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Stakeholders' views on identifying patients in primary care at risk of dying:

a qualitative descriptive study using focus groups and interviews

Abstract

Background

Strategies have been developed for use in primary care to identify patients at risk of declining health and dying, yet little is known about the perceptions of doing so or the broader implications and impacts.

Aim

To explore the acceptability and implications of using a primary care-based electronic medical record algorithm to help providers identify patients in their practice at risk of declining health and dying.

Design and setting

Qualitative descriptive study in Ontario and Nova Scotia, Canada.

Method

Six focus groups were conducted, supplemented by one-on-one interviews, with 29 healthcare providers, managers, and policymakers in primary care, palliative care, and geriatric care. Participants were purposively sampled to achieve maximal variation. Data were analysed using a constant comparative approach.

Results

Six themes were prevalent across the dataset: early identification is aligned with the values, aims, and positioning of primary care; providers have concerns about what to do after identification; how we communicate about the end of life requires change; early identification and subsequent conversations require an integrated team approach; for patients, early identification will have implications beyond medical care; and a public health approach is needed to optimise early identification and its impact.

Conclusion

Stakeholders were much more concerned with how primary care providers would navigate the post-identification period than with early identification itself. Implications of early identification include the need for a team-based approach to identification and to engage broader communities to ensure people live and die well post-identification.

Keywords

early identification; electronic medical record; end of life; life-limiting illness; primary care; qualitative research.

INTRODUCTION

The identification of older patients with advanced life-limiting chronic illness earlier in their disease trajectory is the first step in the delivery of high-quality end-of-life care.¹ Indeed, identification of those approaching end of life often occurs too late for desired care plans to be put in place and carried out,² potentially leading to suboptimal care in the last days and weeks of life. Early identification is associated with better outcomes in the form of goal setting, coordination of care, access to services, care delivery, fewer hospitalisations, fewer hospital deaths, and increased bereavement support.²⁻⁴ However, providers find it difficult to identify older patients who are at risk of dying.^{2,5,6} At the same time, patients and families recognise the importance of planning for quality care for those at risk of declining health and dying,^{7,8} and yet remain hesitant to approach the issue if their provider does not raise it first.⁷

Because of their upstream contact and longstanding patient-provider relationships, primary care providers, such as family physicians and nurse practitioners, are well positioned to identify people who would benefit from a palliative approach to care. This would enable timely advance

care planning as well as conversations about goals of care, comfort measures, informational needs, and care delivery and integration as a patient nears the end of life.

Internationally, primary care-based strategies have been developed for earlier identification of patients at risk of declining health and dying in order to optimise interventions.⁹⁻¹² In the UK, for example, the Gold Standards Framework for Primary Care⁴ includes identification triggers and prognostication guidance tools to identify people who would benefit from a palliative approach to care.^{9,10} However, these identification methods have not been as successful as hoped,^{4,13} are not systematic, and typically rely on labour-intensive identification during the course of clinical care. An audit of nine Scottish general practices, after the introduction of an intervention to enable anticipatory care planning, found that 60% of all those who died were identified before death as needing a palliative approach to care; of those dying of cancer, 75% were identified, whereas 41% of patients with organ failure and 66% of patients with frailty/dementia were identified before death.¹⁴

The authors have developed a validated algorithm using primary care electronic

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How this fits in

Identifying patients with advanced life-limiting chronic illness earlier in their disease trajectory is the first step in the delivery of high-quality end-of-life care. Strategies have been developed for use in primary care to identify patients at risk of declining health and dying, with increasing interest in using electronic medical record data to automatically identify these patients at the practice level. This study shows that Canadian stakeholders perceive early identification in primary care, including use of electronic medical record-based identification strategies, to be acceptable and aligned with the positioning of primary care. Their concerns focus more on what to do after identification to ensure that primary care providers are able to support identified patients in advance care planning and optimally deliver a palliative approach to care post-identification.

medical record data to identify people who are at risk of dying within 12 months.¹⁵ Such an algorithm can be incorporated into the back-end of electronic medical records to systematically and routinely generate practice-based lists of patients who would benefit from a palliative approach and conversations about end of life, such as advance care planning and goals of care discussions. Although identification is fundamental to providing timely end-of-life care, little is known about the perceptions of doing so or the broader implications and impacts. The objective of this study was to explore the acceptability and implications of using a primary care-based electronic medical record algorithm to help providers identify patients in their practice at risk of declining health and dying.

