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Development and application of a chronic kidney disease-specific health literacy, knowledge and disease awareness assessment tool for patients with chronic kidney disease in Taiwan

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ABSTRACT

Objectives This study aims to develop an assessment tool for health literacy and knowledge specific to chronic kidney disease (CKD) for use in examining the associations between health literacy, disease-specific knowledge and disease awareness among patients with CKD in Taiwan.

Design An assessment tool in Mandarin and Taiwanese was developed based on patient input, panel discussions with experts and a literature review, and checked for validity and reliability in a pilot test. Formal data were collected through population-based sampling with a set quota according to region and hospital accreditation level. Cross-sectional data were collected to confirm the reliability and validity of the assessment tool. Levels of health literacy, disease knowledge, and disease awareness were then reported and analysed.

Setting Sample hospitals included 10 medical centres, 18 regional hospitals and 15 local hospitals in Taiwan. Researchers were granted Internal Review Board approval and obtained agreement to collect data in all study settings.

Participants Patients at least 20 years old who had been diagnosed with CKD of any stage were eligible to participate. The formal assessment collected 1155 valid questionnaires, yielding an 87.3% response rate. The mean age of participants was 67.48 years (SD=12.87, range 22–98), while 484 (41.95%) were female and 78% were aware they had CKD.

Results The self-devised instrument proved to have excellent reliability and validity. Use of the instrument in the main study showed that CKD-specific health literacy was significantly associated with age (β=−0.33, p<0.00), educational attainment and disease awareness (β=0.13, p<0.00). CKD-specific knowledge was also significantly associated with age (β=−0.18, p<0.00), educational attainment and disease awareness (β=0.19, p<0.00).

Conclusions This CKD-specific health literacy and knowledge assessment tool developed for Mandarin and Taiwanese-speaking patients is reliable and well validated. Patients with CKD who are aware of and understand their disease performed better in the assessment.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ To our knowledge, there are few disease-specific health literacy instruments with which to compare our assessment.
⇒ This nationwide study only provides an initial understanding of health literacy, disease knowledge and disease awareness among patients with chronic kidney disease (CKD).
⇒ The results only apply to Taiwanese patients with CKD, with limited generalisability to global populations.

BACKGROUND

Chronic kidney disease (CKD), often called a 'silent epidemic' for its difficulty to detect, is regarded as one of the most significant chronic diseases in the world. This quiet killer is especially prevalent in Taiwan, which in 2018 reported the highest incidence of treated end-stage renal disease (ESRD) in the world at 523 people per million compared with 395 per million in the USA, according to an annual report by the US Renal Data System (USRDS).[1] Not only did Taiwan record the world's highest rate, but it is also climbing, growing 6.1% between 2003 and 2016.[2] In 2017, NT$503.63 billion (US$1=NT$27.93) was spent on acute and chronic kidney diseases, accounting for the largest portion of the country's National Health Insurance expenditures. Approximately NT$433 billion was spent on dialysis alone,[3] not to mention the costs associated with lost productivity.

Slowing the progression of CKD relies on patients taking responsibility for their own care, including following nephrologists' instructions on diet, fluid intake and exercise.[4 5] Success therefore hinges on key factors such as health literacy, adherence behaviour

and disease awareness, as well as a commitment to accommodating CKD.[4 6] Among these factors, disease awareness is especially crucial, as it helps patients understand risk and accept their disease, and ensures they are willing to learn from and cooperate with health providers. Good disease awareness enhances health literacy, thereby helping patients better manage their condition.[5 7]

Disease awareness is defined as understanding individual risk, disease status and disease history, as well as fully committing to managing a disease.[8–10] Patients with chronic diseases are expected to take an active role in managing their illness and understanding risk to slow its progression. Patients must also learn disease-specific information to best make their own judgements on questions of care. However, CKD awareness among patients is low according to previous studies and our own clinical observations.[10] In Taiwan, the national prevalence of CKD as of 2006 was 11.93%, but only 3.54% of the participants in one study were aware of their condition.[11]

Once disease awareness is improved, health literacy may follow. As defined by the American Medical Association, health literacy is 'a constellation skill, including the ability to perform basic reading and numerical tasks required to function in the healthcare environment.'[12] According to Nutbeam, health literacy encompasses three domains: basic/functional literacy, communicative/interactive literacy and critical literacy, including cognitive and social skills that incorporate the abilities required to read, comprehend and analyse information.[13] As health literacy significantly affects healthy lifestyle choices and adherence,[14] enhancing patients' health literacy could lead to better physician–patient communication and more effective utilisation of medical resources, ultimately improving patients' self-management behaviour and health outcomes.[15–18]

There are already some commonly used tools to measure health literacy, such as the Test of Functional Health Literacy in Adults,[19] Newest Vital Sign,[20] the European Health Literacy Survey[21] and the Health Literacy Questionnaire.[22] A systematic review of studies measuring CKD literacy revealed that most researchers used the Rapid Estimate of Adult Literacy in Medicine, the Short Test of Functional Health Literacy or the Brief Health Literacy Screen.[23] As for health knowledge, some assessment tools have been designed specifically for patients with CKD, including the Perceived Kidney Knowledge Survey and objective knowledge tool, and the Kidney Disease Knowledge Survey (KiKS) developed by Wright *et al*.[24] Believing that disease-related knowledge should include perceived knowledge (what patients actually know) in addition to objective knowledge (what patients expect to know), Wright *et al* developed KiKS based on the Kidney Disease Outcomes Quality Initiative Guidelines.[25] Two other researchers, Devraj and Wallace, developed a Chronic Kidney Disease Self-Management Knowledge Tool to measure how well patients understand kidney disease and self-management behaviour.[26] However, few instruments have been designed to measure CKD-specific health literacy, with most health professionals instead using general literacy instruments.[23 27] In addition to CKD-specific health education, health literacy is also crucial to ensure that patients with CKD understand their illness and can make decisions based on this knowledge.

