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Employment perspectives of children with chronic kidney disease

Zaposlitvene možnosti otrok s kronično ledvično boleznijo

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Abstract

The employment of patients with childhood onset of chronic kidney disease (CKD) is influenced by the entire course of disease during childhood as well as later in adulthood. Frequent school absenteeism, weaker neurocognitive functioning and physical health problems contribute to lower academic achievement and educational level and to emotional problems such as low self-esteem, loneliness, anxiety and depression. Young adults with CKD are less independent and achieve fewer developmental milestones and later than their healthy peers. Lower educational level and frequent episodes of sick leave make them less attractive for potential employers. Among the most important predictors of the quality of life and employment are the age at which end-stage kidney disease occurs and the available treatment modality (kidney transplant vs dialysis). Despite their disabilities, most patients feel capable of working and want to be employed. It is reasonable to keep raising the awareness of educators and employers about the limitations of CKD and to provide help to the patients when searching for employment.

Izvleček

Na zaposlenost bolnikov s kronično ledvično boleznijo (KLB), ki so zboleli v otroštvu, vpliva celoten potek razvoja bolezni med odraščanjem in tudi kasneje v odraslosti. Pogoste odsotnosti od pouka, slabše nevrokognitivno delovanje in težave s telesnim zdravjem prispevajo k slabšemu učnemu uspehu, nižji stopnji dosežene izobrazbe in čustvenim težavam, kot so slabša samopodoba, občutek osamljenosti, anksioznost in depresivnost. Mladi odrasli s KLB so manj samostojni in dosežejo manj razvojnih mejnikov ter kasneje kot zdravi vrstniki. Zaradi nižje dosežene izobrazbe in predvideno pogostih bolniških odsotnosti so manj privlačni za delodajalce. Na kakovost življenja in zaposljivost bolnikov s KLB pomembno vplivata tudi starost, pri kateri nastopi končna ledvična odpoved, in način nadomestnega zdravljenja. Kljub vsem težavam se večina bolnikov čuti sposobne za delo in si želi zaposlitve. Smiselno je ozaveščati učitelje in delodajalce o omejitvah KLB ter pomagati bolnikom pri iskanju zaposlitve.

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1 Introduction

Chronic kidney disease (CKD) affects approximately 7–9 children per million of the similarly aged population (1). Onset is much rarer in childhood than in adulthood (in the US, it is estimated that approximately 10% of adults have CDK) (2). It has a significant impact on how children with CKD live and grow up. The course of the disease is unpredictable and issues often coincide with critical life events important for continued development. Children with CKD are susceptible to many short-term and long-term consequences in the educational, behavioural and emotional landscape. The quality of life is especially low with regard to physical health. Authors of some studies have even found lower quality of life than with children with other chronic diseases (3,4).

Because of advancements in supplementary treatment in the 1980s, patient survivability has grown significantly. The long-term consequences of CKD and its therapy are consequently mostly still unknown (5). Because of the infinitesimal patient population, studies in this field are rare and only performed on a small number of participants.

In most studies, employment is mentioned as one of the health-related quality of life factors, which is only just gaining value as an indicator of the treatment success. Before, the most used indicators were patient and graft survival in patients after kidney transplant. However, employment is undoubtedly a key component of the quality of life and has a significant impact on the social aspect of life (6).

The employment possibilities of children with CKD are affected by the complete course of the disease and related issues from childhood onward. The age of onset of end-stage renal disease (ESRD) and its treatment is very important. Patients with a later onset of ESRD have better chances of completing education and employability (5). Due to frequent school absences, children with CKD have poor grades and find it difficult to maintain contacts with their peers. This impacts their self-esteem and can lead to emotional issues, such as anxiety and depression, both with children and adolescents, as well as in adults (7). Patients with CKD achieve fewer developmental milestones and much later than their peers from the general population. A study from Denmark has found that compared to their peers from the general population and their peers with other chronic diseases, they achieve independence at a later stage and that a greater share of young adult CKD patients live with their parents (8).

In adulthood, they find it harder to obtain employment, as employers have reservations because of expected frequent absences and their lower level of education (5,6,9). In spite of all the issues, most patients are motivated for employment and feel capable of performing their job. Unfortunately, the proportion of such patients is higher than the proportion of patients who are actually employed (6).

