

Decision Making in the Treatment of Early Colorectal Cancer: A review of the literature.

Introduction:

Colorectal cancer is the second most common cause of cancer death in the United Kingdom (Cancer Research UK, 2014). Depending on the location within the large bowel or rectum and extent of the disease, options for treatment vary. A National Bowel Cancer Screening Programme (BCSP) was introduced into England in 2006, with an aim to reduce colorectal cancer mortality (Hewitson et al, 2008). The program offers faecal occult blood tests (FOBT) every two years to all men and women aged 60-74. FOBT is designed to detect traces of blood in stool. Large colonic polyps and colorectal cancer can bleed into the bowel lumen, thus causing a positive FOBT prior to the lesion becoming symptomatic. Individuals with a positive FOBT result are invited for colonoscopy. Colonoscopy enables the detection of cancer and the detection and removal of adenomas. Screening the population for bowel cancer in this way, before the onset of symptoms, has led to increased numbers of patients being diagnosed with colorectal cancer at an early stage (Logan et al, 2012; Ellul et al, 2010).

The National BCSP has also led to an increase in unexpected polyp cancers (Logan et al, 2012), whereby polyps are removed during colonoscopy and found to contain a focus of cancer. If there are clear resection margins following histopathological assessment, this leads to a dilemma whether further treatment in terms of surgery is necessary (Williams et al, 2013).

Treatments for early stage colorectal cancer and polyp cancers often involve several options which are preference sensitive, meaning there is not one correct decision. Many less invasive surgical procedures are now available. These are summarised in Table 1. Because of this increase in treatment options, patients have increasingly more complex decisions to make to balance improvements in quality of life against possible reduction in survival. Making the right decision on an individual basis is both an issue of quality, in terms of individual lifestyle factors, and safety, in terms of likelihood of disease recurrence from less invasive treatments or mortality and morbidity of major surgery. This decision is therefore of great significance.

Table 1: Newer treatments for early stage colorectal cancer		
Abbreviation	Name	Description
EMR	Endoscopic Mucosal Resection.	An endoscopic technique developed for the removal of sessile benign and early malignant lesions in the GI tract using submucosal lift to act as a cushion and removal of the lesion either whole or piecemeal using a snare (Hwang et al, 2015).
ESD	Endoscopic submucosal dissection.	An endoscopic technique like EMR, but specifically used to remove lesions en bloc. With ESD the submucosa is dissected under the lesion with a knife rather than a snare (Maple et al, 2015).
TEMS	Transanal Endoscopic Microsurgery.	An operative technique for local removal of early rectal cancers using a dedicated rectoscope Usually performed under general anaesthetic, for lesions between 4 and 15cm from the anal verge. Able to perform full thickness resection of the neoplasm with 1cm margin (Althumairi et al, 2015).
TAMIS	Transanal minimally invasive surgery.	Like TEMS, although uses single incision laparoscopy port, through which conventional laparoscopic instrumentation can be used. Can be used for early rectal cancers anywhere in the rectum up to 15cm from anal verge. Able to perform full thickness resection of the neoplasm with 1cm margin (Althumairi et al, 2015).

Literature surrounding the complex process of decision making within the context of early stage colorectal cancer is limited. This is most likely because the increase in diagnosis is relatively recent. Similarities can be drawn from other preference sensitive decisions in the treatment for colorectal cancer, for example choice of operative procedure for treatment of rectal disease.

The UK Government aims to increase patient involvement in treatment decision making (Department of Health, 2012), especially where options are preference sensitive. **Shared decision making is the term used to describe the process whereby clinicians and patients use best available evidence together with information about the individual patients' values, beliefs and treatment goals to make decisions together (Elwyn et al, 2012).** Studies have demonstrated patients and healthcare professionals frequently place different emphasis and priorities on the endpoints of treatment including risks and side effects (Pieterse et al, 2008; Masya et al, 2009), therefore establishing patients' preferences for treatment, considering individual values and goals is

increasingly significant. The aim of this paper is to review the current literature surrounding patient involvement in decision making following a diagnosis of early stage colorectal disease.

