Welcome
8th Annual Palliative Care Research Network Symposium

‘Out-of-hours Palliative Care’
Aims to improve the experience of palliative care

Karen Charnley Director
AllHPC Partners - 25
Funders

- HSC Public Health Agency
- Health Research Board
- The Irish Hospice Foundation
- Health Service Executive
- EU Flag
Three Work Programmes

1. **Integrate palliative care** research, education and practice development in the health and social care systems across the island of Ireland

2. **Partner with users, carers and communities** to ensure that palliative care provision meets their needs and continues to do so

3. Support the development of **specialist palliative care** to meet the current and emerging demands of the health system
Palliative sector’s Institute with key role in brokering relationships
• PCRN Strategic Plan 2017 – 2022
• Growing membership of PCRN (49) and Early Career Researcher Forum (109)
• Funding - Supporting members to respond to national and international opportunities
• Service user / carer engagement - Voices4Care
• Knowledge transfer – supporting transfer into policy, practice and education
• Capacity building - ECRF, webinars, seminars and symposium
• Supporting links with clinical sites
• Collaborating with International networks and experts
• Re-fresh of panel in early 2019 (47 members currently)
• Involved in ongoing work of AIHPC
• Engaged in palliative care programmes in both jurisdictions
• Engaged with AIHPC partners

• Palliative care experience videos
• AllHPC Project ECHO – HSE Funded
  – Dublin and mid-west nursing homes with specialist palliative care hubs in Our Lady’s Hospice and Milford Care Centre (>670 participants to-date)
  – Community based allied health (across Ireland) with specialist occupational therapists and physiotherapists (26 participants)
• Erasmus EDUPALL project undergraduate palliative medicine
• Education Network (44 members) - building capacity and supporting innovation in education delivery
• Supporting undergrad, post grad and CPD
• Online education
• Engaging with Government Departments and Agencies

• Supporting National Palliative Care Programmes
  – National Clinical Programme for Palliative Care (RoI)
  – Regional Palliative Care Programme – Palliative Care in Partnership (NI)

• Supporting links between palliative care policy, practice, research and education (under-grad, post-grad, CPD)
Practice

- Supporting practice networks including CEO of Hospices Network

- Membership of relevant national, all island and international networks

- Hosting and supporting workshops and conferences
Online information gateway

www.thepalliativehub.com
Palliative Care Week
8-14 September 2019

- Sixth successive year of Palliative Care Week
- Aims to ‘build awareness and understanding of palliative care’
- AllHPC develops concept and materials in collaboration with sector and engages with media and social media
- Palliative and wider health sector central to success of week
- Raising awareness of AllHPC
Thank you

www.thepalliativehub.com
www.aiihpc.org

Further information:
kcharnley@aiihpc.org
Value of palliative care research to support practice and policy

Charles Normand
Professor of Health Policy & Management
Trinity College Dublin
Professor of the Economics of Palliative Care and Rehabilitation, King’s College London

02/10/2019
Acknowledgements

This presentation draws on findings from a number of studies in which I played a role. I am grateful to my collaborators and colleagues for their significant contributions.

Peter May, Melissa Garrido, Brian Cassel, Egidio Del Fabbro, Sean Morrison, Diane Meier, Amy Kelley, Melissa Aldridge, Eoin Tierney, Bridget Johnston, Lorna Roe, Karen Ryan, Regina McQuilan, Irene Higginson, Gao Wei, Yi Deok Hee, Adrienne Sweetnam, Padhraig Ryan, Hannah Rose Douglas, Orla Hardiman, Katy Tobin and others.
Outline of Presentation

• From insight and passion to evidence and science
• Understanding where we are and where we are going
• Understanding what works for whom and how
• Understanding what is good value
• Understanding what people want
• From evidence to changes in systems and practice
• From evidence to changes in policy
From insight and passion to evidence and science

• Pioneers of palliative care had huge insight and were able to change agenda

• As palliative care has grown, needs have become more complex and diverse, and the role for research and new knowledge has increased.
From insight and passion to evidence and science 2

Roles for palliative care:

• Come earlier
• Have moved beyond end of life concerns
• Have moved beyond symptom management
• Must work with more complex disease and multimorbidity
• Must be carried out in close co-operation with other health care professionals and families.
From insight and passion to evidence and science 3

• Optimising experiences for people with complex needs requires high level skills and team work
• The trend towards ever more specialised specialists makes this more challenging
• Much of what we now know presents challenges to older people’s services more widely and primary care
• Much of the current evidence suggests much is right, but much is not.
Understanding where we are and where we are going

• Ireland has one of the more developed systems of palliative care in Europe

• Access to palliative care skills is uneven across the country

• Tilda data suggest that around half of decedents die without adequate management of pain and depression.
Understanding where we are and where we are going 2

• The annual number of deaths is set to rise by about a third
• In the future people will die older and with more chronic diseases diagnosed
• A reasonable estimate is a doubling of people with palliative care needs by 2050.
Understanding what works for whom and how

- Compared to what? Effects and effectiveness have to be judged versus counterfactual
- Measurement tools for quality of life and quality of experience in palliative care are limited
- Important to take account of effects of different trajectories of care on wider family
- Some constraints on what studies designs are feasible.
Understanding what works for whom and how 2

We do know:

- Careful assessment of needs and planning of care changes trajectory of care for the better
- This is particularly the case for people with very complex needs
- This is particularly the case for people with a cancer diagnosis
- This is particularly the case when done early in the end of life period.
Understanding what works for whom and how 3

We do know:

• Intervening with patients in ED who are known to have palliative care needs improves experiences and lowers cost

• Supporting informal carers allows them to switch to tasks that only they can do

• Living better and living longer is only sometimes a choice – often there is no trade-off.
Understanding what is good value