METHOD

This qualitative descriptive study¹⁶ used focus groups, supplemented by one-on-one interviews, with healthcare providers, managers, and policymakers in two Canadian provinces. Data collection and analysis procedures largely employed a grounded theory approach,¹⁷ although there was no attempt to develop a mid-range theory from the data.

Participants

Participants were healthcare providers (physicians, nurses, and social workers), managers, and policymakers working in primary care, palliative care, geriatrics, long-term care, and home care in Nova Scotia and Ontario, Canada. They were purposively

sampled to gain maximum variation with respect to care setting and profession or role. Four researchers identified potential participants based on their knowledge of individuals working within or responsible for programmes and services in each care setting. A research coordinator initially approached each potential participant via email or telephone to introduce the study and invited them to participate, with a follow-up attempt 1 week later for those who failed to respond.

Data collection

Six focus groups were conducted to gather participants' views on the acceptability of using early identification strategies in primary care (including electronic medical record-based strategies) and the clinical, policy, and social implications of primary care-based identification. Patton¹⁸ and Rubin and Rubin¹⁹ provided practical guidance for the focus group questions (further information available from the authors on request). The focus group questions were not piloted before data collection; however, they were developed through an iterative process that included input from researchers with expertise in qualitative methods, primary care, and palliative care; primary care providers; a social worker; a decision-maker; and two community citizens. Two researchers in each province, experienced in qualitative methods, facilitated the focus groups, which included three to five participants per group. These facilitators did not have clinical backgrounds; rather they were PhD or Master's-trained health services researchers. In Nova Scotia, most participants did not previously know the facilitators; in Ontario, most participants knew the facilitators before taking part in the focus groups. In all instances, participants knew the facilitators through interactions in professional settings. All focus groups were grouped by profession/role (healthcare providers or managers/policymakers) although some managers/policymakers had dual roles, practising as clinicians as well. Five telephone interviews were conducted with participants who were unable to attend the focus groups because of scheduling conflicts. The same questions were used to collect the interview data. All focus groups and interviews were audiotaped and transcribed verbatim by an experienced transcriptionist.

Data analysis

Concurrent with data collection, the data were analysed using a constant

comparative approach.¹⁷ This entailed open and axial coding of focus group and interview transcripts, specifically reading/re-reading the transcripts, applying a coding scheme to the transcribed text, and grouping the coded text into more abstract categories and themes. Researchers coded the data from each province, with regular team meetings to review the coded data, discuss and confirm emerging themes, and probe theoretical saturation. These processes were iterative and continued until researchers perceived that the final themes were adequately captured and reflected the entire dataset. Data collection and analysis continued until theoretical saturation was reached, that is, the point whereby no new substantive information was being collected to develop the explanation.¹⁷ Qualitative software NVivo (version 10) was used to assist with data management and to enable comparison and synthesis of codes.

RESULTS

Twenty-nine healthcare providers, managers, administrators, and policymakers participated in this study (Table 1). Seven of these participants held dual roles as managers or policymakers and clinicians. The analysis resulted in six themes prevalent across the dataset:

- early identification is aligned with the values, aims, and positioning of primary care;
- providers have concerns about what to do after identification;
- how we communicate about the end of life requires change;
- early identification and subsequent conversations require an integrated team approach;
- for patients, early identification will have implications beyond medical care; and
- a public health approach is needed to optimise early identification and its impact.

There were no substantive differences in perspectives across provinces or professional roles. There was a tendency for some participants with dual roles to adopt a more clinical versus decision-maker perspective.

