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Integrated care pathways for cancer survivors - a role for Patient-Reported

Outcome Measures and health informatics

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Abstract

Introduction: Modern cancer treatments have improved survival rates and changed the nature of cancer care. The acute and long-term physical and psychosocial comorbidities associated with treatment place increasing demands on healthcare services to provide suitable models of follow-up care for the survivor population. Aim: We discuss the value and challenges of incorporating patient reported outcome measures (PROMs) and eHealth interventions into routine follow-up care. We draw on our 15 years' experience of developing electronic systems for capturing patient reported data in oncology settings, with particular reference to eRAPID a new online symptom reporting system for cancer patients. **The** redesign of healthcare pathways: New stratified care pathways have been proposed for cancer survivors with an emphasis on supported self-management and shared care. The potential role of PROMs in survivorship care pathways: PROMs can be used to evaluate rehabilitation services, provide epidemiological 'Big Data' and screen patients for physical and psychological morbidities to determine the need for further support. In addition, electronic PROMs systems linked to electronic patient records (EPRs) have the capability to provide tailored self-management advice to individual patients. Integration of PROMs into clinical practice: The successful clinical utilisation of PROMs is dependent on a number of components including; choosing appropriate questionnaires, developing evidence-based scoring algorithms, the creation of robust electronic platforms for recording and transferring data into EPRs, and training staff and patients to engage effectively with PROMs. Discussion: There is increasingly positive evidence for using PROMs and eHealth approaches to support cancer patients' care during treatment. Much of what has been learnt can be applied to cancer survivorship. PROMs integrated into eHealth platforms and with EPR have the potential to play a valuable role in the development of appropriate and sustainable long-term follow-up models for cancer survivors.

Introduction

Increasingly successful cancer treatments have led to a dramatic increase in the number of people living with and beyond cancer. Approximately 2 million people in the UK have had a cancer diagnosis at some point in their lives and this is expected to rise to 4 million by 2030 [1]. The term 'cancer survivor' has been defined as '*someone who has completed initial cancer management and has no apparent evidence of active disease, or is living with progressive disease and may be receiving cancer treatment but is not in the terminal phase of illness' [2]. Within this paper, we refer to the more traditional definition of a cancer survivor as someone who has completed treatment and is now receiving follow-up care without evidence of active disease.*

Cancer and its treatments have long-lasting effects, and survivors are at a higher risk for comorbidities and psychosocial problems throughout their lifetime [3]. Cancer survivors are generally monitored for recurrence at hospital-based appointments, the frequency of which is variable, dependant on local practice, disease and treatment. This method of follow-up is neither efficient nor sustainable. Hospital-based routine follow-up appointments put an increasing burden on already stretched healthcare services, and are not set up to address the complex needs of cancer survivors. The focus is on detecting recurrence, with little time or opportunity for oncologists to provide the desired support, or make appropriate referrals to specialist services. In addition, multidisciplinary teams are rarely established to deal with the broad range of medical, psychological and social problems experienced. General Practitioners (GPs) are accessed for general healthcare, but they also report not feeling equipped to deal with the complex issues of cancer survivors. There is often a lack of clarity on the roles of the different healthcare providers and the patient in monitoring health [4].

Recent initiatives are focussing on improving outcomes for people living with and beyond cancer by moving towards care pathways with a more patient-centred approach and an emphasis on quality of life, rather than survival alone, by encouraging self-management with

appropriate risk stratification and interventions to support rehabilitation back into an active life [2, 5].

Aims

The aim of this paper is to discuss the potential use of patient reported outcome measures (PROMs) in future care pathways for cancer survivors. We outline; 1) The redesign of future care pathways for cancer survivors, 2) the potential role of (PROMs) in facilitating and structuring these care pathways and the need to develop an integrated health informatics system to support this. 3) The main considerations integrating PROMs into clinical practice, drawing on existing literature and evidence from our 15 years of experience using PROMs with patients on active treatment where we have moved towards the online collection of PROMs and integrating this data into electronic medical records. 4) The significant challenges of implementing such a large-scale infrastructure are discussed.

