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Symptom appraisal and help-seeking in men with symptoms of possible prostate cancer: a qualitative study with an ethnically diverse sample in London

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Abstract

**Background:** Prostate cancer mortality in Black men is disproportionally high. This problem may be overcome by reducing delays in the pathway to diagnosis, particularly those occurring before initial medical help-seeking. A greater understanding of symptom appraisal and help-seeking could support the development of targeted interventions for improving early presentation among Black men.

**Aim:** To provide an in-depth understanding of men’s pre-consultation experiences following the onset of possible prostate cancer symptoms, identifying both general trends as well as potential differences which may exist between Black and White men.

**Design and Setting:** Qualitative study of 18 Black and White men in London who had recently seen their general practitioner (GP) with urinary symptoms, erectile dysfunction or haematuria.

**Method:** Semi-structured interviews from a previous multi-methods study of primary care use by men with symptoms of possible prostate cancer were analysed using thematic framework analysis.

**Results:** Symptoms were often interpreted as being unimportant. Most delays occurred due to the absence of reasons to seek help which, in Black men, often stemmed from poor prostate cancer awareness. This was possibly a consequence of their reluctance to seek health information and discuss health issues with others within their social network. Friends and relatives played an important role in symptom appraisal and help-seeking which may link with these differences.

**Conclusion:** Cognitive biases, cultural stigmas and everyday interpersonal interactions should be important targets for strategies seeking to reduce delays and improve early presentation in Black men.

**Keywords:** prostate cancer, ethnicity, men, primary care, symptoms, help-seeking
How this fits in

Ethnic inequalities in prostate cancer outcomes have been linked to a higher incidence of aggressive disease and advanced-stage diagnoses in Black men. Most Black men with prostate cancer are diagnosed after presenting with symptoms to primary care, and whilst unlikely to be the main explanation for outcome inequalities, an understanding of the events during this pathway could inform strategies to tackle inequalities in prostate cancer outcomes through earlier diagnosis. Existing evidence highlights the influence of symptom appraisal and help-seeking in cancer diagnostics, although it is unclear how this applies to Black men in the UK with possible prostate cancer symptoms. The present study gives clarity to this issue, highlighting the potential for improving early presentation in symptomatic Black men whilst illustrating the role which GPs can play in facilitating early diagnosis.
1. Introduction

Prostate cancer is the most common cancer among UK men and a leading cause of cancer deaths each year. There are important differences in prostate cancer incidence and mortality by ethnicity in the UK.\(^{(1)}\) The incidence is about three times higher in Black men than White men, in part due to biological factors resulting from complex gene-environment interactions.\(^{(2)}\) The case-specific mortality rate is 35% greater in Black compared with White men,\(^{(3)}\) which may be linked to a greater incidence of advanced-stage diagnoses in the Black group.\(^{(4)}\) Whilst Black men more frequently develop aggressive sub-types of prostate cancer,\(^{(5)}\) tumour characteristics may not fully explain the differences in advanced-stage diagnoses, and by extension the higher mortality among men of this broad ethnic group.\(^{(6, 7)}\) Advanced-stage diagnoses may result from poor access to healthcare - linked to lower socioeconomic status and other structural factors\(^{(8)}\) - although there is currently no clear evidence to support this explanation in the context of free universal healthcare in the UK.\(^{(9)}\)

