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''Medical and psychosocial aspects of donation and kidney transplantation from living donor and strategies for coping with stress''

Abstract

The presented series of four publications is characterized mainly by psychological processes related to kidney transplantation from a living donor. Common hypothesis for original papers in this cycle was, that an act of donation and transplantation of the living dnonor kidney despite experience of stress, does not affect psychosocial functioninig of the donors and has a positive effect on reletions ot the donor and recipient. This work describes the benefits of donation and the accompanying psychological mechanisms, especially in relation to kidney donors. It also covers the issues of health education of the medical personnel, which is an essential element of success in the treatment of patients with chronic kidney disease. In the first paper (Publication No. 1), the health benefits resulting from the transplantation of live donors are defined and discussed. Currently, there is a lack of knowledge about the postoperative quality of life of recipients who received a kidney from live donors (LD), as compared to those who received an organ from brain-dead donors (DD). A total of 89 patients after renal transplantation participated in the study: 48 from the LD group and 41 from the DD group. Patients' health status was determined by direct methods (data from an interview) and indirect (laboratory tests). All participants in the study received questionnaires to measure quality of life and emotion specifications. LD kidney recipients were slightly younger than DD recipients (40 years vs. 49 years). Patients both after LD and DD transplantation obtained a similar health assessment by indirect methods and direct methods. Differences, however, occurred in the results of research on psychosocial functioning. Patients with LD had a greater sense of happiness ($P < 0.01$) and self-efficacy ($P = 0.07$). In addition, these patients showed greater involvement in social life ($P < 0.2$) and were more satisfied with their social relations ($P = 0.07$). In terms of social functioning, LD recipients showed a higher quality of life ($P < 0.1$) as well as satisfaction with their environment ($PA < 0.1$). In addition, correlations between quality of life and cognitive assessment in the emotional functioning of recipients in the LD group were also significant. In the area of physical and professional activity as well as daily routine, LD and DD patients performed similarly. Based on this study, it was concluded that patients receiving a live donor kidney could benefit from this form of treatment, with greater psychosocial benefits. This effect is not dependent on somatic parameters (comparable data from the history and results of laboratory tests).

The obtained results indicate that in order to achieve a high quality of life after transplantation, patients should receive assistance from the integrated system of medical care in the emotional and cognitive process of adaptation to a new life situation, and conscious support from loved ones. Next study (Publication No. 2) is a review, addressing the role of medical personnel in the process of education of patients and their families in the field of living donation and transplantation. In 2010-2016, according to the Central Statistical Office, the number of dialysis patients in Poland increased by over 6,000 (in 2010, 17193 patients were dialyzed, and in 2016 - 23356 patients) [7]. Patients with progressive chronic kidney disease are exposed not only to somatic disorders. The disease often causes a radical deterioration of the psychosocial functioning of the patient. Preparing the patient for organ donation should be treated as a sequence of adaptation processes. Therefore, it is important for the medical staff to conduct educational meetings that improve the patient's knowledge about the transplantation at its particular stages. The medical staff is also obliged to familiarize the patient not only with the benefits of transplantation, but also with possible complications. They should make the patient aware of the goal of kidney transplantation, which is to extend and improve the quality of life of the patient. At the Transplantation Institute, the recipient and donor are invited to meet with the transplant coordinator, nephrologist, surgeon and psychologist. During the meeting, patients are informed, among other things, about possible hazards of the surgery itself. Both the donor and the recipient are legally obliged to express a formal consent for kidney removal and transplantation. The recipient also receives information about the benefits of this method of treatment. The patient's education also includes knowledge about the treatment after transplantation. The postoperative period requires from the patient regular controls in the transplant center. The recipient must also take immunosuppressive drugs. Chronic renal failure and accompanying long-term treatment (including hemodialysis) is associated with a sense of discomfort and change in the quality of life of the patient [11]. This term refers to the subjective assessment of the life activities of the patient, that is, somatic, mental, family and social functioning. One of the methods of influencing the shaping of the lifestyle of individuals and social groups is health education. This function, in the case of patients undergoing hemodialysis, is performed by the medical staff of the dialysis station in their daily work. Effective prophylaxis, proper nutrition, healthy lifestyle during the disease and during dialysis treatment allows not only to improve the quality of life of patients and the elimination of risk factors worsening the health condition; it also provides the basis for starting with patients a dialogue on kidney transplantation, potentially from a living donor. Doctors and nurses of dialysis centers undertaking patient education should know and apply appropriate educational methods. In order to gain trust, arouse interest and gain a patient for cooperation, they must use verbal and non-verbal techniques to communicate with patients. According to the studies conducted, the best health promoters in the dialysis station are nurses. This was shown in the paper "Nurse's educational role in relation to a