To better understand and identify health literacy among patients with CKD, we have developed a tool to assess CKD-specific health literacy for Mandarin and Taiwanese speakers. Data collected using the assessment tool were then used to examine associations between health literacy, disease-specific knowledge and disease awareness among patients with CKD in Taiwan, suggesting a need for earlier intervention to improve health literacy and thereby delay progression into ESRD.

METHODS

Study design

First, an assessment tool for measuring CKD-specific health literacy was developed for Mandarin and Taiwanese speakers based on patient input, panel discussions and a literature review,[24 28–30] and checked for validity and reliability in a pilot test. Formal data using the tool were collected through population-based sampling with a set quota according to region and hospital accreditation level. Cross-sectional data were collected to confirm the reliability and validity of the assessment tool. Levels of health literacy, disease knowledge, and disease awareness were then assessed and analysed.

Study population and sample

This study used Taiwan's National Health Insurance database (2010–2014) to estimate the number of patients with CKD in Taiwan. After determining there were about 870 000 people 20 years or older with CKD over the 4-year period, the 'International Classification of Disease 9th revision (ICD-9) code' as defined by the USRDS and Taiwan's National Health Insurance Administration was used to determine inclusion criteria.[31 32] The sample size was based on the equation $n = \frac{\frac{z^2 \cdot p(1-p)}{e^2}}{1+\left(\frac{z^2 \cdot p(1-p)}{e^2 N}\right)}$ and maintained a 95% level of confidence with a margin of error of ±3%. The process suggested a sample size of 1067 to represent the total population of patients with CKD in Taiwan (N=population size; e=margin of error; p=desired vol/population; z=z score).[33]

The 1067 suggested samples were weighted proportionally by hospital accreditation level (medical centre, regional hospital and district hospital) and hospital region (northern, central, southern, eastern and outlying island). After confirming the distribution of the total population, data were collected in 43 sample hospitals, including 10 medical centres, 18 regional hospitals and 15 local hospitals in Taiwan. Researchers were granted Internal Review Board approval and obtained agreement to collect data in all study settings. Data were collected in face-to-face interviews from March to November 2017. Interviewers

were trained before the study began. For inclusion in the study, participants had to be at least 20 years old and have been diagnosed with CKD of any stage. Patients who had received dialysis treatment, were pregnant or were unable to respond to questionnaires were excluded. This study did not exclude patients with comorbidities such as high blood pressure, diabetes or high hyperlipidaemia, with details included in the demographics section. Patients on dialysis were excluded because the guidelines and intensity of dialysis care differ greatly from CKD care.[34] This study instead focuses on patients with CKD whose disease progress could be slowed by better health literacy and disease management.

Nephrologists agreed to refer patients with CKD who met the inclusion criteria to researchers immediately following a doctor visit. Once eligible candidates agreed to participate, they were referred to a researcher who was waiting outside the nephrology clinic. Interviewers first explained the purpose of the study, then invited eligible subjects to participate. After disclosing it would take about 20–25 min to complete the survey, the interviewers obtained oral and written consent, leaving eligible participants free to choose whether to participate.

Instrument development and validation

Instrument development

An instrument in Mandarin and Taiwanese to assess CKD-specific health literacy and knowledge was developed based on a literature review, four focus groups with patients and panel discussions with physicians. The literature review confirmed the current definition and tools to measure CKD-specific health literacy and knowledge. Meanwhile, the focus groups served to assess concerns and habits of patients with CKD, while panel discussions with experts assessed the difficulties faced by physicians treating CKD.

For the focus groups, a total of 16 patients with CKD (9 men and 7 women) were referred by nephrologists to share their cognitive experiences of the disease, adherence behaviour, and how they select and respond to health-related information. Only patients in the early stages of CKD who regularly visit nephrologists were included. Age, gender and success with disease management were also taken into consideration to ensure group heterogeneity. Four focus groups were held in hospitals located in northern, central, southern and eastern Taiwan in order to mitigate possible effects of geographical variance on the results. Participants were informed and gave consent to participate prior to the start of the focus groups. All interviews were conducted in spare hospital rooms and each took 90–120 min to complete. Interview guidelines are included in online supplemental appendix 1. All focus groups were audio recorded and transcribed verbatim, then coded by two authors. The codes were then checked and retained when inter-rater reliability exceeded 0.8. Data saturation was confirmed when no new themes emerged in the third and fourth focus groups. Qualitative results of the focus groups revealed three findings: participants who denied their illness were reluctant to follow doctors' orders; participants understood the importance of maintaining a healthy diet, but only a few followed recommendations; and patients were most likely to maintain a healthy lifestyle with sufficient social support.

Confirmed by expert panels and a literature review, researchers concluded that the most important determinants to successful CKD management are disease awareness, health literacy and knowledge, and demography. These key factors then guided the development of a CKD-specific health literacy questionnaire.

Basic/functional literacy refers to basic literacy and cognitive abilities, such as the reading and writing skills needed to function effectively in daily life. Communicative/interactive literacy refers to more advanced cognitive skills, such as the ability 'to extract information and derive meaning from different forms of communication, and to apply new information to changing circumstances'.[12] Advanced/critical literacy refers to the ability to 'critically analyse information, and to use this information to exert greater control over life events and situations'.[13]

The 'disease awareness' category of questions (three items) in the questionnaire was designed to measure whether patients know they have an illness and if they have changed their daily behaviour to manage it. Questions were as follows: 'Do you have CKD or a related disease?' (Yes/No), 'Does this illness impact your lifestyle?' (Yes/No), and 'Have you changed your lifestyle to manage this illness?' (Yes/No).

