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HEALTH FORUM

DIALOGUE SUMMARY

IMPROVING PAIN AND SYMPTOM MANAGEMENT IN CANCER CARE IN ONTARIO

26 NOVEMBER 2015

EVIDENCE >> INSIGHT >> ACTION

Dialogue Summary:
Improving Pain and Symptom Management in Cancer Care in Ontario

26 November 2015

McMaster Health Forum

For concerned citizens and influential thinkers and doers, the McMaster Health Forum strives to be a leading hub for improving health outcomes through collective problem solving. Operating at regional/provincial levels and at national levels, the Forum harnesses information, convenes stakeholders, and prepares action-oriented leaders to meet pressing health issues creatively. The Forum acts as an agent of change by empowering stakeholders to set agendas, take well-considered actions, and communicate the rationale for actions effectively.

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Conflict of interest

The authors declare that they have no professional or commercial interests relevant to the dialogue summary. The funders reviewed a draft dialogue summary, but the authors had final decision-making authority about what appeared in the dialogue summary.

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Dialogue

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SUMMARY OF THE DIALOGUE

Participants generally agreed with the challenges presented in the pre-circulated evidence brief, but suggested that there were two overarching challenges that were more important to acknowledge:
1) the current 'paradigm' underpinning cancer care in the province is not conducive to comprehensive, patient-centred pain and symptom management across the entire continuum of care; and
2) a persuasive business case for focusing on improving pain and symptom management across the entire continuum of care has not been developed.

Four additional, more specific challenges were also discussed: 1) existing pain and symptom management guidelines have not been tailored to meet the diverse needs of patients and their informal/family caregivers, healthcare providers and teams, and the full scope of system settings in which pain and symptom management could be provided; 2) limited attention has been paid to ensuring culturally sensitive engagement of patients and their families; 3) non-physician healthcare providers have been under-utilized, and physicians have not been trained to understand how their role can be complemented by other providers; and 4) funding arrangements are not optimally designed to support the changes needed to underpin improvements.

At the outset of deliberations about the options, most participants agreed that the term 'elements of a comprehensive approach' should be used to reflect the need for broader system transformation. The elements were considered within the context of a collectively identified need for a transformed system, and included: 1) strengthen efforts to translate knowledge about pain and symptom management best practices to patients and their families, to providers and to the full range of organizations in which pain and symptom management support is (or could be) delivered; 2) support the increased uptake of pain and symptom management guidelines by healthcare providers and organizations through targeted payments; and 3) strengthen the models of cancer care to optimize the integration of pain and symptom management best practices. Participants discussed each element more generally than they were originally framed in the brief, and didn't consider them in the narrow context of improving the uptake of pain and symptom management guidelines. While most participants were supportive of the three elements presented in the evidence brief, they said that developing a strong business case should be considered as a fourth element. When considering the full array of options, participants reiterated the need for efforts to pursue system transformation as well as a 'paradigm shift' to change the way cancer care is viewed, but most agreed that it was still unclear what concrete approaches could help achieve this now.

Participants provided suggestions about next steps, which could be grouped into three broad types of commitments. First, participants committed to pursuing activities that would help to lay the groundwork for the broad system transformation and paradigm shift that most felt were needed to improve cancer care (and pain and symptom management) in Ontario. Second, participants committed to improving processes that they are engaged in to ensure the existing system is working to provide the best, most comprehensive care possible. Third, most participants committed to supporting individuals who are living with cancer to become 'activated patients.'

