Chapter 10

Breaking the Silos: Integrated Care for Cancer *and* Chronic Conditions

Lauren J. Cortis, Paul R. Ward, Ross A. McKinnon and Bogda Koczwara

Abstract People with cancer and a chronic condition have complex care needs that require input from multiple care providers in a variety of settings. Delivering these different aspects of care in isolation can give rise to fragmentations of care, experienced by patients as a disjointed and cumbersome care experience and by clinicians as gaps in communication and information flow. Fragmented care contributes to an ineffectiveness, inequality, inefficiency and higher cost of care. Reducing fragmentation through better care integration is thus a key health care priority for patients, health care providers and payers. This chapter reviews existing strategies to improve integration of care and reduce fragmentation and their respective strengths and limitations and argues further work is needed in developing novel models of care that support efficient and effective integration of care for patients with chronic conditions and cancer.

Keywords Integration · Team based care · Continuity of care · Health system design · Multidisciplinary care · Coordinated care

Key points

- Health care delivery in cancer and chronic conditions involves different health care providers, settings and health care systems. This increases likelihood of fragmentation which contributes to ineffectiveness, inequality, inefficiency and increased costs of care delivery.
- While a multidisciplinary care approach is designed to ensure input of multiple providers into cancer care planning, its application is frequently limited to cancer specific issues.

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- Integrated care offers an attractive conceptual model to deliver seamless care but there has been little empirical application of this approach in the cancer setting.
- There are multiple barriers to greater integration of care of cancer and chronic conditions, including lack of awareness of the problem, lack of common language and lack of system integration.

10.1 Introduction

Cancer is a complex condition which usually requires the input of multiple care providers in order to meet a patient's cancer-related needs. In cancer services, this team of provides is commonly known as the multidisciplinary team (MDT) (Fig. 10.1). People living with chronic conditions *and* cancer also have care needs that extend beyond cancer and its management, including concerns relating to management of non-cancer conditions and their interaction with cancer and its treatment. These needs are dynamic, varying in nature and intensity across time. Meeting these needs is unlikely to be achieved by the cancer MDT alone, rather it requires coordination across the healthcare workforce, incorporating of a broad collection of care providers spanning disciplines (medical, nursing, allied health), professional approaches (specialist and generalist) and settings of care (primary, secondary, tertiary) (Fig. 10.2). This type of multi-team system of care presents challenges to healthcare systems, care providers, and ultimately the patients themselves [1].

Despite the increasing recognition that contemporary healthcare systems need to enhance their capability for providing chronic care of complex conditions and multimorbidity, most health care systems are designed to meet the needs of people with single disease states in a short term or acute setting [3]. Within health care systems, services are often comprised of different teams, with separate information systems, performance indicators and payment models, contributing to the formation of organizational silos [4]. These silos exist at various levels, ranging from healthcare sectors and institutions to clinical units and individual disciplines. Within teams there is a tendency for attitudes and behaviors to be more homogenous and inwardly focused, giving rise to gaps between groups or teams and at the boundaries of care [5]. These holes may accentuate barriers to inter-professional relationships and information flow [6] which present as fragmentations in care. For the health care system this can result in inefficiency, ineffectiveness and inequality [7]. For clinicians, this can impede clinical decision making and workflow, affecting their ability to understand the patient as a whole and consider whether more aggressive or more conservative approach to management is warranted [8]. Most importantly for the patient, this can result in a disjointed care experience, feeling of "falling through the gaps" [9] and the need for a considerable effort to personally manage their overall care which may be beyond the capabilities of those more vulnerable on the grounds of poor health and/or limited health literacy [10].

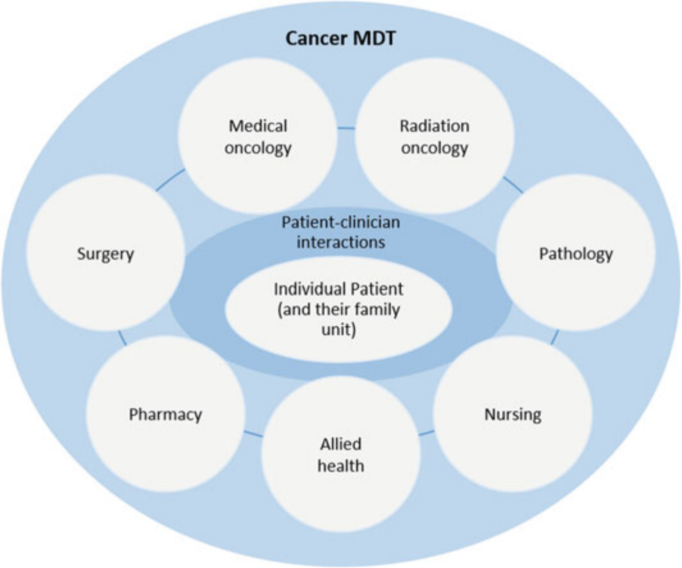

Fig. 10.1 An illustration of a cancer MDT, adapted from Levitt et al. [2] with permission from the National Academies Press, Copyright 2013, National Academy of Sciences