The 'CKD-specific health literacy' category consisted of questions intended to measure functional (four items), communicative (eight items) and critical (five items) health literacy, defined respectively as the ability to understand an illness, communicate effectively and make judgements based on facts.[13] The 12 items were presented as a multiple-choice cloze test, with one point awarded for each correct response. The questions were written based on reading materials from the US National Kidney Disease Education Program and the Health Promotion Administration (HPA) of Taiwan's Ministry of Health and Welfare.[35 36]

'Disease-specific knowledge' questions tested participants on basic kidney functionality (four items), kidney disease prevention (three items), healthy lifestyle habits (five items), diet (four items) and medication (two items) based on reading materials prepared for KiKS and by the HPA.[25 36] The 21 items were presented as true-or-false questions, with a 'do not know' option. One point was given for each correct answer.

Demographic data included gender, age, educational attainment, area of residence, socioeconomic status, disease history, CKD stage and accreditation level of hospitals visited.

Validation

Face validity was checked by a three-round Delphi method. Sixteen experts—four nephrologists (MD/

PhD), two pharmacists, two dietitians, three nurses/health educators and five professors with PhDs—were invited to score items, revise wordings and allocate items to the appropriate dimensions. Scores ranged from 1 to 3, with 1 meaning remove the item, 2 recommending revision and 3 meaning keep the item without revision. Items that averaged a score of 2 or higher were kept.

Pilot test

For the pilot test, 50 eligible participants were selected from a medical centre, regional hospital and district hospital in the Taipei area. The majority were men (n=34, 68%) and average age was 67.84 years (SD=13.90, range=37–93). Kuder-Richardson Formula 20 (KR-20) results for health literacy and disease-specific knowledge were 0.78 and 0.76, respectively,[37] indicating good reliability. Data collected in the pilot test were not included in the main study.

Statistical analysis

Construct validity of CKD-specific health literacy and knowledge was checked through confirmatory factor analysis. Descriptive statistics were reported for demographic variables, disease awareness, CKD-specific health literacy and disease-specific knowledge. A t-test/One-way analysis of variance (ANOVA) was used to report bivariate association of the study variables. After ensuring that the study variables were normally distributed, the relationship between literacy, disease knowledge and disease awareness by healthcare facility accreditation was determined through multiple regression. Data were analysed using the IBM SPSS V.22.0 and LISREL V.9.3.

Patient and public involvement

Patients and the public were not involved in this study.

RESULTS

Construct validity and reliability

To confirm construct validity, the factorial structure of the items was tested by confirmatory factor analysis. Based on the model fit index, two items relating to CKD-specific knowledge were deleted to ensure best fit (table 1), leaving 17 items to measure health literacy and 16 items to measure CKD-specific knowledge. Confirmatory factor analysis coefficients are shown in figures 1 and 2. The KR-20 reliability of health literacy and CKD-specific knowledge were 0.68 and 0.81, respectively.

Descriptive statistics

A total of 1155 questionnaires were collected from 1323 eligible candidates, yielding an 87.3% response rate and surpassing the original goal of collecting 1067 valid questionnaires with a response rate of 85%. The mean age of participants was 67.48 years (SD=12.87, range 22–98) and the mean time since diagnosis with CKD was 5.33 years (SD=6.38, range 0–60). Slightly more than half of the participants (58.1%) were men, and 57.2% had attained at least high school education. By disease level, 5.5% were in stage 1, 13.0% were in stage 2, 16.7% were in stage 3A, 26.1% were in stage 3B, 20.2% were in stage 4 and 18.4% were in stage 5. Regarding comorbidities, 70.6% reported also having hypertension, while 49.6% reported having diabetes. Although 75.9% of the participants had been educated by medical staff, 22.0% reported a lack of disease awareness. All missing data were identified and corrected during interviews.

Table 1 Confirmatory factor analysis-model fitting index

	CKD-specific health literacy	Disease-specific knowledge	Fitting index
Overall model fit			
X^2	495.04	435.48	Smaller is better
RMSEA	0.053	0.056	<0.05
Absolute fit			
GFI	0.95	0.95	>0.9
AGFI	0.94	0.93	>0.9
Comparative fit			
NNFI	0.84	0.95	>0.9
CFI	0.86	0.96	>0.9
ECVI	0.49	0.45	Smaller is better
Parsimonious fit			
PNFI	0.71	0.74	>0.5
PGFI	0.72	0.66	>0.5

X^2, Chi-square; AGFI, Adjusted Goodness of Fit Index; CFI, Comparative Fit Index; CKD, chronic kidney disease; ECVI, Expected cross-validation Index ; GFI, Goodness of Fit Index; NNFI, Non-Normed Fit Index; PGFI, Parsimonious Goodness Fit Index; PNFI, Parsimonious Normed Fit Index; RMSEA, Root Mean Square Error of Approximation.