Method:

A literature search was undertaken using the following electronic databases: Allied and Complementary Medicine Database (AMED), Medical Literature Analysis and Retrieval System Online (MEDLINE), Psychology Information (PsychINFO), Cumulative Index to Nursing and Allied Health Literature (CINAHL), Psychology Articles (PschARTICLES) and Psychology and Behavioural Sciences Collection. Reference lists of articles identified as meeting the inclusion criteria were also searched by hand to identify further articles. A date limit was set to 2007. This date was chosen to allow the inclusion of only the most recent studies including those reviewing more modern treatment options. The UK National BCSP was launched in 2006, and it was anticipated this would trigger more research into earlier stage disease. The date last searched was 12th April 2017. Available literature published within the ten-year period from 2007-2017 was considered.

The inclusion criteria were:

- Research which explored patient involvement (from a patient or clinician perspective) in treatment decision making following a diagnosis of early colorectal cancer.
- Research available within the timeframe of 2007-2017.
- Published in English language.

The exclusion criteria were:

- Research which focused on palliative care, oncology, screening or genetic testing.
- Conference extracts, editorials, letters or opinions.

Where other tumour sites were included within the studies, the article was included, but only data on colorectal cancer was reviewed. A total of 12 papers (9 research studies, 3 systematic reviews) were included which met the criteria of the review. An overview of the 9 research studies is provided in Table 2a, and the systematic reviews in Table 2b.

Table 2a: List of research studies reviewed

Author (year)	Study description	Study Origin	Summary of results	Potential biases identified.
Beaver et al (2007).	Qualitative exploratory study, using in depth interviews. Aim: to explore views on patient participation indecision making, as described by health professionals caring for people with colorectal cancer.	England	Choices in relation to surgical treatment were viewed as limited. Health professionals made assumptions about patient preferences based on characteristics such as age.	Sample of patients taken from three NHS Trusts in the Northwest of England, therefore Generalisation may not be possible elsewhere. Large numbers of nursing staff interviewed compared to consultants.
Shepherd, Tattersall and Buttow (2007).	Quantitative survey of cancer clinicians to document views on shared decision making and discover if their views differed according to doctor characteristics. Multiple cancer specialities included in study.	Australia	Clinicians did not report using shared decision making routinely in their practice. Colorectal surgeons may feel patients need more direction because of lack of treatment options.	Self-reported nature of questionnaire design. No method to review individual scenarios. Low response rate from questionnaires (59%)
Pieterse, et al (2008).	Mixed methods study. Aim: to assess what role clinicians prefer in deciding about treatment, and how they view patient participation in treatment.	The Netherlands.	Almost all participants preferred a shared process of decision making. Clinicians cannot accurately predict how treatment outcomes affect individual patients.	Participants had previously participated in a study for rectal cancer, therefore selection bias may contribute.
Beaver et al (2009).	Quantitative study: an attitude rating scale was used to explore colorectal cancer patients' views of involvement in decision making.	England	Patients wanted to be informed and involved in decision making, but did not necessarily want to take on the role of decision maker.	Use of cross-sectional study-capturing views at one moment in time. Findings are limited by response bias. Study measured attitudes. Attitudes do not necessarily determine behaviour.
Harrison et al, (2008)	Mixed methods study, interviews performed to investigate preferences for treatment for rectal cancer.	Australia	Patients had strong preferences against treatment options which frequently differed from those of physicians.	Sole focus was on rectal cancer; however, scenarios were used on patients recently treated for all colorectal cancers. The results of the study may have been different if only patients with rectal cancer had been recruited.

