

Title page

Decision making in the management of adults with malignant colorectal polyps: an exploration of the experiences of patients and clinicians

Authors:

1. Dr Clare Westwood RN, DProf (Main author/ contact)

Advanced Endoscopy Practitioner

University Hospital North Tees and Hartlepool

Endoscopy Unit

North Tees Hospital

Hardwick Road,

Hardwick

Stockton on Tees

TS19 8PE

Email: clarebarry72@hotmail.co.uk; clare.westwood@nhs.net

Tel:07905496704

Contribution: Study lead, drafted the manuscript, completed revisions to manuscript.

2. Dr Tom Lee

Consultant Gastroenterologist

North Tyneside General Hospital,

North Shields,

NE29 8NH

Email: Tom.Lee@northumbria-healthcare.nhs.net

Contribution: Contributed to conception and design of study.

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3. Professor Robert McSherry

Professor of Nursing and Practice Development in Health and Social Care
University of Chester
Faculty of Health and Social Care
Riverside Campus
Castle Drive
Chester
CH1 1SL
Email: r.mcsherry@chester.ac.uk

Contribution: Contributed to study conception and design; Critically revised the manuscript

4. Dr Josette Bettany-Saltikov

Senior Lecturer
Teesside University
Southfield Road
Middlesbrough
TS1 3BX
Email: J.B.Saltikov@tees.ac.uk

Contribution: Contributed to study conception and design; Critically revised the manuscript

5. Dr Jamie Catlow

Endoscopy Fellow
University Hospital North Tees and Hartlepool

Endoscopy Unit
North Tees Hospital
Hardwick Road,
Hardwick
Stockton on Tees
TS19 8PE
Email: Jamie.catlow@nhs.net

Contribution: Critically revised the manuscript

Abstract:

Aim: A diagnosis of colorectal polyp cancer presents a treatment dilemma. The decision between segmental resection versus endoscopic surveillance is difficult due to a lack of good quality clinical evidence for either option. The aim of this study was to understand the decision making experiences of both clinicians and patients when faced with such a diagnosis.

Methods: Qualitative, semi-structured interviews were undertaken with ten clinicians involved in the care of patients diagnosed with polyp cancer and five patients who had experience of a diagnosis of polyp cancer. All clinicians and patients were from four hospital Trusts across the North of England. Interviews were audio recorded, transcribed verbatim and analysed using the principles of Interpretative Phenomenological Analysis.

Results: Analysis of the interview transcripts evidenced that clinicians and patients were supportive of a shared approach to treatment decision making in the context of a diagnosis of colorectal polyp cancer. Uncertainty, influences and information were among the themes identified to be preventing this happening at present. This study identified themes which were common to both groups. These were: complexity of the risk information; lack of patient information resources; system factors and time.

Conclusion: This research study has evidenced several factors such as uncertainty, complexity of risk information and influences on decisions which are preventing patients being involved in treatment decisions following a diagnosis of colorectal polyp cancer. Recommendations for improvements in practice, including a framework to assist treatment decision making in the future have been highlighted.

DR CLARE WESTWOOD (Orcid ID : 0000-0001-8564-3336)

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Abstract:

Aim: A diagnosis of malignant colorectal polyp presents a treatment dilemma. The decision between segmental resection versus endoscopic surveillance is difficult due to lack of good quality clinical evidence for either option. The aim of this study was to understand the decision-making experiences of both clinicians and patients when faced with such a diagnosis.

Methods: Qualitative, semi-structured interviews were undertaken with ten clinicians involved in the care of patients diagnosed with a malignant polyp and five patients who had experience of a diagnosis of malignant polyp. All clinicians and patients were from four hospital Trusts across the North of England. Interviews were audio recorded, transcribed verbatim and analysed using the principles of Interpretative Phenomenological Analysis.

Results: Analysis of the interview transcripts evidenced the difficulties faced by both groups when faced with treatment decisions following a diagnosis of malignant colorectal polyp. Some of these difficulties were specific to either the clinician or patient group. Themes which were common to both groups included: complexity of risk information; external influences, unexpected diagnosis; and time. In addition, hospital system factors were disclosed which also influenced clinician and patient experiences.