SUMMARIES OF THE FOUR DELIBERATIONS

DELIBERATION ABOUT THE PROBLEM

Participants generally agreed with the key challenges presented in the pre-circulated evidence brief related to the use of pain and symptom management guidelines in cancer care in Ontario, which included: 1) healthcare providers do not consistently use pain and symptom management guidelines in practice; 2) health-system arrangements in Ontario are not optimally suited to promoting the uptake of pain and symptom management guidelines in clinical practice; and 3) poor documentation of care provided to symptomatic patients makes it challenging to establish the full extent of the problem. However, at the outset of deliberations about the problem, many participants agreed that, while extremely important, these challenges were not the most important drivers of the problem and should not be the primary focus of discussions. Instead, several participants pointed to – and the majority of participants agreed about – the need for a revised approach to thinking through the broader, overarching challenges related to integrating pain and symptom management across the entire continuum of cancer care. Within this context, participants cited two overarching issues that presented the most important challenges:

1) the current 'paradigm' underpinning cancer care in the province is not conducive to comprehensive, patient-centred pain and symptom management across the entire continuum of care; and
2) a persuasive business case for focusing on improving pain and symptom management across the entire continuum of care has not been developed.

Participants also discussed a number of additional, more specific challenges, that many agreed were likely the consequence of these two overarching problems.

Two overarching challenges related to improving pain and symptom management in cancer care in Ontario

First, many participants suggested that the most important problem that needed to be addressed in order to improve cancer pain and symptom management in Ontario is the outdated 'paradigm' through which cancer care is viewed, organized and delivered in the system. In particular, most participants acknowledged that Ontario's cancer care system is currently focused on the diagnostic and treatment stages of care that involve oncologists, rather than on the full continuum of care, and rather than on the

Box 1: Background to the stakeholder dialogue

The stakeholder dialogue was convened in order to support a full discussion of relevant considerations (including research evidence) about a high-priority issue in order to inform action. Key features of the dialogue were:

1) it addressed an issue currently being faced in Ontario;
2) it focused on different features of the problem, including (where possible) how it affects particular groups;
3) it focused on three options (among many) for addressing the policy issue;
4) it was informed by a pre-circulated evidence brief that mobilized both global and local research evidence about the problem, three options for addressing the problem, and key implementation considerations;
5) it was informed by a discussion about the full range of factors that can inform how to approach the problem and possible options for addressing it;
6) it brought together many parties who would be involved in or affected by future decisions related to the issue;
7) it ensured fair representation among policymakers, stakeholders and researchers;
8) it engaged a facilitator to assist with the deliberations;
9) it allowed for frank, off-the-record deliberations by following the Chatham House rule: "Participants are free to use the information received during the meeting, but neither the identity nor the affiliation of the speaker(s), nor that of any other participant, may be revealed"; and
10) it did not aim for consensus.

Consensus was not aimed for because coming to agreement about commitments to a particular way forward can preclude identifying broad areas of agreement and understanding the reasons for and implications of specific points of disagreement, as well as because even senior health-system leaders typically need to engage elected officials, boards of directors and others on detailed commitments.

Participants' views and experiences and the tacit knowledge they brought to the issues at hand were key inputs to the dialogue. The dialogue was designed to spark insights – insights that can only come about when all of those who will be involved in or affected by future decisions about the issue can work through it together. The dialogue was also designed to generate action by those who participate in the dialogue, and by those who review the dialogue summary and the video interviews with dialogue participants.

full range of healthcare providers involved in care. Several participants stated that most pain and symptom management initiatives are anchored to these stages as well, despite the fact that individuals living with cancer may experience a variety of potentially distressful symptoms during any of the stages between prevention and screening to survivorship. Additionally, several participants noted that a paradigm shift is now particularly important given there are more people than ever living long term post-treatment, and given the diversification of individual patient needs. Many participants viewed the need for a paradigm shift as related to broader trends towards ensuring patient-centred health systems, both within Canada and internationally.

A number of participants also acknowledged that Ontario's cancer care system is currently focused on single treatments, and not the clusters of interrelated strategies that complement each other, and that are delivered by multidisciplinary teams. One participant noted that a patient "lives with all of their pain and [distressful] symptoms at once, and we need to approach things with these clusters of needs in mind." Several participants supported the need to develop multiple, complex approaches to supporting individuals living with cancer, rather than single approaches, although a number of participants noted the significant difficulties in doing so successfully. Some participants also acknowledged that it was essential to shift towards system-based approaches that emphasized integration of the cancer care system with primary and community care. Overall, several participants stated that the fundamental elements of a paradigm shift would ideally align with the chronic care model, where the goal is to have well-prepared teams delivering proactive, comprehensive, individualized care to 'activated patients'.

