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Comparison of Wishes in Two Groups of Patients with Life-threatening Illnesses

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ABSTRACT

The aim of this study was to evaluate the self-reported wishes of cancer and dialysis patients (3-19 years) and examine its possible association with patients' demographics and clinical characteristics. This is a cross- sectional study and included cancer undergoing chemotherapy and renal failure that were dialyzing during a period of 6 months. From a total of 46 patients that participated in this study, the majority of cancer patients are younger (<6 years) than the chronic renal failure patients (52% vs 13 %, p=0.01). The Cancer patients' wish to buy staves is 4 times more in comparison to the other group. The current study provides valuable information for charity to adequately manage cancer patients'humanitarian aid and the better psychological health.

Key words: Cancer, Chronic kidney disease, Dialysis, Wishes.

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1. INTRODUCTION

Patients who suffered from life-threatening illnesses such as cancer or chronic renal failure, they are forced to take dramatic circumstances and experienced a variety of mental and physical problems. Cancer is a major cause of death in children of worldwide, and the incidence tends to increase with time. As part of the epidemiological transition, cancer incidence is estimated to increase in the future (1). Chronic kidney disease (CKD) is a progressive condition presented in decline in renal function of the point of kidney failure, which needs renal replacement therapy (dialysis or kidney transplantation) (2). Children who are suffering from certain diseases such as cancer or chronic renal failure which at the best time require communicating with their peers and mobility, they are forced to take dramatic circumstances and along with experienced a variety of mental and physical problems. Distress is frequently encountered in cancer patients during treatment and follow-up. Between 30% and 40% of cancer patients experience clinically high psychosocial distress for which professional care may be needed (3, 4). Elevated distress levels have been associated with reduced health-related quality of life (5, 6), low satisfaction with medical and decreased treatment adherence (7). The outcomes of childhood chronic physical illness on the risk of emotional problems continue past of childhood and adolescence. So Mental health prevention and intervention strategies targeting children with chronic physical illnesses can have long-term benefits (8, 9). Therefore, guidelines were developed by professional organizations of psychological interventions (10, 11). Patients, who perceive social environment supportive, they report a higher quality of life, better psychological health, less supportive healthcare needs or are less often refer (12-14). In addition, the patients that experience sufficient social support are less likely to have an additional psychosocial and/or paramedical health care (15). So, it is needed the social support care in the child with a life-threatening illness and ask them to use his experience of fantasy and dreams about desires that provide a way for adults to know how they are experiencing their world. Encouraging the child to express hopes and beliefs is crucial to the improvement of healing (16). Knowledge the specific patient's wishes and trying to

satisfy them, in addition to a better compliance with the patient's healing process, help to optimize the investment of aid and it caused that the help is more effective, also it reduces the cost of the public sector (12-15). Since the awareness of the children wishes are effective in policy making of aid and awards from the Charity and also, it is better to effect to communicate with the patients, so this study was aimed to determine prospectively the wishes of patients with cancer and renal dialysis.

2. MATERIALS AND METHODS

This is a cross-sectional study and lasted from June to December 2016. 46 individuals aged 3-19 years with the definitive diagnosis of cancer or chronic renal failure who referred to Taleghani Hospital of Gorgan by using non-probability and available sampling were enrolled. Definitive diagnosis of Cancer and chronic renal failure, awareness of the disease, willingness to participation in the study are the Inclusion criteria. Patients with the mental disease are excluded. The participants with cancer that undergone chemotherapy (n=23), and chronic renal failure participants undergone dialysis (n=23) were invited to the study. After retrieved the inform consent, the patients were asked, who write the wishes on the page, and in the children with the lower age, we asked them to make the wishes and tell their parents or nurse to write and save presentations. Data collection tool was the questionnaire which in the first part is included of patient's sex (female, male), age (<=6,7-12 and >12 years), type of disease (cancer, chronic renal failure), duration of disease (years) and monthly income (* Iranian Rial). Categorized wishes are included with having the health (Kidney transplant, well, have kidney, etc.), the desired job or what job would you like to have in the future? (To be a doctor, etc.), to buy staves (Television, Bed,) and to do the spiritual (Being human, see the Imam Reza, Pilgrimage of Imam Reza, the mother's lap). The full interview script is provided in Table 1. Patients were divided in to three ages of <6, 7-12, >12 years. Patients in both groups of oncology and chronic renal failure were categorized. All of the interviews were conducted by a research coordinator trained by the senior author. The child was allowed to participate in the interview alone if both the child and the parent agreed. Questions were open-ended. Participants were asked “what do you wish” and a checklist to be used in the inter review process. The wishes of patients are expressed by the patients and by the researcher are listed in four groups (Table 1).