• Palliative care led services is not simply a cheaper option - good palliative care may not save money

• There is considerable scope for savings from reducing futile and ineffective care

• Given the context and types of complex interventions it is often difficult to demonstrate the effectiveness of palliative care using conventional outcome measures.
Understanding what people want 1

- Focus on measuring preferences started as answer to problem of measuring outcomes
- Some important findings have come from studies on preferences of service users
- People want good, timely, low hassle access to skilled clinical services
- People do not trade off this with other (legitimate) goals of palliative care.
Understanding what people want 2

• Preferences are not necessarily stable over time

• There is only a partial match of the preferences of patients and their main carers – proxy decision making risks some unwanted choices

• In many cases trying is valued at least as much as succeeding

• The style and approach can be as important as the ability to intervene effectively.
From evidence to changes in systems and practice 1

- Palliative care is a medical and nursing specialty, is a set of services and is an approach to care that works with the wider provider community.
- Many of the issues revealed in palliative care research apply strongly also in other specialties and primary care.
- Good palliative care is one version of good integrated care.
From evidence to changes in systems and practice 2

• Development of specific palliative care services and interventions must run in parallel to serious engagement with closely related services.

• Given the demonstrated value of careful, timely, thoughtful support for decision making it is crucial to get away from short, rushed interactions where people have complex needs.

• There is a need to focus on the process of care delivery as much as on the content of care.
From evidence to changes in policy

The evidence suggests at least 3 urgent needs in policy making:

• We need to plan for a very rapid increase in capacity to meet palliative care needs
• We need to apply much of the evidence to the wider health system
• We need to make choices about how we best combine more specialized skill sets with a much fuller integration of palliative care approaches.
From evidence to changes in policy 2

- The experience of rapidly changing models of palliative care delivery suggests we need to develop a skilled but flexible workforce.

- Since the rest of the health system is out of line with palliative care we need to consider how best to apply the finding especially in older people’s services and primary care.

- We need to move beyond the discussion of specialist and generalist palliative care to one around building suitable teams to meet diverse and complex needs.
They were remarkable and insightful, but

- It has all got so much more complicated!
Thank You for Your Attention
Professor Joanne Reid, Chair of PCRN
As the leading Network for palliative care research on the island or Ireland, members undertake internationally recognised research that enhances palliative care knowledge and expertise and improves the quality of life of people with life limiting conditions.
PCRN Strategic Plan 2017 - 2022

Developed in collaboration with PCRN members, Voices4Care members, hospice and palliative care providers, health care professionals, policy makers and funders

Five Key Strategic Areas

1. Improve Quality of Life for People with Life-limiting Conditions and Carers
2. PCRN Sustainability
3. Research Leadership and Capacity
4. Service User, Carer and Community Involvement
5. Collaborate and Co-lead Research Community

Disseminate Research Knowledge
Palliative Care Research Network 2019

49 Leading researchers on island of Ireland who focus on palliative care

9 Universities and Palliative Care Providers

University College Dublin, Trinity College Dublin, Dublin City University, Royal College of Surgeons Ireland, National University of Ireland Galway, University College Cork, University of Limerick, Queens University Belfast, Ulster University and Palliative Care Providers

8 Disciplines

Medicine, Nursing, Psychology, Occupational Therapy, Physiotherapy, Pharmacy, Health Economics and Law

Highlights 2019

86 peer reviewed publications in palliative care

8 new PCRN members

Prof Gerard Fealy, Nursing, (UCD)
Dr Bridget Johnston, Health Economics, (TCD)
Dr Siobhan Fox, Psychology, (UCC)
Prof Dympna Casey, Nursing, (NUIG)
Dr Helen Kerr, Nursing, (QUB)
Dr Suja Somanadhan, Nursing, (UCD)
Dr Emer Guinan, Physiotherapy, (TCD)
Dr Aidan McKiernan, Psychology, (Laura Lynn Ireland Children's Hospice/UCD)
Interdisciplinary All Ireland Seminar
Designing and Developing Technologies for Palliative Care
June 2019

• **Aim:** To stimulate innovative research in technology that produces practical solutions for people with palliative care needs

• **On the day:** 37 organisations represented by health, science and engineering researchers, clinicians, industry experts, service providers and funding organisations (Science Foundation Ireland (SFI), Enterprise Ireland)

• **Seminar impact:** Collaborative applications to SFI and EU for research into advance care planning and Virtual Reality (VR) symptom management; potential for further EU collaborations with PCRN members and Waterford Institute of Technology (WIT) TSSG

“I thoroughly enjoyed the seminar. It was very well conceived and organised. There are plenty of potential collaborations we could build from this, which could be of benefit to patients.”
Top 10 All Ireland Palliative Care Research Priorities

Supporting **early and mid-career researchers** through Early Career Researcher Forum

Supporting **hospices and clinical sites** with research prioritisation

Nominating members to **leadership roles**, Prof Sonja McIlfatrick to European Association of Palliative Care (EAPC) Board

Building capacity through **Joint Seed Funding Awards**, Irish Cancer Society/AllHPC
Service User, Carer Involvement

- **Reviewing research proposals** for funding applications

- Supporting research projects with **plain language usage and providing guidance** for research projects on steering groups

- **Panel members** at AllHPC events

Research Knowledge Dissemination

- Dissemination with peer-reviewed **Knowledge Transfer and Exchange** model and regional workshops (70 participants)

- **Research Zone** on Palliative Hub Professional

- Awarded ‘**Champion of Plain English**’ from National Adult Literacy Agency (NALA)
Impact of Palliative Care Research Network

Leading and Collaborating on EU Projects

• Family carer decision support interventions for people with dementia
• Psychosocial and educational interventions for people with advanced cancer and carers
• Better treatments for breathlessness at end-of-life
• Anticipatory care planning intervention for older adults at risk of functional decline

Collaborating on National Projects

• Analysing palliative and end-of-life care data for future planning
• Models of palliative care for people with Dementia
• Economic policy evaluation of palliative care
• Public health approach to awareness of palliative care and advance care planning
• Clinical phenotype for cachexia in chronic kidney disease
• Models for rehabilitative palliative care across hospital and community
• Reconceptualisation of palliative care as a human right
• ECHO Nursing Homes Evaluation
Thank you

www.thepalliativehub.com/Research
www.aiihpc.org
Early Career Researcher Forum

Dr Aoibheann Conneely, ECRF Committee
Our Lady’s Hospice and Care Services, Dublin
Early Career Researcher Forum

Who are we?