Conclusion: This research study has evidenced several factors such as uncertainty, complexity of risk information and influences on decisions, which are preventing patients being fully involved in treatment decisions following a diagnosis of malignant colorectal polyp. Recommendations for improvements in practice, including a framework to assist treatment decision making in the future have been highlighted.

What does this paper add to the literature?

This qualitative study is, to the author's knowledge, the first exploring clinician and patient experiences of treatment decision making following a malignant colorectal polyp diagnosis. Key factors influencing how treatment decisions are made have been identified. As a result, a framework is proposed highlighting critical factors for consideration to deliver patient centred care.

Introduction

Malignant colorectal polyps are defined as polyps removed endoscopically where subsequent histology confirms the presence of carcinoma. Prevalence of malignancy in colorectal polyps ranges from 0.2 to 5%¹. Incidence has increased secondary to greater use of diagnostic colonoscopy and the introduction of bowel screening programmes. Analysis of the first million tests from the English Bowel Cancer Screening Programme (BCSP) revealed 61% of bowel cancers diagnosed through the programme were early stage with 10% being malignant polyps.

Options for treatment following an unexpected diagnosis of malignant polyp are either formal surgery to remove the section of bowel where the polyp was, or a watch and wait approach. There is currently a lack of good quality clinical evidence for either option⁶. Evidence exists that most patients whose malignant polyp was removed endoscopically have a low but non-zero risk of residual disease or cancer recurrence³⁻⁵. This risk can be assessed histologically

after polyp removal. A risk stratification is presented within a position statement from the Association of Coloproctology of Great Britain and Ireland (ACPGBI)⁶.

Despite unfavourable histological criteria being identified (such as poor differentiation or lymphovascular space invasion), most patients who undergo surgical resection will have a specimen negative for residual cancer. Recent analysis states even in patients identified as 'high risk', only 14.5% had evidence of residual disease following surgery⁵. With overall colorectal surgical mortality reported as 1%-8% (correlating with age and co-morbidity)⁷ the requirement to discuss 'best' estimates of residual cancer risk together with surgical mortality and morbidity risk with patients is essential.

Shared decision making is viewed as an optimal approach for achieving patient centred care and is defined as the situation whereby patients are fully involved, with decisions made in partnership with clinicians rather than by clinicians alone⁸. Sharing decisions is endorsed within the National Institute for Health and Care Excellence (NICE) Quality Standard. Current consent guidance also states that patients should have the opportunity to discuss all treatment options and risks together with their consequences prior to making any decisions on treatment¹⁰.

Treatment decision making post diagnosis of malignant polyp is complex. Treatment options involve potential risks of over and under treatment with consequential disfiguring surgery, morbidity, and mortality. Outcomes from either treatment could significantly impact patient health and quality of life.

The study aim was to explore experiences of clinicians and patients of treatment decision making following a diagnosis of malignant polyp. The objective was to use the results to improve patient centred care for future patients.

Method

A qualitative approach using Interpretative Phenomenological analysis (IPA)¹¹ was selected to capture in-depth experiences of clinicians and patients. Face to face, semi-structured interviews were used with a topic guide focussed on experiences of treatment decision making (Appendices 1 & 2). Interviews lasted 30-50 minutes. All interviews were audio recorded, securely stored and transcribed verbatim by the researcher. Clinician interviews were arranged at the NHS Trust site where the participant was employed, or at a preferred NHS premises. Patients were interviewed in their own home, or, if preferred, an NHS site.

All participants were recruited from four English NHS Trusts within the Northern region. Clinicians were recruited via email invitation to the Northern Region Endoscopy Group and the Network Site Specific Colorectal Cancer Group. Patients were recruited through Colorectal Clinical Nurse Specialists (CNS), who introduced the study. Those interested were invited to return a form to the researcher. Clinicians and patients were sampled with inclusion criteria in Table 1. Ethical approval was granted from Teesside University and the Health Research Authority (IRAS 183107); approval was also obtained from local NHS Trusts.

Recruitment was open for 18 months. Six patients diagnosed with a malignant polyp were approached by local CNSs at these four sites; all six contacted the researcher to take part. One patient could not be contacted and was withdrawn from the study.