Advanced-stage diagnosis may also arise from delays in the pathway to diagnosis.\(^{(10)}\) Despite doubt which surrounds the link between lower urinary tract symptoms and prostate cancer,\(^{(11, 12)}\) the absence of prostate cancer screening in the UK means that diagnosis most commonly occurs following presentation to primary care with lower urinary tract symptoms (LUTS), erectile dysfunction or visible haematuria.\(^{(12, 13)}\) However, a multi-methods study of UK men showed that Black men may not fully disclose possible prostate cancer symptoms during initial consultation in primary care.\(^{(14)}\) In addition, the study found that general practitioners (GPs) may delay investigation of men in this group, especially if patients have comorbidities, such as diabetes, which shares similar symptoms. These differences may lead to delays and a prolonged diagnostic interval – the period between initial primary care consultation and diagnosis.\(^{(15, 16)}\) Delays may also arise in the time between symptom onset and presentation to healthcare – the period known as the patient interval.\(^{(15, 16)}\) For example, Black men may misinterpret possible symptoms due to a lack of awareness/knowledge of prostate cancer.\(^{(17, 18)}\) They may also delay help-seeking due to complex psychosocial and structural barriers related to fear, stigma, fatalism, and religious/cultural beliefs and norms.\(^{(17, 19, 20)}\) Recent studies
found no statistical evidence of ethnic differences in patient interval duration and only a small difference in diagnostic interval to explain the mortality gap in prostate cancer.\textsuperscript{(14, 21)} As such, it has been assumed that inequalities in symptomatic diagnosis are unlikely to be a major cause of ethnic inequalities in prostate cancer outcomes among UK men.\textsuperscript{(22)} Yet a significant proportion of men (including Black men) in the UK delay presenting by at least 12 months following the onset of symptoms,\textsuperscript{(14)} meaning that there may still be scope to tackle the mortality gap by reducing delays prior to primary care consultation. Doing so necessitates an understanding of symptom appraisal and help-seeking processes preceding presentation. Martins et al.,\textsuperscript{(14)} reported findings from quantitative data on ethnic differences in patient interval but did not specifically explore men’s pre-consultation experiences. This means that important ethnic differences may still exist in a qualitative analysis. A greater understanding of symptom appraisal and help-seeking could provide insights which support the development of targeted interventions for improving early presentation among Black men. Likewise, any benefit gained from this understanding may also extend to other ethnic groups.

In the present study, we performed a secondary analysis of qualitative data from men who had recently reported possible prostate cancer symptoms in UK primary care. We aimed to provide an in-depth understanding of men’s pre-consultation experiences following the onset of possible prostate cancer symptoms, identifying both general trends as well as potential differences which may exist between Black and White men.

2. Methods

We thematically analysed qualitative data from a previous multi-methods study of primary care use by an ethnically diverse sample of men with symptoms of possible prostate cancer.\textsuperscript{(14)} Sampling, recruitment and data collection procedures are detailed elsewhere,\textsuperscript{(14)} but outlined briefly below. Ethical approval for the present study was granted in April 2022 by the University of Exeter CMH Research Ethics Committee.
2.1. Setting and participants
Between March 2016 and October 2017, patients presenting with possible prostate cancer symptoms to general practices were recruited in and around London. Practices were recruited to the study with the help of the Clinical Research Network. We searched practices’ electronic health records for patients aged ≥40 years who attended with LUTS, erectile dysfunction and/or haematuria (with or without other non-specific cancer symptoms e.g., weight loss) within the previous 6 months. Those with benign prostatic hyperplasia or a previous history of prostate cancer were excluded. Potential participants were surveyed via secured postal services and a subset invited to participate in face-to-face interviews. Participants provided self-defined ethnicity, which was then merged into combined ethnic groups by the study team based on the UK census definition. Interviewees were purposively sampled based on age, level of education, and ethnicity. Twenty-three men participated in the face-to-face interviews: nine Black, nine White and five Asian.

2.2. Data collection and processing
Interviews were conducted at the participants’ homes or workplace lasting about 60 minutes. The interviews were semi-structured, using a schedule developed from similar interviews undertaken with people referred with possible cancer or recently diagnosed with cancer (23, 24) (see Appendix 1). The interviews explored men’s experiences from noticing possible prostate cancer symptoms to being offered investigations. Recruitment ended when thematic saturation was reached, that is, when no new information pertinent to the study was identified. (25) All interviews were audiotaped, professionally transcribed verbatim, and anonymised via a confidential service. The interview data were coded and analysed by three researchers (TM, FW, and CP) in the previous study, which focused mainly on the primary care interphase of patients’ pathway. In the present study, BS performed a secondary analysis of the data focusing on the pre-presentation phase only, with support from TM.

