Enhancing the primary healthcare system's ability to identify and plan with seriously ill frail elderly

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Overview

- Why we think early identification is important
- What we are doing
- What we expect to find

My goal is to get you excited about early identification and care planning

Research team

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Partners: Nova Scotia Health Research Foundation, Nova Scotia Hospice Palliative Care Association, Capital Health District Dept of Family Practice

*Knowledge user members; ¶HQPs; §Citizen members

Early identification

- Identification is an essential first step toward delivering high quality end-of-life (EOL) care
- Identification often occurs too late for proactive needs and desired care plans to be put into place
- Early identification is associated with ⇧outcomes
  - Goal setting, coordination, access to services, fewer hospitalizations, fewer hospital deaths, increased bereavement support

Harrison et al 2012 *Br J Gen Pract*
Baker et al 2012 *Br J Gen Pract*

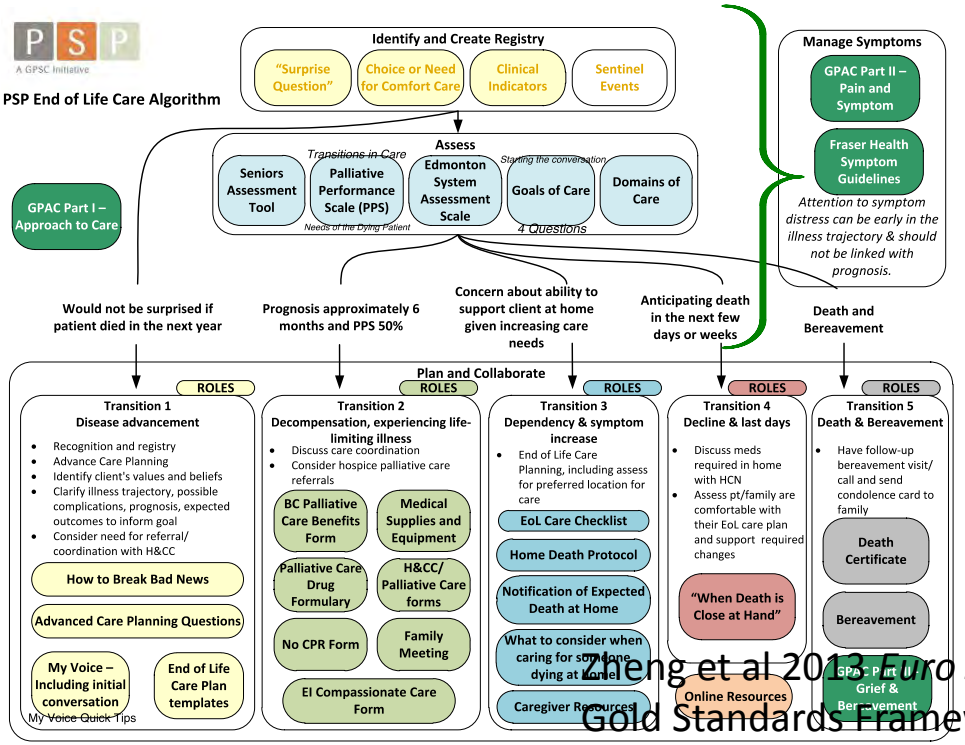
Primary health care (PHC)

- Upstream contact and longitudinal patient-provider relationships
- Most Canadians are seen by a PHC provider
- Well positioned to identify persons and initiate timely, person-centred conversations about EOL care
- Initiating a palliative approach ‘upstream’ in PHC may avoid the need for acute care and improve outcomes from acute care when accessed

Identification in PHC

- PHC-based strategies developed for earlier identification of patients at risk of declining health and dying

- Current ider ul as hoped, not s nsive identificatio



Zheng et al 2013 *Euro J Palliat Care*
Gold Standards Framework

Unintended consequences

- Little known about perceptions of early identification or the broader social implications and impacts

- UK Dying Matters Campaign (2012)
  - Aimed to help GPs identify the 1% of patients estimated to have < 1 year to live in order to begin conversations and plans for EOL care

Thousands of patients have already been placed on 'death registers' which single them out to be allowed to die in comfort rather than be given life-saving treatment in hospital, it emerged last night.

