The role of the general practitioner in the care for patients with colorectal cancer

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Chapter 1

General introduction
One third of the Dutch population is expected to be diagnosed with cancer in their lifetime. Nowadays people are more likely to live beyond a cancer diagnosis, and make the transition into being a cancer survivor. Main factors contributing to this are advances in earlier detection, better staging and improved treatments. The downside of this great development however, is an increased pressure on the organization of health care. People living with and beyond cancer have specialized health care needs. The organization of cancer care is heavily debated over the recent years, with an increased role for the Dutch general practitioner (GP) being proposed. Colorectal cancer (CRC) is the third most commonly diagnosed cancer in males and the second in females, and its incidence is expected to rise due to an ageing population. This make it an interesting example to define the current role of the Dutch GP in this care to assess possibilities for an increased role in the future.

1.1 Epidemiology of colorectal cancer

In Western Europe, CRC is the third most commonly diagnosed cancer in males and the second in females, with an age standardized incidence rate of 39.1 and 24.9 per 100,000 for men and women, respectively (1). In The Netherlands, it was the second most commonly diagnosed cancer for both males and females in 2015, with a total of 15,807 new cases (2). Age is one of the largest risk factors, apart from having a family history, especially having a first-degree relative with CRC (3,4), and having inflammatory bowel disease (5). CRC is diagnosed at a median age of 66 years for males and 70 years for females (6). Due to ageing of the population it is expected that CRC incidence will further increase with 3% per year, up to 17,000 new cases in 2020 in the Netherlands (7). In addition to this, the implementation of a nationwide screening program for people aged 55−75 could lead to an even greater rise in incidence of CRC in the coming years (8). The increase in CRC incidence is also attributed to factors related to a Western lifestyle. These include high consumption of red and processed meat (9), excessive alcohol consumption (10), smoking (11), diabetes (12), and obesity (13).

1.2 Colorectal cancer mortality and early diagnosis

CRC is a well treatable cancer, but survival of CRC is dependent on the stage of the tumor at diagnosis. Five year survival rate is around 90% when CRC is diagnosed at a localized stage, meaning that the cancer has not gone through the outermost layers of the colon/rectum, has not reached nearby organs, and has not spread to lymph nodes. This decreases to roughly 85% when diagnosed at regional stages, meaning there is regional lymph node involvement, and to about 35% when diagnosed at metastasized stages (14-16).

Worldwide, and also in the Netherlands, mortality rates of CRC have decreased over the last two decades, and survival rates have increased (1,17). This is attributed to colorectal cancer screening programs, reduced prevalence of risk factors, improved staging and treatments, and improved access to high quality health care (18-20).
In the Netherlands, European standardized mortality rates for CRC were 19.0 per 100,000 in 2014 (21). This is favorable compared to countries with comparable health care systems such as the United Kingdom, having a European standardized mortality rate of 27.1 per 100,000 in the same time period (Figure 1) (22,23). Interestingly, in the United Kingdom and comparable countries mortality rates fell by more than 30% for both sexes over the past decades. In the Netherlands, a lower decline was achieved of 11.6% and 16.7% for men and women, respectively (24).

![European standardized mortality rates in the Netherlands and United Kingdom between 1990 and 2014.](image)

Figure 1: European standardized mortality rates in the Netherlands and United Kingdom between 1990 and 2014.

Some of the improvements in the UK are most likely the result of improved diagnostics in primary care (25). In the UK much effort has been put into reducing the patient and diagnostic interval, by promoting awareness about cancer symptoms, earlier diagnosis (26,27), and urgent referral pathways which were introduced for suspected cancer in 2000 (28).

The patient interval is the period between the first symptom a patient notices and the first presentation (29), which for CRC is frequently the greatest proportion of the total time to diagnosis (30). This may be due to patients attributing their symptoms to benign conditions in order to remain normality, or do not mention them because of the private nature of the complaints (31).

