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Long-term management with phosphate binders in chronic kidney disease: Patient satisfaction levels with information received from their healthcare professional

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ABSTRACT

Background: Phosphate binding medications (PBM) are commonly used in the management of chronic kidney disease (CKD). Nurses caring for patients in the renal dialysis unit are primarily responsible for educating patients on action and usage of PBMs. **Methods:** Information was collected using two validated scales; The Satisfaction with Information about Medicine Scale and beliefs about medicines scale, from 41 renal dialysis patients using PBM for more than 6 months at a regional renal dialysis unit in 2012. **Results:** The results of this study show a high proportion of patients are not fully satisfied with the information they receive on their PBMs. 36% ($n = 15$) had total scores that fell below the total satisfaction score midpoint (<8). The relationship between satisfaction with information and concerns of taking PBM showed a medium negative correlation with higher levels of satisfaction with information on PBM associated with lower levels of concern about PBM use. **Conclusion:** Further research should identify the level and type of information needed to ensure patients are fully satisfied.

KEY WORDS: Chronic kidney disease, nursing, medication compliance, patient education

INTRODUCTION

In patients with chronic kidney disease (CKD), risk of morbidity, including vascular calcification, cardiovascular events, metabolic bone disease and fractures is increased [1]. Management of the condition varies depending on classification and progression of the disease with pharmacotherapy aimed at controlling blood pressure, osteoporosis, anemia and metabolic acidosis. Maintaining hemostasis is important to decrease complications, especially in cases where the ability of the kidneys to remove phosphorus is reduced [2]. Elevated phosphate levels can result in decreased calcium levels causing serious systemic effects and untreated hyperphosphatemia can cause secondary hyperparathyroidism, renal osteodystrophy and metastatic calcification of the blood vessels and soft tissue [2,3]. International treatment guidelines of hyper-phosphatemia in CKD patient undergoing dialysis, includes dietary phosphate restriction and phosphate binding medications (PBM) to lower serum levels toward normal [4].

Phosphate binding medication limits the absorption of dietary phosphate in the Gastro Intestinal Tract [5]. However, non-compliance with PBM is shown to be prevalent in CKD patients [6]. Patients are shown to prefer certain PMB formulations because of their taste and pill burden, with non-adherence being attributed to gastric intolerance, polypharmacy, patient awareness [7], type of dosage form (e.g., chewable), taste [6] and lack of knowledge about the importance of phosphate control [8]. Compliance with PBM is shown to be associated with age and suggests that increased age results in higher level of adherence [9]. There is limited evidence showing the relationship between compliance to PBM and length of time on dialysis, transplant history and regimen complexity. However, the interplay between psychosocial predictors and adherence is shown to have a significant relationship and in particular where concerns are related to benefits of taking medication, potential adverse effects of non-compliance and perceptions of others' expectations regarding adherence [9].

The consequences of non-adherence to long-term therapies such as PBM include poor health outcomes and increased healthcare utilization and associated costs. Interventions aimed at improving adherence are primarily targeted at prevention of risk factors and secondary prevention of adverse health outcomes [10]. Improving adherence requires a continuous and dynamic process to assess the patient's readiness to adhere, to provide the patient with advice and to follow the patient's progress. While clinical evidence shows that phosphate control in renal patients is suboptimal, educational strategies are shown to produce a better understanding of the requirements of PBM [8,11]. However, patients' knowledge in relation to the usefulness and importance of PBM remains scant with limited research identifying levels of patient satisfaction with the information provided to them by their healthcare team. Equally the level of information on medication required by patients varies significantly with some patients requiring more than provided to make informed decisions [12,13]. Identifying concerns and improving satisfaction levels with information provided on medication use is thought to reduce non-compliance with medication regimes, particularly in chronic illness [14-16]. The aim of this study was to identify patients' satisfaction with information provided on PBM and to identify concerns and beliefs regarding PBM use in CKD.

