Inflammatory bowel disease advice lines during the COVID-19 pandemic: a retrospective service evaluation

Abstract

Background: The COVID-19 pandemic significantly impacted on healthcare delivery worldwide, affecting many services, including those for inflammatory bowel disease (IBD). **Aims:** To evaluate the impact of COVID-19 on worldwide IBD telephone advice-line services. **Methods:** A mixed-methods 25-item online survey was distributed to IBD specialist nurses globally using IBD professional networks, email and social media. Data were analysed using descriptive statistics (quantitative data) and content and thematic analysis (qualitative data). **Findings:** Across 21 countries, 182 IBD specialists participated. With adjustments, all advice lines remained functional. Call content changed, and call volume increased exponentially. Strategies were recommended to maintain services. IBD specialist nurses faced considerable challenges, including overwhelming workload, disrupted referral pathways, fragmented IBD clinical team support, isolation and greatly lowered morale. **Conclusions:** To cope with similar future crises, advice-line training, resilience coaching and ringfencing of the IBD clinical team are essential. Development of global guidelines for maintaining advice-line functionality in any scenario is recommended.

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The first wave of the COVID-19 pandemic had a significant impact on almost all healthcare systems around the world. Many services were restructured to enable healthcare systems to accommodate admissions from COVID-19 (Sohrabi et al, 2020). Management of long-term conditions was affected across the world, as services under pressure adjusted to enforced changes, while continuing to support patients, including those with inflammatory bowel disease (IBD) (Burch 2020; Kennedy et al, 2020a; Willan et al, 2020).

The importance of advice lines to people with long-term conditions, including IBD, is well established (Correal et al, 2019; Timpel et al, 2020; Younge at al, 2020aa or b?). First offered in the UK 25 years ago (Phillips, 1995), advice lines are now a core part of IBD clinical support and care delivery worldwide, having been shown to reduce flare severity and duration by giving patients access to earlier intervention, thereby avoiding unnecessary hospitalisation and associated costs for patient and services (Squires et al 2016; Bager et al, 2018; Harris et al, 2020; Nicolaides et al, 2020). Access to an IBD team through an advice line provides patients with confidence that in a flare they will be supported by healthcare professionals (HCPs) who they know (Bager et al, 2018).

With IBD advice lines at the centre of routine support and care for patients (IBD UK, 2019; Harris et al, 2020), evaluating the impact of the pandemic on this essential service is

of fundamental importance. Patients have reported difficulty in reaching their IBD clinical teams, and one-in-five reported having a flare while the UK was in lockdown (Crohn's & Colitis UK, 2020). Disruption to the size and structure of IBD teams in relation to staffing has added pressure (Kennedy et al, 2020b) as call volume has increased. Some patients are in 'at risk' categories for developing COVID-19 disease (Department of Health and Social Care, 2021), creating significant and understandable anxiety and stress, so an increase in call volume might have been expected. However, it was not known: whether there had been any change in the nature of calls received (Mir et al, 2020); what impact changes to staff levels and skill mix would have on IBD advice-line management; or how HCPs who were answering calls and emails were coping with the increased workload.

The purpose of this service evaluation was to understand how global advice lines were affected during the first wave of the COVID-19 pandemic, between March and June 2020. The specific objectives were to: understand changes to service delivery; explore reasons for and impact of any restructuring on staff; and compare responses from around the world.

Methods

A mixed-methods survey was developed using an embedded design and based on the authors' experience as IBD clinicians involved in setting up and operating IBD advice lines. The embedded design supports collection of quantitative data, which are analysed and presented to describe factors of interest and augmented by simultaneous collection of qualitative data to explain those factors (Creswell and Plano-Clark, 2007).

The 25-item online survey was developed during a virtual meeting between three of the authors, piloted on a sample of 16 IBD nurses and signed off by these three authors before release. The survey was designed using MSForms, and it included nine demographic questions, eleven quantitative questions with response options and six qualitative questions.

Data collection

Data were collected between 3 July and 31 August 2020. The invitation to take part and the link to the online survey were cascaded to IBD colleagues delivering UK and international IBD services, via the official channels of national committees and societies, including the British Society of Gastroenterology (BSG), the European Crohn's and Colitis Organisation (ECCO), and the UK Royal College of Nursing (RCN) IBD nurse network, and via IBD nurse contacts in Denmark, Australia, New Zealand, Sweden and Canada.

Ethical considerations

Neither university nor NHS ethics approvals were required for this survey, which was classed as a service evaluation. The project was approved by Dorset County Hospital NHS Foundation Trust (audit number 5184). Participants opted whether or not to remain anonymous when completing the survey via the online platform (MSForms). Participant details that have been collected have been kept in accordance with the General Data Protection Regulations 2016/18 (Intersoft Consulting, 2020) in a secure, password-protected cloud location. Consent was implied by completion of the online survey.