The diagnostic interval, the period between first presentation of symptoms to a clinician and the diagnosis of cancer, is another challenge in CRC. Several alarm symptoms for CRC have been identified that may guide the diagnostic process in primary care (32,33). The most predictive of these is rectal bleeding. However, the proportion of people presenting this in primary care and being diagnosed with CRC, the positive predictive value, is low: 2.4% (32). Other alarm symptoms such as abdominal pain, constipation, diarrhea, or weight loss show even lower positive predictive values (32,33). The low positive predictive value of alarm symptoms might make a GP reluctant to refer a patient because of the high risk of unnecessary colonoscopy and its adverse effects. In contrast, the majority of patients diagnosed with CRC have been shown not to present alarm
symptoms like rectal bleeding (34). The lack of a clear symptom pattern may preclude a symptom based early diagnosis.

The combination of the patient interval and the diagnostic interval can be considerably lengthy in CRC and lead to unfavourable staging and prognosis at diagnosis (35,36). The efforts to reduce diagnostic delay in the UK may have improved early diagnosis of CRC and therewith mortality rates (25,28). Recent Dutch research suggests that 10–25% of patients with cancer show substantially long diagnostic intervals, and delay appears to be especially long for CRC (37). However, little is known about the diagnostic trajectory for CRC in the Netherlands, and what factors contribute to delays.

In addition, the UK and other surrounding countries have implemented screening programs for CRC since the early 2000’s (38). This may have further lowered mortality rates. In the Netherlands a screening program started in 2014. This implies that in addition to an increasing incidence of early onset CRC in the next few years, a further reduction in CRC specific mortality rates may be expected in the Netherlands. However, despite this screening, it is expected that the majority of patients will still be identified through symptomatic presentation in general practice (39-41). This is due to interval cancers occurring after a negative screening test (39), in patients not in the screening program, and sub-optimal uptake of screening or follow-up diagnostic tests (41,42). It is therefore important to examine what characterizes the diagnostic process in terms of health care use, possible delays, and factors contributing to these delays, in Dutch general practice.

1.3 Rethinking cancer care: substitution to general practice?

The increase in incidence of CRC, combined with better survival, leads to a substantial increase in the number of people being treated for or having survived CRC. It is expected that the 10-years-prevalence of CRC in the Netherlands will rise from roughly 70,000 in 2015 to 92,000 in 2020 (7). In 2011, the costs of cancer care in the Netherlands were € 4,300 million, the majority (73%) being spent on hospital care (43). These costs are expected to rise further in the years to come, not only due to the prevalence of cancer but also to the increased incidence (7). Also, the implementation of screening leads to more diagnostic activity (colonoscopy) in secondary care, further driving hospital costs related to CRC. This has led to a call for effective resource allocation of cancer care, possibly by substituting parts of care from expensive secondary care to cheaper primary care services (44). In 2011 the Dutch Cancer Society (KWF kankerbestrijding) called for coordination of cancer follow-up care by general practice (45). The Dutch Society of General Practitioners (NHG) issued a position paper in 2014, in which substitution of follow-up care is suggested for the 5 most prevalent cancer types – breast, lung, prostate, colorectal and melanoma- provided that evidence-based guidelines are developed (46). This position met resistance from practicing GPs, united in the National Union General Practitioners (Landelijke Huisartsenvereniging – LHV), stating that key conditions had to be met concerning communication between GPs and specialists, and more time for GPs to coordinate this care. Interestingly, the current role played by the GP after CRC diagnosis, is largely unknown.
1.3.1 Treatment for colorectal cancer

After referral due to suspicion of CRC or to a positive screening test, CRC is histologically confirmed by a biopsy taken during colonoscopy in secondary care. Curative treatment of CRC usually consists of surgery, possibly complemented with (neo)adjuvant therapies (47). A colostomy (often temporarily) is frequently required after surgical treatment, especially for patients with rectal cancer (29% versus 12% for patients with colon cancer) (16). Side effects of all therapies are frequently observed among patients. Bowel problems such as incomplete evacuation, flatulence, bloating, fecal incontinence, and chronic diarrhea are frequently reported (48,49), as are urinary problems (50), and sexual dysfunction (51). Given the role of the GP, as a gatekeeper and as a generalist in health care, it might be that the GP is consulted for these problems. Whether that is the case, how often this happens, and for what problems the GP is involved during CRC treatment has never been studied in the Netherlands.