2.3. Data analysis
We used thematic framework analysis with an iterative analytical process which followed five stages: familiarisation with data, development of a thematic framework, applying data to the framework, mapping and questioning the data and thematic interpretation. (26) The conceptual framework was developed using an inductive-
deductive approach guided by the data and the Model of Pathways to Treatment.\textsuperscript{(15)} The thematic framework focused on the patient interval, with codes being grouped into four categories based on key events occurring prior to primary care presentation: i) \textit{initial appraisal of symptom/s} ii) \textit{consequences of symptom/s} iii) \textit{responses to symptom/s} iv) \textit{re-appraisal and help-seeking}. We identified new codes and applied relevant codes from the original analysis to this framework. Data were charted into a coding matrix to aid comparison across ethnic groups and facilitate the development of themes. We adopted a phenomenological approach and searched for semantic level themes, drawing on the most commonly discussed attitudes and experiences. The primary researcher is a clinician whose experience in consulting with men presenting to primary care with cancer symptoms is reflected in the interpretation of themes.

3. Results

The present study comprised of 18 men (Black n=9, White n=9). Asian men were not included due to insufficient data relating to the pre-presentation phase in this group which significantly limited the interpretation of our findings. Participants were aged between 44 to 75 years old and were from a range of educational and occupational backgrounds. A detailed breakdown of participant characteristics can be found in Table 1.

The most commonly experienced symptoms were increased urinary frequency/nocturia (n=11), urgency/urge incontinence (n=10) and erectile dysfunction (n=9). One-third of men initially saw their GP for a reason other than their symptoms of possible prostate cancer (n=6). In those whose symptoms were the reason for attending, erectile dysfunction was rarely the primary reason (n=2). Five men had attended more than once for the same symptom/s without previous investigation. Almost all men with LUTS or erectile dysfunction waited at least 6 months following the onset of symptoms to seek help. Many men waited over 1 year, with two waiting almost 10 years. Men with haematuria presented within days or short weeks after first noticing the symptom. The most significant delays arose from
men not perceiving a reason to seek help because their symptoms were stable, attributable, manageable and/or not severe enough to significantly impact their life.

In relation to the findings, we have presented a number of sub-themes under four headings, each relating to a key stage of the pre-presentation pathway. The interdependence between each process means that there is significant overlap between the timing and content of each subtheme. Each subtheme is outlined using illustrative quotes to explore how biological, psychosocial and structural factors influence symptom appraisal and help-seeking. Quotes are followed by participant number, ethnicity and age range in years.

3.1. Initial appraisal of symptom/s

Symptom attribution: Men were keen to understand the cause of their symptoms and often adopted an analytical approach; “I don’t drink, I don’t smoke, I don’t do drugs… why would I have a problem like this?” (B3, Black, 50-59). Most attributed their symptoms to ‘getting old’, medications or eating/drinking habits; “I’m a pub goer. I drink beer and it tends to be later in the evening so I’m going up to go to the loo… in the night, anyway” (W1, White, 70-79). Many Black men attributed symptoms to their diabetes based on their GP’s advice about the close overlap between symptoms; “the doctor said go and shed weight… he didn’t ask me too much questions, because diabetes has explained everything to him” (B8, Black, 60-69). Erectile dysfunction was rarely seen to be linked to urinary symptoms or possible prostate pathology except in relation to diabetes.

Symptom knowledge and recognition: Some men believed that they could not have a prostate issue because they were ‘not old enough’. Only three men recognised that their symptoms could indicate prostate cancer, all of whom were White. These men knew family and friends with prostate issues; “immediately, I thought, I’ve got a prostate problem… it seems to be the thing to have at the moment… so many of my friends are suffering from prostate issues” (W6, White, 60-69), “everyone you talk to in the allotments… they’re all having problems” (W8, White, 70-79). Yet most men felt that symptoms would settle down by themselves or could not be treated; “I don’t know why you put it off… it’s more about thinking, well, what can they do, yeah?”
(W4, White, 50-59), “I don’t think there’s anything the doctors could do that would help” (B2, Black, 70-79).

3.2. Consequences of symptom/s

*Emotional impact:* Both Black and White men were embarrassed by their symptoms, particularly the thought of wetting themselves; “you run into a bush or somewhere to start weeing against somebody’s wall or somebody’s garden… if I don’t wee at that time I’m gonna be wet” (B3, Black, 50-59), “I wouldn't completely urinate before I reached the lavatory, but I would dribble in a way which I found very unpleasant and unattractive” (W7, White, 70-79). Black men often felt unable to talk to friends about their symptoms because they were embarrassed about being labelled as an ‘old man’. Some men wanted “a quick answer, like, you know, a reassurance” (B2, Black, 70-79) whilst others ‘didn’t lose any sleep thinking about it’ because they could rationalise their symptoms. White men were generally more fearful about what may be causing their symptoms, often because they had haematuria which they linked to a serious cause; *Participant:* “there is an initial, kind of, panic…” *Interviewer:* “When you first saw the blood?” *Participant:* Yeah”. (W3, White, 50-59).

