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"You don't know what to expect": Unmet Needs in Patient Experience of Capsule Endoscopy

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Key words: Capsule endoscopy; patient experience; endoscopy

Abstract

Objective

Video capsule endoscopy (VCE) is a tool for investigation of the gastrointestinal tract and a non-invasive alternative to colonoscopy. Despite its increasing use, patient experience and acceptability of VCE remains under-examined. This qualitative study examined the experiential nature of undergoing this novel investigation, seeking potential areas for improvement.

Methods

Patients aged ≥18 years who had undergone VCE for any indication at two NHS sites were invited to participate in semi-structured telephone interviews which explored VCE experience from point of procedure booking to receipt of results. Recruitment continued until no new data emerged that challenged analysis (n=21). Thematic analysis was undertaken, with coded data organised initially as a sequential description of the procedural pathway, then into higher order themes.

Results

Participants discussed their experiences of VCE, including undergoing patency tests, problems encountered in situating the capsule, and experiences and expectations of passing the capsule. Three higher order themes were developed: expectations & unknowns; perceptions of risk; and comparison of VCE with other endoscopic procedures. Participants described a range of unmet information needs despite receiving written information, most notably: capsule appearance and size and experiential nature of swallowing it; capsule siting and potential additional procedures to achieve this; and mechanisms and timelines for receiving results.

Conclusions

Patients are generally accepting of VCE but report a number of areas of unmet information needs. Improving information provision around this relatively new endoscopic procedure would improve patient experience. Procedure-specific patient reported experience measures should be developed to enable robust assessment of VCE experiences.

- **What is already known on this topic**: Video Capsule Endoscopy (VCE) is increasingly being used within endoscopy for a range of indications, however, little is currently known about the patient experience of this novel investigation.
- **What this study adds**: Whilst VCE is generally acceptable to patients, several unmet information needs have been identified, including: sensory experience of VCE; procedures for siting the capsule; passing the capsule; and receiving results.
- **How this study might affect practice**: Patients would benefit from greater information provision, not least because very few will have family or friends who have undergone the procedure and can discuss the experience. Short video accounts from patients who have undergone VCE, made available online, could provide a simple solution to inform and reassure patients across the procedural pathway. Patients would also benefit from development of a validated Patient Reported Experience Measure (PREM) for VCE, in order to measure procedure acceptability and appropriately target and tailor service improvements.

1. Introduction

Video capsule endoscopy (VCE) is increasingly used for a range of gastrointestinal (GI) presentations. Originally utilised for examination of the small bowel, its application has expanded to include large bowel assessment (colon capsule endoscopy (CCE)), as well as a pan-enteric Crohn's capsule, which examines the entire small and large bowel. VCE entails patients swallowing a pill-sized capsule with an integrated camera, which passes through the GI tract recording images (supplementary image 1). VCE is being welcomed as a less invasive alternative to traditional endoscopic procedures and a mechanism to reduce colonoscopy demand.[1–3] For instance, the recent National Health Service England (NHSE) pilot, which invited symptomatic patients on colorectal pathways with low or intermediate risk factors to undergo CCE rather than conventional colonoscopy, was extended to include patients on waiting lists for polyp surveillance, reducing colonoscopy demand whilst still investigating and visualising the bowel.[4]

In recent years there has been growing emphasis on understanding and assessing patient experience of health care services, as a measure of service quality.[5,6] Patient Reported Experience Measures (PREMs) have achieved greater prominence, with patient views and experiences now central to service evaluation and improvement, not least because better patient experience is associated with better patient outcomes.[7,8] Understanding and measuring patient experience not only enables assessment of procedure quality, but also allows us to identify mechanisms to maximise test participation and repeat attendance for disease surveillance.[7,9]

