Experiences of implementation in community palliative care in Australia

Professor Samar Aoun
Professor of Palliative Care
School of Nursing, Midwifery and Paramedicine
Faculty of Health Sciences
NHMRC's current perspective in Australia

- Research Translation remains a core element of NHMRC's strategy for health and medical research
- simply creating knowledge is not enough.
Evidence - The Translation Gap - Practice

Crossing the valley of death
Failure to translate evidence into practice
(from a presentation by Prof Steve Webb, October 2013)

- Is manifested in substantial waste in healthcare - in the order of 20 to 40% of healthcare expenditure may be wasted (Berwick and Hackbarth, JAMA 2010)

- In Australia, on average patients received only 57% of the recommended care (Runcimen et al MJA, 2012)
  - Ranging from 90% for coronary heart disease to 38% surgical site infection; 24% obesity; 19% antibiotic use

- New evidence is of somewhat lesser importance until the healthcare system is capable of implementing the evidence that already exists
NHMRC has invited the Research Translation Faculty to develop a Case For Action (CFA) for each Major Health Issue.

The primary objective of each CFA is to help NHMRC take action to address gaps between what we already know from research is effective, and what is actually done in clinical and public health practice and policy.
PUSH? - The Translation Gap – PULL?

 Crossing the valley of death
PUSH vs. PULL to improve the availability of or access to evidence?

- "Push evidence across the gap" pushes interventions to people who are not necessarily actively seeking the information.

- "Pull evidence across the gap" geared to people who are actively pulling information into their lives because of a current need, want or problem. In short they are specifically looking for answers, options, information and/or resources.

Pull translation is more effective than Push translation.
THE CSNAT AUSTRALIAN TRIAL
Research Team

- Associate Professor Chris Toye, Curtin University, Australia.
- Professor Gunn Grande, Manchester University, UK.
- Professor Gail Ewing, Cambridge University, UK.
- Professor Kelli Stajduhar, University of Victoria, Canada.
- Kathy Deas and Denise Howting: Research Assistants, Curtin University, Australia.
Interventions directly supporting carers

Working alongside existing practice

Integrated into existing practice
Challenges to integrate interventions in standard practice

- Test the effect of the intervention
- Demonstrate the relevance to family carers
- Demonstrate the relevance to service providers
- Intervention needs to fit in service practice
- Change behaviour of service providers
Reasons for undertaking this project: Standards for Providing Quality Palliative Care

Addressing Standard 3

Ongoing and comprehensive assessment and care planning are undertaken to meet the needs and wishes of the patient, their caregiver/s and family.

The criteria includes for specialist palliative care: Assessment tools that have demonstrated validity and sensitivity with specific populations are used when appropriate.
Reasons for undertaking this project:
Standards for Providing Quality Palliative Care

Addressing Standard 5

The needs of the primary caregiver/s are assessed independently and are documented with supportive strategies in the plan of care. The need for information, emotional support, education and respite relevant to their role is assessed and included in the care plan.
The Australian Trial

- This study was conducted during 2012-14 in 3 sites of the Silver Chain Hospice Care Service, Western Australia’s largest provider of home based palliative care.

- The intervention consisted of at least two visits from nurses (2-3 weeks apart) to identify, address and review family caregivers’ needs.
Carer Support Needs Assessment Tool

Carer study ID: ............................................................... Carer Name: ............................................................... Nurse Name: ............................................................... CSNAT Visit (please circle): .............................................. 1st  2nd  3rd  4th  5th  
Date Completed: ............................................................ Patient location during visit: ............................................................... Form completed by (please tick):  □ Carer and Nurse Together  OR  □ Carer Alone

Your support needs now

1) We would like to know what help you need to enable you to care for your relative (friend, family member or loved one) and what support you need for yourself. Please tick the box that best represents your needs now, for each statement.

