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Health Literacy

Communicative and critical health literacy, and self-management behaviors in end-stage renal disease patients with diabetes on hemodialysis

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ABSTRACT

Objective: Health Literacy (HL) has been linked to disease self-management and various health outcomes, and can be separated into components of functional, communicative and critical skills. The high comorbidity between diabetes and end-stage renal disease (ESRD) poses concerns for compromised disease self-management. This study aimed to identify the relationships between HL and self-management behaviors in end-stage renal disease patients with diabetes.
Methods: Self-report questionnaires measuring HL and self-management with the Functional, Communicative and Critical HL scale and Summary of Diabetes Self-Care Activities, respectively, were implemented with a sample of 63 patients. Socio-demographic and clinical characteristics were obtained from medical records.
Results: Self-management in diabetes was associated with communicative and critical HL, but not functional HL. Educational attainment was associated only with functional HL. No relationship between HL and glycated hemoglobin (Hb_{A1c}) was identified.
Conclusion: Communicative and critical HL skills are associated with self-management in ESRD patients with diabetes. Education levels are not related to self-management.
Practice implications: Healthcare professionals and health information aiming to improve self-management in ESRD patients with diabetes should consider their capacities of communicative and critical HL instead of solely assessing functional HL.

1. Introduction

Health literacy (HL) has been defined as "the degree of which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions" [1], and "cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health" [2]. Central to these definitions of HL are abilities to acquire, assimilate, and apply health-related information in manners appropriate to one's health. Providing a more concrete framework, Nutbeam proposed HL as encompassing elements of functional, communicative and critical skills [3]. Functional HL refers to basic literacy skills of reading and writing; communicative HL is aligned with distinct abilities necessary to extract information and derive meaning from various forms of communication. Together with critical HL – being able to critically evaluate obtained health-related information for enhanced control over life circumstances – HL is regarded as an entity with separate components each warranting different skill sets and subsequent outcomes.

Inadequate HL levels have been linked to a myriad of health-related outcomes, including increased mortality, lower physical functioning and quality of life, suboptimal utilization of health services, decreased capacity for disease self-management, elevated risks of medication errors and escalated healthcare costs [4,5]. Low HL is associated with inappropriate medication intake and an inability to interpret health labels and/or health-related information [5], and such phenomena induce poor treatment adherence. Across conditions of diabetes, cardiovascular disease and HIV, poor medication adherence and disease self-management have been highlighted as possible mediators between low HL and deficient disease outcomes [6–10]. In this light, Nutbeam's framework has helped to advance the understanding of possible mechanisms between HL and disease outcomes, as communicative and critical HL have been demonstrated to be associated with improved

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glycemic control and diabetes knowledge in two previous studies [11,12]. Abilities to extract information, derive meaning, and critically analyze health-related information can therefore be inferred to play a role in optimal disease management.

This HL research paradigm should be extended to patients with co-existing diabetes and End-Stage Renal Disease (ESRD). Both diabetes and ESRD involve complex multifaceted regimes that include medical aspects, i.e. dialysis, medication (and/or insulin) and lifestyle changes such as diet and fluid regulation, and physical activity [13,14]. Managing diabetes in context of ESRD and vice versa may become particularly challenging due to their competing needs/demands, the added complexity or regimes, as well increased symptoms. ESRD patients with diabetes are called to make complex decisions and reconcile contradictory treatment guidelines, which underscore the relevance of HL skills for this multi-morbid population. Diabetes patients are recommended to increase fruit and vegetable consumption, but ESRD patients are advised to limit such intake due to high potassium content for example [15]. A meta-analysis taking into account multiple self-management behaviors in context of diabetes has estimated an overall adherence rate of 67.5% [16], and medication adherence has been identified to range between 36 and 93% [16,17]. However, it is highly tenable that the added intricacy from multi-morbidities will further compromise treatment adherence [18]. Qualitative studies have highlighted how misinformed beliefs about medication and irrational thinking play a role in medication non-adherence in diabetic kidney disease patients [18,19], but there has been no quantitative research delving into aspects of literacy as a psychosocial factor potentially associated with self-management and adherence in the context of renal disease. The World Health Organization estimated a total of 346 million people to suffer from diabetes worldwide, and further projected this prevalence to increase twice between 2005 and 2030 [20]. ESRD is the leading complication of chronic diabetes [21], and patients with diabetes are the fastest growing segment of the dialysis population, simultaneously representing the patient group most at risk for poor clinical outcomes [22]. Overall, the co-existence of diabetes and ESRD leads to synergistic adverse effects – higher mortality mainly due to cardiovascular complications, reduced quality of life, and an increase in burden on healthcare services [23–25]. As poor adherence is linked to poor prognosis and disease outcomes [26], understanding drivers of poor self-management in this at-risk population is hence paramount to guide better management for these patients.

