TVN Mindmerge Victoria

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Integrating a quality of life assessment and practice support system in palliative home care

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Objectives

Do right by our patients

This presentation reports on a collaborative in-progress research initiative about the implementation and integration of an electronic innovation, the **Q**uality of life Assessment and **P**ractice **S**upport **S**ystem (QPSS), into routine palliative home care for older adults who have and advancing life-limiting condition and their family caregivers.

Background

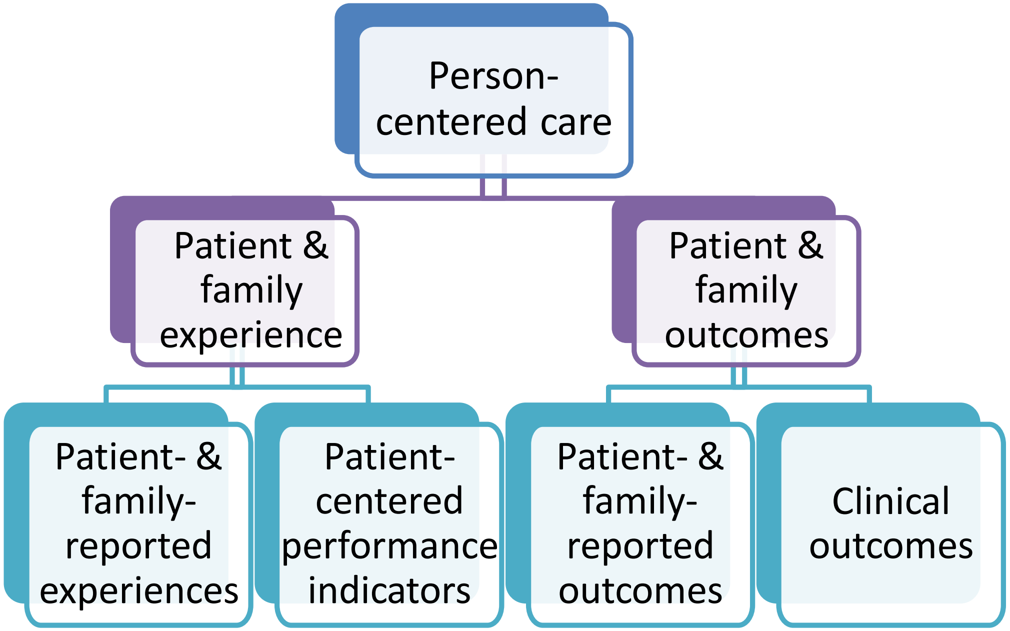
Research project

Emerging results

Person-centered outcomes

Essential building blocks for person-centered care

“Our aim should be to find out what each patient wants, needs, and experiences in our health care system” M. Gerteis et al. (1993)



Person-centered care

Patient & family experience

Patient & family outcomes

Patient- & family-reported experiences

Patient-centered performance indicators

Patient- & family-reported outcomes

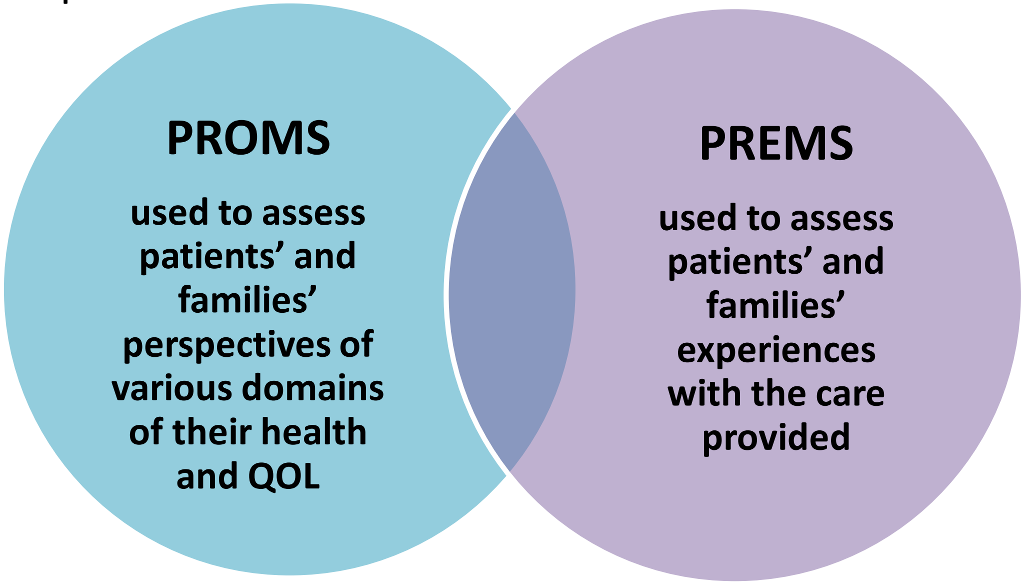
Clinical outcomes

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.