Quantitative analysis

Descriptive quantitative analysis was conducted on all numerical data. The chi-squared test was used to account for differences between data from UK and the rest of the world (RoW) participants. Likert scales were converted into ordinal data and analysed using the t-test. Multivariate analysis was performed using ordinal logistic regression. All analyses were undertaken using R Studio version 1.2 (R Studio, 2019). Significance was considered when $p \leq 0.05$.

Qualitative analysis

The responses to questions 12, 14, 17, 18 and 20 provided opportunities to expand on answers to related quantitative questions and were analysed using content analysis. This method notices the number of times a comment or theme arises and presents results using descriptive statistics supported by narrative from the data (White and Marsh, 2006). Thematic analysis, based on the analytical hierarchy described by Spencer et al (2003), was carried out on the detailed free-text responses to question 19. This method groups similar statements/ideas together and then looks beyond the descriptive to give some insight into context or meaning, using detailed quotes from participants to illustrate each theme.

Key words
- Advice line
- Inflammatory bowel disease
- Pandemic
- Service evaluation
- Specialist nurses

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Results (demographics)

In total, 182 IBD HCPs from around the world participated. Two duplicate responses were removed (1.1%), providing data from 180 (98.9%) participants. Of these, 81 (45%) were employed in tertiary (university) hospitals, 93 (51.7%) in district general (regional) hospitals, and six (3%) in other facilities, such as private hospitals. The majority 137 (76.1%) were from the UK and Channel Islands, 20 (11.0%) from mainland Europe, 13 (7.2%) from Australia, four (2.2%) from New Zealand, two (1.1%) from Canada and one (2.2%) from the US, Argentina, Colombia and Egypt respectively. Of the 180 participants, 178 reported their professional title: 164 (92.3%) were nurses, 12 (6.7%) were medical staff and two (1%) were support staff. Of all job titles and role descriptors, the most common was clinical nurse specialist (CNS), accounting for 70 (39.3%) responses.

Quantitative and qualitative (content analysis) data are presented concurrently to enable association of free-text responses with the originator question. For example, question 11 provided five response options for participants to indicate what had caused changes in their staffing levels, including 'Other', and question 12 invited those who selected 'Other' to give more detail in a free-text response. Several questions permitted participants to give more than one response.

Results (quantitative and qualitative content analysis)

Changes to service structure

In total, 87/136 (64%) of UK participants maintained their IBD advice lines without changes, compared with 23/47 (48%) in the RoW ($p<0.01$). In the UK, 99/136 (73%) reported differences to the usual calls they received prior to the pandemic, compared with 31/44 (71%) in the RoW ($p<0.076$). In the UK, 27/136 (20%) reported receiving any formal advice-line training, compared with 5/44 (11%) ($p<0.2$) in the RoW. COVID-specific training was provided for 10/136 (7%) in the UK and 3/44 (7%) in the RoW (*Table 1* and *Figure 1*).

Of all 180 participants, 162 (89%) reported changes to service structure. The majority (n=66, 33%) reported a decrease in staff numbers; 34 (17.7%) experienced an increase in working hours, while 25 (12.6%) reported decreased working hours. Only 10 (5%) had an increase in staff to operate the advice line, while 63 participants (31.8%) offered further explanation of staffing levels during the peak of the pandemic.

No change in staffing levels

Of the 19 participants (30%) who reported no change in staffing levels, one commented 'but we had to justify not being redeployed three times during the initial phase'. Five respondents

Table 1. Inflammatory bowel disease (IBD) advice lines during the COVID-19 pandemic, in the UK and the rest of the world (RoW), %

Question	Answer	All (n=180)	UK (n=133)	RoW (n=37)	Difference	P value
Did you run an advice line before the pandemic?	Yes	94.4	97.8	84.1	13.7	<0.01
	No	5.6	2.2	15.9	13.7	
Were you able to run an IBD advice line once the pandemic started?	Yes	61.1	64.0	52.3	11.7	<0.076
	With changes	33.9	34.6	31.8	2.7	
	n/a	5.0	1.5	15.9	14.4	
Did reasons for calls differ before and after the pandemic?	Yes	72.2	72.8	70.5	2.3	<0.01
	No	7.8	7.4	9.1	1.7	
	Maybe	20.0	19.9	20.5	0.6	
Did you receive formal helpline training before the pandemic?	Yes	17.8	19.9	11.4	8.5	<0.2
	No	76.7	77.9	72.7	5.2	
	Maybe	5.6	2.2	15.9	13.7	
Did you receive any COVID-specific training?	Yes	7.2	7.4	6.8	0.5	<0.01
	No	87.2	90.4	77.3	13.2	
	Maybe	5.6	2.2	15.9	13.7	

