Generalized Self-Efficacy Scale (GSES) by Schwarzer & Jerusalem [26] in the Polish adaptation by Juczyński [27] was used. It is a 10-question research tool that enables the measurement of the subjective feeling of self-efficacy when encountering various difficult situations. There were 4 answers to choose from for each question. They were scored as follows: 1 point – "Not at all true", 2 points – "Hardly true", 3 points – "Moderately true", and 4 points – "Exactly true". The numerical values were added together to give an overall score ranging from 10 to 40 points. After summing up all the points, a self-efficacy score was obtained. The higher the number of points the respondent receives, the higher the self-efficacy index. The raw scores are then converted into standardized sten norms. The interpretation of the results is as follows: 1-4 sten scores are low, 5-6 sten scores are average, and 7-10 sten scores are high. The coefficients of correlation of individual statements with the overall score were high and ranged from 0.47 to 0.63, while the average Cronbach's *alpha* coefficient was 0.85. The reliability of the scale assessed in a group of 85 people using the test-retest method (after 5 weeks) was 0.78 [16].

Ethics

This study was approved by the Bioethics Committee at the Medical University of Warsaw, with the

number AKBE /190/2021. Furthermore, the consent of the Deputy Director for Nursing, the Head of the Clinic, and the Ward Nurse were obtained. All eligible participants were informed about the objectives of the study. They were also assured of voluntary participation and confidentiality of the information.

Statistical methods

The normality of the distributions was tested with the Kolmogorov-Smirnov test. The hypotheses were verified using the Mann-Whitney U test and Spearman's rho correlation coefficient. The results were considered statistically significant when the value of the calculated test probability met the condition of a p -value ≤ 0.05 . Calculations were made using the Statistica 10.0 software by StatSoft Polska.

RESULTS

Characteristics of the study group

Women constituted 81.63% of the research group and men constituted 18.6%. Most of the respondents (44.9%) were aged 30–39 and came from large cities with 31,000 to 300,000 inhabitants (38.8%). Secondary and higher education was completed by 46.9% of participants. Most (63.3%) were professionally active and 91.8% of the respondents were in a relationship. They typically had one or two children (44.9% and 42.9%, respectively). The vast majority of the respondents could count on their partner's support (91.8%), which is consistent with the number of people being in a relationship. They mainly assessed their communication with the medical staff as very good (42.6%), and 83.7% declared that they could count on the staff's support. Only 20.8% of the research subjects used the help of a psychologist (Table 1).

Table 1. Socio-demographic characteristics of the research group

Participants	n	%
Sex		
Female	40	81.63
Male	9	18.6
Age		
20-29 years old	7	14.2
30-39 years old	22	44.9
40-49 years old	19	38.9
More than 50 years	1	2.0
Place of residence		
Village	14	28.6
City with up to 30,000 inhabitants	3	6.1

Participants	n	%
City with 31,000 to 300,000 inhabitants	19	38.8
City with more than 300,000 inhabitants	13	26.5
Education		
Elementary	0	0.0
Vocational	3	6.1
Secondary	23	46.9
Higher	23	46.9
Professional status		
Professional work	31	63.3
Care/leave	18	36.7
Marital status		
In a relationship	45	91.8
Single	4	8.2
Number of children		
One child	22	44.9
Two children	22	42.9
Three children	4	8.2
Four/five children	1	2.0
Partner support		
Yes	41	84.6
No	8	15.4
Communication with medical staff		
Excellent	4	8.5
Very good	21	42.6
Good	14	27.7
Rather good	10	21.4
Poor	0	0.0
Medical staff support		
Full support	41	83.7
Partial support	8	16.3
Using the help of a psychologist		
Yes	10	20.8
No	39	79.2

MAIN RESULTS

The sten score for the level of satisfaction with life measured on the SWLS scale was 5.88, which indicates an average level of satisfaction with life. In the case of the measurement according to the WHOQL BREF, a different level of quality of life was observed, depending on the domain. In the physical and mental domains, the score describing the quality of life is slightly above the average maximum value ($M=12.93$, $SD=1.65$ and $M=13.04$, $SD=1.52$, respectively), whereas for the social and environmental domains, the scores were close to the maximum value ($M=16.40$, $SD=2.26$ and $M=15.09$, $SD=2.11$, respectively). According to the GSES scale, the participants obtained a sten score of 7.09, which indicates high values in terms of self-efficacy (Table 2).