• All island multi-disciplinary forum
• Free to join
• Open to all researchers or clinicians
  – From any discipline
  – Who consider themselves in the early-to mid-stages of research career with an interest in
    • Palliative care
    • End-of life-care
    • Whose research may influence people with palliative care needs

If you are interested in the ECRF and/or would like to join visit
http://www.professionalpalliativehub.com/research/ecrf
Benefits of ECRF Membership

• Peer and mentor support
• Develop links with senior researchers from our Palliative Care Research Network
• Participate in free capacity building
• Publish blog articles
• Receive regular funding and event updates on a fortnightly basis relevant to palliative care
• Hear about career development opportunities
• Transfer and exchange knowledge across disciplines
ECRF Members

109 members

New members from:
• University College Cork
• Ulster University
• Trinity College Dublin
• National University of Galway, Ireland
• University of Limerick
• Our Lady’s Hospice & Care Services
• Lauralynn Children’s Hospice
• Care Alliance Ireland
• St Vincent’s University Hospital
Early Career Researcher Forum Committee

Chair: Monika Pilch - Trinity College Dublin

Vice-Chair: Mary Nevin - Trinity College Dublin

Membership Officer: Dr Cliona Lorton - Our Lady's Hospice and Care Services

Communications and Activities Officers:
- Dr Deborah Muldrew - Ulster University
- Dr Serena Fitzgerald - University College Cork

General Members:
- Dr Aoibheann Conneely - Our Lady's Hospice and Care Services
- Aidan O'Donoghue - Trinity College Dublin
- Stacey Power - Cork University Maternity Hospital
- Yvonne Muldowney - Trinity College Dublin

Representing:
- Medicine, Psychology, Nursing, Dietetics
What do we plan to do?

• Implementation of Social Media Strategy
• Membership
• Capacity building activities
  – Needs Analysis
  – Website
  – Webinars
  – Networking
  – Mentoring Scheme
• Funding Applications
Thank you

If you would like to contact us email:
info@aiihpc.org
Out of hours Palliative Care

Outcomes of VOICES4CARE discussions

ASHLING Hotel 2019
In 3 groups 3 questions were addressed:

Q1. What do you think is important in considering palliative care outside normal working hours?

Q2. What sort of palliative care support do you think should be provided outside normal working hours?

Q3. Where should this out of hours care be provided and by whom?
Out of hours palliative care tended to be provided by:

- Home / carer / family / community support perhaps on rota basis;
- G.P. / now doc / locum;
- Hospital / oncology ward / palliative care nurse;
- Hospice / nurses / palliative care nurse / chaplain / support workers.
Interaction / transference / communication

the ‘ings’:

• Prescribing
• Dispensing
• Administering
• Advising
• Delivering
• Recording
+ Geography
Mediated by:

- personality
- education
- language of both parties
- social circumstances
- geography
- culture
Language is important so that we all mean and understand the same *thing*

*Sometimes professional language can get in the way of meaning!*
OUTLINE OF LIKELY ILLNESS PATHWAY TO PATIENT AND CARER

FOLLOWED BY

OUTLINE OF CONTINUITY OF CARE PLAN
Continuity Of Care Plan

ONE DESIGNATED PERSON - CARER

would liaise regularly with prescribing medics

in the event of need for urgent consultation

would know who the go-to person or protocol was
An Out of Hours Medical Emergency Plan

A phone service ‘a la’ the Samaritans centred in each hospice

feasibility personnel cost

Is there a palliative care hub and spoke model that could be adapted?
Medical card

Ensure that back-up facilities, if and when needed will be available in time

Bed
Hoist
Wheel chair
Shower
Toilet
Commode etc.
Frustrations
(not in any order)

• Admission through A&E
• GP’s not in the loop
• Locum and now doc less in the loop
• Need for patient medical records on-line
• No back-up for carers
• Night nurses not readily available
• Uneven provision geographically
• Some hospital departments on seeming ‘work-to-rule’
• Port-a-cath skill set
Thank you
Out-of-hours services: Rights-based approach

Dr John Lombard
School of Law, University of Limerick
Introduction

J Lombard, “Bridging the Divide between Law and Palliative Medicine”
*Palliative Medicine*

Human Rights

• Human rights are the basic rights and freedoms that all people should enjoy. (HIQA, 2019).

• A pole star to guide behavior
• A floor of protection below which duty-bearers cannot fall.

• The Irish Constitution; The European Convention on Human Rights Act 2003; UN Convention on the Rights of Persons with Disabilities
Human Rights

• Human rights based approach ... a conceptual framework

• The empowerment of rights-holders to claim and exercise their human rights

• Strengthen the capacity of duty-bearers who have an obligation to respect, protect, promote, and fulfil human rights.