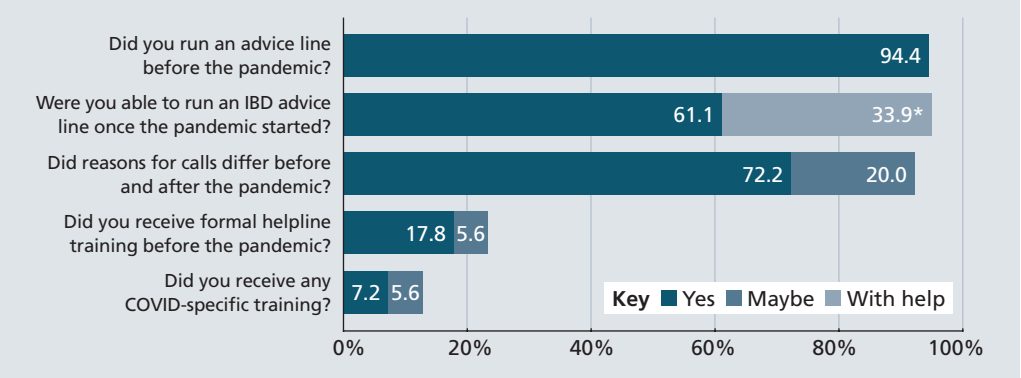

Figure 1. Inflammatory bowel disease (IBD) advice lines during the COVID-19 pandemic (n=180)

(8%) explained that they were the only IBD nurse anyway, so were 'allowed to continue in the role'. Even where no staff changes were reported, the way the service was delivered did alter (n=9, 14.2%).

Staff changes due to COVID-19

Staff changes usually resulted in decreased numbers, due to redeployment of nurses and consultant colleagues, illness among staff and colleagues leaving the service. For example, a respondent reported:

'A staff member resigned as a result of COVID-19 and the pressure placed on them.'

Impact of staff changes

Nine respondents (14.2%) highlighted that maintaining a restructured service presented challenges. One reported that:

'Staff worked quite a few unpaid hours to meet the demand of the phone and email enquiries.'

Nurses worked either more hours or the same hours over fewer days:

'The increased hours were not formally agreed. We just did it because patients and parents were anxious.'

Factors affecting the ability to staff the advice line

Of all 180 respondents, 170 (94.4%) reported the impact of several factors on being able to staff the advice line (*Table 2*). Redeployment had the greatest impact, but all categories (childcare, non-COVID sickness, COVID sickness, shielding and self-isolation) were disruptive. Ordinal logistic regression analysis was not performed, because no differences were found on univariate analysis.

Of all respondents, 23 (69.7%) described a variety of reasons for staff absences, including colleagues who needed to shield or self-isolate due to a family member showing symptoms. Enabling shielding colleagues to continue to work created additional tasks for team members remaining in the hospital:

'She needed to call/email the nurses based in the hospital to complete some of the tasks accrued during phone clinic/emails, because she could not do certain jobs from home'.

Four (12%) reported non-COVID-related sickness and injuries that depleted staff numbers, and six (18%) reported other reasons for absences, including maternity, annual leave and being caught up in travel restrictions.

Table 2. Factors affecting ability to staff advice lines, mean Likert score (1=strongly disagree, 5=strongly agree)

Factor	All (n=170)	UK (n=136)	Rest of world (n=44)	Difference	P value
Childcare	2.56	2.57	2.54	0.03	0.94
Staff sickness (non-COVID)	2.75	2.79	2.62	0.17	0.4
Staff sickness (COVID-19)	2.79	2.82	2.7	0.12	0.7
Redeployment	3.16	3.17	3.11	0.06	0.13
Shielding	2.75	2.81	2.51	0.3	0.22
Self-isolation	2.86	2.89	2.76	0.13	0.62
Other impacts	2.48	2.53	2.32	0.21	0.61

Reasons for advice-line calls during the pandemic

Participants provided 1631 responses, with an average of 148 responses (range 131–170) across 11 response options; 170/180 (94.4%) indicated that questions relating to taking medications (biologics, small-molecule drugs and oral immunosuppressants) were the commonest reasons for calls to the advice line, although there was a similar level of demand for information across all pre-defined topics (*Figure 2*). As to the reasons that patients had given for calling the advice line during the pandemic, 37 (20.5%) respondents offered further multiple explanations.

Shielding information

Eight (21.6%) respondents described patients' requests for shielding information, particularly in respect to their need (or not) to shield from family members with COVID-19 symptoms if they were on immunosuppressants, and whether they could continue to work if their children (with IBD) were shielding. UK respondents reported patients' concerns about the 'mismatch between receiving a government shielding letter and a moderate risk letter from the IBD team'.

