Breaking down silos: Building better palliative care
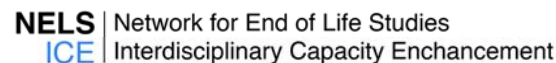
Co-Principal Investigators
Dr. Alix Carter, MD, MPH
Rebecca Earle, RN, MSc(A)

Project Team
Dr. Gerri Frager, MD
Dr. Marie-Claude Gregoire, MD, MSc
Grace MacConnell, RN, MN
Todd MacDonald, ACP

EHS
Emergency Health Services

NELS | Network for End of Life Studies
ICE | Interdisciplinary Capacity Enchancement

IWK Health Centre

Conflict of interest

* The investigators have no conflict of interest to declare

* The investigators are grateful for project funding received from NELS ICE

* Thank you to research assistant, paramedic Todd MacDonald, and to all participants

Background

* Advance Directives may include information about how to treat pain, breathlessness, seizures, cardiac or respiratory arrest

* Goal is to ensure individual and family's wishes are respected and pain/suffering is avoided

* **Challenges:**

    * tendency to avoid discussing death and dying

    * in absence of clear AD, confusion arises and default is to follow usual care

    * in the case of paramedics: must follow a scripted protocol and do everything/transport

    * if family do not want to transport, there is a difficult discussion re: "acting against medical advice" and "refusing care" and family must sign refusal

Study purpose

✳ **Gap:** patients at the end of life are touched by many parts of the health care system - these parts often work in silos

    ✳ Silos are between: those who write ADs, those who use them and those who have means to make them accessible

✳ **Purpose:** Break down silos

✳ Find a way to ensure the wishes of the most vulnerable of patients:

    ✳ are known and accessible to health professionals in times of crisis

    ✳ have content that has clarity and meaning

Methods

* **Phase 1:** Candidate items for content:

  * RA conducted manual search of IWK directives binder

* Systematic review: Medline, Cinahl, Embase

  * "Palliative Care"[Mesh or title/abstract] OR "Terminal Care"

  * "Cardiopulmonary Resuscitation" OR "Resuscitation Orders" OR "Resuscitation") OR ("Advance Directives" OR "Living Wills" OR "Emergency Treatment OR "Advance Care Planning" OR "Medical Records" OR "LIFE-SUSTAINING TREATMENT"

  * FORMAT OR CONTENT OR template

  * List of candidate items finalized

Methods

* **Phase 2:** Survey derived from Phase 1

    * province-wide invitation to all paramedics, ED's (poster, email, websites)

    * representative panel of 12 each: paramedics, nurses and physicians

    * 3-round survey using Delphi methodology

    * survey: 5 –point Likert scale

    * opportunity to add items after first 2 rounds

Methods

* **Phase 3:** Facilitated focus group to determine workable method to make AD accessible

  * panel of technology experts, dispatchers, paramedics, IT communication experts, palliative care, general pediatrician,EDs, DHW

  * snowball method to invite panel members

  * pre-meeting structured interviews to establish basis for discussion

Results
Phase 1: What is the content now

* **A) review of existing directives (IWK)**

* 120 directives in binder

* >70% had name and specialty of doctor, year of birth, date of protocol, in hospital treatment instructions

* 12.6% had no physician name on them

* 41.2% listed next of kin

* 25.2% addressed respiratory compromise

* 16.8% addressed cardiac arrest; 1.7% addressed onther rhythms

* 37.0% addressed transport (yes/no/conditions)

* Allergies listed 25.2%

* Medications listed 26.9%

Results
Phase 1: what is the content now

- **B) review of the literature**

- 42 articles

- 2 authors reviewed title and abstract for relevance

- 36 articles retained

- one team member abstracted data from each article

- Physician info (7 articles)

- Effective date (6)

- Next of kin (6)

- Feeding (18)

- Pain (10)

- Respiratory compromise/ventilation (9)

- Cardiac arrest (16)

- Other terms added to list include: religious needs, patient and family awareness, lay person terms, need for "legal" form, ICU admission, organ/tissue donation, choice of location and caregiver, autopsy, surgery and other in hospital treatments

Results

Phase 2: what content do end users need?

