

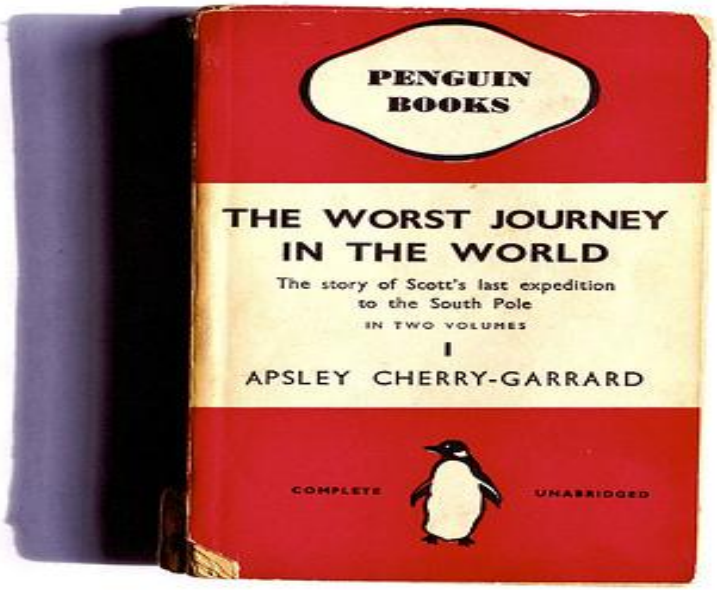

# Navigating the relationship between 'specialist' and 'generalist' palliative care. Lessons from the UK and NZ

Merryn Gott
University of Auckland



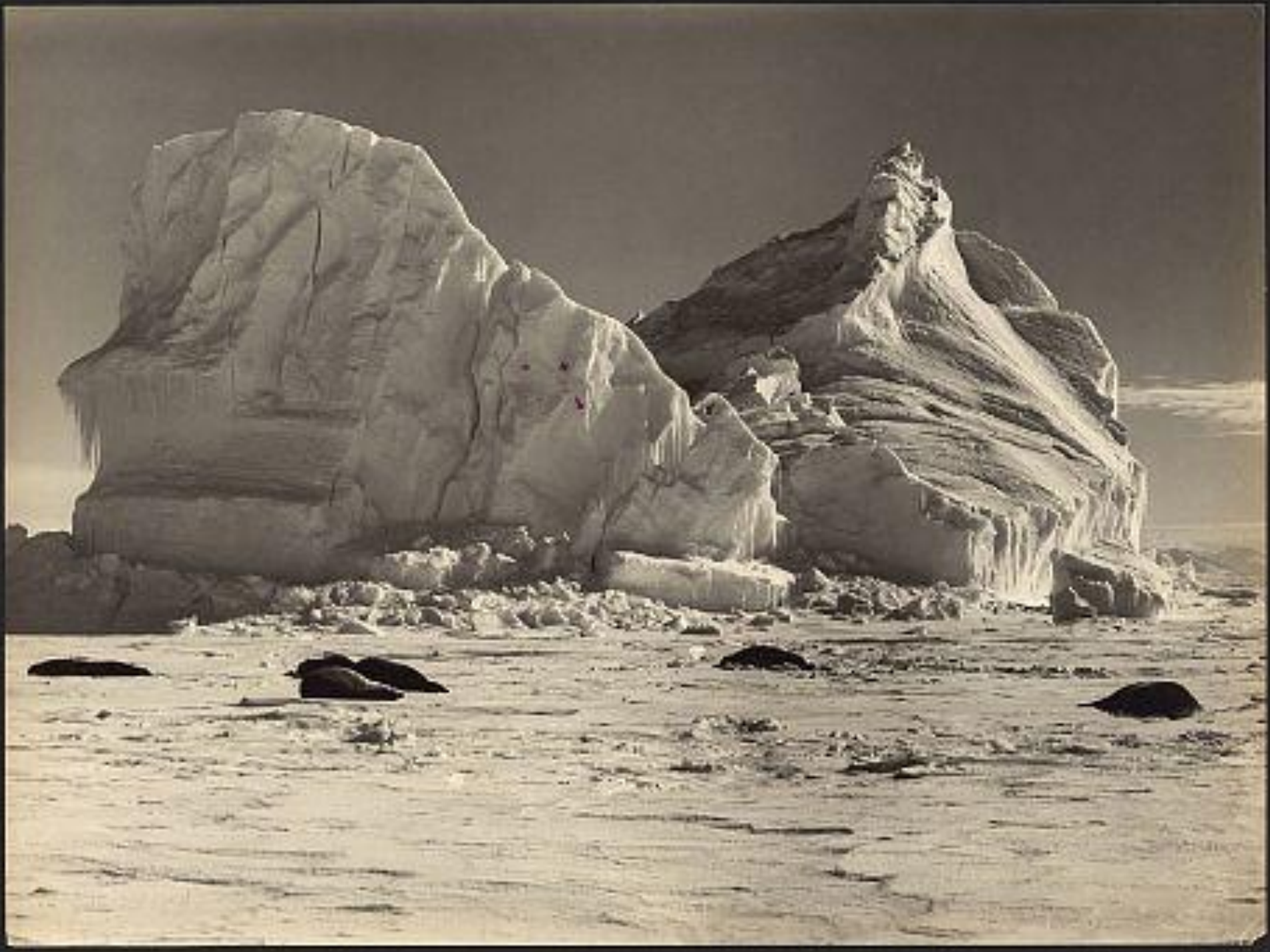




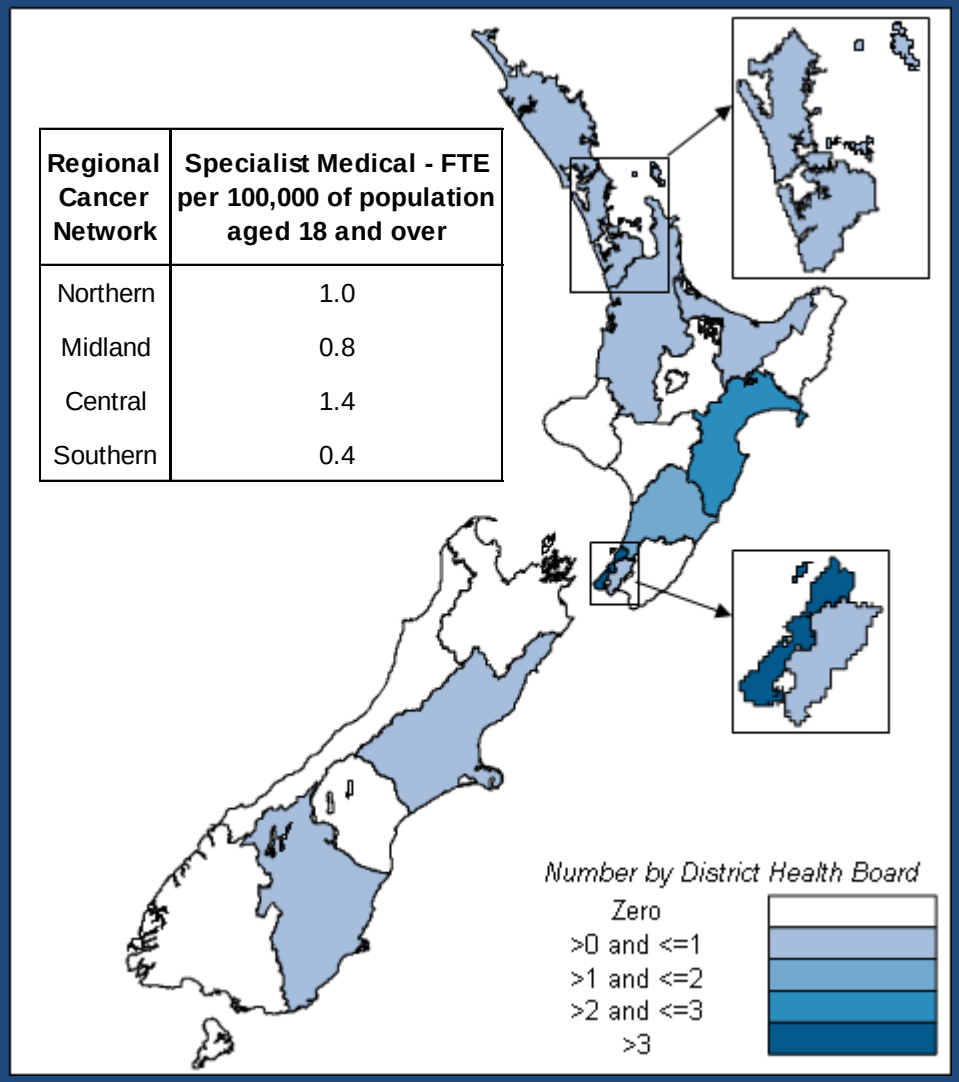

PENGUIN BOOKS
THE WORST JOURNEY IN THE WORLD
The story of Scott's last expedition to the South Pole
IN TWO VOLUMES
I
APSLEY CHERRY-GARRARD
COMPLETE
UNABRIDGED



By way of the Ferrar Glacier they reached the ice-cap after considerable troubles, not the least of which was the loss of the data necessary for navigation contained in an excellent publication called *Hints to Travellers*, which was blown away.