Quality of Life (QOL) Assessment

definitions

Patient-Reported Outcome Measures (PROMs) and 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

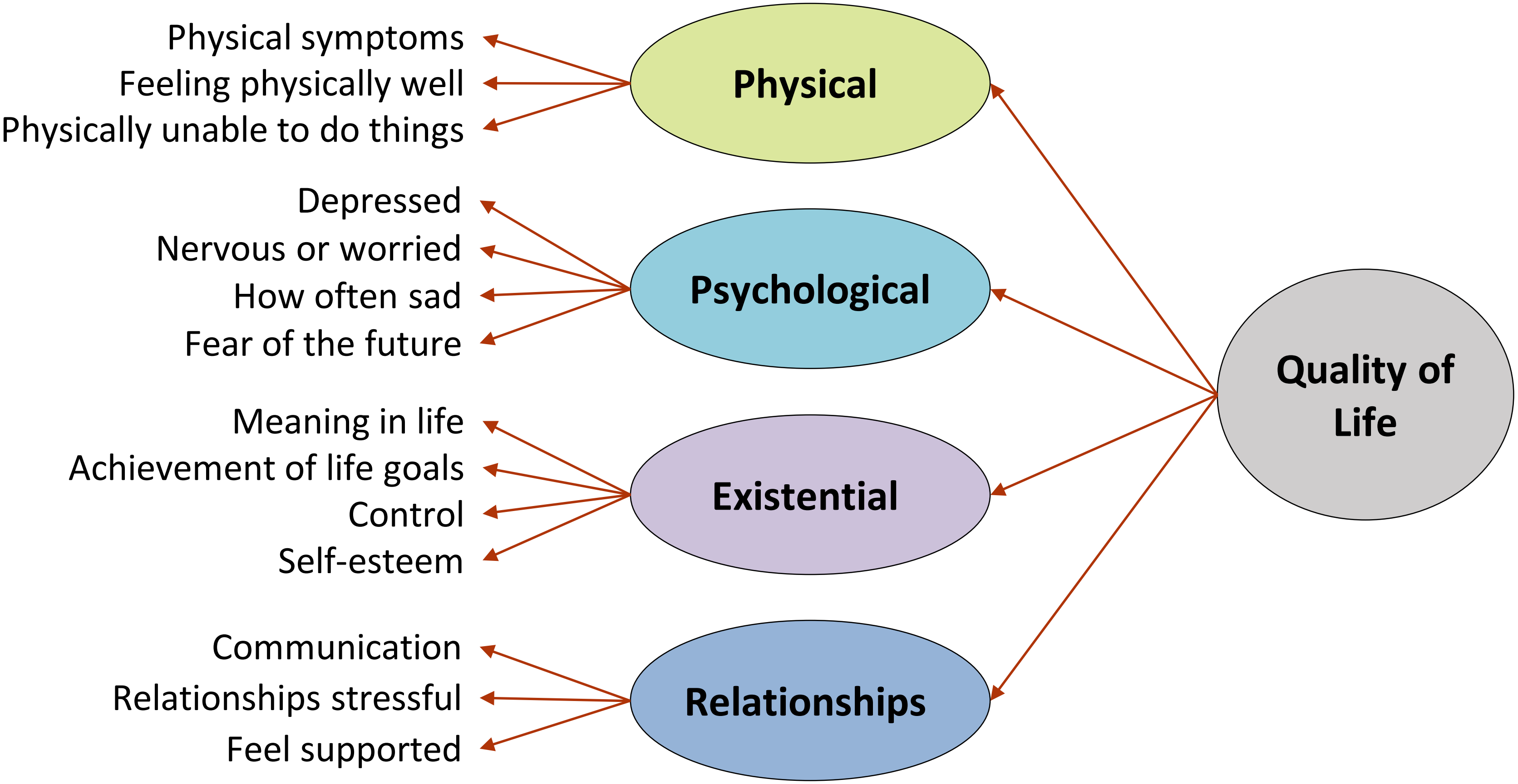
PREMS

used to assess patients' and families' experiences with the care provided

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.