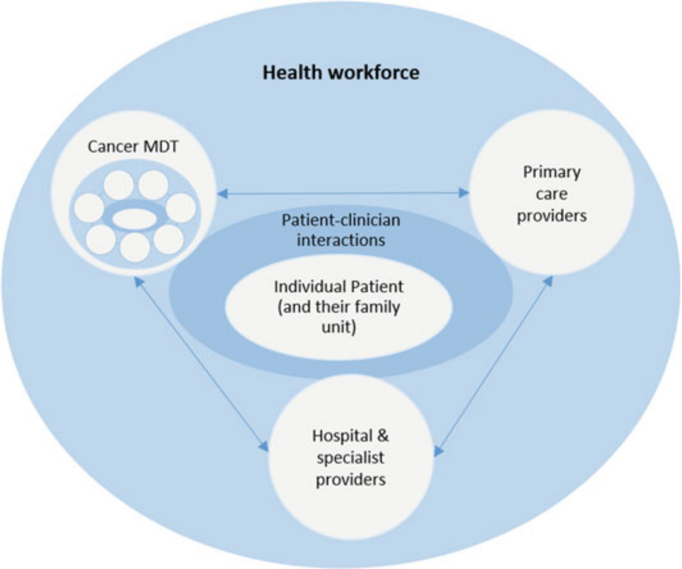

Fig. 10.2 An illustration of a coordinated healthcare workforce, adapted from Levitt et al. [2] with permission from the National Academies Press, Copyright 2013, National Academy of Sciences

Integrated care is an evidence based approach designed to overcome fragmentations of care, in order to improve patients' healthcare experience, care outcomes and to the efficiency of the healthcare system [11]. While integration strategies such as multidisciplinary care, coordinated care and shared care are utilized within the oncology setting, they are usually limited to cancer-related health needs. This can be problematic for patients who have a chronic condition as well as cancer, where it can be difficult to determine what is cancer-related and what is not, creating confusion for patients and care providers alike. Current understanding of the fragmentations of care encountered in the management of such patients is limited, as is the exploration of integrated care as a strategy to improve care at the primary-specialist interface.

In this chapter we will examine the key conceptual elements of integrated care and its relevance to the care of patients with cancer and chronic conditions, how the integration strategies of multidisciplinary care, coordinated care and shared care are applied within the setting of oncology and their respective strengths and limitations. We will then consider barriers to care integration and potential strategies to overcome them, and consider gaps in evidence and future directions for research and practice.

10.2 Increasing Complexity—Increasing Fragmentations in Care

It is hypothesized that healthcare involving multiple providers and organizations results in poor coordination between providers and suboptimal care [12]. While the hypothesis is broadly accepted, it remains largely untested, with limited empirical evidence to support or refute it. The underlying premise supporting the hypothesis is the relationship between complexity and error.

Within a simple system, there are limited points where things can go wrong. For example, if a GP prescribes empiric antibiotic therapy for an uncomplicated urinary tract infection in a young, healthy and independent adult patient, in most circumstances it is expected that this will yield a favourable patient outcome with low likelihood of adverse events. By contrast, in a patient with a history of antibiotic use, other medical conditions, age related organ impairment, concomitant medications and limited understanding of English, what initially appeared as a simple problem becomes a much more complex scenario. One now needs to consider factors such as the possibility of antibiotic resistance, drug interactions, and altered drug clearance as part of the clinical decision making process. All of these factors add to the number of decisions that need to be made and the probability that one of these decisions may lead to an adverse outcome. This does not just occur through errors in judgement, but also due to failures in communication, such as insufficient transfer of critical information between care providers, or patients obtaining insufficient or conflicting information from care providers. While the decisions that clinicians make are connected by a mutual individual patient, they are often made in isolation and reflect the care provider or team's focus on specific aspects of that individual's health.

Within a complex system of issues and providers, it may be unclear which provider is responsible for which aspect of care, such as the continued prescribing and ongoing monitoring of drug therapy. For the patient, not knowing who is responsible for what part of their treatment can create practical challenges as they attempt to coordinate their medication management across their conditions. Lack of clarity in roles and responsibilities can also lead to patient frustration and reduced trust in care providers [12] as well as the need to repetitively provide information to multiple clinicians, which is considered by patients to be disturbing and burdensome [12].

Management of medications can be a useful surrogate marker for the complexity of the health care needs of patients with coexisting cancer and chronic conditions. The total amount of medications used is increasing as the population ages and chronic conditions become more prevalent [13]. In addition to providing therapeutic benefit, multiple medications are important contributors to excessive healthcare costs and patient harm [14]. While it is possible for any patient using one or more medications to experience a preventable medication-related hospital admission, it has been shown to be more likely in patients taking multiple medications [15], as is the case in patients with multiple chronic conditions, including cancer. This issue is particularly challenging in cancer patients, as their cancer medications are often delivered intermittently and thus are not easily identified in their medication supply, and non-cancer health care providers are often unfamiliar with cancer drugs and their side effects.

This is not to say that polypharmacy is the only risk factor for care fragmentation —rather a simple example. In real life, a patient using multiple medications has multiple other care needs and multiple health care providers and information sources, creating a setting for a high risk of fragmentation and concomitant gaps in care.

When considering what fragmentations of care may be encountered, one can review the multiple layers of the environmental context that potentially influence the care of patients with cancer and chronic conditions (Fig. 10.3). Potential sources of fragmentation are present at all levels of the health system, including macro (system), meso (organizational) and micro (clinical). Trying to understand how disjointed healthcare experiences relate to contextual causes, rather than simply identifying that they exist, is necessary to þdevelop targeted integration strategies to improve care outcomes. If we return to the example of medication management, evidence suggests that in patients with breast cancer there is a reduced level of adherence to cardiovascular [16] and diabetes medications [17], beginning in the treatment phase and persisting into survivorship. While this indicates that medication management is not currently optimised across all conditions (i.e. fragmentation exists), it does not tell us how much this is associated with potentially changeable patient behaviour or clinical decision-making (i.e. targets for integration strategies).

