Understanding patient perspectives of the impact of anaemia in chronic kidney disease: A United States patient survey

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Abstract

Background Anaemia, a common complication of chronic kidney disease (CKD), is associated with reduced health-related quality of life and physical functioning. This study investigated the knowledge, perceptions and awareness of anaemia in patients with CKD in the United States. Methods Between 29 August and 17 September 2018, an online survey was administered to consenting patients in the United States aged ≥18 years with self-reported CKD, with or without anaemia; patients with cancer were excluded. The survey comprised 27 questions, exploring anaemia knowledge, health-related quality of life, anaemia management, practitioner–patient relationships, and the information sources patients used. Results Of 446 patients with CKD, 255 (57.2%) were diagnosed with anaemia and 191 (42.8%) reported not being diagnosed with anaemia, or were unsure/could not remember (non-anaemia cohort). In patients with anaemia, 71.0% were aware of the relationship between CKD and anaemia versus 52.9% of those in the non-anaemia cohort. In the anaemia cohort, 46.3% of patients were aware of their haemoglobin level, compared with 27.2% of patients in the non-anaemia cohort. Symptoms most commonly reported as being made worse by anaemia included lack of energy (82.4%), feeling ill (31.4%), and the ability to enjoy life (30.2%). Despite 67.4% of patients with anaemia in CKD believing that their condition was well or very well managed, only 50% reported being informed about different treatments without having to prompt their healthcare professional, and 43.9% were seeking more information and support about managing their condition. Conclusions In the United States, patients with anaemia and CKD perceived that anaemia had a negative impact on their physical health and emotional wellbeing. Our findings emphasize the lack of disease awareness regarding anaemia in patients with CKD, suggesting that patients would benefit from further education regarding its management, and available treatment options.

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Running title: US patient perspectives of anaemia in CKD

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Disclosures

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Author contributions

A. Dunn, S. Grandy, E. Palaka and E.T. Wittbrodt contributed to the study design and data collection. E.T. Wittbrodt, E. Palaka, F.O. Finkelstein, N. Guzman and S. Grandy performed the data analysis and interpretation. All authors critically reviewed the manuscript, approved the final version, and accept accountability for the overall work.

Data sharing statement

Data underlying the findings described in this manuscript may be obtained in accordance with AstraZeneca’s data sharing policy described at: https://astrazenecagrouptrials.pharmacm.com/ST/Submission/Disclosure.

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Figure 1. Beliefs about (A) causes of anaemia, and (B) symptoms associated with anaemia

A

![Bar chart showing beliefs about causes of anaemia]

Aligns with evidence
- Anaemia is associated with low hemoglobin levels
- People living with kidney disease are at high risk of anaemia
- Anaemia can be treated
- Anaemia might be caused by something other than kidney disease

Does not align with evidence
- Anaemia is caused by low blood sugar
- Anaemia is caused by irregular heart rhythm
- Anaemia is something a patient can easily live with, without treatment
- Anaemia has little to no impact on health

Figure shows the percentage of patients who selected each statement in response to the question "Which of the following statements about anaemia do you think are correct?"

*Question asked to participants was phrased as "Anaemia is caused by low hemoglobin levels."

B

![Bar chart showing beliefs about symptoms of anaemia]

Fatigue, or feeling tired
Weakness
Dizziness
Paleness
Problems with concentration
Headaches
Difficulty breathing or shortness of breath
Chest pain

Figure shows the percentage of patients who selected each statement in response to the question "Which of the following do you think are symptoms of anaemia?"
Figure 2. (A) Perception of chronic disease impact on HRQoL (anaemia cohort, n = 255): (B) worsening of physical symptoms attributed to anaemia by these patients

Patients were asked the following question ‘Below are feelings that people who have a chronic condition, such as kidney disease, have mentioned that they can relate to. Please tell us how much these apply to you on a scale of 1 to 5, with 1 being ‘not at all’ and 5 ‘very much’.

Abbreviation: HRQoL, health-related quality of life.

Patients were asked the following question ‘Which of these feelings would you say is made worse by your anaemia?’
Figure 3. (A) Perception of chronic disease impact on HRQoL (anaemia cohort, n = 255): (B) worsening of emotional symptoms attributed to anaemia in CKD by these patients

A

Proportion of patients (%)

Fatigue
I am sleeping well

General malaise and feelings
I am content with the quality of my life right now
I have accepted my illness
I am able to enjoy life

Daily activities
I am able to work (including work at home)
I am enjoying the things I usually do for fun
My work (including work at home) is fulfilling

Fatigue
I have a lack of energy
I am forced to spend a lot of time in bed

General malaise and feelings
I feel ill
I have pain
I am bothered by side effects of treatment
I have nausea

Daily activities
Because of my physical condition, I have trouble meeting the needs of my family

Abbreviation: HRQoL, health-related quality of life.

