

TREATMENT SUMMARY

Implementation of cancer treatment summaries in NHS Ayrshire and Arran

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Abstract

Cancer incidence is increasing year on year; survivorship rates are also increasing, as is the use of novel agents and additional treatment lines. These factors, along with evidence that suggests people are struggling to cope with the long-term effects of their diagnosis and its treatment, suggest we need to transform our approach to care and make better use of primary care, community assets and self-management.

Transforming Care After Treatment (TCAT) was launched in 2013. A partnership between the Scottish Government, Macmillan Cancer Support, NHS Scotland and local authorities, it is intended to support and enable cancer survivors to live as healthy a life as possible for as long as possible.

NHS Ayrshire and Arran worked with local patients and other partners to develop an action plan to meet TCAT's aims. In 2014, the TCAT team began to introduce initiatives that would support holistic care throughout the extended cancer pathway. One such initiative was a treatment summary. The approach to its implementation and patients' and GPs' perspectives of its initial effect are outlined in this paper.

Keywords

cancer, follow-up, late effects, primary care, supported self-management, survivorship, Transforming Care After Treatment, treatment summary

Background

The world of cancer has changed. Earlier detection and better treatment outcomes means that more people are surviving cancer. However, despite living longer, people are not necessarily living well (Macmillan Cancer Support 2014a). Many survivors experience ongoing and late effects of cancer and its treatment. These effects can manifest as physical or psychosocial problems, and they can have a profound effect on the quality of life (Langendijk et al 2008, Macmillan Cancer Support 2013, DeSantis et al 2014). Cancer incidence is also increasing year on year – in 2013, 32,000 people were diagnosed with cancer in Scotland, a 12% increase in incidence over ten years, and should this trend continue, 40,000 people will be diagnosed with cancer in 2027 (Scottish Government 2016a). In addition, new treatments have been introduced, the use of systemic anti-cancer therapy is increasing year on year (National Chemotherapy Board 2016), people are undergoing second-, third- and even seventh-line treatments (National Confidential Enquiry into Patient Outcome and Death 2008), and more than 70% of people with a

cancer diagnosis also have at least one other condition (Barnett et al 2012). Together, this results in increased complexity, which requires additional medical resources.

As such, cancer services must transform their approach to care. Long-term follow-up must be carried out in primary care. Only this shift will allow oncologists to see those with new diagnoses, those undergoing active treatment and those with complex needs (Merport et al 2012). However, primary care services and the patients themselves must also be better equipped to deal with the ongoing and late effects of cancer, and therefore minimise the effects on their quality of life.

The Transforming Care After Treatment (TCAT) programme is a partnership between the Scottish Government, Macmillan Cancer Support, NHS Scotland and local authorities that supports a redesign of care following active treatment of cancer. The five-year programme was launched in 2013, and is intended to support and enable cancer survivors to live as healthy a life as possible for as long as possible.

To support transformational change in cancer services, a call for funding was

released before TCAT's official launch. Teams were invited to submit proposals that would demonstrate a move towards person-centred, high-quality care, while reducing unnecessary follow-up and better supporting people affected by cancer. NHS Ayrshire and Arran worked with local patients and other partners to develop an application that would meet these aims by redesigning and co-producing cancer services. The proposal was accepted and in 2014, the TCAT team began to introduce several initiatives that would support holistic care throughout the extended cancer pathway.

One such initiative was the introduction of a treatment summary. A scoping exercise carried out by Macmillan Cancer Support in 2010 revealed GPs received considerable information from secondary care, but lacked a simple summary of their patients' cancer diagnoses, treatment and ongoing management plans (Macmillan Cancer Support 2014b). It also found that discharge and clinic letters were often missing vital information, and their formats did not allow people to self-manage or be fully managed effectively in the community. As a result, patients were experiencing unnecessary delays and many were being needlessly referred to secondary care (Macmillan Cancer Support 2014b). More recently, other practitioners, including practice nurses and link workers, have taken on tasks in primary care, increasing the likelihood of their interacting with a patient diagnosed with cancer. This provides further rationale for a summary of treatment that is easy to read and understand.

To solve these problems, a group of Macmillan GP advisers came together and identified information that would be helpful for primary care following the treatment of an individual for cancer. The group then created a treatment summary template, which was tested, evaluated, refined and tested again, resulting in a final template being produced and advocated for use through the National Cancer Survivorship Initiative.

The final template gives an overview of:

- » The patient's diagnosis and cancer staging.
- » Whether they have been treated with curative or palliative intent.
- » Treatment to date.
- » Side effects of treatment.
- » Potential signs and symptoms of a recurrence.
- » Any actions agreed through holistic needs assessment and care planning.