Until recently, most PREMs in endoscopy have been clinician-derived, without significant patient input. Such measures may overlook aspects of procedures that are significant to patients but not considered important by clinicians. For example, clinicians may place different temporal boundaries around aspects of the procedures than patients would. For instance, patients' concepts of endoscopic procedures have been shown to extend beyond the temporal confines of the procedure itself, given that many are required to start bowel preparation prior to procedures and may wait weeks for receipt of histological results which conclude the investigation for that individual.[10] The Newcastle ENDOPREM, originally developed from patient accounts of undergoing upper/lower GI endoscopy and CT colonography, measures experiences across the entire procedure pathway, from referral for the procedure to receipt of results, based on events of relevance to patients. [11,12]

Patient experience and acceptability of VCE remains under-examined. A comparison of patient experience of CCE and colonoscopy in Ireland found that patients (particularly those under 50) reported higher satisfaction and comfort scores with CCE, than for colonoscopy.[13] An evaluation of CCE in Scotland found that patients perceived CCE to be of significant value; however, it also highlighted the need for provision of clearer information and management of patient expectations.[14] Given the increasing application of VCE it is crucial that we develop a foundational understanding of patients' perspectives of undergoing this procedure to ascertain markers, and thresholds, of 'good' patient experience, to inform PREM development.

We report findings of a qualitative study which examined patient experience of VCE, examining experiential aspects of the procedure from procedure booking to receipt of results. The findings will later be used to modify the Newcastle ENDOPREM for VCE.

2. Methods

2.1 Participants

Individuals aged ≥18 years who had undergone VCE for any indication were eligible to participate. Patients were identified by clinical staff at two NHS organisations in England (South Tyneside and Sunderland NHS Foundation Trust, Sheffield Teaching Hospitals NHS Foundation Trust) which serve socio-economically and geographically diverse areas.

Eligible patients were approached about the study by their clinical team. Interested patients were provided with a study information pack, containing an invitation letter, participant information sheet, and consent form. Consent was taken by a research nurse, who provided the university research team with contact details to schedule an interview.

Interviewees were purposively sampled for type of capsule (small bowel, colon, Crohn's) and indication (polyp surveillance as part of NHSE pilot, iron deficiency anaemia, inflammatory bowel disease assessment, imaging abnormalities and symptoms such as abdominal pain or change in bowel habit). Maximum variation was sought in relation to age, sex and ethnicity.

2.2 Data Collection

Consenting participants took part in a one-to-one semi-structured interview, with a trained qualitative interviewer (EH), between August 2023 and January 2024. An interview topic guide was developed by the research team, comprising clinical and academic experts, and informed by existing evidence. It was used flexibly, allowing participants to talk about their experience in a natural way, whilst ensuring that all key topics were covered as well as allowing unanticipated topics, raised organically by patients, to be fully explored.

All participants chose to be interviewed by telephone. Interviews were conducted between 9 and 99 days following the procedure (mean 28.3 days) and lasted an average of 45 minutes (range 24-72 minutes). They were audio-recorded, pseudo-anonymised and transcribed verbatim.

2.3 Data Analysis

Transcripts were analysed thematically [15]. Initial coding took place concurrently with fieldwork to ensure that key topics were fully explored within later interviews. An initial code list was developed by two researchers (EH & CD), including deductive codes derived from topic guide content and inductive codes, from *in vivo* coding of the first three transcripts. The code list was applied to all transcripts. Analysis remained open to novel concepts which were noted within the data.[16] In these instances, a new code was incorporated into the code list and earlier transcripts reviewed to ascertain its presence. Recruitment continued until no new data arose which challenged developing themes. Coded data were organised initially as a sequential description of the procedural pathway, then into higher order themes describing patients' perceptions of VCE. Final analytical constructs were discussed and refined by a wider team (EH, CD, LN, LS).

Ethical approval was granted by the South Yorkshire Research Ethics committee (Reference 22/YH/0039, IRAS ID 287820).