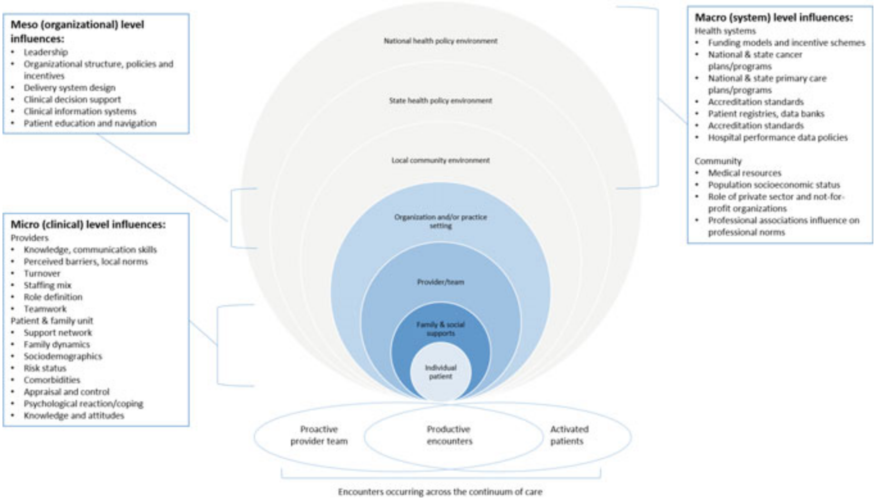

Fig. 10.3 The care of patients with cancer and a chronic condition is influenced by multiple layers. These represent potential sources of fragmentation, and opportunities for integration initiatives, adapted from Taplin and Rodgers [18] by permission of Oxford University Press

10.3 Care Integration—A Solution to Overcome Fragmentation

Integrated care is a conceptual term originating from organizational and systems theory that has been broadly applied in the healthcare literature. While there are in excess of 150 definitions of integrated care, most definitions agree that its key feature is the aim of improving outcomes for a target population through fostering coordination within and between healthcare organizations [11]. As such, integrated care refers to a broad concept that covers a range of approaches, which aim to improve the experience of patients, the outcomes of care and enhance overall efficiency. Integration is a nested concept within integrated care, used to describe the processes and methods that seek to bring about integrated care [11].

It is important to acknowledge that the understanding that an individual has of integrated care at a systems level is shaped by the health system context in which they reside. In the USA and countries with existing integrated care delivery systems, integrated care has come to be somewhat synonymous with full organizational integration and managed care. In this context, integrated care is seen as a structural or environmental concept, while coordination of care relates to practical implementation of interventions to improve patient care. In the UK and countries with a strong primary care system, like Australia, where the GP acts as the gatekeeper to other services and care providers, integrated care may be understood as a system that supports coordinating a patient's overall care, such as care networks and organizations that commission service providers. Across all health care systems, at an individual level, integrated care refers to the ease of addressing individual's diverse health care needs in a seamless fashion.

10.3.1 Dimensions of Integration

In designing an integration strategy, it is useful to consider it across five dimensions:

- Degree of integration (from informal working relationships of providers to coordinated networks, to full system integration)
- Level of the health system (health system, organization, clinical setting)
- Focus (target population)
- Direction (horizontal—affecting organizations at same level and, vertical—affecting organizations at different levels i.e. primary and secondary care)
- Type of intervention involved.

Interventions used to achieve integration may address any of the vast number of sources of fragmentation (Fig. 10.3). These include system redesign, including alignment of policies and governance and operational support systems to facilitate integrated management, building the culture of coordination and collaboration, facilitating professional relationships between care providers, designing integrated clinical care pathways. The design of an appropriate integration strategy should be determined by the objective of the overall integrated care initiative, the stakeholders involved and the health system environment in which it will be implemented [19]. No one type of integration is considered better than the other. It is generally felt preferable to use multiple types of integration strategies in conjunction with one another [19].

10.3.2 Measures of Integrated Care

There is no global measure of integration or integrated care available to evaluate it. There are tools that measure components of integration within existing systems and it is recommended that a comprehensive approach assessing multiple dimensions, components and perspectives is taken in order to reflect the complexity of the intervention [20]. Unfortunately, these tools do not necessarily translate across health jurisdictions or contexts. Most measurement tools evaluate integration from the perspective of health service providers within systems that are already integrated, little assess integration from patient perspective [21, 22].

10.4 Integration Approaches in Cancer

It may perhaps come as a surprise that integrated care is not a term commonly used in the cancer literature. There has only been a single systematic review assessing the efficacy of integrated care interventions in cancer [23]. Of the 33 studies included, none were found to address all components of integrated care. Rather, the cancer literature is comprised of research investigating aspects of integrated care through integration interventions or exploration of phenomena relating to integration. This includes multidisciplinary care, coordinated care and shared care.

10.4.1 Multidisciplinary Care

Multidisciplinary team (MDT) care, often considered the foundation of contemporary cancer care, encompasses a multitude of integration strategies that facilitate access to evidence based, holistic care through inclusion of multiple disciplines of providers, such as inclusion of other health professionals [24–36], care pathways [37–39] and multidisciplinary clinics [40, 41]. MDT care is care delivered by a group of health professionals whose scope of practice covers all the relevant expertise required to meet an individual patient's care needs and considers all relevant treatment options [42]. The desired outcome of the MDT is the development and maintenance of a single collaborative treatment plan for an individual patient.

