An electronic quality of life and practice support system (QPSS) for person-centered older adult care

Richard Sawatzky, PhD, RN
Trinity Western University

Kara Schick-Makaroff, PhD, RN
University of Alberta
Welcome to the CFN Webinar Series

• Our webinar series showcases CFN-supported research on frailty and late-life issues
• 20+ CFN webinars in 2016
• Webinar & slides posted on CFN website: www.cfn-nce.ca

Carol Barrie
Executive Director
Network Update

- **Renewal**
  - CFN is currently preparing for application to renew our funding for a second five-year term
  - Actively looking for partners in funding Fellowships, projects and KT initiatives
  - Contact Jackie St. Pierre (jackie@cfn-nce.ca)

- **Video Contest**
  - Open competition
  - Looking for videos on what *frailty* means to you

- **CFN Network News coming soon**
  - Watch for updates on projects and trainees funded in recent competitions

- **Annual Progress Reports due by April 29, 2016**
Q-&-A session

- Follows Dr. Sawatzky and Dr. Schick-Makaroff’s presentation
- Submit your Qs online during presentation
- We will answer as many Qs as time permits
- Webinar is recorded and available for viewing online within 1-2 days:

  www.cfn-nce.ca/news-and-events/webinars
Presenters

An electronic quality of life and practice support system (QPSS) for person-centered older adult care

- Canada Research Chair in Patient-Reported Outcomes
- Research scientist with the Centre for Health Evaluation and Outcome Sciences (CHEOS) at Providence Health Care
- Clinical background is in palliative care and medical nursing care

- Assistant Professor in the Faculty of Nursing at the University of Alberta
- Completed master’s and PhD at University of Victoria
- Research interests are centred upon enhancement of quality of life for people living with chronic and life-threatening illnesses

Richard Sawatzky
PhD, RN

Kara Schick-Makaroff
PhD, RN

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An Electronic Quality of Life and Practice Support System (QPSS) for Person-Centered Older Adult Care

Canadian Frailty Network Webinar, April 20, 2016

Richard Sawatzky, PhD, & Kara Schick-Makaroff, PhD
Presenters

Richard Sawatzky
Trinity Western University +
Centre for Health Evaluation and Outcomes Sciences,
Providence Health Care, Vancouver, British Columbia.
Canada Research Chair (Tier II) in
patient-reported outcomes
rick.sawatzky@twu.ca

Kara Schick-Makaroff
University of Alberta.
Faculty of Nursing, Edmonton, Alberta.
kara.schickmakaroff@ualberta.ca
QPSS initiative team*

**Principal Investigators**
Rick Sawatzky, Trinity Western University (nominated PI)
Robin Cohen, McGill University (co-PI)
Kelli Stajduhar, University of Victoria (co-PI)
Kara Schick-Makaroff, University of Alberta (co-PI, eHIPP project)

**Co-Investigators**
Researchers from Trinity Western University, University of British Columbia, University of Victoria, McGill University, Ersta University College (Sweden), Manchester University (UK), Cambridge University (UK)

**Industry partners**
James Voth, Founder and Director, Intogrey
Bruce Forde, CEO Cambian (eHIPP project)

**Administrators and Clinicians**
Neil Hilliard and Carolyn Tayler
Directors of End of Life Care
Barbara McLeod
Clinical Nurse Specialist Hospice Palliative Care
Jean Warneboldt
Tri-Cities Palliative Physician

**Patients and Family Caregivers**

**Highly Qualified Personnel**
Danica Friesen
Undergraduate student, Trinity Western University
Jennifer Haskins
Palliative-Focused Nurse, Fraser Health
Melissa Kundert
Palliative-Focused Nurse, Fraser Health
Judy Lett
Hospice Palliative Care Clinical Nurse Specialist, Fraser Health
Kathleen Lounsbury
MSN student, Trinity Western University
Marian Krawczyk
CFN Interdisciplinary Fellow, Trinity Western University
Esther Mercedes
Doctoral student, McGill University
Charlene Neufeld
Spiritual Health Practitioner, Fraser Health
Sharon Wang
Research assistant, MSN, Trinity Western University

*Includes several projects
QPSS Partners

Health care services
- Health Authorities (Fraser Health)
- BC Ministry of Health Patient-Centered Measurement Working Group

Professional and community associations
- Canadian Virtual Hospice
- Canadian Association of Retired People
- Family Caregivers of British Columbia

Industry
- Intogrey Research and Development Inc.
- Cambian Inc.
Conflicts of interest

The presenters have no conflicts of interest related to this study.