Table 1: Clinician and patient participant inclusion and exclusion criteria

Clinician participants.	
Inclusion criteria	Exclusion criteria
Any registered healthcare professional, i.e. physician, surgeon or specialist nurse who had input into the decision-making process for patients diagnosed with malignant colorectal polyp.	Nil
Practicing in an NHS Trust within the Northern Region.	
Patient participants	
Inclusion criteria	Exclusion criteria
Adult patients (over 18 years old) identified by the local clinical nurse specialist as having had a polyp completely removed with histology confirming adenocarcinoma within the polyp.	Any patient identified where the polyp histology clearly indicated that the polyp has not been completely removed.
Able to give consent.	Unable to give consent.
Living within the Northern Region.	Any patient who had previous contact

	with the researcher.
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Data analysis

A thematic analysis following the principles of IPA¹¹ was used. Firstly, transcripts were read several times to identify themes. The data was 'coded' using insights into participants' experiences and perspectives. As the analysis developed, patterns in 'themes' were derived. This method was used separately for both the patient and clinician data. This approach is illustrated in Appendix 3.

Given the low prevalence of malignant polyps, IPA¹¹ was chosen as it enables a deeper interpretation and understanding of those experiencing this phenomenon. This study pragmatically considered all respondents over an 18-month period as a sufficient sample size, limited by time constraints and access to our study population. A small sample may be viewed as a limitation but is essential for the richness of data and depth of analysis, leading to a greater insight than simply continuing until thematic saturation is achieved.^{12,13}

Results:

The clinician group consisted of healthcare professionals who held responsibility for treatment decision making following a diagnosis of malignant colorectal polyp. The group consisted of gastroenterologists (n=2); colorectal surgeons (n=5); and clinical nurse specialists (n=3).

The patient group consisted of five patients, two diagnosed through the National Bowel Cancer Screening Programme (1x FOBt screening; 1x Bowel Scope). Three were diagnosed through the symptomatic service. Ages ranged from 50 to 70. All received their diagnosis between 6-12 months of interview. Four patients chose surveillance as their treatment plan, one underwent surgical intervention.

Clinician interviews:

Three major themes were identified from interviewing clinicians: 1) Decision outcome uncertainty. 2) Influences on the decision; 3) Clinicians perspectives on the difficulties faced by the unexpected diagnosis. These themes are summarised within Table 2

Table 2: Summary of themes identified from clinician interviews

Theme	Example quotes
1: Decision outcome uncertainty.	
Clinician uncertainty: <ul style="list-style-type: none">• Polyp assessment• Lack of data	<i>“And when you try to tell them there is a theoretical risk with a 20% risk of associated lymph nodes outside of the bowel wall, which we cannot see now, we can’t tell, yeah, it is a very difficult conversation. It is one of those situations where I don’t know, I don’t like it to be honest” (C5: Surgeon)</i>

Perceived uncertainty for patients	<i>"you know you can do something but it might not be necessary, and on the one that's not necessary, you could be doing harm, and you get percentages within percentages, and you've got to look at the guy's face!" (C4: Surgeon).</i>
2: Influences on the decision	
Clinician influence <ul style="list-style-type: none"> • Perceived attitude of patient to risk. • Past experiences of clinician. • MDT influence 	<i>"there's always a risk, kind of whichever side of the fence you sit on, you will always influence the patient decision. You can never be completely neutral... my thoughts are if you can avoid an operation all the better." (C1, Gastroenterologist)</i> <ul style="list-style-type: none"> • <i>"My experience is the patients I guess fall into 3 camps.... in my experience, although I try and tease a preference out of them, they will just...'Ooo I don't know'... continue to sit on the fence and need that guidance from you, so roughly speaking, that's the cohort of patients, that's the split as I see it I guess." (C2: Gastroenterologist.)</i> • <i>"I think one of the drawbacks of the MDT is that you are the only person in there that has met the patient nearly always, erm, so while the MDT might give some stamp of approval, it's just around and about.. (C3, Surgeon)</i>
Patient family and friends.	<i>"My dad had x, y, z and that was a very bad thing, I never want it done" I still say, .."Look, you know, I think we've got to keep things open"..just try and make sure that they are not closing any avenues really early on, or committing to any avenues early on." (C6, CNS)</i>
3: Clinicians perspectives on the difficulties faced due to the unexpected diagnosis	
Informing the patient	<i>"...we've biopsied this thing, it looks really benign and you probably won't need anything done, so as soon as they've heard it for the first time, you probably won't need anything done, it might already be down that you have to steer them back." (C6, CNS)</i>
Time	<i>"Also, you need more time in the clinic, to do these things. The problem is in the middle of a `rushed` surgical clinic it's very difficult (C5: Surgeon)</i>