The second overarching problem that participants focused on was the lack of a persuasive business case that would convince providers, planners and policymakers of the benefits of more intensely focusing on improving pain and symptom management. In particular, many participants noted that, while initiatives like the Screening for Distress model had raised awareness about the need to support a broader range of pain and symptom management at different stages of the cancer care journey, it wasn't persuasive in highlighting the opportunity costs associated with *not* strengthening pain and symptom management in the province.

Additional challenges related to improving pain and symptom management in cancer care in Ontario

In addition to these two overarching problems, participants also discussed four additional, more specific challenges: 1) existing pain and symptom management guidelines have not been tailored for all users and settings; 2) limited attention has been paid to ensuring culturally sensitive engagement of patients and their families; 3) non-physician healthcare providers have been under-utilized, and physicians have not been trained to understand how their role can be complemented by other providers; and 4) funding arrangements are not optimally designed to support the changes needed to underpin improvements.

Starting with the first of these four challenges, a number of participants agreed that existing pain and symptom management guidelines have not been tailored to meet the diverse needs of patients, their informal/family caregivers, healthcare providers or healthcare teams, or to be appropriate in the full range of settings within which pain and symptom management could be provided. Specifically, several participants highlighted the fact that guidelines are not presented in ways that enable them to be dynamic and adaptable in the face of individual patient needs. A number of participants also highlighted the fact that healthcare professionals in the cancer care system work in fast-paced, complicated and busy environments, where the primary focus is on diagnosis and getting treatments right. In this context, many providers feel that they are already providing adequate symptom management in the time they have available, which reduces the chance that they'll feel the need to consult pain and symptom management guidelines. Additionally, some participants also suggested that the guidelines had not been tailored for communication with patients or their families, which was also viewed as a major challenge.

The second additional problem identified by participants was the limited attention paid to ensuring culturally sensitive engagement of patients and their families. Specifically, a number of participants emphasized the need to consider how to best empower patients and their informal/family caregivers to engage in the complex decision-making processes that are encountered across the entire cancer care continuum – from the regional cancer centre to the community, and in the home. Some participants felt that people need to be asking more questions about care and engaging in decisions with their healthcare providers about pain and symptom management, while a number of participants urged caution on this point for at least three reasons. First, what participants frequently referred to as the 'patient activation' model of care (which includes efforts to educate and empower patients, support shared decision-making and enable self-management), was viewed as largely a North American approach that isn't necessarily reflective of what all people from all cultures want (or expect) of their care. In particular, some people may prefer that the doctor or nurse makes all the decisions for them. Second, it is important to acknowledge that some patients and their families may be apprehensive about asking too many questions for fear of how it may affect their own treatment options (e.g., if they ask questions that indicate they are in pain, will they have to forgo their next round of chemotherapy?). As such, it may be too bold to expect patients to want to be 'activated.' Third and finally, while empowering patients to become more active in their care is of central importance in the cancer care system in Ontario, the need for robust patient-education strategies that ensure patients have concrete 'tools' to communicate their needs is fundamental to achieving this goal. More generally, many participants discussed how a transition towards greater patient and family engagement generally, and the notion of patient activation more specifically, would also help to move the system away from views that individuals with cancer were sick all of the time, to one where patients were viewed as empowered individuals capable of engaging in their cancer journey.

