



International Palliative Care Family-carer Research Collaboration

Newsletter

July 2016

Featured Member



Professor Kelli Stajduhar, RN, PhD -
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Dr Kelli Stajduhar has worked in oncology, palliative care, and gerontology for over 30 years as a staff nurse, nurse clinician, clinical nurse specialist, educator, and researcher. She is a Professor, School of Nursing and Institute on Aging and Lifelong Health at the University of Victoria. Her clinical work and research has focused on the health service needs for people who are dying and their family members and on the particular needs of marginalized and vulnerable populations. She is the recipient of numerous awards, including Post-Doctoral, career investigator awards and is the recipient of the Anselm Strauss Award from the U.S. Council on Family Relations, the Award of Excellence for Nursing Research from the College of Registered Nurses of BC and the UVic Craigdarroch Award for Excellence in Knowledge Mobilization. Dr. Stajduhar publishes and speaks widely on issues pertaining to palliative care, family caregiving, health system design for those with chronic life-limiting illness and on establishing research partnerships and collaborations with health authorities. Along with leading several externally-funded research projects, she is the Scientific Lead of iPANEL (Initiative for a Palliative Approach in Nursing: Evidence and Leadership), an applied nursing health services and policy research initiative comprised of researchers, clinicians and administrators with a focus on investigating the integration of a palliative approach into the care of people with chronic life-limiting illness. Her strong belief in applied health services research, a commitment to engaging clinicians and administrators in research, and her pragmatically oriented and collaborative approach has allowed Dr Stajduhar to develop strong research partnerships and collaborations with health authorities across BC, Canada, and internationally.

"I became interested in research when I was working as a clinical nurse specialist in palliative care and I realized the power that evidence had to inform my own practice and of those around me. I have been so inspired by my clinician colleagues and believe that some of the best research arises out of everyday problems that are identified in practice – those are the ones that have relevance. Right now I lead several studies, both qualitative and quantitative including a randomized control trial of the carer support needs intervention tool in palliative home care, a large ethnographic study of access to palliative care for those with structural vulnerabilities (homelessness, mental health and substance use issues), and two projects examining the integration of a palliative approach into acute care and long term care settings. What I enjoy most about research is engaging with participants and collaborating with some amazing people in clinical practice. Being a member of IPCFCRC has been a great opportunity to connect with colleagues interested in caregiving research – some of these connections have even led to doing research together internationally!"

An integrated perspective on home based palliative care – the results of the INTEGRATE-HTA project

Submitted by Louise Brereton and Wija Oortwijn on behalf of the INTEGRATE-HTA team

Background

Health Technology Assessment (HTA) methods have some limitations when used to assess complex health technologies such as palliative care. The INTEGRATE-HTA project developed concepts and methods that enable a patient-centred, comprehensive, and integrated assessment of complex health technologies. The methods were applied in a case study on home based palliative care (HBPC).

Methods

Using a range of methods including evidence reviews; expert elicitation; and extensive lay and professional stakeholder consultations across seven countries (England, Germany, Italy, Lithuania, the Netherlands, Norway and Poland) we assessed:

- Effectiveness, economic, socio-cultural, ethical, and legal issues;
- Patient preferences and patient-specific moderators of treatment;
- Context and implementation issues regarding HBPC, with and without an additional element of caregiver support, known as “reinforced” and “non-reinforced” HBPC respectively.

Results

The existing evidence base shows that reinforced HBPC interventions are neither better nor worse than non-reinforced HBPC with respect to patient outcomes, and most studies show no effect across carer outcomes. There is an absence of cost effectiveness data. Provisional economic modelling suggests that reinforced carer support interventions may be cost saving. Adapting to changing roles and relationships amongst the patient-carer dyad and professionals; preserving patient and informal carer independence in decision making and avoiding carer burden are challenges to the acceptability of HBPC for informal carers. The number of agencies involved in providing care and the degree to which services are coordinated affect the implementation. These issues may be influenced by professional training, cultures and cooperation styles. Furthermore, informal carers’ access of to the health and social system, difficulties in navigating the system and barriers to actually utilizing them are often reported.

Conclusions

The case study conclusions are restricted by the limited amount and quality of evidence available about HBPC. None-the-less, the concepts and methods developed in the INTEGRATE-HTA project appear to be feasible and potentially valuable additions to existing HTA methods to unlock the value of highly complex technology.

