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THE PSYCHOLOGICAL IMPLICATIONS OF DIAGNOSTIC DELAY IN COLORECTAL CANCER PATIENTS

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ABSTRACT

Cancer patients rate rapid diagnosis as one of the most important aspects of their hospital-based care, but very little research has examined the psychological implications of diagnostic delay. Diagnostic delay can have both short and long-term effects on a patient's psychological wellbeing, quality of life, and satisfaction with care, as a result of what happens during the pre-diagnostic period, and the consequences any delay may have on the patient's prognosis and treatment.

A third of patients undergoing investigations for suspected cancer have clinically significant levels of distress, and both distress and quality of life during this time are similar to people with a confirmed diagnosis of cancer. Patients who experience diagnostic delay also have a higher number of consultations and medical tests and are more likely to experience substandard quality care, but the effect of this on psychological outcomes among both patients and family members remains underexplored. Patients undergoing investigations for suspected colorectal cancer have informational and emotional needs, some of which remain unmet. Population subgroups that may be particularly vulnerable to distress during the diagnostic phase include women, younger adults, and people with lower social support, low optimism, and high intolerance of uncertainty.

Further research is needed into the effect of rapid diagnostic pathways on psychological outcomes, but also needs to explore the role of particular experiences during the diagnostic phase, such as number of consultations and diagnostic errors on patient wellbeing, and not just time to diagnosis.

INTRODUCTION

Cancer patients rate rapid diagnosis as one of the most important aspects of their hospital-based care (1), but while a great deal of research has examined the prognostic implications of diagnostic delay, very little has examined its psychological consequences. Diagnostic delay, which can include patient delay in seeking help as well as time from first contact with health care until a diagnosis is established, can have both short and long-term effects on a patient's psychological wellbeing, quality of life, and satisfaction with care, as a result of what happens during the pre-diagnostic period, and the consequences any delay may have on the patient's prognosis and treatment.

THE PRE-DIAGNOSTIC PHASE

During the pre-diagnostic phase, people with symptoms suspicious of cancer face the threat of serious illness while having to undergo invasive medical tests, which may be uncomfortable or frightening, and attend numerous appointments. Some may also experience substandard care that directly contributes to a delay in their diagnosis.

Distress and quality of life

Receiving the diagnosis has been rated as the most stressful aspect of having cancer among breast cancer patients, but periods of waiting were also high on the list (2). In a review of research into distress in the diagnostic phase, Brocken et al (3) found between 33-60% of patients undergoing investigations for cancer (breast, malignant melanoma, ovarian, prostate, and lung) reported clinical-levels of anxiety prior to diagnosis (i.e. high enough to be classified as an anxiety disorder using psychiatric assessment tools). While most studies found anxiety reduced in people with benign outcomes, anxiety levels were sustained or increased in people diagnosed with cancer. Although a couple of studies showed a *reduction* in anxiety following a cancer diagnosis (in patients with

melanoma (4) and ovarian cancer (5)), both samples were small, and in the latter study baseline anxiety was measured prior to surgery probably inflating baseline scores.

Suspected cancer patients also reported poorer quality of life than members of the general population, with some studies showing poorer quality of life in the pre-diagnostic phase compared with post-diagnosis, while other studies showed no change post-diagnosis, regardless of whether the outcome was benign or malignant (3). On the basis of their review, Brocken et al (3) conclude that patients with suspected cancer have similar or worse levels of anxiety and quality of life than patients with a confirmed diagnosis of cancer.

The majority of the studies included in Brocken et al's review were on patients with suspected breast cancer, with none on people under investigation for colorectal cancer. Similar rates of post-diagnostic distress have been reported in breast and colon cancer patients (32.8% for breast and 31.6% for colon) (6), suggesting similar pre-diagnostic rates might also be expected. A more recent study in Denmark, of consecutively recruited patients onto a cancer patient pathway (which would have included people with suspected colorectal cancer), reported similar rates of distress as Brocken et al (3), with one third of patients reporting clinical levels of anxiety during the pre-diagnostic phase. Consistent with previous findings, they also observed reductions in anxiety and improvements in quality of life and symptomatology among those receiving a non-cancer diagnosis, with no change in these variables among patients diagnosed with cancer (7).

