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Article

Family Resilience in Maintenance Haemodialysis Patients: A Study on Disadvantaged Children

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Abstract: This paper introduced the concept of family resilience, related assessment tools, summarized the influencing factors of family resilience in maintenance haemodialysis patients, including protective factors and risk factors, and put forward peer support, exercise intervention, gratitude intervention and other interventions that can enhance the family resilience of haemodialysis patients. Finally, some suggestions are put forward for children in distress in families on hemodialysis. The purpose of this review is to provide references for scholars to further conduct relevant research on the family resilience of maintenance haemodialysis patients in China.

Keywords: maintenance haemodialysis; family resilience; influencing factors; interventions; review

Chronic kidney disease has now become a well-known social and public problem. With the development of time and deterioration of the condition, chronic kidney will evolve into end-stage renal disease. At this time, the patient's kidneys lose their excretory and re-absorptive functions, and a large amount of toxins accumulate in the body. Haemodialysis (the most common form of renal replacement therapy used in clinical practice for the treatment of end-stage renal disease) [1]. According to China's haemodialysis case information registration system, There are about 3 million haemodialysis patients worldwide, and it is estimated that the number will reach 5.4 million by 2030[2] . As the number of years on dialysis increases, patients will develop many haemodialysis-related complications, including infection, heart failure, malnutrition, etc.[3] . Some studies have shown that the level of family resilience of MHD patients can directly affect their quality of life[4] The study showed that the level of family resilience of MHD patients can directly affect their quality of life. Patients with higher family resilience can receive more care and spiritual support from their families, and their psychological state and spiritual beliefs will be better[5] .

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It is of great significance to explore the dynamic evolution and developmental characteristics of family resilience in MHD patients, and to formulate an intervention program applicable to the families of MHD patients, in order to improve the clinical outcomes of MHD patients and to promote the happiness and success of the families of MHD patients[6] .At present, the research on family resilience of MHD patients is still in its infancy in China, and this paper reviews the relevant studies on family resilience of MHD patients in order to draw the attention of domestic scholars to the family resilience of this group of MHD patients, and to facilitate the follow-up research.

1. The concept of household resilience

Due to the broad scope of family resilience, there is currently no standardized definition of family resilience. The current concept of family resilience includes the following: ① trait theory: this perspective of family resilience as a personality trait, character. McCubbin[7] and others believe that family resilience as a way to help families break through the crisis and adversity characteristics, performance. ②Process theory: This perspective sees family resilience as a series of dynamic processes through which individuals successfully cope with and adapt in the face of adversity, such as difficulties and challenges. Hawley[8] et al. found that family resilience is a developmental process, and that under the synergistic effect of protective and risk factors, resilient families are able to cope with stresses in various contexts in a unique and positive way. ③Consequentialism: family resilience is the response of families to crisis and adversity using a variety of resources and internal and external forces[9] . Ultimately, it allows individual patients and their families to stimulate the potential to break through adversity and gain positive experiences, thus effectively combating stress and recovering from trauma. In summary, the author believes that although the definition of family resilience has not been unified for the time being, there are basically the following commonalities: 1) the family as a whole functional unit; 2) unexpected stressors: the family encounters adverse situations such as illnesses, disasters, abject poverty, trauma, etc.; 3) positive coping: in the face of adversity, the family is able to stimulate and make effective use of positive and enterprising qualities; and 4) the family recovers from crises and achieves growth.

2.Tools for measuring household resilience

2.1 Family Resilience Assessment Scale (FRAS)

The FRAS was developed by Sixbey[10] in 2005 and is the most widely used and developed family resilience scale. The scale consists of 6 dimensions, namely, family communication and problem solving, utilization of socio-economic resources, maintaining a positive attitude, family connectedness, family spirituality, and giving meaning to adversity, with a Cronbach's alpha coefficient of 0.96. Currently, the scale has been debugged and applied in Poland [11], South Africa [12] , and Singapore [13], etc. The Chinese version was developed by Fan Yingwei, Dong Chaoqun , etc. The Chinese version was developed by Fan Yingwei and Dong Chaoqun. The Chinese version of the scale was localized by Chinese scholars Fan Yingwei[14] and Dong Chaoqun[15] , and was applied to cancer patients and chronic disease patients for reliability and validity tests, with Cronbach's alpha coefficients of 0.944 and 0.96, respectively. However, due to the large number of entries in the scale and the time-consuming process of filling in the scale, it needs to be further debugged in the future and validated, so that it is more suitable for the Chinese population.

