Patient perspectives on pruritus in intrahepatic cholestasis of pregnancy: a multinational survey

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Introduction

Cholestatic pruritus is one of the disease-defining symptoms of intrahepatic cholestasis of pregnancy (ICP). In severe refractory cases, pruritus can lead to iatrogenic delivery with significant perinatal morbidity associated with prematurity. In a large double-blind randomised controlled trial, up to 11% of participants with ICP were electively delivered for severe maternal symptoms. Current therapies offer minimal effectiveness for cholestatic pruritus associated with ICP, which for many women may not be worthwhile.

Aim

To characterise the severity of cholestatic pruritus, the impact on quality of life, and the effectiveness of available treatments from the patient’s perspective.

Methods

A 30-question web-based survey was distributed to international participants via an ICP patient support group: key questions are outlined in Table 1. Participants were asked to assess itch severity and sleep disturbance using a numerical rating scale (NRS) of 0–10 (0, none; 10, most severe). Anonymized responses were collected between August 25 and September 10, 2020. Results were tabulated and percentages are presented based on non-missing data.

Table 1. Selected survey questions

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<th>Itch Survey Questions</th>
<th>In which country do you currently live?</th>
<th>Which of the following medications are you taking, or have you taken in the past to treat your ICP itch?</th>
<th>Has your itch contributed to changes in your fatigue level?</th>
<th>When you have experienced itching, is it/was it worse at certain times during the day?</th>
<th>How would you rate the worst itch you experienced during most recent ICP pregnancy?</th>
<th>In which country do you currently live?</th>
<th>During an episode of itching, have you had to miss school or work?</th>
<th>If YES, at what time of the day is/was it the worst?</th>
<th>If YES, how long did your itching disrupt your day-to-day responsibilities and/or routine?</th>
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Results

Of 688 women who responded, 352 (51.2%) lived in the UK, 162 (23.5%) in the US, 54 (7.8%) in Australia, 19 (2.8%) in Canada, 10 (1.5%) in New Zealand, 8 (1.2%) in Ireland. 77% reported that itch was associated with mood changes, including but not limited to increased anxiety, feelings of hopelessness and/or irritability. 77% reported itching symptoms were worse at night; 94% reported itch-related sleep disturbances, with median degree of disturbance confirmed presence of pruritus. 71% were NOT asked about ICP by their prenatal care providers; 89% of providers did investigate further once the participant confirmed presence of pruritus.

Conclusions

This international survey underscores the debilitating effects of pruritus in ICP. A large proportion of participants experienced a substantial impact on quality of life, most of which was not elicited by their prenatal care providers. A majority reported taking ≥2 medications for itch, most without knowledge of their providers. Consistent with prior studies, most participants reported neither partial nor resolution of ICP-associated pruritus with existing therapies.

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