# Total FTE palliative care medical specialists per 100,000 by region and DHB, 2007/08



# Increased emphasis on 'generalist'/'primary' palliative care at a policy level

- The term palliative care is intended in its broadest sense to encapsulate both specialist and generalist care (Aus DoH).
- NZ policy guidance defines 'generalist' palliative care as that 'provided for those affected by life-limiting illness as an integral part of standard clinical practice by any health care professional who is not part of a specialist palliative care team' (NZ MoH).
- EoL Strategy for England: need to ensure that 'end of life care is not seen as an isolated issue, for specialists only' (UK DoH).

Clare Gardiner, Merryn Gott and Christine Ingleton

# Factors supporting good partnership working between generalist and specialist palliative care services:

## a systematic review


### Abstract

**Background**
The care that most people receive at the end of their lives is provided not by specialist palliative care professionals but by generalists such as GPs, district nurses and others who have not undertaken specialist training in palliative care. A key focus of recent UK policy is improving partnership working across the spectrum of palliative care provision. However there is little evidence to suggest factors which support collaborative working between specialist and generalist palliative care providers

**Aim**
To explore factors that support partnership working between specialist and generalist palliative care providers.

**Design**
Systematic review.

**Method**
A systematic review of studies relating to partnership working between specialist and generalist palliative care providers was


### INTRODUCTION

The need to increase the numbers of health professionals involved in palliative and end-of-life care has become a priority of palliative care policies across the developed world. Ageing nations and expanding populations mean annual numbers of deaths are predicted to rise by as much as 17 per cent over coming years.[1] In the UK, the recent palliative care funding review has estimated that, currently, up to 457 000 people need access to a palliative care, but around 92 000 people are not being reached.[2] In the UK in 2009, there were 507 specialist palliative care inpatient services, whose remit is to care for patients who require continuous or high levels of support;[3] however, the care that most people receive at the end of their lives is provided not by specialists but by generalists, such as GPs, district nurses, nursing home staff, hospital staff, and others who have not undertaken specialist effective palliative care.[9] However, difficulties incorporating palliative care into a generalist workload have been reported, as has defining the role of palliative care outside the specialist setting.[10,11] A recent study by Gott *et al* reported significant challenges in generalist working in England and New Zealand. Difficulties with defining the nature and limits of generalist palliative care, as well as negotiating partnership working were reported; these reveal a significant gap between palliative care provision as enshrined in policy and the reality reported by frontline staff.[6]

A key focus of UK policy is improving communication, partnership working, and multidisciplinary involvement across the spectrum of palliative care provision.[9] Although good communication and improved partnership working between specialist and generalist providers have been identified as facilitators for optimum

# Factors facilitating successful collaboration (n=22 papers)

- Good communication between providers;
- Opportunities for education;
- Clear definition of roles and responsibilities;
- Access to specialist palliative care; and
- Coordinated and continuous support.
- BUT Little is known about the direct impact of collaborative working on patient outcomes

*Original Article*

PALLIATIVE MEDICINE

*Palliative Medicine*
26(3) 232–241
© The Author(s) 2011
Reprints and permissions:
sagepub.co.uk/journalsPermissions.nav
DOI: 10.1177/0269216311408993
pmj.sagepub.com
SAGE

# 'That's part of everybody's job': the perspectives of health care staff in England and New Zealand on the meaning and remit of palliative care

**Merryn Gott** *The University of Auckland – School of Nursing, Auckland, New Zealand*
**Jane Seymour** *University of Nottingham – School of Nursing, Midwifery and Physiotherapy, Nottingham, UK*
**Christine Ingleton** *University of Sheffield – School of Nursing and Midwifery, Sheffield, UK*
**Clare Gardiner** *University of Sheffield – School of Nursing and Midwifery, Sheffield, UK*
**Gary Bellamy** *The University of Auckland – School of Nursing, Auckland, New Zealand*

## Abstract

**Background:** the right for patients of all diagnoses to be in receipt of palliative care from an early point in the diagnosis of a life-limiting condition is now enshrined in policy in a number of countries and increased emphasis is placed upon the role of generalist palliative care. However, little is known as to how this policy is enacted on the ground.

**Aim:** to explore understandings of, and perceived roles in relation to, palliative care provision amongst generalist and specialist health care providers in England and New Zealand.

**Design:** qualitative data were collected via individual interviews and focus groups.

**Setting/participants:** participants comprised generalist and specialist palliative care providers working in a variety of settings in England ($n = 58$) and New Zealand ($n = 80$).

**Results:** the following issues with significant implications for this new phase of development for palliative care were identified: (1) difficulties with terminology and perceived roles/responsibilities; (2) problems of integrating palliative care into a generalist workload; (3) challenges in generalist/specialist partnership working; and (4) the potential negative consequences of specialization.