Meanwhile, in Australia and Canada, callers were requesting letters for official bodies, such as 'University/college application extension request letters, scholarship letters, residence exemption or accommodation request letters, travel cancellation letters'.

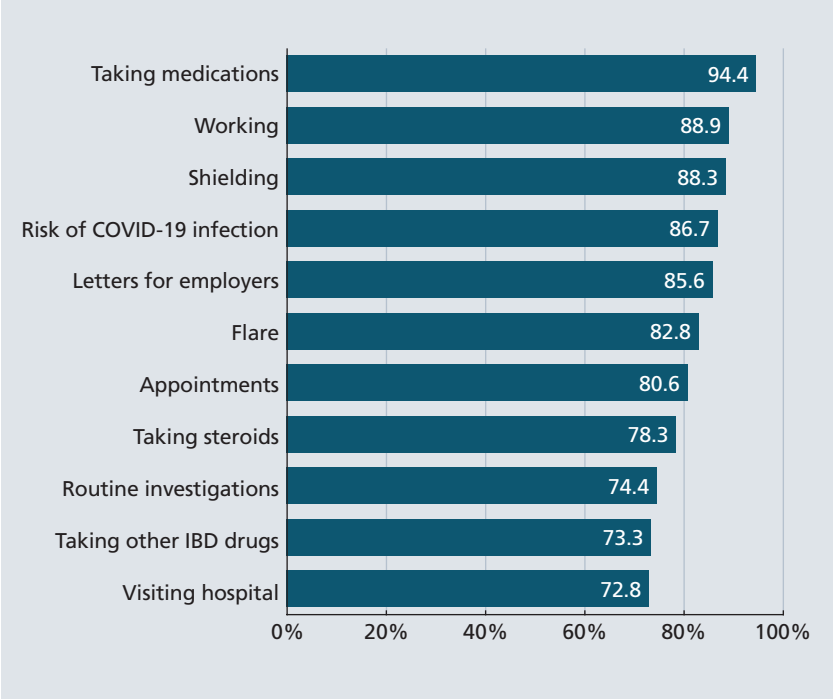

Figure 2. Reasons for calls to inflammatory bowel disease (IBD) advice line (n=180)

Mental wellbeing

Four (10.8%) respondents made comments such as 'patients were extremely worried', citing psychological impacts, including stress and anxiety, on patients and their parents as reasons for calls.

Queries about family members

Globally, callers were concerned about family members, particularly around risks of children with IBD attending school, or those without IBD bringing the virus home from school to where another child or adult was shielding. Callers also wanted to know, once lockdown started to ease, about various family members (themselves, their partner or their child) returning to work or school. In Denmark, there were calls from patients:

'If their employers did not have up to date restrictions or [the caller was] in doubt of how to cope with recommendations for safety protection.'

Access to healthcare

Some UK respondents (n=16; 43%) reported calls from patients unable to access services they needed to manage their IBD at home. In the UK, community GP services also locked down and provided only essential services. One respondent described 'an increase in demand for blood testing, as some GP practices do not regard 3-monthly immunosuppressant blood monitoring as essential.'

The only similar non-UK comment came from Australia, and this also mentioned patients requesting blood tests via the advice line. In the UK, not being able to access these primary care services appeared to impact patients negatively:

'Two small bowel perforations in the last 3 months on account of GP inaction. I cannot contain my fury at this!'

UK advice lines also received calls from IBD patients about non-IBD health issues, whether elective surgery would go ahead and whether it was safe to attend the infusion unit.

Table 3. Top tips for managing increased workload in inflammatory bowel disease (IBD) services

