Introducing electronic quality of life assessments in hospital palliative care: A micro-meso-macro framework

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Welcome

• Q&A session

• Please submit your Qs online during presentation

• We will answer as many Qs as time permits

Carol Barrie, Executive Director
Reminder: Survey & Webinar

- **Survey will pop up on your screen after webinar**
  - Feedback on how to improve webinar series

- **Webinar slides & video available for viewing online within 1-2 days at:**
  - cfn-nce.ca/news-and-events/webinars
Reminder: Upcoming Webinars

Register at:

- **Wednesday, December 6, 2017 at 12 noon ET**
  Exploring the preferences of older Canadians living with frailty for aspects of inpatient care: A best-worst scaling experiment – CFN-funded Catalyst Grant Program – Nick Bansback and Logan Trenaman, University of British Columbia

- **Wednesday, January 10, 2018 at 12 noon ET**
  Identifying older patients at high risk of poor outcomes after joint replacement surgery – CFN-funded Frailty Measures Implementation Grant Program – Daniel McIsaac, Ottawa Hospital Research Institute

- **Wednesday, January 24, 2018 at 12 noon ET**
  Reducing post-discharge potentially inappropriate medications amongst the elderly: a multi-centre electronic deprescribing intervention – CFN-funded Catalyst Grant Program – Todd Campbell Lee and Emily McDonald, McGill University Health Centre
2017 Catalyst Grant Competition

- Addresses ongoing concern of polypharmacy and related medication issues in older Canadians living with frailty

- Presented in collaboration with the New Brunswick Health Research Foundation (NBHRF) and the Canadian Institutes of Health Research (CIHR)

- Competition is now closed. Thank you to those who submitted applications
2017 Knowledge Translation Grant Competition

- Designed to advance previously funded CFN research evidence into practice

- Award recipients will be announced in the coming weeks
New Funding Opportunity

• A competition based on the results of the Canadian Frailty Priority Setting Partnership will be launched within the next month

• We are currently seeking partner organizations interested in co-funding this competition

• Stay tuned for further communication
New Funding Opportunities (HQP)

• 2018 Interdisciplinary Fellowship Program (IFP) and Summer Student Awards (SSA) are set to launch in December

• Details will be communicated through our website (www.cfn-nce.ca), Twitter (@CFN_NCE) and upcoming newsletter
Presenters

Introducing electronic quality of life assessments in hospital palliative care: A micro-meso-macro framework

- Professor at Trinity Western University
- Holds a Canada Research Chair in Person-Centred Outcomes at Trinity Western University
- Lead on Patient-Reported Outcomes at the Centre for Health Evaluation and Outcome Sciences (CHEOS) at Providence Health Care in BC

- Medical Anthropologist interested in all aspects of death, dying and institutionalized end-of-life care
- Lord Kelvin Adam Smith Fellow in the Department of Interdisciplinary Studies with the End-of-Life Studies Group at the University of Glasgow
- Former CFN Interdisciplinary Fellow

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2017-11-22
Introducing electronic quality of life assessments in hospital palliative care: A micro-meso-macro framework

The Quality of Life Assessment and Practice Support System (QPSS) initiative

Canadian Frailty Network Research Webinar

November 22, 2017

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Presenters

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The research is conducted in partnership with two companies that have a vested commercial interest in person-centred health information systems:

- Cambian Business Services Inc.
- Intogrey Research and Development Inc.

None of the investigators have any financial interest in the companies or their products. The studies are funded through federal competitive operating grants (Canadian Institutes for Health Research; Canadian Frailty Network).
Outline

1. Quality of life assessment

2. The Quality of Life Assessment and Practice Support System (QPSS) Initiative

3. Results from two studies:
   1. Integrating a QPSS in a multi-disciplinary palliative care unit
   2. Relational use of the QPSS by palliative outreach consult nurses

4. Conclusions & discussion
“The imperative of person-centered care means that patients’ and families’ quality of life, as well as their experiences with health care, should be routinely, and comprehensively, acknowledged and assessed.”

Öhlén, ... Sawatzky (2017)

“Our aim should be to find out what each patient wants, needs, and experiences in our health care system”

M. Gerteis et al. (1993)
Quality of Life Assessment
Giving voice to patients and families

The use of PROMs and PREMs to facilitate routine monitoring of fluctuations in people’s quality of life, including the health outcomes and healthcare experiences of patients and their family caregivers.

