

Life's quality of chronically dialyzed children in Poland

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ABSTRACT

Introduction: The paper presents the possibility of assessing the quality of life (QOL) of children on dialysis.

Purpose: To evaluate the QOL depending on the health status of children on dialysis, to compare the subjective assessment of the QOL and to identify some of the factors independently affecting the QOL.

Materials and methods: The study has been conducted on a group of 28 children on dialysis. Research tools: Poland abbreviated version of the survey assessing the quality of life of The World Health Organization Quality of Life (WHOQOL); survey constructed on the basis of the Polish version of Kidney Disease and Quality of Life™ Short Form (KDQOL-SFTM) Version 1.2 and a questionnaire assessing QOL of children and adolescents with end-stage renal disease on dialysis

and transplantation of kidneys by Rubik, Grenda, Jakubowska - Winecka and Dabrowska.

Results: There were no significant differences in QOL between children treated with peritoneal dialysis and Hemodialysis (HD). While there is a strong correlation between the severity of depressive symptoms and the treatment's duration, financial status and parents' education.

Conclusions: The phenomenon of reduced QOL must be counteracted. Medical pediatric staff of dialyze centers should especially pay attention to the problem of life's quality, due to the intensity of disease's impact on growing organism, should actively counteract the phenomena of its decrease by continuous therapeutic education of patient and his or her family.

Key words: Sick children, quality of life, renal replacement therapy

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INTRODUCTION

There has been much development in renal replacement treatment in Poland, during recent years. Still when dialysis treatment starts, family, economical and professional situation of the patient and his or her family often diametrically change. It is especially prominent when it is a child that is sick. Necessity of finding itself in new situation bourns problems of socio-psychological nature for all of family members, not only the little patient. Progress in medical sciences enabled an optimization and individualization of dialysis treatment, not only prolonging the life of patients but also determining the quality of their life. The life's quality issue has been treated with wider and more systemized attention from scientists and publicists during last years. Often it is spoken of life's quality in connection with concern for further improvements of living conditions, development and creation of conditions for versatile personality development. Life's quality term [1] appeared in scientific studies in between sixties and seventies, evolving in time. At first it had been understood as a good life in purely consumer sense, later on it has been expanded to include areas of being – which enforced a necessity of introducing new evaluation criteria such as: health, education, freedom etc. Moreover more attention has been put to connection existing between quality of person's life and his or hers kinds and areas of needs. Quality of those needs and degree of their fulfillment have become an essential element of life's quality. Until recently, the exponent of treatment's effectiveness and care for a patient was his or hers lifetime. Prolongation of life was treated as a criteria of improving the level of health care. Survival was treated as an indicator of treatment's effectiveness. In time people noticed that those indicators and criteria were insufficient and unsatisfying. There has been a need for a tool due to which the feelings of the patient could be measured. Measure of life's quality was introduced to measure efficiency of treatment and care, which according to World Health Organization (WHO) is defined as: "complex method of individual's own evaluation of physical health, independence in life and degree of independence from environment, as well as relations with environment and personal beliefs and convictions" [2]. In medicine quality of life is measured with reference to the health of an individual, but both physical and biological domains are taken into consideration. Fatherly WHO's introduction of holistic definition of health in the fifties of XX century, induce to include research also in social and sociological matters. It was then, when non-linear, multi-directional research that did not concentrate on one narrow problem became popular. Those methods tried to find all factors, which mutually overlapping, really

affects comfort of living. All those elements constitute for conditions in which people live [3].

Because of the fact that quality of life's research contribute towards better understanding of holistic human nature, in which the big part is played by subjective evaluation of the patient itself [4], we have decided that the aim of this paper would be an evaluation of life's quality, depending on health of chronically dialyzed children, as well as comparison of its subjective evaluation and identification of some of factors influencing this particular group of patients.