A study conducted in Canada on patients with a confirmed diagnosis of colorectal cancer attending clinics for follow-up care, asked patients about their specific needs during the pre-diagnostic phase. The study found that patients reported high anxiety levels during this time, and the most frequently identified needs were informational and emotional, reported by 31.6% and 20.3% respectively (8). Although the majority (84%) said their needs had been met, a high proportion of patients (77.9%) also reported that they had not been directed to any sources of help in coping with their anxiety

during the pre-diagnostic phase, suggesting patients require more emotional support during this time. In addition patients were most likely to report needing more information after receiving test results.

Rapid diagnosis and feedback

Research has also examined whether speeding up the diagnostic process improves psychological outcomes. Prompt feedback of test results is clearly important to patients. Patients with symptoms of suspected colorectal cancer report higher levels of satisfaction with the way test results are conveyed when results are given following colonoscopy, where results are often given immediately and face to face, rather than CT colonography, where there is a delay due to the need for radiological reporting of results (9). However, the majority of this sample did not have cancer and rapid feedback may be valued differently by people with benign versus malignant outcomes. Among people ultimately diagnosed with cancer, a more rapid diagnosis means a speedier transition from healthy person to patient. As a result, people have less time to prepare for bad news which may adversely affect their psychological wellbeing. On the other hand, it reduces the period of uncertainty which may be beneficial, particularly for people who find uncertainty difficult to manage.

There is limited evidence that rapid diagnostic pathways, e.g. one or two-stop shops, can improve psychological outcomes. In their review, Brocken et al (3) found rapid pathways reduced the period of distress among those found to have benign disease, with no evidence of benefit, or harm among those diagnosed with cancer (3). Although one study, comparing women diagnosed with breast cancer at a one-stop shop vs. a two-stop system, found higher levels of depression among women attending the one-stop shop eight weeks later, differences were small (10) and not considered clinically significant (3). In addition, depression was measured from the date of the biopsy, and not from the date at which women were told of their diagnosis, so women in the one-stop shop had known about their diagnosis for one week longer which might account for the differences between the two groups. A more recent study, albeit among lung cancer patients, did find evidence of short-

term benefit, with lower distress associated with a more rapid diagnosis among both patients with benign and malignant outcomes, although this benefit was no longer apparent 3 months later (11).

The review by Brocken et al (3) excluded studies on cancer screening, but research in this area suggests that rapid diagnosis is beneficial to patients. Qualitative research into the experience of having colorectal cancer (CRC) detected at flexible sigmoidoscopy screening found that many people described the diagnosis as relatively untraumatic, due to the absence of a period of symptoms and associated worry about a potential cancer diagnosis, and the need for simpler treatment which often comprised surgery alone (12). In addition, a cross-sectional study on colorectal cancer survivors in Scotland, between 3.5 and 12 years post-diagnosis, showed people with screen-detected disease reported lower levels of perceived diagnostic delay and better quality of life than people diagnosed symptomatically (either following a negative screening result or because screening was not offered), even when demographic, and prognostic factors were controlled for, although actual delay was not measured (13). Although people with interval cancers are more likely to have right-sided disease (14), there were no differences in perceived diagnostic delay or quality of life among people with interval cancers compared with people whose cancers had been diagnosed in a geographical area not offering screening at that time. The same data showed that higher levels of perceived diagnostic delay were associated with greater cancer-related distress and more suspected cases of post-traumatic stress disorder (PTSD). Part of the relationship between perceived delay and cancer-related distress was explained by quality of life, but not by disease stage at diagnosis, or treatment received (15). The exact reasons for the relationship between perceived diagnostic delay and cancer-related distress were unclear, and could relate to the traumatic experiences associated with delay. When it comes to experiencing cancer as a traumatic stressor, criteria for PTSD (in DSM-5) specify that "Medical incidents that qualify as traumatic events involve sudden, catastrophic events". The need for emergency admission to hospital, or the discovery that their cancer has been

misdiagnosed by their primary healthcare provider or missed by previous investigations, could contribute to the development of distress or trauma.