- Round 1: 58 candidate items

    - No indicators met significance for exclusion as "not important"

    - 27 items (46.6%) met significance for retention as "important"

    - 13 items added

- After round 2, no items met significance as "not important"

    - 12 items were retained as "important" of which 6 had been added after round 1

Retained after 2 rounds

- After hours contact for someone from care team/doc who helped write the AD

- Effective date of last revision

- Next of kin, Relationship to patient, Contact info

- Decision making capacity

- Directives about hydration

- Directives about pain control

- Whether would want IV access

- How to treat seizures

- Respiratory distress, specifics regarding secretions

- Breathlessness

- Whether would want supplemental Oxygen

- Resp distress requiring ventilatory support

- Whether to treat cardiac arrest

- Whether to treat other non-arrest rhythms

- Whether would want blood transfusion

- Whether would want blood fractions

- If/ When/ Where to transport

- Allergies

- Medications

- Past medical history

- Organ donation

- Specific conditions to limit care

- Overall goals of therapy

- Choice of caregiver

- Preference for place of death

- Directives should include medical and plain language terminology

- Emergency situations should be grouped together

- Emergency situations should all be covered on page 1

- There should be a provincial standard form

- There should be one form for all directives

- Form should be laid out in order of treatments

- Form should be signed by patient and family

Controversies after 2 rounds

- **Health Card Number**: MD and medics thought was important, RNs did not

- **Feeding:** RN and MD important, medic not

- **Surgery, antibiotics, dialysis, anxiety**: RN and MD "important"

- **Use of term "kept alive artificially":** RNs voted out, medics almost voted in

- **Use of term "kept alive by machines":** RN and MD voted out, medics unsure

- **"treat all emergencies" and "usual care unless specified"** were in for MD and medic, out for RN

- Almost in for all: whether would want ICU, venipuncture, people not to be present, list of who is aware

Results Phase 3: how can we make AD accessible to end users?

- Current experience

  - Grey areas difficult for unknown patients

  - Schools have major struggle

  - Long term care facilities noted to be quite variable, may benefit from standardization and policies/education

  - Hospitals: Multiple versions, hard to find, doesn't communicate with out of hospital

  - Patients with no doctor are lost (*rural)

Results phase 3

- Communication, language are major obstacles/opportunities

  - Many forms only address death not what comes before

  - Fear of getting no care

- Broader system issues: do we have the resources?

- *EHS Special Patient Program (SPP)* covers some of these people now

  - Could address standardization and education

  - Current format may take too long to update and needs resources/revamp

Results phase 3: solutions

- Centralized database essential

- Provincial EMR/sharepoint maybe helpful but not timely

- EHS SPP could work

  - A pilot program was suggested

  - Adults and peds needs may differ on some issues

  - Database would need updating

  - Personnel would need to be dedicated

- Perhaps even the existence of SPP would encourage writing and DISCUSSION

- Could be platform for education, clarity of language and intent

Limitations

✳ Phase 1 limited to pediatric population in single province, may not capture full range but supported by literature review

✳ Phase 2 Delphi limited by participation by MD and RN – medics may be over-represented, all from single system but from whole province

✳ Phase 3 Focus group snowball method may not capture full range of opinion or possibility

Conclusion

✳ Silos between stakeholders, schools, long term care, in and out of hospital

✳ A concensus-based template for content has been derived from an evidence-based list of candidate indicators

   ✳ Some items may need to be included because they meet a specific need of one stakeholder group

✳ A standard form with emergency conditions and meeting needs of all is desirable and possible

✳ A centralized database and significant education of citizens and providers is critical for accessibility and uptake