1. Decision outcome uncertainty

Uncertainty related to evidence available to support treatment options. These uncertainties appeared to increase the difficulties clinicians experienced when approaching treatment discussions with patients.

“And when you try to tell them there is a theoretical risk with a 20% risk of associated lymph nodes outside of the bowel wall, which we cannot see now, we can’t tell, yeah, it is a very difficult conversation. ... I don’t like it to be honest” (C5: Surgeon)

Several reasons for these difficulties were discussed, including concerns about quality of polyp histology reports. Clinicians stated certain elements of assessment were often missing, such as depth of invasion, and presence or lack of lymphovascular invasion (LVI).

Clinicians did not therefore feel confident they had enough high-quality data related to individual cases to provide the true context of risk involved to patients. Clinicians felt uncomfortable with this level of uncertainty.

“If you operate on them, almost invariably they will have almost every complication under the sun, and there’s nothing in there. If you don’t operate on them, they will develop metastases”

Participants articulated concern that if they themselves found data confusing, then how could they present this information to patients and encourage them to make treatment decisions.

2: Influences on the decision

Clinicians acknowledged various influences, which potentially add bias to consultations. These included outcomes from patients treated previously. As the incidence of unexpected malignant polyps is low, clinicians are more likely to remember individual cases. This memory may influence consultations, especially if the patient had a bad outcome.

“That past man I used [the experience] to tell another lady who had a similar thing. I thought about that man, (C10, Surgeon)

The influence of the MDT was fundamental. Some recognised the MDT decision should be used as a recommendation, rather than a definite decision on treatment.

“at the MDT, we would try and come up with a consensus together, talk through options and then go back to the patient” (C1, Gastroenterologist)

Others were concerned about the strong voice of the MDT:

“ a lot of clinicians have a strong opinion as to what they would do, and I guess that colours the MDT discussion to a fair extent...although it is a multidisciplinary meeting, there are often one or two voices that push things through their way” (C6, CNS)

Clinicians expressed concern there was nobody present at the meeting who knew the patient and could truly represent their values and preferences.

“I think one of the drawbacks of the MDT is that you are the only person in there that has met the patient, so while the MDT might give some stamp of approval, it’s just around and about..” (C3, Surgeon)

3: Clinicians perspectives on the difficulties faced due to the unexpected diagnosis.

Clinicians highlighted difficulties in relation to the initial patient consultation. At polypectomy, there was no obvious suspicion of malignancy, thus the patient had not received the ‘warning shot’ prior to leaving the endoscopy department. Beginning a consultation about treatment options within the context of an ‘unexpected’ cancer diagnosis adds another dimension to the complexity of the conversation.

“in the first consultation, usually they are shocked. Because they left the endoscopy unit, telling they have a polyp. And at the next clinic you are with the colorectal surgeon who tell them, “actually there is cancer in this polyp” And their next question is “does that mean I’ve got bowel cancer?” So it’s not easy.” (C5: Surgeon).

The challenge of communication in this situation was concerning. Imparting a diagnosis of cancer, outlining treatment options, including risk profiles was described as ‘*an impossible task*’. The challenge is compounded by a lack of supporting tools such as information leaflets.

“I don’t have a particular resource that I can use or refer to....there is nothing in particular.” (C2: gastroenterologist)

Time pressures were an additional concern. Firstly, relating to time allocated to each consultation and secondly allowing patients ‘time to think’, with additional clinic appointments potentially lengthening patient pathways.