A statistically significant difference was observed between the size of the place of residence ($\rho=-0.3$, $p=0.04$) and education ($\rho=-0.33$, $p=0.021$) versus the quality of life at the social level (DOM_3), indicating a lower quality of life among people from larger cities and with higher education. The number of children turned out to be significantly related to the SWLS scale, respondents with more children had a higher satisfaction with life ($\rho=0.397$, $p=0.007$). Higher results in terms of satisfaction with life (SWLS) and self-efficacy (GSES) were obtained among professionally active people ($Z=111.5$, $p=0.047$). A relationship was also observed between the support of medical staff and the quality of life in the mental domain – DOM_2 ($Z=72.5$, $p=0.013$, Table 3).

A statistically significant positive relationship was found between self-efficacy (GSES) versus satisfaction with life (SWLS) and three out of the four domains of quality of life (WHOQOL BREF). The higher the self-efficacy among the respondents, the higher

Table 2. Descriptive statistics according to the scales: SWLS; WHOQOL BREF (DOM_1 , DOM_2 , DOM_3 , DOM_4); GSES

Parameter	M	SD	Me	Mo	Min.	Max.
SWLS						
SWLS	21.76	5.80	21.00	20.00	8.00	34.00
SWLS _{sten}	5.88	2.01	6.00	5.00	1.00	10.00
WHOQOL BREF						
DOM_1	12.93	1.65	13.14	12.00	8.00	16.00
DOM_2	13.04	1.52	12.80	12.00	10.40	18.40
DOM_3	16.40	2.26	16.00	17.33	9.33	20.00
DOM_4	15.09	2.11	15.00	14.50	10.00	19.50
GSES						
GSES	31.43	4.15	31.00	30.00	22.00	40.00
GSES _{sten}	7.09	1.57	7.00	7.00	4.00	10.00

M – mean; SD – standard deviation; Me – Median; Mo – mode; Min. – minimum; Max. – maximum.

Table 3. SWLS, WHOQOL BREF, GSES scores vs socio-demographic variables

Parameter		SWLS	WHOQOL BREF				GSES
			DOM ₁	DOM ₂	DOM ₃	DOM ₄	
Age	Spearman's rho	-0.131	0.126	-0.072	-0.146	0.029	0.112
	p	0.390	0.388	0.621	0.318	0.846	0.459
Place of residence	Spearman's rho	-0.161	0.073	-0.128	-0.303	-0.049	-0.055
	p	0.303	0.629	0.396	0.040	0.745	0.721
Education	Spearman's rho	-0.217	0.168	0.002	-0.330	-0.075	-0.086
	p	0.152	0.249	0.992	0.021	0.610	0.569
Number of children	Spearman's rho	0.397	0.117	-0.092	0.153	0.244	0.016
	p	0.007	0.423	0.530	0.294	0.091	0.917
Sex	Z	100.5	132.0	106.0	173.0	162.0	107.5
	p	0.308	0.211	0.050	0.854	0.641	0.051
Professional status	Z	111.5	156.5	188.0	158.0	158.0	111.5
	p	0.047	0.292	0.845	0.307	0.315	0.047
Partner support	Z	72.5	69.5	83.5	98.5	75.0	72.5
	p	0.818	0.239	0.492	0.886	0.330	0.820
Medical staff support	Z	123.0	92.5	72.5	116.5	128.5	93.5
	p	0.522	0.059	0.013	0.220	0.382	0.061
Using the help of a psychologist	Z	122.5	164.0	152.5	188.0	175.5	145.0
	p	0.182	0.327	0.223	0.698	0.491	0.627

Spearman's rho – Spearman correlation; Z – Mann-Whitney U test; p – statistical significance.

the intensity of life satisfaction ($\rho=0.48$, $p=0.001$), quality of life at the somatic ($\rho=0.53$, $p<0.001$), so-

cial ($\rho=0.48$, $p=0.001$), and environmental ($\rho=0.45$, $p=0.001$) levels (Table 4).

Table 4. Correlation between self-efficacy versus satisfaction with life and quality of life

Parameter		SWLS	WHOQOL BREF			
			DOM ₁	DOM ₂	DOM ₃	DOM ₄
GSES	Spearman's rho	0.476	0.529	0.116	0.479	0.454
	p	0.001	<0.001	0.437	0.001	0.001

Spearman's rho – Spearman correlation; p – statistical significance.

DISCUSSION

Key results

In this study, the quality of life and self-efficacy among parents of children after organ transplantation, as well as the correlation between the quality of life and self-efficacy, were assessed. In the entire research group, the average sten score of satisfaction with life according to the SWLS questionnaire was 5.88. Slightly higher results were obtained according to individual domains of the WHOQOL BREF questionnaire, at the borderline between average and high results. With the GSES scale, the sten score was 7.09, indicating a fairly high sense of self-efficacy. In addition, a statistically significant positive correlation

was found between the quality of life and self-efficacy.