Patient-Reported Outcome Measures (PROMs) and Patient-Reported Experience Measures (PREMs), provide information about patients’ perspectives of their quality of life (QOL) and healthcare experiences without prior interpretation by a clinician or any other person.
Example PROM for Palliative Care

The McGill Quality of Life Questionnaire (MQOL) Revised

Physical symptoms
- Feeling physically well
- Physically unable to do things

Psychological
- Depressed
- Nervous or worried
- How often sad
- Fear of the future

Existential
- Meaning in life
- Achievement of life goals
- Control
- Self-esteem

Relationships
- Communication
- Relationships stressful
- Feel supported

Quality of life

Example PREM for Palliative Care
Canadian Health Care Evaluation Project (CANHELP)

EXAMPLE QUESTIONS:

You were treated by doctors, nurses, and other members of the health care team in a manner that preserved your sense of dignity.

Your emotional problems (for example: depression, anxiety) were adequately assessed and controlled.

<table>
<thead>
<tr>
<th>Domain</th>
<th># questions</th>
</tr>
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<tbody>
<tr>
<td>Relationships with care providers</td>
<td>3</td>
</tr>
<tr>
<td>Illness management</td>
<td>9</td>
</tr>
<tr>
<td>Communication</td>
<td>3</td>
</tr>
<tr>
<td>Decision making</td>
<td>4</td>
</tr>
<tr>
<td>Feeling at peace</td>
<td>1</td>
</tr>
</tbody>
</table>

Each question is rated on (1) Importance, (2) Satisfaction.

### QOL assessment instruments for use in palliative care

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Construct being measured</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td><strong>MQOL-R</strong>&lt;br&gt;McGill Quality of Life Questionnaire - Revised</td>
<td>Quality of life domains&lt;br&gt;physical, psychological, existential, and Social</td>
<td>14 items + 1 global measure</td>
</tr>
<tr>
<td><strong>ESAS-R</strong>&lt;br&gt;Edmonton Symptom Assessment Scale - Revised</td>
<td>Current symptoms</td>
<td>11 individual items measuring symptoms and well-being (1)</td>
</tr>
<tr>
<td><strong>QOLLTI-F</strong>&lt;br&gt;Quality of Life in Life Threatening Illness - Family Carer Version</td>
<td>Quality of life domains&lt;br&gt;environment, patient condition, caregiver’s own state, outlook, quality of care, relationships, financial</td>
<td>16 items + 1 global measure</td>
</tr>
<tr>
<td><strong>CANHELP-Lite</strong>&lt;br&gt;Canadian Health Care Evaluation Project Questionnaire</td>
<td>Satisfaction with end of life care&lt;br&gt;e.g., relationships with doctors and nurses, illness management, communication, decision making</td>
<td>2 versions:&lt;br&gt;-Patients: 20 items&lt;br&gt;-Family caregivers: 21 items</td>
</tr>
</tbody>
</table>
Quality of Life Assessment
Use of PROMs and PREMs to enhance person-centred care

Routine use of PROMs and PREMs can:

• Make patients’ and family caregivers’ concerns regarding their QOL more visible
• Raise awareness of problems that would otherwise be unidentified
• Lead to improved clinician-patient communication
• Result in improved care plans
• Improve collaboration among healthcare professionals

Despite the benefits of QOL assessments, the use of PROMs and PREMs to support homecare for older adults who have life-limiting illness has been limited.

EXAMPLE REFERENCES RE. USE OF PROMS IN PALLIATIVE CARE:
Quality of Life Assessment and Practice Support System (QPSS) Initiative
QPSS Innovation Community

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- Canadian Virtual Hospice
- Canadian Association of Retired People
- Family Caregivers of British Columbia

industry partners
- Cambian Business Services Inc.
- Intogrey Research and Development Inc.

health care services
- Health Authorities: Fraser Health; Alberta Health Services
- BC Ministry of Health Patient-Centered Measurement Working Group
An innovative, integrated health care information system for person-centred care that facilitates:

- use of QOL assessment instruments (including PROMs and PREMs) at point of care
- instantaneous feedback with information about scores, score interpretation, change over time, and targets for improvement
- capacity to integrate with other health information systems
QPSS Intervention