For the past two decades, MDT care has been considered a key approach to promote the consistent delivery of evidence-based cancer care internationally, including many areas of Europe, Australia, USA, Canada, UK and New Zealand [43]. It has been adopted as an underlying principle of national cancer management policies and cancer guidelines since the late 1990s [44]. It is argued that the policy shift to MDT as the preferred method of cancer care delivery was not driven by newly available empiric evidence, but rather by political and public pressures to improve access to evidence based cancer care and improved patient outcomes [43, 44]. The key driving force behind the introduction of MDT care, has not been the desire to improve integration of care or delivery of patient centered, holistic care but rather, recognition that for many cancers, effective anticancer treatment is delivered through multiple treatment modalities i.e. chemotherapy, radiation therapy, surgery, some of which need to be delivered concurrently. Appropriate treatment decision making and planning, needs to involve representatives of multiple cancer related professions, like surgery, medical and radiation oncology. Indeed, these professions remain at the core of the multidisciplinary team today. MDT have now become ingrained into standard cancer care, and while there continues to be an absence of randomized controlled trials, there is a growing body of evidence to demonstrate that MDT care in cancer improves guideline compliant follow up and timeliness of follow up, positively impacts therapy planning and implementation and improves pain control and adherence to oral medications [1].

In the USA, MDTs evolved from tumor boards (or cancer conferences), which were originally designed as a formalized method to engage multiple medical specialists (e.g. radiology, surgery, pathology, medical oncology) into the collective review of patient cases for the purposes of audit and education [45]. These boards developed into a proactive opportunity to plan treatment for newly diagnosed patients and discuss complex cases. Such a consultative approach allows for consensus opinion on treatment to be reached, but it does not necessarily utilize a team approach, with the physician who is presenting the case ultimately responsible for treatment decisions and their implementation although many MDTs use a team structure to facilitate collaborative treatment planning. The focus of MDT may not solely be cancer pathology, but may be inclusive of the patient's psychosocial needs. Patient involvement is considered essential to ensuring patient-centered care, although it is not widely adopted.

Delivering effective MDT care does not organically result from simply gathering a group of healthcare providers around a common patient. Effective teamwork requires structure, leadership and work by all team members. Features common to effective MDTs include existence of a shared vision, defined membership with clear roles and responsibilities of team members in line with their scope of practice, and establishing a communications framework including meetings and documentation standards [1].

As a result, the performance of a MDT, and ultimately patient outcomes, can be variable depending on the quality of how well these elements are delivered, as demonstrated in the UK analysis of more than 1000 multidisciplinary teams working across six cancer types [44]. MDT performance is influenced by team structure, team processes, and the context in which care is being delivered, including institutional, technical and environmental factors [45]. While it is expected that there would be wide ranging variation in context of care, considerable diversity in MDT structure and processes may also exist.

10.4.1.1 MDT Focus/Scope

The focus or scope of the MDT may vary both in terms of clinical focus and place in the cancer trajectory.

Clinically, the MDT may focus solely on the cancer pathology or, as is becoming increasingly common, it may also include other aspects of care like psychosocial care. In most cases, anything that is not considered directly related to the effects of cancer or its treatment sits outside the scope of the cancer MDT, such as the management of non-cancer conditions. While this approach may seem relatively straightforward, it can present challenges in practice, where it is not uncommon for chronic conditions to present during the diagnosis and treatment phase, potentially triggered by the cancer or its treatment. This has implications when determining which care team is responsible for meeting these needs. For example, it is known that corticosteroids, commonly used in the management of cancer, are associated with numerous short and long term effects, including an increased risk of osteoporosis. Does the fact that it may be cancer treatment-related make prevention, monitoring and management of osteoporosis the responsibility of the cancer MDT? If such clinical responsibilities are left unclarified, they may result in duplication (tests, workload) or unmet need.

Many cancer MDTs confine their operations to the diagnosis and treatment phase. This presents similar issues in determining the roles and responsibilities of care providers, as patients move into survivorship or end of life care. Specific clinical responsibilities that may remain unclear as a patient moves from treatment to survivorship include the management of late-stage effects of cancer or its treatment (e.g. fatigue, cognitive impairment), non-primary cancer surveillance in cancer survivors and management of ongoing psychosocial effects and rehabilitation needs.

10.4.1.2 MDT Composition and Size

The composition and size of the MDT is determined by the defined scope of the MDT and the needs of the patient. The size of the MDT should allow for enough health professionals to ensure the patient's needs are met [45]. As the focus of clinical care broadens from cancer pathology to more holistic care, so does the number of health professionals involved, expanding beyond medical disciplines to include nursing, allied health and pharmacy (Fig. 10.1). Clinical roles and responsibilities of team members are expected to be in line with their professional scope of practice, while administrative and communication responsibilities, such as documentation of MDT meetings may be allocated to specific MDT members.

Bigger is not always better for MDTs. Expanding MDT size and diversity brings challenges in team coordination and communication. According to Fennell and colleagues, team effectiveness is impaired when size exceeds 10 members, when membership is not constant across the treatment process and when not all members are relevant to a given discussion [45]. One approach to facilitating consistent membership is to structure the MDT according to disease type, with core membership comprising the minimum disciplines required to provide quality routine care [42]. Membership is extended for individual cases according to patient needs, to include health professional who care for the individual patient (e.g. GP) and referred specialist providers (e.g. physiotherapist for a patient with lymphedema). Membership is therefore dynamic, expanding or contracting as needs change throughout the care continuum. It should be noted that this distinction between core and non-core members is made from the perspective of the oncology clinicians in relation to developing team processes, it does not imply a hierarchy of care providers, nor does it reflect the patient perspective.

Cancer MDTs function within a practice philosophy of evidence based medicine. While this aids in establishing team norms amongst healthcare professionals, it cannot be assumed that the patient shares these values. A strong foundation of evidence based medicine is essential to a high functioning MDT, but may be a potential source of conflict for patients who access external care providers and seek treatment options that are not supported by evidence.

