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EDITORIAL COMMENT

Incorporating patient-reported symptom assessments into routine care for people with chronic kidney disease

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Abstract

In this issue of *Clinical Kidney Journal*, Brown and colleagues show that symptom burden is high across all stages of chronic kidney disease (CKD). Still, management of symptoms in kidney patients leaves room for improvement, which may partly stem from symptoms being underreported. The use of patient-reported questionnaires may facilitate a more systematic approach to symptom assessment, but to date, the majority of these instruments have been used only in the context of research studies. In this editorial, we review how systematic patient-reported symptom assessments can be incorporated in CKD care. We show examples from an initiative in the UK where 14 renal units explored how to collect and use symptom burden assessments as part of their routine ways of working. We also discuss how to move from paper-based questionnaires towards digital collection of patient-reported symptom data. Lastly, we introduce wearable and smartphone sensors as novel methods for collecting information to support and enrich symptom assessments while minimizing data collection burden.

Key words: chronic renal insufficiency, medical informatics, patient reported outcome measures, symptom assessment, telemedicine

Symptom burden in CKD

The symptom burden in people with chronic kidney disease (CKD) is high. Whereas the vast majority of studies have investigated this in people with end-stage renal disease (ESRD) [1], in the current issue of the *Clinical Kidney Journal*, Brown *et al.* show that this may also be true for earlier CKD stages. They used the Leicester Uraemic Symptom Score to cross-sectionally assess 11 symptoms in a cohort of 283 patients with CKD Stages 1–5 who did not require renal replacement therapy (RRT). Participants

reported a median of five and six symptoms in CKD Stages 1–2 and 3–5, respectively. This resembles what has been reported in ESRD studies using similar questionnaires, with the mean number of symptoms ranging from 5.7 in Jablonski [3] to 7.5 in Davison *et al.* [4]. Brown *et al.* [2] found excessive tiredness, sleep disturbance and pain in the bones and joints to be the most commonly reported symptoms. This largely overlaps with the most prevalent symptoms reported in the recent study by Senanayake *et al.* [5], who investigated symptom burden in a comparable population. Also, in more advanced stages of CKD,

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fatigue or lack of energy was identified as the most frequently reported symptom [1].

This high and consistent symptom burden across CKD stages suggests that routine assessment and management of symptoms may be relevant throughout the patient journey and not just towards the end, especially since a high symptom burden is associated with low quality of life, depression and treatment non-adherence [6–10]. In addition, kidney patients have identified improved symptom management as a priority [11], which is reflected in international guidance for CKD management [12], haemodialysis adequacy [13] and supportive renal care [14]. However, despite their high prevalence, impact and importance, management of symptoms in kidney patients leaves room for improvement.

Symptom reporting

Suboptimal symptom management may stem from symptoms being underreported. Studies repeatedly show that health care professionals may not appreciate the full spectrum of kidney patients' symptom experience, which leaves many symptoms, such as pain, depression and itch, untreated [15–19]. For example, a recent study in 6256 patients and 268 medical directors from 17 countries found that nearly 20% patients who were (almost) always bothered by itch did not receive treatment for it; a similar proportion said they had not reported itch to health care professionals [19]. The reasons for this underreporting are largely unknown, but may include patients disengaging from or getting no opportunity for reporting their symptoms or not knowing whom to report them to [20].

The use of questionnaires may facilitate a more systematic approach to symptom assessment, which in turn may inform the timing of RRT start [21] or increase responsiveness of end-of-life kidney care [22]. In addition to the instrument used by Brown et al. [2], there are many other symptom questionnaires available for self-report [1], including the modified Edmonton Symptom Assessment System [4] and the Dialysis Symptom Index [23]. Yet, the majority of these instruments have only been used in the context of research studies. Therefore, as advocated by Brown et al. [2] and others [24, 25], the challenge now is to integrate them into routine care to optimize symptom management.

Patient-reported symptom assessments in routine care settings

Documented examples of how renal services have incorporated patient-reported symptom assessments in routine practice are scarce. In 2015, the National Health Service in England launched the Transforming Participation in Chronic Kidney Disease (TP-CKD) programme [26]. The programme aimed to develop ways to support people in self-managing their kidney disease. This included a pilot study in which renal units explored how they could incorporate symptom burden assessments into their routine ways of working. With the UK Renal Registry coordinating data collection, so far >4000 symptom scores have been collected from >3700 kidney patients using paper questionnaires across 14 renal units. In the following two subsections we present some examples of how TP-CKD units collected and used patient-reported symptom data.