Patient interviews

Three main themes were identified with significant implications for clinical practice. 1) Diagnosis: the emotional turmoil of an unexpected abnormality; 2) Making sense of uncertainty; 3) Living with uncertainty. These themes are summarised in Table 3.

Table 3: Summary of themes identified from patient interviews

Theme	Example quotes
1:Diagnosis: the emotional turmoil of an unexpected abnormality.	
Initial investigation: emotional preparation.	<i>"I was in the waiting room, and then me phone went, and they said you`re going for scans and I said what are you talking about coz I didn`t know. And I said what do I want scans for? I was sitting by myself and I was worried like. (P3, surveillance)</i>
The anxious wait.	<i>"We`d thought after it`d gone that long, we thought that the appointment was purely to say, "have you had any problems?" "Has</i>

	<i>there been any other symptoms” (P1, Surveillance)</i>
2: Making sense of uncertainty.	
Information and understanding.	<i>“You don’t want to bombard yourself with everything cos you end up being as low as you can be. I know it’s the trendy thing to Google everything.” (P1, Surveillance)</i>
The influence of family and others.	<i>“ [my wife] used to work in the medical industry, she worked for Holister until about 3 years ago. So she did stomas and stuff of that nature and all the incontinence and what have you.” (P3, Surveillance)</i>
Time to understand and decide.	<i>“I liked it when I went back and had a chat with him to be honest. Because you can take it in better, obviously then the shock of it is off you.” (P3, surveillance)</i>
3: Living with uncertainty.	
Resulting apprehension.	<i>“I still feel I’ve done the right thing, particularly since I’ve had another colonoscopy and they said everything looks good” (P2, Surveillance)</i>
World in a spin.	<i>“Sometimes I’m alright and sometimes you get horrible...just comes in your head.” (P3, surveillance)</i>

1) Diagnosis: the emotional turmoil of an unexpected abnormality.

Patients described experiencing ‘emotional turmoil’. Any diagnosis of cancer has a huge emotional impact, however the unexpected nature of a malignant polyp diagnosis appeared to increase the upheaval. Hospital system factors added to the turmoil experienced. For example, because the polyp removed was not assessed as ‘suspicious’ by the endoscopist, histology was not fast tracked as urgent. The additional time taken from endoscopy to receiving results led to complacency. Patients interpreted the delay as “no news is good news”.

“... I didn’t hear nowt for like four and a half weeks and I thought oh, well I’m alright, otherwise, I had forgotten about it. Because me mate had went, and he had to have an operation, but they told him in 4 days. He’d gone in on the Sunday of the next weekend. So, I thought I’m alright, there’s nowt the matter with us,”

(P3, Surveillance)

2) Making sense of uncertainty.

Making sense of their diagnosis was difficult for patients, often compounded by influences from family and friends with anecdotal information regarding the disease.

“I was sitting on me hands when he told me it was cancer. I`d gone down there on me own. The doctor kept saying the cancer had gone, but how could it? Me mate had bowel cancer and he was in hospital for days. He had to have a bag on. It took me ages to understand like. It wasn`t till I went back to see the doctor again with the wife, and he explained again like” (P3 Surveillance)

Patients appreciated time spent with the clinician. Additional appointments to discuss concerns and treatment options helped make sense of the uncertainty.

“The day he told me all this, it didn`t really sink in, it takes a little bit...a got a shock to be honest. I was sitting there, and my mouth went all dry to be honest when he told me it was cancer. You know, you just sort of go `boof”. (P4, Surveillance)

Although not an easy task, patients were able to make decisions in relation to their own values and personal situation.

“I wouldn`t say the decision-making circle was that clear. It was a case of one thing drives another. And it would take a rather unique individual to say, depending what your life is like and how old you are, where you want to be in life and where you see yourself going. But it would take a unique individual to say no, I`m not having the surgery. (P5, Surgery)

3) Living with uncertainty.

Uncertainty in relation to cancer recurrence was described by patients who had chosen a surveillance pathway as their treatment option. This uncertainty appeared to be worse immediately prior to a regular clinic follow up.

“I just hope that when I get me scan it`s clear. And when they go up with the camera, it`s clear. That`s all what`s on me mind now like.” (P3, Surveillance)

The patient who had chosen surgery was very clear he had no regrets at all with the decision.