2 Characteristics of chronic kidney disease and treatment

CKD is an advancing functional or structural kidney impairment that lasts more than three months (2). Advancement is described in five stages, with the fifth stage representing end-stage renal disease (ESRD). This is a life-threatening condition that demands the introduction of supplemental treatment in the form of haemodialysis, peritoneal dialysis or kidney transplant. The course of the disease is unpredictable and ERSD is

frequently accompanied by comorbidities (4). Complications with CKD may include increased blood pressure, anaemia, issues with metabolizing minerals and bones, falling behind in growth and development, metabolic acidosis, electrolyte loss and hyperkalaemia (2). CKD used to be connected with a high level of impairments in mental development, microcephaly and epileptic seizures, although lately, such issues are less frequent (10). Neurocognitive issues may still occur, especially with ESRD (11). Patients with ESRD are more inclined to develop cardiovascular diseases, infections and cancer, which are the most frequent causes of death (12). The disease is accompanied by a low body height which affects the development of the child's self-esteem and quality of life. Blood haemoglobin level has an additional effect on how children function (13). The presence of comorbidities is one of the most significant predictors for success in school and general quality of life (3).

Important comorbidities also include psychiatric issues, such as depression and anxiety (8). Some authors report that only slightly less than 9% of patients with ESRD were hospitalized for psychiatric diseases (14), while one of the studies found a nearly 20% prevalence of depression, which means that this is the most frequent psychiatric comorbidity to ESRD (15). These findings pertain to adult patients; however, the prevalence of depression in childhood and adolescence is also high. One of the studies reported depression symptoms in 30% of patients who participated (7). Hospitalizations related to psychiatric diseases are more than double for patients on dialysis therapy than for patients with other chronic diseases (ischaemic heart disease, cerebrovascular disease or stomach ulcer) (16).

Most adult patients with ESRD are treated with different types of supplemental therapy (3). Dialysis treatment is time-consuming and has a significant impact on day-to-day life (8). Patients in dialysis treatment frequently report being tired. Over the long-term, they have higher mortality rates, especially from cardiovascular diseases (5). Children in dialysis treatment have lower neurocognitive functioning than patients after kidney transplant, and their condition may improve after a transplant (17).

Kidney transplant is one of the best methods of supplemental treatment for children and adolescents with ESRD, as it is related to longer survival, a better quality of life and lower costs compared to dialysis treatment (4,18). According to some studies, the quality of life is even comparable with the quality of life in the general population (13). Nonetheless, some adverse factors are still present after the transplant, such as hospitalizations, transplant rejection reactions, other medical complications and side effects of medications; therefore, the assessed levels of quality of life are still significantly lower than those of healthy individuals (5,19-21).

3 Education

CKD has an important effect on schooling and education. Because of frequent examinations and hospitalizations, children are frequently absent from school and have reported low energy levels (9). There is a greater risk that they will not finish their year (22). Consequently, they attend fewer peer activities, which can lead to social exclusion and stigmatization (3,5,8). The difficulty of maintaining relationships with their peers affects their self-esteem and school results (13).

Children with CKD are constantly at risk of an exacerbation of neurocognitive functions, which results in lower grades

in school and learning difficulties (9). Compared to their peers, they achieve lower results in IQ tests, mathematics and reading, memory and executive functions. They have issues with tasks that assess abstract verbal and visual-motor skills (13,22). The impact of CKD on intelligence is greater in younger children (23).

The consequences of childhood CKD are cumulative in nature, as they frequently disrupt educational and social development and maturation in critical moments during adolescence, especially if the disease progresses to ESRD. For patients with onset of ESRD before puberty, the disease has the most severe impact if it occurred during a critical period, such as entering school or moving to a higher level of education (5). They also had problems if they had to postpone or retake finals because of the disease. Patients who had onset of ESRD during puberty and were able to participate in the educational process, developed firmer foundations and were consequently more employable.

Children report that they cannot keep up with their peers and participate at the same level in school activities (3). Their emotional distress can lead to anxiety disorders and depression and recreational drug use (8,9).

Children who have received a kidney transplant report better quality of life and better school results than those who undergo dialysis treatment. One of the studies found no differences in school results between patients who had a kidney transplant during childhood and the general population (24). However, specific quality-of-life indicators also point to issues in patients with a transplanted kidney, as they report missed classes and issues with forming bonds with their peers (13).

Most of the studies did not find significant differences in the quality of life between patients on haemodialysis and those on peritoneal dialysis, even though the latter have fewer dietary limitations and fewer disruptions in domestic and school activities. Children notice that peritoneal dialysis treatment provides them with greater flexibility and a more normal life and improves their quality of life and success at school; however, it also increases the load on the parents (13).

Along with all the problems related to the disease itself, socio-demographic factors also influence the school success of children with CKD. It has been established that better school results and a higher quality of life of these patients are related to a better socio-economic status of the family, especially with a higher level of education of the mother, the family income and the father's profession and employment status (23,25). Lower quality of life is related to the female sex, Non-European or North American citizenship, and parents being unmarried (13). In families of patients who had ESRD before puberty, parents often separated (5). Single parents who took care of the child themselves were generally not employed or were employed part-time. It is much more difficult for a parent to be without a partner's support if their child suffers from a chronic disease. Children from single-parent families have also more frequently reported emotional problems (3).