The redesign of healthcare pathways

In recent years, initiatives have been launched to agree an individualised care plan with patients on completion of primary treatment. These care plans encourage supported self-management where appropriate and the involvement of the multidisciplinary teams needed to address the complex needs of cancer survivors [5]. This approach, although still in the early days of application with cancer patients, has shown benefits with other chronic illness populations including reduced healthcare service use and better reported functional health, improved quality of life and increased patient satisfaction [6].

The National Cancer Survivorship Initiative (NCSI) propose that within this model of care, patients can be stratified into three broad categories for follow-up care, dependent on risk and personal preferences. 1) *Supported self-management*: patients are given the knowledge and skills to self-manage, with clear pathways for referral based on self-reports; 2) *Shared*

care: the patient has regular contact with healthcare professionals and both are responsible for the monitoring of physical and psychosocial effects and 3) *Complex case management*: the patient requires intensive support from healthcare services to meet their needs. PROMs are of particular relevance for supported self-management but have other potential uses in survivorship care pathways.

The potential role of PROMs in survivorship care pathways

Patient reported outcome measures are defined as 'any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else.' [7]. PROMs may potentially facilitate new pathways for survivor care in three ways:

Screening

In 2007, the UK National Cancer Survivorship initiative proposed that PROMs should be routinely used in addition to blood tests and imaging for stratified risk assessment to determine when re-assessment or additional support is needed [8]. In 2014, the American Society of Clinical Oncology (ASCO) recommended that all cancer survivors should be screened for fatigue, anxiety and depression at periodic intervals throughout the cancer journey and throughout their lifetime [9, 10].

Evaluation of rehabilitation interventions

In the same way that PROMs are now routinely collected in clinical trials to evaluate treatment efficacy, PROMs are used to evaluate rehabilitation interventions for cancer survivors. Interventions promoting physical activity have demonstrated increases in health-related quality of life and are an important part of supported self-management [11].

Epidemiology or "Big Data"

Large-scale collection of PROMs data in routine practice or epidemiological studies can identify issues which are important to different groups of cancer survivors [12, 13], particularly when comparison data is available for matched non-cancer samples [14]. In 2014 Macmillan published the findings of an analysis of linked cancer registry and inpatient Hospital Episode Statistics, from a programme called "Routes to diagnosis" aiming to improve outcomes for cancer survivors by assessing big data to understand variations in survival outcomes, morbidity and cost between patient groups [27]. There are plans to expand on this analysis by including data from other sources and potentially, PROMs could be used to add valuable insight from the patient perspective. The feasibility of this approach has already been proven in the UK and the Netherlands, with studies collecting routine PROMs via the web from cancer survivors and integrating data into national cancer registries [12, 15].

The development of health informatics has made the routine use of PROMs possible. The integration of electronic systems supporting PROMs in the redesign of care pathways is essential to fully exploit the potential of technology in improving cancer survivor care. The integration of PROMs with Electronic Patient Records (EPR) and the provision of advice based on algorithms can facilitate supported self-management. Standardised reporting of the combined data will evaluate late effects of treatments and rehabilitation interventions. Pooled data with cancer registries and the large clinical dataset will incorporate cancer survivors' perspectives into big data.

Integration of PROMs into clinical practice

There is growing evidence from randomised clinical trials incorporating PROMs in the routine care of cancer patients during treatment can help identify psychological and physical problems, monitor them over time, facilitate patient-doctor communication and engage

patients in decision-making [16-19]. However, statistically significant results are limited, and effect sizes are generally small to moderate. Heterogeneity between studies makes it difficult to assess the true impact of PROMs as studies differ in their implementation of PROMs interventions, and the outcomes measured [20].

There is little evidence of the benefits of using PROMs in follow-up care for cancer survivors due to the paucity of quality studies [21], however early research suggests that alternative methods to traditional hospital-based care such as telephone-based or nurse-led or GP led care are acceptable to patients and do not compromise safety or quality of life [22, 23]. This approach can be extended to follow-up care utilising PROMs in redesigned care pathways. However, the introduction of new care pathways is a complex healthcare innovation requiring a whole system approach [24] with careful planning, design and the successful implementation of a number of essential components (see Table 1). This is an iterative process and a flexible approach is needed to adapt to specific challenges which may arise [25].