The case study report and methodological guidances are available at:

<http://www.integrate-hta.eu/downloads/#results>

Funding

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Disclaimer

The sole responsibility for the content of this presentation lies with the authors. It does not necessarily reflect the opinion of the European Union. The European Commission is not responsible for any use that may be made of the information contained therein.

Online Forum

The IPCFRC online forum provides a web based communication system for IPCFRC members. It is a resource that aims to foster discussion about family caregiver research in palliative care across the IPCFRC membership database. IPCFRC members can use the forum to ask questions to the IPCFRC community, establish networks, discuss their research, enquire about previous research or existing instruments, or to notify others in the membership about upcoming events and grant opportunities that are of relevance to family caregiver research in palliative care. The focus of the content of the correspondence should always be relevant to family caregiver research in palliative care.

The way the forum operates is as follows:

- To post a message, click the 'Post to the Forum' link on the [IPCFRC website] or type the following email address into a new email: ipcfrc@medstv.unimelb.edu.au
- When you post to the forum, your message is sent directly to all IPCFRC members. Everyone who receives an email has the opportunity to reply to the group by pressing the 'reply' button. You can unsubscribe from this list at any time by pressing the 'unsubscribe' button at the bottom of each post.

When you post to this forum, always remember to adhere to the following:

- Write only public (never private) messages. Lists are a public forum; personal comments should be sent directly to the person, not the entire list.
- Stick to the purpose of the list; the more topic-specific the contributions are, the more useful the list is for everyone.
- Make the subject line descriptive of your topic.
- Sign your posting by listing your contact information or auto-signature.
- When you are replying to a list message please be aware that this list is set up to automatically reply-all. If your reply is not of interest to everyone on the list, change the address to the person to whom your reply is directed.
- Be mindful of what you write; never write anything you would not say to someone directly. Never use the Forum for personal attacks or profanity.
- Avoid using humour or making political or religious comments.
- Do not send chain letters, spam, flames, or solicitations.
- Avoid posting attachments.

To report errors, please contact centre.palliativecare@svha.org.au with the subject 'IPCFRC Online Forum Error'.

Review of literature related to family carer research

One of the initiatives of the IPCFRC is to compile a listing of publications related to family caregiver research in palliative care. This list is updated annually, and serves as a basic resource to aid those who are looking for peer-reviewed publications related to family caregiver research in palliative care. The 2016 version is now available as a downloadable resource on the [IPCFRC website].

Recent articles relevant to IPCFRC members

In each edition we will feature some recently published articles relevant to IPCFRC members.

If you have published in a peer-reviewed journal recently and the subject matter is relevant to the IPCFRC community, please email centre.palliativecare@svha.org.au with the subject 'IPCFRC Newsletter' and we will feature your publication in an upcoming edition.

Aoun SM, Breen L, Howting D, Rumbold B, McNamara B, Hegney D. (2015). "Who needs bereavement support? A population based survey of bereavement risk and support need". *PLoS One* 10(3): e0121101.

Aoun SM, Deas K, Howting D, Lee G. (2015). "Exploring the support needs of family caregivers of patients with brain cancer using the CSNAT: A comparative study with other cancer groups". *PLoS One* 10(12): e0145106.

Breen LJ, Aoun SM, Rumbold B, McNamara B, Howting D, Mancini V. (2015). "Building community capacity in bereavement support: Lessons learnt from bereaved former caregivers". [Epub ahead of print] *Am J Hospice Palliat Med*. doi:10.1177/1049909115615568.

Collins A, Hennessy-Anderson N, Hosking S, Hynson J, Remedios C & Thomas K. (2016). Lived experiences of parents caring for a child with a life-limiting condition in Australia: A qualitative study. [Epub ahead of print] *Palliat Med*. doi: 10.1177/0269216316634245.

Henriksson A, Hudson P, Öhlen J, Thomas K, Holm M, Carlander I, Hagell P, Årestedt K. (2015). "Use of the preparedness for caregiving scale in palliative care: A Rasch evaluation study". *J Pain Symp Manage*. 50(4):533-541.

Holm M, Årestedt K, Carlander I, Fürst CJ, Wengström Y, Öhlen J, Alvariza A. (2015). "Short-term and long-term effects of a psycho-educational group intervention for family caregivers in palliative home care - results from a randomized control trial". [Epub ahead of print] *Psychooncology*. doi: 10.1002/pon.4004.

Holm M, Årestedt K, Carlander I, Wengström Y, Öhlen J, Alvariza A. (2016). "Characteristics of the family caregivers who did not benefit from a successful psychoeducational group intervention during palliative cancer care: A prospective correlational study". [Epub ahead of print] *Cancer Nurs*. doi: 10.1097/NCC.0000000000000351.