METHODS

A cross-sectional study was conducted at a regional renal dialysis unit located in the Republic of Ireland over a 2 month period in 2012. This unit is a major center located in 1 of 4 regional areas within the country. A total of 85 patients were registered as renal dialysis patients, with 41 patients being deemed eligible for inclusion to the study. Exclusion criteria included patients under the age of 18 years, those deemed not sufficiently in a stable condition to participate in the study as determined by their physician or Clinical Nurse Manager, patients who were <6 months on dialysis and those with poor comprehension of the English language. Each of the eligible patients was then invited to participate in the study following attendance at a routine appointment. All 41 patients agreed to take part and were provided with an information leaflet explaining the nature, purpose, benefits, potential outcome and expected duration of participation and rights to withdraw. A copy of the informed consent was given to each participant and each was informed of patient confidentiality. The researcher ensured that all participants fully understood the research and their role in the study prior to administering the questionnaire. Ethical approval was granted by the regional Ethics Committee of the Health Service Executive.

Measures

The questionnaire consisted of three parts. Initially the participants were asked to complete a section on their demographic details. This included information on sex, age, duration of dialysis treatment, educational attainment and their requirements for assistance in managing their medication.

To measure patients' satisfaction with the information on PBM the Satisfaction with Information about Medicine Scale (SIMS) developed by Horne *et al*. [12] was used. This is a 17 item scale consisting of 2 subscales. Items 1-9 referred to the information received about the "action and usage" of PBM medication. The items 10-17 referred to the information received about the "potential problems" of PBM medication. Participants are asked to indicate if the information they received was "too much," "about right," "too little," "none received" or "none needed." Participants indicating "about right" or "none needed" were classified as "satisfied" and received a score of "1." Whereas, participants who marked "too much," "too little" or "none received" were classified as "dissatisfied" and score zero. Scores were added to obtain a satisfaction rating for each subscale. As the participants were highly aware that phosphate binding medication was required for the lifetime of their disease, this question was removed from the scale and then re-tested for internal reliability using the remaining 16-items. Cronbachs alpha co-efficient for SIMS (total) was 0.83, while the action and usage and potential problems subscale were found to be 0.75 and 0.86 respectively and above the acceptable 0.7 level for internal reliability [17].

The third section of the questionnaire used the Beliefs about Medicines scale (BMQ) to assess patients beliefs about the medication prescribed to them [18]. The version used was specifically validated for use in chronic illness and consisted of two sub scales. Five of the questionnaire items (1-6) measured the necessity of PBM and serum phosphate control. A further five items (5-10) measured concerns regarding PBM. Responses to each statement were scored on a 5-point Likert scale (5= strongly disagree, 4= agree, 3= uncertain, 2= disagree, 1= strongly disagree).

Data Analysis

Data were coded and entered into statistical package for social sciences (SPSS) version 20 for analysis. The SIMS score ranged from 0 to 16, in which a total score of zero indicated a complete dissatisfaction with information on paranormal belief scale (PBs) and a total score of 16 indicated a complete satisfaction with information on PBMs. The total BMQ scores ranged from 10 to 50, in which a total score of 10 was highly indicative of disagreement and a total score of 50 was highly indicative of agreement to the items in the BMQ scale. Descriptive statistics were used to show levels of satisfaction on both the SIMS and BMQ scale. Difference between groups on the SIMS scale was tested using Mann–Whitney U Test. The relationship between satisfaction with information on medication and belief about medicines prescribed as measured by SIMS and BMQ scales was investigated using Pearson product-moment correlation coefficient.

RESULTS

Among the participants (n = 41), one reported a maximum total satisfaction score (SIMS) of 16 and one participant had a score of zero [Table 1]. The median satisfaction score on the SIMS scale was 8. 36% (n = 15) had total scores that fell below the total satisfaction score midpoint (<8). In the "action and usage" subscale, 12.1% of the sample (n = 5) scored below the midpoint (<4). In contrast, 63.4% of the sample (n = 26) scored below the midpoint for the "potential problems" subscale (<4). Figures 1 and 2 summarize the results in both SIMS subscales.