Consultations, investigations and diagnostic delay

Diagnostic delay does not just mean a longer period of waiting for a diagnosis, it is also associated with a greater number of medical consultations and investigations. A UK-based study showed diagnostic delay was associated with a higher number of consultations with a primary care provider prior to referral to a specialist, with 20% of patients ultimately diagnosed with colorectal cancer having 3 or more visits before being referred (16). The main predictor of number of consultations was cancer type, attributed to the non-specific nature of symptoms associated with some cancers more than others, making them harder to diagnose, with colorectal cancer classified as being of intermediate diagnostic difficulty (17).

People who experience a delay in their diagnosis also undergo a greater number of diagnostic tests than those who are dealt with promptly (16). Undergoing additional tests may contribute to patients' psychological burden, over and above extending the waiting time for a diagnosis. Concern over test results has been cited as the most common cause of anxiety in patients waiting for diagnostic procedures in an oncology clinic (18), but undergoing procedures involves a number of additional challenges. Diagnostic tests and further investigations for colorectal cancer such as colonoscopy, computed tomographic (CT) colonography and MRI can be uncomfortable as well as anxiety-inducing (e.g. (9, 19)). Patients may need to undergo bowel preparations; injections, some involving radioactive ligand (e.g. PET-CT) which may promote fears about radiation risk; as well as scans, such as MRI which are noisy and require full body immersion into a relatively narrow tube, causing anxiety and claustrophobia in a substantial proportion of patients (19, 20).

Diagnostic delay can also impact patient satisfaction with their care, particularly if the patient believes the delay was due to lack of action by a physician or felt the wait for tests or referrals had been too long (21). A greater number of visits prior to diagnosis is associated with lower patient satisfaction with care (21). In addition, patients who reported that the time between seeking help and confirmation of cancer diagnosis was 'about right' vs. 'a bit long' vs. were more likely to report that they were satisfied with the communication around cancer diagnosis, prognosis and treatment (75% vs. 41% reporting high-mid levels of satisfaction) (22). In a study on patients with anal cancer, Chui et al found that any delay was associated with reduced satisfaction but this was much greater if the patients believed the cause of that delay was the fault of the medical profession rather than the patient failing to seeking medical help promptly (21).

Although there are a number of factors influencing diagnostic delay, in some cases patients may have good reason to believe any delay in diagnosis is the result of substandard medical care. Initial misdiagnosis (treating the symptoms, or attributing symptoms to a disease other than colorectal cancer), failure to examine the patient, and negative or false negative results have all been associated with increased diagnostic delay (23). A retrospective review of colorectal cancer miss rate in a district general hospital in the UK found an 8% false negative rate across three investigative modalities (double contrast barium enema, colonoscopy and computed tomographic colonography) with lowest rates for colonoscopy and highest for barium enema (24). The psychological consequences of misdiagnoses and false negatives are under-explored. One study on the consequences of a false negative in FOBt colorectal cancer screening in Scotland found no evidence of poorer psychological outcomes following a 'missed' cancer compared to people who had been diagnosed in the absence of an invitation to undergo screening (10), with no significant differences between the two groups on measures of perceived diagnostic delay, quality of life or depression, however the study was conducted during the pilot phase of FOBt screening and patient expectations about test performance may have been lower than for an established screening service.

Research into GP and patient perspectives on so-called "quality deviations" (QD) (defined as an event 'that should not have happened and that you don't want to happen again'), showed GPs in Denmark rated one third of cancer patients as having a QD, with longer diagnostic delay associated with GP report of a QD (25). Although both GPs and patients reported a similar proportion of QDs, they showed poor levels of agreement about what counted as a deviation. Reports of a QD by GPs were more strongly associated with diagnostic delay (time elapsed) than patient reports of QD (26), suggesting that for patients, quality of care is more strongly associated with factors other than length of time to diagnosis.