Collection of patient-reported symptom data

For data collection, all units used the Patient Outcome Scale-symptom module for renal disease [27], which was combined with the EuroQol-5 dimensions-5 levels (EQ-5D-5L) [28] and the Patient

Activation Measure [29] into one survey. As haemodialysis patients frequently attend the hospital, many units chose to initiate data collection in this population. A number of units collected data in outpatient settings, for example, asking transplant patients to complete the survey while waiting for their clinic appointment.

To ensure high-response rates and include patients who may feel less able to complete questionnaires, some units provided additional face-to-face support. For example, one unit used an existing service where patients supported their peers with survey completion during haemodialysis sessions; and there are plans to extend this model to low clearance and transplant clinics. Those delivering peer support followed a basic course [30] complemented with instructions on using and interpreting the questionnaires. In other units, nurses, pharmacists or administrative staff coordinated and supported data collection. Overall, units felt that having peer or staff support in place was a facilitator for successfully collecting patient-reported symptom data in routine practice.

There were also some barriers to symptom data collection that emerged from the programme. In line with what is known from the literature on patient-reported outcomes [31], units reported a lack of resources to handle the workload associated with collecting data, as well as survey fatigue and a lack of perceived benefits among patients and staff. Also, many units encountered difficulties in keeping track of when individuals needed to be invited for their next symptom assessment. Collecting symptom data at regular intervals within the same patients is essential for monitoring symptom status and the effect of treatment decisions. A potential solution might be the use of existing systems to 'order' or 'prescribe' symptom assessments as if they are a laboratory test or drug. Lastly, the use of paper questionnaires proved time-consuming and logistically complex: forms had to be printed, distributed and returned via postal mail, physically stored by renal units and manually scanned into electronic format by the UK Renal Registry. This resulted in substantial time lags between data capture and feedback to patients and renal units.

Using patient-reported symptoms to inform practice

Symptom assessments will not improve kidney patient outcomes unless health care professionals, in partnership with patients, use these data to guide care. One unit introduced symptom scores and other survey results as input for individual care planning at quarterly multidisciplinary meetings; scores were included in the letters informing patients about their care plan. Another unit had nurses attending haemodialysis sessions, where they reviewed the reported symptom burden for all patients and flagged scores that warranted discussion during the consultation. To further engage patients in discussing symptom scores with the renal team, they could access results via the national patient portal in addition to their laboratory values [32].

Overall, however, clinical staff participating in TP-CKD found it difficult to use the survey results, which confirms suggestions that making sense of patient-reported data is challenging [31]. To address this, the programme organized on-site workshops where clinical teams discussed their unit's survey results with a facilitator. These discussions focused on familiarizing teams with their data and supporting them with interpretation.

Digital collection of patients' symptom reports

Moving from paper-based to digital collection of symptom data may address some of the barriers identified in TP-CKD. Digital collection can improve the feasibility, sustainability and

cost-effectiveness of capturing and aggregating the data [33]; increase flexibility in what, when and from whom data are captured; facilitate centralized collection at scale; and enable symptom data to be collected once for multiple purposes, including disease management, clinical audits, commissioning of services, and research.

One common example of digital collection entails patients completing their symptom assessments in the hospital using a tablet computer [34]. This method was tested in a study among 56 people on home dialysis attending an outpatient clinic who completed the modified Edmonton Symptom Assessment System [4] in the waiting room prior to their consultation. Mean completion time for the assessment was 2.55 (± 1.04) min and 66% of participants reported being very satisfied with use of the tablet. Another example regards patients submitting symptom assessments online outside the clinic context at a time and place that is convenient for them, using a computer [35] or smartphone [36]. If combined with algorithms to support interpretation of symptom scores as part of a telemedicine system, such online patient reports can be used to tailor the timing and frequency of clinic visits to patient needs [37, 38].