Overall median satisfaction scores were found to be marginally higher in males (Md = 9, n = 24) compared with females (Md = 8, n = 17). Those in the under 50 years category scored higher (Md = 8.5, $n = 10$ compared to those over 50 years (Md = 8, $n = 31$). However, those on dialysis for 6 years or less were comparative with those on dialysis for 7 years or more (Md = 8). Having assistance in managing their medication produced a moderately higher SIMS score (Md = 10.5, $n = 8$) in comparison to those not needing assistance (Md = 8, $n = 33$). A Mann–Whitney U test was used to test the difference between groups on SIMS scores. There was no statistically significant difference found in total satisfaction scores across age groups ($z = -0.366, P = 0.737$), length of time on dialysis ($z = -0.288, P = 0.788$), sex ($z = -0.972, P = 0.331$) or those with assistance in taking their medication ($z = -1.506, P = 0.132$).

Table 1: The demographic details of the participants

Demographics	Frequency	Percentage
Sex		
Male	24	58.5
Female	17	41.5
Age		
18-50 years	10	24.4
51 years+	31	75.6
Highest level of education		
Primary education only	17	41.5
Secondary education	16	39.0
Third level education	8	19.5
Length of time on HD		
6-months to 6 years	29	70.7
7 years+	12	29.3
Assistance in managing their medications		
Yes	8	19.5
No	33	80.5

Table 2 shows the results of participants in the BMQ scale. 95.2% ($n = 39$) showed a level of agreement to the item "controlling my phosphate level is important to me" while 92.7% of the sample ($n = 38$) reported that they understood the need to manage their phosphate levels. When questioned whether the number of tablets that they are taking is a problem for them, 73.2% ($n = 30$) showed a level of disagreement with this statement. Concerns surrounding phosphate binder use was confined to a small sample of <10% ($n = 4$). The medication appeared to be well-tolerated with 73% ($n = 30$) of the participants indicating that it did not give them unpleasant side-effects. 24% ($n = 10$) of the sample seemed uncertain that missing a dose was problematic while a further 17% ($n = 7$) thought that "it didn't matter too much if doses were missed." 22% ($n = 9$) of participants seemed uncertain with the statement "without this medicine I would be very ill" while a further 7.3% ($n = 3$) disagreed.

The relationship between satisfaction with information on PMB as measured by SIMS scale and necessity of taking PBM as measured on the BMQ showed a small positive correlation, however, this was not statistically significant, ($r = 0.288$, $n = 41, P = 0.067$). The relationship between satisfaction with information and concerns of taking PBM showed a medium negative correlation between the two variables, $r = -0.341$,