Emergency presentation

Emergency presentation of colorectal cancer is associated with more advanced disease at diagnosis and lower survival rates (27), and a quarter of colorectal cancers in England are diagnosed via this route (28). Even after adjusting for disease stage, emergency presentation is associated with higher mortality and shorter disease-free survival, suggesting such patients have more aggressive tumour biology (e.g. extramural vascular invasion) (29). Although conclusive data supporting the role of diagnostic delay in emergency presentations is lacking (28), rates of emergency presentation vary across primary health care providers suggesting some variability is attributable to patient and provider factors (27). Patients who present via an emergency route in England are significantly less positive about their care than those who present through a planned cancer pathway (30). This is perhaps unsurprising given that such patients are also more likely to present with pain and obstruction (28) have longer surgeries, longer admissions and more readmissions (29). However the psychological consequences of emergency presentation among cancer patients has not been explored.

Vulnerability and resilience

Few studies have examined predictors of emotional wellbeing during the pre-diagnostic phase. However studies on predictors of anxiety or depression after a cancer diagnosis show certain sectors of the population are more vulnerable, for example, people with a family or personal history of psychiatric disorder, people with low socio-economic status, women, and those of a younger age (7, 31-33). Intolerance of uncertainty, defined as a tendency to react negatively to uncertain situations (34), is associated with higher levels of negative affect such as fear and worry in the short-term and is also a risk factor for the development of pathological anxiety (35). In addition it has been shown to correlate with higher anxiety among men with low risk prostate cancer, undergoing active surveillance of their condition (36), as well as higher depression and poorer emotional wellbeing among lung cancer patients (37). This research suggests that diagnostic delay, and the associated period of uncertainty, may be particularly detrimental to people who find uncertainty difficult to manage and further research should be directed at understanding subgroups who may be particularly vulnerable to distress in the pre-diagnostic phase.

Research on resilience, defined as "healthy adaptation in the context of adversity", has also been limited to the study of how people cope with cancer (38-40) rather than coping in the pre-diagnostic phase, although diagnostic workup of symptoms has been identified as one of the many events people with cancer have to deal with (41). In their model of resilience in cancer, Deshields et al (41) propose that personal attributes and environmental circumstances influence how individuals respond initially along the distress-resilience continuum, but that this initial response can be "recalibrated", either as a result of the individual's coping responses or through psychological interventions. Factors such as older age, male gender (42), optimism and social support (43) are associated with greater resilience. While the absence of other stressors is also beneficial (44), there is evidence for "stress-induced resilience": a study on breast cancer survivors showed moderate acute stress was associated with greater resilience, while either low or high levels of acute stress prior to a cancer diagnosis was

associated with lower resilience (45). Interventions that can be used to foster resilience include promoting emotional expression, reminding people of their previous successful coping efforts in the face of difficulties, and cognitive-behavioural therapy focused on reducing worry (41) (also see (43)).

Summary

Research to date shows a substantial proportion of people undergoing investigations for cancer have higher levels of distress and poorer quality of life than the general population, with rates similar to people with a confirmed diagnosis of cancer. Patients who experience diagnostic delay have a higher number of consultations and medical tests and are more likely to experience substandard quality care. Further research is needed into patient experiences during the pre-diagnostic phase that may affect psychological wellbeing and quality of life, including what procedures and diagnostic routes people take, as well as their perceptions of what counts as efficient and good quality care, and identify and provide support for areas of unmet need. More research needs to be done to identify vulnerable subgroups of the population and offer support where necessary. For example, cognitive-behavioural treatments can help reduce intolerance of uncertainty, through techniques aimed at getting people to recognise, accept and deal with uncertainty (46) and greater psychological support for people undergoing investigations for cancer could help patients cope better with the difficulties they face during the pre-diagnostic phase. In addition, although research has examined the psychological impact of cancer on family caregivers across the cancer trajectory, this has typically focused on the point of diagnosis onwards (47), with little work examining the impact of the diagnostic phase on family members. Although a recent study has examined patient and carer perspectives on a lung cancer diagnosis following emergency admission (48), the research focussed on lay understanding of symptoms and help-seeking behaviours before hospital admission, rather than the psychological impact of a delayed diagnosis.

A summary of prediagnostic variables, and psychological effects is in Table1.