There is evidence that patient-centered treatment plans are more likely to be implemented, clinically appropriate and acceptable to patients [46]. Indeed, it is considered by many that the inclusion of the patient or their advocate in the MDT decision-making process (e.g. involvement in the MDT meeting) is essential to achieve effective MDT care [45]. Clinicians have been shown to be generally poor at judging patient preferences [47] and studies suggesting that patients who do not attend MDT meetings have a limited opportunity to input to or influence the decision-making process of the MDT [48]. However, most MDTs do not allow for patient's attendance at the meeting and indeed, not all patients want to be included in the MDT. A Canadian study demonstrated that while nearly all patients want to be informed and presented with treatment options, half prefer to leave the decision to their doctor [49]. Clinicians acknowledge the need to keep the patient informed, but have expressed concerns that the presence of a patient in the high paced, explicit and technical MDT discussion may negatively impact the efficiency of the meetings and be potentially alarming to patients [44, 48].

Inclusion of the patient in the MDT is not the only method of providing them with greater involvement in their care, but as it stands, the best method for accurately representing patient views and ensuring they are appropriately informed remains unclear [44, 46]. Other strategies that have been shown to positively impact patient satisfaction by supporting greater patient involvement in their care include interventions involving provision of information to patients, decision aids and providing an audiotape of the consultation [23].

10.4.1.3 Multidisciplinary Team Processes

Regular MDT meetings are the key mechanism to achieving joint decision making and communicating actions, along with clear identification of MDT members and presence of a communications framework. An open and inclusive discussion is required to achieve consensual decision making.

In order to ensure sufficient attendance and participation of core team members, the conduct of MDT meetings tend to be centered on the needs of specialist providers. They are usually held within hospital or specialist locations and include discussion of an agenda of patients under the care of the oncology team, with case conferences about individual patients convened as necessary. Multiple analyses have demonstrated that the decision making that occurs within cancer MDTs relating to newly diagnosed patients tend to be medically dominated, maintaining a narrow focus on cancer pathology [46, 50, 51].

Methods to enhance MDT processes have been explored in the literature, including the use of integrated care pathways. An integrated care pathway is "*a complex intervention for the mutual decision-making and organization of care processes for a well-defined group of patients during a well-defined period*" [52]. Evidence that suggests care pathways reduce variation in outcomes for high-risk cancer within and between countries [53]. Integrated care pathways and programs of care have been explored relating to specific cancer types including breast cancer

[54] and head and neck cancer [39]. Pathways and programs to support the management of specific supportive care needs have also been explored, including post-operative management [37], febrile neutropenia in pediatrics [38], end of life care [55], depression care [56, 57] and pain management [58].

10.4.1.4 MDT Approach to Multimorbidity and Cancer

Cancer MDTs are designed to suit the needs of patients for whom cancer is the single clinical focus of care. They are generally based on the premise that care needs can be met by specialist providers in a hospital or similar specialist setting for a discrete period of acute need, usually the treatment phase. These are not the circumstances encountered in the management of patients with cancer and a chronic condition.

Failure to consider aspects such as the impact of patient preferences and comorbidities on treatment options in addition to cancer pathology has been shown to adversely impact the quality of MDT clinical decision making [46]. Despite this, those clinicians with the most comprehensive knowledge of the patient and responsibility for coordinating the management of non-cancer conditions (i.e. GPs) are often not in attendance. What results is that many MDTs do not benefit from the input of the primary care provider at the point of decision making, instead functioning reactively. If it becomes apparent that a non-cancer condition is going to impact the agreed treatment plan a number of consequences may arise: the plan may be amended by an individual clinician outside of usual clinical governance; treatment could be delayed to allow further discussion at the next MDT meeting, or; if the problem is recognized after the treatment plan has been implemented it could result in the administration of inappropriate treatment [50].

An alternative model that is yet to receive much attention is the proactive undertaking of holistic needs assessments at defined times along the continuum of care, and incorporation of this information into MDT meeting discussions [48]. There has been exploration of this in the care of frail elders, where incorporating holistic geriatric assessment that provides knowledge extending beyond that obtained by standard oncology assessment has been shown to positively influence cancer treatment planning and decision making [59–62]. Whatever the solutions may be, they must address the existing limitations in MDT scope, membership and processes that currently stand in the way of meeting the needs of patients with cancer and chronic conditions.

10.4.2 Coordinated Care

Coordinated cancer care refers to the orderly way in which patients with cancer receive their cancer care where there exists a designated primary point of contact within the MDT (a care coordinator). Cancer care coordinators/case managers/patient navigators are health professionals (nurse or other) with the specific role of supporting the MDT, including the patient and GP, in order to improve continuity of care and facilitate a patient-centered approach. There is also some exploration of the role of lay patient navigators, someone who undertakes a patient support role to help patients navigate the complex health system throughout the cancer care continuum and reduce barriers to access [63].

Care coordinators have been shown to play a critical role in patient education and in linking patients with support services [64]. They have also been demonstrated to improve patient experience and achieve greater adherence to therapy through a randomized trial investigating the use of a navigator early in the care trajectory of patients with newly diagnosed breast, colorectal and lung cancers [65]. As with the cancer MDT, the focus of coordinated care in cancer is organizing the provision of all elements of comprehensive cancer care including diagnosis, treatment and supportive care, within the paradigm of evidence based medicine, usually limited to the diagnosis and treatment phase. Anything that is not considered directly related to the effects of cancer or its treatment are out of scope. This has obvious implications for patients managing a chronic condition throughout their cancer care, particularly if they experience worsening of their condition or newly presenting conditions.

