

Ongoing Concerns And Desired Enhancements



Desire for peer support prior to irrigation - Patients described wanting to hear from peers with lived experience before starting irrigation, valuing first-hand insight beyond clinical advice.



Need of a support group - Patients described mixed views on support groups, with some valuing shared experiences and others preferring clinician-led help due to time, comfort, or relevance.



Environmental impact - Patients described concern about the environmental impact of single-use plastics and waste, though most continued irrigation despite concerns due to symptom relief.

Conclusion

Patients started irrigation with **low awareness** and **inconsistent early care**, often after years of unmanaged symptoms.

Supportive training helped adaptation, though **early fears** and **practical challenges**, especially with high-volume systems, were common.

Privacy and **embarrassment** shaped social comfort, with younger patients more hesitant to discuss irrigation.

Most experienced better **symptom control** and **improved confidence**, though a minority saw limited benefit.

Future needs include optional peer support, more compact and sustainable devices, smoother logistics, and clearer early education.

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'It Changed My Life, Or It Was Too Much': A Patient-centred Account Of The Rectal Irrigation Pathway

Aim

This study explored patients lived experience of the rectal irrigation pathway to identify the practical, emotional and service-level factors that shape uptake, sustained use and quality of life.

Methods

Semi-structured, focus groups interviews (in-person and virtual) were conducted with up to 4 adults in each group who were current, former, or declined users of rectal irrigation. Interviews were recorded and transcribed verbatim.

Discussions were guided by hypothesised barriers, with new barriers added until thematic saturation was reached. Final themes were organised into domains supported by patient quotations.

Results

Six interview sessions, including **27 participants**, were held. There was a **female** predominance (24, 89%), and the median **age** was 54 years (range, 24 –77 years). **Virtual sessions** were attended by 4 (15%) patients.

Ethnicity – White British (63%), White other (15%), Black British (7%), Black other (7%), Asian (4%) and Other (1%). **Socioeconomic** diversity was achieved, with participants drawn from all index of multiple deprivation deciles.



Limited knowledge – Patients expressed surprise and frustration at having little or no prior awareness of rectal irrigation as a tool to manage their symptoms.



Early risk perception and fears – Patients described initial anxiety about potential harm, doing the procedure incorrectly, and uncertainty about how they would respond.



Fitting into daily routine - Patients described time-management challenges with some finding it burdensome while others gradually adapted as it became more manageable.



Inconsistent primary-care engagement with most clinicians having limited knowledge of irrigation while some dismissing patient concerns.



Privacy - Patients described going to great lengths to keep irrigation hidden, stressing over equipment being seen in shared or small spaces.
Stigma- Patients described feeling stigma rooted in family taboos and the belief that bowel irrigation is an 'older person's' issue.



Irrigation away from home - Patients felt mixed about using irrigation away from home, with worries about leaks, embarrassment, bathroom size & luggage space, yet some found it liberating when facilities were suitable.



Device ergonomics and technical challenges - Patients noted practical challenges with setup, handling, and storage. They described irrigation equipment for e.g., high-volume systems as awkward and time-consuming compared to low-volume options.



Symptom control - Patients described significant improving in bowel control, reduced discomfort, urgency, and reliance on laxatives.
Return to normality - Irrigation restored a sense of normality, enabling daily routines and social life without constant bowel-related disruption.