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. 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. 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.

**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.

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. 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.

**References**


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