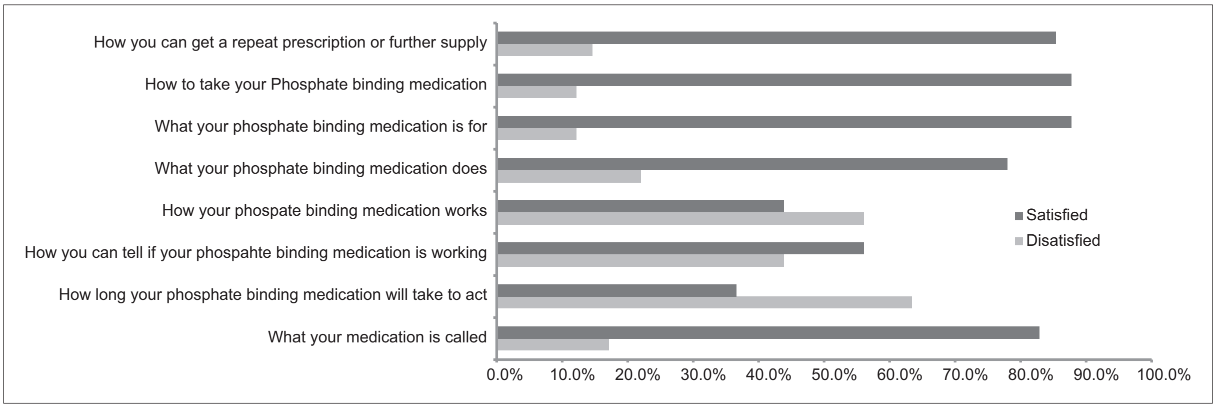

Figure 1: Satisfaction with Information about Medicine Scale action and usage subscale

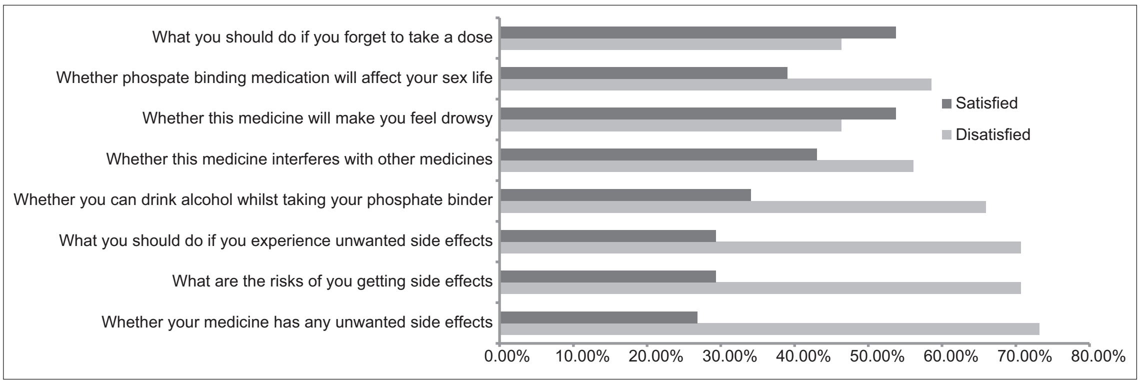

Figure 2: Satisfaction with Information about Medicine Scale potential problems subscale

Table 2: Beliefs about medicines scale

Question	Strongly agree (%)	Agree (%)	Uncertain (%)	Disagree (%)	Strongly disagree (%)
1. Controlling my phosphate level is important to me	22 (53.7)	17 (41.5)	1 (2.4)	1 (2.4)	0
2. I understand why I need to manage my phosphate levels	16 (39)	22 (53.7)	3 (7.3)	0	0
3. My health at present depends on phosphate binders	16 (39)	22 (53.7)	3 (7.3)	0	0
4. Missing doses of phosphate binders does not matter too much	2 (4.9)	5 (12.2)	10 (24.4)	16 (39)	8 (19.5)
5. The number of tablets I have to take is a problem for me	1 (2.4)	7 (17.1)	3 (7.3)	25 (61)	5 (12.2)
6. Without this medicine I would be very ill	15 (36.6)	14 (34.1)	9 (22)	3 (7.3)	0
7. Having to take this medicine worries me	2 (4.9)	2 (4.9)	3 (7.3)	27 (65.9)	7 (17.1)
8. This medicine gives me unpleasant side effects	1 (2.4)	4 (9.8)	6 (14.6)	24 (58.5)	6 (14.6)
9. I worry about long term effects of this medicine	2 (4.9)	6 (14.6)	7 (17.1)	22 (53.7)	4 (9.8)
10. I worry about becoming too dependent on this medicine	0	4 (9.8)	7 (17.1)	22 (53.7)	8 (19.5)

$n = 41$, $P = 0.029$ with higher levels of satisfaction with information on PBM associated with lower levels of concern about PMB use.