2.2 Family Resilience Rating Scale

The Family Resilience Scale was developed by Yan Dai in 2008[16]. The scale divides family resilience into two dimensions with ten key factors: ①family beliefs (Difficulty

Interpretation, Positive Foresight, Life Excellence); and ②family strengths (Problem Solving, Intimate Harmony, Social Support, Well-orderedness, Emotion Sharing, Positive Communication, Co-operation and Co-ordination). A 5-point Likert scale was used, with scores ranging from 1-5 in order from "non-conformity" to "conformity" and a total score of 49-245, with higher scores representing higher levels of family resilience. The Cronbach's alpha coefficient of the total scale is 0.912. Our scholar Lai Siu-qin[17] applied this scale to children with chronic kidney disease, and it was well adapted. The scale was compiled based on the social background and family patterns in China, so it has high credibility when studying the family resilience of MHD patients in China.

2.3 Family Hardiness Index (FHI)

The FHI was developed by McCubbinin 1996[18] to measure the Family Hardiness Index. It has high influence in the international arena. The scale consists of 20 entries divided into three dimensions: responsibility, control, and challenge; Chinese scholar Liu Yang[19]localized and revised it in 2011, and tested its reliability by testing the family resilience of 330 hospitalized children. The Sinicized scale still retained 20 entries with a total score of 20-80, with higher scores indicating higher levels of family resilience. The Cronbach' s alpha coefficient of the total scale is 0.803. Because of the relatively small number of entries in the scale, it is easy for subjects to answer and is widely used. It has been applied to patients with chronic diseases[20] , heart failure[21] , schizophrenia[22] , Alzheimer's disease[23] , cancer[24] and so on.

2.4 Family Resilience Questionnaire

The Family Resilience Questionnaire[25] was developed in 2019 by our scholars Bu Tong et al. by combining the above scales with a good localization fit. The questionnaire consists of 4 dimensions, namely, perseverance, amicability, openness, and supportiveness, totaling 20 entries. A 5-point Likert scale was used, ranging from 1-5 on a scale from "very poor fit" to "very good fit", with higher total scores representing higher levels of family resilience. The questionnaire has an appropriate number of items and is based on China's social background and family patterns. Our scholar Liu Liang[26] Liu Liang, a scholar in China, has applied this scale to elderly MHD patients, and the Cronbach's alpha of this questionnaire is 0.951.

3.Factors influencing family resilience in maintenance haemodialysis patients and their carers

3.1 Protective factors

3.1.1 Self-efficacy

Individuals with a sense of self-efficacy are able to take positive action, mastery and control in the face of adversity. Tang Ling[27] 's study found that enhanced self-efficacy interventions can significantly increase the level of resilience and improve the quality of life of haemodialysispatients. Patients with a high sense of self-efficacy are more likely to have a strong belief in overcoming the disease and regaining their health. Connor[28] used self-efficacy as one of the judgment indicators when compiling the resilience scale. Therefore, in clinical practice, healthcare workers should pay more attention to haemodialysis patients with low self-efficacy, and take relevant interventions to improve their self-efficacy, which in turn will promote the improvement of family resilience.

3.1.2 Family factors

Family functioning refers to the extent to which family members communicate with each other, fulfill their family roles, and cope with and adapt to family stresses and interrelationships[29] . Some studies have shown that family functioning has a direct positive effect on patients' self-management behavior[5] . Good family relationships have a positive effect on patients and can influence the way haemodialysispatients behave, leading to changes

in haemodialysispatients' self-management behaviours. XuMei[30] et al. confirmed that family support has a direct correlation with the survival rate and quality of life of haemodialysis patients with uremia. The reason may be that family members can not only support and help haemodialysis patients spiritually, but also provide substantial care in daily life, which is the main source of hope for haemodialysis patients.

