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Factors affecting the community participation in kidney transplant recipients; an experience from the lower northern region of Thailand

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Abstract

Kidney Transplantation offers the closest thing to a normal life for patients with end-stage renal disease who have had long waiting times. Post transplant care needs community participation which concerns many factors. The objective of this research was to study factors affecting community participation for caring kidney transplantation recipient period. We developed a questionnaire and conducted site investigations into 300 people by random sampling of the community who caring kidney transplantation recipients from eight provinces in the lower northern region of Thailand. The results showed that factors that significantly affected community participation were social support, community care, high income, government officials, and always joining with community activities. All factors together have a 63 percent power of prediction for community participation. However, this study found that high income had a negative effect on community participation.

Keywords: Community participation, Kidney transplantation, Lower northern Thailand

1. Introduction

The prevalence of chronic kidney disease (CKD) cases is about 10% of the worldwide population and is the cause of death over one million per year. This is associated with a high treatment cost and mortality rate in the health care system [1]. There were 3.2 million end-stage renal disease (ESRD) cases in 2017 and increased to 3.4 million in 2018. The number of ESRD cases was estimated to be 4.9 million in 2025, which is an average annual increase of 6 percent per year. Whereas Asia Pacific countries have the highest incidence of renal failure in the world with an average increase of 8 percent per year [2].

Generally, ESRD patients need renal replacement therapy (RRT). Kidney Transplantation (KT) is the best treatment of RRT to improve the quality of life [3]. At present, there are over 80,000 KT recipients in over 80 countries worldwide [3,4]. In the United State there are over 662,000 KT recipients [5]. So, ESRD is an important chronic disease that impacts health and health determinants in many countries.

In Thailand, the prevalence of ESRD patients receiving RRT is 1,306.6 per million population and the incidence of those was 317.71 per million population in 2015 [6]. The number of ESRD patients tended to increase throughout the 15 years since 2000. The Northern region has been ranked in the first of peritoneal dialysis (PD) and the second of hemodialysis (H/D) of the country [6]. The amount of ESRD patients has an impact on the health budget of over 10 percent of the National Health Security Office funding [7]. In 2018, there were 473 KT recipients from 6,082 ESRD patients on the waiting list. The longest waiting time for KT after initiating RRT is 20 years, 8 months, and 19 days. The average waiting time for KT is 5 years. Kidney Transplantation seems to be the treatment that gives a “new life” for ESRD patients [8]. However, postoperative care is also important. When KT recipients are discharged from the hospital, they all need to know about self-care and also the care available from their communities.

Caring for KT recipients in the lower north of Thailand emphasizes information and therapy in tertiary care hospitals and places a low priority on community participation. Therefore, patients have complications such as stroke, sepsis, poor immunosuppressive drug compliance, and death. There are many factors affecting health outcomes, complications, graft survival, and mortality of KT recipients including care from family and social support. Many studies show that KT recipients who have social support have better immunosuppressive medication adherence than those who have no support [9-11].The KT recipients who have community care were less stressed and anxious [12]. Also, they will have a better quality of life [11,13,14]. Thus, community participation in caring for KT recipients is important to achieve excellent health outcome [15-17]. This research aims to explore factors affecting community participation for the care of KT recipients in the Lower Northern region of Thailand.

2. Materials and methods

2.1 Study setting and sampling

In the lower north of Thailand**,** there are eight provinces, and one tertiary hospital, Buddhachinaraj Phitsanulok Hospital, that provides a Kidney Transplantation Center. In each province**,** there are 4-38 KT cases from an overall recipient total of 109 cases. The participants were individuals who take care of KT recipients in the community including family members, caregivers, friends, village volunteers, leaders of the community, health care providers, and government officers. 300 samples were calculated from twenty times of variables and multistage random sampling by proportionate. Inclusion criteria were the following:
1) They were staying in eight provinces in the Lower Northern region of Thailand.
2) Those older than 20 years.
3) Agreed to sign an informed consent.
Exclusion criteria were the following:
1) Recipients who either refused to sign the informed consent.
2) Who withdrew from the research.