Acute cancer treatment causes a disruption to the usual care for patients who are managing a chronic condition prior to diagnosis with cancer. Literature suggests that patients who usually self-manage their chronic condition can be expected to need greater support during times of acute illness [12] yet they are known to have reduced contact with their GP and other care providers during acute cancer treatment [66]. When a patient experiences worsening of an existing condition or is diagnosed with a new chronic condition during acute cancer treatment there is further potential for role confusion between providers. If management of the chronic conditions is considered to be within the scope of cancer care coordination the management of the chronic condition would be facilitated through direct care provided through the cancer MDT or specialist provider via MDT referral. By contrast, if the management of the chronic condition is considered outside the scope of cancer care coordination this would imply the patient should seek care through standard channels of care, usually care provided directly from the GP or specialist via GP referral. What often results is the patient or their caregiver informally taking on the role of overall care coordination, acting as the conduit to ensure information transfer between all care providers [66].

10.4.3 Shared Care

Shared care refers to a joint participation of primary care physicians and specialty care physicians and other health care providers in the planned delivery of care [67]. It is a structured process with the aims of improving the level of communication and relationship between the MDT, the patient (and/or advocate) and their GP, and fostering the environment necessary for collaboration in provision of cancer care. Shared care between specialist and GP is receiving growing recognition as an integration strategy that offers potential to benefit patients by improving the structured transitions of care and promoting continuity of care with the GP.

There is a growing body of evidence exploring shared care between the GP and cancer services in treatment [68] and survivorship care [69–71]. It has been shown to increase contacts with the GP and improve patient satisfaction, with no effect on quality of life [72], improve clarity over roles and responsibilities of care providers relating to cancer care and provide facilitate information sharing [73]. Literature shows that, with simple guidelines, primary care providers are able to provide care to cancer survivors that is equivalent to that given by cancer specialists [73]. There is some concern however that an unintended consequence of GP sub-specialization is that GPs may function more as specialists than as primary care providers, resulting in unmet needs relating to chronic condition management and preventive care [74].

Collaborative care plans have been investigated in the setting of shared care in the diagnosis and treatment phase [68] and survivorship care [75] (where they are referred to as survivorship care plans) although they are yet to be utilized as part of routine clinical care. They are designed to provide clear documentation of responsibilities and outcomes relating to cancer treatment, its potential consequences, and recommendations for follow up cancer screening and diagnostic tests [72]. They have been shown to provide clarity in roles and responsibilities of care providers and enhance transfer of information between specialist and primary care relating to cancer care [73]. Collaborative care plans however, generally focus on a single disease state and are not designed to cater for the needs of patients with multimorbidity [76]. It is therefore unlikely that care plans alone will provide clarity regarding roles and responsibilities of care providers in areas of clinical ambiguity, such as interpreting if a generalized symptom relates to a late effect of treatment, is a manifestation of chronic disease, or a consequence of polypharmacy (the use of multiple medications) or others.

10.4.4 Novel Integration Strategies

What is considered to be a novel strategy to improve integration depends on the healthcare context in which you are situated. Many of the clinical models of care reported in the literature are being implemented within the integrated delivery systems of the US. Key features of these systems include discrete patient populations (often defined by enrollment), alignment of financial models and shared information systems [77]. In regions that do not have these integrated delivery systems in place, like Australia and Europe, initiatives that promote integration through the transfer of information such (e.g. patient held electronic health record), or assist in identifying vulnerable patient groups (e.g. hospital avoidance programs [77]) are increasingly being utilized.

A number of integration strategies are designed to overcome some of the recognized shortfalls of existing models of cancer care. One area of focus is promotion of information exchange. This includes initiatives that aid information flow between care providers such as decision-support systems and patient information systems [78], and strategies that improve information transfer between patients and providers, such as the patient held health record [79]. Another focus has been the way in which patients receive their multidisciplinary care, such as multidisciplinary ‘one-stop’ clinics and shared medical appointments.

Multidisciplinary one-stop clinics are not new in cancer where they have been utilized within specific clinical settings such as breast and prostate cancer. However, there has been little exploration of how they may potentially benefit patients with chronic conditions and cancer. One-stop clinics involve an individual patient consulting multiple care providers either as a single appointment or sequentially within a single clinic session. Evidence suggests that they reduce negative subjective health outcomes (anxiety and depression) [39], improve symptom control and patient satisfaction [80], improved practice patterns [40], improve quality of care, patient satisfaction and patient retention [41].

Shared medical appointments (SMAs) have been utilized in the USA, primarily in non-cancer chronic conditions, since the late 1990s. They are increasingly gaining recognition in other regions, such as Europe and Australia, as a potential model of care. An SMA is a medical consultation that is shared by a group of patients in a confidential setting. The consultation is generally led by a medical clinician or advanced practice nurse, with other disciplines included depending on the intent [81]. For example, a shared consultation for patients with steroid induced diabetes may include a dietician and pharmacist. In the general chronic condition setting, SMAs have been demonstrated to not only improve the availability of peer-education and support, but also improve access to specialist and multidisciplinary care, enhance therapeutic relationships, reduce waiting lists and promote self-management and psychosocial care [81]. There has been little exploration of SMAs within cancer. A Dutch study demonstrated that SMAs were a feasible method of enhancing breast cancer survivorship care, but did not find the same positive impact on psychosocial care, potentially increasing fear in some patients [82]. SMAs appear to be a promising model of care worthy of exploration in cancer, but further research is required to establish their cost-effectiveness and to determine the optimal criteria (e.g. professions involves, number of patients) [83].