Johansen *et al.* [39] performed a systematic review of randomized controlled trials that evaluated the effect of digital symptom reporting on the quality of health care. They included 29 studies in a range of conditions, including respiratory and lung diseases ($n = 12$ studies), cancer ($n = 6$) and psychiatric disorders ($n = 6$); no studies in CKD were identified. The symptom reporting interventions under investigation aimed to support monitoring of patients' disease status or treatment response over time ($n = 12$), self-management ($n = 9$), the consultation ($n = 7$) or remote delivery of care ($n = 1$). The review showed the benefits of digital symptom reporting in terms of reduced symptom distress, improved symptom severity through better self-management and better health-related quality of life. They also found that clinicians perceived digital symptom reports as useful for identifying problems and enhancing communication with patients. Some studies focusing on self-management support saw a reduction in the number and duration of consultations.

Although the review of Johansen *et al.* [39] suggests that digital symptom reporting has the potential to improve health care and outcomes, it is still unclear to what extent it will be acceptable to patients. Despite the increasing percentage of Internet users, studies have shown that people who are older, less educated and less affluent are less likely to use health technology as part of their care [32, 35, 40]. Further, not all people with long-term conditions may be willing to self-report their symptoms, because they perceive it as 'work' or as a reminder of the negative aspects of their health [41]. Also, clinicians may appreciate subjective symptom reports differently than technically measured information [41], such as a creatinine value or electrocardiogram (ECG). We need to further explore these factors in order to ensure broad patient and clinician engagement in digital symptom reporting and successfully incorporate it in routine practice settings.

Novel methods to assess symptoms

One solution to engage people who are reluctant or unable to actively interact with questionnaires or health technology may come from devices that enable passive data collection, including wrist-worn activity trackers and sensors in smartphones. By simply wearing or carrying these devices, they automatically record information on body movements, location and other behaviours without the need to actively engage with the technology.

Accelerometers are a well-known example. They allow longitudinal tracking of activity and can be worn around the wrist like a watch while minimizing disruption of everyday life; a pilot study with accelerometers in 29 haemodialysis patients reported that the majority of participants felt able to incorporate the device into their daily activities [42]. In terms of supporting symptom assessment, accelerometers have been shown to accurately detect scratching activity in patients with dermatologic conditions [43], which is likely to generalize to people with kidney disease who are bothered by itching. 'Scratching reports' generated from accelerometer data might provide a visual aid for patients and clinicians to discuss the severity and impact of itching. Especially since patient reports of nocturnal itching do not always correlate with observed scratching activity [44], objective scratch reports would complement subjective patient reports, creating a more comprehensive clinical picture of the symptom to better guide treatment decisions. In addition, wrist-worn accelerometers can facilitate assessment and management of disturbed sleep [45] and potentially also support detection of fatigue by using patients' step count as a proxy [46].

Smartphones are another type of technology that provide an opportunity to passively collect data on symptoms. In addition to a built-in accelerometer and gyroscope, smartphones have a location probe [i.e. global positioning system (GPS) technology] to track an individual's geolocation. Several studies, many of them conducted in older populations, have shown that from geolocation data we can derive how often and how long people are away from home, the distance and the mode by which they travel and the number and types of places they visit [47–49]. This information facilitates monitoring of patients' mobility and independence levels. An observed decrease in mobility might, for example, trigger a social worker review of the need for community care or referral to a physiotherapist to assess and improve physical abilities. Furthermore, combining geolocation information with data from other smartphone sensors may help detect symptoms of depression [50].

The above-mentioned examples illustrate that wearable and mobile sensors have the potential to support symptom monitoring and detection, complement subjective symptom reports and trigger and inform treatment decisions with minimal burden and intrusiveness of data collection. Yet, these novel methods are still far from being widely used in routine practice, and future initiatives will need to further establish their added value for the management of symptoms and other aspects of CKD. As for data collected through symptom questionnaires, the main challenges of passively collected data include building an infrastructure for data gathering and analysis, developing meaningful feedback for clinicians and patients and convincing them of its added value and integrating this feedback into health records and patient portals. Tackling these challenges requires a multidisciplinary approach including clinicians, patients, technology engineers and data scientists.

Conclusion

The high burden and suboptimal management of CKD symptoms warrant a more systematic approach towards symptom assessment as part of renal care. Routinely and digitally capturing patient-reported symptom information in clinical practice settings, either actively through questionnaires or passively through mobile sensors, has clear potential to support this. Future work should aim to increase and sustain the engagement of a broad range of patients and clinicians in this endeavour,

while developing an integrated infrastructure for capture, analysis and feedback of patient-reported symptom data.

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Conflict of interest statement

None declared.

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