Theme	Subtheme	Supporting quotes
Messaging and information	Signposting to external sources of information	• 'Set the email to say "Flare calls only—contact NHS Direct about COVID and admin staff about appointments"' • 'Signpost patients to guidance via voicemail message and make it clear that flaring patients' calls will take priority'
	Consistency	• 'Speak to the team to ensure everyone is in agreement of advice ASAP, so it can be relayed to patients/families' • 'Make rules within your team and stick to those' • 'Network to use info others are using, so [you are] not reinventing wheel'
	Pre-empting patient need	• 'Be proactive and contact high-risk patients before problems arise; if they have clear information on hours, schedules, medication etc, the volume of calls can be reduced'
Managing the workload	Prioritising and triaging	• 'We have admin [staff] to triage calls and deal with non-clinical [questions]—admin then add patients with clinical questions to a central "IBD advice line" clinic template, and we call those patients back after 2pm; this then enables other work to be done around the advice line' • 'Ask patients to leave information as to why they are calling rather than just their contact details—to help with prioritising who needs contact first'
	Maintain the multidisciplinary team (MDT)	• 'Escalate [flare calls] early to a doctor nominated to respond to queries, to 'get help with biologic prescribing' and 'difficult situations /conversations' and ensure 'better support for nurses for complex advice'
	Adjust the IBD services	• 'Increased workload was significantly managed better with having reduced hours for helpline calls messages, leaving more working hours to manage them' • 'We set up a hot clinic for face-to-face, with an IBD consultant twice a week for the very unwell who we couldn't manage remotely'
Nurses' wellbeing	Taking breaks and taking care of the self	• 'Take small breaks regularly to stretch, get some fresh air, and clear the mind after so many calls with anxious, upset patients—you need to be refreshed, as each call is different and often challenging' • 'Empathise with your patients, but remember not to take that emotional/anxiety baggage with you—doing this doesn't make you a bad nurse who doesn't care; it stops you from burning out and [helps you] be able to function to look after the many'
	Sharing the load	• 'Share the advice line between staff [to avoid staff getting overloaded by responding to calls all the time]'
	Acknowledge all efforts	• 'Recognise that not only those working directly with COVID patients have had a difficult and busy spring/summer, but also those making the rest of the healthcare system work'
	Seeking moral support	• [In the UK] 'Lean on the IBD Nurse Facebook page' • 'Working remotely has its own challenges, but I had members of my family who would take care of me'
Managing own and patient expectations	Managing patient expectations	• 'Set expectations; state what you can and can't do' • 'Inform [patients] of any redeployment commitment and keep them aware of the reduced service'
	Setting realistic staff expectations	• 'Accept that it may not be possible to achieve everything as you would have done previously' • '[Nurses] should not feel guilty for letting patients wait for non-urgent queries' • '[It is] important to acknowledge what the huge increase [in calls] from anxious patients can do to nurses'
Meeting patient and parent needs		• 'Even if you don't have the staff for it, you need to open up for the patients; they need much more information and support' • 'Talk calmly and listen carefully … to reassure patients as much as possible'
Staffing levels		• 'Don't agree to full redeployment of your team' • 'If redeployment is necessary, backfill with staff who can't be patient-facing and increase administrative support to triage calls appropriately'

Composite themes

Of all respondents, 170 (94.4%) offered advice on managing any increased workload and on doing so in a pandemic (*Table 3*). Recommendations were similar for both situations, resulting in six composite themes:

- Messaging and information, including consistent messaging and signposting to external resources
- Managing the workload, including triaging and prioritising
- Managing patients' and own expectations,

including being realistic about what services can be given to patients and by clinicians
- Self-care and wellbeing, including looking after oneself and colleagues, taking breaks and emotional self-care
- Meeting parent and patient need, doing what can reasonably be done to support people
- Staffing, protecting the IBD clinical team.

Results (qualitative thematic analysis)

Question 19 provided opportunity for participants to describe the challenges they had faced during the pandemic in greater detail. Comments cannot be attributed to specific participants via pseudonyms, since it was collected anonymously, but a wide range of comments from participants across the world have been used. The rich and powerful data generated four core themes:
- Overwhelming workload
- Disrupted support services
- Patient concerns and expectations
- Personal impacts.

These, each with subthemes, provide a complex picture of the professional and personal challenges participants had faced in providing advice line services during the pandemic (*Figure 3*). Although presented in sequence below, these themes interrelate and influence each other in subtle ways.

Theme one: overwhelming workload

Although participants had already reported that advice lines remained active—albeit with some adjustments—they were actually dealing with a huge and often overwhelming workload. This was mainly driven by an increase in the volume and nature of calls and demands for information and clarification.

Subtheme: volume and nature of calls

Participants reported very challenging two-to-four-fold increases in call volume:

'I never expected the call volume to explode the way it did. It was devastating to pick up the phone and have 35–40 messages each time. It would take 3–4 hours to clear the calls, then you pick them up again and there are another 30–40 messages. Choosing who was priority was difficult and time consuming … it stopped me from sleeping, as I was worrying about the patients I hadn't called back.'

The nature of calls also changed, and several services, despite providing signposting to external COVID-19 resources, still received calls about shielding from worried patients who wanted reassurance. Adding to the workload were a range of other factors, including 'having to train someone at the same time', dealing with increased call volume 'without increased staffing' and 'also running the infusions from a safe and separate hub'. Efforts to respond to calls while 'reassuring patients about their treatment as well as dealing with routine duties was overwhelming'. Calls often generated follow-on work, and 'everything took longer to organise,' thereby adding to workload. The demands on nurses were enormous:

'The increased workload resulted in many hours over-rostered time, tiredness and increased stress levels. [There was a] sense of failure in not meeting patients' and [organisations'] needs.'