*Quality of life:* Urinary symptoms impacted quality of life the most; “you don’t sleep… I seriously think I urinated five times” (W4, White, 50-59), “let’s say my girlfriend is lying next to me… I have to jump over her to go and wee three or four, five times… it makes [her] mad” (B3, Black, 50-59). Urinary symptoms were a particular issue in working men; “as a part-time Uber driver, I need my drink while driving but passenger in your car, no time for a wee… by the time I get there, I’ve wee-ed myself” (B3, Black, 50-59), “I’d think of which stations had got a good toilet… it was costing me a fortune getting on and off the tube” (W9, White, 60-69).

3.3. Responses to symptom/s

*Coping and self-management:* Most men initially self-managed their symptoms because symptoms were ‘quite manageable’ and simply ‘inconvenient’; “I just come in and strip off and wash my clothes” (W9, White, 60-69). White men often modified their lifestyle by drinking less tea and coffee in the evenings. Black men commonly experimented with home remedies which often had less success; “we’re from Barbados, and they have all kind of remedies over there… there was some slimy
thing... it was horrible but I forced it down. Waste of bloody time” (B4, Black, 60-69).
Many men adapted their lives to manage the consequences of their symptoms; “I walk with a spare pair of trousers, just in case” (B2, Black, 70-79).

Seeking information: White men openly discussed their problems and would ‘joke about men of a certain age’ with their friends, whereas Black men were more likely to see it as a taboo subject; “if I met you as a man, and we’re mates, I’m not gonna come and tell you and say, oh, guess what” (B5, Black, 50-59), “it’s a little bit more personal, isn’t it?... other people don’t talk about their personal things” (B9, Black, 60-69). Many men discussed reservations about using the internet to search for information about their symptoms, although several men (mostly in the White group) still did; “I looked at it, Google, but once you open Google you can find, you know, one million things… most of them quite extreme” (W2, White, 50-59). Black men were less likely to use the internet; “I wouldn’t know where to start… I get frustrated” (B4, Black, 60-69). They would often not seek any information at all, and when they did they sometimes obtained misinformation; “back home when you have a weak erection... they call it jedijedi (haemorrhoids), isn’t it?” (B6, Black, 60-69), “from what I’ve heard… it (Viagra) gives you heart failure” (B5, Black, 50-59).

3.4. Re-appraisal and help-seeking
Deciding to seek help: Men would decide to actively seek help once they perceived their symptom/s to be important (and so had a reason to seek help) and were then triggered by a specific stimulus. Both were achieved when symptoms had not improved or had increased in frequency/severity over a short period of time and become severely detrimental to quality of life. Many men perceived symptoms to be important once attempts to self-manage became ineffective because it caused them to question their initial symptom attribution; “I couldn’t rationalise it… I couldn’t put a definite finger on it” (B1, Black, 50-59). The nature of the symptom/s was also important, with haematuria frequently causing immediate concern since it was associated with a serious cause; “if you’ve got blood in your urine something’s wrong, obviously” (W5, White, 40-49). Symptoms which men considered to be abnormal within their social network were also important; “I have a couple of friends in my age group.... who are still very active sexually and I think, oh, right, well, what’s wrong with me” (B4, Black, 60-69). Once men perceived a reason to seek help, it
was often the encouragement from their partner or friends which triggered them to book an appointment; “[My wife] just kept on at me about the colour of my urine” (B4, Black, 60-69), “my friend was checking me, have you had chance, have you checked with the docs yet” (B2, Black, 70-79). White men, in particular, were triggered by gaining an awareness about the dangers of prostate cancer from friends; “a number of friends of mine have suffered from prostate cancer… it’s obviously so common in men that I thought, well, perhaps I ought to go” (W1, White, 70-79).