Taken together, this study primarily aimed to explore functional, communicative and critical HL among ESRD patients with diabetes (hereafter termed D-ESRD patients), and to examine their specific relationships with self-management behaviors. Findings from this research will be instrumental in allowing healthcare professionals or public health practitioners to either tailor health-related information specific to a domain of HL in this patient group, or strengthen specific constituents of HL so as to facilitate the understanding and application of treatment-related health information for better disease self-management and/or treatment adherence for improved disease outcomes.

2. Methods

2.1. Study population and setting

Participants were undergoing hemodialysis (HD) at National Kidney Foundation (NKF), a renal organization providing dialysis treatment to 62% of ESRD patients in Singapore [27]. Devised as an additional study to an on-going randomized controlled trial (RCT) aiming to improve renal self-management in established HD patients, samples were sought from the trial's current patient pool [28]. The following inclusion criteria were imposed: (1) D-ESRD patients on HD for 6 months and above, (2) aged 21 and above, and (3) ability to give informed consent. Exclusion criteria included (1) inability to understand written and/or spoken English, (2) severe visual and/or hearing impairment, and (3) mental and/or emotional disorders. Patient recruitment for this study was independent of their intervention status (treatment or control group) as the parent RCT undertook a double blind approach. Patients assigned to the intervention group were only identified subsequently ($n = 15$) during data analysis for bias control.

Cross-sectional questionnaires were administered. Participants were approached while undergoing HD at their corresponding dialysis center, and were provided with a full explanation of the study's objective and procedures by a trained research staff before informed consent was sought, followed by the questionnaire's implementation. Participants were sought from a total of 14 NKF dialysis centers.[1] No socio-demographic or ethnical differences between patients registered in the dialysis centers were anticipated in lieu of Singapore's urban planning policies that ensure an equal representation of ethnic groups in parts of the island (patients are typically assigned to a dialysis center nearest to their residence) [29].

Sixty-seven patients were identified to be eligible for study participation. Four patients however rejected to participate, citing physical fatigue as reason, constituting a response rate of 94%. All participants received a supermarket voucher worth 10 SGD (approximately 8 USD) as reimbursement. This study was conducted with ethics approval from National University of Singapore and University of Tokyo's Institutional Review Board.

2.2. Measures

2.2.1. Health literacy

The Functional, Communicative and Critical Health Literacy (FCCHL) scale [11], a recent scale developed in respect to the framework of HL as separate components of functional, communicative and critical HL [3] was used to assess HL levels. With five items for each sub-scale of functional and communicative HL, and four for critical HL, this 14-item self-report measure was rated on a range of 1–4 (never to often) for each item. The scores for the items in each sub-scale were summed and divided by the number of constituting items in the sub-scale to give a score (theoretical range for each HL domains is still 1–4). Scores were reversed for functional HL. Higher scores indicate higher levels of HL. The FCCHL scale was originally developed to measure levels of HL in the three domains, as opposed to a screening tool to classify patients with adequate or inadequate HL levels [refer to [11,30,31]]. It has adequately high internal consistencies of functional, communicative and critical HL. Internal consistencies were also found to be adequately high in this study; Cronbach's α were 0.85, 0.82, 0.79 and 0.86 for functional, communicative, critical and total HL, respectively.

2.2.2. Self-management behaviors of diabetes

The Summary of Diabetes Self-Care Activities (SDSCA) revised version [32] is a well-validated self-report measure of diabetes self-care. This revised 11-item scale comprises sub-scales for six domains of diabetes self-care behaviors, including general diet, specific diet, exercise, blood glucose testing, foot care and smoking using the average number of days per week (i.e. 0–7) each self-care activity has been performed, with two items per sub-scale. Items from the first five domains of diabetes self-care are together referred as the 10 core items. Smoking status was scored differently, as either '0' (non-smoker) or '1' (smoker). The average score between each sub-scales'

[1] Comparative analyses between participants recruited from dialysis centers could not be performed due to the limited sample size.