We discuss these points within the scope of our experience integrating electronic PROMs into clinical care for patients receiving cancer treatment, particularly in the context of eRAPID programme, a complex intervention designed using the whole system perspective.

"Electronic patient self-Reporting of Adverse-events: Patient Information and aDvice" (eRAPID)

The Psychosocial Oncology and Clinical Practice Research Group at the University of Leeds and St James's Institute of Oncology have developed eRAPID - an online system for patients to report adverse events during and after cancer treatment [26]. Patients can log into the online system from home and answer questions about their current symptoms. When patients report mild problems, they receive automated self-management advice. When patients report serious symptoms, they are asked to contact the hospital and an immediate alert is sent to a member of the hospital medical team. All patient reported data is transferred in real-time to individual electronic records in the hospital. Figure 1 illustrates the process of eRAPID data. eRAPID is being evaluated in a randomised trial in patients receiving systemic cancer treatment.

In a usability study prior to the trial, we invited patients receiving chemotherapy for early breast cancer to help us test the system in real life (see Table 2). 12 patients used the eRAPID system to complete weekly PROMs during four cycles of chemotherapy. 2 Clinical Nurse Specialists (CNSs) and 8 doctors used the PROMs data in consultations. Feedback from patients and staff was invited and information on any triggered alerts was collated. Below, we discuss the findings in the context of the components outlined in Table 1.

Choosing questionnaires

When selecting PROMs, it is important to consider the goals of data collection. The purpose of PROMs in eRAPID is to assess symptoms and side effects of cancer treatment and therefore we decided to use the Common Terminology Criteria for Adverse Events (CTCAE) [27], reworded into language suitable for patient self-report [28]. Clinicians are already familiar with these items, and have established management strategies for most side effects.

For cancer survivors, a broad range of measures could potentially be collected but it is important not to cause overburden with long and cumbersome questionnaires. Early involvement of all stakeholders is required to determine what measures should be used, at what time, and for what purpose. Technological advances have the advantage of facilitating a screening technique to determine if more in-depth assessment may be beneficial. For example, the ASCO guidelines on screening for anxiety and depression recommend just two items from the Personal Health Questionnaire are used to initially screen for issues. Dependent on the patient's answers, the full questionnaire can be administered, or no further assessment may be deemed necessary at that time [10].

Evidence-based clinical algorithms

We have developed clinical algorithms for eRAPID which provide tailored automated selfmanagement advice for lower-level treatment side effects, and an alert to the hospital (and advice for the patient to contact the hospital) for more severe side effects. The algorithms are based on established CTCAE grading criteria and guidelines developed by the UK Oncology Nursing Society [29]. These algorithms were reviewed by senior consultants in the relevant disease groups, and will be evaluated during the RCT by assessing patient safety through processes of care and improvements in quality of life.

In order to facilitate supported self-management for cancer survivors, evidence-based clinical algorithms are needed to determine what action needs to be taken, e.g. self-management advice, a referral to primary or oncology care, a referral to specialist services or a rehabilitation intervention. Clinical algorithms for survivorship care will require extensive consideration from multidisciplinary teams, and continuous evaluation of safety and effectiveness. However, the large scale collection of PROMs data can make significant contributions to these evaluations and inform future algorithms.

The electronic platform (infrastructure)

QTool is an online questionnaire management system that was developed for the University of Leeds. In an earlier study called ePOCS, QTool was used to remotely collect PROMs from cancer survivors at 3 different time points and integrate this data into national cancer registries [30]. For eRAPID, we have integrated QTool with the local EPR in Leeds, and patients PROMs data can be transferred in real-time and displayed to clinicians in tabular or graphical form. This innovative solution allows patients to complete the web-based QTool questionnaire from home, and results are immediately available to their clinicians to support care, as illustrated in Figure 1. Within QTool, patients can also view graphs depicting their longitudinal symptom scores. Ideally for cancer survivors, PROMs should be integrated with

electronic records held in both hospital and primary care, though the challenges associated with integrating IT systems in community settings are well recognised [31].