It can be argued that within the context of general multimorbidity, clinical management needs to move away from clinical guidelines based upon individual disease states, and needs to transition towards models that incorporate clinical judgment and patient priorities into goal-oriented care that addresses overall health [8, 76, 84]. Reuben and Tinetti argue that an approach that aligns treatment goals across conditions enables patients to actively participate in identifying and achieving outcomes that improve overall health and prompts clinicians to have the difficult conversations with patients that are necessary when the desired goals are not attainable [84]. Such an approach is particularly relevant in the context of advanced or terminal cancer, and in caring for frail elders.

As it stands there is limited exploration of novel approaches to improve the interface of primary and specialist cancer care. What evidence does exist is primarily practice based reports, with few robust clinical trials [23, 56, 57, 85]. There is a need for investigation of initiatives that creatively utilize all aspects of the healthcare workforce, along with rigorous evaluation.

10.5 Integration Approaches and Multimorbidity

While patients with multimorbidity are expected to gain the most from integration initiatives, most evidence focuses on single disease states. There is limited empirical evidence investigating integrated care models of care, with little to guide models of care in the context of multimorbidity [86, 87].

There have been two published meta-analyses of systematic reviews exploring the literature regarding integrated care strategies applied within the context of general multimorbidity. Each review demonstrated that integrated care programs positively impact patient outcomes in chronic conditions [88, 89]. More recently, Mitchell and colleagues published a systematic review of integrated models of care delivered at the primary-secondary interface of care to improve outcomes for patients with chronic conditions. Their analysis of ten studies supported the findings of the meta-analyses, demonstrating that integrated care initiatives have a modest impact on clinical outcomes, substantial impact on process outcomes and mixed cost data in the context of general multimorbidity [90].

While these reviews were not specific to cancer populations, it has been shown that the principles relating to what make integrated care strategies successful transcend healthcare context and clinical setting [91]. Thus, the findings may not be immediately translatable to the oncology setting, but in an area where evidence is sparse, they do offer some valuable insight into what may work in a setting of multimorbidity.

10.6 Barriers to Achieving Integration for Cancer and Chronic Conditions

There are multiple barriers to overcoming the fragmentations of care encountered in the care of patients managing cancer and chronic conditions. Perhaps the most fundamental barrier relates to the limited evidence promoting awareness and understanding of the problem itself. Further to this, there is an absence of shared understanding across the health system of the strategies available to address recognized fragmentations in care (i.e. integrated care) presenting difficulties in developing effective collaborative solutions. Lack of system integration demonstrated by rigid funding models and absence of shared information systems present challenges when trying to implement integration initiatives in practice. Finally, effective collaboration and teamwork form the basis of all integration strategies; achieving this in practice is not necessarily an easy task.

The logical starting point for any integration initiative is establishing a shared understanding of the problem in order to design a solution to overcome it. With so little evidence available regarding the management of patients with chronic conditions and cancer, it cannot be assumed that the problem is recognized nor understood. Recognition of the issues across both primary and specialist care is a critical barrier to achieving integration at a system level. Similarly, there is no shared understanding across the health system of what integrated care entails and therefore no validated measures for assessing or benchmarking services. The lack of shared terminology has the potential to create challenges when attempting to put policy into practice, from intervention design through to implementation. Differing semantic understanding of integration may impede stakeholder buy in and collaboration. For example, 'integrated care' may be understood by a policy maker to result in a system that combines governance, administrative and financial structures, but by clinicians as a system that streamlines clinical processes and multidisciplinary teamwork. Inability to consistently measure integration initiatives may result in missed opportunities to identify variations in practice that could be addressed by specific interventions [78].

Another significant challenge to implementing integration strategies that cross the boundary of specialist and primary care is the way in which most health systems are designed. Different sectors and institutions often have separate IT infrastructure and funding models that prevent collaboration. For example, many community-based health services are designed to be accessed through primary care. For example, in Australia if a patient with cancer needs to access a publicly funded community based psychologist they cannot be referred by the cancer MDT under their cancer management plan. Rather, they must be referred by their GP under a GP Mental Health Treatment Plan, or by a psychiatrist under an appropriate assessment and management plan [92]. Thus any attempts to integrate care using these services can only occur through primary care and not acute cancer sector. Such barriers relating to system integration may be difficult to change at a grass roots level, potentially resulting in duplication of services or work around solutions.

Perhaps the most commonly encountered barrier to successful implementation of an integration initiative are the individual agents themselves (healthcare providers, managers, policy makers), regardless of clinical context or care setting. In an environment rich in professional tribalism, it can be difficult to establish normative integration. Similarly, convincing clinicians to participate in the collaborative approach necessary to put policy into practice, can present significant challenges [93]. Integration initiatives are fundamentally reliant on team collaboration. This brings with it a multitude of barriers including confusion or lack of role clarity, professional self-interest, competing ideologies and values, lack of mutual trust and conflicting views about client interests and role [91].

10.7 Overcoming the Barriers to Integration

Many of the systemic barriers to integration may not be able to be influenced at a grass roots level. It is possible however, to increase awareness and understanding of the problem, and to arm primary and specialist care providers with the knowledge and skills required to develop and implement clinically relevant solutions. Research that improves our understanding of the issues encountered in the management of cancer and chronic conditions is essential to achieving recognition of the problem across policy makers, managers, care providers and patients. Research that strengthens the knowledge base relating to integrated care is also needed to establish the shared taxonomy and conceptual application required to develop valid measures that enable benchmarking of services.