• FREDA principles – Fairness, Respect, Equality, Dignity, and Autonomy
Human Rights

- Document violations of the rights of patients and advocate for the cessation of these violations.
- Pressure government departments into addressing issues.
- Sue for violations of national human rights laws.
- Use human rights for strategic organisational development and situational analysis.
- Organise and mobilise communities around a human rights imperative.
- Push for law reform.
- Develop guidelines and standards.
- Conduct human rights training and capacity building
- Integrate a human rights approach in health services delivery.
Human Rights & OOH Services


- Barriers to OOH Services – can be framed in terms of human rights
Conclusion

• Human rights as central to the provision of palliative care

• Human rights offer legal, political, and moral weight

• An opportunity to use law as a tool for change
Thank You
Effectiveness and cost-effectiveness of out-of-hours palliative care: Barriers and challenges

Bridget Johnston
Centre for Health Policy and Management
AllHPC Annual PCRN Symposium
14 November 2019
Background

• Over 70% of Irish patients prefer to spend their palliative period at home provided they can access appropriate services and supports.

• Approximately three quarters of the week occurs ‘out-of-hours’ and the need for support during this time is common.
  • Poor patient outcomes have been linked to inadequate community supports and a lack of patient confidence in out-of-hours access
  • Out-of-hours care provision that meets the needs of patients and their families is fundamental to achieving an integrated palliative care approach.

• Priority-setting exercises with patients, carers, volunteers, and health and social care professionals have identified “the best ways of providing palliative care outside of working hours” in both the United Kingdom and Ireland
Background

- The Department of Health commissioned this review to inform the revision of national palliative care policy and address the recognised challenges in providing out-of-hours palliative care.

- Three major recent policy developments inform the context:
  - Updated national palliative care policy from 2020
  - Sláintecare reform programme, including universal palliative care provision within first five years
  - National Cancer Strategy 2017-2026

- A multi-disciplinary report team including researchers, information specialist, policy advocates and a clinician
  - Dr Bridget M. Johnston, Dr Peter May, Ms Rachel McCauley, Dr Regina McQuillan, Dr Mary Rabbitte, Ms Caitriona Honohan, Mr David Mockler, Professor Steve Thomas
Research questions

• Four questions covered in the evidence review

• What is the effect of out-of-hours specialist and generalist palliative care services on patient and family/caregiver outcomes, and on costs and cost-effectiveness?

• What are the models of out-of-hours palliative care services in high-income countries that have such programmes?

• What are the indicators used to measure the effectiveness of out-of-hours palliative care services in those countries?

• What are the barriers to, and facilitators of, implementing out-of-hours palliative care services in those countries?
What is the evidence for the effects of out-of-hours or after-hours hours specialist and generalist palliative care services on patient and family/caregiver outcomes, and on cost and cost-effectiveness (health system and societal perspectives)?
Method

- **Eligibility Criteria – PICO**
- **Databases searched:**
  - EMBase, MEDLINE (OVID), CINAHL, AMED, WOS, SCOPUS, ECONLIT, Cochrane Library, PsycINFO
- **Grey literature sources:**
  - Google Scholar, OpenGrey, ClinicalTrials.gov, WHO ICTRP, ProQuest Dissertations & Theses (UK & Ireland), RIAN, Lenus, EThOS
- **Snowball sampling**
- **Screening of titles and abstracts**
  - COVIDENCE
- **Screening of full text reports**
  - COVIDENCE
- **Assessment of methodological quality/bias**
  - Critical Appraisal Skills Programme (CASP)
Results

- **1,500 citations:**
  - 834 duplicates
  - Reviewed 666 unique title/abstracts - 626 were deemed irrelevant
  - 40 full texts
  - **One** study met the eligibility criteria - did not pass quality assessment due to critical omissions in reporting

- The database search therefore identified **zero peer-reviewed studies** evaluating impact of out-of-hours palliative care for adults on patient/carer outcomes and/or economic outcomes.

![Diagram of search and selection process]

- Excluded at full text (n=39)
  - Design: Not a comparative evaluation (n=22)
  - Intervention: Not OOH PC (n=12)
  - Population: Not adults with PC needs (n=2)
  - Outcomes: Not patient/family or economic endpoints of interest (n=1)
  - Time period: Study finished before 1/1/96 (n=1)

- Excluded at quality assessment (n=1†)

- Included in the review (n=0)

- Studies meeting eligibility criteria (n=1)
• Describe in detail the models of out-of-hours or after-hours specialist and generalist palliative care services in high-income countries that have such programmes.

• Identify and appraise the indicators used to measure the effectiveness of out-of-hours or after-hours specialist and generalist palliative care services
Method

• **Review of governmental, academic, and health organisation websites**
  o Policy and practice documentation of national and regional government bodies
  o Documents drawn up by organisations with a primary focus on palliative care.

• **Grey literature database search**
  o OpenGrey, ClinicalTrials.gov, WHO ICTRP, ProQuest Dissertations & Theses (UK & Ireland), RIAN, Lenus, EThOS.

• **Additional Google/Google Scholar searches**

• **Expert review:**
  o Experts in palliative care policy, practice and academic institutions.
  o Feedback with relevant evidence, or indicate concurrence – quality assessment.
Models of care

- A documentary review of policy and practice documents in 16 high-income countries identified acceptance of the importance of integrated, 24-hour palliative care in principle.

- Detailed description of the organisation of out-of-hours care within this ideal was rare.

- No models of care measured – look to instances of innovation.