<table>
<thead>
<tr>
<th>Need</th>
<th>Do you need more support with…</th>
<th>No</th>
<th>A little more</th>
<th>Quite a bit more</th>
<th>Very much more</th>
</tr>
</thead>
<tbody>
<tr>
<td>a</td>
<td>understanding your relative’s illness</td>
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<td>b</td>
<td>having time for yourself in the day</td>
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<td>c</td>
<td>managing your relative’s symptoms, including giving medicines</td>
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<td></td>
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<td>d</td>
<td>your financial, legal or work issues</td>
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<td>e</td>
<td>providing personal care for your relative (e.g. dressing, washing, toileting)</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>f</td>
<td>dealing with your feelings and worries</td>
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<td></td>
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</tr>
<tr>
<td>g</td>
<td>knowing who to contact if you are concerned about your relative (for a range of needs including at night)</td>
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<td>h</td>
<td>looking after your own health (physical problems)</td>
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<td>i</td>
<td>equipment to help care for your relative</td>
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<td>j</td>
<td>your beliefs or spiritual concerns</td>
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<td>k</td>
<td>talking with your relative about his or her illness</td>
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<td>l</td>
<td>practical help in the home</td>
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<tr>
<td>m</td>
<td>knowing what to expect in the future when caring for your relative</td>
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<td>n</td>
<td>getting a break from caring overnight</td>
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<td></td>
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<tr>
<td>o</td>
<td>Anything else (please write in):</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2) Please circle the THREE priority items (from above list) which are most important to you as a carer.

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This section is to be completed by Silver Chain Nurse

Any actions identified for the 3 priorities

---

RUG-ADL Score:

<table>
<thead>
<tr>
<th>Bed Mobility</th>
<th>Toileting</th>
<th>Transfers</th>
<th>Eating</th>
</tr>
</thead>
</table>

Kamofsky Score: ..............................................

SAS:

<table>
<thead>
<tr>
<th>Pain</th>
<th>Fatigue</th>
<th>Breathing</th>
<th>Insomnia</th>
<th>Nausea</th>
<th>Bowel</th>
<th>Appetite</th>
<th>Vomiting</th>
</tr>
</thead>
</table>

© All rights reserved, Gail Beving and Gurne Grande 2015. For permission to use the CSNAT tool, contact Dr Gail Beving, Centre for Family Research, University of Cambridge, Free School Lane, Cambridge CB2 3RF (ggb26@gcam.ac.uk)
UNDERSTANDING CARER SUPPORT NEEDS
INVITATION TO TAKE PART IN A STUDY

Silver Chain Service and Curtin Health Innovation Research Institute and are undertaking a study to develop better support for carers.

Carers may experience different needs at some time during their caring journey.

We use the Carer Support Needs Assessment Tool (CSNAT) to help you identify any needs so that carers can receive appropriate support.

The aim of the research is to better understand the support needs of carers in palliative care.

YOUR PARTICIPATION
1. Complete a simple, 15 - 20 minute questionnaire on the telephone (to better understand your needs)
2. Complete the same questionnaire on the telephone again 4 weeks later (to look for any changes in your needs)
3. Fill out a short form to identify & prioritise your needs (twice over 4 weeks)

FOR MORE INFORMATION PLEASE CONTACT
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Kathy Deas
P: (08) 9236 1757
Mobile: 0411 806 386

Make tomorrow better.

Curtin University
CURTIN HEALTH INNOVATION RESEARCH INSTITUTE

Silver Chain

Curtin University
Phases of Trial

Phase 1: A stepped wedge cluster trial was used with an intervention group (n=233) and a control group (n=89). Total recruitment 620; attrition rate 45%; significant decrease in caregiver strain (p=0.018, $d=0.348$).

Phase 2: Feedback on using the CSNAT was sought from 233 family caregivers in the intervention group through telephone interviews - 100% response rate.

Phase 3: Feedback on using the CSNAT was sought from 44 nurses from 3 service bases via surveys with closed and open ended questions - 70.5% response rate (31/44).
Original Article

Supporting family caregivers to identify their own needs in end-of-life care: Qualitative findings from a stepped wedge cluster trial

Samar Aoun, Kathleen Deas, Chris Toye, Gunn Grande and Kelli Stajduhar

Abstract

Introduction: The Carer Support Needs Assessment Tool (CSNAT) in Community Palliative Care Using a Stepped Wedge Cluster Trial

Samar M. Aoun, Gunn Grande, Denise Howling, Kathleen Deas, Chris Toye, Lakmihana Trossung, Kelli Stajduhar, Gail Ewing

Abstract

Family caregiving towards the end-of-life entails considerable emotional, social, financial and...
PHASE 1
### The stepped wedge cluster trial design

