Help-seeking for distress and mental health needs following stoma surgery

Initiating help-seeking

Some young people perceived that psychological needs didn’t warrant professional attention, and that negative emotions were a normal response to their circumstances.

Stoma nurses saw identifying psychological concerns as a key part of their role. Surgeons and gastroenterologists also felt stoma nurses were best placed for this.

Some young people who did seek support for distress reported feeling unsure about available support services, and sometimes felt lost trying to navigate the care system.

Young people reported most often disclosing emotional concerns to their GP, followed by IBD nurse, then stoma nurse. This was informed by the strength of the relationship with the professional.

Assessing psychological needs

GPs were the most confident group in assessing psychological needs, but acknowledged their lack of stoma-specific knowledge.

Professionals highlighted the difficulty in distinguishing between clinically significant symptoms and a ‘normal’ response to life-changing event.

When professionals normalised distress patients sometimes found this to be dismissive and invalidating.

Providing support for psychological needs

Stoma nurses highlighted lack of formal training in managing mental health needs, and would sometimes refer young people to specialist services.

Patients were often signposted to their GP for psychological concerns, who may signpost to IAPT. However, young people highlighted lack of specialist stoma expertise in IAPT services, which they desired.

Young people and professionals highlighted the need for a specialised psychological service to be embedded in the stoma care pathway for IBD patients.

The absence of a clear referral pathway for psychological support as part of the IBD service made it difficult for secondary care professionals to facilitate patients accessing support.