In hospitals in Slovenia and abroad, there are hospital schools where hospitalized children can continue learning. Educational programmes in hospitals have a long tradition, with origins in the second half of the 19th century (26). Experts agree that educational support outside of schools is essential for chronic diseases (27). However, very few studies have been conducted on their effectiveness and long-term impact on quality of life (28-30). In one of the few studies on this topic, conducted in Taiwan, it was especially

established that there are too few such programmes (31). This topic requires longitudinal studies that would monitor the long-term effects of hospital educational programmes.

4 Concluding school and finding employment

Problems that children with CKD faced during school are highly related to their chances of employment. Young adults are in a critical period of completing their education and finding their first employment, which can be postponed because of the disease and treatment.

Especially sensitive are patients switching from paediatric to nephrologist care and patients who, as young adults, received their first treatment at units intended for adults. Young adults face limitations that are actually very similar to the limitations children and adolescents face (9). Medical units for adults generally do not provide treatment tailored to young adults, which can lead to exclusion from a much bigger group of patients who are on average 65 years old.

A low level of educational achievement is the most frequent reason for lower employability (5). The proportion of adolescents who quit school at 16 is higher and the proportion who are university-educated is lower than in the general population. Most patients report that their education was extended or faced a setback because of ESRD (9).

In general, CKD patients achieve fewer developmental milestones or achieve them at a higher age. The parents' protective behaviour, typical for families of children with chronic diseases, contributes to these patients developing a lower level of independence (8). In spite of a different socio-economic status, most young adult patients still live with their parents (5). Self-help and self-care strategies are very important in treating chronic disease (9). Deprivation in social development is also related to later psychosexual development and self-esteem, which can also be very important in finding employment (8).

Communication skills are also very important in finding employment, such as presenting the disease to a future employer as well-managed and that the issues they had been through in the past have been resolved. It is also exceptionally important to know the right moment to disclose the medical condition to the employer. Patients have reported that disclosing it at an inappropriate time resulted in discrimination and reduced their possibility of employment (5).

The modality of treatment and comorbidities have a significant impact on employability. Because of the time demand of dialysis treatment, these patients have exceptional difficulty in obtaining employment. After a kidney transplant, patients were more motivated to achieve more in their professional field (9).

In spite of the negative impact of ESRD on employability, most young adults felt capable and ready for work (5). More than a third of people in treatment with peritoneal dialysis reported that they wanted to work but could not find employment. Most likely, employers do not know enough about the disease, which is the consequence of poor knowledge of CKD in the general population (32).

5 Work

A longitudinal study in which patients who suffered ESRD in childhood were monitored for 30 years established that patients gradually progressed and achieved several milestones, even though much later than the general population (4). Achieving milestones when developing

independence was positively related to the probability that they found a partner and achieved a higher level of education. After 30 years of monitoring, 70% of patient lived with a partner. Compared to the general population, fewer patients were employed and had children. Patients were still more frequently living with their parents or in institutions. A similar study reported that just under a third of patients lived in independent households, and the proportion was somewhat higher among patients with a higher level of completed education (24).

Several authors reported lower levels of employment among CKD patients (9,24,32). A higher level of unemployment and lower level of completed education are partially the reasons for patients' lower income (13,33). The Slovenian study found that 33.3% of patients over 20 years of age had obtained basic education (elementary school, regular or special needs, vocational school), 58.3% obtained medium education (of which 28.6% graduated with matura exams required for university enrolment), and 8.4% had higher education (34). Patient employment was somewhat lower than in other studies, while the proportion of unemployed was significantly higher compared to the unemployment level in the Republic of Slovenia at the time (7% for December 2008).

In adulthood, employment is the most important factor for predicting the quality of life. Patients are also highly motivated to hold on to their jobs (4). A high level of education and marital status were not related to patients' quality of life (33). Unfortunately, most studies report a lower proportion of employed patients (approx. 50%), than the proportion of patients who feel capable feel capable of working and want employment (approximately 70%) (6).

The most important factors for predicting social and professional functioning are the type of supplemental treatment, the duration of supplementary treatment and comorbidities. Comorbidities, dialysis, shortness and fewer milestones achieved are related to poor socio-employment functioning (3,4). Chronic fatigue and psychomotor disabilities are the most frequent reasons for unemployment. It is interesting that patients with children had a lower risk for problems in social functioning (33).