Subtheme: lack of information and misinformation

Participants explained that, when the pandemic started, there was little information available to them to adequately support and advise patients, yet there was an: 'increased demand from senior management for information and production of lists and letters, with no time allocated for the work'. Respondents reported concerns about having to advise patients when there was a

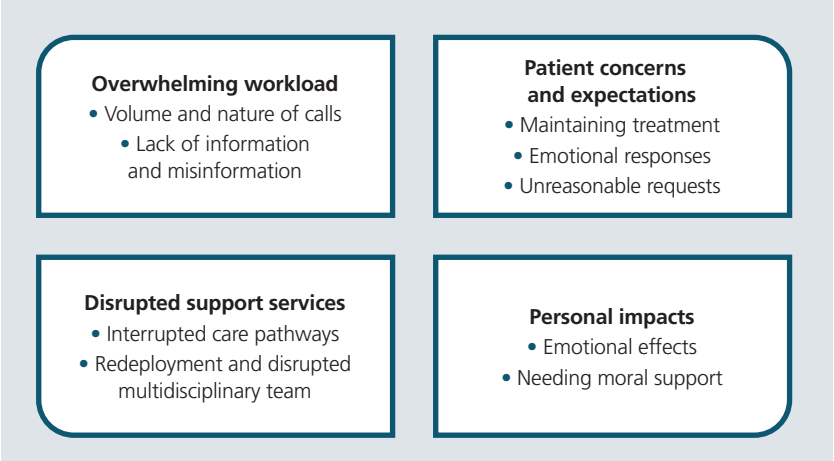

Figure 3. Challenges of running an advice line during the COVID-19 pandemic

'lack of clear evidence-based information on how to manage flares/immunosuppressants in the COVID-19 context, particularly in the early stages'. They also reported struggles to deal with the rapidly-changing information:

'The instructions … changed a lot. So, the instructions you gave in the beginning were different than those you gave a week later. That was frustrating, and patients got confused'.

For many respondents, the call burden was directly related to the mismatch between shielding advice provided directly to patients by government sources and that provided by the HCPs following medical guidelines. In the UK, participants reported risk-stratifying their caseload according to the BSG, only to then have to deal with calls to 'sort out the mismatch between our risk level and the government sending shielding letters often inappropriately'. As well as creating an additional workload, this situation caused concern for individuals:

'Bad dissemination and inconsistency of information made me reticent to give information to patients … [It] made me feel very exposed as a clinician.'

For specialist nurses who are used to offering solutions to distressed and anxious patients, the conflicting or absent information was problematic:

'We almost never had the answers. Most of it was trying to apply public health and organisational guidance (not written with the family in mind) to a specific family situation.'

Being or feeling uninformed added a subtle pressure, with callers often assuming that the HCPs would have more information in respect to risk and shielding than had already been provided by the government.

Theme two: disrupted support services

The challenges of coping with the dramatic increase in workload were compounded by changes to regular IBD service delivery. Changes to staff numbers and availability due to redeployment, disruption to the MDT and interrupted care pathways made it even more difficult to deal with all callers and escalate care for those in need of clinical support.

Subtheme: redeployment and disrupted multidisciplinary teams (MDTs)

Redeployment meant that those left behind to run the advice line were stripped of their clinical support team. With senior medical colleagues working elsewhere, nurses had to work harder to resolve the issues arising from advice line calls:

'Our consultants were pulled to cover COVID, so a lot of decision-making was put on myself. We had no multidisciplinary team (MDT) for complex patients, so I went around trying to get consensus answers for management—lots of leg work.'

With no access to redeployed gastroenterologists and MDTs cancelled or postponed, nurses were under a lot of pressure. One participant stated, simply but powerfully:

'I have decision fatigue.'

Subtheme: interrupted care pathways

Changes to usual care pathways, working practices and routine and diagnostic tests added further stress, as participants were trying to assess patients without the usual facilities:

'Faecal calprotectin testing stopped, and [there was] no IBDdoc/similar for calpro testing and therefore no results. No endoscopic procedures were being undertaken. Therefore, making clinical decisions without (a) good history-taking, (b) blood markers (not always reliable) or (c) exclusion of infection in mc/+s stool sample'

Some participants explained that their infusion services were relocated to a COVID-safe 'hub', with staff split between covering that service and the advice line. This, redeployment and loss of MDT support meant that HCPs were working in isolated, difficult conditions:

'Work practices changed. Phone clinics instead of face to face [and] office space

was a huge issue, as it was not possible to maintain 2 m distancing, so work hours were changed to ensure that this was complied with.'