The studies are supported by health authorities and a business partners who have a vested interested in the results.
1. Introduction

2. Background

3. Demonstration of the QPSS

1. Results of two CFN-funded catalyst projects:
   “Integrating Quality of Life Assessments into Acute Care for Older Adults with Chronic Life-limiting Illness” (2014-2015)
   “Integrating a Quality of Life Assessment and Practice Support System in Palliative Homecare” (2015-2016)

3.1 Aim and objectives
3.2 Design
3.3 Results

4. Discussion
How do we ensure that the care we provide is both informed by and makes a difference to what really matters to individual people?
“Our aim should be to find out what each patient wants, needs, and experiences in our health care system”

M. Gerteis et al. (1993)

Building blocks for person-centered care

The imperative for person-centered care requires that the full range of healthcare needs relevant to the quality of life of older adults who have life-limiting conditions, and of their family caregivers, is routinely assessed.
The use of self-report instruments 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) & Patient-Reported Experience Measures (PREMs) provide information about patients’ perspectives of their QOL and healthcare experiences without prior interpretation by a clinician or any other person.

PROMS

used to assess patients’ and families’ perspectives of various domains of their health and QOL

PREMS

used to assess patients’ and families’ experiences with the care provided
Example PROM for palliative care

The McGill Quality of Life Questionnaire (MQOL) Revised

Physical
- 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)

<table>
<thead>
<tr>
<th>Domain</th>
<th># questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationship with doctor</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

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.

Reasons for using PROMs and PREMs

**Health professionals**
- At point of care, to inform treatment decisions, monitor patients’ conditions, promote patient-clinician communication, reveal health and quality of life concerns that may otherwise have not been noticed

**Health researchers**
- Examine the effectiveness of treatments and the impact of healthcare interventions
- Better understand the impacts of treatments and services on people’s health from their point of view

**Health service decision makers**
- Evaluate the efficacy, effectiveness and cost-effectiveness of healthcare services and programs

**Health care recipients**
- Monitor symptoms and concerns and communicate with health care professionals
Quality of life assessments
Routine use of PROMs and PREMs at point of care

Routine use of PROMs and PREMs can:

• Make patients' and family caregivers' concerns 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 and the availability of many PROM and PREM instruments, their routine use at point of care has been limited

Example references:


Benefits of e-QOL
Assessment Instruments

1. Reduce patient burden
2. Reduce clinician burden
3. Enhance visualization and monitoring of patient concerns through ongoing and immediate feedback
4. PROM & PREM information become part of administrative data for program evaluation and cost-effectiveness analysis

An innovative, integrated health care information system for patient- and family-centered 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
- documentation of interventions planned to address areas of unmet need
- tracking and assessing whether an implemented intervention has achieved the desired result
- capacity to integrate with other health information systems
QPSS Initiative

Complex intervention

Target populations

Sectors of care

- Home and community care
- Tertiary care
- Outpatient clinics
- Palliative consult team

QPSS integration in care for older adults who have life-limiting conditions

Patients and family

Clinicians and decision makers

Ultimate goals: enhanced person-centred care, shared decision making, and continuity of care
QPSS Demonstration
QPSS Research: CFN catalyst projects

Investigating the routine use of electronically administered QOL assessment instruments as practice support tools in palliative care for people who have chronic life-limiting illnesses and for their family caregivers
The project involves working with clinicians, clients and family caregivers to answer the following research questions:

1) How can we best facilitate the integration and routine use of electronically-administered quality of life (QOL) and healthcare experience assessment instruments as practice support tools in palliative care for older adults who have chronic life-limiting illnesses and for their family caregivers?

2) Does the routine use of these instruments improve quality of care, as indicated by patients’ and family caregivers' reports of enhanced QOL and experiences with the care provided?
QPSS design and implementation
An integrated knowledge translation approach*

D. Select, tailor & implement interventions
Determine how a QPSS can be used to support person-centered palliative care for patients and their family caregivers.

E. Monitor knowledge use
Qualitatively evaluate the process of integrating a QPSS in palliative care.

F. Evaluate outcomes
Quantitatively evaluate the impact of use of a QPSS on the QOL and health care experiences of patients and their family caregivers.

G. Sustain knowledge use
KT activities aimed at sustainability, and building on the outcome evaluation.

Knowledge Creation Regarding the use of PROMs & PREMs

A. Identify Problem
How can we best facilitate the integration and routine use of electronically-administered QOL and healthcare experience assessment instruments as practice support tools in palliative care for older adults who have chronic life-limiting illnesses and their family caregivers?

B. Adapt knowledge to local context
Understand clinicians', patients', and family caregivers' points of view about how to best adapt and integrate a QPSS into their practice.

C. Assess barriers to knowledge use
Identify strategies for overcoming barriers and building on facilitators regarding the routine integration of QOL assessments in practice.