3. Results

A total of 49 eligible patients were approached about the study, 38 of whom agreed to receive further information. Of these, 21 took part in an interview. Participant characteristics are shown in Table 1. Twenty participants were of White British ethnicity and one was Asian. Participants' postcodes were used to ascertain Index of Multiple Deprivation, with participants residing in varied areas in terms of deprivation, ranging from IMD 1 to 9.[17]

Quote ID Number	Sex	Age*	IMD[1]	Type of capsule[2]	Indication[3, 4]
01	M	25-29	1	SBCE	Assess IBD
02	F	25-29	5	SBCE	Assess IBD
03	M	25-29	-	Colon	Assess IBD
04	M	55-59	2	SBCE	Abnormal imaging
05	M	65-69	7	SBCE	Assess IBD
06	F	55-59	2	Colon	Symptoms
07	M	70-74	9	SBCE	IDA
08	F	75-79	9	SBCE	IDA
09	F	40-44	4	SBCE	IDA
10	F	65-69	5	SBCE	IDA
11	F	65-69	2	SBCE	IDA
12	M	40-44	8	SBCE	IDA
13	M	55-59	1	SBCE	IDA
14	F	50-54	1	SBCE	Symptoms, raised FCP
15	M	55-59	8	Colon	Polyp surveillance (NHSE pilot)
16	F	55-59	4	Colon	Polyp surveillance (NHSE pilot)
17	M	50-54	1	Colon	Polyp surveillance (NHSE pilot)
18	M	60-64	9	SBCE	Symptoms, raised FCP
19	M	50-54	1	SBCE	IDA
20	F	50-54	2	SBCE	Symptoms, previous abnormal VCE
21	F	45-49	3	Crohn's	Assess IBD

[1]IMD – Index of multiple deprivation: 1 is most deprived and 10 is least
[2]SBCE- Small bowel capsule endoscopy
[3]IDA- Iron Deficiency Anaemia
[4]IBD- Inflammatory bowel disease
** Ages are given as ranges to protect confidentiality*

Table 1. Participant characteristics

3.1 VCE

Procedural Pathway

Participants discussed their experiences of the events that occurred across their VCE procedure pathway. We organised these events temporally into three periods: ‘before’, ‘during’ and ‘after’ the test (Figure 1).

3.1.2 Before the test

Participants discussed receiving written information through the post after their appointment was booked. This was usually followed by a telephone call from a nurse, which provided further information about the procedure and its risks, as well as the opportunity to ask questions. Some patients underwent a patency ‘dummy’ capsule at the hospital to ensure the test capsule would not become stuck. For one patient, this increased anxiety, however most participants welcomed this, stating that it provided reassurance ahead of swallowing the capsule proper.

> *“I thought it made sense to do. It made me feel more comfortable that’s for sure.” P20*

Eight participants had to stop certain medications for a few days before the procedure, for example, opiates. This was generally acceptable; however, for a few this negatively impacted their quality-of-life.

> *“It was two weeks of hell, I had to stop pretty much all my pain meds, which meant I was not fun to live with and pretty much bedbound for at least a week” P05*

All patients took bowel preparation prior to the procedure, to aid visualisation of the bowel. Many described this as being the most unpleasant event within the procedure pathway but ultimately conceived of it as something that was manageable.

> *“it’s a rough evening, but, yes, needs must…It’s one of those things.” P01*

3.1.3 During the test

Patients attended hospital on the day of the procedure to swallow the capsule, then were required to complete a 30-minute walk (if physically able) to aid its progression through the GI system. Some who had colon or Crohn’s capsules were also required to take ‘top-up’ doses of bowel preparation to ensure adequate visualisation of the bowel and effective passage of the capsule. Standard procedures were sufficient for most participants but, for a few, additional exercises and procedures were needed to progress the capsule. These included being asked to lie down on each side, injections of medication (metoclopramide) to move the capsule out of the stomach, and an endoscopic "push" (using an endoscope to move the capsule from the stomach into the small bowel).

> *"I was sent for another walk the second time, then the third time I lay on the bed for half an hour, then she came back and said "no, it was still in the stomach". And then somebody else came along and said, later on, that I should have had the injection before then…I was getting a bit concerned… they eventually had to get…a doctor from the endoscopy unit to come and have a look saying yes… that I would have to go down for this, you know this, what they called was a push." P04*

Nursing staff assessed progression of the capsule by viewing images on the data recording equipment, which was worn by patients. Most found wearing the data recording equipment to be acceptable; however, those who had to wear it overnight did note that it was uncomfortable. In addition to discomfort, one wheelchair user also experienced concern about damaging the equipment, by nature of their movement and momentum with the wheelchair.