2.2 Questionnaire

A questionnaire was designed base on the literature review and developed by the researcher. It was a rating scale 6 level questionnaire that has 60 items categorized into 4 parts. The first part was characteristic data. The second part was community care consisting of 5 elements, which are taking immunosuppressive drugs, daily activities, emotion, preventing complications, and follow-up. The third part was social support, having 4 elements which are money, physical strength, material, and emotion. The final part was community participation, having 4 elements which are decision making, implementation, benefit, evaluation. The questionnaire was to verify the quality of research tools by three professionals. The content validity index (CVI) was 0.85 and the reliability was 0.90.

2.3 Data collection and analysis

All participants in this study were voluntary and they signed informed consent before their inclusion. They received an Information Sheet for Research Participant before the checklist and could ask the research team questions at all times. We asked permission from the Public Health Provinces Office in each province before collecting data from 7 Feb - 7 Apr 2020. Finally, 300 valid questionnaires were collected. The definition representing about 91% of the total sample sent out. Data were analyzed by descriptive statistics and multiple regression analysis (MRA).

3. Results and discussion

3.1 Participants

The demographic data showed that most participants were female (65%). The average age was 48.65 years old. The participants were agriculture 27.7%, employed, and trade 39.3%. Most income ranges were 5,001-15,000 Baht per month (39%) and high income > 15,000 Baht per month (36%), education level was high school (39.3%). 91.3% of participants had no experience of caring for KT recipients whereas 8.7% had the experience. The community leaders, village volunteers (44.3%) were dominant in social roles, and government officials/district hospitals (18.7%). Most participants (62.7%) did not receive information about KT. They joined with community activity sometimes (44.7%) and frequency/always (20.7%) whereas 34.7% never joined. The level of knowledge was moderate (55%) and the high attitude level was 87.7% (Table 1)

Table 1 Participants characteristics (n = 300).

Demographic characteristics	Frequency	Percentage
Gender		
Male	99	33
Female	201	67
Age		
20- 40	70	23.3
41- 60	195	65
> 60	35	11.7
Min =20 Max = 84 Mean = 48.65 S.D =12.11		
Career		
Agriculture	83	27.7
Employed/trade	106	39.3
Government official/ state enterprise	101	33
Marital status		
Single	181	60.3
Couple	119	39.7
Income		
< 5,000 Baht/month	74	24.7
5,001 – 15,000 Baht/month	117	39
> 15,000 bath/month	109	36.3
Education		
Primary school	83	27.7
High school	118	39.3
Bachelor or higher	99	33
Experience in caring for RKT		
Yes	26	8.7
No	274	91.3
Social role		
Family/caregiver/friends	111	37
Leader community/village volunteer	133	44.3
Government official/district hospital	56	18.7
Get information		
Yes	112	37.3
No	188	62.7
Joined with community activity		
None	104	34.7
Sometime	134	44.7
Frequency/always	62	20.7
Knowledge level		
High	107	35.7
Moderate	165	55
Low	28	9.3
Min=3 Max= 10 Mean=6.61 S.D.=1.50		
Attitude level		
High	263	87.7
Moderate	22	7.3
Low	15	5
Min=1 Max= 10 Mean= 8.13 S.D.=1.60		

3.2 Community caring level

The community caring level results showed that taking immunosuppressive drugs and daily activity was at a low level, which was 47.7% and 38.3%, respectively. While emotional (47.7%) and complications prevention (48%) were at a high level. Also, follow up by community was approximately equal with a high level (37%) and low level (36%). Overall community caring levels were approximately 35.7% at a high level, 30.3% at a moderate level, and 34% at a low level (Table 2).