Example PROM for palliative care

The McGill Quality of Life Questionnaire (MQOL) Revised



Physical symptoms
Feeling physically well
Physically unable to do things

Physical

Depressed
Nervous or worried
How often sad
Fear of the future

Psychological

Meaning in life
Achievement of life goals
Control
Self-esteem

Existential

Communication
Relationships stressful
Feel supported

Relationships

Quality of Life

Cohen, S. R., Sawatzky, R., Shahidi, J., Heyland, D., Jiang, X., Day, A., Gadermann, A. M. (2014). McGill Quality of Life Questionnaire (MQOL) – Revised. *Journal of palliative care, 30*(3), 248.

Example PREM for palliative care

Canadian Health Care Evaluation Project (CANHELP)

Domain	# questions
Relationship with doctor	3
Illness management	9
Communication	3
Decision making	4
Feeling at peace	1

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

Heyland, D. K., Cook, D. J., Rocker, G. M., Dodek, P. M., Kutsogiannis, D. J., Skrobik, Y., et al. (2010). The development and validation of a novel questionnaire to measure patient and family satisfaction with end-of-life care: The Canadian Health Care Evaluation Project (CANHELP) Questionnaire. *Palliative Medicine, 24(7), 682-695.*

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.

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:

Antunes, B., Harding, R., & Higginson, I. J. (2014). Implementing patient-reported outcome measures in palliative care clinical practice: A systematic review of facilitators and barriers. *Palliat Med, 28(2), 158-175.*

Catania, G., Beccaro, M., Costantini, M., Ugolini, D., De Silvestri, A., Bagnasco, A., & Sasso, L. (2015). Effectiveness of complex interventions focused on quality-of-life assessment to improve palliative care patients' outcomes: a systematic review. *Palliat Med, 29(1), 5-21.*

Benefits of e-QOL Assessment Instruments

1. *Reduce patient burden*
2. *Reduced clinician burden*
3. *Enhanced 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*

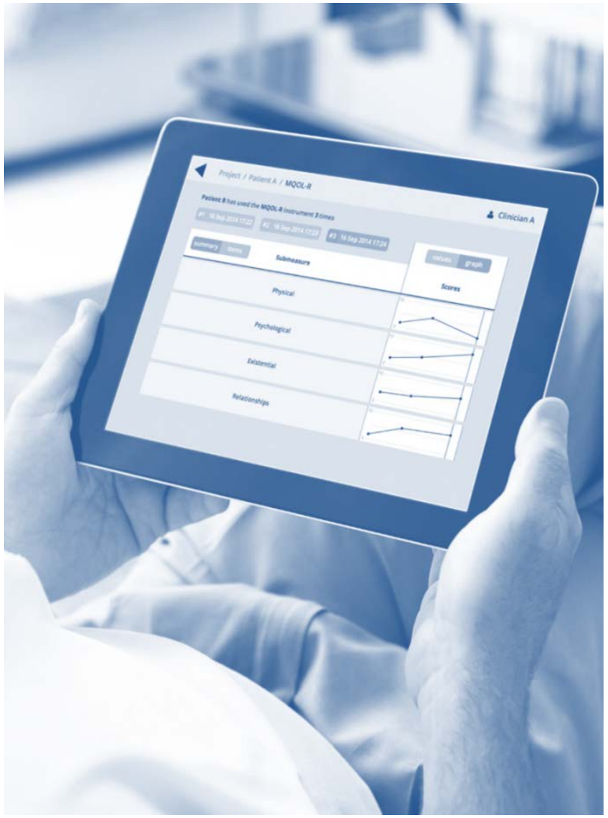
Example reference: Jensen, R. E., Snyder, C. F., Abernethy, A. P., Basch, E., Potosky, A. L., Roberts, A. C., . . . Reeve, B. B. (2014). Review of electronic patient-reported outcomes systems used in cancer clinical care. *J Oncol Pract, 10(4), e215-222.*