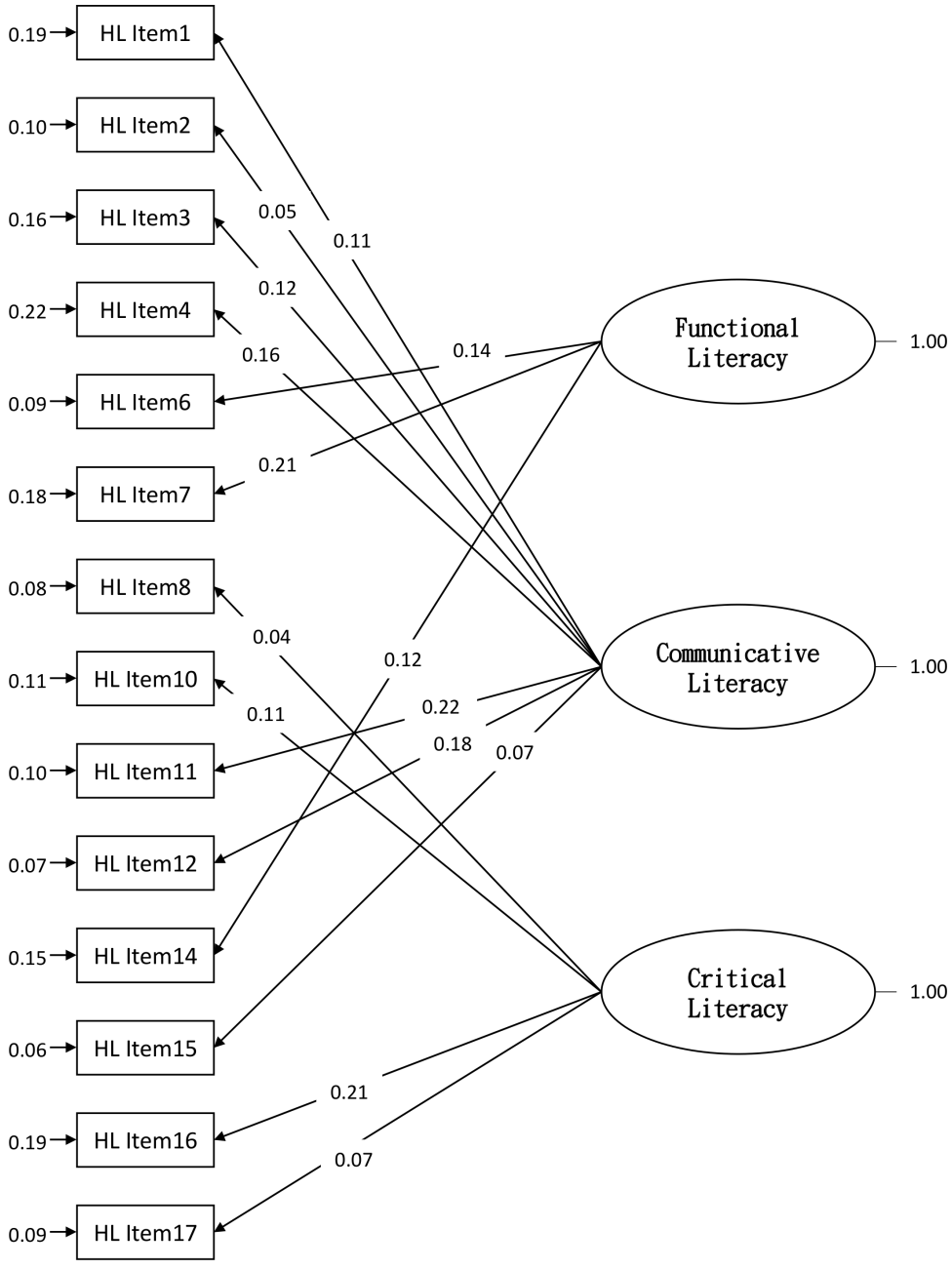

Figure 1 Confirmatory factor analysis of the three dimensions of chronic kidney disease-specific health literacy (HL).

Mean scores were 4.06 (SD=1.19, range 0–5) for functional literacy, 4.12 (SD=2.01, range 0–7) for communicative literacy, 2.57 (SD=1.75, range 0–5) for critical literacy and 8.75 (SD=5.70, range 0–17) for total health literacy. Mean scores for CKD-specific knowledge were 2.30 (SD=0.97, range 0–3) for basic knowledge, 2.35 (SD=0.93, range 0–3) for prevention, 3.22 (SD=0.97, range 0–4) for lifestyle, 2.50 (SD=1.17, range 0–4) for dietary intake, 1.30 (SD=0.67, range 0–2) for medication and 11.67 (SD=3.44, range 0–16) for overall CKD knowledge.

Bivariate analysis

Male participants recorded significantly higher rates of communicative health literacy, critical health literacy and basic kidney knowledge than women (table 2). Participants who were younger, had higher educational attainment or previous health education, and were aware of having CKD recorded better CKD-specific health literacy and knowledge.

There was no significant correlation between CKD awareness and gender or age, but CKD stage and previous health education had a significant effect. Disease awareness was relatively split among those in stages 1 and 2, with 36 of the participants in stage 1 saying they were aware of their disease and 28 saying they were not, while 88 in stage 2 said they were aware and 60 said they were not. Participants in pre-ESRD stages were slightly more aware of their disease, but the greatest jump occurred at

