Shared decision-making about treatment for colorectal cancer: The perspective of older patients

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Background

Shared decision making (SDM)

The White Paper, *Equity and Excellence: Liberating the NHS* set out the Government’s plan for a patient centred National Health Service based on the principle of shared decision making:

‘no decision about me without me’ (DOH, 2010, p. 13).

SDM is a process whereby:
‘patients are actively involved in shared decision making and supported by healthcare professionals to make fully informed choices about investigations, treatment and care that reflect what is important to them.’

(NICE, 2012)
Older Adults and colorectal cancer

• Approximately 40,000 new cases of colorectal cancer each year in UK
• Almost 75% occur in people over 65 (Cancer Research UK, 2014)
• Half of people with colorectal cancer survive for at least 5 years but older people have a worse prognosis than younger patients (Dekker, 2011)
• Older people increasingly likely to have multiple health problems, lack social support and find travel difficult (DOH, 2012)
• Most common treatment is surgery (80%) but may also receive chemotherapy after surgery (Cancer Research UK, 2014)
What existing research tells us

- UK cancer survival rates for older people are the worst in Europe (Moller et al, 2011)
- Overall cancer survival rates are improving but less so for people aged 74 to 84 and survival for 85+ is getting worse (Moller et al, 2011)
- Cancer clinical trials often exclude older people on the basis of age or morbidity (Seymour et al. 2011)
- Older people less likely to have their symptoms fully investigated and are less likely to be referred for essential treatment (British Geriatric Society, 2011 – survey of 200 geriatricians)
- Lack of research into the influences of emotional and social factors on treatment decision making (Tariman et al, 2010)
- Often incongruence between family and patient if family make decisions on part of patient (Siminoff et al, 2006)
- A UK survey of medical oncology trainees (n=64) found that 21% confident of ability to treat older patients compared to 81% confident to treat younger patients (Kalsi et al, 2013)
Treatment decision making

• ‘Patients should have the opportunity to make informed decisions about care and treatment in partnership with health professionals and families’ (NICE, 2011: Guidelines for colorectal Cancer Treatment)
• Diagnosis and treatment of colorectal cancer involves discussion of bodily functions and invasive procedures
• Intensive cancer treatment improves clinical outcomes but potentially decreases quality of life (DOH. 2012)
• Patients may focus initially on being cancer free and getting through surgery rather than longer term implications (Park et al, 2014)
• Post cancer treatment there may be uncertainty about future, change in bowel function and altered body image
• Dekker et al. (2011) compared population survival data for 9397 patients with colorectal cancer in the Netherlands. They found that patients over 75 tended to present later, have more comorbidity, receive less aggressive treatment, and be more likely to discontinue treatment early.

• If older patients survived the first year, they had the same cancer related survival as younger patients (Dekker et al. 2011)
Basis for this research

• Matthias et al. (2013) argue that a tendency of research into SDM to focus on easily observable aspects of the decision making process which misses the complexity.
• Johnson (2012) recommends research to develop an understanding of the treatment decision-making process for older patients to facilitate the provision of relevant information and support.
• Strohschein et al. (2011) suggest research needs to focus on the patient’s actual experience of health related decisions and on understanding the structure, content, influencing factors, and consequences of patient decision making itself.
The missing piece?

- Geriatrician?
- Family
- Other Health Professionals
- GPs
- Surgeons
- Guidelines /Protocols
- Oncologists
- Patient perspective

Shared decision making
Study aim

- To understand the experience of treatment decision making from the perspective of the older person with colorectal cancer
Eligibility

Inclusion criteria

- Age: We purposively selected patients from the ‘young old’ (65-74), ‘old’ (75-84) and older old (85+) age ranges
- Diagnosis of potentially curative colorectal cancer
- Patients who had the option of treatment
- With recent experience of treatment decision making (past 18 months)
- Those who health care professionals judged to have the capacity to give informed consent to participate in research
<table>
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Methodology

• Qualitative interview study
• Patient and public involvement – study, information sheet and topic guide reviewed by patient research group Beating Bowel Cancer
• Proportionate Review - NHS Research Ethics Committee
• Potential participants initially approached by Colorectal Clinical Nurse Specialist and given information sheet
• Contacted by researcher who answered questions and if they wanted to go ahead arranged time for interview
• Interviews conducted in person or by telephone
• Interviews lasted between 35 and 90 minutes
Framework approach to analysis (Ritchie & Lewis, 2003)

Data management and interpretation sequential with the aim of ordering data to facilitate interpretation

- Initial themes based on topic guide

Interpretation involved:

1. Thematic analysis and categorisation
   e.g. Information sources, outcomes of shared decision making

2. Explanatory analysis
   e.g. Factors influencing the decision made, what influences the way people feel about the decision made
Findings

Factors influencing decisions

- Previous experience of treatment (especially chemotherapy)
- Fears about treatment (chemotherapy, colostomy, ileostomy)
- Age ‘I have had a good life’
- Previous experience having cancer
- Family history of cancer ‘It was inevitable’
- Family wishes
- Concerns about own ability to cope
- Wanting to live
- Quality of life ‘don’t want to be sick and bald’
- Happy to trust the consultant to make the right decision
- Comorbidity
Treatment pathways after diagnosis

No treatment

Further treatment
- Patient sometimes unaware of decision making process – happy with decision

Surgery

No further treatment – patients choice
- Patient more aware of decision making process – happy with decision

No further treatment – medical decision
- Patient less clear about decision making process – not always happy with decision
Treatment pathways after diagnosis

No treatment

- Patient less aware of decision making process – happy with decision

Further treatment

- Patient more aware of decision making process – happy with decision

- Medical decision

- Patient less clear about decision making process – not always happy with decision

'I have no family which is a terrible disadvantage in this situation and I wouldn’t wish that on anybody, you really need either a supportive partner or family or something because you are out there in the wilderness and all my friends that I spoke to were very against my ideas, they thought I should have the operation which of course upset me more than ever. I just wanted to somebody to say you must do what’s right for you’ (Julia, 79)
Treatment pathways after diagnosis

No treatment

- Patient sometimes unaware of decision making process – happy with decision

Surgery

- If you want to hang around a bit you’ve got to go along with what the hospital says (Alan 79, married)

Further treatment

- Patient more aware of decision making process – happy with decision

- Patient less clear about decision making process – not always happy with decision

No further treatment – patient’s choice
Treatment pathways after diagnosis

No treatment

- Patient less aware of decision making process – happy with decision
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- Patient less clear about decision making process – not always happy with decision

Surgery

- No further treatment – patient's choice
- No further treatment – medical decision

There is no way they did anything I did not want them to do (Amy 84, widowed)
They said I am not well enough to stand chemotherapy and so the position is I am left as I am. I don’t feel very happy about that – I think about the end all the time (Iris, 83. Single)
Factors influencing feelings about decision

- Family support
- Social support
- Overall health
- Medical follow up (or lack of)
- Prognosis
- Effects of cancer and treatment
- Ownership of the decision
Limitations?

?geriatrician

Family

Other health professionals

Patient perspective

GPs

Oncologists

Guidelines /protocols

surgeons
Conclusion and what next?

• Many older people have clear ideas about what treatments are acceptable to them
• Most older people are cognitively intact and able to make their own decisions
• We were unable to answer the question posed by Macmillan Cancer Support regarding *don’t offer or don’t want*. However, we found a number of our participants did not want treatment

**What next?**

• Exploring the older person’s preconceptions of chemotherapy
References


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