The third additional problem identified was that non-physician healthcare providers have been under-utilized in Ontario, and physicians have not been trained to understand how their role can be complemented by a range of other providers. As discussed at several points in the dialogue, participants felt that the current cancer care system was oncologist dominated and focused too heavily on diagnosis and treatment. As such, the many allied health professionals who provide other types of care (e.g., psychosocial, nutritional, etc.) in settings outside of the cancer care system (e.g., in the community) are not routinely utilized, despite their importance to the well-being of patients and their families. While most participants agreed that a truly multidisciplinary team-based approach is required, many also noted that cancer care physicians have not traditionally been trained to think about care in this way. As such, they aren't aware of their role vis-a-vis the contributions of other providers – both within cancer care more generally, and in the context of pain and symptom management more specifically. Furthermore, many professionals are overwhelmed by the prospect of needing to address the full range of pain and symptom management needs on their own, and haven't been trained about pain and symptom management or about how to engage other appropriate providers or teams to deal with a patient's full range of needs. A number of participants noted that this isn't only the case for physicians, and all members of the healthcare team need to be trained on how they can work together to provide comprehensive pain and symptom management support.

The fourth additional problem identified by participants was that funding arrangements are not optimally designed to support the changes needed to underpin improvements. In particular, while certain funding arrangements (e.g., Quality Based Procedures) provide support for some activities related to pain and symptom management, they are not designed to facilitate broader team-based care or to support the full range of patient treatment needs (e.g., psychosocial treatment). Some participants felt that with the move in Ontario towards Quality Based Procedures (QBPs) for funding cancer centres, there will be a reduction in funds available to facilitate additional outreach, integration and innovation for improved pain and symptom management, given care packages will be carefully circumscribed. A number of other participants noted that the likelihood of additional funding to support pain and symptom management is unlikely, so there was a need to proceed under the assumption that there will be ‘no new money’. As such, there is a need to think about how existing resources are distributed, to determine whether we’re achieving the right balance among patients, staff, system sustainability (including prevention and screening) and research and innovation.

DELIBERATION ABOUT ELEMENTS OF A COMPREHENSIVE POLICY AND PROGRAMMATIC APPROACH

Participants began deliberations about the options presented in the pre-circulated evidence brief, which included:
1) strengthen efforts to translate knowledge about pain and symptom management best practices to patients and their families, to providers and to the full range of organizations in which pain and symptom management support is (or could be) delivered;
2) support the increased uptake of pain and symptom management guidelines by healthcare providers and organizations through targeted payments; and
3) strengthen the models of cancer care to optimize the integration of pain and symptom management best practices.

However, as the discussion unfolded, it became clear that many participants felt that the term ‘options’ wasn’t entirely appropriate because it implied that one had to be chosen over the others despite the need for comprehensive solutions that address the full range of problems identified. Instead, many participants agreed that they should be referred to as ‘elements of a comprehensive approach,’ since they weren’t mutually exclusive, and needed to be considered within the context of broader system transformation (which would include many elements). Given the deliberations that followed proceeded to discuss elements rather than options, the remainder of this summary also refers to elements.

It is also important to note that deliberations about each of the elements proceeded after an agreement among the majority of participants that the most important element that cross-cut all others was the need for broad system transformation and a paradigm shift to fundamentally alter the way cancer care is viewed, organized and delivered in Ontario. This notion imbued each of the deliberations that followed.

Element 1 - Strengthen efforts to translate knowledge about pain and symptom management best practices to patients and their families, to providers and to the full range of organizations in which pain and symptom management support is (or could be) delivered

Most participants were generally supportive of the first element, but several suggested at the outset of deliberations that this approach constituted ‘business as usual,’ and would not adequately address the root causes of the problems discussed earlier. Particularly, as the majority of participants agreed that the real need was a fundamental transformation in how the cancer care system functions in Ontario alongside a paradigm shift, element 1 pursued on its own was viewed by participants as too simplistic an approach for improving pain and symptom management. However, while deliberations about element 1 were underpinned by this acknowledgment, participants discussed what was needed to strengthen existing knowledge translation efforts within a broader system transformation and paradigm shift, and they focused on three specific needs: 1) to tailor existing guidelines to specific contexts and for team-based care; 2) to systematically identify the barriers that exist in order to determine which behaviour-change approaches are most relevant; and 3) to listen to patients and their informal/family caregivers in order to provide them only with the information they want, when they want it.