patient in need of renal replacement therapy", conducted at the Department of Hygiene and Epidemiology, Medical University of Bialystok [8], which showed that the best health promoters in the dialysis station were nurses (45%), then medical staff (38%) and psychologists (8%). More than half of the patients felt that the knowledge transmitted was understandable. The remaining part did not always understand all the information given to them. The group of patients surveyed mostly awaited information about their illness, complications related to dialysis and nutrition rules. According to the respondents, the best form of education were lectures and individual conversations. The vast majority of patients confirmed that the medical staff in the dialysis station, and in particular the nursing staff, was able to answer all the questions asked. In conversation with the patient, the dialysis center's medical staff should consider individual characteristic of the patient, with particular emphasis on his resistance to stress and the ability to deal with it. The current mental state of a person qualified for transplantation from a living donor has to be evaluated, together with the presence of absolute contraindications (mental disorders in the active phase, dementia, suicidal thoughts) and relative contraindications, such as mental retardation, suicidal attempts or thoughts in the past, personality disorders, schizophrenia in stabilization phase. What is important is the patient's motivation to undergo the transplant surgery, approval to receive a kidney from a specific donor and the type of relationship between the donor and the recipient. During the qualification process, the activities are mainly focused on the protection of freedom of choice of the donor, while the analogous rules must also apply to the recipient. The described problems indicate the need and emphasis on broader education of medical personnel in the field of communication with the patient. Education should also be extended to workshops for medical staff in the field of communication skills, paying attention to the importance of words and information passed on to the patient, because we often use medical nomenclature incomprehensible by the patient. Providing information on the disease and its impact on the quality of life is a very important element in the process of treatment. The next study (Publication No.3) covers the subject of the donor-recipient relationship as a result of the procedure of transplantation from a living donor. The decision to donate a kidney to a loved one is often associated with emotional stress. The recipient often remains alone with all doubts and feelings of guilt towards the donor. It is important, therefore, that in this process both the recipient and the donor should be fully aware of the decision. Kidney transplantation from a living donor according to sociological exchange theory can be considered as an act of donation. Exchange is a universal law, it refers, among other things, to giving good which is a reward. The tangible and intangible goods are exchanged, and benefits follow. The concept of "pure gift" defines a situation when an individual, without expecting anything in return, gives something of value. The most important types of pure gift are those given to you by your spouses and parents-children. In light of this, a donation for a loved one can and should be treated as an act of a pure gift, in which the donor, giving up his organ, does not

expect anything in return. According to research conducted in New Zealand by Martin PM et al. [9], patients waiting for transplantation were positive about the donation from a living donor. The strongest hesitancy and concern was shown by a group of patients who were in a difficult financial situation. Other concerns raised related to the anxiety about the survival of the donor and the overall success of the procedure. The knowledge about the impact of the procedure on further activity and health after surgery is a key factor in donor's decision process. Research carried out by Agerskov H. et al. [10], in turn, revealed factors that influenced decisions on kidney donation. They were dependent primarily on the recipient's emotional attitude, life situation or relationships between the donor and the recipient. The key motivation was the willingness to help a loved one. The close emotional relationship with the recipient was one of the most important arguments for the decision to donate the kidney.

The main purpose of the presented work was determining whether there has been a change in the relationship between the donor and the recipient after donation. Interests were also focused on the area of identification of changes in relations between them, as well as on the direction of these changes. The following research questions were set up:

1. Do donors, despite the time lapse, consider the decision to donate the kidneys right?
2. Do donation donors see changes in relationship with kidney recipients?
3. In what areas do donors identify the possibility of changes in relationships and what direction do they take?
4. What are the changes in the relationships identified by donors?
5. How does the donor-recipient relationship look like in the opinion of donors?

The study was conducted among patients after kidney donation, transplanted to a family recipient or in a close emotional relationship. The study was conducted using a non-anonymous questionnaire. The questionnaires were prepared at the Department of General and Transplant Surgery of the Infant Jesus Clinical Hospital in Warsaw and sent to all donors who received the kidney in 1993-2009 (the shortest time from surgery was 3 years, the longest - 18 years, average: 9, 9 years) and whose addresses were available (n = 119). In total, 59 questionnaires were received (return: 43.7%). The final assessment was with data collected from 52 subjects aged 23-73 (average: 55.12 years), containing at least 75% of completed responses. Among the respondents, 54% were women, and 46% - men. When asked whether the donation decision was correct, 100% positive replies were received. Each of the 49 patients who answered, decided to donate the kidneys and would take it again if they could turn the time back. Following donation, patients perceived either a positive change in the relationship with the kidney recipient (37%) or the relationship has not changed (63%). Importantly, no one answered that the relationship deteriorated. The majority of respondents positively assessed the changes in relations

