

The Promotion of Patient Resilience in a Pediatric Dialysis Unit: A Case Report

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Introduction - Resilience: Concept and definition

Resilience is a basic human capacity to bounce back from adversity, to turn traumatic helplessness into learned helpfulness, and to develop confidence in changing direction when a chosen path becomes blocked.²⁻⁵

Resilience is not a quality possessed by a few people only. It is a universal human capacity, transcending ethnic, socioeconomic, and cultural, geographical boundaries. Resilience allows a person to prevent, minimize or overcome the damaging effects of adversity in ways that are not only effective, but could lead to an individual's increased ability to respond to future adversity.²⁻⁵ Resilience is a dynamic process of human adaptation to face unfavorable events and risk factors (poverty, violent neighborhoods, abuse, troubled families, disease, etc.) through protective factors found within the person's environment, supportive social networks, friends, and/or well-functioning family.^{3,4} Cyrulnik highlights the positive impact of good humor, optimism, and self-respect or self-confidence on the resilience process.³ Children and adolescents on chronic renal replacement therapy (RRT) are exposed to major stresses and risk such changes as severe depression, medication noncompliance, etc. The main goals of this report are: a) to emphasize the contribution of the pediatric dialysis unit (PDU) and health care staff (HCS) to the protection and promotion of the resilience process, b) to assess the importance of patients' human environment (other than the HCS staff as protective factors e.g. relatives of other patients, companions, etc).

We describe the experience of an adolescent on RRT to illustrate the positive impact of PDU setting and its social network in promoting resilient attitudes, even amidst extreme risk factors.

Resilience in patients on chronic dialysis

In a search of the medical literature, we found few papers that described research specifically oriented towards resilience in children with end-stage-renal-disease (ESRD). Investigations of adults, who began RRT during childhood, described how these patients cope over time with adversity. Reynolds et al compared the social adjustment of 45 young adults who began RRT as children with 48 healthy controls and found that these patients were less socially mature than their age and sex-matched controls. Early onset of RRT and the current health status were associated with poorer social outcomes. However, most of them were employed and their quality of life does not appear to be substantially impaired. The authors concluded that long-term RRT leads to suboptimal or delayed social functioning.⁶ Groothoff et al pointed out that the health perception of young adults with childhood onset ESRD was surprisingly positive despite RRT and chronic disease.⁷ Compared to healthy and gender-matched individuals, adult patients with childhood ESRD showed higher unemployment levels.⁸ Adults with childhood ESRD have a better mental health perception than those with adult onset of the disease.⁸ Morton et al compared psychiatric adjustment of 45 young adults with childhood ESRD to a sex and age

matched group; they found that adult lifetime psychiatric morbidity was comparable in both groups, but the dialysis group showed a trend towards more depressive status.⁹ White et al examined different resilience processes based on the Family Resilience Model across three ethnically diverse adult patients (Anglo-Americans, Mexican-Americans, and South Koreans) on hemodialysis (HD) and their caregivers according to their needs and ways of life. The perception of patients and their families with regards to stressors imposed by HD and chronic illness varied significantly among the groups. The resilience process differs in various ethnic groups but none were above a moderate rate of resilience. Despite differences in the three groups, the degree of resilience remained in the moderate range.¹⁰ Riis et al have found that adult patients on HD are as “happy” and pleasant as healthy people and have an average mood. Patients in the renal group become adapted to their condition. These authors speculated that healthy people tend to underestimate the quality of life of ESRD – patients.¹¹

Pediatric dialysis unit (PDU): An environment that can promote resilience

PDU is a unique setting for interpersonal encounter(s) and intimate long-term socialization among patients, their biological or foster parents, formal and informal caregivers, non-relative adults, peers and the wide range of HCS, from cleaning staff to pediatric nephrologists. Social network support in the PDU setting provides an opportunity to shape, influence, control and enhances the resilience process and to provide protection factors to buffer risk factors and their deleterious effects.

PDU is a meeting place, potentially positive or negative. It can turn out to be effective in buffering distal (poverty, poor housing) or proximal (family disruption) risk factors. Social workers are of crucial importance in helping to remove bureaucratic and other obstacles to access to benefits provided to chronic renal patients and to optimize their use (low-cost transportation and electricity, free drugs, foods, entertainment activities, extra money for the family, etc).¹² However, the PDU setting could also be a risky place if there is a bad patient-HCS relationship or unwonted people’s attitudes or if the staff is careless or clumsy in announcing catastrophic dialysis events or threats (personal experience, unpublished data).