Table 1: Summary of the psychological implications of different aspects of diagnostic delay

Prediagnostic variables	Psychological effect
Length of time	Prolongs period of anxiety and poor quality of life among both people found to have cancer and those with benign disease.
Increased number of consultations and diagnostic tests	May increase anxiety. Reduces patient satisfaction with care.
Malpractice	Little research on psychological impact.
More advanced disease at diagnosis	Associated with increased anxiety, depression, greater likelihood of post-traumatic stress disorder and poorer quality of life.
Premorbid factors	Little research on factors specifically associated with poorer psychological outcomes in the diagnostic phase.
Emergency presentation	Reduces patient satisfaction with care but little research on psychological impact.
Information	Limited evidence suggests patients need additional information particularly after they have received test results.

THE POST-DIAGNOSTIC PHASE

Colorectal cancer survivorship can be affected by emotional difficulties; bowel, urinary and sexual problems; negative body image; and fear of recurrence with such problems impacting on the patient's social life and ability to work (49). Such problems can be exacerbated by later disease stage at diagnosis or the receipt of adjuvant therapies. Detection of colorectal cancer via screening in asymptomatic patients picks up cancers at an earlier stage and leads to a reduction in mortality (50) showing that earlier detection can improve prognosis. However the relationship between diagnostic delay and stage at diagnosis in patients with symptomatic colorectal cancer is complex, with both

short and long delay associated with higher mortality (51). While some studies have found no association between delay and mortality, the possibility that longer diagnostic delay did not impact on mortality could not be excluded (e.g. (52)).

Stage, treatment and emotional difficulties

Emotional difficulties following a cancer diagnosis include depression, anxiety, and stress-related responses including post-traumatic stress disorder (PTSD). Such difficulties are often comorbid among cancer survivors (53). A recent meta-analysis of the prevalence of anxiety and depression among people two or more years post-diagnosis found anxiety rates of 17.9% (95% CIs: 12.8 to 23.0) and depression rates of 11.6% (95% CIs: 7.7 to 16.2) (54). A large study of patients with colorectal cancer attending cancer clinics in Scotland found marginally lower rates of depression at 7% (95% CI: 6.1-8), with higher rates among women, younger patients, and people with higher levels of deprivation (32). Rates of anxiety were not examined. Although symptoms of full- PTSD are typically less frequent than those of depression and anxiety, they are found in a significant minority of cancer survivors (e.g. 6.4% point prevalence, with a lifetime risk of 12.6% (55))

Rates of emotional disorders such as depression and post-traumatic stress disorder are higher among cancer survivors than people with no history of the disease (56, 57), and patients with more advanced disease are more likely to report high distress (58) and the presence of PTSD (55, 59) than patients with earlier disease stage at diagnosis. Although distress tends to be higher shortly after patients learn the diagnosis than at later stages in their disease trajectory (22, 60), patients display different emotional trajectories over time. A longitudinal, prospective study in Australia examined distress in colorectal cancer patients from 5 months to 5 years post-diagnosis. The authors used the Brief Symptom Inventory-18 (a measure combining anxiety, depression and somatisation) and identified four different patterns of distress over time: consistently low distress (experienced by 19.4% of the sample), medium level distress (going from case to non-case, experienced by 29.4%), medium

increase distress (going from non-case to case, experienced by 38.5%), and high distress (remaining at case level across time, experienced by 12.5%) (58). The odds of being in a distress trajectory other than the consistently low one was higher for patients with later stage disease –stages III or IV compared with stages 0,I or II (controlling for age, gender, educational level and social support). Although treatment type was a significant predictor of distress group in unadjusted analysis, it was not significant when other variables were added into the model. Examination of the different subscales found disease stage also predicted poorer trajectories of anxiety and somatisation although not depression.

Patients with more advanced disease are more likely to receive chemotherapy and radiotherapy, and higher anxiety, depression and symptoms of traumatic stress have been observed in patients who have chemotherapy or radiotherapy in addition to surgery compared with those having surgery alone (61), although this study did not examine the effect of disease stage independently of treatment received.

Qualitative research on the concerns of Stage II and stage III colorectal cancer survivors who had completed active treatment, found higher distress was associated with treatment-related toxicities such as peripheral neuropathy (numbness/ tingling in the hands and feet), a side-effect of the chemotherapy drug oxaliplatin, and major challenges in daily activities particularly around caring for their colostomy (62). Oxaliplatin causes neuropathy in the majority of patients during the therapy itself, with 12% of patients experiencing persistent neuropathy 4 years after treatment (63). Severe peripheral neuropathy during treatment has been associated with higher rates of depression and anxiety, and poorer sleep quality (64), impacting on people's ability to carry out everyday activities as well as work (65).