Author (Year)	Study description	Study Origin	Summary of results	Potential biases identified.
Shepherd, Butow and Tattersall (2011).	Qualitative study, investigating factors which motivate cancer doctors to involve their patients in treatment decisions.	Australia	Clinicians expressed differing support of patient involvement in decision making dependent on context, impact and effect the involvement may have.	Participants were recruited from a pool of clinicians who had been involved in similar studies. These participants may have been more supporting of patient involvement, and may have avoided expressing negative views.
El Turabi et al (2013).	Quantitative survey study, examining a single question from the National Cancer Patient Survey, examining patient experience of involvement in treatment decision making.	England	Younger patients had less positive experience of decision making. Rectal cancer patients had worse experiences compared to colorectal cancer patients.	The use of a large-scale survey to investigate quality of decision making is questioned. Response bias, including recall and disease severity would have an impact on results.
Snijders et al (2014).	Quantitative study, aimed to explore surgeons' opinion on pre- op information which should be given to rectal and sigmoid cancer patients and to evaluate what was communicated. Surgeons attitudes to shared decision making were also compared with patient involvement.	The Netherlands.	Insufficient information is given to patients with rectal and sigmoid cancer to guide them on their preferred treatment option. Patients were hardly involved in the treatment decision.	Only first outpatient consultations were studied, therefore some communication with the patient could have been missed. Surgeons were aware they were being recorded, they may have provided more information than usual.
Hirpara, et al (2016).	Qualitative study, using semi structured interviews. Aims: to explore the complexities of shared decision making within colorectal cancer surgery.	Canada	Patients perceived a lack of choice and control in decision making. Patients identified several facilitators to shared decision making, including a robust support system, including family.	Restricted sample population of one large urban area. Almost half of the study population had required treatment with radiotherapy, suggesting the presence of advanced disease. Participants recruited were all under the care of one surgical oncologist.

Table 2b: List of systematic reviews

Author, (year)	Study description	Study Origin	Summary of results	Potential biases identified.
Hubbard, Kidd and Donaghy (2008)	Systematic review of the literature about patients' preferences for involvement in cancer treatment decision making.	Scotland	Patients preferences for involvement in decisions vary considerably. It is not possible to predict which patients prefer an active role.	Did not complete a full search of all available literature.
Damm, Vogel and Prenzler (2014).	Systematic review to identify patient's preferences concerning treatment preferences and involvement in the decision-making process.	Germany	Colorectal cancer patients have preferences regarding treatment options and outcomes, which are individual and depend on personal factors.	Studies reviewed are mainly prior to 2009 (only one study 2011). Lack of availability of newer surgical techniques would have an impact on responses.
Currie et al (2015)	Systematic review aimed to assess the use of patient preference in colorectal cancer treatment.	England	Patients are prepared to trade significant reductions in life expectancy to avoid certain complications of colorectal surgery, particularly stoma formation.	The studies reviewed included patients who had their treatment in the late 1990s and early 2000s, and may be less applicable now with newer surgical techniques including less invasive options.

Overview of themes derived from analysis of the papers:

To provide a comprehensive review of the findings from the papers reviewed, the following discussion of the literature review results will be presented under general themes. These themes were derived by the author from the analysis of the papers. The first theme related to the situations when it is felt 'ok' to share treatment decisions with patients. Other themes which were derived from reading the papers could be divided into clinician and patient factors. Clinician factors included the barriers of time pressures, and the perceptions of clinicians that patients should or should not be involved due to personal or disease specific factors. Patient factors included disease culture, decision awareness, information giving and the involvement of family members. These themes will now be illustrated.

Results

Can all decisions be shared?

Involving patients is considered more important and more likely to occur where survival outcomes for different treatment options are similar (Shepherd, Tattersall & Butow, 2007; Shepherd, Butow & Tattersall, 2011). Patients are understandably more often encouraged to be involved where decisions are preference sensitive. These are described as 'grey' or where more than one treatment option is considered appropriate. These 'grey' areas contrast with more 'black and white' decisions, for example in an emergency or where clear evidence exists for one of the pathways. In these situations, it is assumed the patient would want to take the decision giving the best outcome. The more impact a treatment option has on a patient's lifestyle the more important a shared decision approach is.