As implied by the history of its development, the aim of the treatment summary is to:

- » Improve communication between primary and secondary care professionals.
- » Support self-management.
- » Enhance outcomes (Macmillan Cancer Support 2014b).

Since its inception, there has been a move to embed the use of the treatment summary in clinical pathways; however, progress has been slow and application piecemeal. Despite this, the reason for its development and introduction remains, and there are increasing calls for its widespread implementation – prime examples being the Scottish Government's cancer strategy (Scottish Government 2016a), which mandates that 'all patients should receive a treatment summary', and NHS England (2016). Site-specific multidisciplinary team guidance, such as Dempsey et al (2016), also advocates the use of treatment summaries to support continuing care, minimise feelings of abandonment, ensure effective communication and ease transition across care sectors.

Methodology

Local implementation

NHS Ayrshire and Arran's engagement in the TCAT programme resulted in head and neck cancer clinical nurse specialists (CNS) adopting the treatment summary template in 2014, colorectal CNSs joining them in 2015. They used improvement methodology to support the introduction of the treatment summary. They started with one patient, reviewing the content to ensure the language used during the completion of the template was appropriate and understandable. They also addressed the treatment summary to GPs, and once they had determined language and usefulness, they



FAST FACTS

70%

of people with cancer have one other condition

LONG-TERM

follow-up must be carried out in primary care

12%

increase in cancer diagnosis in Scotland in ten years

worked towards its routine use by copying it to patients. Later, they changed the approach altogether, addressing the treatment summary to the patient and copying it to the GP.

Initially – and this still remains true in some specialities – the CNS typed the treatment summary. Later, to support the administrative process and limit the effect on clinical time, the template was uploaded as a digital template. This enables CNSs to dictate the treatment summary for typing and processing by administrators.

Each treatment summary continues to be written specifically for each patient and it is copied to the patient's GP. It was hoped that this change in focus, moving away from traditional clinic letters that are copied to patients, would help to place patients at the centre of their care. It was also envisaged that this shift would empower patients to take control of their own health and support them to make informed decisions now and in the future.

However, for this to be successfully achieved, the language used to complete the summary was of paramount importance. The language and processes in health and social care can be difficult to understand, and can affect patients' confidence and ability to participate in their own care (Scottish Government 2014). When a patient is faced with challenging and stressful situations, such as a cancer diagnosis or transition through care sectors, these challenges can be further heightened.

Therefore, actions must be taken to support health literacy and enable the treatment summary to fulfil its goal. For example, staff completing the evaluation summary should use simple language and minimise the use of jargon. The content of the treatment summary should also be explained during the consultation and techniques such as 'teach-back' and 'chunk and check' can be used to confirm understanding and reinforce important messages and information (Scottish Government 2014).

The language used was also discussed with clinical teams during local implementation, as terminology brought concerns. For example, the perceived black and white nature of the field in the treatment summary concerning whether a patient has been treated with curative or palliative intent led to patients asking questions about their life-expectancy and the nature of their prognosis. Details about staging also worried some patients. However, the completion of these fields is vital not only for GPs who are being asked about travel insurance, palliative care registers and

benefit forms, but for the creation of informed and empowered patients. It is believed these concerns can be addressed through open and honest discussion with patients when their treatment summaries are being completed.

To further support self-management, the outcome of a holistic needs assessment and care plan at the end of treatment is incorporated into the treatment summary. This not only reiterates to patients the actions that have been agreed, it also highlights what they must take forward and communicates to the GP what support services have been instigated. It also highlights any psychological and practical issues that may not usually be acknowledged through routine health sector correspondence.

Evidencing effects

All head and neck cancer patients ($n=21$) and their corresponding GPs ($n=19$) who had received a treatment summary between January and August 2015 were sent a questionnaire in September 2015. The purpose of the questionnaire was to ascertain their views on the acceptability and usefulness of the treatment summary so local teams could make planned and informed decisions about the implementation of treatment summaries across NHS Ayrshire and Arran. To maximise response rates, GPs were sent an electronic questionnaire and patients were sent a paper copy by post with a stamped addressed envelope for return.

A more detailed project evaluation was also carried out to determine the effect of NHS Ayrshire and Arran's wider TCAT project. Part of this evaluation involved a postal questionnaire and stamped addressed return envelope being sent to the 25 patients who were diagnosed with a colorectal cancer and received a treatment summary between July 2015 and March 2016. As well as general questions about support needs and use of services, the questionnaire asked patients whether they received a treatment summary and, if so, whether they discussed the contents of the summary with their GPs or practice nurses.

All questionnaires were anonymous and completion was entirely voluntary.

Results

The small sample size and qualitative nature of the work carried out meant only basic frequencies could be calculated.