MATERIALS AND METHODS

To measure the quality of life tools are used with an aim of presenting subjective feelings of a patient in a quantitative way. Most often different kinds of questionnaires are used for this purpose [4], in which authors propose group of questions (mostly closed) and few answers to choose for each of them. They are characterized by being easy to compile by statistical methods. Fulfilling following conditions: accuracy, stability, reliability. Those tools can be assigned to two categories: general (evaluating general quality of life; due to that, they can be used for different groups of patients; their construction allows for given trait to be examined in different aspects), and specific (used to examine specific groups of patients, for example: dialyzed people; questions included are often directed on one specific factor). This also happened in this paper, in which diagnostic survey was used as a research method, with questionnaire as a tool. Questionnaire was constructed based on:

- Polish shortened version of the questionnaire evaluating the quality of life [5]: *The World Health Organization Quality Of Life (WHOQOL)*, belonging to the group of general questionnaires;
- Polish version of the questionnaire: *Kidney Disease and Quality of Life™ Short Form (KDQOL-SF™) Version 1.2*, belonging to the group of specific questionnaires [6];
- Questionnaire evaluating quality of life of children and youth with an end-stage renal failure, treated with dialysis and kidney transplantation, created by a team under scientific supervision of doctor Jacek Rubik (rights given by authors).

All statistical analysis of collected research materials were conducted in Microsoft Excel and statistical package Statsoft, Inc. (2010), STATISTICA 9.1. Because examined phenomena are qualitative in nature, in preliminary analysis they were described by numbers and corresponding percentages (percentage distribution of given answers, expressed in absolute numbers – "N" sample size and percentage values). It has been done with an aim of statistically ordering research

material and possibility of using it for qualitative data interpretation. In further statistical analysis chi squared test was used as primary method of log – linear analysis. This analysis was used to find interdependencies for whole examined group. Because for the interpretation of the results, P (probability) is of the biggest importance, $p \leq 0.05$ was used as the significance level. If in the process of analysis obtained p smaller than that, then this value was found statistically irrelevant.

Research was conducted on 31 children from pediatric dialysis centers in two selected city in Poland, characterized by similar circumstances socio-demographic-economic. Research material that was statistically analyzed (completely filled) included 28 survey questionnaires, that were fulfilled with beforehand expression of acceptance of taking part in the research, which constitutes approximately 8% of whole population of dialyzed children in Poland at that time (2011/2012) and is the limitation of the presented research results. This

material is preliminary study for research in the long term time.

Only people with at least two months of former dialysis time prior to the research were qualified to take part in it. Patients were assigned to three groups depending on the method of renal replacement treatment: APD (automated peritoneal dialysis), consisting of 12 people, representing 43% of examined population, CAPD (continuous ambulatory peritoneal dialysis), consisting of 5 people, representing 18% and HD (hemodialysis), consisting of 11 people, representing 39% of examined people, moreover the time of renal replacement treatment was taken into account. Time varied among the group from 2 up to 132 months, with an average of 37.4 months in the entire group. In HD Group, average time of treatment was 46 months, in CAPD group it was 32 months and APD – 31 months. Detailed social and demographical characteristics of the examined group is shown in table 1.

Table 1. Social and demographic characteristics of an examined group

| | Feature | N | % |
|---|---|----------|----------|
| PATIENT'S AGE | 0 – 6 years old | 11 | 39 |
| | 7 – 12 years old | 6 | 21 |
| | 13 – 18 years old | 11 | 39 |
| LIVING PLACE | Big city (>150k. citizens) | 12 | 43 |
| | City (<150k. citizens) | 7 | 25 |
| | Country | 9 | 32 |
| SCHOOL | Primary School | 6 | 21.5 |
| | Junior High School (Gymnasium) | 6 | 21.5 |
| | High School | 3 | 11 |
| | Do not attend any | 13 | 46 |
| RENAL REPLACEMENT TREATMENT'S TIME | 2 – 12 months | 9 | 32 |
| | 13 – 36 months | 12 | 43 |
| | > 36 months | 7 | 25 |
| MATERIAL SITUATION OF THE FAMILY | Revenue per capita < 500 pln | 8 | 29 |
| | Revenue per capita 500 – 1000 pln | 14 | 50 |
| | Revenue per capita 1000 pln | 6 | 21 |
| SOCIAL STATUS OF THE FAMILY | Full family (both parents/legal guardians) | 22 | 79 |
| | Incomplete family (only mother/father/guardian) | 6 | 21 |

RESULTS

Based on acquired research material we have attempted to evaluate quality of life of patients in pediatric dialysis stations where the research was conducted. Comparison of resulting evaluations of life's quality among respondents, depending on the used method tool is presented in the table 2.