A study on symptoms among colorectal cancer patients undergoing chemotherapy, found they

reported an average of ten symptoms, with the most common being peripheral neuropathy (64 %), lack of energy (62 %), feeling drowsy (49 %), and nausea (45 %), with lack of energy being one of the symptoms patients found most distressing (66). In a large sample study of outpatient cancer patients with different types of cancer attending a regional centre in Scotland, clinically relevant fatigue (defined as fatigue worthy of further clinical attention) was reported by 33% of colorectal cancer patients. Across the sample of mixed cancer sites as a whole, both presence of local and distal disease, and receipt of radiotherapy or chemotherapy in the previous two months, were independently associated with a higher likelihood of fatigue, with the majority of respondents not in active treatment (67). Such symptoms can impact patient distress, with this research also showing the presence of fatigue was associated with higher levels of distress (measured by the HADS) (67).

Stage, treatment and quality of life

Quality of life typically comprises the patient's subjective assessment of their physical, functional, psychological, and social wellbeing, and as such overlaps with emotional outcomes and symptoms. Poorer quality of life is often reported among patients with more advanced disease (e.g. (68, 69). While Foster et al (70) found no relationship between disease stage at diagnosis and quality of life, people with advanced disease (stage IV) were excluded from the study.

As with emotional outcomes, trajectories of quality of life in colorectal cancer survivors have been shown to vary across individuals. In a related study to the one reported earlier on trajectories of distress, Dunn et al (69) looked at quality of life over time from 5 months to 5 years post-diagnosis (assessed using the FACT-C, which contains physical, functional, social/family, emotional wellbeing and colorectal cancer specific symptom subscales), and found four different trajectories: constant high quality of life (26.2%), constant medium (47.1%), medium decrease showing dramatic decrease in quality of life two years post-diagnosis (7.4%), and constant low quality of life (19.2%). Again, disease stage, but not treatment received, predicted membership of the quality of life trajectories

'medium decrease' and 'constant low' compared with reference category of 'consistently high' quality of life. Neither disease stage nor treatment received predicted membership of the trajectory 'constant medium' compared with the trajectory of 'constant high' quality of life (69). However other studies show links between specific treatments and their associated sequelae and quality of life.

Treatments such as radiotherapy can increase the risk of bowel and urinary incontinence (71). Patients with diarrhoea have reported poorer quality of life 6 weeks after potential curative surgery for colorectal cancer (72) and in the longer term (56). In a systematic review of quality of life in long-term colorectal cancer survivors (5 or more years post diagnosis) Jansen et al (56) found overall quality of life was comparable with the general population with some evidence of slightly lower physical quality of life in colorectal cancer survivors. However quality of life was lower among patients with bowel problems such as diarrhea (e.g. (73)). Pollack et al (71) looked at patients who had previously taken part in a randomised controlled trial (an average of 15 years ago, to establish whether preoperative radiotherapy reduced local recurrence in rectal cancer patients). They found higher levels of faecal and urinary incontinence and diarrhoea in patients receiving radiation compared to those having surgery alone, although only among patients who had not had a stoma.

One risk factor for non-reversal of temporary stomas is more advanced disease (74). Stoma-related complications, such as leakage, have been reported in over 40% of patients (74, 75); and stomata can have adverse effects on quality of life (56, 70, 76) and impact on the patient's body image and sexual function (77).

Research consistently shows an adverse effect of radiotherapy on long-term bowel and sexual functioning, but evidence concerning the long-term adverse effects of chemotherapy is mixed. For example, Arndt et al (78) found chemotherapy recipients reported poorer role and social functioning 1-3 years post-diagnosis, while others found no association between receipt of chemotherapy and

quality of life (e.g. (79). These differences may be due to the age group being studied as more pronounced deficits are typically observed among younger age groups (e.g. under 70 (80))

Perceived quality of care at the time of cancer treatment (i.e. treatment information problems, problems with the control of nausea and vomiting, and pain and discomfort) has also been shown to predict subsequent quality of life in colorectal cancer patients, controlling for demographic and clinical variables (81) highlighting the importance of patient-centred care during treatment for cancer.