Clinician factors:

Initial review of the studies identified that the opinions of clinicians regarding barriers to involving patients in treatment decisions are often neglected. Where clinicians are asked to participate in

studies (Beaver et al, 2007; Shepherd, 2007; Pieterse, 2008) the aim was to establish their views on involving patients in decisions. Without an understanding of the challenges clinicians may encounter during a shared decision making process, success is unlikely.

Clinician barriers to sharing decisions:

Appraisal of the literature uncovered three commonly cited barriers to implementing shared decision making by health professionals. Firstly, is the barrier of time pressure (Beaver et al, 2007; Beaver et al, 2009; Damm, Vogel and Prenzler, 2014; Snijder et al, 2013). Secondly is a lack of perceived applicability of involving patients in decisions due to patient characteristics (such as age and ability to understand information); (Beaver, et al, 2007; Beaver et al, 2009), and thirdly, there is a lack of perceived applicability due to the clinical situation (such as the stage or situation of the cancer) (Shepherd, Tattersall & Butow, 2007; Beaver et al, 2007) leading the clinician to make assumptions that patients would not want to be involved in the decision.

Time pressure:

Time pressure barriers are reported as two-fold. Firstly, from a clinician perspective, lack of time within the outpatient clinic consultation to allow adequate discussion (Beaver et al, 2009). Secondly, a lack of time to allow patients to decide (Damm, Vogel and Prenzler, 2014). Confounding this problem is pressure for clinicians to achieve targets such as adherence to NICE guidelines for suspected cancer diagnosis (NICE, 2015). Targets such as these may prevent an optimum environment for full patient involvement, with pressure for patients to embark on their chosen treatment pathway within a target time, reducing time available for them to deliberate within their own environment. Pressure to see patients within target of two weeks from referral may also increase numbers of patients for the clinician to see in clinic, and reduce time available for consultations. These targets should not prevent patients being given as much time as they require to decide on options with such huge consequences.

To alleviate the barrier of limited time identified within some of the studies (Damm, Vogel and Prenzler, 2014; Beaver et al, 2009) for patients to consider the information on treatment options,

a second consultation with the consultant could be offered. Second consultations could enable patients time to discuss options with family/ specialist nurse; although one study by Snijders, et al, (2014) identified that a second consultation pre-operatively may not be practical. Certainly, within the UK, short timescales to surgery due to adherence to targets (as previously discussed, NICE, 2015), would be a barrier to this suggestion. Alternatives to a second consultation could be considered; for example, giving printed information, videos describing therapeutic options and risks and benefits before the first consultation. The availability of such resources, especially for diagnoses such as polyp cancers, are at present scarce (Snijders et al, 2014).

Lack of perceived applicability of involving patients in decisions due to patient characteristics:

Shepherd, Tattersall and Butow, (2007); Shepherd, Butow and Tattersall, (2011) and Harrison et al, (2008) all suggest that clinicians appear to value the concept of shared decision making although they acknowledge that patients do not always want to be fully involved in the process.

Whilst the difficulties in distinguishing the desire of patients to be involved in decision making have been identified (Beaver et al, 2007; Pieterse et al, 2008; Hubbard et al, 2008), the challenge for clinicians is to minimise misunderstandings and misinterpretations of risks and benefits involved in the choices available (Harrison et al, 2008; Snijders et al, 2014). The findings of one study by Hirpara et al (2016) mirror other studies (Beaver et al, 2007; Pieterse et al, 2008; Hubbard et al, 2008), which have been unable to identify specific characteristics for individual patients to enable clinicians to predict the level of involvement a patient may prefer.

The ‘active’ decision maker role assumed by some knowledgeable patients can result in frustration for health professionals when choices are made in the absence of scientific evidence (Beaver et al, 2007). There can be disbelief that patients may not always choose options based on prolonging their life. This perspective represents a lack of appreciation by health care professionals of the importance of quality of life to patients, and how individual opinions differ. Currie et al, (2015) highlighted the importance of discussing patient choice in relation to colorectal surgery, identifying that patients are prepared to trade significant reductions in life expectancy to avoid certain complications, particularly stoma formation.

