Breaking down silos:
Building better palliative care

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Conflict of interest

- The investigators have no conflict of interest to declare
- The investigators are grateful for project funding received from NELS ICE
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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
<table>
<thead>
<tr>
<th>After hours contact for someone from care team/doc who helped write the AD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Effective date of last revision</td>
</tr>
<tr>
<td>Next of kin, Relationship to patient, Contact info</td>
</tr>
<tr>
<td>Decision making capacity</td>
</tr>
<tr>
<td>Directives about hydration</td>
</tr>
<tr>
<td>Directives about pain control</td>
</tr>
<tr>
<td>Whether would want IV access</td>
</tr>
<tr>
<td>How to treat seizures</td>
</tr>
<tr>
<td>Respiratory distress, specifics regarding secretions</td>
</tr>
<tr>
<td>Breathlessness</td>
</tr>
<tr>
<td>Whether would want supplemental Oxygen</td>
</tr>
<tr>
<td>Resp distress requiring ventilatory support</td>
</tr>
<tr>
<td>Whether to treat cardiac arrest</td>
</tr>
<tr>
<td>Whether to treat other non-arrest rhythms</td>
</tr>
<tr>
<td>Whether would want blood transfusion</td>
</tr>
<tr>
<td>Whether would want blood fractions</td>
</tr>
<tr>
<td>If/ When/ Where to transport</td>
</tr>
<tr>
<td>Allergies</td>
</tr>
<tr>
<td>Medications</td>
</tr>
<tr>
<td>Past medical history</td>
</tr>
<tr>
<td>Organ donation</td>
</tr>
<tr>
<td>Specific conditions to limit care</td>
</tr>
<tr>
<td>Overall goals of therapy</td>
</tr>
<tr>
<td>Choice of caregiver</td>
</tr>
<tr>
<td>Preference for place of death</td>
</tr>
<tr>
<td>Directives should include medical and plain language terminology</td>
</tr>
<tr>
<td>Emergency situations should be grouped together</td>
</tr>
<tr>
<td>Emergency situations should all be covered on page 1</td>
</tr>
<tr>
<td>There should be a provincial standard form</td>
</tr>
<tr>
<td>There should be one form for all directives</td>
</tr>
<tr>
<td>Form should be laid out in order of treatments</td>
</tr>
<tr>
<td>Form should be signed by patient and family</td>
</tr>
</tbody>
</table>
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 consensus-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