## Qualitative methods

<table>
<thead>
<tr>
<th></th>
<th>Clinicians</th>
<th>Patients</th>
<th>Family caregivers</th>
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</thead>
<tbody>
<tr>
<td>Recruitment</td>
<td>Team meetings</td>
<td>Referral by clinicians</td>
<td>Referral by clinicians and patients</td>
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<tr>
<td>Data collection</td>
<td>• Interviews (24)</td>
<td>• Interviews (35)</td>
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<tr>
<td></td>
<td>• Focus groups (14)</td>
<td>• PROM &amp; PREM questionnaires*</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• QPSS data*</td>
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<tr>
<td>Qualitative analyses</td>
<td>Content and thematic analysis of transcribed interviews and focus groups</td>
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*not reported in this presentation*
**Participants**
Clinicians in palliative care (hospital and home care)

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<thead>
<tr>
<th></th>
<th>Home care settings</th>
<th>Hospital setting</th>
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<tbody>
<tr>
<td></td>
<td>Clinician focus groups (n = 34)</td>
<td>Clinician interviews (n = 24)</td>
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<tr>
<td>Age: mean (range)</td>
<td>47 (34-61)</td>
<td>40 (23-63)</td>
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<tr>
<td>Gender: % female</td>
<td>91%</td>
<td>79%</td>
</tr>
<tr>
<td>Occupation: MD</td>
<td>6%</td>
<td>8%</td>
</tr>
<tr>
<td>Occupation: RN</td>
<td>74%</td>
<td>83%</td>
</tr>
<tr>
<td>Occupation: Other</td>
<td>18%</td>
<td>8%</td>
</tr>
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</table>
### Participants

 Older adults receiving palliative care and their family caregivers

<table>
<thead>
<tr>
<th></th>
<th>Home care settings</th>
<th>Hospital setting</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Patient</td>
<td>Family</td>
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<tr>
<td>Total participants</td>
<td>45</td>
<td>37</td>
</tr>
<tr>
<td>Age: mean (range)</td>
<td>70 (46-95)</td>
<td>63 (22-89)</td>
</tr>
<tr>
<td>Gender: % female</td>
<td>38%</td>
<td>81%</td>
</tr>
<tr>
<td>Ethnicity: % Canadian</td>
<td>22%</td>
<td>11%</td>
</tr>
<tr>
<td>Country of birth: % Canada</td>
<td>67%</td>
<td>51%</td>
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Outline

User-centered design and adaptation of the QPSS
- Selection of instruments to be included in the QPSS
- Desirable features of the QPSS

Implementation of the QPSS in practice
- Challenges in uptake by clinicians
  - Technical challenges
  - Research-related challenges

Support for QPSS in practice
- Tangible support
- Competence
Selection of QOL assessment instruments

**Literature review**

- More than 200 PROM and PREM instruments have been used in older adult populations
- Our synthesis focused on categorizing these instruments and providing recommendations for making informed decisions about the selection of PROMs and PREMs for seriously ill older adults


**Focus groups with clinicians**

- Instruments must measure symptoms, physical function, emotional, psychological, and existential concerns
- Importance of distinguishing “screening” and “assessment”
- Potential for linkage with clinical assessments
- Concern regarding potential response burden
QOL Assessment Instruments
For seniors who have life-limiting conditions and their family caregivers

Selected QOL Assessment Instruments:

• Edmonton Symptom Assessment System – Revised (ESAS-R)

• McGill Quality of Life Questionnaire – Revised (MQOL-R)

• Quality of Life in Life-Threatening Illness – Family caregiver version 2 (QOLLTI-F v2)

• Canadian Health Care Evaluation Project Lite Questionnaire (CANHELP Lite)
  • Patients
  • Family caregivers
<table>
<thead>
<tr>
<th>Industry</th>
<th>QPSS – Desirable features</th>
</tr>
</thead>
</table>
| **Usability** | • Focus on the experiences of clinicians and patients/family caregivers  
• User-centered design from the outset. Interfaces designed with clear focus on the needs of clinicians, patients, and family caregivers |
| **Patient/family caregiver experience** | • Instruments can be completed independently (preferred) or via clinician interview |
| **Clinician experience** | • Designed for workflow integration (goal to reduce or replace time costs):  
  • Searching for patient records  
  • Review past instrument administration  
  • Option to include clinical events and indicators  
  • Option to link assessment with practice guidelines  
  • Printable reports: individual-level and aggregate |
QPSS – Desirable features

Security
- Integrated solution including dedicated tablets, secure applications, and secure servers with minimal external dependencies
- Tablet goes into “lock down” mode when shared with patient or family caregivers for completion of instruments

Adaptability/modularity
- Modular platform that can accommodate practically any instrument (not just PREMs and PROMs)
- CLINROs, screening tools, clinical indicators etc...