Practice innovation

The Quality of Life Assessment and Practice Support System – QPSS

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

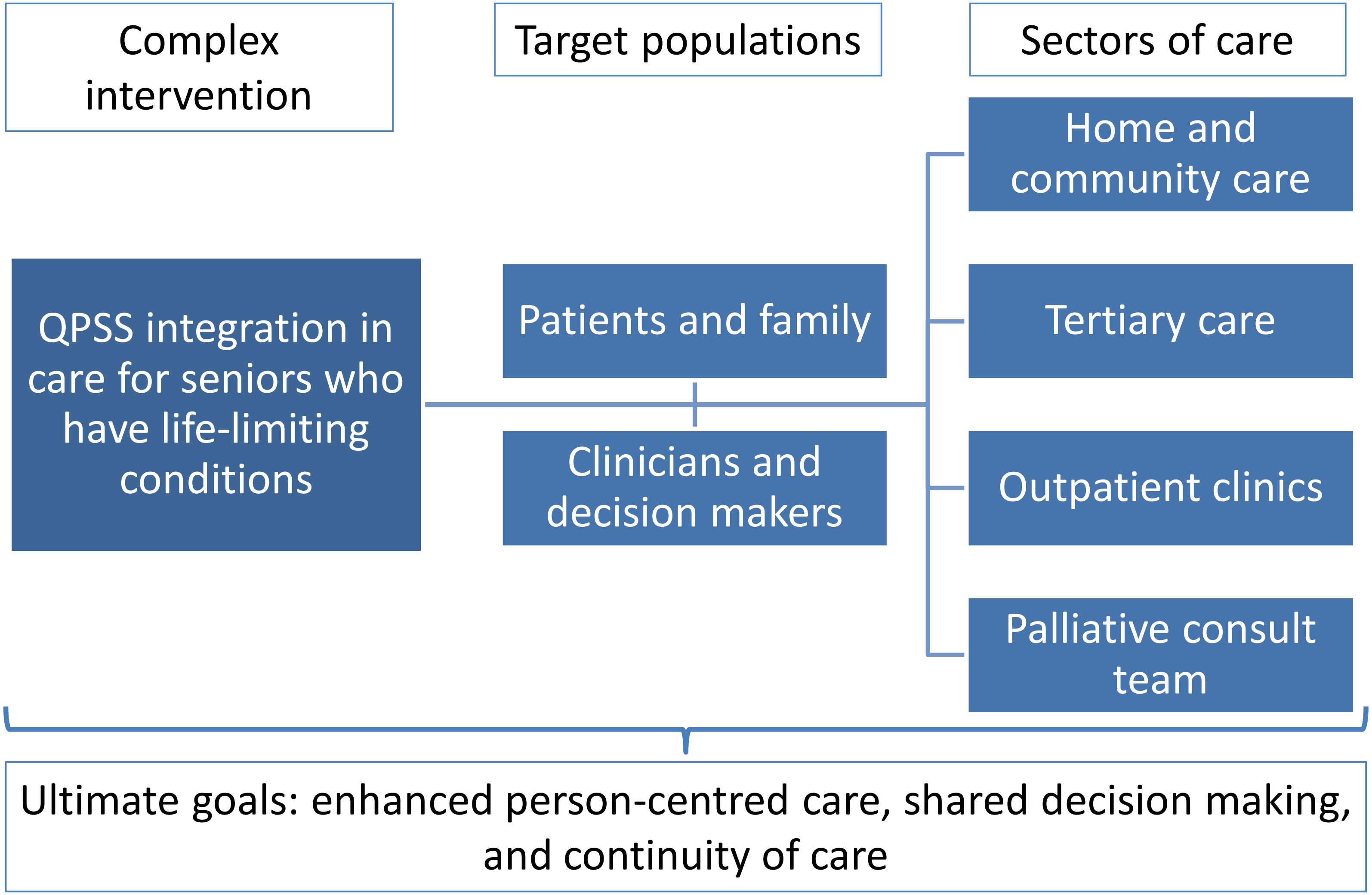


Patient B has used the MQOL-R instrument 3 times

QPSS Research Initiative

Investigating the routine use of electronically administered QOL assessment instruments as practice support tools in health care for people who have chronic life-limiting illnesses and for their family caregivers

QPSS Research Initiative



Complex intervention

Target populations

Sectors of care

QPSS integration in care for seniors who have life-limiting conditions

Patients and family

Clinicians and decision makers

Home and community care

Tertiary care

Outpatient clinics

Palliative consult team

Ultimate goals: enhanced person-centred care, shared decision making, and continuity of care

Research project

Integrating a quality of life assessment and practice support system in palliative homecare

The project involves working with clinicians, clients and family caregivers to answer the following <u>research questions</u>

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 homecare nursing for older adults who have chronic life-limiting illnesses and for their family care givers?