When discussing the need to tailor existing guidelines to specific contexts and for team-based care, many participants acknowledged that a failure to tailor the existing set of guidelines was a major barrier that hindered their use by providers across the continuum of care. Some participants suggested that the guidelines don't currently seem to acknowledge the reality that pain and symptom management support can be delivered by many different types of providers and across many different types of settings. Additionally, some participants suggested that as the system increasingly orients itself towards team-based models of cancer care, pain and symptom management guidelines should be adjusted to ensure they are appropriately framed to work within the dynamics of this new reality. Many participants agreed that the diversity of providers and settings meant that multiple strategies for tailoring and supporting the use of pain and symptom management guidelines are required.

After tailoring, participants discussed the need to systematically identify current barriers to guideline use that exist at the level of healthcare providers in order to determine which behaviour-change approaches are most appropriate. A number of participants suggested that the 'diagnosis' of barriers across providers and settings had yet to be done in a consistent way in Ontario, which is why existing strategies to support the use of best-practice guidelines have been mostly ineffective. One participant described a recent pilot study they conducted that found a widespread reliance on passive knowledge translation strategies in Ontario (e.g., provider education about guidelines) that didn't target specific barriers to uptake. Additionally, when discussing how to identify and overcome the full range of barriers, several participants identified the current care culture as an underlying barrier. However, many participants noted that this barrier wouldn't be overcome by targeted strategies, and could only be addressed within the context of broader system transformation and a paradigm shift. As a final consideration related to overcoming barriers, many participants agreed that any targeted approach needs to ensure a low 'hassle factor' – that is, efforts to incorporate best-practice guidelines into comprehensive pain and symptom management needed to make sure that this process was not viewed as a hassle by healthcare providers.

Participants also discussed the need to listen to patients and their informal/family caregivers in order to provide them only with the information they want, when they want it. Within this discussion, a number of participants suggested that many patients and their informal/family caregivers could easily be overwhelmed by information overload, particularly as they progress through the various stages of their cancer care journey (some of which can be distressful). One participant pointed to the volume of information provided to individuals living with cancer when they received prescription medication at their pharmacy as an illustration of how too much information could be confusing and distressful in its own right. Another participant suggested that patients are struggling with decision-making due to a glut of information. While participants felt that providers were trying to do the right thing, this approach to educating patients was not truly responsive to their unique needs. As such, most participants agreed that it was important to first improve how the system interacted with patients and their informal/family caregivers, which would enable opportunities for listening to their real needs, after which the most appropriate responses for information provision could be adopted. One participant suggested that a potential solution was to provide 'chunks' of information based on asking patients what they want to know and need to know. A number of participants noted that patient education could not be separated from the idea of 'patient activation,' which was discussed during deliberations about the problem, and some participants reminded the group of the concerns surrounding this shift in the patient's role – particularly the need to maintain cultural sensitivity and an attentiveness to each patient's needs in the unique context of living with cancer.

Element 2 - Support the increased uptake of pain and symptom management guidelines by healthcare providers and organizations through targeted payments

When discussing element 2, the majority of participants agreed that money cannot be considered a solution on its own, but could support changes in certain behaviours, and the reallocation of funds could be used in tactical ways (i.e., not in an ongoing manner) to achieve desired outcomes. Three specific considerations served as the focus of discussions about element 2: 1) it is important to clearly define the outcomes that we hope to achieve with changes to targeted payments; 2) there is a need to acknowledge the current funding and remuneration landscape in Ontario to move towards achieving these outcomes; and 3) the existing fiscal climate means no new resources will be made available.

As a first piece of pursuing element 2, several participants stated that there was a need to take a step back, and seriously consider which outcomes need to be changed and why, before moving forward with any changes to how organizations are funded, or how providers are remunerated. Furthermore, a number of participants suggested that if there is a tactical approach that can be taken, it should start not only by defining the outcomes that are important, but also by clarifying which indicators can be used to measure outcomes as a way of determining if targeted payments are achieving their desired outcomes. One participant suggested, and a number agreed, that one approach could be linking payments to deliverables, such as care quality and patient satisfaction, which are important in the context of the existing cancer care strategy in Ontario.