3.1.3 Social support

QiuYuan[31] et al. found that social support can further enhance the psychological resilience of haemodialysis patients through the mediating role of family resilience. The reason may be that the higher the level of social support, the more effectively family members can collect internal and external resources and seek more medical information. Thereby further expanding the support network and collaborating with medical staff to cope with family crisis. Tang Ling[27] et al. showed that social support, as an external protective factor of resilience, has a positive effect on MHD patients' ability to resist external difficulties and achieve positive growth. The more social support MHD patients receive, the stronger their psychological endurance, and the higher the level of family resilience[32] . Therefore, in clinical work, healthcare professionals should pay attention to the positive impact of social support on the family resilience of MHD patients, and assist MHD patients to use the social support system to better face adversity and challenges.

3.2 Risk factors

3.2.1 Demographic factors

Related studies[33,34] have shown that demographic factors of low education, low income, and age, are risk factors for family resilience in MHD patients. Caregivers of patients with lower education levels are prone to fall into the negative emotions of lifelong treatment of haemodialysis patients and have difficulty in dealing with problems in a timely and effective manner when facing various emergencies[35] . Low-income families are less able to withstand risks, and the medical burden and daily expenses of long-term dialysis can easily overwhelm the psychological defenses of the whole family, leading to a decrease in family resilience[32] . In addition, the incidence of haemodialysis complications increases with the age of the patient. Many patients are prone to co-infections due to immunocompromised and malnutritional factors, resulting in increased fluctuations in psychological resilience[36] .

3.2.2 Negative emotions

Negative emotions such as anxiety and depression are important factors affecting family resilience[37] . A series of complications caused by long-term dialysis can lead to physical decline, weakening of social roles, gradual loss of self-esteem, and a series of mental disorders in MHD patients[38] . At the same time, family members of patients are also prone to self-blame due to the physical and psychological changes of the patients, which gradually develops to the questioning of their own ability, thus affecting the motivation to cope with the disease and leading to the reduction of family resilience[39] . Therefore, it is necessary to pay attention to the psychological counseling of patients and their families in clinical care, carry out psychological care with the family as a whole, and at the same time find effective resources to actively improve the negative emotions of patients and their families.

3.2.3 Response modalities

Coping styles with illness affect the level of family resilience in MHD patients. According to a study conducted by[38] , MHD patients' coping styles of facing and avoiding the disease are positively associated with psychological resilience, while coping styles of giving in are negatively associated with psychological resilience. Facing coping[39] means that patients face up to their illness and actively seek help from others, while yielding coping means that patients are defeated by the disease and believe that they are unable to overcome the disease,

so they do not take any measures to change the status quo. Cao Xiaoyiet al.[40] pointed out that MHD patients' negative coping with the disease is positively correlated with their various physical and mental burdens. And patients' excessive perceived burdens will seriously affect the level of family resilience[41] . It is suggested that Health care workers try to give strong psychological support to patients in clinical nursing to help them face the disease positively and cooperate with the treatment proactively.

4.Intervention strategies to enhance the level of family resilience in maintenance haemodialysis patients

4.1 Peer support

Peer support refers to a mutual aid system of giving and receiving that consists of individuals with the same background or common experiences[42] . Wang Guo-Qing[43] et al. first applied the peer support model to the care of MHD patients, and found that peer support interventions could effectively alleviate the negative emotions of MHD patients, such as anxiety and depression. The study of Jin Minyan[44] showed that peer support has a strong facilitating effect on the self-management ability of MHD patients. In the future, clinical workers may consider constructing a diversified social support system led by peer support to enhance patients' beliefs and confidence in positively coping with their illnesses, so as to improve the level of family resilience of MHD patients.

4.2 Gratitude Intervention

Gratitude is a personality in which an individual responds to the favours or help of others with feelings of gratitude, leading to a positive experience or outcome for themselves. A study by Happenstance English[45] pointed out that gratitude interventions can effectively increase the level of gratitude and psychological resilience of haemodialysis patients. When patients' psychological elasticity is increased, their sense of belief in treatment and disease recovery is significantly enhanced, which enables the whole family to adapt to and fight against the disease in a more positive frame of mind. This suggests that clinicians can study the impact of gratitude intervention on family resilience in haemodialysis in the future, and assist haemodialysis patients and carers to improve family resilience.