Early identification is aligned with the values, aims, and positioning of primary care

Participants viewed primary care-based identification as acceptable, with primary care described as an ideal setting (for most patients) for early identification and advance care planning conversations to occur. This perception was due to longitudinal patient-provider relationships that develop in primary care, as well as the upstream nature of primary care, allowing important conversations to occur before more serious events necessitate contact with acute care:

'The other benefit is that we see them over a long period of time, so the earlier we start ... The one thing I think that we bring, that a family doctor does bring, is a very long relationship and therefore a very solid lever to ease them into the process.' (Healthcare provider [HCP], focus group [FG] 2)

Participants perceived early conversations as integral to preparing patients and families for end of life, increasing communication among patients and families, and allowing them to focus on important life affairs, such as emotional or spiritual closure, relationship building or repairing. As one participant said:

'I can see a lot more closure on the family and a lot more relationship building and so on if they were to know that this person was in their last months or year of life.' (HCP, FG3)

Many also noted that early identification might benefit the healthcare system via reducing healthcare provider stress and workload, for example, by preventing crisis situations or reducing the need to rapidly access needed services or supports for patients close to death because they were not anticipated or planned earlier, and ensuring more effective use of resources.

Providers have concerns about what to do after identification

Participants' concerns were not around early identification *per se*, but rather around what to do after identification. These concerns included how best to initiate sensitive and supportive conversations, and

Table 1. Participants by province and role (n = 29)

Role	Ontario	Nova Scotia
Healthcare providers ^a	6	10
Managers/administrators/policymakers	1	5
Dual role ^b	3	4

^aHealthcare providers included physicians, nurse practitioners, clinical nurse specialists, registered nurses, care coordinators, and social workers. ^bSome participants held dual roles in the healthcare system: both managerial/administrative roles and clinical roles.

whether supports would be available to help providers deliver a palliative approach to care post-identification. Participants perceived that many primary care providers lack the knowledge and skills, particularly communication skills, to sensitively and effectively initiate conversations around a patient's values, wishes, and goals for future health care. They believed that this was particularly important for patients experiencing general decline or frailty versus those with a terminal diagnosis, given the added challenges of initiating conversations with patients who may be entirely unaware of their poor health status or prognosis. Thus, the introduction of primary care-based identification would necessitate enhanced training among primary care providers, as emphasised by one provider:

'I think we require a lot more [training] than we're getting ... the clinical implications will be way more powerful and appropriate. People just aren't trained up to do this.' (Dual role, FG5)

Participants highlighted several issues further underlining the need for improved training in communication skills and in delivering a palliative approach to care. First, patients will differ in their preferences regarding end-of-life conversations and thus conversations must account for individual needs and preferences, including cultural differences. Second, there is a pervasive medicalised culture of treatment until the very end focused on 'fixing' the problem. This culture was exemplified by one participant when thinking through the clinical application of the identification algorithm:

'I think my first reaction, if I see a thing pop up on my screen and say risk of dying in 12 months, my first instinct is going to be "Okay, what can I fix? What am I missing? What things can I work on to improve their health?" Which I think is OK.' (HCP, FG4)

Participants further emphasised that this culture would need to change to truly integrate a palliative approach into care.

To facilitate care post-identification, participants emphasised the need for provider- and patient and family-based supports. For providers, these supports included tools such as checklists, decision support tools, and toolkits to engage in advance care planning and delivering a palliative approach to care:

'So now we have a tool, so now we have to

do something with it, we have to put those things in place. Would be possible to have an algorithm that leads you through what needs to be done? ... Because otherwise you are overwhelmed with stuff.' (HCP, FG2)

Participants perceived that patient/family supports must include informational and educational resources, multidisciplinary services, and programmes to address patients' and families' emotional and psychosocial needs, as well as community-based resources to allow people to remain in and die at home (when this is a patient's preference). Participants thought that many of these supports are lacking in existing primary care and community settings. Some expressed ethical concerns about early identification given that many patients' and family members' goals may not be met at present because of a lack of available community-based programmes and services for patients nearing end of life. As one participant stated:

'I think about the lack of resources though. So if there is this strategy [for early identification] ... uhm, what do you do with that when you don't have the resources in the community in terms of, like, intervening?' (HCP, FG3)

How we communicate about the end of life requires change

The data demonstrated widespread agreement among participants that advance care planning is occurring too late in current practice, with these conversations usually triggered in response to a definable moment, crisis, or diagnosis of a terminal illness. Participants recognised that advance care planning is not a one-time discussion, but rather an ongoing process involving multiple discussions over time adapted to patients' and families' changing needs and preferences:

'It's not a one-time conversation either, right? It's something that you, it's an ongoing conversation.' (Manager/policymaker, FG5)

Yet, they highlighted there is limited time for quality conversations, and workloads often prevent the required depth of discussion.

As a result, participants believed end-of-life conversations need to be systematised within healthcare settings, and viewed a practice-based electronic medical record algorithm plus supports as tools that would help facilitate a more systematic and coordinated approach in primary care. They

viewed the algorithm as a useful trigger to initiating end-of-life conversations and one that would objectively validate their own perceptions of a patient's declining health, and believed it would help normalise these conversations for providers and, eventually, patients and families. Participants also emphasised the need to reframe end-of-life conversations away from when a patient might die to how the patient will die. In other words, this was to reframe discussions around quality versus quantity of life:

'It's the journey. It is really the journey, how you live well in that last 12 months. That needs to be the focus, I think, to some degree to talk about, you know, how you go out with a bang. And how do we have that conversation, I think, rather than you know the time is ticking ... It is "focus on what you really want to do now, we are going to help you do that so we all want to know what you want to do so that we can help you do it".' (HCP, FG2)

Early identification and subsequent conversations require an integrated team approach

Although participants viewed primary care as an ideal setting for early identification, they believed that end-of-life conversations cannot be limited to a specific profession or setting. Participants emphasised that end-of-life conversations require a team approach and process, both inside and outside of primary care. Inside primary care practices, a team approach was believed necessary to mitigate capacity issues (for example, family physicians cannot do everything) and leverage each team member's unique skillset and expertise, such as family physicians, advance practice nurses, social workers, and pharmacists:

'We have kind of silo practices, and I can't help but feel that if you were on your own, those are very difficult conversations to have because it is not just a conversation, it's a number of conversations. It's a bit of a story that has to happen. And I can't help but feel that whatever the need of the team might be, a physician, social workers, nurse, whatever you have, I think you need to have that team around you as a physician to have these. I think it is very difficult to do it in isolation as a professional ... If you want to have that shift in culture, then it is not one conversation by one provider at one episode of care.' (Dual role, FG1)

Outside of primary care, participants viewed improved integration across

healthcare settings as paramount to realising the benefits of early identification and advance care planning. Everyone involved with a patient's care should be aware of their advance care plan. Conversations and goals of care planning are part of everyone's job, and they need to be well coordinated and communicated across healthcare providers and settings:

'There's many people involved. It's not just the primary care and it's not just frontline staff. Somehow that whole network of care providers needs to be on the same page with the patient ... who initiates the dialogue, how that's carried through.' (HCP, FG6)

For patients, early identification will have implications beyond medical care

Participants noted that early identification will not only trigger medical discussions but will also prompt patients to undertake life planning. In other words, they perceived that primary care-based identification would not only lead to discussions around a patient's values, wishes, and goals for future health care, but also around important life issues and considerations. Participants discussed how 'the things that matter' to many patients as they near end of life are not medical in nature but rather related to spending time with family, repairing relationships, and/or finding emotional or spiritual closure. They noted that many providers might not feel equipped to discuss such issues, or neglect to address them in the context of their medical duties:

'I get caught up with the details of pain relief and whatever, and I don't sometimes stop to say, like the guy I saw the other day, "You should get up to your cottage and enjoy it as much as you can." That didn't come out at all.' (HCP, FG2)

Yet participants viewed helping patients address their important life issues as a key component of supporting a good dying experience.