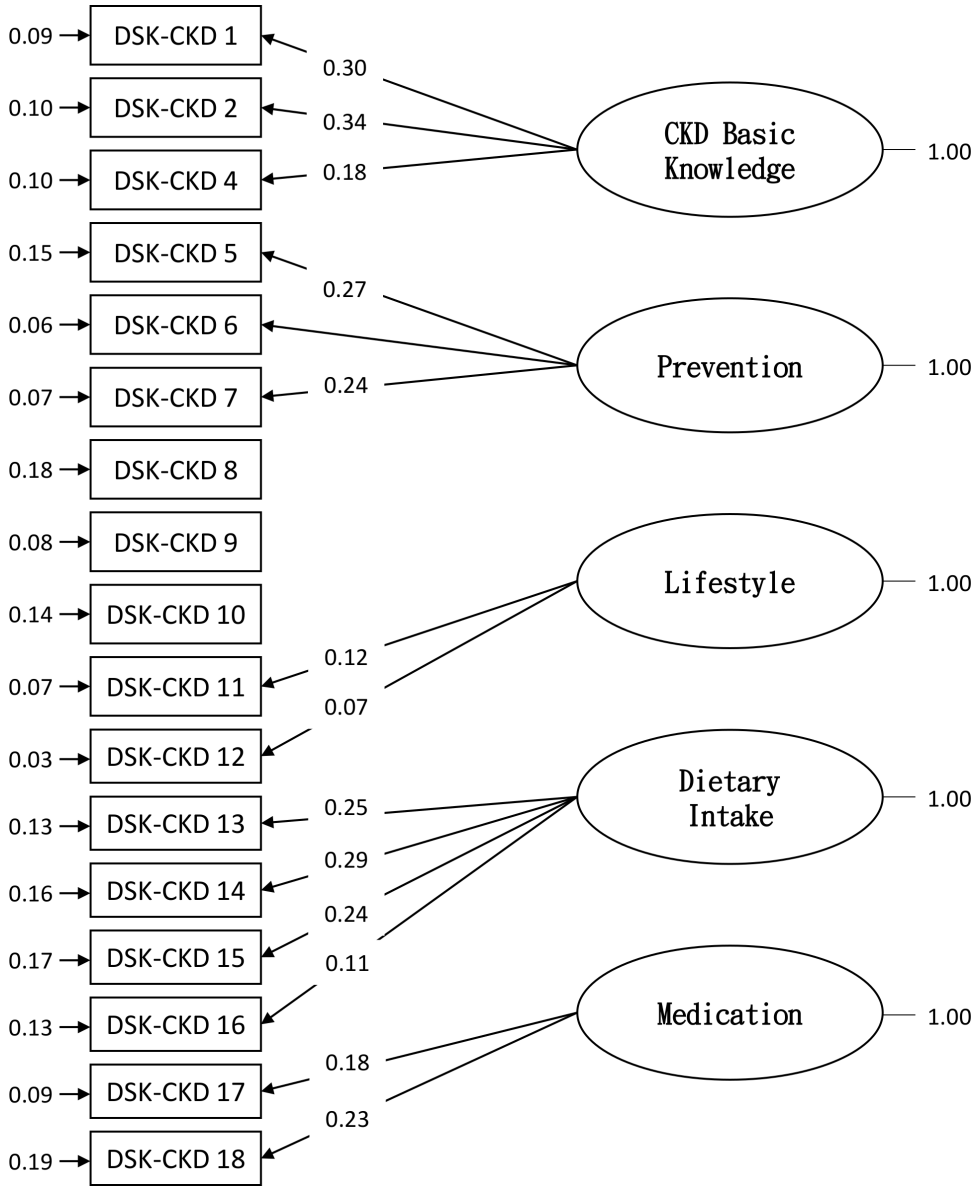

Figure 2 Confirmatory factor analysis of the five dimensions of disease-specific knowledge of chronic kidney disease (DSK-CKD).

stage 5, with 184 reporting awareness to only 29 who said they were unaware of their condition.

Regression analysis

Linear regression was employed to explore the relationships between demographic variables, CKD awareness, and CKD-specific health literacy and knowledge (table 3). The results show that CKD-specific health literacy was significantly associated with age (β=−0.33, p<0.00), educational attainment and disease awareness (β=0.13, p<0.00). It was also linked to disease stage, as participants in stage 5 presented significantly worse health literacy than participants in stage 1. CKD-specific knowledge was also significantly associated with age (β=−0.18, p<0.00), educational attainment and disease awareness (β=0.19, p<0.00), although there was no significant correlation between CKD stage and disease-specific knowledge.

DISCUSSION

Instrument and major findings

This CKD-specific health literacy and knowledge assessment tool in Mandarin and Taiwanese developed to enable better management of CKD by measuring basic/functional, communicative, and critical literacy and knowledge proved to have very good reliability and validity. We therefore recommend its use in assessing the overall health literacy and knowledge of patients with CKD to identify deficiencies and better target educational efforts.[38]

Although health literacy has been criticised for its poor definition and tenuous connection to health promotion,[39] many studies have managed to redefine its frameworks and enhance its feasibility, enabling its use as a tool in bridging the gap between patients and healthcare

Table 2 CKD-specific health literacy, knowledge and disease awareness by demographics (n=1155)