Table 2 Community caring level (n=300)**.**

Community caring	Level					
	High		Moderate		Low	
	Frequency	Percent	Frequency	Percent	Frequency	percent
Take immuno-suppressive drug	103	34.3	54	18	143	47.7
Daily activity	90	30	95	31.7	115	38.3
Emotional	143	47.7	93	31	64	21.3
Complications prevention	144	48	110	36.7	46	15.3
Follow up	111	37	84	28	105	35
Overall	107	35.7	91	30.3	102	34

3.3 Social support level

Social support was at a low level in terms of money and physical strength, 44.7%, and 57%, respectively. Emotional was at a moderate level (51.7%). Material support was mainly at a moderate (42.3%) and low level (38.3%). Overall social support was at a moderate level (42%) (Table 3).

Table 3 Social support level (n=300)**.**

Social support	Level					
	High		Moderate		Low	
	Frequency	Percent	Frequency	Percent	Frequency	Percent
Money	48	16	118	39.3	134	44.7
Physical strength	68	22.7	61	20.3	171	57
Material	58	19.3	127	42.3	115	38.3
Emotional	117	39	155	51.7	28	9.3
Overall	64	21.3	126	42	110	36.7

3.4 Community participation level

All elements of community participation were at a low level. Decision-making participation was 51.3%, implementation participation was 47.7%, benefits participation was 49% and evaluation participation was 55.7%. Overall community participation was at a low level of 51%, a moderate level of 32.3%, and a low level of 16.7% (Table 4).

Table 4 Community participation (n=300).

Community participation	Level					
	High		Moderate		Low	
	Frequency	Percent	Frequency	Percent	Frequency	Percent
Decision-making participation	57	19	89	29.7	154	51.3
Implementation participation	75	25	82	27.3	143	47.7
Benefit participation	53	17.7	100	33.3	147	49
Evaluation participation	44	14.7	89	29.7	167	55.7
Overall	50	16.7	97	32.3	153	51

3.5 Relationship between factors and community participation

Correlation shows that the relationship between factors and community participation were nine variables as follows: social support, community caring, age, married, experience, information, high-income government official and community activity (Table 5)

Table 5 Relationship between factors and community participation (n = 300).

Variable	1	2	3	4	5	6	7	8	9	10
Community participation	1									
Social support	0.00**	1								
Community caring	0.00**	0.000**	1							
Age	0.01*	0.000**	0.002**	1						
Married (refence=single)	0.011*	0.005**	0.197	0.162	1					
Experience	0.000**	0.000**	0.000**	0.324	0.035*	1				
Information	0.000**	0.000**	0.000**	0.316	0.035*	0.000**	1			
High income (reference=low income)	0.000**	0.397	0.133	0.465	0.214	0.269	0.059	1		
Government official (reference=family /caregiver/friends)	0.000**	0.000**	0.000**	0.033*	0.030*	0.003**	0.000**	0.000**	1	
Community activity (reference=none joined)	0.019*	0.299	0.429	0.245	0.020*	0.194	0.002**	0.001**	0.331	1

**Correlation is significant at the 0.01 level (two-tailed).
*Correlation is significant at the 0.05 level (two-tailed).

3.6 Factors affecting community participation

Multiple regression analysis (MRA) shows that 5 factors affected the community participation including social support (Beta=0.441), community caring (Beta=0.332), high income (Beta=-0.169), government official (Beta=0.83), and joined with community activity (Beta=0.076). All factors together have a 63 percent power of prediction for community participation ($p< 0.005$) (Table 6)

Table 6 Factors affecting community participation (n=300).

Factor	β	Beta	*P*-value
Social support	0.616	0.441	0.000*
Community care	0.361	0.332	0.000*
High income (reference=low income)	-0.551	-0.169	0.000*
Government official (reference= Family/caregiver/friends)	0.333	0.83	0.026*
Frequency/always joined with community activity (reference=none joined)	0.249	0.076	0.036*

**P*-value< 0.05, Constant=361 R^2=0.63 Adjust R^2=0.62.

The results showed that community participation in caring for KT recipients in the lower northern region of Thailand was at a low level in terms of decision making participation, implementation participation, benefits participation, and evaluation participation with an overall score of 51%. Of the five factors affecting community participation, social support (Beta=0.441) and community care (Beta=0.332). Overall, social support was at a moderate level (42%). These findings are particularly important and give direction to improve community care for KT recipients**.** In the community, health care providers in district hospitals proceed primary health care by community participation with community leaders, village volunteers, family, caregivers, government officials, and all stakeholders involved in the health care system to take action. For example, community participation activities such as elderly society, home health care, chronic renal failure self-help group or diabetic club, and other chronic disease models but KT recipients are not explicitly cared for in the community.