A public health approach is needed to optimise early identification and its impact

Participants discussed the need for a public health approach to early identification and end-of-life care, which engages communities and the public at large. They noted that the current system — wherein many patients are identified too late in their illness trajectory and do not benefit from well-coordinated care that meets their needs and goals — has considerable health

and system consequences, and there is great potential to improve quality of life as people near end of life. To truly benefit patients and families, participants believed we must broaden our focus beyond the medical care delivery system to recognise communities' and governments' roles in delivering high-quality end-of-life care. For example, participants mentioned the important role of charitable (such as the Alzheimer's Society and Meals on Wheels), community (such as seniors' groups), and faith-based organisations in ensuring that people have the practical, social, and spiritual supports they need to live well as they near the end of their lives.

Finally, many participants acknowledged that death and end-of-life care should be approached as social issues rather than purely medical issues, and thus would benefit from community engagement and involvement. As one participant stated:

'If we are looking at being progressive about this ... do we look at the broader social determinants of health? Do we look at community leaders? And how do we influence them so that they are now saying, "Oh wait, as a community we know that we have a number of individuals who are not doing so well"? I think that there is a really big opportunity to think differently than we traditionally have.' (Dual role, FG1)

DISCUSSION

Summary

This study is among the first to empirically investigate the acceptability and implications of using a primary care-based electronic medical record algorithm to help providers identify patients at risk of declining health and dying. Despite identifying some practical challenges, participants viewed primary care-based identification as acceptable and aligned with the positioning of primary care. In fact, these stakeholders were much more concerned with how primary care providers would navigate the post-identification period than with early identification itself.

Participants were also acutely aware of the implications of early identification, including the need for a team-based approach to identification and subsequent delivery of care, the non-medical life impacts on patients and families, and the importance of engaging broader communities to ensure that people live and die well after identification. These findings are important to consider as jurisdictions begin to prioritise and develop efforts to proactively identify people who may benefit from a palliative approach to care before

they reach the final stages of their illnesses.

Strengths and limitations

This study was conducted in two Canadian provinces only and therefore may not be generalisable to other areas. The aim of qualitative research is not to achieve generalisable results but to gain a rich understanding of people's perceptions and experiences. However, the findings were markedly similar across provinces and participants, despite differences between provincial health system characteristics and across participants' roles and settings. Specifically, the provinces differ with respect to population size (13.4 million residents in Ontario versus <950 000 residents in Nova Scotia) and health system organisation (there are 14 health authorities in Ontario versus one health authority in Nova Scotia). Moreover, to gain diverse viewpoints on the topic of interest, participants were purposively sampled to gain maximum variation regarding care setting and role; in other words, they did not self-identify to be participants in this study because they were proponents (or opponents) of early identification and/or primary care-based delivery of palliative care. Together, these features serve to strengthen the transferability of findings to other similar settings with publicly funded healthcare systems.

Comparison with existing literature

Despite a growing emphasis on the identification of people who might benefit from a palliative approach to care,^{9,10,12} few researchers have explored the acceptability and implications of identifying people at risk of declining health and dying earlier in their illness trajectory. One exception is a 2015 study from Scotland that tested the feasibility of running computerised searches of primary care electronic medical records to identify patients with deteriorating health who would benefit from palliative care planning.⁶

As part of that work, the authors explored the acceptability of such searches from the perspective of primary care providers and reported somewhat divergent findings. Specifically, they reported resistance among primary care teams to expand patient identification using computerised (electronic) searches of electronic medical record data and hesitancy about labelling patients as 'palliative' because of its association with terminal care. Participants in the current study did not express such hesitancy, nor did they identify concerns around the premature identification of people for whom

treatments might be unilaterally withdrawn. Such fears were previously expressed in the UK, particularly around implementation of the Liverpool Care Pathway.²⁰ Rather, the participants in the current study viewed earlier identification as a means to allow people to live and die as well as possible. The authors of the Scottish study⁶ also reported that many primary care providers grappled with identifying precisely what they might do to enhance the care of many of the patients identified by the computerised search. Participants in the current study did specify many supports and resources necessary for patients and families post-identification. At the same time, they also expressed concerns about their ability to access these supports if they were to begin identifying patients in their practices.