> *"The main problem is they're not designed for wheelchairs. So you're whizzing around in your wheelchair like Nigel Mansell sort of thing and…the camera's banging against, you're worried that you're going to be damaging it." P05*

Most patients were allowed to leave the hospital to complete the test at home, providing that the capsule was seen to progress through the GI tract, though some did choose to stay in the hospital for convenience. Most returned to the hospital later on the same day for the capsule's location to be checked and equipment returned, though a few were required to come back the following morning. Everyone reported being provided with an information sheet about passing the capsule before leaving the department, and a contact number to discuss any concerns.

3.1.4 Following the test

Whilst the clinical input into the procedure was 'completed' once the recording equipment was returned, for many participants, it was not until they had passed the capsule that they considered the procedure to have ended. In the days following VCE some participants saw the capsule in the toilet bowl after having a bowel movement but, by the time of interview, not all participants were certain that the capsule had passed. Some sought advice from their clinical team, whereas others remained unconcerned.

> *"It was flashing in the toilet bowl…it was about eight o'clock that night, I felt like I needed to go to the toilet, I went up and I just heard a ting noise and that was it. Looked down…and there it was like a little submarine in the dark, just flashing at us." P01*

> *"It's not causing me any discomfort. And if it has, it has [passed]. But other than that, no, it's not given me any concern or anything. I'm not in any pain or discomfort…it's not bothering me" P07*

Not everyone had received their results by the time of interview and these patients all expressed a lack of clarity as to how results would be communicated.

> *"When I returned the equipment that was it. I was just told I can go home. It wasn't clear what to expect next. I just assumed they would reach out to me once they're ready." P01*

For those who had received test results, they were generally copied into a letter from the endoscopist to their GP, informing them of the findings. Several participants described how the complex technical language left them confused. Others also felt uncertain as to next steps for their care and/or management of ongoing symptoms.

> *"So the results letter isn't to me, the result letter's to [GP] and it said…"a single non- bleeding angioectasia" and I was like, well I don't know what that is. So it was sent to him not me, so that's fine, he knows what one is, but the first thing I did was I had to go on to Dr Google" P12*

3.2 Patients' Perceptions of VCE

Three higher-order themes were developed to describe patients' overarching experiences of undergoing VCE: expectations and unknowns; perceptions of risk; and comparison to other endoscopic procedures.

3.2.1 Expectations and Unknowns

Patients described varying expectations about different stages of the procedure, summarised in Figure 2. Some participants discussed how the relative novelty of the test in the NHS meant they did not have any friends or family members with whom they could discuss experiences of the procedure.

> *"Even reading about what other people's experiences are would have helped a bit because, you know, going in you don't know what to expect. You might be told but it's one thing being told the processes and hearing about someone's experience of it." P20*

A few participants expressed uncertainty about what the test would entail. Others - particularly those who were concerned that they might have cancer - were nervous, either about the sensory experience of the procedure, or the potential diagnosis. Those with previous experience of endoscopic procedures, particularly those who had taken bowel preparation before, reported less anxiety.

> *"After the appointment with the consultant…I did like look it up [the procedure]. Because I was just like "ooh what's that" because I hadn't heard of it before" P19*

> *"Having the bowel prep again I was a bit like, it's not nice, not by any way, shape or form. But to be honest after having the endoscopy and the colonoscopy like, I wasn't too anxious about this at all." P02*

One of the greatest areas of uncertainty and concern for participants was the unknown nature of the capsule, in terms of size, shape and sensory experience of swallowing it. While the patency test eased such concerns for most who underwent it, for one participant, difficulties experienced during the patency test, and subsequent realisation of the difference between patency and test capsules, caused increased worry.