Analytics/integration
- Capture usage data in addition to assessment data
- Data can be aggregated and analyzed at any level
- Designed for integration with electronic medical records and other databases
Feedback mechanisms

Reporting of assessment results

- Graphical displays that present changes in identified concerns over time
- Ranking of most important concerns or needs
- Assessment results must be accessible in “real time” at point of care
- Importance of producing printable reports that can be used in rounds and filed in paper charts

Linkage with current practices

- Integration of prompts for potential interventions to address identified concerns or needs
- Tracking of interventions that have been applied
Use of QPSS in practice

Contradictory opinions regarding communication and relationship building, use of QOL information for care planning, time and perceived burden.

“I find it’s so impersonal; it’s difficult for me to get a client to tell me, you know, do you feel your relationship with your doctor is very important and are you satisfied? In a way it’s a lot of juice to extract from a client, from the situation, so I go easy, but I see that it could be good for my practice to use it more.” (Clinician)

“I have a client in his 90s ... his wife said to me yesterday that she's finding it really helpful because it's ... like, reflecting on his care and his situation and that he's coming up with things that he hasn't made her aware of. So it's kind of enriching the level of care that he's going to get, from his feedback.” (Clinician)
Use of QPSS in practice

Use of QOL assessment instruments: Providing structure for holistic assessment, improvement in communication, opportunities for reflection, as well as the risk of assessment burden.

“I found the questions were very easy to understand. And it was easy for me to just read them on the tablet. And when I got used to not pressing too hard and using the light touch, I found it very easy to use. I'm very surprised... How did you feel?” (Family caregiver)

“... as a nurse, I tend to focus quite a bit on physical symptoms. But it's a really, really nice tool to find out what the other symptoms are that we're not able to pick up on – psychological, emotional, existential. So I felt that's a great tool to use for patients. Then we get to focus on those.” (Clinician)
Implementation of QPSS

Challenges in uptake by clinicians

• Technical challenges
  – Log in issues
  – Forgot tablet charging in the office
  – Use of technology to aid with assessment
  – Wireless “dead zones” in the community and at the home health office

• Research-related challenges
  – Consent processes
Support for QPSS in practice

Tangible support

- Holistic, therapeutic relationship in homecare
- In-person training, seminars, and on-site champions

Competence

1. To introduce the QPSS to clients and as a part of daily practice
2. To collaboratively select appropriate QOL-assessment instruments based on client needs
3. To review the QPSS data to identify facets of the clinical situation that could benefit from further discussion and in-depth assessment
4. To engage in intervention, where appropriate, based on a combination of the QPSS data, further assessment and clinical judgment
5. To use the QPSS in evaluating the effects of interventions, over time, where deemed clinically appropriate
Discussion
Implementation considerations

Institutional-Level
- Understanding pre-existing organizational contexts
- Responding to current changes in health care system
- Addressing tensions regarding quantification and standardization

Technical-Level
- Clarity on technical and system capacities
- Prompt resolving of unanticipated difficulties
- Integration with existing technologies in the health care system

Local-Level
- Framing of shared objectives and goals
- Ongoing consultation with clinicians
- Prolonged implementation timeline

User-Level
- Ensuring immediate benefit
- Ongoing education and competency of clinicians
- Knowledge translation to build clinician autonomy
Next steps

Multi-site evaluation studies of the QPSS in older adult populations

- **In progress:** Integrating a quality of life assessment and practice support system in homecare services for older adults with life-limiting illness and their families. Funded by the CIHR Electronic Health Innovation Partnership Program. (2015-2019, $750,000)
- **Proposed:** Investigating a quality of life assessment and practice support intervention in acute care for older adults who have chronic life-limiting illnesses

Proposed technological developments

- Electronic health record integration
- Integration with clinician reported information
- Computerized adaptive testing to reduce response burden

Making the needs and concerns of frail elderly visible

- Education of clinicians regarding the use of QOL assessment information
- Embedding information about the perceived health outcomes and health care experiences of older adults and their families in health services administration and decision making
For further information or to receive future updates on this initiative, feel free to contact:

Richard Sawatzky rick.sawatzky@twu.ca

Kara Schick-Makaroff kara.schickmakaroff@ualberta.ca

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

M. Gerteis et al. (1993)
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Frailty measures for persons with intellectual, developmental disabilities – results of CFN-funded Knowledge Synthesis Grant – Hélène Ouellette-Kuntz, Queen’s University

Wednesday, May 18, 2016 at 12 noon ET
Pilot of e-commerce, mobile device to improve physical transfers of nursing home residents – results of CFN-funded Catalyst Grant – Greta Cummings, University of Alberta

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