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?

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

Research Design

The project involves working with clinicians, clients and family caregivers to answer the following research questions

Mixed-methods integrated knowledge translation study that involves 2 stages:

1. Local adaptation

- Focus groups and interviews with clinicians', patients', and family caregivers to understand how to best adapt and integrate a QPSS into palliative homecare nursing
- Collection of pre-intervention outcomes evaluation data

2. Evaluation

- Qualitative evaluation of the process of QPSS integration
- Quantitative evaluation of impact on the QOL and health care experiences of clients and FCGs

Samples

Qualitative data

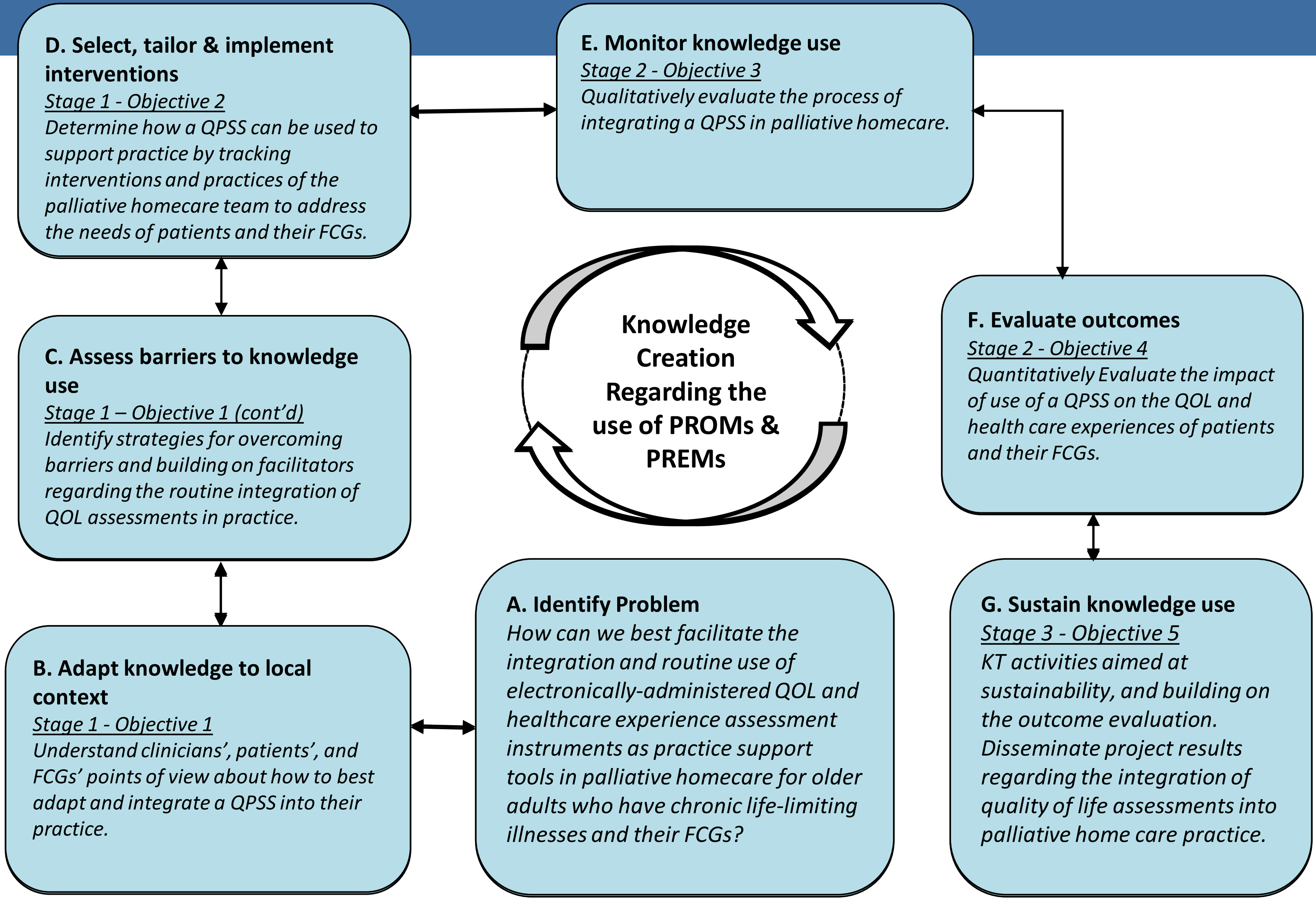
- Entire homecare nursing team
- 10 clients who are registered with the palliative support program
- 10 family caregivers who are most involved in the client's care