<table>
<thead>
<tr>
<th>Time periods</th>
<th>First</th>
<th>Second</th>
<th>Third</th>
<th>Fourth</th>
<th>Fifth</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Base 1</strong></td>
<td>Control 1</td>
<td><strong>Intervention 1</strong></td>
<td>Intervention 2</td>
<td>Intervention 4</td>
<td>Follow up</td>
</tr>
<tr>
<td><strong>Base 2</strong></td>
<td>Control 2</td>
<td>Control 4</td>
<td><strong>Intervention 3</strong></td>
<td>Intervention 5</td>
<td>Follow up</td>
</tr>
<tr>
<td><strong>Base 3</strong></td>
<td>Control 3</td>
<td>Control 5</td>
<td>Control 6</td>
<td><strong>Intervention 6</strong></td>
<td>Follow up</td>
</tr>
<tr>
<td></td>
<td>Post-bereavement</td>
<td>Post-bereavement</td>
<td>Post-bereavement</td>
<td>Post-bereavement</td>
<td>Post-bereavement</td>
</tr>
</tbody>
</table>
Recruitment flowchart

Carers recruited
n = 620

Intervention n = 441

Withdrawn n = 18
Patient died n = 12
Inappropriate referral n = 4
Lost to follow-up n = 2

Completed baseline
n = 423

Completed follow-up
n = 233 (55.1%)

Control n = 179

Withdrawn n = 16
Patient died n = 10
Inappropriate referral n = 5
Carer withdrawal n = 1

Completed baseline
n = 163

Completed follow-up
n = 89 (54.6%)

Withdrawn n = 74
Patient died n = 68
Patient terminal stage n = 2
Discharge from service n = 1
Deteriorating carer health n = 1
Carer too busy n = 1
Lost to follow-up n = 1

Withdrawn n = 190
Patient died n = 151
Patient terminal stage n = 7
Discharge from service n = 9
Deteriorating carer health n = 6
Carer too busy n = 11
Lost to follow-up n = 6
% family carers needing more support in first and second visit from nurse

- knowing what to expect in the future: 31.70% (Time1), 36.00% (Time2)
- having time to yourself in the day: 40.30% (Time1), 40.30% (Time2)
- dealing with your feelings and worries: 28.00% (Time1), 28.00% (Time2)
- understanding your relative's illness: 20.40% (Time1), 28.00% (Time2)
- talking with your relative about their illness: 24.20% (Time1), 12.90% (Time2)
- practical help in the home: 12.90% (Time1), 24.20% (Time2)
- looking after your own health: 33.30% (Time1), 36.00% (Time2)
- your financial, legal or work issues: 28.00% (Time1), 28.00% (Time2)
- managing your relative's symptoms: 20.40% (Time1), 24.20% (Time2)
- equipment to help care for your relative: 51.60% (Time1), 51.60% (Time2)
- knowing who to contact if you are concerned: 12.90% (Time1), 24.20% (Time2)
- providing personal care for your relative: 33.30% (Time1), 36.00% (Time2)
- getting a break from caring overnight: 28.00% (Time1), 28.00% (Time2)
- beliefs & spiritual concerns: 12.90% (Time1), 24.20% (Time2)
Summary of Phase 1 Results

- Total recruitment = 620 family carers.
- 45% attrition for both groups between baseline and follow-up mainly due to patient deaths resulting in 322 carers completing the study (233 in intervention and 89 in control).
- The intervention was associated with a significant reduction in Caregiver Strain, while control participants experienced an increase in strain.
- The observed significant small to moderate effect size of this intervention is comparable if not larger than those reported in a recent meta-analysis of caregiver interventions.
PHASE 2
Family Carer Feedback at completion of intervention

Interviews questions (n = 233)

- How easy or difficult was it for you to complete the CSNAT?
- Did you feel that completing the assessment process was helpful in getting the support you needed?
- Did this experience of identifying your needs affect what you did yourself?
- Did you feel that your needs as a caregiver were acknowledged/listened to in a way that was distinct from the needs of the patient?
- Do you think the CSNAT assessment process could be improved in any way?
Family Caregivers’ Feedback - Four Themes

Process of completing CSNAT straightforward and easy by 94%.

1) Practicality and usefulness of the systematic assessment
   • *It formalised what I probably knew I needed, but it's difficult to articulate when you're going through it … so yes it was very good* (P237)

2) Evoked feelings of confrontation yet acceptance
   • *Emotionally - it makes you reflect where you are in process. A little confronting as you had to look at questions and be honest with yourself in where you are in process.* (195)
   • *Going through the form was helpful - like someone needs to shake you & wake you up out of the shock. It's like bad trauma....* (P371)
3) Validation, reassurance and empowerment

- *Form is fantastic as the carer is recognised. Often the carer is forgotten and if carer “goes down” the patient suffers.* (P515)

- *It gave me the reassurance I needed. It does make you feel less isolated, knowing if anything goes wrong, I'm not the only one making decisions.* (P498)
4) Accessing support responsive to needs

• Responsibility was taken off me – it was excellent when SC started showering. You don't feel trapped - when you get a break and step into the real world. (P600)

• Form made it happen. Enabled nurse to provide exactly what [was needed]. Clearly define and [it] makes it happen quickly. (P242)
PHASE 3
CSNAT Training for Nurses

- 6 main training sessions (2 sessions for each site, 2-3 hours) were undertaken at the start of the intervention to accommodate the availability of staff.