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<thead>
<tr>
<th>Datapoint</th>
<th>Key findings</th>
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<tr>
<td>Models of out-of-hours specialist and generalist palliative care</td>
<td>• Patient-centred, 24-hour, community-based service models.</td>
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<td></td>
<td>• Efficient and equitable care.</td>
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<td>• Well-established frameworks.</td>
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<tr>
<td>Definition of out-of-hours</td>
<td>• Weekdays: 5/6pm to 8am (most countries); 7/8pm to 9am (some countries).</td>
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<td>Target population</td>
<td>• Weekends and public holidays: all times except Saturday mornings, which is in-hours (France, Australia; all times (all other countries).</td>
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<td>• WHO definition of all people with life-limiting illness (most countries)</td>
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<td></td>
<td>• Stratification by need (Australia)</td>
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<td>• Exceptionalism for cancer (Japan).</td>
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Innovation examples

Specialist Paramedic Training in the UK

- Macmillan Cancer Support UK
- Training generalist ambulance staff with specialist palliative skills
- Allows for:
  - rapid transfer of the dying to their chosen place of death if necessary
  - appropriate transport for the patient and carer
  - information systems are in place to ensure access to the patient’s end of life plan

Telehealth in Japan

- E-health systems currently being utilised by over 100 local government institutions,
- Rapid development due to significant funding in the last five years
  Primary function - transmit users’ health-related data to medical institutions
    - Blood pressure, ECG, oxygen tension
- Particularly useful for patients in remote locations
Performance indicators

• We identified only one set of performance measures specifically for out-of-hours palliative care
  • UK Department of Health 2011

• These include:
  o Adequate advanced care planning preparation
  o Access and communication between out-of-hours palliative care services
  o Access to drugs, particularly opioids.
  o Appropriate palliative specialisation competency
  o Updated and detailed patient information sharing

• However...
  • These measures had not been assessed for validity or usefulness
  • Not embedded into clinical programmes – just recommendations
Identify the barriers to and facilitators of implementing out-of-hours or after-hours specialist and generalist palliative care services

Findings organised into:

1. **Macro** - the societal, national or international level;
2. **Meso** - the mid-range perspective, typically analyses at the community or organisational level;
3. **Micro** - the local perspective, typically analyses at the individual or household level.
Method

• Describe and organise all identified barriers and facilitators, discuss in the context of the evidence, similarities and differences identified in previous research questions.

• Reviewed all material used in previous chapters including titles and abstracts returned by the systematic review (n=666)

• Where abstract indicated potentially relevant material, full paper reviewed for references to barriers, facilitators and implementation.
### Barriers

#### Macro
- Lack of resources for practitioners and patients to rely upon in emergency and out-of-hours situations
- Lack of knowledge
- Reluctance to refer among clinicians
- Reluctance to be referred among patients and family members
- Lack of advanced care planning at an appropriate time
- Ineffective communication
- Inadequate anticipatory practices
- Incentives for hospitals

#### Meso
- Time and budgetary limitations for clinicians and management
- Lack of clarity of roles and responsibilities
- Lack of team cohesion or collaboration in multidisciplinary teams
- Lack of clarity on referral policies
- Poor discharge planning and co-ordination across services
- Increased burdens on in-hours colleagues often follow

#### Micro
- Difficulty in accessing information
- Perceived lack of formal support and acknowledgement
- Time constraints

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<tr>
<th>Non-SPC Nurses</th>
<th>Paramedics</th>
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<tr>
<td>Difficulties in accessing information</td>
<td>Lack of protocols for moves between care settings</td>
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<td>Perceived lack of formal support and acknowledgement</td>
<td>Insufficient palliative care education</td>
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<td>Time constraints</td>
<td>Poor clarity of objectives</td>
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<tr>
<td>Inadequate information-sharing and support from other services</td>
<td>Inadequate integration with and support from other providers</td>
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<tr>
<td>Insufficient resources to provide OOH appointments or home visits</td>
<td>Variation in knowledge of GPs</td>
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<tr>
<td>Inadequate integration with and support from other providers</td>
<td>Variation in knowledge of GPs</td>
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## Facilitators

### Macro
- Effective communication during in-hours periods
- Electronic patient records
- Advanced care planning early in the disease trajectory
- Equipping patients and caregivers with tools and knowledge

### Meso
- Improving cohesion amongst multidisciplinary teams
- Palliative care in- and after-hours provided by **on-site staff in rural residential care**
- Improved access to medications through initiatives

### Micro

#### Patient Perspective
- Familiarity with the care team
- Continuity of care
- GP Palliative care familiarity and approach

#### GP & Consultant Perspective
- Accessibility of person and place
- Appropriate supports for the provider
Policy Implications & Concluding Thoughts (1/2)

• Importance of integrated, 24-hour care for people with serious and complex medical illness is widely acknowledged

• Scant details on how to organise, provide and evaluate out-of-hours palliative care effectively
  • Complex intervention and evaluations may not capture/report data on individual components of service
  • Future studies using statutory data or original research

• The evidence gaps must be urgently addressed
  • Statutory data source
  • Original research across settings using flexible and pragmatic approaches

• Need for creation of new out-of-hours services and capacity but also improved integration of pre-existing in- and out-of-hours services
Policy Implications & Concluding Thoughts (2/2)

• Ireland is typical among high-income countries with well-established services
  • Commitment to providing integrated palliative care but underdeveloped evidence base

• Service planning in the context of limited international evidence
  • Population-based needs assessment for generalist and specialist services
  • Timing and phasing of services
  • Evaluative framework

• Future developments could include
  • Pilot programmes utilising innovation of other countries
  • Pilot programmes in line with identified “gold standard” elements of out-of-hours care
  • Pilot new programmes overcoming identified barriers
  • Ensure these programmes are measured and evaluated in terms of efficacy, equity, and efficiency.
Thank You!