To compare results acquired with three different research tools, we have used unified percentage comparative scale, assuming:

- 0 – 15% → very low quality of life
- 16 – 30% → low quality of life

- 31 – 45% → unsatisfactory quality of life
- 46 – 60% → average quality of life
- 61 – 75% → satisfactory quality of life
- 76 – 90% → high quality of life
- 91 – 100% → very high quality of life

Results obtained due to survey questionnaire prepared by doctor Jacek Rubik's team, were slightly worse from those obtained due to two other tools, and at the same time it was a tool prepared and taking into account certain specification of polish population, in further statistical analysis chi squared test (χ^2) was used, to find correlation between chosen variables.

Following variables were chosen: social status, time of treatment, material status, level of education of parents/guardians, treatment method, living place. They were one after another correlated with variables pointed as important by doctor

Rubik's team, such as: physical activity, general health, social functioning, severity of depression's symptoms. 24 interdependencies were analyzed, however 6 of those yielded results statistically significant, which is shown in table 3.

Table 2. Evaluation of quality of life of respondents, depending on the used method

| TOOL USED | | N | % |
|--|--------------------------------|----|------|
| SURVEY QUESTIONNAIRE OF DR. JACEK RUBIK GROUP | Very low quality of life | 0 | 0 |
| | Low quality of life | 2 | 7.1 |
| | Unsatisfactory quality of life | 4 | 14.3 |
| | Average quality of life | 7 | 25.0 |
| | Satisfactory quality of life | 15 | 53.6 |
| | High quality of life | 0 | 0 |
| | Very high quality of life | 0 | 0 |
| QUESTIONNAIRE KDQOL | Very low quality of life | 0 | 0 |
| | Low quality of life | 0 | 0 |
| | Unsatisfactory quality of life | 0 | 0 |
| | Average quality of life | 3 | 10.7 |
| | Satisfactory quality of life | 11 | 39.3 |
| | High quality of life | 13 | 46.4 |
| | Very high quality of life | 1 | 3.6 |
| QUESTIONNAIRE WHOQOL | Very low quality of life | 0 | 0 |
| | Low quality of life | 0 | 0 |
| | Unsatisfactory quality of life | 0 | 0 |
| | Average quality of life | 5 | 17.8 |
| | Satisfactory quality of life | 15 | 53.6 |
| | High quality of life | 8 | 28.6 |
| | Very high quality of life | 0 | 0 |

Table 3. Correlation of chosen variables with a test of chi squared

| No. | ARIABLES | χ | $p \leq 0.05$ |
|-----|--|--------|---------------|
| 1. | Social status Physical activity | 10.18 | 0.037 |
| 2. | Time of treatment Depression's symptoms | 19.99 | 0.010 |
| 3. | Material status Depression's symptoms | 19.33 | 0.013 |
| 4. | Parents' level of education Social functioning | 16.80 | 0.032 |
| 5. | Parents' level of education Depression's symptoms | 19.10 | 0.014 |
| 6. | Treatment's methods Physical activity | 16.08 | 0.041 |

Results submitted in table 3, are the evidence of:

- dialyzed children from full families show substantially higher levels of physical activities than those from incomplete families;
- the longer time of renal replacement treatment, the more severe are the depression's symptoms;
- depression's symptoms became worse, as the material status of the family decreases;
- the higher education level of the dialyzed children's parents/guardians, the lower are the deficits in children's psyche, and therefore fewer symptoms of depression;
- method of treatment and therefore certain restrictions of each one of them condition lower children's physical activity. The fewest restrictions in this area exist in the case of APD treatment, thus it is the one that is evaluated highest by the children treated this way. The lowest results remain for the children treated with CAPD method.