Table 1. Type of wishes

Variable	Wishes
Type of Wishes	
Health	Healthy, refer to home, jumping, the renal transplantation, Absence of drugs. Kidney transplant, well, have kidney, driving.
To buy staves	Mobile phone, Toys, Computer, Bicycle, Tablet, Bed, A Room, TV.
Spiritual	Being human, see the Imam Reza, Pilgrimage of Imam Reza, the mother's lap, see the family.
Job	Professor, Nurse , Doctor , god job

The ethics of this study were in accordance with the ethical standards of the ethic committee and with the 1964 Helsinki declaration. Demographics and the categorized wishes data were collected. Descriptive statistics were used. Data were analyzed with SPSS software version 20 (SPSS Inc. Chicago, IL, USA), P-value of 0.05and lower was considered significant. Data are expressed as mean, standard deviations (SD) and percentages. Mean and SD was used to evaluate descriptive data. $\chi 2$ Test was used to compare categorical variables, and Student t- test and analysis of variance were used to compare the continuous variables. Informed consent was obtained from all individuals participants included in this study.

3. RESULTS AND DISCUSSION

From a total of 46 patients that participated in this study, There is a significant difference in the type of wish in two groups, so that the wishes of the majority of cancer patients (83%) are to buy the tools, but this wish in the dialysis group is 22%. the chi square test show significant this difference.(p=0.001). There are not significant differences in the sex of patients, duration of disease in two groups (Table 2).

Table 2. Demographic Characteristics in two groups of patients

Variable	Cancer (n=23)	Dialysis n=(23)	P-value
Age:(n,%)Years	12 (52)		
<6	6 (26)	3 (13)	0.016
7-12	5 (22)	9 (39)	
>12		11 (48)	
Sex :(n, %)	13 (56.5)		
Male	10 (43.5)	11 (49)	0.555
Female	2.02±1.2	12 (52)	
Duration of disease (Mean±Sd)		2.39±1.7	0.493
Duration of disease (n. %)	9 (39)		
<=1 years	11 (48)	6 (26)	
1-3	3 (13)	14 (61)	0.619
3-5		3 (13)	
Income (n, %) (Iranian Rial)	22 (96)		
<5000000	1 (4)	12 (52)	
5000000-10000000	0	5 (22)	
10000000-15000000	0	1 (4)	0.0001
>15000000	7.39±4.12	0	
Age (Mean±SD)		12.43±5.23	
Duration of disease (Mean±SD)	2.08±1.2		0.001
		2.39±1.7	0.49

The majority of cancer patients are younger (<6 years) than the chronic renal failure patients (52% vs 13 %, p=0.01). In addition, the monthly income is reported less than 5,000,000 Iranian Rial in the majority of cancer patients (96 %) that this is significant difference to chronic renal failure patients (96 % v.s 22%), (p=0.001) (Table 3). The Cancer patients' wish to buy staves is 4 times more in comparison to the other group. (83 % VS 22 %, p=0.01, OR=3.9) (Table 3). By using the Chi-square test, there is a relationship between the lower income (<5000000 Iranian Rial) with to buy staves in total patients. In other words, it is reported significantly more desire to buy staves in lower income, (p=0. 01) (Table 4).