> *"After doing the dummy one…I did have some trepidation about the second one and thinking…"is my throat going to be too dry?" I'm thinking "will I be able to swallow it?" But, in saying that, the actual capsule itself, it's smoother; whereas, the other one …it feels a bit rougher." P07*

Some patients reported that the time spent in the hospital waiting for the capsule to progress was longer than they had expected; similarly, they had not expected to have to undertake physical movements, such as walking or '*star jumps' (P04)*, to aid progression.

For those who had not passed the capsule by the time of the interview, there was uncertainty about how they would know it had passed, or whether they should actively look for the capsule at each bowel motion. No participants described a negative sensory experience related to passing the capsule, however, some did find the idea of having to search for the capsule in their stool unpleasant.

> *"I'm still nervous now… I am not going raking around, when you've been to the toilet, and I don't go very often, I am not going raking around… inside of it. And I haven't seen any kinds of flashing lights. I mean I always use bleach down the toilet so maybe it has come out, I don't know. And I am still nervous now because I don't want to have to go back in." P04*

3.2.2 Perceptions of Risk

Perceptions of procedural risk differed between participants, as well as changing across the VCE pathway. Risks associated with VCE were generally discussed by nurses during the pre-procedure phone call, and again on the day of the procedure. Participants reported feeling well informed about risks overall. One patient, however, did reflect that they lacked clarity about what specifically would happen next should the capsule fail to progress. Those who were part of the NHSE pilot all perceived VCE to be less risky and more convenient than colonoscopy. The patency test provided reassurance to many regarding the risk of the capsule getting '*stuck,'* however, some did feel that having to undergo this additional procedure was an inconvenience.

> "*It's reassuring because if I can swallow the…patency one, the risk was low because if it got stuck it was going to dissolve so there was no major… risk, so it's always good to have a dummy run so that if there's going to be a problem it would have flagged up any potential problems." P05*

Following the test, those who had not seen the capsule pass were concerned that it may be stuck inside their bowel. Whilst some sought advice and help from the clinical team, others carried on as "*there was no way on this planet I was going back into hospital." P05*

3.2.3 Capsule Endoscopy vs Other Endoscopic Procedures

Many participants had previous experience of endoscopic procedures, particularly colonoscopy. Some were undergoing VCE because an endoscopic procedure had not yielded a diagnosis or explanation for their symptoms. In these cases, participants welcomed VCE, as they saw it as a means to *'get some answers*' (*P12)* that their initial endoscopy had failed to provide. Overall, VCE was seen as an easier, '*more chilled' (P19),* endoscopic procedure, because participants were able to go home after the capsule had been seen to progress and were not required to take as much time off work as they would for a colonoscopy.

The sensory experience of the procedure itself was also considered preferable to endoscopy: it was seen as less painful and less invasive than colonoscopy, and patients also spoke of the benefits of not having to undergo sedation. When asked to reflect on whether they would be willing to have VCE again, most expressed a preference for VCE over other, more invasive, endoscopic procedures if given the choice. However, a small number of participants stated that they would not opt for VCE again, either because it ultimately resulted in needing a colonoscopy anyway, or because the endoscopic push required to progress the capsule was a traumatic experience.

> *"Because I felt so ill all that day, and having to take the medication, and then it failing for my body I just thought I probably would go for a colonoscopy rather than the capsule one [in the future] because obviously it hasn't worked for me." P09*

4.1 Discussion

This study describes patient perspectives of undergoing VCE and reveals aspects and timepoints within the pathway which are of particular importance to patients. Whilst there has been some, albeit limited, work exploring VCE experience, this qualitative study adds to the body of evidence, highlighting, for the first time to our knowledge: patient experiences of undergoing patency tests, both positive and negative; problems siting the capsule and subsequent procedures required to achieve this; patients' experiences and expectations of passing the capsule; and a series of areas of unmet information needs.