DISCUSSION

Currently evaluation of life's quality is part of full clinical evaluation and plays a special role in the case of patients with chronic diseases, aggravating every area of person's life: physical, psychical, social, emotional, family and professional [7–10]. Child just as every other patient is biopsychological unity, that is why everything that he or she feels and has to go through, have an influence on his or her behavior and functions of organism [11]. According to Sapilak and Steciwko, the most important factors influencing the QOL of dialyzed people include: mood disorders, renal replacement therapy side effects, co morbid conditions, level of support and acceptance from the environment, material conditions and care for dialyzed on wards [12–14]. The research that was conducted concerned the quality of life of patients with CKD, the factors affecting the quality of life are independent of age. When it comes to somatic ailments associated with dialysis, then the research of those two authors indicate that the most commonly expressed are: fluctuations in blood pressure, itching, cramps and muscle pain [12]. Our findings indicate that little patients express also: lack of appetite, nausea and stomach upset. However, the most dominant, and difficult to master complaint is dry and itchy skin, similarly to adult patients. One of the consequences of chronic kidney disease, which is often difficult to bear for adult patients and to young patients it might become that the biggest problem are restrictions in fluid intake and dietary regime.

According to Kiliś-Pstrusińska *et al.* [15] dialyzed children reported a higher level of nervousness. In Sapilak and Steciwko research

life's quality was examined with a use of KDQOL questionnaire and evaluated in a scale of 0 – 100 and yielded a result of 53.3%. Results of our research in a group that is a subject of this paper, positioned substantially higher than that, because the average was 73% [12]. Indicator of quality of life related to health by A 2 among children with CKD is significantly lower ($p < 0.0001$) than in healthy children in the same age group. The lowest rate occurred among children on hemodialysis 50.54 points on a scale of 0 to 100 [16]. This difference might be the effect of dissimilarity of examined group, however we could not find any other research concerning the population of polish children. KDQOL survey questionnaire is very well expanded and developed tool, containing 79 questions. For a child such questionnaire is difficult and takes a lot of time. Not all of the questions are fully understandable, which is also topped by the fact that children's perception and concentration are significantly lower than those of an adult. That is why quite often, even in the middle of the questionnaire survey they have reported reluctance to further testing. Order of fulfilling questionnaires was also very deciding factor. All of respondents fulfilled KDQOL survey at the very last. Those factors could create a partial interference in the final results of life's quality evaluation.

One of the sources to quality of children's life research that we could reach were the results of Children Health Center in Poland, in which life's quality of children and youth with end stage renal failure treated with Hemodialysis, but mainly after renal transplantation. Because research was conducted on similar group of patients, we have included the questionnaire in our research, after the previous agreement with the authors. Due to that we can compare the results we have received in Szczecin's and Poznan's clinics with those received in Children Health Center in Warsaw. In the evaluation of physical activity the biggest number of points received patients from the APD group. Substantial statistical relevance was also proven in this area, which could not be achieved in the research of doctor Rubik. Patient treated with an automatic dialysis have much higher possibilities of physical development, due to specification of the treatment itself – conducted at home, mainly at night. APD as a more physiological treatment than HD, leads to fewer side effects and complications, which is why it should be more commonly used among children. Comparison of quality of life, evaluated based on the sum of points obtained in individual areas, for young, dialyzed patients with given methods in Warsaw's researches did not yield substantial differences. Our results in this area are much lower, which might be the effect of different life standards in every one of the surveyed clinics, that differ not only in size but also in access to different form of support (psychologist, nutritionist

and physiotherapist), and therefore conditioning life's quality. Those aspects potentially influenced the outcomes of patients' evaluation of their own life quality. The next difference, that have occurred in an evaluation of quality of life in examined group, was a disproportion between evaluations of patient dialyzed with APD and those dialyzed with CAPD and HD. People that are dialyzed automatically, valued the quality of their lives the highest, moreover in particular, examined areas of importance, areas of life, they have too, provided the highest values among the respondents. This was also supported by the research conducted by Majkovicz *et al.* [17]. They have noticed that patients treated with APD do not feel fatigue or sleepiness, which occurs quite frequently in patients treated with Hemodialysis. An important aspect of peritoneal dialyze is the fact that it is conducted at home [10]. It is a method which can be adjusted to the needs of patient's lifestyle, method more physiological, conducive to education, which is essential for patients – children. It is also not without a meaning for little patients, that less often when compared to HD contacts with hospital (every 4 to 6 weeks) have positive impact on their comfort and therefore quality of life. That is why right relations of hospital's staff with patients is so important here. Staff should take into consideration life's situation of the patient when preparing a schedule for future visits and controls [17]. Majkovicz *et al.* [17] point the problem of decreasing quality of personal life for people treated with HD, that is worse social functioning, exasperation and aggression, which was not a result of our research. It is on the contrary. Our results show that children treated with HD in our group express the highest levels of social activeness. Those differences might have occurred because Majkovicz *et al.* [17] research group consisted mostly of children after transplantation and dialyzed were of lesser percentage. However due to obtained differences in results of quality of life evaluation among children treated with dialyze, they are worthy being discussed. Similarly to the research conducted by doctor Rubik, we did not find essential differences concerning an evaluation of current situation and degree of optimism in groups of children treated with HD and peritoneal dialyze. When it comes to an evaluation of current situation, respondents no matter what method they were treated with, granted on average 5 points in a scale of 1–10. Because of the differences that occurred in the evaluation of "hope for the future" in the context of method of treatment, people treated with CAPD, gave on average 7.4 points in the scale of 1 – 10, while APD or HD yielded 8.3 in the same scale. This difference most likely occurs, due to the fact that this method is used mostly among infants and newborns, often starting the treatment process right after the birth, when parents