regarding intimacy. Most often (92%) was emphasized a new, deeper character and increased proximity. Two (8%) respondents who registered the negative direction of change mentioned disappointment and intensification of conflicts and quarrels. The surveyed group also positively assessed the change in relationships in spending time together. It is worth noting that there were no negative changes, 8 (29%) donors said they spend more time with the recipient and talk more often, 5 (18%) - that they spend more time with the recipient, and 15 (53%) did not note changes. All of the 31 (100%) responders unanimously defined their relationship with the recipient as very good. The results confirmed the deepening of the relationship between the donor and the recipient. Changes in relations were positive, deeper character and deeper interpersonal relations were emphasized, as well as a sense of increased closeness between the donor and the recipient. Women after the donation procedure spent more time with the recipient. The donor spending more time with the recipient made a more positive assessment of medical care received in the perioperative period and in the check-up procedure. The purpose of the next work (Publication No. 4) was to determine if in a situation of extreme stress caused by donation, there would be a change in the quality of life of the donor, also whether the donor will be able to develop strategies to cope with such a strong stress defined as resilience. They were directed to verify of hypotheses:

a. kidney donors will register a change in quality of life after kidney donation surgery
b. after donation, a change in the donor and recipient relationship will occur
c. donation will be a situation of extreme stress for the donor
d. donation of the kidney will cause the donor to develop a post-traumatic event
e. donation will be associated with resilience in donors
f. kidney donors will develop strategies to cope with traumatic stress.

23 subjects, aged from 25 to 63, who decided to donate the kidney, were included in the study. Donors with recipients were connected by family or emotional relations. The research was carried out in two stages. The first took place three days before the procedure, and the second half a year later (after 6 months). The study was anonymous and did not affect the qualification process for donation and transplantation in any way. The following tools were used to conduct the study: Author's questionnaire - Donors before transplantation, Author's questionnaire - Donors after transplantation, PTGI-R questionnaire (two-sided, Tedeschi, Calhoun 1996, Polish adaptation, Ogińska-Bulik, Juczyński 2010), PRE questionnaire (two-sided, Garnefski , Kraaij, Spinhoven 2001, 2002, Polish adaptation: Marszał-Wiśniewska, Fajkowska-Stanik 2010) and SPP25 Questionnaire (one-sided, Ogińska-Bulik, Juczyński 2008). The study confirmed all the hypotheses, except the first, where in the situation of extreme stress, which is the donation of the kidney, there was no change in the quality of life after donation. A group of donors who did not observe any change prevailed over a group of donors who observed such

a change. It was shown that after donation of the kidneys, kidney donors better assess their relations with the recipient, present higher openness, resistance to stress, higher intensity of posttraumatic growth. This means that a stressful situation can challenge adaptive strategies to regulate emotions, which means controlling the emotions and not being able to influence them when taking action in stressful situations. .

Conclusions

On the basis of the presented works, which are a series of publications, one can create a psychological picture of the living kidney donors. These are people in whom the donation has stimulated the processes of coping with stress and adaptation to the crisis situation, which enabled them to appreciate their lives more deeply and to deepen relationships with their relatives. At the same time, it is worth pointing out that donating the kidney for transplantation strengthened the bond between the donor and the recipient. The results of these studies can be used to promote the idea of kidney transplantation from living donors. They may be particularly useful for psychologists and physicians who are preparing the donor-recipient pairs for kidney donation and transplantation.

Summary.

A relatively small number of studies on living kidney transplantation describe the psychological problems of the donor-recipient relationship, or psychosocial problems during the qualification for donation and after the procedure. Authors (including own research) emphasize that the most important and the most difficult stages are the interview itself with the candidate for donation. The potential organ donor must make a fully informed decision about giving a kidney to a loved one. However, the psychologist should assess his motivation. The justification for donation to save the health of the closest person is not enough. The motives must come from a strong emotional relationship with the patient. Achieving high quality of life for patients (both donors and recipients) after renal transplantation requires systemic support. This means not only the need for professional and widely available medical care, or the involvement of institutions that have a significant impact on the patient's life, but also the education of relatives who can and should provide direct support (transplantation as a change). It also means the need to monitor and support adaptive cognitive and emotional processes in this group of patients and their families by clinical psychologists. The quality of life of both donors and recipients is strongly connected, but not fully dependent, on their somatic state. Aspects that are equally important are self-efficacy and social support. One of the factors that influence the achievement of positive, psychological effects of donation is the ability to deal with difficult situations and adapt to them. Therefore, not only medical care, but also psychological, or

holistic approach to the donor - recipient pair will help to improve long-term results in both the donor and recipient populations, which was emphasized in the doctoral dissertation.