Quantitative data

- Comparator group: 30 clients and 30 family caregivers in stage 1
- Intervention group: 30 clients and 30 family caregivers in stage 2

QPSS design and implementation

An integrated knowledge translation approach*



D. Select, tailor & implement interventions
Stage 1 - Objective 2
Determine how a QPSS can be used to support practice by tracking interventions and practices of the palliative homecare team to address the needs of patients and their FCGs.

E. Monitor knowledge use
Stage 2 - Objective 3
Qualitatively evaluate the process of integrating a QPSS in palliative homecare.

C. Assess barriers to knowledge use
Stage 1 – Objective 1 (cont'd)
Identify strategies for overcoming barriers and building on facilitators regarding the routine integration of QOL assessments in practice.

Knowledge Creation Regarding the use of PROMs & PREMs

F. Evaluate outcomes
Stage 2 - Objective 4
Quantitatively Evaluate the impact of use of a QPSS on the QOL and health care experiences of patients and their FCGs.

B. Adapt knowledge to local context
Stage 1 - Objective 1
Understand clinicians', patients', and FCGs' points of view about how to best adapt and integrate a QPSS into their practice.

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 homecare for older adults who have chronic life-limiting illnesses and their FCGs?

G. Sustain knowledge use
Stage 3 - Objective 5
KT activities aimed at sustainability, and building on the outcome evaluation. Disseminate project results regarding the integration of quality of life assessments into palliative home care practice.

*Adapted from: Graham, I., Logan, J., Harrison, M. B., Straus, S. E., Tetroe, J., Caswell, W., & Robinson, N. (2006).

Selection of QOL assessment instruments

Sources of information

Literature review (funded by TVN knowledge synthesis grant)

Patient- and family-reported experience and outcome measures for elderly acute care patients: A knowledge synthesis. R. Sawatzky (PI), S. Bryan, R. Cohen, D. Dixon, A. Gadermann, K. Schick Makaroff; K. Stajduhar. Knowledge users: C. Tayler (principal knowledge user), D. Roberts, J. Lett, L. Cuthbertson, M. McGregor; N. Hilliard. Technology Evaluation in the Elderly Network (2013-2014).

Focus groups with clinicians

Integrating Quality of Life Assessments into Acute Care for Older Adults with Chronic Life-limiting Illness. R. Sawatzky (PI) & R. Cohen (PI), K. Stajduhar, K. (Co-PI), Tayler, C. (Principal knowledge user), & team. Technology Evaluation for the Elderly, Catalyst Program; $99,856. May 1 2014-April 30 2015.

PROMs and PREMs for the seriously ill

Results

Literature review

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

Sawatzky, R., Chan, E. C. K., Bryan, S., Cohen, S. R., Cuthbertson, L., Dixon, D., Lett, J., Gadermann, A., Hilliard, N., McGregor, M., & Stajduhar, K. (2015). Patient- and Family-Reported Experience and Outcome Measures for Use in Acute Care: A Knowledge Synthesis. http://figshare.com/articles/PATIENT_AND_FAMILY_REPORTED/1412721

Focus groups with clinicians

- Instruments must measure symptoms, physical function and emotional, psychological, and existential concerns.
- Concern regarding potential response burden.
- Importance of distinguishing “screening” and “assessment”.
- Potential for linkage with clinical assessments.

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)

Feedback system

Reporting of assessment results

- Graphical displays that present changes in identified concerns over time
- Ranking of areas of most important areas of 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

Emerging findings

Qualitative data from clients and family caregivers

Advantages of using the tablet modality: Simplicity and ease of use, increased speed of access to information, increased completion of tools at multiple time points, ability to see trends in items over time, and potential decrease in the amount of paper charting.

"*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)

Participants	Clients	Family caregivers
Gender		
Male	1	2
Female	4	4
Highest Education		
High School	2	2
College/University	3	3
Country of birth		
Canada	4	3
Other	1	2

Emerging findings

Focus groups with palliative home care clinicians from BC and Montreal (N = 30)

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

“As nurses we don’t use these tools enough, we will use them once, the pain scale, and then it won’t always be redone a second time, I think that if we have a tablet it will be easier, done more quickly, it’s analysed, we have all the results, it’s not just our words, there is something there to describe the situation. I think it’s super useful.” (Clinician)

“…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)

Emerging findings

Focus groups with palliative home care clinicians

Contradictory opinions about the tablet modality: Potential interferences with communication and relationship building, patients' physiological barriers to use, anxiety using technological mediums, damage and loss of the tablets.