Fear of recurrence, social distress and ability to work

Among colorectal cancer survivors, five or more years post-diagnosis, between one quarter and one third of patients report concerns about recurrence (27-33%), and worry about developing another type of cancer (26-30%); with a higher proportion reporting concerns about symptoms indicating a recurrence (34-41%) and worry about future diagnostic tests (41-44%) (82). In a study conducted in the Netherland, fear of recurrence in colorectal cancer survivors was not associated with disease stage or treatment (83). However it was associated with distress and quality of life, and indirect relationships between disease stage and treatment on fear of recurrence via distress and quality of life are a possibility, and remain to be explored.

Some procedure-related concerns, such as the effects of cancer risk caused by ionising radiation associated with medical imaging, become more apparent in the post-treatment phase, while patients earlier on in the treatment process are more concerned with surviving the initial disease (84). This raises the possibility that an increased number of diagnostic tests may add to the worries patients experience after treatment has ended.

Disease stage at diagnosis and the type of treatment patients receive can also have wider impact. Social distress (indexed by concerns about everyday living, money worries, and concerns about

oneself and other people) 12-36 months after a colorectal cancer diagnosis was higher among people with more advanced disease, those with recurrent or non-treatable disease, patients with a stoma, and among patients who had had radiotherapy (85). Gastrointestinal cancer survivors are more likely to be unemployed than people with no history of the disease (48.8% vs. 33.4%). Reasons given by cancer survivors for unemployment included physical limitations, and/ or cancer-related symptoms (86). In addition, the treatment the patient receives also impacts on the psychological wellbeing of family care-givers, for example Graca-Pereira et al (61) found higher anxiety and traumatic stress among partners of patients who had chemotherapy or radiotherapy in addition to survey vs surgery alone.

Summary

Later disease stage at diagnosis adversely affects emotional and quality of life outcomes in colorectal cancer survivors. Adjuvant treatments, such as radiotherapy and chemotherapy can cause long-term symptoms such as diarrhoea or peripheral neuropathy that can also impact on patient's quality of life and distress. In addition, having a stoma can adversely affect body image, although may reduce rectal symptoms, leaving the overall effect of having on stoma on quality of life unclear. Although associations between diagnostic delay and disease stage at diagnosis remain unclear, with more convincing associations for rectal compared with colon cancer (87), it remains a possibility that a delay in diagnosis of colorectal cancer may result in more advanced disease and the need for adjuvant treatments, both of which adversely affect people's emotional and physical wellbeing for years after the initial diagnosis.

Conclusion

Undergoing investigations for cancer can be stressful, and rates of distress and poor quality of life among patients with suspected cancer are the same as those with a confirmed diagnosis. Rapid diagnostic pathways will reduce the period of distress for people eventually diagnosed with benign disease, and may also benefit people ultimately diagnosed with cancer, although further research is

needed to confirm this. However, patients who experience diagnostic delay do not simply wait longer for a diagnosis, they also have a higher number of consultations and medical tests and are more likely to experience substandard quality care, which impacts on patient satisfaction. The psychological consequences of these experiences have been underexplored, and research into which sectors of the population are most vulnerable to adverse outcomes arising from delay is also lacking.

Priority areas for future research are summarised in Table 2.

Table 2 Priority areas for future research

Suggested priority of further research on psychological aspects of diagnostic delay in CRC
The impact of rapid diagnostic pathways on psychological wellbeing among people diagnosed with colorectal cancer
Better understanding of patients' views about the relative importance of time to diagnosis versus quality of care.
Effect of particular experiences associated with diagnostic delay, such as number of investigations and consultations, as well as medical errors, and not just time to diagnosis, on psychological wellbeing and quality of life.
The role of demographic and psychological factors in vulnerability to distress in the diagnostic phase, such as age, gender, socio-economic status, history of mental illness and intolerance of uncertainty.
The impact of diagnostic delay on friends and family.

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