Holm M, Carlander I, Fürst CJ, Wengstrom Y, Årestedt K, Öhlen J, Henriksson A. (2015). "Delivering and participating in a psycho-educational intervention for family caregivers during palliative home care: A qualitative study from the perspectives of health professionals and family caregivers". *BMC Palliat Care* 14:16.

Rumbold B, Aoun S. (2015). "An assets-based approach to bereavement care". *Bereavement Care* 34(3):99-102.

Recent IPCFRC Event

An open meeting for current and prospective IPCFRC members was held at the [9th World Research Congress of the European Association for Palliative Care] in Dublin, Ireland on Thursday 9th June 2016. The meeting was chaired by Professor Peter Hudson (Australia) in partnership with Jean Kutner (USA) and Anette Alvariza (Sweden). Some suggestions arising from the meeting (which will be considered by the IPCFRC Executive Committee) included:

- Establishing a repository of current family carer studies undertaken by IPCFRC members.
- Formally involving a consumer/ carer group on the IPCFRC Executive Committee.
- Holding a family caregiver themed research session / pre-conference seminar at the 10th EAPC World Research Congress in Bern, Switzerland in May 2018, or the 15th EAPC World Congress in Madrid, Spain in May 2017.
- Extending the next open meeting to an hour and inviting members to share research interests and ideas to foster potential collaborative research proposals.
- Establishing strategy for social media engagement, i.e. Twitter, Facebook, etc.

Upcoming IPCFRC Event

An open meeting for current and prospective IPCFRC members will be held at the [21st International Congress on Palliative Care] in Montreal, Canada on Thursday 20th Oct 2016 at 1.15-1.45pm (Location: Palais des Congrès - room TBA in the on-site Congress programme). Meeting Chair: Professor Peter Hudson. All Congress delegates are welcome to attend.

Open meetings provide the opportunity for members and prospective members to hear about what is happening in the IPCFRC community and what IPCFRC has to offer, as well as meet the IPCFRC Executive Committee and their fellow IPCFRC members.

Conferences relevant to IPCFRC members

2016 Australian and New Zealand Society of Palliative Medicine (ANZSPM) Biennial Conference
Dates: September 8-11, 2016
Location: Perth, WA
Website: [2016 ANZSPM Biennial Conference]

1st National Symposium on Academic Palliative Care Education & Research
Dates: September 30 - October 1, 2016
Location: California, USA
Website: [1st CSU Palliative Care Symposium]

18th International Psycho-Oncology Society (IPOS) World Congress of Psycho-Oncology
Dates: October 17-21, 2016
Location: Dublin, Ireland
Website: [IPOS 2016]

21st International Congress on Palliative Care
Dates: October 18-21, 2016
Location: Montreal, Canada
Website: [ICPC 2016]

2016 Marie Curie Annual Palliative Care Research Conference
Dates: October 19, 2016
Location: London, UK
Website: [2016 Marie Curie Annual Research Conference]

The International Society for Quality of Life Research (ISOQOL) 23rd Annual Conference
Dates: October 19-22, 2016
Location: Copenhagen, Denmark
Website: [2016 ISOQOL Conference]

continued ...

Conferences relevant to IPCFRC members

continued ...

4th Australian Palliative Care Research Colloquium

Dates: October 27-28, 2016

Location: Melbourne, Australia

Website: [[4th Australian Palliative Care Research Colloquium](#)]

6th International Seminar of the European Palliative Care Research Centre (PRC) and European Palliative Care Research Network (EAPC RN)

Dates: December 1-3, 2016

Location: Banff, Canada

Website: [[6th International Seminar of the PRC and EAPC RN](#)]

Membership

The IPCFRC now has over 200 registered members from many countries of the world, including; Australia, Bulgaria, Cameroon, Canada, Denmark, France, Germany, Ireland, Japan, New Zealand, Nigeria, Norway, Spain, Sweden, Thailand, UK & USA.

Individuals from all continents with a genuine interest in palliative care research related to family carers may become individual members of the IPCFRC. Membership is free. To formalise your membership please complete the [[online form](#)] on the IPCFRC website.

Forward IPCFRC to a friend!

Please forward this newsletter to friends or colleagues interested in family carer research. They can also sign up for [[free membership](#)]!

Update your details!

We are now collecting information on member research interests and expertise.

[[Update your details now](#)]

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