- 3 refresher sessions (1 session for each site) lasting 1-2 hours to discuss nurses’ experiences, issues with recruitment.

- Research team had monthly meetings with the Champion in the service (a senior clinical nurse manager) to follow progress and discuss challenges at each site.

05.05.2015
Nurses’ Feedback

- The practicalities of CSNAT implementation
- Perceived benefits to caregivers compared to standard practice
- Perceived benefits to nurses compared to standard practice
- Assisting caregivers to provide care for their relative compared to assisting caregivers with support for themselves
- Potential integration into standard practice
Perceived benefits to caregivers compared to standard practice

- Early intervention provided support to caregivers before a situation arose (when overloaded or too stressed)
- Cathartic nature of assessment allowed caregivers to share difficulties or grief
- Caregivers more involved with decision making, taking on a new focus: looking for/prioritising solutions reported to reduce anxiety
- Caregivers found process validating: legitimised allowing the focus to be on them
- Prompted reflection, and gave the caregiver courage to ask for help
Perceived benefits to nurses compared to standard practice

- CSNAT was effective in eliciting concerns from caregivers (71%)
- Provided guidance, focus, and structure, in the context of a single (early) conversation that was documented consistently in service records
- Prompted nurses to review or assess the supports they put in place (68%)
- Identified needs and service responses that would not have otherwise been identified.
- Assessment results challenged staff preconceptions
- CSNAT helped to ensure that what should be a normal part of practice was more reliably implemented
Assisting caregivers to provide care for their relative compared to assisting caregivers with support for themselves

- More solutions or actions taken were within the service capacity if they related to assisting caregivers *provide care* (77%) compared to providing *direct personal support* (56%)

  - *Direct/personal support* - some caregivers refused to accept help during the shared action planning
  - not having set times for volunteers to provide respite was a concern for caregivers
  - Resources were described as varying between settings in the short period before patient dies
Potential integration into standard practice

- Majority of nurses agreed CSNAT should be integrated in standard practice (two-thirds)
- Recommend formal recognition of the caregiver as a client of the service, with a corresponding time allocation to address caregivers’ needs
- Ongoing training of CSNAT needed for the staff
- Integration of CSNAT into existing documents
- Reviews of support documented in existing notes, and electronic recording of results.
- Recommend CSNAT assessments be discussed at clinical meetings
Conclusions

This intervention proved successful as several essential criteria were met:

- Determined that the intervention is effective in significantly reducing caregiver strain.
- Demonstrated the relevance of the intervention to family caregivers
- Intervention relevant to service providers and has sufficiently impacted on the nurses’ experience to facilitate translation into practice.
Challenges at many levels

- Study Design
- Organisation
- Clients
- Staff
Challenges (1)

- Movement of nurses between trial sites: nurses with intervention training moved between bases due to staff sickness to cover work load – (unable to recruit enough for Control Group)

- Research process burdensome and often confused with potential routine implementation

- Research process confusing for some staff despite training-varying skills and understanding

- High attrition due to progressive illness of clients
Challenges (2)

- 3 general managers for palliative care for the duration of the project.
- Changes within organisation: demand-management effect on recruitment
  - clients enrolled in study were discharged if health improved (re-admitted if health deteriorated)
- Acceptance of research project takes time
  - acknowledged benefits to carers
  - difficulty maintaining enthusiasm of staff for length of project
Challenges (3)

- Nurses workload impacted on them remembering the administer the CSNAT
  - reminder system set up for nurses within organisation
  - Care Coordinators liaising with staff

- Gatekeeping by nurses due to:
  - concern for carer wellbeing/unsuitable
  - undeveloped research culture
Challenges (4)

- Staffing issues in recruitment and turnover
  - difficulty contacting relevant/current nurse to follow up info on participating carers
  - part time staff, holidays, move to different base or section
  - nurses not handing over clients/carers info for study (and CSNAT forms) on to next nurse
Influences for uptake