Clinicians perception that younger patients want more information and choice was one of the findings reported by Beaver et al, (2007). This perception may hinder the options for the older generation to engage in the decision making process. Beaver et al, (2009) report that older patients are traditionally used to paternalistic approaches to treatment decisions in healthcare and may appear unwilling to enter discussions regarding concerns and priorities for treatment outcomes, believing 'the doctor knows best'. Williams et al, (2013) acknowledge there may be a perception that any side effects of treatment are not as important to older patients as they have a shorter life expectancy; however, deterioration in health may have an impact on the levels of independence and social isolation, therefore it is important that clinician assumptions are avoided.

Lack of perceived applicability due to clinical situation.

Earlier studies (Shepherd, Tattersall & Butow, 2007; Beaver et al, 2007), report that health professionals felt choices in colorectal cancer treatments were limited with the only options being whether to have surgery or not. As discussed previously, both studies relate to treatment options for definite bowel cancer, where options for treatments were limited. Since the publication of these studies, the National Bowel Cancer Screening Programme has led to diagnosis of disease at an early stage, with increased preference sensitive options, and an increase in the necessity to base options around patient values and preferences.

Power relationships between clinician and patient may also affect patient involvement in decision making. For example, when a surgeon discusses the choice between surgery or no surgery in the treatment of a polyp cancer. Shepherd, Butow & Tattersall (2011), report that surgeon bias towards surgery may contribute to patient interest in surgery. Research around this topic however, is scarce. Recommendations made by Shepherd, Butow & Tattersall (2011), are that the perspectives of patients who declined surgery are studied further to understand why they have made this decision.

Patient factors:

El Turabi et al, (2013) explored variation in involvement in decision making as part of the English 2010 National Cancer Patient Experience Survey, one of the largest ever undertaken. They found more positive experiences of involvement are associated with reduced decisional conflict, greater satisfaction with treatment decisions and improved patient wellbeing. This could translate into further improvements for Trusts such as reduced dissatisfaction with services, complaints and litigation. Results of the survey concur that the younger age group report substantially less positive experience, reflecting the expectation of greater involvement as previously discussed.

Trust in health care staff is still identified as a major facilitator in decision making (Hirpara, et al, 2016), having previously been reported within a survey of colorectal cancer patients' attitudes in decision making (Beaver et al, 2009). One of the aims of the study by Beaver et al, (2009), was to explore patient attitudes towards involvement in decision making. The study also included the development and piloting of an attitude scale to enable this exploration to be achieved. Results from the study showed that most patients wanted to be involved in their treatment decisions (94.7%), however this did not necessarily mean they wanted to completely make the decision on their own. Most patients (95.5%) reported that trust in the doctor to decide the best treatment for them was very important to them, however, they also reported that if the doctor told them everything, they were more likely to want to make decisions.

Disease culture:

Disease culture refers to the social and public profile of the disease (Shepherd, Butow & Tattersall, 2011). The existence of active consumer groups encourages patients to be more educated about the disease and to play an active role in treatment decisions. The higher profile in terms of public involvement, charities improving disease awareness and options for early diagnosis means patients are more likely to want to be involved. Although it appears colorectal cancer may not enjoy the

same high profile as other cancer disease groups such as breast, national charities and the national BCSP are very active in promoting awareness and may be of benefit to future patients.