1. PURPOSE
   Obtain patients’ and family caregivers’ appraisals of their QOL and care experiences

   ACTION
   Client/patient & family caregiver complete QOL questionnaires

   EXAMPLES OF POSSIBLE ACTIONS
   - Review QOL assessment results with client/patient and FCG
   - Request completion of additional QOL assessment questionnaire
   - Refer to other services, as needed

2. PURPOSE
   Support QOL assessments in clinical practice

   ACTION
   Review QOL questionnaire results

3. GOAL
   Enhance person-centered care, shared decision-making, and continuity of care

   EXAMPLES OF POSSIBLE ACTIONS
   - Review QOL assessment results with client/patient and FCG
   - Request completion of additional QOL assessment questionnaire
   - Refer to other services, as needed
QPSS initiative

**COMPLEX INTERVENTION**
- QPSS integration in care for people with complex health challenges

**TARGET POPULATIONS**
- Patients and family caregivers
- Clinicians and decision makers

**SECTORS OF CARE**
- Primary care
- Tertiary care
- Outpatient clinics
- Consult teams

**ULTIMATE GOALS:** enhanced person-centered care, shared decision making, and continuity of care
QPSS Initiative Research Projects

1. Integrating quality of life assessments into acute care for older adults with chronic life-limiting illness (funded by CFN)

2. Integrating a quality of life assessment and practice support system in palliative home care (funded by CFN)

3. Integrating a Quality of Life Assessment and Practice Support System in Routine Clinical Practice:
   - Hemophilia clinic study
   - Palliative consult team study (Fellowship of Dr. Marian Krawczyk, funded by CFN)

4. ePRO Kidney: Electronic patient-reported outcomes in clinical kidney practice (Led by Dr. Kara Schick-Makaroff, funded by CIHR)

5. Integrating a quality of life assessment and practice support system in home care services for older adults with life-limiting illness and their families (funded by CIHR, eHIPP)
Two projects focusing on QPSS implementation in hospital-based settings

Integrating a QPSS in a multi-disciplinary palliative care unit

Relational use of the QPSS by palliative outreach consult nurses
Project 1: Integrating a QPSS in a palliative care unit

- How do hospital palliative care clinicians relate to different health care system priorities when integrating PROMS and PREMs into their practice?
Macro-Meso-Micro Framework

Health Care System Priorities

**MACRO**
- Accountability and health policy at regional, provincial and national levels

**MESO**
- Quality improvement at organizational levels

**MICRO**
- Enhanced person-centered care at the individual level

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Society-level focus on population health and decisions about cost, equity and health policy

Organization-level focus on identifying gaps in services, decisions about different types of treatments, and cost effectiveness

Heterogeneous stakeholders

Multiple health care priorities

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Individual-level focus on shared decision-making and enhanced continuity of care through integration in practice
KNOWLEDGE ABOUT THE USE OF PROMS & PREMS

STAGE 1: Local adaptation
- Development of site-specific implementation protocols
- Focus groups with clinicians
- Trying out the QPSS in practice
- Interviews with patients and family caregivers

STAGE 2: Evaluation
- Randomized controlled trial
- Patient- and family-caregiver outcomes
- Cost-effectiveness
- Qualitative evaluation of implementation

STAGE 3: Sustainability
- Knowledge translation
- Integration with other health information systems

Integrated Knowledge Translation Approach*

Setting and Sample

- **Setting**
  - 10-bed palliative unit providing specialized interdisciplinary team support within 300-bed suburban acute care hospital (B.C., Canada)

- **Data collection**
  - 5 focus groups with clinicians on user-centered design and implementation considerations
  - 24 interviews with clinicians on perspectives about PROMs and PREMs and use in practice

- **Qualitative interpretive analysis**
  - Experiences and perspectives of using QPSS
  - Perspectives about PROMs and PREMs in routine palliative care

### Clinician participants (n=25)

<p>| | |</p>
<table>
<thead>
<tr>
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<tbody>
<tr>
<td>Age: median(range)</td>
<td>43 year (23-63)</td>
</tr>
<tr>
<td>Years in position practice: median (range)</td>
<td>8 years (1-26)</td>
</tr>
<tr>
<td>Gender: female</td>
<td>80%</td>
</tr>
<tr>
<td>Born in Canada</td>
<td>72%</td>
</tr>
<tr>
<td>Occupation</td>
<td></td>
</tr>
<tr>
<td>Medical doctor</td>
<td>8%</td>
</tr>
<tr>
<td>Registered nurse</td>
<td>76%</td>
</tr>
<tr>
<td>Other</td>
<td>16%</td>
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Results: Practice Tensions

- Challenges experienced by clinicians who negotiate health care priorities expressed by diverse stakeholders within complex health systems.