“At the back of my mind I would have been thinking what’s happening, what’s next? So with hindsight I think I’m in a far better position having done it.” (P5, Surgery)

Comparison of patient and clinician experiences

Comparing experiences of both groups offers an understanding of the similarities and differences around treatment decision making. Table 4 offers a summary which identifies that although common themes were identified, experiences can sometimes differ.

Table 4: Experience of decision making. Themes common to both patients and clinicians.

Experience	Patient	Clinician
Uncertainty & complexity of information	<p>Appreciate honesty from clinician</p> <p><i>“Quite candid conversations... which was good. Obviously, the risks are you miss something by taking it off with the loop and you monitor to see if anything else develops. But the monitoring, it can end up as second stage. Which is liver and lungs” (P5)</i></p>	<p>Perception that patients are unable to comprehend risk/benefit data</p> <p><i>“They will never understand it in my opinion. Even for a clinician it is sometimes very tricky, let alone a patient” (C9)</i></p>
	<p>Able to understand risk information, depending on how it is presented</p> <p><i>“I thought the ratios were quite good cos the man in the street can understand that you know, 1:1000, 1:4 it’s one of us (laughs)”</i></p> <p><i>“f you take part of my bowel away, that disrupts any life. It affects me lifestyle, it</i></p>	

	<p><i>affects what (wife) has to cook for me, it affects how we live and you know, just how we get through life.” (P2)</i></p>	
	<p>Misunderstanding malignant polyp as more advanced bowel cancer.</p> <p><i>“... I’d heard of people having bowel cancer and that’s all I could think of” (P3)</i></p>	
Influences	<p>Family and friends- in particular previous experiences related to colorectal cancers</p> <p><i>“I’ve seen the other family members go through treatments and the side effects of these treatments” (P2)</i></p>	<p>Past experiences of treating patients diagnosed with malignant polyp</p> <p><i>“that man I used (the experience) to tell another lady who had a similar thing” (C10)</i></p>
		<p>MDT</p> <p><i>“People who have a strong opinion tend to voice that opinion the loudest, so although it is a multi-disciplinary meeting, there are often one or two voices that sort of push things through their way” (C2)</i></p>
		<p>Perception of patient understanding</p> <p><i>“you get percentages within percentages, and you’ve got to look at the guy’s face” (C4)</i></p>
Unexpected diagnosis	<p>“No news is good news”</p> <p><i>“we’d thought after it’d gone that long, we thought that the appointment was purely to say, “have you had any problems?” (P1)</i></p>	<p>Difficult conversations related to malignant polyp vs bowel cancer</p> <p><i>“they left the endoscopy unit, telling they have a polyp. And at the next clinic you are with the colorectal surgeon who tell them, ‘actually there is cancer in this polyp’ And their next question is ‘does that mean I’ve got bowel cancer?’ You see what I mean? So it’s not easy. They expect you to tell them what to do next. They don’t realise that this is very much in the grey area and whatever we decide, there’s no perfect solution.” (C5)</i></p>

	<p>Hospital system Unclear pathways</p> <p><i>“ I was in the waiting room, me phone went, and they said ‘you`re going for scans’ and I said ‘what are you talking about’ cos I didn`t know”. (P3)</i></p>	<p>Hospital process issues related to initial benign assessment</p> <p><i>“.. they are a surprise find, they get discussed at the MDT on a Thursday and the patient might be rang on the afternoon, ‘can you come to clinic tomorrow?’ so there is that heightened anxiety before you start” (C6)</i></p>
Time	<p>Appreciation of a second outpatient clinic discussion (and clinical nurse specialist support)-</p> <p><i>“I like it when I went back and had a chat with him to be honest. Because you can take it in better..... obviously then the shock of it is off you”. (P3)</i></p> <p><i>“(The CNS) ...always there when we needed someone to talk to, and you never feel a bother”. (P1)</i></p>	<p>Difficulties experienced due to busy outpatient clinic</p> <p><i>“the way we work is it`s very difficult for me to squeeze in extra patients in our clinic, with such a demand on our time” (C1)</i></p>

Discussion

To date, and to the authors knowledge, there are no randomised controlled trials evaluating options of surgery or surveillance for malignant polyp treatment. This qualitative study used an Interpretative Phenomenological Approach to understand clinician and patient perspectives on treatment decision making following such a diagnosis. Current practice guidance⁸⁻¹⁰ states that a shared approach to decisions is both desirable and appropriate in this situation. Analysis of patient and clinician interviews identified there are multiple areas where improvements could be made to current practice. Utilising the findings from this study, a conceptual framework was developed (figure 1).