Email: bjohnst@tcd.ie
Twitter: @BriMJohnston or @PaCE_TCD
Out of hours support for terminally ill people in N.
Craig Harrison, Policy and Public Affairs Manager, Marie Curie Northern Ireland
Current OOH support for terminally ill patients

- No. people on Palliative Care Register +200%, 2007-2017
- Lack of robust and standardised OOH services across NI
- Capacity issues in GP OOH, District Nursing
- Community services over capacity and no self-referral

Crisis or deterioration out of hours often leads to one place... **Emergency Department**.
Emergency admission trends among patients in last year of life

- > 6,000 emergency admissions among cancer patients in last year of life (2015)
  - 3 in 4 had at least one emergency admission
  - 1 in 6 had three or more
  

- Average of more than 2 emergency admissions among patients with lower respiratory conditions in last year of life (2015)

  Marie Curie (2018). In and out of hospital: Understanding disparities in emergency admissions in the final year of life.

- Estimated total 200,600 emergency bed days for those in last year of life (2015)

  Marie Curie (2018). In and out of hospital: Understanding disparities in emergency admissions in the final year of life.
Emergency bed days per 1,000 deaths in N. Ireland (2015)

- Cancer deaths: 18,554
- Non-cancer deaths: 16,908
- All deaths: 17,382

Marie Curie (2018). In and out of hospital: Understanding disparities in emergency admissions in the final year of life.
Negative outcomes from A&E and emergency admissions

• Over 30% of those waiting >12 hrs on a trolley in ED are in last year of life
  Sean McGovern, SE Trust.

• Older people -5% muscle strength p/ day lying a hospital bed
  National Audit Office (2016). Discharging older patients from hospital.

• 46,000 delayed bed days across NI (2017-18) – **204 deaths waiting for discharge**
“During the last 12 months Dad was admitted to hospital a handful of times. He absolutely hated being there and couldn’t get back out again fast enough. He much preferred being looked after at home, with his family around him, and was very clear with all of us that he didn’t want to spend any time in hospital if it could be avoided. That was very important to him.” – Elizabeth, whose dad had terminal lung cancer
Marie Curie Rapid Response Service: OUTLINE

• Flexible access to OOH palliative nursing care
• Delivered in partnership with GP OOH
• Referrals from DNs, NIAS, GP or self-referral
• Operating in every Health Trust in N. Ireland
Marie Curie Rapid Response Service: IMPACT

![Bar Chart]

- Care after Death: 2% Visits, 1% Calls
- Complex Interventions: 3% Visits, 3% Calls
- Catheter Related Activity: 17% Visits, 16% Calls
- Information: 17% Visits, 16% Calls
- Symptom Management: 27% Visits, 5% Calls
- Personal Care: 28% Visits, 4% Calls
- Admin of Meds: 49% Visits, 5% Calls
- Emotional Support: 69% Visits, 79% Calls

Legend:
- Blue: Visits
- Orange: Calls
Marie Curie Rapid Response Service: IMPACT

- I received the support I needed: 93%
- I was made more comfortable by the Rapid Response nurse: 93%
- I felt less worried or anxious, knowing that I could call the Rapid Response Service: 90%
- My family member/friend was less worried or anxious, after I had received support from the Rapid Response Service: 85%
Marie Curie Rapid Response Service: IMPACT

- 1,500 patients supported Jan-Oct 2015 (N, S and W Trusts only)
- 43% patients received at least one visit which prevented hospital admission
- Just 1% visits ended with hospital admission
- 60% service users would have phoned ambulance or gone directly to A&E without RRS
“People often express how much it means to them when we visit and that they couldn’t manage without the service. I was recently involved with one family – the father had a very complex condition and acute pain at times, but it was his wish to remain at home and through the Rapid Response Service we made this happen. He never had to visit hospital and died at home surrounded by his family.” – Marie Curie Rapid Response Nurse
For more information contact:
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Email: craig.harrison@mariecurie.org.uk
Follow us on Twitter @MarieCurieNI

We're here for people living with any terminal illness, and their families. We offer expert care, guidance and support to help them get the most from the time they have left.

mariecurie.org.uk
Charity reg no. 207994 (England & Wales), SC038731 (Scotland) A003
Irish Cancer Society
Night Nursing Service

Mary Ferns
Night Nursing Manager
Introduction

• Background
• Statistics/Costings
• Challenges
• Role of Night Nurse
Night Nursing Service

Background

- Service was established in 1986

- Now offer 10 nights of care per patient - 11pm-7am Can go up to 14 on an individual patient basis

- Referrals for cancer patients
  - Specialist Palliative Care Teams - 98% of referrals community/hospital
  - GP’s and PHN’s

- Referrals for Non Malignant Patients  
  - Funded by IHF
    - Community Specialist Palliative Care Team only
Service Statistics

• 180 Night Nurses employed by the Society

• Service Coordination
  ➢ NN Manager
  ➢ 3 Administrative staff

• 95% of booking requests fulfilled in 2018

• 26% of bookings are non-malignant
Statistics Cancer Jan - Sept

- Count of booking_ref
- Paid
- Count of patients
- Count of no_nurse

Year: 2017, 2018, 2019

- 2017: 267, 318, 482
- 2018: 6822, 5440, 1378
- 2019: 7225, 5459, 1401
Statistics Non Cancer Jan - Sept

- Count of booking_ref
- Paid
- Count of patients_w...
- Count of no_nurse...

Year:
- 2017: 447
- 2018: 441
- 2019: 506

- 2017: 94
- 2018: 104
- 2019: 187
Costings

• €350 per night
  ➢ Night Nurses Salary
  ➢ Education and Training - Manual Handling - CPR -
  Annual Study Day - McKinley Syringe Driver Training

Recruitment Costs -
  ➢ Recruit 30-40 nurses per year
  ➢ Garda Vetting
  ➢ Pre-employment Medicals
  ➢ Induction Day
  ➢ Clinical Placements
Challenges for service

- No Night Nurse Available
  - Surge in demand in service in a particular area on a particular night
  - Patient’s in remote areas are difficult to cover - Cork vs Cork West 2019 - 33 nights in Cork not covered - 26 of those in West Cork
  - Recruitment of nurses is difficult as work is not guaranteed
  - Nurses not available at Holiday periods and Bank Holiday Weekends
Challenges for families

• 70% of patients wish to die at home, 23% of them do so.

