

Assessment of palliative need in patients with chronic kidney disease by the new Three Levels of Need Questionnaire (3LNQ) is not exhaustive

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ABSTRACT

INTRODUCTION: The purpose of the study was to test and evaluate the Three Levels of Needs Questionnaire (3LNQ) as a method to clarify if help is needed and provided for 12 palliative problems in patients with chronic kidney disease stage 4 (CKD4).

MATERIAL AND METHODS: A total of 33 patients from a consecutive sample of patients with CKD4 were given two questionnaires. The 3LNQ measures problem intensity and unmet needs for 12 palliative problems. An open question was added allowing the patients to describe additional symptoms not included in the 3LNQ. The EuroQol 5-Dimensional 3-Level Questionnaire was distributed in order to determine the patients' health-related quality of life.

RESULTS: A total of 27 patients returned the two questionnaires (81.8%). Their average age was 69.3 years (range: 49-82 years). The prevalence of the 12 palliative problems ranged from 19-89%, whereas the prevalence of unmet needs ranged from 11% to 44%. The patients reported a median of seven problems and two unmet needs. Besides the 12 problems addressed by the 3LNQ, the following problems were mentioned by the patients: arthritis in the feet, morning cough, muscle cramps/pain, and nightly urination. The patients' mean health-related quality of life score was estimated to 0.791 (interval: 0.564-1).

CONCLUSION: The 3LNQ is usable to indicate problem intensity and unmet needs in patients with chronic kidney disease stage 4. However, the questionnaire does not cover all the problems from which patients with chronic kidney disease suffer. Further research into the complexity of need of specialised palliative care for these patients is needed in order to help them optimally.

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The prevalence of chronic kidney disease (CKD) has been estimated to 10-15% in adult populations, and more woman than men suffer from CKD. In Denmark, approximately 5,000 patients were in need of renal replacement therapy (RRT) in 2012 and the number is increasing. The annual mortality rate among patients in RRT is 20-30% and increases with age [1, 2].

Patients suffering from CKD often have a high bur-

den of symptoms and reduced health-related quality of life (HRQoL) [3-5]. A systematic review found that the most frequent symptoms from which patients with CKD suffer include fatigue, pruritus, constipation, anorexia, pain, sleep disturbance, anxiety, dyspnoea, nausea, restless legs and depression [5].

Specialised palliative care (SPC) has a positive effect on HRQoL and symptom burden [6-8], and the main purpose of SPC is to alleviate physical and psychological problems and to improve HRQoL in patients suffering from serious and complicated diseases. The Danish Health and Medicines Authority now recommends SPC to patients suffering from end-stage CKD [9], but patients are still not regularly referred to SPC units in Denmark [10-12], and patients often die while still in RRT [2, 13].

The aim of this study was to test and evaluate a newly developed questionnaire, the Three Levels of Needs Questionnaire (3LNQ) as a method to determine the extent of the presence of 12 palliative problems in patients suffering from CKD stage 4 in Denmark. Another aim was to identify whether these patients receive sufficient help to alleviate their problems. Patients with CKD of stage 4 were chosen as their future treatment may not be RRT alone, but SPC as well. Hence, it is relevant to identify these patients' early palliative needs. 3LNQ has previously been tested on Danish cancer patients with good results; therefore, we attempted to use it in patients with CKD [14, 15].

MATERIAL AND METHODS

Collection of data and patient population

This was a pilot study based on a consecutive sample of CKD4 patients at Aalborg University Hospital. Between 9th April and 26th April 2013, both days included, 33 questionnaire envelopes, each containing two questionnaires, a covering letter and a stamped return envelope were distributed in connection with an ordinary consultation in the Nephrological Outpatient Clinic.

Baseline characteristics were found by using the EuroQol 5-Dimensional 3-Level Questionnaire (EQ-5D). The EQ-5D is a short, self-reporting generic instrument describing HRQoL by generating a single index number for health status from 0 (dead) to 1 (perfect health).

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 TABLE 1

Characteristics of the study population.

	n	%
<i>Age, yrs</i>		
40-49	1	4
50-59	3	13
60-69	8	35
70-79	6	26
80-89	5	22
<i>Sex</i>		
Men	12	44.5
Women	12	44.5
Unknown	3	11
<i>Treated at the outpatient clinic</i>		
0-6 months	6	22
6-12 months	2	7
1-2 yrs	1	4
2-5 yrs	11	41
> 5 yrs	7	26
<i>Formal education</i>		
None	9	39
Skilled worker	13	57
Theoretical	1	4
<i>Civil status</i>		
Married/cohabiting	11	41
Divorced/separated	4	15
Widow/widower	10	37
Unmarried	1	3,5
Other	1	3,5
<i>Smoking habits</i>		
Current smoker	2	8
Former smoker	14	56
Never smoked	9	36
<i>Children</i>		
Yes	23	85
No	4	15
Mean EQ-5D score = 0.79	21	78
Mean VAS score = 63 (range 40-100)	23	-

EQ-5D = EuroQol 5-Dimensional 3-Level Questionnaire; VAS = visual analogue scale.