Some staff, having to shield or self-isolate, were asked to work from home, often: 'without adequate resources—i.e., work mobile phone, headphones, desks—and having to access phone lines remotely'. The cumulative effect was notable:

'A sense of working in isolation—consultants almost absent due to COVID-19 rota changes and MDTs cancelled—and some questionable decision-making in early stages of lockdown drove a lot of IBD nurse anxiety. The lack of endoscopy was very frustrating, and constantly sitting at a computer trying to problem-solve and figure out workarounds for things we previously took for granted has been mentally exhausting.'

Theme three: patient concerns and expectations

Driven by a lack of information, or exposure to misinformation, participants reported finding it very difficult to support patients' emotional needs, persuade them to maintain their treatment and address their sometimes-unreasonable requests.

Subtheme: emotional responses

Participants found it difficult to meet their patients' emotional needs:

'It was challenging to relay [the changing information] to parents, as well as reassure in individual cases. I felt drained at times by the volume of daily calls, request and need for relevant information and reassurance of parents and children in my service.'

Even though most services provided signposting messages to direct callers to official information, participants reported that 'people still wanted lengthy discussions about their worries and concerns, which is understandable'. Others commented that they perceived heightened patient anxiety, and a 'reduced willingness to accept advice/recommendations' was being influenced by media impact. There was concern about the mental health of shielding patients, 'especially when I tell them they did not need to be shielding in the first place'.

Subtheme: maintaining treatment

Participants were also challenged by callers who were so concerned about the risk of COVID-19 that they did not want to continue with immunosuppressants or 'refused to come to hospital when unwell or have a blood test'. Nurses spent a lot of time 'explaining the rationale for continuing medication', which included convincing them to 'come to the hospital to get their intravenous medication or take their subcutaneous medication'.

Subtheme: unreasonable requests

Participants reported that some patients expected 'more than we could provide, for example, wanting us to confirm they couldn't work, but our local guidelines did not support this'. Many patients asked for individual letters to be sent to employers:

'Patients and their families expected the IBD nurses to write to employers about shielding, to make decisions about their personal lives and expectations.'

There were also reports of calls about unrelated issues, including 'dealing with prescriptions as they had run out of meds', 'asking us to chase appointments' and 'finding a pharmacy'.

Theme four: personal impacts

The cumulative effect of themes one, two and three is expressed in this final theme. The emotional effects were significant, with participants stressing their need for moral support.

Subtheme: emotional effects

IBD nurses are used to running efficient and effective advice line services, responding promptly to patient need and putting appropriate care plans in place or adjusting those as required. They reported finding the impact of the pandemic to be intense:

'A colleague had to self-isolate and then was off sick due to bereavement. I ran the

advice line on my own. Calls increased by 300%. The nurse manager didn't support; the consultants didn't support, as they were busy on wards. I felt very isolated, as the nurse's office is away from the main hospital, so some days I didn't see anyone. It was a very difficult time.'

Others reported 'a lot of self-doubt at times as to whether I was doing the right things or giving the right advice' and feeling that they were 'not doing a good enough job'. Others 'felt guilty about not being redeployed, while being overwhelmed by the increased workload' from the advice line. Repeatedly, participants reported that they and their teams 'are absolutely exhausted' and some may have reached their tipping point:

'I don't like coming to work. I have been working without any breaks all the time, and I am feeling mentally and physically exhausted. [I am] considering giving up nursing.'

Subtheme: needing moral support

Getting and giving support, and having one's contributions acknowledged, mattered. The lack of the usually cohesive MDT deprived participants of an important source of professional and moral support:

'Being isolated from the clinicians that we usually work closely with, I really missed their support and someone to bounce ideas off'.

Others explained that, even when they did see the clinical team, 'it was often rushed and all about clinical issues, and never time to just catch up and check in to see if we were all OK'. Senior managers could be unhelpful:

'I have no support from my matron, as he does not know what the helpline involves. My managers think the helpline is for "worriers".'

Providing moral support to the IBD nurse team became 'the lot of the senior nurse … sometimes it would be nice to be supported rather than always being the one giving the support.' Others, including those working alone, found support from national networks:

'Being a lone IBD nurse is tough at the best of times, but I've felt particularly alone during the pandemic. I'm very thankful to have contact and support from other IBD nurses around the country.'

Discussion

Using a mixed-methods survey and analysis, this study has been able to evaluate both quantitative and qualitative impacts on HCPs delivering advice-line services for patients during the initial height of the global COVID-19 pandemic. The majority of advice lines remained open, but with many needing restructuring to maintain services, and IBD nurses were key to keeping these services running. Facilitating necessary home-working arrangements for HCPs who were required to shield or self-isolate or had caregiver responsibilities impacted on their ability to be physically at the hospital. Home working perhaps seemed an ideal solution, yet access to essential equipment and IT support to facilitate this was not straightforward for all. Barriers remain when it comes to demonstrating that this way of working is productive, cost-effective and responsive to a clinical need (Kennedy et al, 2020b).