After defining the outcomes that are being sought with the tactical use of changes in payments (both to organizations and providers), many participants identified the need to acknowledge the current funding and remuneration landscape in the province before developing an approach to pursue element 2. Specifically, existing funding mechanisms in the cancer care system in Ontario channel resources to organizations providing treatment (e.g., regional cancer centres), and remuneration mechanisms channel resources primarily to physicians. Some participants noted that the QBP model used to fund cancer centres is increasingly expanding to include a wider package of care that often includes a more comprehensive range of pain and symptom management supports, but there are limits on the types of services covered. For example, psychosocial specialists are paid as part of QBPs, but these payments are limited to consults (and don't include treatment). In general, participants agreed that taking stock of this context provided valuable insights into what the government is prepared to pay for and how resources are channelled, which established a more realistic starting point for thinking through how to adjust payments within current structures to achieve goals. For example, a number of participants suggested that current funding arrangements may not be conducive to incentivizing change across the full scope of settings and among the entire range of healthcare providers who are involved in providing comprehensive pain and symptom management across the continuum of care. As such, if the goal is to change practice to support team-based care, adjustments to remuneration models that include a wider array of providers may be required.

As a final consideration within discussions of element 2, participants continually reiterated that the existing fiscal climate meant that changes to payments were not about adding resources into the system, but about shifting and re-purposing existing resources to achieve outcomes. Most participants agreed about this, but providing concrete details of how to best shift resources proved challenging. In part, a number of participants felt that this was related to the complexity of individual patient needs, the complexity of the existing cancer care system, and the additional complexity that would be created if there was more emphasis on care provided by a wider range of providers working in teams across a wider range of care settings. In particular, a number of participants spoke to the challenges of balancing the tradeoffs with shifting resources (e.g., away from oncologists to other allied health professionals) while continuing to acknowledge the importance of the elements of the system we already have in place. A number of participants also suggested that caution should be exercised if using targeted payments, and in particular bonus payments, as they could disrupt team-building efforts in the event that one type of provider is rewarded for achieving outcomes and others on the team are not.

Element 3 - Strengthen the models of cancer care to optimize the integration of pain and symptom management best practices

At the outset of deliberations about element 3, a number of participants agreed that components of this element resonated most with them, particularly because theses components focused on changing the way cancer care is organized in Ontario. For many participants, this aligned well with the need for a broad paradigm shift, which was discussed earlier in the dialogue. However, rather than focus on how models of care could be optimized specifically to ensure the integration of best-practice guidelines focused on pain and symptom management, several participants expressed the need to discuss aspects of element 3 in more general terms, as they believed them to be fundamental to broader system shifts. In particular, the following components were deemed the most important by most participants: 1) strengthening team-based cancer care; 2) improving transitions between providers and across care settings; 3) leveraging available technology to support needed system transformation; and 4) activating patients in culturally sensitive ways.

The first component that was deemed important by participants when deliberating about element 3 was the need for strengthening the extent to which the cancer care system in Ontario incorporated a wide range of healthcare professionals into team-based models of care. There was a general consensus that, while teams were functioning in some cancer care settings, more needed to be done to ensure teams were scaled up across the province and across the full continuum of cancer care. Collectively, participants proposed several benefits to teams in the context of pain and symptom management, including:

- the ability to provide patients and their informal/family caregivers with a comprehensive package of care, given the broader range of skills possessed by a wider variety of healthcare professionals;
- the flexibility and dynamism required to be truly patient-centred, because teams presented opportunities to adjust the care provided to patients based on their stated preferences; and
- the opportunity to more appropriately allocate responsibilities to the right healthcare professional, while clarifying and optimizing providers' roles (e.g., shifting responsibility for reviewing symptom screening results from oncologists to nurses).

A number of participants also stressed that, for team care to work, it was important to establish strategies that would help promote a culture where collegial collaboration and relationship building among healthcare professionals is the norm. A number of participants also suggested the need to strengthen healthcare professional training programs so that in future all providers in the cancer care system understand their own role, and how it relates to the role of their colleagues.