There is a current global drive, particularly in the UK, for the redesign of healthcare systems and care pathways to integrate new eHealth solutions. These include Telehealth, the development of new technologies which remotely monitor patients physiological measures such as bloods, and Telecare, the development of technologies to remotely monitor patients in their homes through the use of sensors and an alert system to increase patient safety [32]. These approaches can be adapted to support cancer survivors.

Training and engagement of patients

During the eRAPID usability study, we worked closely with participating patients to learn from their experiences. We interviewed patients at the end of the testing to explore their views of the system and reasons for compliance/non-compliance. The main findings are summarised in Table 3.

Patients reported the self-management advice as a motivator for regular completion. In our previous work, we found that cancer patients are not always confident making decisions about when to contact the hospital for advice on treatment side-effects [33]. Patients on follow-up are likely to experience similar feelings and worry about wasting clinicians' time, and may appreciate clear guidelines on contact and the support to self-manage when possible.

Patients reported that the graphs depicting symptom scores over time was another motivation to complete PROMs regularly. There is an emerging literature on patient engagement with technology called 'the quantified self', which is particularly relevant for health applications where symptoms or health behaviours can be monitored over time [34]. Research has shown that while many patients can accurately interpret graphically presented

quality of life data, this may be more difficult for older and less-educated patients [35], and therefore it is important to facilitate other options for data presentation where possible.

In concordance with the findings of Judson et al (2013) [36] the most commonly reported reason for non-compliance was simply forgetting to complete the questionnaire. Patients favoured having a reminder system using automated e-mails or text messages. In the ePOCS study [12], this method of reminders proved effective and acceptable to survivors on follow-up.

In the UK, a qualitative study explored reasons patients declined or withdrew from the whole system demonstrator eHealth programmes. Reasons included misunderstandings or worries about the level of technical expertise needed, concerns about technologies leading to a disruption or replacement of normal health services, and concerns that the interventions could undermine their own coping strategies [37]. In the ePOCS study, participation was higher if patients were approached face-to-face than if by telephone or letter, suggesting that some patients concerns can be alleviated through direct interactions where the purpose and scope of PROMs completion can be explained [12].

Training and engagement of clinicians

Previous work by our research group has shown that regularly assessing and feeding back PROMs to physicians enhanced patient-doctor communication and led to improvements in patient well-being [18]. However, although PROM feedback to clinician's increased discussion of symptoms such as pain and nausea, physicians did not often specifically refer to PROMs during the consultations [38] and more complex psychosocial needs were ignored, even when severe problems were reported.

In order to ensure effective use of PROMs data by oncologists, we developed an interactive small group training session, based on communication skills training. DVD scenarios with

real doctors and patient actors were used to facilitate discussion of different ways of integrating the information into the consultation and strategies for managing multiple issues and complex problems. Brief, one-page guidelines were developed for oncologists on dealing with emotional distress, with screening suggestions and practical information on referrals [39]. The training package and guidelines were evaluated in a pilot study (see Table 2). Preliminary results suggest the training package was effective. In post training consultations doctors explicitly referred to the PROMs data more often (48.4% vs 76.7%) and there was more frequent discussion of physical function and pain [40]. These findings are helping to guide the development of the eRAPID staff training package.

Worries about time, overburdening and a lack of guidance in responding to problems without a clear management strategy are potential barriers for clinicians in using PROMs in oncology clinical care [41]. While our previous work has suggested that integrating PROMs into clinical care does not necessarily increase the length of consultations [17], the time pressures and workloads of healthcare staff must be acknowledged and considered in any training.

Evaluation of cost-effectiveness and implementation strategies

Providing evidence on the effectiveness and costs of new healthcare interventions is essential in today's healthcare environment, but equally important is to start planning implementation strategies alongside the evaluations. In the eRAPID programme, a traditional randomised trial is planned evaluating benefits for: patients, professionals and cost-effectiveness. In parallel, we are working with oncologists and nurses to support small pilot projects that use the eRAPID approach in clinical practice. For example, a pilot study in a nurse-led outpatient clinic for early prostate cancer patients on hormonotherapy or surveillance, N = 136 patients were invited via posted clinic letters to complete an online Distress Thermometer and discuss it with the nurse. Although the intervention was not maintained beyond the pilot phase, an audit of patient and staff perspectives after 6 months provided valuable lessons for future implementation of online PROMs. The intervention was

notably more successful when there was a clinical champion within the team supporting both staff and patients. In addition, sustainability beyond the pilot phase was hindered by a lack of wider organisational change to allow for ongoing implementation.