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3,000 doctors putting patients on 'death lists' that single them out to be allowed to die

By STEVE DOUGHTY FOR THE DAILY MAIL

PUBLISHED: 00:23 GMT, 18 October 2012 | **UPDATED:** 06:48 GMT, 18 October 2012

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Thousands of patients have already been placed on 'death registers' which single them out to be allowed to die in comfort rather than be given life-saving treatment in hospital, it emerged last night.

Nearly 3,000 doctors have promised to draw up a list of patients they believe are likely to die within a year, Department of Health figures showed yesterday.

As part of an unpublicised campaign endorsed by ministers, GPs have been encouraged to make lists – officially known as End of Life Care Registers – of people they believe are going to die soon and should be helped to do so in comfort.

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GPs have been paid bonuses to put elderly patients on controversial 'death lists' in an attempt to save the NHS money by cutting the number of people who die in hospital.

Revealed: How GPs are paid £50 bonus to put elderly on 'death lists'

- **GPs paid to draw up 'end-of-life advanced care plans'**
- **Documents seen by Mail on Sunday say 'key objective' is 'reducing healthcare costs'**
- **Every death outside of hospital saves the NHS almost £1,000**

By JONATHAN PETRE FOR THE MAIL ON SUNDAY and STEPHEN ADAMS FOR THE MAIL ON SUNDAY

PUBLISHED: 22:23 GMT, 19 October 2013 | **UPDATED:** 22:23 GMT, 19 October 2013

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GPs have been paid bonuses to put elderly patients on controversial 'death lists' in an attempt to save the NHS money by cutting the number of people who die in hospital.

They have been given £50 a time to draw up 'end-of-life advanced care plans' for patients they predict will pass away within a year.

The payments are designed to encourage doctors to start talking about death with elderly and seriously ill patients and to keep a record of where, ideally, they would like to die.

Those behind the 'yellow folder' scheme – so named as that is where the care plan forms are kept – insist its main aim is to give patients a better death.

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Our burning question

How do we ensure EOL conversations happen in a timely, appropriate, and responsive way so we can deliver high quality, person-centered care and optimize patient, family, and health system outcomes for seriously-ill, older persons living with frailty in Canada?

Specific objectives

1. Develop a validated electronic algorithm to help PHC providers identify older persons in their practice who are frail and/or at risk of declining health and dying
2. Investigate how the algorithm can best be adapted and implemented within varied PHC settings
3. Understand the clinical, policy, and social implications of PHC practice-level identification for providers, policymakers, patients, families, and citizens
4. Provide evidence-based recommendations and an action plan for improving the capacity of PHC providers to engage in EOL conversations and ACP upon identification

Develop a validated algorithm

Cohort = patients 70+ from CPCSSN dataset

1. Development = retrospective examination of MaRNet-FP data (Maritime practices)
   - Multivariable logistic approach to assess probability of death
   - Variables built on feasibility work from another TVN-funded study; indicators from GSF, SPICT, laboratory results, medications, frailty scales
2. Validation = apply algorithms to patients from other CPCSSN datasets
3. Application = apply and revalidate algorithms prospectively in real-world setting

Taljaard et al 2014 *BMJ Open*
Manuel et al 2012 *J Epi Community Health*

Adaptation & implementation

- Focus groups with PHC providers (4 in NS, 2 in ON)
  - Satisfaction; benefits and challenges of identifying 'at-risk' patients using EMRs; barriers/facilitators to implementation and scale-up; supports required to help providers act following identification
- Semi-structured interviews with key stakeholders in PHC EMRs, EMR tool development/policy, and tool implementation in PHC settings (4-6 per province)
  - Algorithm adaptation; barriers/facilitators to implementation and scale-up