The differences in acceptability between this study and the Scottish study may reflect the prevailing sociohistorical context in which identification will occur. For example, the UK has arguably experienced more public controversy regarding caring for people at the end of life. Indeed, media scrutiny of the Liverpool Care Pathway was widespread, leading to an independent review of its use and experience in England.²⁰ Acknowledging this controversy, the authors of the Scottish study stated:

*'A badly-designed and implemented computer search would rightly attract negative press attention if it focused on planning for "dying" rather than helping people live as well as possible to the end of their life.'*⁶

Such controversy has not occurred in a widespread way in Canada. Moreover, there is increasing support in Canada for the important role that primary care providers in particular play in delivering a palliative approach to care.^{21–23} This is evidenced in Nova Scotia's provincial palliative care strategy, which is explicitly rooted in primary care.²¹ Participants believed that two main implications of early identification were the need for increased communications skills training for primary care providers and enhanced post-identification supports and resources for primary care providers and patients and families. The former is not surprising: many practising clinicians continue to report discomfort and hesitancy when initiating end-of-life discussions^{24–27} and, as a result, many end-of-life communication skills training programmes have been developed worldwide.^{28–30} However, the impact of these programmes remains unclear, with recent

systematic reviews^{31–33} finding only low-quality evidence on their effectiveness for measures such as providers' self-efficacy and communication scores, and very little evidence that they impact patient-level outcomes. Many jurisdictions are intervening with the aim of improving post-identification discussions and resources. One example is the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) process in the UK.³⁴ ReSPECT provides a framework to support conversations about goals of care, including guidance on how to frame these conversations and a template for a summary care plan that remains with the patient.

Participants discussed the need for a public health approach to early identification and end-of-life care to maximise impact. They thought that engaged governments and communities are needed to increase the reach and effectiveness of formal medical care services, including optimising the social supports that patients and their families need as they near end of life. This aligns with attempts to integrate health and social care in many jurisdictions.³⁵ Scotland, for example, has recently enacted legislation that requires the local integration of health and social services.³⁶ Such integration aims to ensure home- and community-based care, and supports are designed around the patient, with potential to better address the health and social needs of people nearing end of life. This also aligns with the compassionate cities and communities approach,^{37,38} which purports that end-of-life care is everyone's responsibility and not just a task carried out by formal medical and social services.³⁹ In this study, participant views may have reflected ongoing efforts to mobilise such communities in Canada as well as a focus of Ontario's Family Health Teams (patient-centred medical homes) on public health, prevention, and avoiding costly interventions in acute care settings.⁴⁰

Despite limited evidence on the effectiveness of a public health approach on end-of-life care and patient and family outcomes, research has demonstrated that community engagement in end-of-life care can have beneficial practical (direct) impacts on at-risk patients and their families, and can help develop community capacity to care for people nearing end of life.⁴¹

Implications for research and practice

Participants were supportive of primary care-based identification, but highlighted numerous implications of implementing identification tools in practice. On a

practical level, these included the need for additional training and provider- and patient and family-based supports to optimise post-identification care as well as a team-based approach to identification. Those implementing early identification strategies, including electronic medical record algorithms, must consider these implications, and understand the best ways to address the stated concerns if they are to achieve maximal impact for patients and families. That providers believe they

need enhanced training means that future research on communication skills training must employ higher-quality designs and more patient-relevant outcomes so that we can design and implement programmes of known benefit. Future research is also warranted on models of community-based care that work for older adults (and their families) who are nearing the end of life and how to adapt and implement such models in varied contexts with differing resources and constraints.

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Ethical approval

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Provenance

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Competing interests

The authors have declared no competing interests.

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