The second component that was deemed important by participants when discussing element 3 was the need to improve transitions between providers and across settings. In particular, a number of participants promoted the 'shared-care model' wherein healthcare providers and teams working in different settings and in different parts of the system took collective responsibility for ensuring each individual receives the most appropriate, high-quality care at the right time. Some participants also suggested that this type of approach could help to reduce patients' perceptions that they were being 'transitioned' through the system. For example, in an integrated shared-care model, providers in regional cancer centres would work closely with those in primary-care settings to ensure information about each patient's unique needs were shared, and coordinated decision-making between providers in different settings would ensure patients were cared for seamlessly by the most appropriate provider and in the most appropriate setting. As one participant stated, there is a need to ". . . remove the barrier at the point where there is a feeling that there is a transition from one provider to another. It should be viewed as an integrated process, rather than a 'hand off'. . ." As a final point in the discussion of improving transitions, a number of participants agreed that regional cancer centres must do a much better job of improving their support of providers in primary- and community-care settings, whether through outreach, or through more emphasis on coordination and follow-up. One participant stated that regional cancer centres ought to be viewed as centres of excellence that empower primary- and community-care providers to provide the highest quality cancer care possible.

A final discussion within the deliberation about element 3 was the need to leverage technological advances to strengthen the cancer care system. A number of participants agreed that information technology is critical for better coordinating services (including transitions between providers and across settings), improving monitoring and evaluation, making administration and care pathways more efficient and less onerous, and improving the ability to share information and get feedback from patients. On this latter point, a number of participants also highlighted that improving feedback from patients would also work towards improving the extent to which the system was responsive and patient-centred. Some participants pointed to recent positive experiences with the Improving Patient Experience and Health Outcomes Collaboration (IPHOC) as an example of the benefits associated with better electronic data collection and management. As one participant noted: "Data drives things in the cancer system, so we need to do better to collect and leverage what we're learning from patients, and [about] care processes."

Element 4 – Establish a strong business case for strengthening cancer pain and symptom management

A number of participants also promoted the consideration of a fourth element, which would focus on developing a strong business case for improving pain and symptom management in Ontario. While no firm conclusions were reached about the exact details of a business case for pain and symptom management, two general points were suggested by participants as important components:

- present a clearly articulated view about the ways in which pain and symptom management can be used to strengthen care outside of the cancer-care system, in combination with other elements included in the care continuum (e.g., by supporting coordinated team-based care to address the full spectrum of patient pain and symptom support needs, team-based models and coordination may be strengthened in other parts of the system); and
- highlight how a lack of focus on pain and symptom management will limit our ability to achieve desired outcomes in the cancer care system in Ontario (e.g., patients who aren't fully supported to cope with distressful pain and symptoms may be less likely to adhere to treatment guidelines, resulting in poorer clinical outcomes).

Considering the full array of elements

In considering the full array of elements, participants reiterated the need for a broad focus on system transformation and a paradigm shift that would redefine how cancer care was approached in Ontario, rather than focusing on the narrower issue of improving pain and symptom management. While deliberations focused on four elements of a potentially comprehensive approach, each of which could be part of a transformation that could unfold, participants were not entirely clear on how best to initiative such an evolution. One participant noted that since the 'what' was established (i.e., system transformation and a paradigm shift) it was now an issue of determining how this could be achieved, with the following questions still remaining:

1. how do we integrate better models of care and establish better care processes to ensure the right care for the right context (e.g., Sudbury's approach to cancer care system strengthening may look very different than Hamilton's)?
2. what quality indicators and outcomes are most important to the full range of stakeholders involved in or likely to be affected by system change (patients and their informal/family caregivers, healthcare providers, planners and policymakers)? and
3. how can we facilitate the behavioural changes required within the context of a broader cultural shift?