Case Presentation

Lea’s parents and five siblings live in extremely disadvantaged circumstances: precarious housing in a slum quarter, extreme chronic poverty, parental alcoholism and delinquency among biological and extended family members (brother in law, sisters’ occasional partners, etc). The primary caregivers for Lea and her siblings are vague and inefficient, with frequent rotations. The governmental agency in charge of protecting children and adolescents recognized the high risks to which the children were exposed and moved Lea and her two sisters into a public foster home (PFH). Visit(s) by their parents became increasingly more sporadic and finally, ceased. Alcoholism was a major cause of their father’s absence. The children ran away from the PFH to the house of another sister, Maria, who lives in similar precarious conditions. Lea was 14 years old when she started chronic dialysis, initially HD and, subsequently, continuous ambulatory peritoneal dialysis (CAPD) and automatized PD (APD). The absence of a primary caregiver made it impossible to conduct chronic dialysis (CD). Then Lea requested to be placed again in a PFH, under the coordination and supervision of the social worker. Despite a conflicting and challenging relationship with the other girls in PFH and the strict religious management (Lea had difficulty in adapting to the disciplined way of life of the PFH, with a set time for sleeping,

watching TV, etc); however, APD was performed efficiently. During this period there were dramatic changes in her personality and attitudes, with improvement in self-care (dialysis procedure), mood and outlook, she resumed her school studies, developed self-confidence and perseverance and adopted new human values (hopes for her future, to have her partner and own family). After 4.4 years on CAPD/APD, Lea received a kidney from a cadaver donor. Then, she moved again to Maria's house, where the high risk social network had remained unchanged. Transfer to the transplant unit had interrupted the close, ongoing, intense and frequent relationship with the PDU-HCS. Once again the patient showed changes in mood, compliance, etc and the graft was lost due to medication non-compliance. Lea was transferred to the HD Unit where she complies in an efficient and cooperative manner. The patient moved again, but this time into her boyfriend's family house.

Despite living in poverty, lacking a supportive family, and being socially marginalized, Lea tended to have a good mood and humor. Her life was full of positive illusions: for instance; she had no doubts about her parents love; she said she was not abandoned by her family, because they were strongly attached and she explained that she needed to live in a PFH only because of economic necessity.

Increased patient vulnerability related to transfer between renal replacement units

Lea was exposed to major stresses: four RRT modalities (APD, CAPD, HD, renal transplantation) and wandering around among two PFH, two biological and non-biological family houses. Lea's story of stressful negative life events and her response to them shows that she was able to develop resilience when supported by the PDU social network. It is not a story of social or academic success, but of compliance to CD with an optimistic mood despite extreme social and biological adversities. ESRD and the PDU setting brought Lea the support she lacked when she "was healthy". Cyrulnik pointed out this paradoxical and unexpected effect, of benefiting from adversity.³ The fluctuations in resilience and compliance associated with the transfer of patients to different RRT modalities and units show the potential hazards of such changes. Major risks of patients' transfer arise from the loss of a social network when the patient is not provided a new one that offers equivalent emotional support. It is necessary to develop a social network adapted to the needs of transplanted high risk patients who have no sustained family or social support.

Resilience is not a rigid and stable quality of a person; it is a dynamic and unstable process, which develops or fades over time and through changes in protective or risk factors.

The main benefits of transplantation, autonomy and withdrawal from dialysis dependence, have had a paradoxical negative consequence; that is the loss of the protective factors provided by the PDU social network. Closely linked to this event was allograft rejection secondary to medication noncompliance.

The care with the patient transferred among various RRTs is critical because such transfer poses potential risks to the compliance process. We hypothesize that the continuous and frequent interpersonal relationship during CD is socially more supportive than the less frequent contact with transplanted patients. For some patients like Lea, without a family and social network, this change could be of utmost importance and be a dramatic negative event. The switch from close dialysis dependence to transplantation autonomy could be the occasion for a slip into a denial

state, and subsequently into non compliance. Successful transition would take into account these risks.

Practical aspects of resilience promotion in the PDU

Children and adolescents on RRT are challenged to build their future happiness-and family and socially productive life through a successful transition to adulthood.

PDU-HCS can do much to support the patient in the effort to develop resilience. Resilience is particularly important during times of *transition*, when vulnerability increases because the various risk factors tend to accumulate namely loss of loved HCS people and PDU social network, new transportation network to access the PDU, etc. The poorly managed transfer of the patient to other RRT units could undermine resilience, with a negative impact on the patient's compliance and biological, psychological, and social life. The experience of our patient illustrates these transfer risks. Transfers to other RRT units must be integrated into a comprehensive transition process in which the social and emotional support is provided.¹³ The promotion of resilience requires appropriate training of HCS so that they can develop policies, practices, skills and interventions that will protect the resilience process and avoid or minimize risk factors.^{14, 15}

According to many, the patients who employ available protective and resilience-promoting factors fall into three categories: a) those who use them spontaneously and efficiently, b) those who use them in a deficient and even opposite way -aggressively attitude towards HCS, and to other supportive environment (friends, family), trying to profit from benefits – misuse of free transportation for dialysis patients, etc and c) those who are unaware that these resources are available and need to be guided toward them. The last two categories will benefit from targeted interventions aimed at improving the resilience process.

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