• Early morning after 7am and evenings after 5pm, families can struggle.

• Only nursing service providing end of life care to adults at night time

• If there is no night nurse in most cases there is no plan B
Family Feedback

‘If available it's a wonderful service but in its absence there is nothing for a family to fall back on. We were unable to get a night nurse for dad's last two nights and were left to fend for ourselves. It was a very distressing situation to be in, firstly to watch our poor dad suffering in such a manner, feeling helpless, and having to perform medical procedures with no medical experience. We felt very alone that night and hope that we made dad as comfortable as possible’
Family Feedback

• There were nights where we would cry watching him in such distress, I do think that his pain was under control but the agitation etc was just awful to watch, especially for my Mam. I don’t feel able to start grieving as I am so full of anger. I am going to go for bereavement counselling and hopefully it will get rid of the anger’
Challenges

• Don’t know what the unmet need is. National average uptake of nights per patient is 4 although we offer 10

• Element of caution when introducing service - fear nights will be exceeded

• Patients are referred late to specialist palliative care
Night Nurses Role

- Pain and symptom management
- Administration of medication
- Reassurance
- Advice
- Friendship
- Understanding
- Psychological support
Night Nurses Role

- Empathy
- Compassion
- Kindness
- Caring
- Walk in the shoes of those who are suffering/grieving
- Emotional presence
- Only one chance to get it right
Night Nurses Own Experience

- Honour
- Privilege
- Humbled
- Personal growth
- Appreciation for life
‘I now see that with having the night nurse present my sister was comfortable, never left alone, free of all pain and above all she was not afraid to die’
Strategy for Health Care Research on the island of Ireland

8th Annual Palliative Care Research Network (PCRN) Symposium
14th November 2019
HRB Basics

- State agency under Department of Health.
  - Budget ~€45m pa (0.3% of health budget), funding portfolio €150m+, staff of 65

- Providing evidence for policy
  - Public Health Alcohol Bill, Food Pyramid, Fluoridation

- Information for service planning
  - Drug use, disability, mental health

- Funding health research
  - Clinical, Population Health, Health Services Research
  - Infrastructure, capacity building, specific projects.
Overview of Health Research Landscape

Government Investment
(Policy Framework)

Dept Education & Science

Dept Business, Enterprise & Innovation

Department of Health

Other Government Departments

Agency/Councils

Agency

Health Research Board

Healthcare Deliverers (HSE)

Basic and applied research in all fields of science & engineering, research infrastructure

Blue-skies, medical technologies, biotechnology, pharma and bio-pharma

Others
(Industry, charities, philanthropy)

IRC
HEA
IDA
EI
SFI

People – Programmes – Infrastructure – Networks

HE sector – Institutes – Industry – Clinicians and decision makers – Government
HRB Strategy 2016-2020

Our mission: to improve people’s health and to enhance healthcare delivery

Vision for Ireland: a global innovation leader driving a strong sustainable economy and a better society (Innovation 2020)
Final year of current strategy (2020)....

• DIFA call (Definitive interventions) - Evaluating definitive interventions, and feasibility studies

• Emerging Investigator Awards (post doc) - Supporting researchers currently at mid-stage of their career

• Collaborative Doctoral Awards (PhD training) - Supporting excellent doctoral training programmes for future health researchers in the conduct of patient-focused research

• Investigator led awards - Projects in Patient-Oriented Research, Population Health Research and Health Services Research

• Clinical Trial Networks - Supporting networks in Ireland, with the aim of developing and delivering a high-quality portfolio of investigator-led trials with relevance to health and social care needs in Ireland

• Clinical Research Facilities
Context for next HRB Strategy (2021-2025)

- R&D for health forum (to be established by DoH 2020)
- Health Research Strategy (2020)
- Launch of HSE Action Plan for Health Research (December 2019) & research governance framework
- Sláintecare implementation
- Establishment of National Research Ethics Office
- Health research regulations and Consent Declaration Committee
- Health Information Strategy
Factors to consider when setting future strategic plans

Aligned to the overall Mission and Vision of the organisation

- Who are we serving and what are their needs?
- How do we best deliver those services to meet their specific needs?
- How do we measure success?
- Regulatory compliance
- Legislation
- Compliance
- Accountability
- Ethics
hrb.ie

Find out more about our work
Strategy for Health Care Research in Northern Ireland

Dr Gail Johnston
Programme Manager
HSC R&D Division, PHA
HSC R&D Division: Who are we?

• Division of the Public Health Agency, Northern Ireland
• Co-ordinate regional R&D strategy for the HSC in Northern Ireland
• Administer the HSC R&D Fund (12m)
• Lead on the regional research governance agenda in alignment with the Health Research Authority, England
• Encourage participation in research across HSC
• Support researchers to seek & secure research funding
• Collaborate with other major funders to build research infrastructure and capacity
HSC R&D Spend

Breakdown of Funding
Total budget spend and Infrastructure spend

- Infrastructure
- Research Funding
- Capacity (e.g. Fellowships)
- Dissemination & Knowledge Mobilisation
- Clinical Trials Unit
- Research Networks
- Trust Research Offices
- HSC Innovations
- Clinical Research Facility
- Trust Capability Funding
- Research Centres/Units
The health, wellbeing and prosperity of the Northern Ireland population will benefit from excellent, world-renowned R&D in health and social care which is led from Northern Ireland
Other Strategic Drivers

