

# Symptom reporting in patients with chronic kidney disease: insights from a UK qualitative study

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# Introduction

- Patients with chronic kidney disease (CKD) stages 4 and 5 experience a high symptom burden
- Studies suggest that symptom burden in patients with advanced CKD managed without dialysis is comparable to that of palliative care cancer populations (Murtagh et al., 2007)

# Current context

In the demanding clinical environment where symptoms may not be systematically assessed, clinician awareness of patient symptom status is dependent on patient voluntary self-report



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# Knowledge deficit

Given the significance of symptom identification as a precursor to the instigation of symptom management strategies, there is little information on the extent to which patients self-report their symptoms to clinicians



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# Objectives of the presentation

1. To explore symptom reporting behaviour in patients with CKD stages 4 and 5
2. To identify barriers to symptom reporting in this patient population

# Methods

- Eighteen semi-structured patient interviews conducted
- Interview schedule used to guide discussion
- Data analysed using thematic analysis to identify themes and patterns across the patient experiences

# Results

- Almost all (n=15) of the study participants stated that they would *not* routinely report their symptoms to clinicians
- Reasons given for not reporting symptoms were clustered around five predominant themes

# Theme 1

Guilt at wasting clinicians' time unnecessarily in busy out-patient kidney clinics

*"I feel guilty about mentioning them [the symptoms]...I feel like I'm wasting the doctor's time"*



# Theme 2

Guilt at impinging on other patients' clinic time

*“His [the consultant nephrologist’s] clinic is always really busy, and there are other patients waiting to see him”*

# Theme 3

Fear of the unknown and of being initiated onto dialysis

*“I thought if I mentioned them [the symptoms], they’d stick me straight on that kidney dialysis”*

# Theme 4

Lack of knowledge that the symptoms were CKD-associated

*“I didn’t think that they [the symptoms] could be due to the kidneys”*

# Theme 5

An assumption that the symptoms were age-related and consequently untreatable

*“I put it all down to age, really...  
I didn't think that they [the  
symptoms] could be due to other  
things”*

# Conclusion

- This part of the study suggests that patients with CKD stages 4 and 5 do not habitually report their symptoms to clinicians
- The consequences are:
  - The non-treatment of potentially manageable symptoms
  - Unnecessary patient suffering and distress

# Applications to practice

The findings from this study underlie a need for standardised symptom assessment in the clinical setting, as a means by which to identify CKD-associated symptoms and target appropriate symptom alleviation strategies



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**Any questions?**

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Thank you

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