Among patients who suffered ESRD as adults, approximately 10% lost their job after the introduction of dialysis treatment (35). There is also a noticeable decline in employment in patients after a kidney transplant (6). Fewer than half of the patients employed before the transplant returned to their job, even though the transplant functioned. Only 5% of patients who were not employed before kidney transplant found jobs after their operation. Employment after a kidney transplant is an important indicator of rehabilitation after an operation and is, along with a higher quality of life, related to longer patient and transplant survival. Lack of self-acceptance, assertiveness, support from colleagues or employers, and insufficient adjustments in the workplace contributed to problems when returning to the workplace or loss of employment (9). In the US, studies have found that the reasons for patients having difficulty returning to work after a kidney transplant include poor physical health, acute episodes of transplant rejection, fear of loss of health insurance or monetary aid because of disability and lack of assistance in finding employment (6). Patients also cited the duration of their disability and the feeling of helplessness. Important indicators of employment after kidney transplant are being employed before the transplant, male sex, and the absence of depression

after transplant (36). A quarter of patients suffered from depression even before the transplant, and 32% after the transplant.

The employment level for patients with dialysis treatment is significantly lower than with patients with a transplanted kidney (approx. 30% vs 70%) (4,24). Treatment with peritoneal dialysis is related to a higher probability of employment compared to haemodialysis (4,32). In the above-mentioned longitudinal study, none of the patients on dialysis treatment had children, as dialysis treatment is related to sexual and fertility dysfunctions (4). Interestingly, adult patients who suffered ESRD in childhood, regardless of the method of supplementary social and psychological treatment, report a quality of life comparable to the general population (13). They only report a lower quality of life in physical health; 75% of patients believe that the disease brought something positive to them and that they are more satisfied with even the little things in life (13,33).

6 Recommended measures

For CKD patients, the most important therapy results are related to a better quality of life, namely those that affect everyday functioning and goal fulfilment related to family and work (37). Death, side effects of therapy, and biological markers traditionally represented as indicators of successful treatment are not as important for patients, as they do not feel their direct effects. For them, it is important how much nausea they feel, how they cope with it, being able to travel, and how disease and treatment affect their family, work and sleep. The highest-rated values include independence and related ability to maintain their employment and ability to work. Their caregivers have assessed that a patient's mental state is important (depression and anxiety), which is also related to the ability to work. Employment brings patients a sense of worth and is related to better psychosocial functioning and mental health. Consequently, measures should also be focused on encouraging employment and thereby a higher quality of life.

When looking for employment, patients should be offered programmes that would provide individual treatment of the obstacles individual patients face, and assistance and counselling when applying for open positions and establishing peer support (9). A patient's work ability should be assessed, helping them obtain job interview and application writing skills, and developing relations with potential employers (6). Proactive measures are needed that encourage the patients' initiative. In Slovenia, an ongoing statewide project named Transition for Young People aims to provide young people with special needs expert assistance when transitioning to the labour market (38).

One study reported very good results of a programme focused on improving quality of life after a kidney transplant. 88% of the programme participants who were employed before the transplant returned to work. 86% of the patients who were unemployed before the transplant found employment within a year (39).

Besides counselling in employment, patients should also be offered counselling in facing everyday challenges, and awareness should be raised among teachers and employers about the disease and effects of the treatment (9). It is imperative to regularly assess neurocognitive functions in childhood and how they change over time, as this directly affects their ability for school work and success.

In programmes for other chronic diseases, it has been established that improved employability is also related to higher levels of physical activity (40). Even

with CKD patients, it has been found that patients who were physically more active had a better quality of life (18). Measures for encouraging and improving physical activity would also be useful (6).

It is reasonable to also focus on managing and easing disease-related anxiety and emotional issues and resolving them through individual or family therapy (22). Strong support from family, friends and healthcare workers had a positive effect on young adults with CKD in achieving their employment goals (9).

7 Conclusion

Children with CKD face issues that together contribute towards poorer employability in adulthood. The time of the onset of ESRD and the method of supplementary treatment are critical. Children who suffered ESRD before puberty have poorer potential for achieving higher educational levels than children and adolescents who suffer ESRD later. Supplemental treatment with dialysis is time-consuming and has a significant impact on day-to-day life. Kidney transplant improves the quality of life and enables better operation across all areas, even though patients have side effects from immunosuppressive therapy, are faced with uncertainty regarding the transplant survivability, and have an increased risk for infections, cardiovascular and malignant disease. Poorer social skills, less autonomy, lower education and especially frequent medical absences hinder patients in finding employment. Despite that, most patients are motivated to find and keep their jobs. The most important proposed measures are raising awareness among teachers and employers about the capabilities and adjustments that patients with CKD need, and help in finding employment.

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