Generalizability

There are not many studies evaluating the quality of life of parents of children after transplantation in the literature. To the best of the authors' knowledge, this topic has not yet appeared in the Polish-language literature. The topics discussed so far concerned the quality of life of parents or carers of children with other diseases or the well-being of the patients themselves [28,29,30]. However, parents of transplanted children struggle with a number of issues related to both the disease and the care of the child and some-

times have to give up their professional work for this reason. Meanwhile, the well-being of parents can be a key factor in improving the well-being of the child [11].

The fact that the results obtained in our study in terms of the quality of life of parents of children after transplantation were rather satisfactory is not quite consistent with the results obtained by Kikuchi et al., who indicated low values of quality of life in parents and family functioning after organ transplantation in their children. The authors also emphasized the need to support parents and family both before and after transplantation, as well as in the long term [31]. In another study, conducted by Manificat et al., mothers had a reduced quality of life resulting from the child's illness and the need for psychological support [11]. Duvant et al., in turn, noted higher quality of life indicators among parents of children after transplantation compared to children suffering from other chronic diseases [2]. Denny et al. found that impaired family functioning is directly related to a decrease in the quality of life [32].

The discovery in our study was an above-average result in terms of self-efficacy demonstrated by the subjects. In our opinion, high self-efficacy enhances the perceived quality of life. Similar results were obtained by Adamus et al., who studied this indicator among mothers of children with cerebral palsy [33]. Studies by Sałacińska also indicated a higher sense of self-efficacy among parents of chronically ill children [34]. Dąbrowska claims that a high level of self-efficacy is related to the determination of mothers to pursue the goal of ensuring the best possible development of their children [35]. It is noteworthy that the extraordinary circumstances in which they find themselves strongly motivate them to seek appropriate treatment for their children. This psychological mechanism is also observed in other aspects of life, parents generally show great determination to ensure the safety and health of their families. This applies equally to the financial, legal, social, and health spheres.

Another important factor determining the quality of life of the respondents was the declared good communication with and support received from the medical staff. In the WHOQOL BREF scale, respondents achieved the highest scores in the social and environmental domains ($M=16.40$ and $M=15.09$, respectively). According to Grochans et al., one of the main factors affecting the quality of life is the effectiveness of the support that those in need receive [36]. Furthermore, a study by Rachel et al. demonstrated that the lack of institutional and social support reduces the quality of life of carers [37]. With our study, a surprising result was the low impact of psychological help on perceived quality of life and self-efficacy, although psychologists are usually part

of the treatment team. This may be due to the fact that only a few of the research subjects reported a significantly low quality of life and required therapy.

In our study, professionally active respondents showed a higher level of quality of life compared to those who declared being full-time carers of their child or on leave. In addition, the people who cared for their child rather than being professionally active were women, i.e., they were more exposed to stress and inconveniences resulting from staying with their child in the hospital or from participating in medical procedures. These results were confirmed by the research conducted by Repka et al., which showed that fathers declared a lower level of fatigue in everyday life and a higher level of satisfaction with life [28]. The same research confirms that working caregivers report less fatigue than those caring for a sick child. This may be due to the fact that fathers spend more time away from home, while mothers devote their time to caring for a sick child. Furthermore, job satisfaction may be an additional factor in improving the quality of life [28]. An important factor influencing the declared quality of life was also the number of children. Our research has shown that parents with only one child report a lower quality of life measured by the SWLS form than parents with more than one child. This may be due to the fact that their thoughts and actions are not focused exclusively on the sick child, but also their other, healthy children. In addition, after reaching the appropriate age, siblings often take over some of the responsibilities related to caring for a sick family member, which relieves the parents mentally and physically.

Limitations of the study

The results of our research should be considered from the point of view of certain limitations, mainly due to the small sample size of the study and the limitation of the study to one center, but also a small number of reports evaluating the aspects we studied, which made it difficult to compare the results with those obtained by other authors. Due to the epidemic situation during the study and the related ban on visits, reaching a larger number of respondents proved difficult. Throughout the study period, only one guardian was allowed to stay with each child. In addition, carrying out this type of study directly at the Organ Transplantation Department is associated with a limited possibility of reaching respondents due to the number of transplants performed. Despite its limitations, this study highlights the importance of support and self-efficacy in terms of quality of life. Thus, it may serve as an indication for medical staff in the area of determining solutions to support parents of children after transplantation.

CONCLUSIONS

The study indicates an average level of satisfaction with life, average to high results in terms of quality of life, and a fairly high level of self-efficacy, which had

an impact on the quality of life of parents of children after transplantation. Research should be continued and extended to other centers to provide further information.

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