Table 3. Type of wishes in two groups of patients

Variable	Cancer	Dialysis	P-value
Type of Wishes (n, %)			
Health	19 (83)	16 (70)	0.300
To buy staves	19 (83)	5 (22)	0.0001
Spiritual	3 (13)	3 (13)	1
Job	3 (13)	8 (35)	0.08

Table 4. Relationship between variable with categorized Wishes (health, the desired job, to buy tools) in cancer and Dialysis patients

Variable	Health	Spiritual	To buy staves	Job
Age:(n,%)Years				
<6	12 (34)	2 (33.3)	11 (46)	2 (18)
7-12	11 (32)	2 (33.3)	7 (29)	5 (45)
>12	12 (34)	2 (33.3)	6 (25)	4 (37)
P-value	0.905	0.997	0.119	0.455
Sex:(n,%)				
Male	20 (57)	2 (33)	15 (62)	6 (54)
Female	15 (43)	4 (67)	9 (38)	4 (46)
P-value	0.229	0.322	0.143	0.327
Duration of disease (n. %)				
<=1 years	12 (34)	2 (33)	7 (29)	5 (45.5)
1-3	19 (54)	4 (67)	14 (58)	5 (45.5)
3-5	4 (12)	0	3 (13)	1 (9)
P-value	0.811	0.579	0.844	0.573
Income(n,%)(Iranian /Rial)				
<5000000	19 (54)	2 (33)	19 (80)	6 (55)
5000000-10000000	10 (29)	3 (50)	5 (20)	3 (27)
10000000-15000000	5 (14)	1 (17)	0	1 (9)
>15000000	1 (3)	0	0	1 (9)
p-value	0.498	0.518	0.011	0.352

There is not a relationship between age, sex and duration of disease with the four groups of wishes (P>0.05). We asked for the cancer and chronic renal failure children and adolescents about their wishes. First, we found that the Cancer group about four times have more likely to wish to buy the tools. This study is the novel research in this context, and it is recommended that in future the quality research to be done. Second, the data show that the consistent relationship with income and patient's wishes that it is significantly more desire to buy the tools in lower income. Our findings have clinical implications and our data show the importance and priority of charity's aid for these patients. This study has the limitations. The sample size was small and drawn from a single center, and most patients had hematologic malignancies, all of which may limit the generalizability of our findings. However, most of our patients were teens, and our findings might be most representative of their perspectives. In addition, our question "what Do you wish, may have raised a bias especially in the child <6 years, therefore, it seems that in this patient, it is better to show the special wishes with drawings of manifest. The decision to utilize drawings that were obtained in a relaxed atmosphere was preferred by the researcher because children are less inhibited and freer to express themselves than under controlled conditions (16). The supportive care of the charity for these patients is an important. However, the results of this research are not representative of other patients in Iran, so this result can be used for the priority of charity aids and psychological support. In addition, further researches with larger sample size in order to assess the priority of the wishes based on the age group for these patients are recommended. In this study, it was not assessed the relation of the expressed wishes by patients with the other socio-demographic variables such as educational level and family relationship status. Therefore, it is recommended to perform the future research with more detailed of children's wishes. Therefore, the charities and clinicians perform more appropriate decision-making for these specific patients.

4. CONCLUSION

The results of this study show that the majority of patients in cancer group are younger and lower income and about 4 times have more likely to wish to buy the tools. The current study provides valuable information for charity to adequately manage cancer patients' humanitarian aid and the better psychological health.

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AUTHORS CONTRIBUTION

Study concept and design: Shima Afshar and Baranak Safaian; Analysis and interpretation of data: Fedyeh

Haghollahi and Mamak Shariat; Drafting of the manuscript: Shima Afshar and Haghollahi; Data collection: Noora Afshar; Statistical analysis: Mamak Shariat.

CONFLICT OF INTEREST

The authors declared no potential conflicts of interests with respect to the authorship and/or publication of this paper.

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