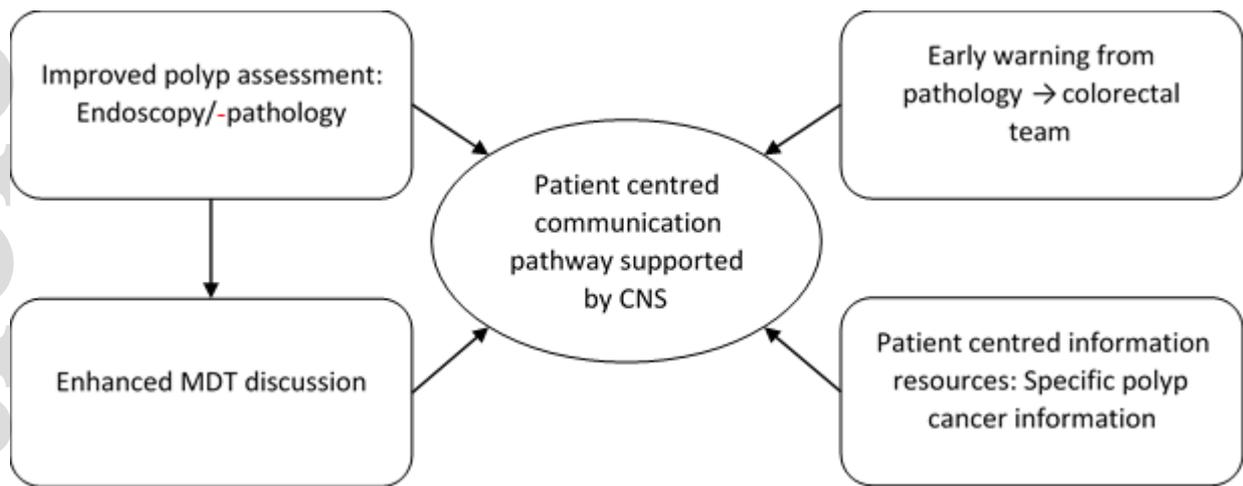


Figure 1: Conceptual framework for enhancements to patient involvement in treatment decisions following an unexpected malignant polyp diagnosis

The framework addresses key issues identified by both patients and clinicians. As always, the colorectal clinical nurse specialists (CNS) hold a central role in supporting patients and navigating clinical pathways. They are pivotal in driving recommended improvements and ongoing support for these patients.

Improving communication links between histopathology and the colorectal MDT, (in particular the CNS) to flag malignant polyp diagnoses early in the pathway could reduce delays and the risk of a ‘no news is good news’ perception. Improved communication would also ensure clinicians were aware of the unexpected diagnosis earlier, to allow adequate and meaningful MDT discussion.

Paramount to patient discussions is the provision of accurate risk/benefit information for each treatment option. Whilst the ACPGBI paper provides a general risk stratification, a more focussed MDT discussion would support individualised case assessment. The use of mortality index scores in relation to surgical options during discussions may also contextualise options for individual patients.

Standardised histological reporting and endoscopic assessment discussed at MDT meetings could better inform decision making. Discussion at MDT including risks of surgical mortality and morbidity with patient values and preferences may reduce levels of uncertainty for clinicians prior to patient consultation. The MDT would therefore generate options with risk profiles, to discuss with patients on an individualised basis.

Treatment decisions are required in the face of uncertainty with many preference sensitive choices. Clinicians should avoid making assumptions about patient goals and values by

asking clear questions before discussing risks and benefits of treatment options openly and honestly. The development of patient centred resources would also aid understanding of risk profiles associated with treatment options specifically for a malignant polyp.