However, traditional experimental methods (such as randomised trials) are resource intensive and not always well suited to healthcare interventions. To evaluate re-designed pathways for supporting cancer survivors quasi-experimental designs, such as observational or quality improvement methods, may be more appropriate. Quality improvement methods make small, incremental changes and evaluate and modify the intervention based on outcomes along the way. They often employ qualitative assessments and are good for engaging stakeholders throughout the evaluation, leading more naturally to a wider implementation [42, 43].

Discussion

There is a growing body of positive evidence and experience from using PROMs and eHealth approaches to support cancer patient care during treatment. Much of what has been learnt can be applied to cancer survivors to enable them to self-manage the consequences of the disease and treatment and return to normal life [44].

PROMs integrated in eHealth platforms and with EPR have the potential to play a valuable role in the development of appropriate and sustainable long-term follow-up models for cancer survivors. Carefully selected PROMs can be used for initial assessment of cancer survivors at the end of their treatment to inform the individualised care plan, help with risk-stratification, and allocation to the appropriate care pathway (self-management, shared care or complex case management). Later, during follow-up stages, survivors can be invited to complete PROMs to monitor problems, often alongside blood tests (tumour markers). Support for self-management can be provided by offering specific semi-automated advice, based on PROMs scores linked to validated clinical algorithms. Such algorithms can direct survivors with persistent low-level problems to available self-help or community services

(psycho-social counselling, voluntary sector services, self-help groups). If new and/or serious problems are highlighted by PROMs, survivors can be directed to community or hospital-based medical review.

Further development and research will be necessary before this vision becomes a reality.

From a clinical perspective, specific criteria for risk stratification and recommendations for follow-up monitoring (routine imaging, tumour markers, worrying symptoms) must be defined for at least the common cancers. These will form the basis of the clinical algorithms guiding care pathways. Producing evidence-based and consensus guidelines for cancer survivors (such as the American Cancer Society Prostate Cancer Survivorship Care Guidelines) are the first steps in this direction, but they need to be adapted to local health care settings and organisations [45].

Health informatics and eHealth underpins this vision for cancer survivor care pathways. Although some IT platforms linking online PROMs with EPR in primary and secondary care exist, they are usually limited to local pockets of excellence, and are not widely available. Significant issues remain around implementing health informatics infrastructure relating to achieving integration without compromising the security of clinical databases, and the ongoing discussions on ethical challenges of sharing personal health data.

However, the biggest challenge to healthcare systems and professionals will be the need to re-organise the existing structures and create new ways to integrate working practices across hospitals and community services, and with empowered cancer survivors. Multidisciplinary teams with special skills in supporting cancer survivors and working across different health sectors have to be created to develop sustainable and cost-effective supporting services.

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Tables and Figure

Table 1 - Essential components for the introduction of PROMs into new care pathwaysEssential components for introducing new care pathways for cancer survivors

- Choosing validated, brief questionnaires to screen for common problems.
- Developing evidence-based clinical algorithms, using the questionnaires results and disease-specific markers that direct the survivors to suitable self-management advice, to potential supportive interventions or to a medical review (nurse-led, GP or oncologist).
- Introducing an electronic platform for remote patient reporting and integrating selfreports with the Electronic Medical Records in the hospital and primary care.
- Training and engaging survivors to use the new approach.
- Training and engaging clinicians how to interpret the PRO results and how act on them.
- Evaluation of cost-effectiveness and implementation strategies for the new care pathways, taking into consideration local procedures and involving clinicians and managers throughout the process.