This study result showed that community care about taking immunosuppressive drugs and daily activity was at a low level of 47.7% and 38.3%, respectively. When KT recipients were discharged to community-based care, they looked in normal health and did not need hemodialysis. However, they must get care from the community and social support, such as help with hard work, money support, avoiding infection from people, reminding of the strict time to take immunosuppressive drugs, and consultation when stressed or having any other problems. Although communities have a high attitude to community participation (87.7%), they may not know how to care for recipients as their knowledge level is moderate (55%). So, community care was low then KT recipients got self-care, low to moderate together. These findings are consistent with other studies in Thailand; some KT recipients, when discharged from hospital, have a moderate level of self-care in diet behavior and complications prevention [18], which is the same as KT recipients in the Northeast region who have a at a moderate level of self-care behavior in daily activities with the pathophysiology of kidney transplantation [19],and the quality of life for them with social and environment relationship is at a moderate level and should to development [20]. So, community care and social support are important in caring for kidney transplantation recipients in the lower northern region of Thailand. According to foreign country reviews, KT recipients who have social support will have good compliance of taking immunosuppressive drugs and a higher quality of life than those who have not [9-11,13,14]. Thus, community participation in caring for KT recipients is very important to health outcomes [15-17].

Community participation is a success factor for community development [21,22]. Social roles in this study that affected participation were government officials and district hospital providers. Because social roles leads to belief and trust from people in the community, and initiate the participation and motivation to develop the district health system [23-25]. Government officials and district hospital providers were government factors that support and promote community participation by providing knowledge, resources, budget, and activities in proceeding participation [24]. Caring for KT recipients is not the same as other chronic diseases in primary care. Thus, in this study, community participation was low, with the concern that government officials and district hospital providers may overlook community participation in caring for KT recipients and lack the connection of care from hospital-based to community-based. These findings are consistent with other studies that indicate health care providers overlook the importance of community participation and the lack of communication that promotes participation in health care service, including missing connections with community leaders and community teams and also having no sufficient support [26,27].

Also, factors that affected the community participation were income and always joining with community activity. Income in this study showed that a high income negatively affected community participation because people whose income is low usually depend more on the government sector for increased income that leads them to community participation than people who have high income [23]. Similar other studies show that people who have a low income have more community participation than high-income people. However, the difference from this study was that high-income people have more community participation than people with low income because they do less hard work for living costs and have more time to participate. While people with low income are busy working hard all time [28]. Participants who always joined community activities were only 20.7%. This has an effect on community participation since joining with community activities could make them harmonious and sympathetic [29]. If community leaders provided a higher number of activities, it could motivate people to join and improve the level of community participation [28].

Community participation not only promotes health and other benefits it also shows a wide viewpoint about health determinants of people. Most studies showed that community participation improved health outcomes [17,30].These results have important implications given the significant factors that affect community participation, and it will impact the quality of life, graft survival, and patient survival of KT. So,Community participation programs that include affecting factors should be implemented for public health intervention

5. Conclusion

This study describes factors that affect community participation in caring for KT recipients in the Lower Northern region of Thailand. Social support affected community participation the most and all factors together have a 63% ($p< 0.005$) power of prediction for community participation. We suggest that take factors affecting community participation to develop a community participation model for the care of KT recipients for future research. The limitation of this study is most KT recipients live in Phitsanulok province. Therefore**,** this can be regarded as a part of the Lower Northern region, and more studies need to be conducted on a larger scale with more KT recipients.

6. Acknowledgments

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7. Ethic approval

This research received ethical approval from Naresuan University ethical committee IR No 1012/62.

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