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Title

Assessing Patient Experience in an Inflammatory Bowel Disease service. Can we measure an effect from socioeconomic deprivation – experience from the AWARE-IBD programme?

Authors

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Background

There is increasing international attention on delivery of services for people with Inflammatory bowel diseases (IBD). Experience of care is defined and measured as 'what' happened, 'how' and 'how often' and is an important facet of service provision. Socioeconomic deprivation may be associated with poor disease-related outcomes and sub-optimal utilisation of services but its effect on experience of care in people with inflammatory bowel disease has not been reported.

Methods

An invitation to participate in a research study nested within the AWARE-IBD quality improvement programme was sent to 4082 patients attending the IBD service at a single UK teaching centre in October 2021. A second invitation was sent in May 2022 followed by telephone recruitment targeted to those from the most deprived deciles based on the index of multiple deprivation (IMD), a measure of relative deprivation for small areas in England ('lower-layer super areas', approximately 1500 residents). Participants returned an IBD specific patient reported experience measure (PREM) via a web application comprising 38 items across 3 domains: 'My Care Team', "What matters to me', 'Living with Crohn's or Colitis'. Each item was scored 1 (poorest experience) to 5 (best experience). Median scores for individual items and by domain was compared in the following demographic groups: IMD decile IMD (1 = most deprived; 10 = least deprived), age, gender, disease type (ulcerative colitis or Crohn's disease).

Results

PREM responses were received from 249/4,082 (6%) patients. Patients from the most deprived decile were underrepresented in respondents compared to the invited cohort (Decile 1 22/249 (9%) vs 667/4,063(16%) p=0.002) and patients from the least deprived decile were over-represented; Decile 10: 38/249 (15%) vs 379/4063(9%) p=0.002). Respondents were otherwise broadly comparable to the invited cohort in terms of age, gender and disease type. Experience of care for respondents for individual PREM items or by domain did not differ according between IMD deciles (Figure 1), age, gender or disease type.

Conclusion

Measuring experience of care is an important part of IBD service quality improvement. No effect from socioeconomic deprivation was demonstrated. This finding conflicts with the literature on links between socioeconomic factors and quality of care and results across a service should be interpreted with caution. Experience of those at greatest risk is difficult to elicit with survey based experience measurement. Instead, tailored engagement exercises are required including qualitative and ethnographic approaches to better understand the impact of deprivation on experience.

Figure 1

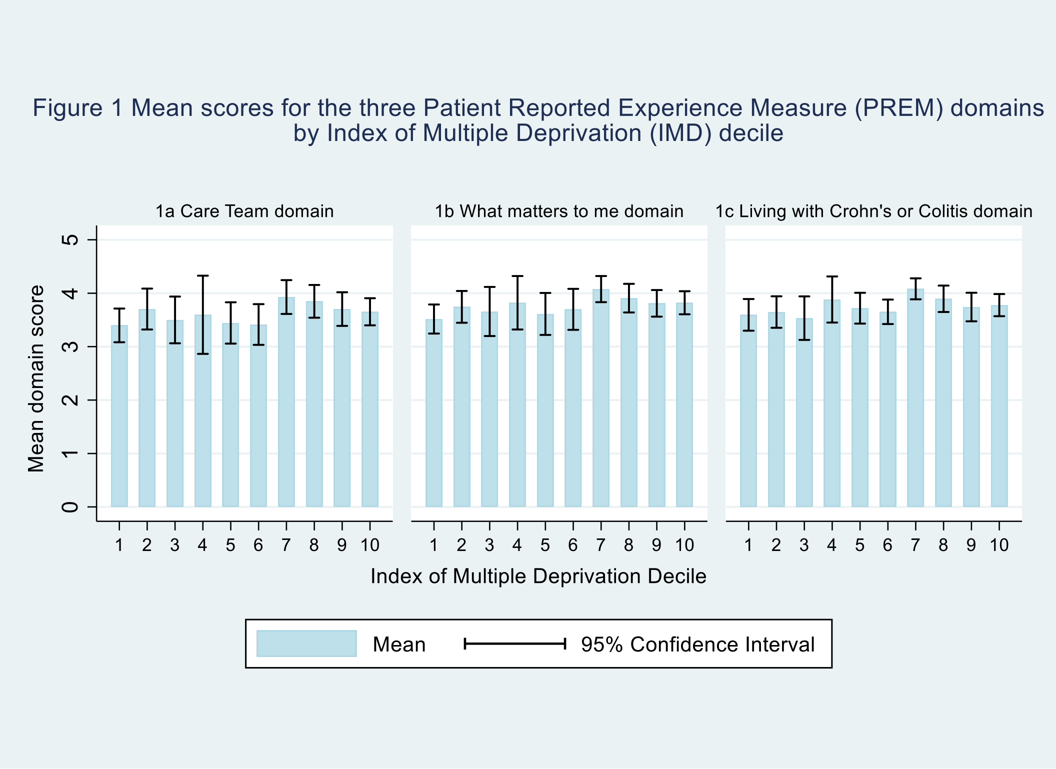
Figure 1 Mean scores for the three Patient Reported Experience Measure (PREM) domains by Index of Multiple Deprivation (IMD) decile
1a Care Team domain
1b What matters to me domain
1c Living with Crohn's or Colitis domain
Mean domain score
0
1
2
3
4
5
1 2 3 4 5 6 7 8 9 10
Index of Multiple Deprivation Decile
Mean
95% Confidence Interval