While redeployment of IBD specialist nurses occurred in some cases, it was changes to the structure of the IBD service that were felt to have been more impactful on the support network that underpins advice-line services. Redeployment of key members of the MDT, including junior doctors, consultants, pharmacists, dietitians and support workers, resulted in a significant reduction in MDT meetings, peer support and ad hoc advice. The pressure and difficulties associated with this were felt by many, although arguably this may have been even more of an issue for those managing the service as a lone nurse, either because of the pandemic or due to previous staffing levels. The pandemic was at different stages around the world at the time of the study, and this may have influenced each country's need to redeploy staff away from the advice lines.

Not only did calls to the advice line increase in number, the nature and focus of these calls changed from pre-COVID-19 queries toward

more specific COVID-19-related issues, including shielding and medication concerns, financial concerns in relation to COVID-19 and general anxiety about what to expect. Managing these queries was extremely challenging at times, given that the information available to IBD teams was often the same as that in the public domain, and this frequently changed. Participants reported the usefulness of resources, including:

- In the UK, information from Crohn's & Colitis UK and the BSG/IBD Registry online COVID-19 self-assessment tool (https://ibdregistry.org.uk/covid-19)
- In the RoW, Crohn's Colitis Canada, the International Organisation of Inflammatory Bowel Disease and the SECURE IBD Registry.

It was concerning that the majority of services were unable to provide figures based on routinely collected audit data. The responses of 110 participants were reported from memory, which could represent pressures already felt before the pandemic (Younge et al, 2020b).

The experience that HCPs reported during this service evaluation survey are veined with the challenges, frustrations and confusion that many people felt during the pandemic. However, this was weighted with the impact of the pandemic on patients as an added emotional burden to the individual HCP managing the advice line. These pressures, along with the sheer number of calls received, produced a moral distress in the individuals who responded to this survey, mirroring the experience of HCPs globally (Greenberg, 2020; Greenberg et al, 2020). Whether working directly with COVID-19 patients or not, HCPs have reported a negative impact on morale resulting from an overwhelming workload and a sense of helplessness.

This theme of distress continues throughout the results, with varying reports about communication impacting on feelings of frustration in a negative way. Concerns were expressed about additional uncountable costs of the COVID-19 pandemic on the IBD patient population's health, and the pressure all services were under mirrored the general concerns relating to the impacts of the pandemic globally (Kennedy et al, 2020b). The top tips suggested by IBD nurses for overcoming the challenges that emerged during the first wave of the pandemic (*Table 3*) show impressive resourcefulness and ability to use many skills to overcome those challenges. To help colleagues make clear, safe, and effective decisions for patients in all care settings, it is important to continue to highlight tools such as the IBD GP toolkit from the Royal College of General Practitioners (RCGP) (2018). It is paramount that patient safety remains central, to minimise any additional impact of the COVID-19 pandemic on patients as the pandemic continues.

This evaluation had some limitations. First, there may have been a reporting bias arising from those who either had difficulties in their service or had a well-running service being more likely to report. Countries were dealing with the pandemic in different ways, and not all were facing the same stage and challenges at the same time. the burden on healthcare would have been different across the world during the survey.

Conclusions

This service evaluation evidences that, during the early months of the COVID-19 pandemic, HCPs made intense efforts to maintain advice-line services to patients with IBD, but they also faced moral distress and emotional burden as consequences. Key themes to emerge were the value of self-care, MDT working and access to existing support networks. Self-care could be facilitated with resilience training; however, there is a danger that this would lead to the conclusion that these workloads and associated burdens are acceptable. It is vital to recognise the importance of the workload that is produced by advice lines. Future work for individual services could involve robust audit of services. The top tips identified in *Table 3* could be used to support the delivery of advice-line services, and training for all staff could support the MDT to manage any additional calls that occur in a pandemic or other emergent situation. There is a suggestion that teamwork played a strong part in respondents' resilience, and encouraging all team members to be involved in the IBD advice line could represent an opportunity for support and development for all.

CPD reflective questions

- What has been the greatest impact of COVID-19 on your clinical area?
- Consider any additional equipment or training that could help you provide affective remote consultantion
- What have you learned from the pandemic that could help you build your team's capacity to deal with a future crisis?

It is clear that there remains much variation in the delivery of IBD advice lines, and future work could include development of a clear set of guidelines on how to manage this essential service, sustaining HCPs who, in turn, offer vital support to people with IBD. **GN**

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