Patients were asked the following question: 'Below are feelings that people who have a chronic condition, such as kidney disease, have mentioned in relation to their emotions. Please tell us how much these apply to you on a scale of 1 to 5, with 1 being 'not at all' and 5 'very much'.

B

Patients were asked the following question: 'Which of these feelings would you say is made worse by your anaemia?'

<table>
<thead>
<tr>
<th>Feeling</th>
<th>Proportion of patients (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I worry that my condition will get worse</td>
<td>50.2</td>
</tr>
<tr>
<td>I feel sad and/or depressed</td>
<td>38.8</td>
</tr>
<tr>
<td>I am satisfied with family communication</td>
<td>22.7</td>
</tr>
<tr>
<td>about my illness</td>
<td></td>
</tr>
<tr>
<td>I feel nervous</td>
<td>22.4</td>
</tr>
<tr>
<td>My family has accepted my illness</td>
<td>20.4</td>
</tr>
<tr>
<td>I am satisfied with how I’m coping with my illness</td>
<td>20.0</td>
</tr>
<tr>
<td>I worry about dying</td>
<td>19.6</td>
</tr>
<tr>
<td>I am satisfied with my sex life</td>
<td>19.6</td>
</tr>
<tr>
<td>I am losing hope in the fight against my illness</td>
<td>19.2</td>
</tr>
<tr>
<td>I get emotional support from my family</td>
<td>17.3</td>
</tr>
<tr>
<td>I feel close to my friends</td>
<td>14.9</td>
</tr>
<tr>
<td>I get support from my friends</td>
<td>13.7</td>
</tr>
<tr>
<td>I feel close to my partner (or the person who is my main support)</td>
<td>13.7</td>
</tr>
</tbody>
</table>
Figure 4. (A) Knowledge of treatment options for anaemia and how this was acquired, and (B) anaemia treatments reported by patients

A

Patients were asked the following question: ‘Do you know about the different treatments which are available for managing anaemia and, if so, how did you find out?’

B

Patients were asked the following question: ‘How is your doctor currently managing your anaemia?’
Figure 5. For the anaemia cohort (n = 255): (A) Patient perceptions of how well their anaemia was being managed, and (B) impact of discussing anaemia in CKD with HCPs

Patients were asked the following question 'On a scale from 1 to 5, how well do you think your anaemia is managed, with 1 being 'very badly managed', 3 being 'neither badly nor well managed', and 5 being 'very well managed'?'

Patients were asked the following question 'After your discussions with your doctors about anaemia, no matter how small, how do you feel?'

Abbreviations: CKD, chronic kidney disease; HCP, healthcare provider.

Patients were asked the following question 'After your discussions with your doctors about anaemia, no matter how small, how do you feel?'
Figure 6. (A) Sources used by patients to look for information about anaemia, and (B) trust in the information received from these sources.

A

B

Patients were asked the following question: "Where have you looked for information about anaemia, or received information about anaemia from?"
Figure 7. Factors that prevented patients with anaemia in CKD from seeking more information about anaemia (anaemia cohort, n = 255)

<table>
<thead>
<tr>
<th>Factor</th>
<th>Proportion of Patients (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>My doctor is monitoring it and will tell me if it gets worse</td>
<td>44.7</td>
</tr>
<tr>
<td>I am happy to manage my anaemia through diet and supplements</td>
<td>26.3</td>
</tr>
<tr>
<td>I don’t feel prevented from finding out more information</td>
<td>15.3</td>
</tr>
<tr>
<td>I don’t feel it is a priority in the overall treatment of my kidney disease</td>
<td>13.7</td>
</tr>
<tr>
<td>I am afraid of the side effects of anaemia treatments</td>
<td>11.4</td>
</tr>
<tr>
<td>I don’t feel my life is being affected by anaemia</td>
<td>9.8</td>
</tr>
<tr>
<td>My doctor doesn’t think it’s necessary</td>
<td>9.8</td>
</tr>
<tr>
<td>I don’t think I can afford treatment</td>
<td>8.6</td>
</tr>
<tr>
<td>I want to avoid taking medication</td>
<td>8.2</td>
</tr>
<tr>
<td>I don’t know who I should talk to</td>
<td>7.5</td>
</tr>
<tr>
<td>I don’t feel confident enough to talk about it with my doctor</td>
<td>4.7</td>
</tr>
<tr>
<td>I don’t want to ask because I’m scared of finding out that I have anaemia</td>
<td>3.5</td>
</tr>
<tr>
<td>Other</td>
<td>3.5</td>
</tr>
</tbody>
</table>

Patients were asked the following question ‘What prevents you from seeking help to find out more about your anemia?’
Figure 8. Factors that would encourage patients to seek more information or greater support about anaemia in CKD (anaemia cohort, n = 255)

Patients were asked the following question ‘What would encourage you to seek more information, or greater support, about anaemia in the context of your kidney disease? Please rate the answers below (rating scale from ‘this would not encourage me to seek help’ to ‘this would definitely encourage me to seek help’ and middle point ‘it may encourage me to seek help’).”