DELIBERATION ABOUT IMPLEMENTATION CONSIDERATIONS

After deliberating about the full array of elements of a potentially comprehensive approach, participants then focused on implementation considerations. At least five potential barriers to pursuing the elements were identified by participants. First, existing provider curricula do not focus on training cancer care professionals about those elements that are needed most in order to transform the system (e.g., how to work with a diverse range of other providers to address the full scope of patient needs). A number of participants noted that changing all relevant curricula will be a challenge, particularly given the extensive range of providers required to support broader system improvements generally, and strengthen pain and symptom management specifically. Second, there is a lack of data and evidence available to fully support the development of a compelling business case for pain and symptom management and for broader system transformation. Third, notions of broad systemic transformation and a paradigm shift are philosophically compelling, but lack practical and concrete imperatives that can help spur action in the short term, and there is still a lack of clarity surrounding the question of 'how' to achieve these objectives. Fourth, the cancer care system must meet the needs of a diverse range of individuals, with unique needs, which creates additional complexity in determining the best way to pursue the elements considered. Fifth and finally, participants noted that it isn't clear who should lead a charge towards broad systemic transformation, and change wouldn't likely be possible without a strong and courageous leader (or leaders).

There were also at least four factors that participants identified as facilitators to pursuing the elements. First, many participants felt that there was an openness to change among stakeholders in the system which has established the right climate for broad system transformation. A second related factor was that participants believed there to be general openness to collaboration among those working in the cancer care system in Ontario, and a willingness to build greater trust, stronger relationships and a deeper understanding between the disciplines. Third, a number of participants believed there to be many opportunities to learn from other jurisdictions who have experience in the reform of cancer care systems (e.g., Alberta and the U.S.), as well as from other models of care that have been used in other sectors (e.g., chronic disease management). Fourth some participants suggested that there were individuals and organizations in the system that are uniquely positioned to take leadership and orchestrate the required systematic transformations. In particular, a number of participants pointed to Cancer Care Ontario and its proven ability to make things happen when it prioritizes a particular issue, with the example of computerized ordering provided to illustrate this point.

DELIBERATION ABOUT NEXT STEPS FOR DIFFERENT CONSTITUENCIES

After deliberations about the problem, elements of a comprehensive approach and implementation considerations, each participant was prompted to reflect on the next steps that ought to be taken. When considered together, participants' proposed next steps fell into three broad types of commitments.

First, participants committed to pursuing activities that would help to lay the groundwork for the broad system transformation and paradigm shift most felt were needed to improve cancer care (and pain and symptom management) in Ontario. This would include efforts such as:

- breaking down silos between providers and across care settings, including conscious efforts to consolidate the language used;
- proactively seeking out opportunities for cross-disciplinary collaboration and team-building;
- engaging the full range of stakeholders involved in providing cancer care in Ontario to establish a set of meaningful process and outcome indicators that can be used as a starting point for improving available data, driving the future agenda, and measuring progress towards achieving goals;

- pushing for funding agencies to acknowledge that changes need to be made to current QBPs so that they account for the 'full-meal deal,' including all forms of psychosocial pain and symptom management each individual living with cancer could require; and
- determining who ought to take leadership to guide broad system transformation.

Second, participants also committed to improving existing processes that they are engaged in to ensure the existing system is working to provide the best, most comprehensive care possible. This included a wide range of efforts specific to the contexts within which each participant worked. For instance, those in administrative roles committed to creating flexibility for their staff so that they could carve out time to 'do the right thing' when it came to pain and symptom management. Those representing healthcare professional groups committed to create new, or strengthen existing, provider education and training so as to facilitate improvements in team-based care generally, and in comprehensive pain and symptom management more specifically. Those who identified as 'researchers' suggested that much could be learned from their work, so they committed to being more proactive about bringing their results forward to the right group(s) of stakeholders so that the system benefits.

Third, most participants committed to supporting individuals who are living with cancer to become 'activated patients.' This included efforts to strengthen patient-engagement strategies, improvements in the collection and use of feedback from patients and their informal/family caregivers, enhancements in the support provided to individuals living with cancer that enable them to better leverage technology and improve their access to the information that matters most to them, and commitments to remaining flexible and culturally sensitive.

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