Accessing help: Some men struggled to take time off work whilst others worried about wasting their GP’s time; “you don't want to make a big drama of little things in case you call the doctor and it turns out to be nothing” (B9, Black, 60-69). Black men often had multiple symptoms which they did not have time to disclose during the consultation; “you have limited time… if you accumulate complaints, you won't be able to discuss” (B8, Black, 60-69). Men often struggled to access their GP due to an absence of walk-in appointments outside normal working hours. Several men were put off because they were unsure if they would be taken seriously by their GP if their symptoms could be attributed to a non-serious cause. Anxiety and embarrassment about seeing the GP was common among Black and White men because it was perceived to threaten their masculinity; “we men… we don’t want to own up that we’re not good” (B5, Black, 50-59). Despite embarrassment about the prospect of a digital rectal examination (DRE), most men were not deterred from seeing their GP and were happy to accept investigations if it could help to uncover the cause of their symptoms. GPs’ gender was an important factor in help-seeking since some men would have been discouraged from disclosing their symptoms if the GP was not of their preferred gender; Interviewer: “if it was a female doctor, would this have affected...?” Participant: “yeah, I probably wouldn't have told her [about urinary symptoms] … I’d have been too embarrassed”. However, no clear overall preferences or patterns emerged within or across ethnic groups; some men preferred to see a male GP, some preferred to see a female GP whilst others were indifferent to the gender of the consulting GP.

4. Discussion
4.1. Summary
Symptoms were interpreted in the context of existing lifestyle choices and co-morbidities and were often attributed to these factors. Symptoms that impacted quality of life were stable and manageable and so men did not initially perceive their symptoms to be important. Men perceived a reason to seek help following changes in symptom nature, duration, frequency, severity and their impact on daily life, or once they could not explain the cause of their symptoms after attempts to self-manage became ineffective. Black men were less likely to recognise that their symptoms could indicate prostate cancer, possibly as a consequence of their reluctance to seek health information and discuss health issues with others within their social network. Friends and relatives influenced symptom appraisal and often triggered the decision to seek help which may link with these differences. Most men encountered personal or emotional barriers including time and embarrassment, although this did not appear to cause significant delays to presentation in either group.

4.2. Strengths and limitations
This is the first study to directly explore ethnic differences in symptom appraisal and help-seeking in men with symptoms of possible prostate cancer. The age range and demographic diversity of the sample provided a wealth of material with which to identify general trends and highlight specific differences between Black and White men. Qualitative themes were structured using the Model of Pathways to Treatment, thereby facilitating comparison with existing and future studies. Likewise, our findings may be transferable to other urological pathologies given the general nature of symptoms explored. Although, analysis in the present study was restricted to symptom appraisal and help-seeking in Black and White men, and so our findings may not apply to other stages of cancer diagnostic pathways or men of other ethnicities. Discussions about symptom appraisal and help-seeking typically focused on events which started several years before primary care consultation and participation in our interviews. As such, a degree of recall bias is possible. Furthermore, the data for the present study predates the COVID-19 pandemic and so our findings may not fully reflect men’s experiences during this period or how the pandemic may have changed symptom appraisal and help-seeking behaviour. We used sociodemographic factors (e.g. age, co-morbidity, socioeconomic status)
primarily for identification purposes. These factors may influence symptom appraisal/help-seeking\textsuperscript{(27)} and prostate cancer survival\textsuperscript{(28)} but we did not explore how they interacted with ethnicity to produce the accounts given by participants. Whilst this is beyond the scope of this study, it is important to recognise that differences in these individual characteristics between the Black and White groups may have influenced our findings. For example, comorbidity was greater in the Black group which may have contributed to the lack of recognition of symptoms in this group due to symptom misattribution.

4.3. Comparison with existing literature

Previous studies have highlighted the importance of cognitive heuristics in symptom appraisal, most notably the rate of change rule and the severity (of interference) rule.\textsuperscript{(29)} That is, symptoms which are either quickly worsening or impacting daily life are more likely to be interpreted as indicating illness. These ‘rules of thumb’ may be normalised when they are common within the social network.\textsuperscript{(27)} Our results support this, demonstrated by the significant delays which occurred in the absence of these factors - a common finding in those with urinary symptoms.\textsuperscript{(30)} This suggests that strategies which seek to improve early presentation in Black men should tackle symptom misinterpretation through focusing on cognitive biases rather than specific symptom awareness.\textsuperscript{(29)} It also emphasises the importance of considering facilitators to help-seeking in the Model of Pathways to Treatment\textsuperscript{(15)} whilst demonstrating the relevance of psychological theory by which it is underpinned.