In order to effect change that results in improved patient care, research must be coupled with broad ranging education of patients and care providers. While it is not known what the most effective type of education intervention is, it has been suggested that education initiatives should be based on a shared curricula that span primary healthcare and oncology, and are inclusive of the full range of health professionals [78]. Ideally such education would be informed by a robust evidence base. In absence of this, education that demonstrates the conceptual basis of integrated care should be encouraged across professional groups and settings to ensure that effective collaboration is not blocked by divergent semantic meanings.

It is thought that a ‘bottom up’ rather than ‘top down’ approach to integration should be encouraged [94], with policymakers articulating the vision (and budget), and clinicians creating the workable solution. Ideally, the development of ‘bottom up’ clinical or service integration strategies occurs within well designed policy that supports them by ensuring the information systems, governance structures and financial management is in place. In reality, this may not be the case and it may not possible to overcome these system barriers for an individual project. In order to minimize the development of tedious mechanisms to work around systemic obstacles, it is recommended to develop strategies that target specific segments of the patient population, identified through population segmentation and risk stratification [19]. The idea being that clinicians are more willing to go to the effort to overcome systemic obstacles if they recognize it is meeting a need for a patient that would otherwise go unrealized.

Establishing normative integration is complex and presents one of the most challenging barriers to overcome. Teamwork can be facilitated by establishing explicit goals, establishing roles and managing interdependent work [95]. Building effective teams requires team members to have the appropriate knowledge and skills to participate in teamwork and may require specific training [95]. Methods that standardize the teams approach to care, such as guidelines and protocols have been found to be common elements of successful integrations initiatives [90]. Another recognized feature is the presence of organizational and cultural leadership [91].

Box 1: Recommendations to overcome the barriers to integration to improve the care for people with cancer and chronic conditions

Overcoming the barriers to integration requires:

- Research base that supports a shared understanding of the problem of multimorbidity and available solutions
- A framework of shared understanding
  - Clarity of definitions and language
  - Promotion a culture of integrated approach to care
- A policy environment that supports integration
  - Improved integration of systems (information systems, governance structures, financial management and incentives)
  - Encouragement of ‘bottom up’ approaches to integration
  - Availability of data to facilitate the identification of target groups through population segmentation, risk stratification and measurement of outcomes
- A practice environment that supports effective teamwork
  - Organizational and cultural leadership
  - Methods that standardize the teams approach to care
  - Clarified expectations within teams (goals, roles and responsibilities, interdependent work)
- Care providers that possess the appropriate knowledge and skills
  - Broad ranging education that spans primary healthcare and oncology, and includes the full range of health professionals
  - Education on the issues encountered in the management of cancer and chronic conditions
  - Education on the conceptual basis of integrated care, skills training regarding development and implementation of integration strategies
  - Education on the features of effective teamwork, teamwork skills training.

10.8 Recommendations for Research and Practice

There is a need for research to address the gaps in knowledge relating to our understanding of the fragmentations of care encountered in the management of patients with chronic conditions and cancer, particularly at the interface of primary and specialist care [66, 73, 90, 96]. Within the cancer literature, the examination of this interface appears to focus on the engagement of primary care providers to undertake specialist aspects of cancer care. There has been less exploration of the role of primary care providers in enhancing cancer care through their holistic knowledge of the patient, and how the healthcare delivery system, available decision support and clinical information systems may facilitate or impede this. There are indications that cancer diagnosis and treatment causes disruptions in the continuity of care with primary care providers and suggestions that this may result in a shift in focus of care away from chronic condition management and prevention activities, yet there has been little exploration of why this occurs and how it can be avoided. While it is generally accepted that fragmentations of care should be expected in the management of patients with chronic conditions and cancer, there is little research providing insight into what they are or why they occur.

Well-designed research is also required to provide the empirical evidence to support the integration initiatives that have been implemented in the oncology setting (multidisciplinary teams, coordinated care and shared care) in addition to novel models of care and strategies that promote patient involvement in their care.

Research that improves our understanding of effective approaches for involving patients in their care may be of particular relevance for patients who are managing a chronic condition as well as cancer, where self-management is considered a critical element of care [97]. Little is known about the impact of cancer on a person's capacity for self-management beyond broad indications that there is an adverse impact on medication adherence [16, 17]. Patients who are diagnosed with a chronic condition during the acute treatment phase may require additional self-management support [10]. Little is known about the self-management support patients receive when diagnosed with a chronic condition during the acute treatment phase. Similarly, little is known about the perceptions and understanding of cancer clinicians relating to self-management support, including awareness of community based chronic disease programs and services.

While there may not be evidence to provide in depth understanding of the fragmentations of care encountered in the management of patients with chronic conditions and cancer, it is likely that clinicians have an understanding of specific issues of concern within their practice. By developing an understanding of integrated care, clinicians can work toward developing collaborative solutions that affect change for their patient population. Importantly, the outcome of these strategies should be measured using approaches that allow flexibility and further improvements, such as Kolb's experiential learning model or the plan-do-study-act cycle of quality improvement [98]. Sharing the outcomes of these initiatives through publication is both a valuable contribution to the knowledge base, and important source of inspiration for colleagues in other practice settings.

10.9 Conclusions

In order to make improvements in the quality of care for patients with cancer and chronic conditions we must increase awareness and understanding of the fragmentations encountered across primary and secondary care. Research must flow in both directions. That is, to consider both how primary care providers can be utilized to enhance cancer care *and* how cancer clinicians can promote continuity of primary care throughout the cancer care continuum.

In addition to improving our understanding of the problems, we must also take steps to arm primary and specialist care providers with the knowledge and skills required to work collaboratively to develop and implement clinically relevant solutions. Integrated care offers the conceptual foundation and theoretical framework upon which this collaboration can be based.

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