Decision awareness:

Hirpara et al, (2016), identified a perceived lack of choice and control by patients. The life-threatening nature of the initial cancer diagnosis can lead patients to believe surgical intervention is inevitable, and there are no decisions to be made. Improving patient awareness of the preference sensitive nature of the decision and the nature of all options available is significant. Recommendations from a study aiming to explore surgeons' opinion on the content of pre-operative information for patients diagnosed with rectal and sigmoid cancers, (Snijders, et al, 2014), include creating an awareness that different options are available for which there may be no best choice. These options may affect the individual in different ways, and choices depend on very individual factors. It may be a surprise to patients to learn the reality that outcomes in medicine are not certain, and real choices are available (Shepherd, et al, 2007

Information giving:

Information giving is considered a major factor in successfully sharing treatment decisions (Beaver et al, 2009; Harrison et al, 2009). The Dutch study by Snijders et al (2014), aimed to explore surgeons' opinions on what pre-operative information should be given to patients undergoing rectal and sigmoid cancer surgery, compared to what is communicated in practice. Results showed that patients were insufficiently and inconsistently informed of the risks of surgery, and information given to them was incomplete. The clinical implications of rectal and sigmoid cancers are that surgery to this area of the bowel is more likely to result in the formation of a stoma than surgery on other areas of the bowel. Even if surgery to the rectum or sigmoid does not involve a stoma, side effects from surgery to this area such as alteration in bowel function are more common and could include incontinence (Knowles et al, 2013). The importance of a study such as that performed by Snijders et al, (2014) is that the implications for patient quality of life are significant in this situation.

Involvement of family members:

Many of the studies surrounding patient involvement in decision making in colorectal cancer focus on the patient's encounter with the clinical team (Beaver et al, 2009; Hubbard, Kidd and Donaghy, 2008; Damm, Vogel and Prenzler, 2014). A recognition of this fact is made by Hirpara, et al, (2016) within a qualitative study aimed at examining complexities of interactions within the decision making process not only with patients but also including their families and the health care team. Following telephone interviews with twenty patients, a key finding was that of the importance of family involvement in the decision making process. Recommendations from the study are that health care teams should have a greater awareness of the impact family members may have on the process. An example may be the patient's concern about how their choice of treatment may impact on the dynamics of family life.

Conclusions:

Shared decision making as a concept has been discussed by healthcare professionals for some time. It is clear from the literature that we are not reaching the goals of shared decisions. Barriers exist preventing clinicians and patients from achieving these. The main barriers being a failure in communicating the preference sensitive nature of the decision to patients, together with the implications of treatment outcomes. Making assumptions of patients' beliefs and values must be prevented.

Many of the studies within this review related to choices between different types of surgery for rectal cancer; for example, low anterior resection and abdominoperineal resection. Whilst this topic still illustrates the complexities of decisions made, it does not necessarily represent the newer problems presented by minimally invasive techniques for early stage disease such as the endoscopic resection of unexpected polyp cancers, or transanal endoscopic microsurgery (Nakajima et al, 2013). These treatments offer patients preference sensitive choices with important life altering decisions to be made.

The treatment decision making process in patients diagnosed with early colorectal cancer or polyp cancer is not clearly understood. Reasons for this lack of understanding stem from the absence of studies exploring the experiences of clinicians and patients in this area. Presumptions of the issues can be made from examining the literature on decision making in similar clinical areas; however, the situation of a patient faced with treatment options following a diagnosis of very early colorectal cancer is unique and needs to be fully understood.

There is an obvious gap in knowledge of the treatment decision making process around early colorectal cancer and polyp cancers. Further studies in this area are required to address this gap, specifically incorporating the perspective of clinicians as this is likely to be the most challenging barrier to overcome. Beyond this recommendation, further studies are required to establish the optimal model for improving the decision-making process in this area.

Table 3: Key Findings
<ul style="list-style-type: none">• Patients may not understand that their treatment options are ‘preference sensitive’.• Time pressures exist, both in the outpatient clinic setting, and the time between clinic appointments to allow patients ‘time to think’.• Patient characteristics such as age may prevent clinicians including patients in treatment decision making.• Clinical situations such as the extent of the disease may prevent clinicians including patients in treatment decision making.• Trust in the clinician is a big enabler for patients to be involved in decisions.• The quality and quantity of information is important to enable a fully informed decision maker.• Family members play a big part in patients decisions.

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