Growing recognition of tensions

Benefits of mandated use
- Standardization and quantification
- Strengthens ability to provide PCC
- QOL everyone's concern

Benefits of discretionary use
- Constrains ability to provide PCC
- QOL domain of social work/spiritual care

Scope of practice
Results: Growing recognition of tensions

Growing recognition of tensions

Benefits of mandated use

- Initial enthusiasm about the potential benefits of mandated PROMs and PREMs use to simultaneously meet macro-, meso-, and micro-level priorities:
  - Enhanced palliative care services
  - Inform clinical practice and quality improvement
  - Enhance person-centred care focusing on QOL of patients and family caregivers

Benefits of discretionary use

- Increasing consideration of meso- and micro-complexities of “real” hospital practices
  - Workflow
  - Competing priorities
- Discretionary use to identify issues relevant to care and treatment
Results: Standardization and Quantification Tensions

- Clinicians referenced numerous positive considerations regarding potential to enhance person-centered care
- Some clinicians acknowledged the ability for generate data for administration, research, and policy
- Ambivalence regarding the purpose and accuracy of PROMs and PREMs
- Concern about negative impact on therapeutic relationships
- Concern regarding existing expertise in QOL assessment
Clinician: I do think that in nursing in general that we tend to rely too much on tools and protocols and not enough on personal communication and just quality assessments. And in my heart I think although these are validated tools, I think they're validated under certain conditions...I think that [we use ESAS-r] in a way that is not validated, for instance, and accreditation would be one reason...I don't think that any tool should be something that's a mandatory thing... And I think actually a lot of these tools are robbing nursing of the art of nursing...I can explore these things in a conversation that is far less clinical, probably more inviting to the person - although at times I think probably they would like the more anonymity of just interacting with a piece of paper or a tablet.
Results: Scope of Practice Tensions

- Routine assessments of QOL responsibility of every team member; routine use would improve every members’ clinical assessment skills and therapeutic relationship skills
- Continued to reference ideal benefits of all staff routinely assessing QOL and experiences of care
- QOL increasingly referenced as outside scope of practice; framed through meso- and micro-level considerations of workload issues, task-based care. PROMs and PREMs use outside “clinical” scope of practice but appropriate for social work and/or spiritual care
Clinician: I think it should be done maybe by either social worker or spiritual care coordinator, people that can sit down and talk about that, because I would feel that I'm not compassionate enough...Sometimes you ask one patient or one family member one question that requires a yes or no answer and they would go into like 10 minute conversation, which also pushes you back from what's waiting for you out there, the bells are ringing and stuff. I cannot relax in knowing that my other people are having pain...I just rather not put myself into those shoes that I ask the question and then I can’t fulfill that, so I’d rather not even initiate that conversation, because I know if I do, and maybe it’s not the best practice, but I feel if I start, I need to finish, and I can’t, and then I feel really bad...[and] when I leave, I have to put that smile back on and go to next room and pretend that nothing happened in the next room.
Project 2: Relational use of a QPSS in hospital palliative consult care

- Knowledge-to-action research project with palliative nurse consultants trialing the QPSS with older hospitalized adults receiving acute care.
- Primary aim of the study to understand consultants’ and patients’ experiences and perspectives of use regarding the desirable features of the QPSS and its use in clinical practice.
- Large tertiary acute care hospital in Western Canada.
Methods and Sample

- User-centered design informed by 3 focus groups with entire POCT team.
- 3 PROMs and PREMs chosen:

<table>
<thead>
<tr>
<th>Assessment</th>
<th>Domains</th>
<th>Items and Response Scales</th>
<th>Recall period</th>
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<tbody>
<tr>
<td>Edmonton Symptom Assessment System (Revised Version)</td>
<td>Pain, tiredness, drowsiness, nausea, lack of appetite, shortness of breath, depression, anxiety, well-being and other problem</td>
<td>10 questions ; 11-point Likert Scale</td>
<td>Present</td>
</tr>
<tr>
<td>Watanabe et al., 2011.</td>
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<tr>
<td>McGill Quality of Life (Revised Version)</td>
<td>Physical, psychological, existential, social, and overall quality of life</td>
<td>14 questions ; 11-point Likert Scale</td>
<td>Past two days</td>
</tr>
<tr>
<td>Cohen et al., 2017</td>
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<tr>
<td>Canadian Health Care Evaluation Project Lite Questionnaire - (Individualized Version)</td>
<td>Overall satisfaction with care, Relationship with doctors, illness management, communication, decision-making, feeling of peace</td>
<td>21 questions; 5-point Likert Scale</td>
<td>Past month</td>
</tr>
<tr>
<td>Heyland et al. 2013</td>
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Methods and Sample

- 2 nurse specialists within (POCT)
  - Consultants >10 years palliative-specific experience; both female
- 20 consenting older adult patients (55+)
- 78% patient response rate

<table>
<thead>
<tr>
<th>Patient demographics</th>
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<tr>
<td>Average age</td>
</tr>
<tr>
<td>Gender</td>
</tr>
<tr>
<td>Educational status</td>
</tr>
<tr>
<td>Diagnosis</td>
</tr>
<tr>
<td>Average length of diagnosis</td>
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</table>
Analytic approach

- Evaluation of implementation grounded in ethnographic approach
  - Direct observation (50 hours)
  - Interviews (POCT nurses and 3 patients)

- Thematic analysis informed by theoretical perspectives from social sciences
Findings

- Over 9 weeks, a total of 47 administrations with 20 patients.

<table>
<thead>
<tr>
<th>Assessment Tool</th>
<th># of patients</th>
<th># of administrations</th>
<th>Time to complete (75th %)</th>
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<tbody>
<tr>
<td>ESASr</td>
<td>12</td>
<td>20</td>
<td>2.8 m</td>
</tr>
<tr>
<td>MQOL-R</td>
<td>17</td>
<td>23</td>
<td>5.1 m</td>
</tr>
<tr>
<td>CANHELP LITE</td>
<td>5</td>
<td>5</td>
<td>12.3 m</td>
</tr>
</tbody>
</table>
Findings

- Mutual preference for relational use: most often assisted patients in using the QPSS.
- Nurses and patients referenced three primary benefits of using the QPSS.

- Facilitate relevant conversations about quality of life and experiences of care
- Promote therapeutic relationship building
- Rapid co-production of new knowledge about quality of life and care experiences
Preference for relational use

Patient

“It’s bringing things to the surface that maybe I need to examine. It helps me understand where I’m at. And I think that is important when you’re dealing with something like I’m dealing with… I preferred both of us sort of sitting together and doing it together. ...it just made for more communication and a little extra discussion...It created a bond”.

Nurse

“It just really connected us to [the patients], and we got so much more information and therapeutic information... where I was like, “Oh, you have shared with me some feelings that you hadn’t even really maybe thought of yourself”. .... You get a lot of information about what somebody is thinking and feeling as a human being and then also all the clinical stuff about symptoms”.
Use of QPSS data

- Review with patient
- Written into patient chart
- Inform larger POCT team
- On the spot discussion with primary care team
Findings: Impact on nursing practice

- Increased visibility of quality of life concerns within hospital
- Incorporated aspects of the standardized QOL assessment questions into routine verbal interactions with non-participating patients
- Increased capacity to provide person-centered care
Findings: Theorizing the QPSS in palliative consult care

- Relational use co-produces new knowledge and relations of care
- The QPSS as an “actor-object”
- Interdisciplinary analytical approach to PROMs and PREMs research
- Benefits of social science theorizing and methodology to better inform health care practice change and policy development
Conclusions

- Clinicians’ work within the confluence of multiple, and at times competing health system priorities; navigating these can result in practice tensions shaping PROMs and PREMs use

- Identify and incorporate awareness of contextual considerations when implementing PROMs and PREMs in routine clinical care

- Address needs for training, education and support regarding the different purposes and approaches to the use of QOL assessment data
thank you!

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Post-webinar survey

Survey will pop up on your screen after webinar

• Feedback on how to improve webinar series

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Next webinar

Register at:


• Wednesday, December 6, 2017 at 12 noon ET

Exploring the preferences of older Canadians living with frailty for aspects of inpatient care: A best-worst scaling experiment – CFN-funded Catalyst Grant Program – Nick Bansback and Logan Trenaman, University of British Columbia