		CKD-specific health literacy				Disease-specific knowledge							
	N (%)	FUN	COM	CRI	Total scores	BASIC	PRE	LIFE	DIET	MED	Total scores	Awareness of CKD	
	Range	0–5	0–7	0–5	0–17	0–3	0–3	0–4	0–4	0–2	0–16	Yes	No
Gender													
Male	671 (58.1)	4.02 (1.22)	4.26 (2.02)	2.73 (1.73)	9.26 (5.67)	2.40 (0.89)	2.39 (0.89)	3.26 (0.96)	2.45 (1.14)	1.29 (0.67)	11.79 (3.29)	535 (46.4)	136 (11.8)
Female	484 (41.9)	4.12 (1.14)	3.93 (1.97)	2.34 (1.75)	8.05 (5.67)	2.17 (1.05)	2.30 (0.98)	3.16 (0.99)	2.56 (1.21)	1.30 (0.67)	11.49 (3.64)	364 (31.6)	117 (10.2)
P value		0.343	0.005**	<0.001***	<0.001***	<0.001***	0.137	0.064	0.122	0.951	0.135	0.101	
Age													
20–29 years	8 (0.7)	4.86 (0.38)	6.00 (1.41)	4.00 (1.41)	14.25 (4.20)	2.50 (0.53)	2.63 (0.52)	3.63 (0.52)	3.13 (0.64)	1.75 (0.46)	13.63 (1.60)	7 (0.6)	1 (0.1)
30–39 years	31 (2.7)	4.76 (0.58)	5.90 (1.37)	4.35 (1.08)	14.71 (3.35)	2.55 (0.68)	2.65 (0.61)	3.58 (0.67)	2.74 (1.21)	1.65 (0.61)	13.16 (2.66)	26 (2.3)	5 (0.4)
40–49 years	58 (5.0)	4.37 (0.92)	5.81 (1.26)	4.05 (1.05)	14.16 (2.78)	2.76 (0.51)	2.72 (0.59)	3.34 (0.83)	2.62 (0.99)	1.45 (0.60)	12.90 (2.14)	44 (3.8)	14 (1.2)
50–59 years	197 (17.1)	4.26 (0.98)	5.13 (1.78)	3.59 (1.58)	12.03 (5.05)	2.63 (0.71)	2.63 (0.67)	3.47 (0.83)	2.89 (1.08)	1.43 (0.62)	13.05 (2.85)	157 (13.6)	40 (3.5)
60–69 years	318 (27.5)	3.98 (1.18)	4.19 (2.02)	2.64 (1.75)	8.98 (5.68)	2.41 (0.91)	2.48 (0.82)	3.32 (0.87)	2.61 (1.17)	1.32 (0.64)	12.14 (3.00)	263 (22.8)	53 (4.6)
70–79 years	338 (29.3)	3.66 (1.45)	3.63 (1.87)	2.04 (1.58)	7.05 (5.16)	2.13 (1.05)	2.22 (1.00)	3.12 (1.00)	2.36 (1.13)	1.24 (0.68)	11.07 (3.53)	254 (22.0)	83 (7.2)
80 years & above	205 (17.7)	3.80 (1.32)	3.04 (1.70)	1.57 (1.33)	5.40 (4.37)	1.93 (1.10)	1.95 (1.11)	2.86 (1.15)	2.09 (1.23)	1.10 (0.71)	9.93 (3.95)	148 (12.8)	57 (4.9)
P value		<0.001***	<0.001***	<0.001***	<0.001***	<0.001***	<0.001***	<0.001***	<0.001***	<0.001***	<0.001***	0.063	
Educational attainment													
Primary school or lower	493 (42.8)	3.57 (1.34)	3.22 (1.75)	1.68 (1.40)	5.83 (4.55)	1.95 (1.10)	2.10 (1.06)	2.93 (1.05)	2.23 (1.17)	1.18 (0.71)	10.38 (3.69)	363 (31.6)	129 (11.2)
Junior high	178 (15.4)	3.86 (1.30)	4.16 (1.74)	2.61 (1.39)	8.86 (5.66)	2.38 (0.90)	2.37 (0.84)	3.28 (0.91)	2.46 (1.19)	1.23 (0.64)	11.71 (3.16)	141 (12.3)	37 (3.2)
Senior high	248 (21.5)	4.23 (1.06)	4.87 (2.01)	3.31 (1.76)	11.21 (5.28)	2.54 (0.75)	2.54 (0.81)	3.48 (0.80)	2.79 (1.13)	1.44 (0.60)	12.79 (2.84)	196 (17.0)	50 (4.3)
College	209 (18.1)	4.28 (1.04)	5.09 (1.78)	3.51 (1.68)	11.87 (5.26)	3.72 (0.62)	2.67 (0.64)	3.47 (0.86)	2.76 (1.05)	1.45 (0.62)	13.08 (2.66)	175 (15.2)	34 (3.0)
Graduate school	25 (2.2)	4.63 (0.88)	6.04 (1.95)	4.52 (0.92)	15.00 (2.94)	2.88 (0.44)	2.68 (0.56)	3.64 (0.64)	3.00 (1.04)	1.40 (0.65)	13.60 (2.08)	22 (1.9)	3 (0.3)
P value		<0.001***	<0.001***	<0.001***	<0.001***	<0.001***	<0.001***	<0.001***	<0.001***	<0.001***	<0.001***	0.025*	
CKD stage													