4.3 Sports Interventions

The study of Wu Yahui[46] et al. showed that aerobic exercise, resistance exercise, and combined exercise can improve somatic function and quality of life of MHD patients. No study has pointed out that exercise intervention can directly improve the level of family resilience in MHD patients, but foreign scholars Gao[47] et al. implemented standard care exercise intervention for rectal cancer survivors, and found that patients in the intervention group had a higher level of family resilience growth. Reasonable exercise approach can help to improve the physical fitness of MHD patients, alleviate sleep disorders, reduce fatigue state, and improve cognitive ability, which is worth to be promoted in the clinic[48,49] . In the future, the time, frequency, and intensity of exercise can be determined according to the gender, age, and underlying disease of MHD patients, and the effects of different exercise modalities on the family resilience of MHD patients can be explored in depth.

4.4 Happiness PERMA Intervention

Well-being PERMA mode (Well-being PERMA mode) The concept refers to the fact that well-being is measured by a combination of five elements: positive emotions (happiness, life satisfaction), engagement, relationships, meaning and purpose, and fulfilment, and the goal is to live a full and flourishing life[50] . Research by our scholar Liu Jie shows that the Happiness PERMA nursing intervention can effectively improve the health resilience and post-traumatic growth of MHD patients[51] . The reason for this may be that the PERMA theory can help

patients fully understand their own character strengths and alleviate negative emotions, thus increasing their confidence in overcoming their illnesses and improving their quality of life.

5.How to help children in distress in haemodialysis families

With the trend of the dialysis population becoming younger, How to ensure the quality of life of children on hemodialysis patients needs to be widely concerned by the society. Children and teenagers are the future of the motherland and the hope of the nation, and it is vital to ensure the healthy physical and mental development of children and young people. The establishment of a good welfare and protection system for children in distress is the most important thing to help children in distress: at this stage, China should coordinate the planning of a systematic framework for children's welfare, and in the protection of the field of children's welfare in families on haemodialysis should involve childcare, education, health care, recreation, children's participation and so on[52] .

On the one hand, relevant departments need pay attention to the basic survival needs of children in hemodialysis families; Food, housing, education, and medical care, and work with relevant departments to establish and complete mechanisms for monitoring, reporting, disposition, assessment, intervention, and care and protection of children in difficult guardianship situations, and urge the implementation of family guardianship responsibilities; For young parents who are working, tax relief policies can be implemented, as well as tuition fee reductions and living expense subsidies for their children when they go to school; and social welfare organizations and public-spirited people can be joined together to provide one-on-one developmental support for these children in difficulty.

On the other hand, attention should be focused on the mental health of children from haemodialysis families. These children, whose parents are often unable to supervise and care for them all the time due to major adversities in their families, do not receive sufficient and effective care and support, and are prone to psychological confusion, and in serious cases, may develop a tendency to depression. Therefore, the relevant departments can provide guidance on supervision, psychological guidance, behavioral modification, social integration and crisis intervention for the different characteristics of children from families with haemodialysis patients. Some psychological counselors with medical background can also be trained to work with local psychosocial service offices to carry out appropriate on-site counselling and door-to-door service activities; the medical sector and psychologists can jointly form a resource linkage and guardianship empowerment to provide a precise and personalized intervention service model.

6.Summary and Outlook

This paper reviews the concept of family resilience, relevant assessment tools, summarizes the influencing factors of family resilience in haemodialysis patients, and proposes implementable interventions. Family resilience is of profound significance for improving the disease prognosis and physical and mental balance of haemodialysispatients, while the research on family resilience in haemodialysis patients started late in China. Most of the current studies focus on the individual resilience of haemodialysis patients, and rarely study the families of haemodialysis patients as a whole. In the future, in-depth research can be carried out in the following aspects: ①Currently there is a lack of assessment tools specific to the family resilience of haemodialysis patients, and it is recommended that in the future, caregivers should use a combination of qualitative and quantitative methods, and combine with China's cultural background to create an evaluation scale suitable for the family resilience of haemodialysis patients. ②The current research related to the influencing factors of family resilience in haemodialysis patients has the problems of small sample size, and the

design of the research protocol is not rigorous, so in the future, scholars can carry out longitudinal surveys with a large sample size and focus on the quality of the research. ③The relevant intervention programs are still not perfect, mostly at the theoretical level, and have not been implemented in the families of haemodialysis patients, and it is hoped that the relevant departments can carry out the family-hospital-community joint support policy for this special group in the future, so as to effectively improve their predicament.

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