Limitations and future work

The findings presented are limited by factors inherent to qualitative analysis. Participants may have skewed experiences based on local patterns of care, however although the study was conducted within the North of England, multiple sites were used to reduce such bias. All but one of the patients interviewed had chosen surveillance following their diagnosis and a broader insight of patients who underwent surgery might have enhanced the study.

The relationship between specific patients and their named clinicians and healthcare team was not explored as part of these interviews. Participants were reassured of their anonymity and that their clinicians were not informed when interviews were undertaken. Although some patients were treated by clinicians interviewed, this was a chance occurrence. Despite this, patients may have minimised negative experiences about the care received, although we attempted to mitigate this by interviewing patients away from the immediate clinical team, conducted private interviews and ensured participants understood their identity would be protected.

Although uptake of interviews amongst contacted patients was high, recruitment of patients to further explore these themes was pragmatically limited by the small number of patients with malignant polyp identified at each site, despite an 18-month recruitment period.

Uncertainty is a common experience in cancer survivorship¹⁴ and can be affected by different clinical factors. Uncertainty can affect both quality of life and psychological well-being. Although the researcher anticipated a degree of uncertainty from patient interviews within this study, the emotion did not appear to translate into regret following their decision. All patients stated that they were happy with the decision they had made. Many admitted that their emotions had been affected by the overall experience and although it was not an aim of this study to understand the long-term effects of a malignant polyp diagnosis, it is an important consideration for the future.

Conclusion

This study is, to the author's knowledge, the first time both patients and clinician's experiences of making decisions following an unexpected malignant colorectal polyp diagnosis have been explored. Improvements in technology, and therefore diagnostic ability, within Endoscopy such as high definition scopes seek to reduce the likelihood of an 'unexpected' malignant polyp diagnosis, however it is unlikely that the 'unexpected' malignant polyp will disappear completely.

As the decision between surgery and surveillance following a diagnosis of unexpected malignant polyp is preference sensitive, it is important that the values and beliefs of the individual patient are considered. Many of the issues raised in relation to patient involvement in decision making can be overcome with minor alterations to current practice. The findings of this study should be used as a foundation to build patient centred care for the future.

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Appendix 1:

Clinician Interview Topic Guide.

Introduction:

This study aims to explore clinician's involvement in decision making with regards to treatment following a patient diagnosis of malignant colorectal polyp. It is hoped that by finding out this information we can help future patients become more involved in making decisions about their care.

The work will be submitted to the University of Teesside for formal academic assessment as part of a Doctorate in Health and Social Care but the results could impact on care in this area and around the country.

The results will also help advance the service and care to others.

With your consent, I will audio record the interview.

Aims of today:

- To explore some of the issues around patient treatment decision making following a diagnosis of malignant colorectal polyp.

Topic guide:

- Process from histology result to treatment
- Influences?
- MDT involvement.

- Patient's preferences.
- Discussing treatment options.
- Use of patient information.
- Timing of patient decision.
- Involvement of significant others.
- Any other thoughts.

Appendix 2:

Patient interview topic guide

Introduction:

This study aims to explore what experiences patients had regarding making decisions on treatment following a diagnosis of polyp cancer. It is hoped that by finding out this information we can help future patients be more involved in decisions about their care.

The work will be submitted to the University of Teesside for formal academic assessment as part of a Doctorate in Health and Social Care but the results could impact on care in this area and around the country.

The results will also help advance the service and care to others.

With your consent, I will record this interview.

Aims of today:

- To explore some of the issues and experiences of making decisions about treatment following your diagnosis of polyp cancer.

Topic guide:

- Start by describing in your own words, what happened. How did you come to find out about the polyp cancer?
- What information was offered, or did you access at the time?
- What information did you find helpful?
- What choices were discussed with regards to treatment?
 - What was asked of your preferences with regards to the options?
 - Would you choose the same option again now?
- How did you make your decision?
- Who did you discuss options with?
- Have you had any problems since your diagnosis/ treatment?
- Do you have any anxieties about follow up? What are they?
- Is there anything else you would like to tell me about your experience?

Appendix 3: Data analysis

