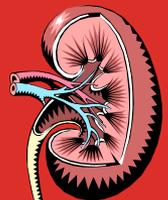




Symptom experience in non-dialysis-dependent chronic kidney disease: a UK qualitative study

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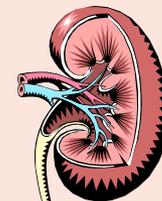
Background

- Studies suggest that symptoms attributable to impaired kidney function are important determinants of ...

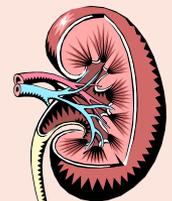
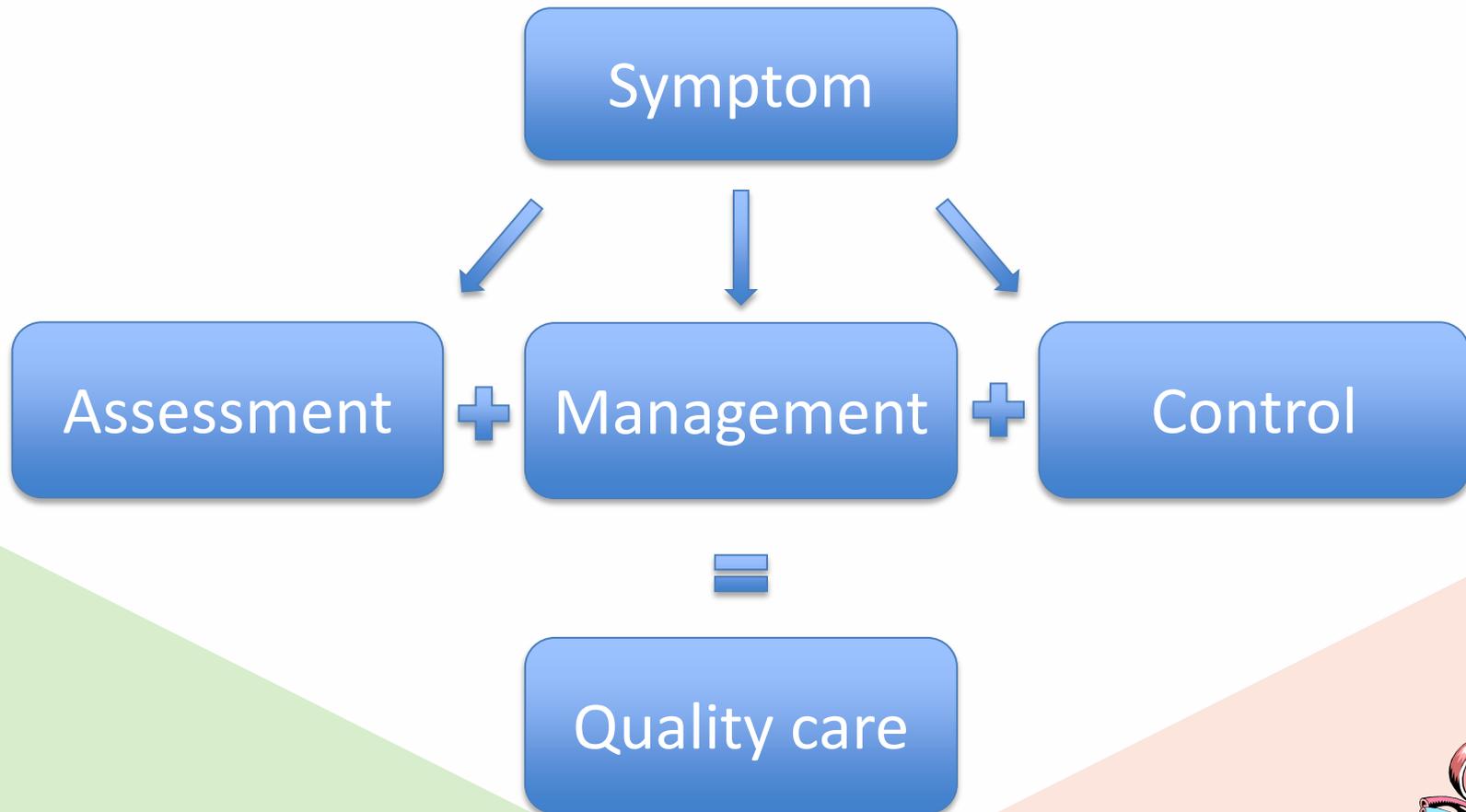
- Quality of life
- Physical function

... in patients with chronic kidney disease (CKD)

Pugh-Clarke, Naish, and Mercer (2006)



Symptoms and care quality



The burden of symptoms

- Symptom burden in patients with advanced CKD managed without dialysis is comparable to that of palliative care cancer populations

Murtagh et al. (2007)

... dearth of information about the nature and range of symptoms in earlier stages of the CKD trajectory



Aim

Overall aim of this study was to explore the patient symptom experience in non-dialysis-dependent CKD stages 4 and 5

Objectives

1. To examine the range of symptoms reported by patients
2. To identify themes and patterns across their experience of symptoms