Continued

Table 2 Continued

		CKD-specific health literacy				Disease-specific knowledge							
	N (%)	FUN	COM	CRI	Total scores	BASIC	PRE	LIFE	DIET	MED	Total scores	Awareness of CKD	
	Range	0–5	0–7	0–5	0–17	0–3	0–3	0–4	0–4	0–2	0–16	Yes	No
1	64 (5.5)	4.26 (1.11)	5.08 (1.61)	3.66 (1.49)	12.27 (4.62)	2.43 (0.89)	2.55 (0.78)	3.27 (0.88)	2.45 (1.26)	1.38 (0.63)	12.08 (3.17)	36 (3.1)	28 (2.4)
2	150 (13.0)	4.01 (1.18)	4.48 (1.99)	3.06 (1.74)	10.07 (5.65)	2.47 (0.87)	2.41 (0.85)	3.25 (0.92)	2.30 (1.04)	1.40 (0.65)	11.85 (3.17)	88 (7.6)	60 (5.2)
3A	193 (16.7)	4.28 (0.95)	4.26 (1.99)	2.61 (1.80)	9.08 (5.77)	2.21 (0.99)	2.29 (0.94)	3.18 (1.01)	2.28 (1.17)	1.26 (0.67)	11.23 (3.51)	137 (11.9)	55 (4.8)
3B	302 (26.1)	4.03 (1.29)	4.09 (2.06)	2.42 (1.72)	8.36 (5.72)	2.25 (0.98)	2.32 (0.96)	3.29 (0.89)	2.52 (1.16)	1.30 (0.69)	11.68 (3.40)	255 (22.1)	47 (4.1)
4	233 (20.2)	3.85 (1.29)	3.93 (2.06)	2.42 (1.72)	8.26 (5.65)	2.29 (1.01)	2.30 (0.95)	3.18 (1.03)	2.59 (1.19)	1.27 (0.68)	11.63 (3.46)	199 (17.3)	34 (3.0)
5	213 (18.4)	4.03 (1.18)	3.71 (1.89)	2.22 (1.68)	7.57 (5.44)	2.30 (0.97)	2.41 (0.94)	3.15 (1.04)	2.71 (1.18)	1.25 (0.66)	11.84 (3.68)	184 (16.0)	29 (2.5)
P value		0.119	<0.001***	<0.001***	<0.001***	0.119	0.294	0.618	0.002**	0.337	0.417	<0.001***	
Years with CKD													
Less than 1	154 (14.5)	3.76 (1.41)	3.62 (1.91)	2.21 (1.60)	7.59 (5.33)	2.16 (1.01)	2.27 (0.91)	3.18 (1.00)	2.29 (1.11)	1.24 (0.63)	11.14 (3.32)	102 (9.6)	51 (4.8)
1–4	488 (45.9)	4.13 (1.13)	4.28 (2.06)	2.77 (1.78)	9.33 (5.80)	2.38 (0.93)	2.40 (0.87)	3.24 (0.93)	2.58 (1.17)	1.30 (0.67)	11.90 (3.30)	389 (36.7)	98 (9.2)
5–9	208 (19.6)	4.07 (1.15)	4.26 (1.94)	2.64 (1.77)	9.00 (5.65)	2.46 (0.85)	2.45 (0.93)	3.34 (0.97)	2.58 (1.16)	1.41 (0.67)	12.25 (3.32)	176 (16.6)	32 (3.0)
10–19	150 (14.1)	4.18 (1.06)	4.17 (1.98)	2.48 (1.71)	8.67 (5.66)	2.24 (1.03)	2.31 (1.02)	3.16 (0.93)	2.50 (1.17)	1.29 (0.68)	11.50 (3.59	122 (11.5)	28 (2.6)
20 years or more	63 (5.9)	3.93 (1.41)	3.83 (2.02)	2.40 (1.89)	7.87 (5.89)	2.25 (1.00)	2.27 (1.03)	3.16 (1.05)	2.60 (1.24)	1.35 (0.68)	11.63 (3.62)	54 (5.1)	9 (0.8)
P value		0.217	0.005**	0.009**	0.011*	0.025*	0.220	0.343	0.095	0.137	0.023*	<0.001***	
Hospital accreditation level													
Medical centre	403 (34.9)	3.84 (1.38)	3.95 (2.00)	2.53 (1.71)	8.48 (5.64)	2.48 (0.77)	2.50 (0.84)	3.34 (0.86)	2.68 (1.09)	1.40 (0.60)	12.40 (2.81)	344 (29.9)	58 (5.0)
Regional hospital	479 (41.5)	4.17 (1.14)	4.37 (1.97)	2.66 (1.79)	9.22 (5.74)	2.34 (0.96)	2.38 (0.87)	3.24 (0.97)	2.53 (1.20)	1.26 (0.68)	11.76 (3.52)	364 (31.6)	114 (9.9)
District hospital	273 (23.6)	4.20 (0.86)	3.95 (2.05)	2.46 (1.74)	8.33 (5.69)	1.97 (1.14)	2.08 (1.10)	3.00 (1.09)	2.16 (1.18)	1.20 (0.73)	10.42 (3.80)	191 (16.6)	81 (7.0)
P value		0.002**	0.002**	0.303	0.063	<0.001***	<0.001***	<0.001***	<0.001***	<0.001***	<0.001***	<0.001***	
Residential region													
Northern	407 (35.2)	3.72 (1.42)	4.14 (1.94)	2.59 (1.71)	8.86 (5.51)	2.38 (0.87)	2.38 (0.90)	3.21 (0.98)	2.48 (1.15)	1.35 (0.66)	11.81 (3.29)	323 (28.0)	83 (7.2)

Continued

Table 2 Continued

		CKD-specific health literacy				Disease-specific knowledge							
	N (%)	FUN	COM	CRI	Total scores	BASIC	PRE	LIFE	DIET	MED	Total scores	Awareness of CKD	
	Range	0–5	0–7	0–5	0–17	0–3	0–3	0–4	0–4	0–2	0–16	Yes	No
Central	384 (33.2)	4.27 (0.97)	4.65 (1.94)	2.81 (1.82)	9.73 (5.77)	2.19 (1.07)	2.33 (0.99)	3.28 (0.92)	2.67 (1.22)	1.29 (0.71)	11.75 (4.71)	328 (28.5)	55 (4.8)
Southern	323 (28.0)	4.37 (0.83)	3.60 (2.02)	2.30 (1.71)	7.68 (5.70)	2.32 (0.96)	2.38 (0.88)	3.13 (1.04)	2.35 (1.11)	1.23 (0.65)	11.41 (3.35)	221 (19.2)	102 (8.9)
Eastern & outlying islands	41 (3.6)	3.67 (1.33)	3.15 (1.86)	2.26 (1.59)	6.95 (5.29)	2.39 (0.86)	2.12 (0.98)	3.41 (0.77)	2.22 (1.17)	1.37 (0.58)	11.51 (3.11)	27 (2.3)	13 (1.1)
P value		<0.001***	<0.001***	0.001**	<0.001***	0.0.31*	0.340	0.118	0.002**	0.071	0.398	<0.001***	
Previous education													
Yes	877 (75.9)	4.14 (1.12)	4.34 (1.98)	2.69 (1.79)	9.23 (5.73)	2.38 (0.94)	2.42 (0.91)	3.26 (0.93)	2.64 (1.18)	1.32 (0.67)	12.02 (3.40)	713 (61.9)	163 (14.1)
No	278 (24.1)	3.71 (1.39)	3.45 (1.96)	2.18 (1.57)	7.24 (5.32)	2.07 (1.03)	2.15 (0.97)	3.07 (1.07)	2.04 (1.03)	1.22 (0.67)	10.56 (3.36)	186 (16.1)	90 (7.8)
P value		0.002**	<0.001***	<0.001***	<0.001***	<0.001***	<0.001***	0.008**	<0.001***	0.022*	<0.001***	<0.001***	
Awareness of CKD													
Yes	899 (78.0)	4.08 (1.19)	4.32 (1.96)	2.68 (1.76)	9.19 (5.68)	2.39 (0.91)	2.44 (0.87)	3.31 (0.89)	2.62 (1.16)	1.33 (0.66)	12.09 (3.23)		
No	253 (22.0)	3.94 (1.22)	3.39 (2.02)	2.16 (1.67)	7.15 (5.49)	1.97 (1.09)	2.04 (1.05)	2.89 (1.16)	2.07 (1.09)	1.18 (0.71)	10.14 (3.75)		
P value		0.294	<0.001***	<0.001***	<0.001***	<0.001***	<0.001***	<0.001***	<0.001***	0.002**	<0.001***		

*P<0.05; **p<0.01; ***p<0.001.
.BASIC, chronic kidney disease basic knowledge; CKD, chronic kidney disease; COM, communicative literacy; CRI, critical literacy; DIET, dietary intake; FUN, functional literacy; LIFE, lifestyle; MED, medication; PRE, prevention.