erapid usability testing pilot	Dr. Training phot study	
Aims: To evaluate and improve how the	Aims: To assess the impact of an interactive	
eRAPID system could potentially work with	training programme (using DVD scenarios of	
real patients and oncology staff in a clinic	simulated consultations) developed to assist	
setting, in order to inform future	oncologists to interpret and respond to	
implementation in an RCT.	issues raised by PROMs.	
Methods: Patients were asked to complete	Methods: The training package and	
the remote eRAPID questionnaire weekly	guidelines were evaluated using a before-	
over 4 cycles of treatment (approx12-15	after design with 3 oncologists and 10	
weeks).	patients per doctor recruited before and after	
Clinicians were asked to review patient	training. Consultations were audio-recorded	
reports in the EPR when seeing patients	and coded to analyse discussion of	
prior to treatment.	symptoms and functions.	
Participants: Patients receiving adjuvant	Participants: Patients undergoing	
systemic treatment for early breast cancer.	chemotherapy for advanced cancer from	
	breast, colorectal and gynaecological cancer	
	clinics.	
Results:	Results:	
• 10 clinicians (2 nurses and 8 doctors)	The patient reported data was	
used the system over 12 weeks.	explicitly referred to more frequently	
Patients found the system easy to	in post training consultations	
use and 42% (5/12) of patients	Physical function and pain were	
completed the QTool questionnaire	discussed more frequently post	
11-13 times over their 4 cycles of	training	
chemotherapy. 33% (4/12) of patients	Doctors responded to severe	
completed 7-9 times and 25% (3/12)	amational distroga DDOMa agarag by	
	emotional distress PROMS scores by	

Table 2 – Overview of eRAPID usability testing pilot and Dr. Training pilot study eBAPID usability testing pilot

completed 4-6 times.	initiating discussions
Feedback about the usability of the	• The training was well received by
system was positive. However, the	staff
perceived usefulness of data was	
dependent on how often the patient	
completed reports, and clinicians	
varied in the extent to which they	
discussed results with patients.	
Main outcomes: We identified key points for	Main outcomes: More intensive and
patient and staff training for the RCT.	interactive training appears to be beneficial
	in assisting staff utilise PROMs in clinical
	practice. Sustainable training methods are
	needed e.g. online resources/training
	modules

Motivators for compliance		Patient quotes
Self-	Patients received advice for	'It gave really good information. I used it
management	managing low-level symptoms	because I had a sore mouth and there
advice	and many of them reported that	were some very good hints there about
	they utilised this and found it	various things Nausea was really bad in
	very helpful.	my first cycle so I spent a long time
		looking at the suggestions for that'
	Patients also liked the specific	
	advice on whether or not they	'I think if you're feeling a bit unwell and
	needed to contact the hospital.	unsure about something, and just, 'do I
		need to say?' That really does help
		because it will say to you whether it's mild
		or whatever, or you need to ring rather
		than either sitting there worrying or
		constantly ringing somebody'
Graphical	After questionnaire completion,	'I thought the graphs were great. It's nice
record of	eRAPID patients were shown a	to have that visual look at where you're
longitudinal	graph illustrating the changes in	at. And partly that was why I did it more
symptom	their symptoms over time. They	frequently as well. I wanted to see things
scores	could also access this graph at	coming down'
	any time from the homepage.	
	Some of the patients particularly	'You do get quite down, but then when
	liked this feature and felt that	you look at the graphs, you can think, 'but
	having a visual representation of	I did get better in week 3, and my mouth
	their symptoms was a	has got better, and my diarrhoea has

Table 3 – Patient motivations for compliance and reasons for non-compliance during eRAPID usability testing

	motivation to complete regularly.	stopped' and you can see that there is a
		pattern and that it will get better'
Reasons for r	ion-compliance	Patient quotes
Forgetting to	The most common reason	'I suppose you could trigger the e-mail
complete	patients gave for not completing	reminder probably, we do check e-mails
	regularly, was that they forgot.	and thenit's a reminder it's not a
	We did not have a reminder	great pressure but it would be more
	system in place for this study.	useful, because I must admit, time flies by
		– or a text alert, that might be easier'
Unclear on	Some patients were not initially	'I didn't know I had to do it every week,
how often to	clear on how often they should	that's another thing. You probably told
complete	be completing the questionnaire.	me, but because of everything else that
		was going on'