DISCUSSION

This study used a valid and reliable tool (SIMS) to assess the patients' satisfaction with information received about PBMs. The SIMS has been evaluated in terms of its ease of use, internal consistency, test-retest reliability and criterion related validity using existing self-report measures of adherence and patients' beliefs about medicines [12]. Equally the patients' beliefs and concerns regarding PBs were assessed using BMQ with the psychometric properties of the BMQ assessed in six different illness groups [18]. This study was successful in assessing patients' level of satisfaction with information and concerns and beliefs about PBM. There are several limitations in the current study. The SIMS questionnaire assesses patients' own views about the medication information they had received, rather than measuring the absolute quantity or quality of that information. This study was conducted in one dialysis unit in the ROI and the study results should be viewed in that context, limiting its generalizability to other patients using PBMs. However, it currently represents approximately 10% of all patients on dialysis in the ROI. The sample size is small and could be considered to lack statistical representation and a much greater sample would be required to look at specific sub-group analysis. There may be an element of responder bias resulting from the method of data collection. However, it was found that the majority of the patients were aware about the necessity of PBMs. Few participants (17%) reported that missing a dose of PBM did not matter to them. While studies report a high percentage of patients quit treatment to avoid its side effects regardless of its clinical relevance, the majority of the patients in the current study reported that they do not experience any unpleasant side-effects. However, there appeared to be high levels of dissatisfaction with information received in relation to the risk of side-effects (70.7%) and whether phosphate binders had any unwanted side effects (73.2%). This finding was reported in a similar study conducted by Paraham *et al.* in their study of patients' satisfaction with information received on phosphate binders in Stage V CKD patients across eight renal units in the UK [19]. Similarly, Ormandy *et al.* also reported that CKD patients would like to know more about the potential adverse effects of their medications [20]. Overall satisfaction with information on the potential problems of taking phosphate was lacking with 63.4% of the participants scoring below the midpoint of <4. Information related to the consumption of alcohol while taking PMBs and additionally in respect of its impact on sex life warrants further consideration.

Compliance to medication regimes is essential in the management of CKD and avoids unnecessary increases in the dosage of PBM following high serum phosphate levels [6]. Nurses have an important responsibility to supervise patients' adherence to their prescribed medication to ensure blood levels are maintained. It appears that patients in the current study showed high levels of agreement that managing their phosphate levels was important to maintaining health and avoiding further illness. However, 20% of the participants worried about long term effects of PBMs. The results of the current study showed some indication that higher levels of satisfaction with information about PBM resulted in higher satisfaction with necessity of use, whereas a more moderate indication showed that concerns were higher about PBM use in patients with lower SIMS scores. Concerns about the long term effects of medication use are thought to be a contributory factor in non-adherence to treatment [21].

The current study found variations in SIMS scores could not be attributed to age, gender, length of time on dialysis, assistance to manage medications. However, on further investigation of the results total satisfaction scores for the age group of 18-30 years were found to be higher than the rest of the age groups studied. It is feasible that younger adults may comprehend information received by their healthcare team to a greater extent and utilize the internet to access more information or gain clarity regarding their treatment and medications [22,23]. Parham *et al.* reported that a small but statistically significant negative correlation was found between age and satisfaction with information about the action and usage of PBM ($r = -0.18$, $P = 0.01$) [19]. That is, the younger adults were more satisfied with the information they received than older adults. They also reported that there were no significant group differences in satisfaction with either action and usage or potential problems for gender, length of time on dialysis and educational status.

The results of this study show that a high proportion of patients are not fully satisfied with the information they receive on their PMBs. It is not clear what type and level of information is actually required and it is important that clinicians can clearly identify the deficits in information provision to help patients with the management of their condition. Education strategies to ensure compliance with medication and particularly for those with chronic disease such as CKD should not be underestimated. Further research should identify the level and type of information needed to ensure patients are fully satisfied. It should also consider if information needs to be adapted to suit people of different age groups.

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