Patients are asked to rank their quality of life on the basis of five dimensions: mobility, personal care, usual activity, pain/discomfort, and depression/anxiety. HRQoL scores are calculated using EQ-5D guidelines and Danish preference weights [16]. Furthermore, the EQ-5D consists of a visual analogue scale (VAS) used to establish self-reported global quality of life. The terminal points are marked as "best possible health" at 100 and "worst possible health" at 0. Finally, the EQ-5D questionnaire contains questions regarding the patient's age, sex, educational level and smoking habits [17].

Three levels of needs-questionnaire

The *problem intensity* and *unmet needs* of the study population were measured using the 3LNQ, developed

by the Department of Palliative Medicine at Bisbebjerg Hospital and the Institute of Public Health in Denmark. The questionnaire was developed in order to gather knowledge about the problems and needs in cancer patients with advanced disease, and it is the only questionnaire that takes into account whether the patients feel that they have received sufficient help for their symptoms/problems [14, 15].

The 3LNQ concerns the following problems: pain, shortness of breath, nausea, lack of appetite, fatigue, depression, worries, difficulty concentrating, problems with execution of physical activity, difficulties in family life and contact with friends, problems with the performance of work and daily chores and problems with sexual life [15].

In order to determine *problem intensity*, patients were asked to state the severity of the 12 problems in the past week, using the following response categories: (1) not at all, (2) a little, (3) quite a bit, or (4) very much.

The *unmet needs* are addressed by first asking the patient if the specific problem is present or not. Subsequently, the patient is asked whether the help for each problem being addressed has been sufficient. If the patient has received no help for the problem, he or she is asked if help is wanted or not. Hence, the *unmet need* is the proportion of patients having received inadequate help (inadequate or partly inadequate) out of those having received the help and the proportion of patients wanting help out of those having received no help. If a questionnaire item concerning *unmet needs* were answered incompletely, the responses were recoded according to the rules as described by the authors of the 3LNQ [15].

Trial registration: not relevant.

RESULTS

Patient characteristics and health-related quality of life

A total of 33 questionnaire envelopes were distributed and 27 returned (response rate 81.8%). For patients who answered the question regarding sex and age, an equal distribution was seen between 12 men and 12 women (and three unknown) with an average age of 69.3 years (range: 49-82 years). The mean EQ-5D utility score was 0.791 (range: 0.564-1), while the mean VAS value was 63 (range: 30-100). Patient characteristics are illustrated in **Table 1**.

Problem intensity and unmet need

The patients reported a median of seven problems (range: 1-11) and two unmet needs (range: 0-10). The most frequent problem was fatigue with 89% of patients reporting the problem as being at least "a little" (**Table 2**).



TABLE 2

	N ^b	Problem intensity				problem, n (%)	severe problem, n (%)
		column A: not at all, n	column B: a little, n	column C: quite a bit, n	column D: very much, n		
Pain	24	10	7	5	2	14 (58)	7 (29)
Shortness of breath	27	11	9	6	1	16 (59)	7 (26)
Nausea	27	17	8	2	0	10 (37)	2 (7.5)
Lack of appetite	26	13	8	5	0	13 (50)	5 (19)
Fatigue	27	3	11	10	3	24 (89)	13 (48)
Depression	27	14	11	1	0	13 (48)	2 (7.5)
Worrying	27	9	12	5	1	18 (67)	6 (22)
Problems concentrating	27	16	9	2	0	11 (41)	2 (7.5)
Limitations in physical activity	25	3	9	12	1	22 (88)	13 (52)
Problems with family and friends	27	22	3	2	0	5 (19)	2 (7.5)
Problems with daily activities and work	27	5	13	7	2	22 (81)	9 (33)
Problems with sexual life	13	9	0	3	1	4 (31)	4 (31)

Prevalence of "problem" and "severe problem"^a.

a) The table should be read as follows: a total of 24 patients responded to the question addressing pain. Of those, 14 had a problem with pain; 7 of the 14 had a severe problem. A problem is defined as at least "a little". A severe problem is defined as at least "quite a bit".

b) The number of responses for each problem.



TABLE 3

Prevalence of unmet needs^a.