"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."

I have a client in his 90s – him and … 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.

Next steps

Scaling up

Ongoing formative evaluation in tertiary and community-based palliative care

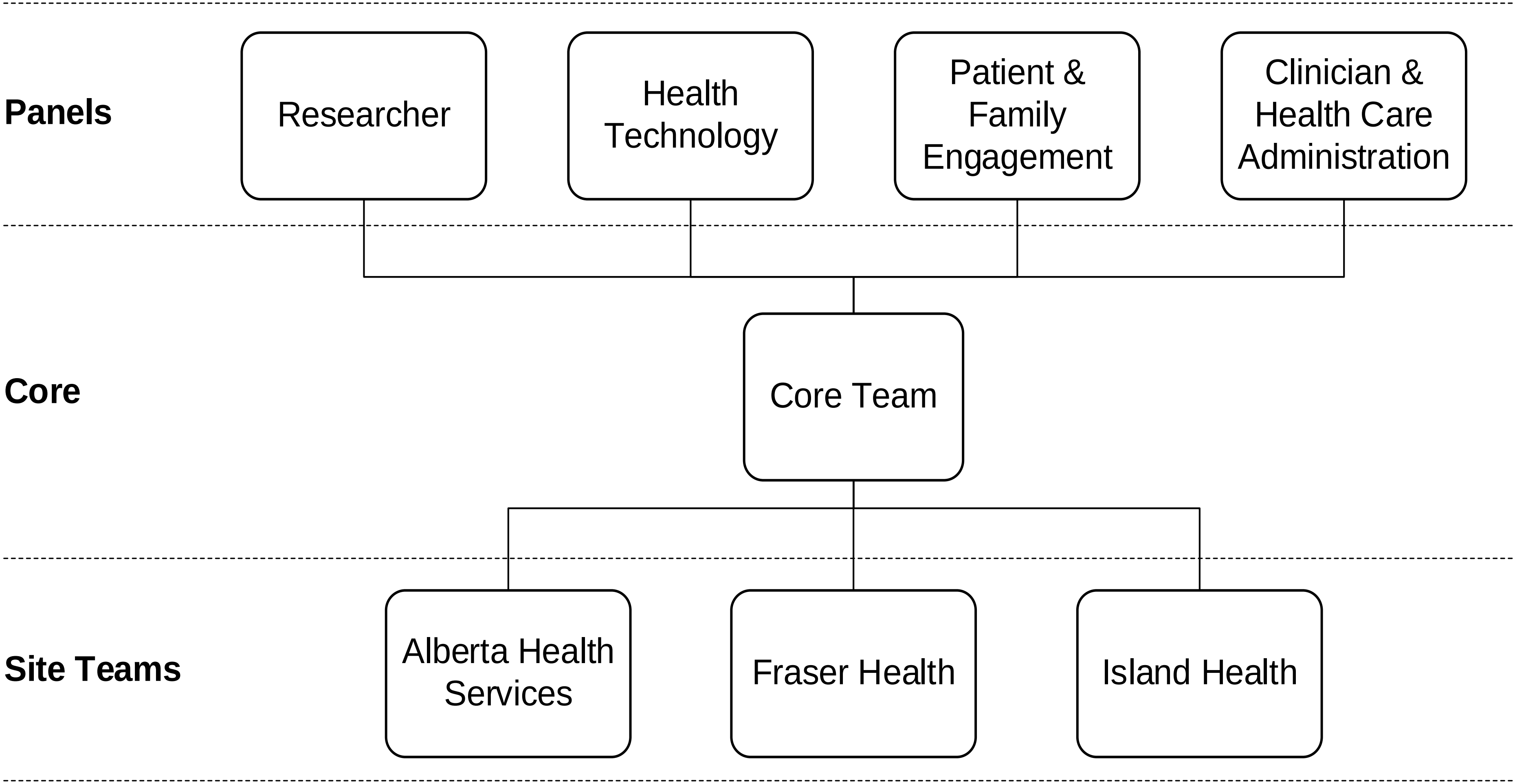
Multi-site outcomes evaluation study:

- Fraser Health
- Island Health
- Alberta Health Services (Edmonton)

Partnership with Intogrey and Cambian:

- Integration with electronic medical records and electronic health records
- Cross-sector integration
- Computerized adaptive testing

Engagement of all stakeholders



Panels

Researcher

Health Technology

Patient & Family Engagement

Clinician & Health Care Administration

Core

Core Team

Site Teams

Alberta Health Services

Fraser Health

Island Health

Research team

Principal Investigators

- Rick Sawatzky, Trinity Western University
- Robin Cohen, McGill University
- Kelli Stajduhar, University of Victoria
- Kara Schick-Makaroff, University of Alberta

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)

Fraser Health Knowledge Users

- 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

Highly Qualified Personnel

- Jennifer Haskins, Fraser Health Palliative-Focused Nurse
- Melissa Kundert, Fraser Health Palliative-Focused Nurse
- Kathleen Lounsbury, graduate student, Trinity Western University
- Esther Mercedes, doctoral student, McGill
- Sharon Wang, graduate student, Trinity Western University

i PANEL
INITIATIVE FOR A
PALLIATIVE APPROACH IN NURSING:
EVIDENCE & LEADERSHIP

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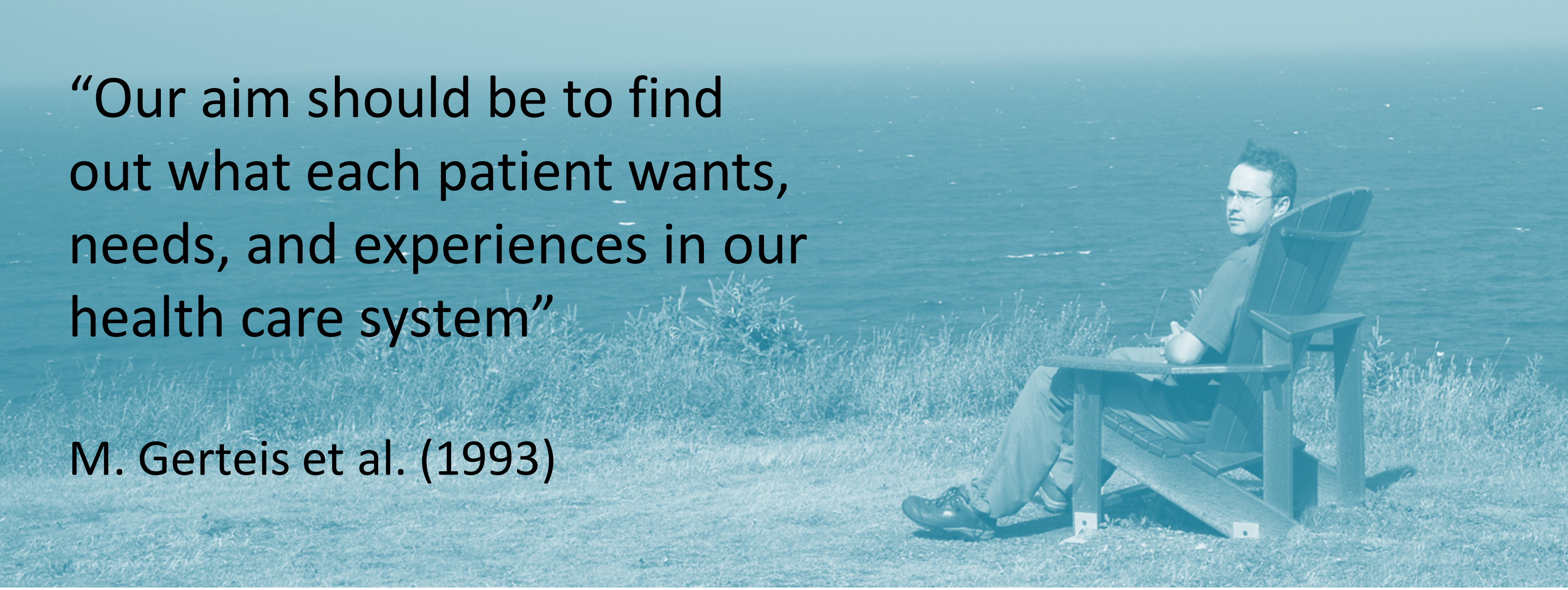

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> M. Gerteis et al. (1993)

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