- Facilitation to support implementation:
  - ‘external facilitation’ from the research team (e.g. provision of training and on-going support).
  - ‘internal facilitation’ from within the service (e.g. clear organisation steer, champion)

- ‘Organisational preparedness’, with regard to existing administration systems, working patterns and competing demands
A Success Story

Barwon Health

community palliative care
AIMS

- Improve the assessment and documentation of carer needs - procedures to support the use of the CSNAT
- Develop action plans to meet the identified needs of carers - plans clearly documented in PC records
- Develop a web-based carer’s toolkit - ensure accurate info is available to carers
Procedures (1)

- CSNAT placed in the plastic sleeve at the front of each client folder
- At initial assessment: nurse introduces CSNAT to carer, explaining purpose and ask them to complete during visit.
- If completion not possible during initial visit, carer to complete prior to next scheduled visit - assistance available
- On completion of CSNAT, nurse discusses any needs identified and collaboratively develop an action plan to address these needs.
Procedures (2)

- Nurse makes any referrals agreed upon with the carer and document a clear plan in Palliative Electronic Record Management (PERM).
- The completed CSNAT is placed in the ‘scanning tray’ in PC office for forwarding to Health Information service and scanning to the patient’s Digital Medical Record.
- Carers’ needs formally reviewed when there is change in phase or other substantial change in circumstance.
- Action and referral plans generated from review process.
- Subsequent review and plans documented in PERM.
Carer Resource Toolkit

- Carer Resource Toolkit provides further information on support available for carers in each CSNAT item.
- Carers informed at admission about the toolkit and provided with a bookmark on website link.
PALLIATIVE CARE
INFORMATION TOOLKIT FOR CARERS

www.barwonhealth.org.au/carer/toolkit

A website to help carers find the information they need
Palliative Care

INFORMATION TOOLKIT FOR CARERS

In Barwon Health, we highly value carers and the contribution they make in caring for their relative or friend. Carers have a vital role in helping palliative care patients who wish to be cared for at home to stay at home. Regardless of where the patient care is occurring, be it in the palliative care unit, at home or in a residential care facility, carers are key support people.

However, sometimes carers need support themselves and information to help them through this time. The aim of this Information Toolkit is to give both carers and Palliative Care staff a single location to find information or to direct them to resources designed to help address carers’ needs. Throughout this toolkit you will find links to further information. Some of the information is specific to services available in the Barwon Health region.

- Understanding your relative or friend's illness
- Having time for yourself in the day
- Managing symptoms, including giving medications
- Help with financial, legal and work issues
- Providing personal care
- Dealing with your feelings and worries
- Who to contact when you’re concerned about your friend or relative
- Looking after your own health
- Equipment to help care for your relative or friend
- Beliefs or spiritual concerns
- Talking with your relative or friend about their illness
- Practical help in the home
- What to expect when caring for your relative or friend
- Getting a break from caring overnight
- Young carers
- Aboriginal and Torres Strait Islander carers
Regular audits of completed CSNAT assessments

- 84% compliance with procedure (over last year)
- 100% completion of a plan to address the needs
Implementation outcome variables
(Peters et al BMJ 2013: Implementation research: what it is & how to do it)

- **Acceptability** – acceptable to carers and staff. Most common carer feedback: “it was an easy to use form and it was fantastic we were also assessing their needs”.

- **Adoption** – initial reluctance that was overcome “CSNAT is now well integrated into our daily practice and adopted by all members of the multi-disciplinary CPC team”.

- **Appropriateness** – no issues have been raised that the assessment tool is not appropriate. It covers a range of domains which are relevant and appropriate for our cohort.
Implementation outcome variables

- **Feasibility** – CSNAT integration within our setting was relatively simply, because it was such a simple tool to use with minimal burden to either staff or carers.

- **Fidelity** – we have been able to implement the CSNAT in a manner congruent with the original development of the form. We have not had to alter our practices or the form.

- **Implementation costs** – we undertake the assessment of carers’ needs within the context of our ‘normal’ practice so I can’t identify any additional costs associated with implementation.
Implementation outcome variables

- **Coverage** – the CSNAT assessment is offered to all carers of CPC patients. We now have **84% compliance** with our procedure and pleasingly when needs are identified CSNAT completion, a plan addressing needs is formulated with the carer and **documented 100% of the time**.

- **Sustainability** – Strategies are in place to ensure use of CSNAT is part of our ‘normal’ practice with carers. The forms are included in our admission packs, the documentation in our notes’ proforma to ensure that the team are being prompted to address carer need and to document accordingly.