	Column									
	B	C	D	E	F	G	H	I		
	had a problem									
	A: responders, N	total, n (B/A, %)	patients who did receive help			patients who did not receive help			unmet need, n ((E+G)/A, %)	
adequate help, n (D/C, %)			inadequate help, n (E/C, %)	wish for help, n (G/F, %)	no wish for help, n (H/F, %)					
Pain	24	13 (54)	10	7 (70)	3 (30)	3	3 (100)	0 (0)	6 (25)	
Shortness of breath	27	14 (52)	10	10 (100)	0 (0)	4	4 (100)	0 (0)	3 (11)	
Nausea	25	11 (44)	8	5 (63)	3 (37)	3	3 (100)	0 (0)	6 (24)	
Lack of appetite	25	11 (44)	7	2 (29)	5 (71)	4	3 (75)	1 (25)	8 (32)	
Fatigue	25	20 (80)	15	7 (47)	8 (53)	5	3 (60)	2 (40)	11 (44)	
Depression	25	10 (40)	6	3 (50)	3 (50)	4	2 (50)	2 (50)	5 (20)	
Worrying	25	12 (48)	6	3 (50)	3 (50)	6	5 (80)	1 (20)	8 (32)	
Problems concentrating	25	6 (24)	4	2 (50)	2 (50)	2	1 (50)	1 (50)	3 (12)	
Limitations in physical activity	23	17 (74)	12	6 (50)	6 (50)	5	3 (60)	2 (40)	9 (39)	
Problems with family and friends	26	7 (27)	3	1 (33)	2 (67)	4	3 (75)	1 (25)	5 (19)	
Problems with daily activities and work	24	17 (71)	11	4 (36)	7 (64)	6	3 (50)	3 (50)	10 (42)	
Problems with sexual life	16	6 (38)	1	0 (0)	1 (100)	5	2 (40)	3 (60)	3 (19)	

a) The table should be read as follows: a total of 25 patients responded to the question concerning fatigue. Of these, 20 patients stated that they had a problem. The unmet need for the question concerning pain is thus: the patients who received inadequate help (8 patients) plus those who wanted help but did not receive it (3 patients). This adds up to an unmet need for 11 patients, 44% of those responding to the question. Both "partly inadequate help" and "inadequate help" are covered by inadequate help.

Besides the 12 problems addressed by the 3LNQ, the following problems were mentioned by the patients: arthritis in the feet, muscle cramp/pain morning cough and nightly urination. Except for morning cough, all these symptoms were considered "quite a bit" or "very much". Of the 12 problems addressed in the 3LNQ, the median number of problems and severe problems were seven and two, respectively.

For the questionnaire items concerning unmet

need, patients having received inadequate help accounted for 50% or more for nine of the 12 questionnaire items (see Table 3). As an example, out of 15 patients who had received help for their fatigue, eight considered the help as inadequate. Patients who wished help, but did not receive it, also accounted for 50% or more with the exception of the questionnaire item concerning sexual life. In contrast to the other items, this item had a remarkably low response rate (16 of 27). The

Elderly patients with serious chronic kidney disease may obtain a better quality of life if palliative care is part of the overall end-of-life treatment received.



total unmet need ranged from 11% (shortness of breath) to 44% (fatigue). The median number of unmet need per patient was two. Notably, the unmet need was distributed among 17 of the 27 patients.

DISCUSSION

This study found that the 3LNQ can be used to clarify problem intensity and unmet needs with regards to 12 palliative problems in patients suffering from CKD of stage 4. The median among our patients was seven problems and two unmet needs. Not all problems related to CKD, as described in the medical literature [5], are covered by the 3LNQ. This indicates that the 3LNQ is insufficient when it comes to uncovering all palliative problems from which patients with CKD4 suffer.

Other symptom assessment tools have been assessed, including the Renal Palliative Care Outcome Scale in the UK [4], the Dialysis Symptom Index in the USA [18], and the Edmonton Symptom Assessment System in Canada [19]. None of these tools have been translated into Danish and hence cannot be used on Danish patients. Since the use of the 3LNQ is insufficient for understanding the specific palliative needs in CDK patients, the translation and testing of such new tools in a Danish context is urgent.

Today, very few patients with CKD stage 5 receive SPC in Denmark, and most patients referred to SPC units are suffering from late-stage cancer [10, 11]. Compared with the 3QLN study of palliative problems in patients with late-stage cancer, it is striking that unmet needs for patients suffering from CKD stage 4 are seemingly at the same level as those of the cancer patients [14]. The percentage of patients who wished for help and the percentage of patients who received inadequate help were also comparable.

The high prevalence of unmet needs indicates that alternatives to current clinical treatment should be considered. It should be evaluated whether Danish patients with CKD stage 4 should be offered SPC as part of their

treatment as it is suggested for patients suffering from CKD stage 5 [2]. Other initiatives to enable the delivery of SPC to Danish CKD patients include the use of specific clinical guidelines on referral and expanding of the capacity in SPC units in Denmark as this is presently very limited [11].

This study further shows that not all patients express a wish for help. The reasons for this remain unknown. Obvious possibilities may be that they do not want the healthcare system to help them, do not see their problem as solvable or relevant, or do not know that help can be given. An English study concludes that barriers may stem from a lack of communication and education [10]. Studies regarding this do not exist in Denmark and should therefore be conducted.

Another reason for implementing alternative treatment strategies is the potentially lower costs of such strategies as RRT is expensive [2].

Further studies should therefore include health economic evaluations to illustrate the effects and costs of treatments offered to patients with end-stage CKD. This is also of great interest as literature shows that costs can be reduced if patients are more involved in their treatment [13].

CONCLUSION

The 3LNQ is usable to indicate problem intensity and unmet need in patients with chronic kidney disease stage 4. However, the questionnaire does not cover all the problems from which patients with chronic kidney disease suffer. Further research into the complexity of need of SPC for these patients is needed in order to help them optimally.

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