

# INFLIXIMAB OR CICLOSPORIN: PATIENT VIEWS ON TREATMENT AND THE IMPACT OF ULCERATIVE COLITIS (UC) ON THEIR LIVES

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## BACKGROUND

CONSTRUCT - a randomised controlled trial comparing clinical and cost effectiveness of infliximab and ciclosporin in steroid resistant UC.

The qualitative element examined quality of life (QoL) across the two groups and patient perceptions. This poster presents patients' opinions about UC treatments and the impact of UC on their lives.

## METHODS

Patients admitted with colitis, diagnosed with UC, who failed to respond to ~5 days of IV steroids, were randomised to infliximab or ciclosporin and followed up for between 12 – 36 months.

Purposive quota sampling identified participants from each trial arm to yield a wide representation of patients (therapy, age & sex) from a range of centres.

Semi-structured telephone interviews took place at three and 12 months after admission (acute severe UC and randomisation).

## ANALYSIS

Standard thematic analysis by three qualitative researchers followed by schematic analysis of whole-page summations of transcripts by seven members of CONSTRUCT.

## RESULTS

20 interviews were completed. Length of disease duration varied, but similar descriptions emerged about living and coping with UC, physical, mental and emotional impact, treatment options, and concerns and hopes for the future. The following findings concentrate on the three month data alone.

- In general, patients who received infliximab spoke more positively about the treatment regimen and side effects than those who received ciclosporin

*Ciclosporin infusion "loss of freedom, I found that quite irritating, personally found that frustrating" (SGT0012)*

*Infliximab - "there is not any managing of it ... it's a 2hr infusion & then you're not due back in for another 6-8 wks so in that way it's fantastic. I'm not having to get up every morning & take about 20 different tablets" (HIG0005)*

- Dramatically debilitating symptoms impact noticeably on patients' QoL and on their family and friends

*"Colitis can make you a prisoner that you don't venture far away from a toilet ... have to memorise where all the toilets are ... makes you a prisoner to the disease" (STH0016)*

- Patients live with ongoing, unpredictable symptoms and unexpected treatment, making it particularly difficult for patients and professionals to manage care
- Unlike other chronic diseases UC is considered embarrassing, making it isolating and awkward for patients to manage work and life routines
- The lack of visibility of symptoms or outcomes impacts on patients' ability to share and discuss openly with others
- Surgery is feared but most patients experience relief and subsequent health benefits following surgery

*"I walked out of there without a bag, that's what meant most to me. It's just the fear of the unknown, the effect it can have on your life" (SGT0001)*

*"I wish I'd had this operation the day I was diagnosed ... it was the moment I woke up after the operation, I thought, cor, this is fantastic, the fog had cleared" (SDT0008)*

- Patients would like to understand what causes UC, its links to stressors and diet and would welcome more extensive information provision
- Ready access to IBD Nurses is important for patients

## CONCLUSION

Study findings indicate that UC patients:

- speak more positively about treatment with infliximab than ciclosporin
- need support to manage the impact of UC on their lives, want prompt diagnosis and relevant treatment provided quickly
- live with constant, unpredictable symptoms, where a flare-up becomes socially isolating and are anxious about deteriorating health
- views after surgery were generally positive, but more research is required into surgical treatment to support those facing surgery and as an alternative to medical treatment
- the profile of UC should be raised to destigmatise the disease and thus the embarrassment felt by sufferers and those living with the outcomes of surgery

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