Overall, participants reported positive experiences of VCE and found it acceptable, which aligns with a recent NHSE survey which found that the procedure was well received by patients.[18] Those who had previously had an endoscopy preferred VCE, which is also broadly consistent with previous work.[13]

Most participants in the current study reported that bowel preparation is an unpleasant, if not *the most* unpleasant, aspect of undergoing VCE. This is not unique to VCE, with patient dissatisfaction with bowel preparation having long been evidenced for endoscopy procedures, including colonoscopy and colon capsule endoscopy, by both ourselves and others.[14,19,20]

The findings indicate that there are many 'unknowns' relating to VCE for patients, which can result in anxiety from pre, through to post, procedure. Despite all receiving written information, a pre-procedure telephone conversation and a pre-discharge information sheet, areas of uncertainty remained. These included information on the capsule itself (size, shape, texture etc), what would happen if the capsule became stuck, and how and when results would be communicated- despite patients being provided with information leaflets containing this information. This suggests that how information is displayed within leaflets (eg are images, graphics and photographs used as well as text?), and the format and timing of information provision are as crucial as the content of the information itself. Future research and co-development of materials should be undertaken to identify the most effective ways to display information as well as optimal timing of information provision and delivery mode.

Experiential accounts of undergoing VCE were difficult for patients to access, and few people had acquaintances who had undergone it; this is likely to be reflected in the wider patient population. Provision of a combination of sensory and procedural preparatory information prior to medical procedures has been shown to be beneficial in reducing procedure-related discomfort and distress [21]. Developing more detailed patient information (and considering different modes of conveying this information) could be beneficial for patients, particularly in relation to some of the more unique aspects of this relatively novel procedure (i.e. the sensory experience of swallowing or passing the capsule, as well as more detail about the procedure steps). The model of VCE pathways illustrated above could serve as a framework upon which to base patient information, ensuring that key events of pertinence to patients are addressed. Short video accounts from patients who have undergone VCE, made available online (augmenting current telephone appointments), could provide a simple solution to inform and reassure patients. Initiatives to improve information provision should be co-developed alongside patients, as well as health literacy experts, to ensure the information is accessible and understandable. For instance, case-studies, vignettes, or real patients' experiences could be delivered in video format to reduce literacy demand, but should also include paper-based alternatives, to avoid digital exclusion. Such enhanced information could be incorporated in the delivery of capsule endoscopy programmes and made available through links in appointment letters, health service apps or patient information websites.

This paper presents what we believe to be the first illustrative example of events within, and aspects of, the VCE pathway which are of significance to patients. Findings will be used to underpin development of a capsule endoscopy iteration of the Newcastle ENDOPREM, to enable appropriate and comprehensive monitoring of patient experience of VCE, as well as evaluation of any interventions to improve patient experience; once developed, the instrument will be made freely available. They may also be used by others to underpin and inform future research or service improvements aimed at improving patient experience of VCE.

4.2 Strengths & Limitations

This qualitative examination built upon an established body of research, and methodological foundation, developed to examine patient experience of endoscopy.[11,20] The study recruited from two NHS hospitals serving geographically and socio-economically diverse areas. It included patients referred for VCE for a series of indications and procedure types, ensuring that we engaged with a breadth of patients and VCE experiences.

The lack of ethnic diversity within the sample is a limitation. It is well recognised that non-White patients report poorer experiences across many aspects of NHS healthcare than White patients.[22] We cannot exclude the possibility that ethnically minoritised patients, those from different cultures, or non-native English speakers, may experience different challenges within VCE pathways than those reported here. For example: poor information provision may be compounded by language barriers; acceptability of, and willingness to undergo, the test shaped by cultural beliefs and values; while intersecting inequalities, such as deprivation, may further hinder test access, through additional challenges in accessing transport to attend hospital. Extending understanding of acceptability of VCE across diverse populations will further inform identification of future areas for service improvement.

5. Conclusion

This study demonstrates that VCE is generally acceptable to patients and is a useful non-invasive alternative to GI endoscopy. However, patients report several unmet information needs, including information about sensory aspects of the procedure, siting of the capsule, and results provision. Patients would benefit from the development of more detailed information, in varying modalities, to improve experience across VCE pathways. Priority should also be given to developing PREMs for VCE, so that any interventions to improve experience may be rigorously assessed.

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