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**Title:**

**Self-reported quality of life in complement 3 glomerulopathy patients delineated by CKD stage: a real-world, multi-country survey**

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**Introduction:**

Complement 3 glomerulopathy (C3G) is a rare, chronic kidney disease (CKD), with an estimated worldwide incidence of 1-2 million people/year. C3G is associated with a high risk of disease progression and later stages are associated with worsening symptoms, but there are limited published data describing the health-related quality of life in patients with C3G. We aimed to evaluate the impact of CKD stage on the health-related quality of life in a multi-country study of C3G patients.

**Methods:**

Data were drawn from the Adelphi C3G Disease Specific Programme, a cross-sectional survey, with retrospective data collection, of nephrologists and their consulting C3G patients conducted in France, Germany, Italy, Spain, the United Kingdom (EU5), China, Japan and the United States from August 2022 – April 2023. Nephrologists completed forms for 1-9 consecutively consulting C3G patients, reporting demographic and clinical information including CKD stage by glomerular filtration rate. These patients were then invited to voluntarily complete a survey, self-reporting impact of fatigue within the last seven days via the Functional Assessment of Chronic Illness Therapy (FACIT) – Fatigue and health-related quality of life via the EQ-5D-5L (US tariff), the EuroQol Visual Analogue Scale (EQ-VAS). Analyses presented here are descriptive.

**Results:**

Overall, 111 nephrologists completed forms for 385 C3G patients of which 344 (89%) had a known CKD stage. Of these patients, 100 (29%) completed a patient survey (EU5 n=29, China n=55, Japan n=5, US n=11,). Median (interquartile range; IQR) patient age at time of survey was 41.5 (32.0-54.0) years and 63% were men. Where reported (n=99), patients had been diagnosed with C3G for a median (IQR) of 1.9 (0.9-3.9) years.

Patient CKD stages are shown in Table 1; due to sampling limitations stages 4 and 5 were combined for analysis.

C3G patients reported higher levels of fatigue than the mean general population score of 43, with patient FACIT-Fatigue scores consistently close to 30, indicative of severe fatigue (FACIT-fatigue scores range from 0-51 with lower scores indicating more severe fatigue). Scores were notably lower for patients at stages 4/5 dropping to 27.8 (table 1). ‘Feeling tired’ was ranked as the second most bothersome symptom (18%) by C3G patients, surpassed only by ‘foamy urine’ (20%).

Patient EQ-VAS scores were lower than the mean general population score of 78.1; mean (standard deviation; SD) patient EQ-VAS scores ranged from 63.60 (17.8) for CKD stage 1 to 46.8 (13.0) for stages 4/5 EQ-VAS scores (lower scores indicate poorer quality of life). Patients also experienced worse EQ5D utility scores compared to the mean general population score of 0.84; for mean patient (SD) ED-5D-5L scores this was 0.67 (0.2) for stage 1 to 0.58 (0.37) for stage 4/5 (table 1).

**Conclusion:**

C3G was shown to impact many aspects of a patient’s quality of life, in particular causing severe fatigue that patients described as the second most bothersome symptom. Quality of life is notably lower for patients with stage 4/5 of CKD. Treatment to slow the progression of kidney disease in C3G patients, particularly to later stages, could help improve patient’s quality of life.

Total = 3,329 /3400 characters (not including table)

**Table 1. Patient reported outcome measure survey responses.**

|                                     | Total<br>(n=100) | CKD stage 1<br>(GFR 90+)<br>(n=16) | CKD stage 2<br>(GFR 60 – 89)<br>(n=35) | CKD stage 3a<br>(GFR 45 – 59)<br>(n=21) | CKD stage 3b<br>(GFR 30 – 44)<br>(n=13) | CKD stage 4/5<br>(GFR <30)<br>(n=15) |
|-------------------------------------|------------------|------------------------------------|--|---|---|--------------------------------------|
| <b>Patient EQ-VAS score</b>         |                  |                                    |  |   |   |                                      |
| Mean                                | 63.0             | 63.6                               | 66.7                                   | 66.3                                    | 65.5                                    | 46.8                                 |
| Standard deviation                  | 15.9             | 17.8                               | 14.0                                   | 12.8                                    | 16.2                                    | 13.0                                 |
| Minimum                             | 25.0             | 40.0                               | 28.0                                   | 40.0                                    | 35.0                                    | 25.0                                 |
| Maximum                             | 95.0             | 95.0                               | 90.0                                   | 81.0                                    | 90.0                                    | 66.0                                 |
| <b>Patient EQ-5D-5L – US tariff</b> |                  |                                    |  |   |   |                                      |
| Mean                                | 0.72             | 0.67                               | 0.77                                   | 0.80                                    | 0.70                                    | 0.58                                 |
| Standard deviation                  | 0.26             | 0.22                               | 0.20                                   | 0.21                                    | 0.31                                    | 0.37                                 |

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|                                       |       |      |      |      |       |       |
|---------------------------------------|-------|------|------|------|-------|-------|
| <b>Minimum</b>                        | -0.35 | 0.32 | 0.27 | 0.30 | -0.15 | -0.35 |
| <b>Maximum</b>                        | 1.00  | 1.00 | 1.00 | 1.00 | 1.00  | 1.00  |
| <b>FACIT – Fatigue</b>                |       |      |      |      |       |       |
| <b>Mean</b>                           | 30.3  | 30.2 | 31.5 | 29.8 | 30.8  | 27.8  |
| <b>Standard deviation</b>             | 11.9  | 11.6 | 12.0 | 11.4 | 15.4  | 11.0  |
| <b>Minimum</b>                        | 4.0   | 12.0 | 12.0 | 13.0 | 4.0   | 12.0  |
| <b>Maximum</b>                        | 51.0  | 51.0 | 50.0 | 46.0 | 48.0  | 46.0  |
| <b>Top 3 most bothersome symptoms</b> |       |      |      |      |       |       |
| <b>Foamy urine</b>                    | 20%   | 31%  | 20%  | 19%  | 23%   | 7%    |
| <b>Feeling tired</b>                  | 18%   | 6%   | 29%  | 10%  | 15%   | 20%   |
| <b>Swollen hands/<br/>feet/ankles</b> | 16%   | 12%  | 11%  | 14%  | 8%    | 40%   |

CKD: Chronic Kidney Disease; GFR: Glomerular Filtration Rate; EQ-VAS: EuroQoL Visual Analogue Scale; FACIT: Functional Assessment of Chronic Illness Therapy; US: United States