Head and neck cancer GP results

Six GPs (31%) responded. Five commented that the treatment summary aided discussion

with patients, and helped with the completion of insurance forms, key information summaries and anticipatory care plans. Respondents also reported that:

- » The treatment summary supported decisions about the patient's condition, care or management ($n=2$).
- » Helped the respondent to understand the patient's diagnosis, treatment and ongoing needs ($n=3$).
- » Improved communication with the patient ($n=2$).

One respondent highlighted a benefit of the treatment summary – it pulls together key information into one short summary: 'I have 33 bits of paper about this (on top of another ten or so about other things since the diagnosis). Primary care is drowning in secondary care overflow.'

Head and neck cancer patient results

The respondents (14%, $n=3$) said they found the treatment summary easy to understand; all had discussed their summaries with their GPs or practice nurses. One respondent believed the treatment summary enabled them to understand the ongoing effects of radiotherapy and all three respondents were encouraged to take actions that supported their ongoing health and well-being, such as accessing services, maintaining a healthy weight and exercising despite fatigue.

Some respondents provided additional comments that further supported the use of treatment summaries:

Patient one: 'My GP and I have discussed various aspects of the end of treatment summary.'

Patient two: 'Found the summary very informative and helpful in my recovery.'

Patient three: 'The summary reminded me that my good lifestyle habits have in fact benefitted me both physically and mentally. [The CNS] encouraged me to open up about my cancer experience.'

Colorectal cancer patient results

In total, 14 patients (56%) responded to the questionnaire; 13 recalled receiving a treatment summary; eight had discussed their treatment summaries with their GPs or practice nurses; five indicated that they had not.

Conclusion

The small sample size from each clinical group is a limitation of this evaluation. However, NHS Ayrshire and Arran's TCAT team is encouraged by the positive responses received from patients and GPs. Further assurance

comes from published studies that investigated the effects of treatment summaries and revealed similar findings (Blinder et al 2013, Macmillan Cancer Support 2014b).

As a result, the TCAT team is confident that the treatment summary is a useful tool that can help to improve communication, empower patients and lead to better care at the end of treatment.

Although the Scottish Cancer Patient Experience Survey (CPES) (Scottish Government 2016b) revealed that 94% of respondents had a good overall experience, there were some areas identified where improvements could be made, such as 'access to wider support' and 'care planning'. The latter is particularly significant, given that statistically, those with a care plan responded more positively than those without (only 22% of patients reported having a care plan in the CPES). Many CPES participants did not feel confident in their ability to self-manage after treatment. Participants described confusion over responsibilities for care, and a lack of understanding over who they should contact for ongoing support, and what should happen next as a result of poor communication.

This was frightening and caused anxiety and isolation. Debilitating side effects as result of treatment also left many struggling to manage physically and emotionally at home. Many participants reported no help or advice about self-care and side effect management following discharge from hospital without a care plan, noting there was no point of contact for their care after treatment had ended (Scottish Government 2016c). However, patients particularly appreciated information that was sensitively provided and gave them a clear idea of what to expect.

These findings provide further justification for a treatment summary that clearly and simply details what has been, will be and/or could be, and where information and support can be sought. Adding outcomes of the assessment of holistic needs and the resulting care plan would further augment this.

These collective findings and recommendations mean the treatment summary continues to be used as standard in head and neck and colorectal pathways across NHS Ayrshire and Arran, with no changes made to the original content of the template. Language and approach have developed over time as users have become more confident with the tool and the positive response from patients became evident. Team members' initial concerns about the level of detail in the template and its potential effect on patients

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have also dissipated – this is largely because all written content is skilfully discussed by CNSs and patients during the completion of the summary, thereby ensuring patients understand the content and their concerns are addressed at the earliest opportunity. The treatment summary’s acceptability and usefulness have resulted in its being introduced into gynaecological cancer pathways; there are also discussions about whether it should be implemented in haematological and breast cancer pathways.

Regional or national collaboration between experts in each tumour site could enable the most common side effects (early and late effects) of common treatment regimens to be tabled; sharing this output could assist in a standardised approach and enable wider implementation of the treatment summary by limiting the time it takes to complete. An electronic template that pulls basic personal

and diagnostic information from other systems and that can be immediately transferred on completion to primary care and other medical systems would further support widespread implementation. However, the integrity and overall purpose of the summary must be maintained through personalisation, clear and concise language, and skilled communication during the template’s completion.

As each tumour site comes on board with the treatment summary, the content and effects of the template will require further evaluation, as one size may not ‘fit all’ – some elements may need to be amended because of the differences in treatment and clinical outcomes expected across the cancer types.

The purpose of the template is to inform and empower individual patients and primary care teams. As such, it must reflect their needs and wishes and not be amended solely by secondary care clinicians.

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