Table 3 Regression model of CKD-specific health literacy and knowledge

	CKD-specific health literacy	Disease-specific knowledge
	β coefficient#	β coefficient#
Demographic variables		
Age	−0.33***	−0.18***
Years with CKD	0.02	0.02
CKD stage (stage 1)		
2	−0.06	0.03
3A	−0.11*	−0.03
3B	−0.12*	0.04
4	−0.14**	0.02
5	−0.21***	0.04
Gender (female)		
Male	0.04	−0.03
Educational attainment (primary school or lower)		
Junior high	0.13***	0.12***
Senior high	0.22***	0.21***
College or higher	0.29***	0.25***
Disease awareness of CKD (no)		
Yes	0.13***	0.19***
R^2	0.34	0.19
Adjusted R^2	0.33	0.18
F value	44.94***	20.50***

*P<0.05; **p<0.01; ***p<0.001.
#: standardised regression coefficient
CKD, chronic kidney disease.

providers.[4 23 34] To reflect health literacy as it is understood in the Taiwanese context, health literacy items were developed to assess everyday obstacles encountered by patients, such as how participants respond to their friends and how they approach follow-up actions. Expanding from Nutbeam's original definition,[13] local patient perspectives were also incorporated into this study, leading to an adjusted definition of health literacy as the ability to comprehend, communicate, use information and make decisions.

Participants recorded higher accuracy rates in functional literacy, basic knowledge and CKD prevention knowledge than in communicative literacy, critical literacy, dietary knowledge and medication knowledge. The lowest-scoring item in communicative health literacy—the section that covers everyday conversations between physicians and patients—was about reasons for adhering to fluid intake instructions (54.1%), while the second-lowest scoring item asked about reasons for collecting urine samples (72.7%). The worst performance in critical health literacy, defined as the ability to use information and make judgements, was in numeracy skill (61.7%), which refers to the use of quantitative data to manage medication use and fluid intake, and to monitor risk. Worse numeracy skills might lead to higher risk, especially in Taiwan and China, where CKD has proven a major issue.[6 34] In the dietary knowledge category, which involves knowing how to choose fruits, cooking oils and carbohydrates for daily meals, only 35.4% of participants with high phosphate levels chose whole grain rice for a carbohydrate, and only 57.8% of patients with pre-ESRD chose bananas for a fruit as physicians recommend. In the section on safe medication usage, only 43.6% of participants correctly identified the statement: 'Long-term use of anti-diabetic medication is highly likely to cause kidney failure in the long run.' Misunderstanding such important information related to disease management is an obstacle to patients taking a more active role in managing their condition.[40] Of all the topics, dietary knowledge proved the most difficult to comprehend and apply. A greater emphasis on dietary knowledge and numeracy skills in patient instruction is therefore recommended to enhance health literacy.[38 41]

Disease awareness

A significantly higher proportion of participants (78%) were aware that they had CKD in this study than in other comparable studies,[9 10] potentially indicating the success of a pay-for-performance pre-ESRD programme launched in 2006 and an early-CKD programme launched in 2011 in Taiwan.[42 43] The result could also be explained through selection bias, as the participants were referred by nephrologists and therefore might understand their disease better than those who visit other types of specialists or do not visit any physicians. More thorough data collection in the future is recommended.

Participants who were aware of their disease reported significantly better health knowledge and communicative and critical health literacy than those who were not aware they had CKD. Patients who understood their disease also performed better in disease health literacy and knowledge.[8] Although a difference between genders was expected, as men are typically more reluctant to admit they have kidney disease due to its connection with sexual dysfunction, a symbol of male pride, this study showed no significant difference in CKD awareness between men and women.[44 45] It also indicated that patients in pre-ESRD stages do not necessarily know their disease better than those in the early stages of CKD.

Implications

From a public health perspective, helping patients embrace their illness is the first step toward disease management. From this starting point, further education on health literacy and knowledge is suggested to improve communicative and critical literacy, while disease-specific education is suggested to improve knowledge about recommended diets and medication.

Limitations

There are three major limitations of this study. First, since all participants were recruited through nephrologist referrals, the results might not accurately reflect the status of those who visited other specialists or do not visit any physicians. Second, the results might be biased due to its cross-sectional design. Further longitudinal studies are recommended to explore causal relationships. Third, the results might not be generalisable to patients with CKD in other countries.

CONCLUSION

This CKD-specific health literacy and knowledge assessment tool developed for Mandarin and Taiwanese-speaking patients is reliable and well validated. While the participants were generally competent in functional literacy, basic knowledge and CKD prevention knowledge, the results showed room for improvement in communicative literacy, critical literacy, dietary knowledge and medication knowledge. Disease awareness played a significant role in performance, as participants who were aware they had CKD scored better on health knowledge questions and items measuring communicative and critical health literacy than those who were not aware of their condition. Patients who understood their disease also performed better than those who did not in CKD-specific health literacy and knowledge tests, showing that disease awareness is highly associated with CKD-specific health literacy and knowledge. We recommend that physicians enhance patients' awareness of their disease to inspire commitment to disease management.

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