Understand clinical, policy, & social implications

- Focus groups with providers and policy-makers (2 per province)
- Interviews with older persons living with frailty/ family members (16-20 per province)
  - Potential implications and impacts of EOL identification; how to minimize possible risks; what to do upon identification
  - Older persons/families' needs and preferences for initiating EOL conversations and ACP; views on how PHC can best meet those needs

Provide recommendations

- Two stakeholder dialogues (1 per province)
  - Informed by the McMaster Health Forum process
  - Citizens, older persons living with frailty/families, policy-makers, providers
  - Multi-stage process
    - Preparatory discussions/consultations
    - Distribution of a pre-event evidence brief
    - 1-day structured, evidence-informed discussion
    - Distribution of a post-event dialogue summary
  - Emphasis on *action*

Study outputs

- Valid electronic algorithm to identify older persons at risk of declining health and dying that is feasible for use with PHC EMRs
- Provider satisfaction with algorithm and computer-based EOL identification
- Knowledge of how to adapt and implement the algorithm across PHC settings in a way that aligns with current technology, addresses key barriers, leverages key facilitators, and supports PHC providers

Study outputs cont'd

- Knowledge of how to approach the issue of EOL identification (including issues on messaging to help mitigate potential harms & reduce the taboo of 'death talk' in general)
- Knowledge of older persons' and their families' needs and preferences related to engaging in EOL conversations and ACP
- Recommendations and implementation considerations to help PHC providers engage older persons with frailty and their families in EOL discussions and ACP upon identification in ways that are sensitive and responsive to their perspectives

Recent developments

Mason *et al. BMC Family Practice*
DOI 10.1186/s12875-015-0312-z

BMC Family Practice

RESEARCH ARTICLE Open Access

Developing a computerised search to help UK General Practices identify more patients for palliative care planning: a feasibility study

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Abstract

Background: Approximately 600,000 people die in the UK annually, usually after months or years of increasing debility. Many patients with advanced conditions are not identified for appropriate support before they die because they are not seen as having "palliative" care needs. General practice information technology systems can improve care by identifying patients with deteriorating health so that their healthcare needs can be reviewed more systematically and effectively. The aim was to develop and test a computerised search of primary care records in routine clinical practice as a tool to improve patient identification for a palliative care approach.

Methods: An iterative process of search design and testing followed by implementation and extended testing of the search output in clinical practice. A three-phase feasibility study: developing a computerised search, determining its ability to identify patients with deteriorating health from any advanced condition, and assessing how primary care clinicians use the results to improve patient care. The setting was twelve primary care teams in two Health Boards in Scotland.

Results: The search identified 0.6–1.7 % of patients in each practice who were not already on the palliative care register. Primary care clinicians judged that 30–60 % of these patients were at risk of dying or deterioration over the next 6–12 months. The most common action taken by GPs was to start an electronic anticipatory care plan.

Conclusions: It is possible to significantly improve the identification of patients for palliative care needs assessment using a computerised search however barriers remain to GPs' finding it acceptable. Time-efficient systems were important as was a generic tool for anticipatory care planning not linked to 'palliative' care.

Keywords: Primary healthcare, General practice, Palliative care, Qualitative research

Background

Approximately 600,000 people die in the UK each year, usually after months or years of increasing debility www.ons.gov.uk/ons/publications/index.html [1]. Although most patients spend the majority of their last year of life at home, around 50 % eventually die in hospital [5].

Most patients are not identified for a palliative care

"Recent controversies over the care of patients thought to be at the end-of-life should cause us to consider the benefits and potential harms of identifying relevant individuals, as well as how we can do it better."

"It is possible to significantly improve the identification of patients for palliative care' at an earlier stage than currently because of its widespread association with terminal care and connotations around "giving up" and "losing hope.""

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TVN Research Team Spotlight: Advance Care Planning