**Conclusions:** these data indicate that, within England and New Zealand, the policy rhetoric of universal palliative care provision is not being straightforwardly translated into service delivery and individual clinical practice. Further research is required to explore and evaluate different models of organization and service provision that empower 'generalists' to provide palliative care, without resulting in deskilling. Finally, definitional clarity at an academic/policy level is also needed.

## Keywords

Generalist, palliative care, palliative medicine, policy, specialism



Surely we have some specialism too?

P: Surely we have some specialism in dying, in older people dying, we have a bit of experience of that (Geriatrician, England)

P: I guess the word ‘palliation’ for me is confusing because, in terms of palliation for things we don’t have a curative answer for, that’s a huge part of general practice (General Practice, NZ)



Maybe they just think that you go in and give them a bath.....

DN: ..all the people who haven't had experience don't know what actually goes on. Maybe they just think that you go in and give them a bath and a wash, which is what a lot of people think still happens
(General Practice, England)

You were treated like a special person because you've taken this area [pall care] on...and that needs to happen with dementia care
(Clinical Nurse Educators, NZ)

There's got to be some funding that's ring-fenced for GPs to look at palliative patients and I think the whole funding for aged care, and to palliate, needs to be hugely increased
(Clinical Nurse Educators, NZ)




# It’s not my job...

Patients can still be left to die in a hospital bed without maybe the same things that we would do in the community and a lot of that is ignorance about palliative care. When I say ignorance they're just not trained because that's not just their job, they've got so many other things (GP, England).



There’s a bit of a power struggle sometimes..

P: There's a bit of a power struggle...that GP has seen them through the birth of their children...he has diagnosed it often, the end of life, the cancer or whatever, he's diagnosed it, he's seen them through the treatment, he's at the end stage with that person and he does not want to relinquish that to somebody else, I can perfectly understand that. So it's taken a long time for our GP, and sometimes we get other GPs that aren't so keen, to realise that hospice is not going to change everything (NZ, Residential Aged Care Facility).



It’s just what you did - now they’re asking specialists...

I've just had a phone call from a GP asking me about pain control in a man who is probably end of life and it was fairly simple, fairly routine, and I thought I'm sure he could do this if this patient wasn't labelled palliative care, dying.  He's an experienced GP and a very simple question about his analgesics. I think some people are quite frightened by the label and the terms that are used around (SPC, England)

P: I guess one of the things that has struck me over the last couple of years is that, particularly in nursing, we have had quite a development of specialisation in nursing and palliative care, I think, has grown with that in the last 10 years particularly in New Zealand. I think that there's a lot of health professionals that devolve their responsibility around palliative care and that might be because they don't feel confident about managing palliative care (SPC, NZ).

# One example of what works

- In some areas of NZ, the specialist palliative care community nurses have a role as relationship 'brokers' between generalists and specialists in palliative care
- They see their responsibility as to facilitate collaborative working in the best interests of the patient and:*'…not to take umbrage but to laugh and smile…'*

Keane B, Gott M, Bellamy G. An exploration of the working relationship between General Practice and Specialist Palliative Care from the perspective of clinical staff. *Health and Social Care in the Community*. Under review.



Where do we go from here?

*A great relationship is about two main things. First, find the similarities. Second, respect the differences.*

# Supportive Holistic Aged Residential Education

Rosemary Frey Michal Boyd, Jackie Robinson, Merryn Gott, Sue Foster, Tess Moeke-Maxwell, Lynda Smith, Jenny Thurston

**Six month pilot study in 2 ARC facilities in Auckland**

**The key components of SHARE are**:

- ***Clinical coaching*** by a specialist palliative care nurse (SPN) from Mercy Hospice Auckland and a Gerontology Nurse Specialist (GNS) from ADHB
- ***Support*** with the development of care plans that reflect the palliative care needs of residents with a life limiting illness
- ***Role modelling*** of conversations related to palliative care (including documentation with residents, families and GP's)
- ***Debriefing*** amongst all ARC staff following a resident's death

**Evaluation**:

- Pre-test/Post-test Staff Questionnaires
- Post-Intervention Staff Interviews
- Records Review Data (results of the GSF-PIG, number of hospitalisations, and number of residents with ACP's).

# Recommendations for interdisciplinary working

- Articulate disciplinary and personal positions & revisit these positions and assumptions throughout the project
- Hold regular project meetings; consider holding them in the different workplaces of team members where practical
- Ensure all terminology and language used in the project is interrogated as a team and that a consensus is reached regarding key concepts where practical
- Explore the ethical principles that each individual adheres to in their work and develop a shared ethical framework for the project
- Establish ground rules early on regarding management of disagreement


Surround yourself with people on the same mission as you.
FB/Sue Fitzmaurice, Author

# You will not sledge alone...