1.3.2 Follow-up of colorectal cancer

After completion of treatment patients enter a follow-up routine, mostly situated in the hospital. The main aim of follow-up is the early detection of recurrent cancer. In Dutch guidelines this follow-up care consists of bi-annual consultation for 2–3 years, and annually up to 5 years after treatment (47). This is complemented by bi-annual ultrasound liver echography or abdominal CT-scan for 1–2 years, and annually up to 5 years after treatment. Moreover, carcinoembryonic antigen (CEA) is tested every 3 to 6 months for 3 years, and bi-annually up to 5 years after treatment. As described earlier, it has been suggested that GPs could coordinate this care, provided that an evidence based protocol is available. Interestingly, the evidence for current hospital based follow-up protocols is being debated as well, with no clear differences in survival between different follow-up routines and tests used for detection of recurrences (52,53). This might provide opportunity to rethink current practices and see whether the GP could fit in. However, it is not known whether the GP is consulted more often, or involved by patients during this phase of their care. Since survivors of CRC show various health care needs related to information about their disease, lifestyle, and psychological support (54). Because most tasks belong to the standard repertoire of GPs, it is likely that they are involved in caring for these patients.

GPs in the Netherlands have been given the responsibility for the care of other chronic diseases, such as diabetes, chronic pulmonary diseases and cardiovascular risk management. One third of all cancer patients are already involved in a disease management program for a chronic disease (55). Possibly, this may lead to an easier enrolment of follow-up care for CRC patients in primary care. Health care use in general practice and reasons for health care use have not been studied thoroughly for patients with CRC during cancer treatment nor follow up.

1.3.3 Preferences and expectations of patients about follow-up

When discussing changes in the organization of health care the patient perspective must be included. By including this perspective future organization of cancer care could be adapted to their views. It is useful to understand whether the expectations of patients correspond with those of doctors and policy makers, and whether their expectations are realistic. This could have
implications for the organization of care, the role of the GP in this care, or provision of information. There is no coherent review of the (rich) literature on patient expectations and preferences regarding follow-up care in terms of content, frequency, duration, and setting for survivors of cancer. Concerning CRC specifically, the perceptions of survivors of about the current role of their GP have not been examined, nor their preferences and expectations for future CRC care.

1.3.4 Late effects of CRC
Survivors of CRC – persons with CRC post treatment until the end of life – show various health problems which may last up to ten years after treatment, including pain, fatigue, sleep problems, depressive feelings and sexual problems (56,57). Long term health problems are most likely to be presented in general practice. Until recently there has been relatively little attention for these invalidating symptoms, because treatment was aimed at survival. With the increasing prevalence of CRC survivors, long term health problems become more pregnant and need to be dealt with. Especially fatigue has been reported to be very invalidating by survivors of cancer (58), which is reported to be twice as prevalent among survivors of CRC compared with an age- and gender-matched reference population without cancer (59). Moreover, fatigue can persist for a prolonged period, being present up to 10 years after diagnosis (60). One of the possible strategies to counter fatigue that has been suggested is physical activity. However, whether physical activity is advisable for these patients, in the period after treatment, has not been thoroughly studied. Such knowledge contributes to the GPs understanding of how to counter fatigue and thus provide patients with proper advice.

Aim of the thesis
The overall aim of this thesis is to describe aspects of the role of the Dutch GP during all phases of CRC; from early diagnosis, treatment and follow-up care, to care for long term health problems. This will be based on analysis of health care use, qualitative research into perspectives of patients about these roles of the GP, and literature reviews. Research objectives presented in this these are:

a) To explore primary health care use and factors contributing to missed diagnostic opportunities among patients developing CRC in the year prior to diagnosis (Chapter 2).
b) To explore primary health care use during active treatment (Chapter 3), and during follow-up care (Chapter 4).
c) To review patients’ expectations and preferences about follow-up care for cancer (Chapter 5).
d) To explore experiences and preferences for the role of the general practitioners among survivors of CRC (Chapter 6).
e) To review the evidence for the effectiveness of physical activity in order to reduce fatigue after treatment for CRC (Chapter 7).
General introduction

References

Chapter 1


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General introduction