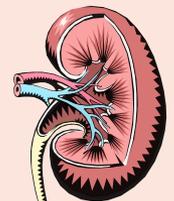
Methods

Qualitative approach

18 semi-structured
participant interviews

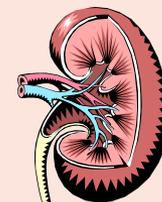
Interview schedule to
guide discussion

Data analysed using
thematic analysis



Results

- Wide range of symptoms reported
- Over 100 different codes extracted from interview data
- Codes refined into 28 overarching symptom themes
- Themes broadly classified into physical and psychological symptoms
- Patients would not routinely verbalise symptoms



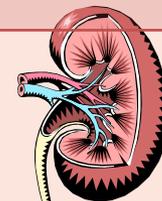
Physical symptom themes (1)

Themes (e.g.)	Codes
<ul style="list-style-type: none"> Altered taste perception 	Unpleasant taste in the mouth; Metallic taste in the mouth; Impaired sense of taste; Absence of taste
<ul style="list-style-type: none"> Altered olfactory acuity 	Impaired sense of smell; Diminished odour discrimination; Food smells unappetising
<ul style="list-style-type: none"> Pruritus 	Itchy skin; Nocturnal itching; Skin that bleeds from scratching; Excoriated skin
<ul style="list-style-type: none"> Temperature sensitivity 	Feeling cold all of the time; Cold intolerance; Heat intolerance; Night sweats
<ul style="list-style-type: none"> Fatigue 	Tiredness; Physical exhaustion; Lethargy; Weariness; Low energy levels



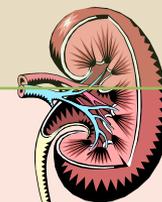
Physical symptom themes (2)

Themes (e.g.)	Codes
<ul style="list-style-type: none"> Impaired sleep quality 	Difficulty falling asleep; Daytime sleepiness; Sleeping intermittently; Sleeping all of the time; Early morning awakening; Not feeling rested upon awakening
<ul style="list-style-type: none"> Changes in the physical self 	Weight loss; Pallor; Gauntness; Hair loss; Dark circles under the eyes; Puffy face; Sallowiness; Swollen legs/feet
<ul style="list-style-type: none"> Musculoskeletal disorders 	Muscle weakness; Joint ache/pain; Muscle wastage; Joint stiffness; Decreased hand grip strength; Bone pain
<ul style="list-style-type: none"> Anorexia 	Lack of enjoyment of food; Decreased appetite; Loss of appetite
<ul style="list-style-type: none"> Gastrointestinal disturbances 	Dry/sore mouth; Early satiety; Nausea; Indigestion; Vomiting; Diarrhoea; Hiccoughs; Constipation



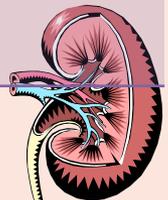
Psychological symptom themes

Themes (e.g.)	Codes
<ul style="list-style-type: none"> Cognitive impairment 	Inability to concentrate; Forgetfulness; Short attention span; Mental fatigue
<ul style="list-style-type: none"> Loss of the former self 	Loss of autonomy; Grief; Dependence on others; Negative self-perception; Frustration
<ul style="list-style-type: none"> An awareness of gradually slowing down 	A sensation of slowing down physically; A perception of slowing down mentally; A perception that the body is failing
<ul style="list-style-type: none"> Denial 	Disbelief; Nonacceptance of diagnosis; Nonadherence to treatment regimens; Disengagement with the renal service
<ul style="list-style-type: none"> Depression 	Feeling sad; Hopelessness; Tearfulness; Despair; Helplessness; Despondency



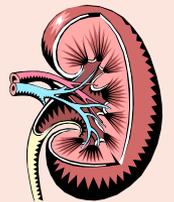
Reasons for not reporting symptoms

Reason given	Illustrative participant quotations
<ul style="list-style-type: none"> • Guilt at wasting clinicians' time 	<p>"I feel guilty about mentioning them [the symptoms] ... I feel like I'm wasting the doctor's time"</p>
<ul style="list-style-type: none"> • Guilt at encroaching on other patients' clinic slots 	<p>"His [the consultant nephrologist's] clinic is always really busy, and there are other patients waiting to see him"</p>
<ul style="list-style-type: none"> • Inadequate knowledge of CKD-associated symptoms 	<p>"I didn't think that they [the symptoms] could be due to the kidneys"</p>
<ul style="list-style-type: none"> • Fear 	<p>"I thought if I mentioned them [the symptoms], they'd stick me straight on that kidney dialysis"</p>
<ul style="list-style-type: none"> • A perception that the symptoms were age-related 	<p>"I put it all down to age, really ... I didn't think that they [the symptoms] could be due to other things"</p>



Conclusion

- Patients with non-dialysis-dependent CKD stages 4 and 5 may have a high symptom burden
- Symptom assessment needs to be routinely incorporated into clinical consultations
- Structured symptom assessment may give patients the opportunity to discuss troublesome symptoms, which might otherwise not be disclosed to health care professionals





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