do not possess sufficient knowledge about the used treatment method, and renal failure is only one of many flaws. Therefore, quite quickly among the parent that are aware of the consequences of those situations, the feeling of hope for better child's health diminishes. Moreover, we have examined the dependencies, that were never before a subject of research among dialyzed children. We have noted few statistically essential dependencies between depression symptoms and time of treatment, material status and parents' education level. The lowest intensity of depression symptoms express people that are dialyzed for the time in between 13 to 60 months, which is associated with an adjustment to the situation and an acceptance of treatment's method. The biggest psyche problems appear when patients are dialyzed for more than 60 months, then it is quite often that both patients and their families lose all hope for transplantation and therefore a normal life. When we analyzed change of quality of life evaluation in time among the APD group, we have observed a tendency for improving a physical activity and increasing general evaluation of life's quality, while in the research of doctor Rubik results were quite opposite. In the case of general evaluation, despite our results pointing on lower values, having in mind that they have changed in time in favor of patients, they seem optimistic. Dr Rubik's team demonstrated significant improvement in the quality of life in the area of social activity and evaluation of patient's own situation compared to previous year. Our results confirm this, however tendency is not significant. Moreover, the group of patient dialyzed with HD method, similarly to Warsaw's Center, we have observed a tendency to improvement of quality of life in most of the life areas. Only the results concerning social activity differed greatly to the detriment of our respondents. Big role in this may play the adaptation processes and individualization of dialyze treatment and those require relatively long time. Only then in patient's subjective evaluation, dialyze treatment itself is seen as a method of improving the quality of life. That is why, hospital's or clinic's staff play substantial role in supporting dialyzed people. According to Podgórska-Kowalczyk, the main source of support is not a family, but health care employees [18].

In a study by Kiliś-Pstrusińska *et al.* [19] parents of children with CKD in addition to material support mainly need emotional support and incentivize to take better care of their sick child. The parents of children with CKD assess the quality of their lives, as well as their physical and emotional functioning as lower. The difference in the perception of functioning of children in different areas by the parents and the patients themselves can lead to conflicts in the family.

Patient's process adaptation, treated with renal replacement is positively influenced by a talk with a person that has already undergone transplantation or the one that is dialyzed for a long time and has already adapted to this situation. Quality of life of dialyzed patients research, due to the fact that it allows to acquire holistic information about a patient, should be treated by therapeutic teams as an integral element of care for this group of patients. This becomes even more important when dealing with young patients and complex care determines their functioning in future life.

CONCLUSIONS

Our research allowed us to formulate those key points:

1. The level of QOL of surveyed patients in dialyze centers participating in the survey are substantially lower than those dialyzed in Children Health Center in Warsaw.
2. There are not significant differences between children treated with peritoneal dialyze and HD in different life areas conditioning quality of life, besides mental health (depression symptoms), in which the best results were in a group of patients treated with an APD method.
3. There is statistically significant relation between the severity of depression symptoms and the duration of treatment for dialyzed children and between physical activity and social status and method of treatment, as well as social functioning and parents' level of education.
4. General evaluation of QOL of the dialyzed children requires actions, leading to its increase. It can be achieved primarily by active counteracting the phenomena of decreasing the level of QOL by integrating the work of therapy team and family, especially in the area of specialized psychological help, both for the young patient and for his family.

Conflicts of interest

None declared.

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