Research on symptom appraisal and help-seeking in ethnic minorities has classically focused on barriers to seeking help such as masculinity, fear and poor access to healthcare.\textsuperscript{(17, 20, 31, 32)} Whilst evident in our data, these were not specific to Black men and did not appear to account for significant delays. More apparent was the absence of reasons to seek help often stemming from poor prostate cancer awareness in Black men, a common finding in minority ethnic groups with possible cancer symptoms.\textsuperscript{(17, 19)} Their attitudes towards seeking health information and discussing health with close contacts may be related to cultural stigmas which undermine the legitimacy of discussing health.\textsuperscript{(23, 32, 33, 34)} This may result in fewer proximal social cues, that is, everyday interpersonal interactions with friends, family and colleagues which help men to recognise and understand the importance of their
symptoms and seek help by legitimising concerns, providing additional information etc.\textsuperscript{(18, 30, 33, 35, 36)} Hence, overcoming cultural stigmas associated with prostate cancer and providing proximal social cues should be a focus of future strategies for improving early presentation in Black men.

Our work offers a possible explanation for why no difference has been found in the duration of the patient interval between Black and White men despite notable differences in their symptom appraisal and help-seeking behaviours: whilst Black men are typically less aware about the risks of prostate cancer, they may be less successful at managing their own symptoms and so perceive a reason to seek help sooner than they otherwise would. Thus, whilst inequalities in symptomatic presentation and diagnosis may not be a major cause of ethnic inequalities in prostate cancer outcomes in the UK, this study highlights the potential which remains for targeted interventions to improve early presentation in symptomatic Black men.

4.4. Implications for research, policy and practice

Future research should continue to build upon recent work which has applied knowledge of symptom appraisal and help-seeking to develop interventions which promote early presentation in Black men, particularly those which target symptom misinterpretation, cultural stigmas and proximal social cues.\textsuperscript{(37, 38, 39)} Our finding that symptoms are easily mistaken for other causes and are rarely perceived as a problem has several important implications for clinical practice since men may not present with their symptoms until they reach an advanced stage of disease, if at all. It means that GPs should actively ask about symptoms and have a low threshold for PSA testing and 2-week wait referral in Black men when there are doubts surrounding DRE findings in order to avoid further delays. It may also be considered whether GPs should actively offer a PSA test to Black men over the age of 50 without them having to request it first (as is stipulated by current NICE guidance). This reflects a potentially necessary shift in focus towards asymptomatic diagnosis, especially given ongoing uncertainty about the value of urinary symptoms in early-stage prostate cancer detection. This perhaps supports the case for targeted prostate cancer screening to identify both those who are asymptomatic and those who have symptoms yet do not present or disclose their symptoms in primary care.
**Additional information**

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**Ethical approval:** Ethics approval for the present study was gained from the University of Exeter CMH Research Ethics Committee via the low-risk approval route (ref: 126/22/04/011). Ethics approval for the original study was gained from West Midlands – South Birmingham Research Ethics Committee (ref: 15/WM/0396), with BS subsequently added to the research team to allow the use of the data for the present study.

**Competing interests:** The author declares no competing interests.

**Acknowledgements:** We would like to give special thanks to the GPs, patients and Clinical Research Network representatives.

**References**


Table 1: Participants’ characteristics by ethnicity

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<th>Interview participants</th>
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<td>60 (57-68)</td>
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<td>4 (44.4)</td>
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<td>Cancer</td>
<td>5 (27.8)</td>
<td>3 (33.3)</td>
<td>2 (22.2)</td>
</tr>
<tr>
<td>Heart disease</td>
<td>8 (44.4)</td>
<td>5 (55.6)</td>
<td>3 (33.3)</td>
</tr>
<tr>
<td>Live alone</td>
<td>7 (38.9)</td>
<td>3 (33.3)</td>
<td>4 (44.4)</td>
</tr>
</tbody>
</table>

Values are n (%), except where otherwise stated. ‡comorbidity includes diabetes, kidney disease, bladder disease, incontinence, Parkinson’s disease, brain and spinal cord disease, anxiety and depression, and other cancers.