- Health and Wellbeing 2026. Delivering Together
- Draft Programme for Government Framework 2016–21
- Innovation Strategy for Northern Ireland 2014-2025
- Living Matters. Dying Matters. 2010
Patient and Public Involvement

- PPI Prerequisite in all funding schemes
- Public Involvement Enhancing Research (PIER NI)
- PPI in Research Support Scheme
- Training
- Public Awareness Campaigns- `Be Part of Research'
Palliative Care Research Spend

Palliative Care Funding as proportion of RD Budget

2018
2017
2016
2015
2014
2013
2012
2011
2010
2009
2008
2007
2006
2005
2004
2003

PC Funding  R&D Budget

0  2,000,000  4,000,000  6,000,000  8,000,000  10,000,000  12,000,000  14,000,000  16,000,000  18,000,000

Funding Opportunities

Applications will:

come from teams which consist of an appropriate mixture of staff from academia, HSC and/or the voluntary sector (i.e. multi-disciplinary and multi-sectoral) demonstrating effective and credible collaboration.

include an all island component and or collaboration with other jurisdictions, especially if such collaborations provide access to expertise that is not available locally.

however, the CI must be based in Northern Ireland and the research must be relevant to the NI context.
Funding Opportunities

Building Capacity

An organisational case study of transition to adult services by young people with life-limiting conditions in Ireland

Developing a Cancer Cachexia Rehabilitation Intervention for People with Inoperable Advanced Non Small Cell Lung Cancer
Funding Opportunities

Promoting informed decision making and effective communication through advance care planning for people with dementia and their family carers.

Pain assessment and management for patients with advanced dementia.

NIHR Funding

Enabling Awards

Needs Led

Opportunity Led

US Ireland R&D Partnership

EU Funding

Cachexia in end stage renal disease

Public attitudes to palliative care and advance care planning.

Funding Projects
Funding Opportunities

Dissemination & Knowledge Mobilisation

Communication Between Healthcare Professionals And Patients Regarding End Of Life Care - Systematic Review

Palliative Care Research Forum NI

A collaborative showcase for impact
£2.2m was awarded to 7 projects

£1.5m (with partners) of further research grant funding has been secured

Over 60 researchers worked across the projects, from a range of disciplines

Over 30 organisations were involved in the delivery of the programme and individual projects

Over 60 researchers worked across the projects, from a range of disciplines

926 participants were involved in the projects and a further 6,826 were involved via the prescribing database

12.5 research posts were created as a result of the funding

28 Journal publications, to date

39 Presentations

11 Posters

1 Theatre Piece

3 Information booklets

2 Seminars

1 Artwork exhibition

Measuring Impact of Research Programme in Dementia Care
Continuing Priorities

– Promote a research culture throughout the HSC

– Demonstrate how HSC R&D is a significant contributor to the health economy
  • Direct investment from HSC R&D Fund
  • Increase in HSC R&D Fund
  • Increased leverage through partnership/consortia
  • Increased grant acquisition by NI researchers from external sources e.g. NETS
  • Increased investment from private sector in health & social care research

– Build on the existing infrastructure and maximise this to support researchers to participate in research of an international standard
  • Data accessibility
  • Skills e.g. health economics, statistics, contracts
  • Leadership and management development in research

– Support research in line with strategic priorities keeping patients and service users at the centre
  • Involve patients and the public in every aspect of research
www.research.hscni.net
Welcome Back

Open Session and Conversation Panel
As a group decide what is the key question you would like to ask the panel in relation to out-of-hours palliative care.

You will have 15 minutes to discuss and decide collaboratively what is your key question.
Quality improvement priorities for safer out of hours palliative care

Dr Sarah Yardley
Dr Andrew Carson-Stevens
Context and concepts
Why complexity matters

What did we know?

Mixed methods research
Integrating theory into empirical studies

What do we know now?
What happens in and out of hours?

Can Advance Care Planning (ACP) help?

Priorities for improvement & future work
Context: Is Palliative Care ‘special’?

Harm: ‘unfolding series of negative events... inextricably linked with feeling unsafe’

- Technological advances
- Patient & carer priorities
- Safety standards
- Interpersonal therapeutic interactions
- Policy directives
- Societal expectations

Collier et al, 2015
Context: Is Palliative Care ‘complex’?

- Multiple interconnected elements
- Relationships that cannot be fully understood by analysis of parts
- Consequences are often unpredictable and yet what matters
- Outcomes depend on intervention, interaction, innovation and responsiveness
- Potential quality and safety risks in gaps between differing standpoints, roles and responsibilities
Complexities grow

Pre-existing: elements of social life

Cumulative: multiple domains with overspill between domains

Invisible: lack of self-advocacy

Non-engagement with those who could address unmet needs

Pask et al, 2018
Problematic concepts?

Safety & risk

“It is often impossible to provide optimal care. We have very few safety strategies which are aimed at managing risk in the often complex and adverse daily working conditions of healthcare”

(Charles Vincent, René Amalberti: Safer Healthcare, Strategies for the Real World)
Also problematic concepts? 
Quality & Improvement

- **Stronger actions**: Best at removing dependence on the human
- **Intermediate actions**: Reduce reliance on the human
- **Weaker actions**: Support / clarify the process but rely solely on the human
How do patients and carers view safety and quality?

Safety is important

Harm is an interpersonal construct

“emotional, social, spiritual, and not solely technical-clinical misadventure”

Iatrogenic harm is not regarded as one off incidents

Safety in care at home

Safety of patient and caregiver inextricably linked

“home is an unregulated and uncontrolled site”

Emotional experience of care as a practice:

“embedded in relationships mediated by communication and tenor of care”

Autonomy to live and take risks in one’s own home

Poor communication with and by professionals seen to be harmful in and of itself

Collier et al, 2015; Lang et al, 2015; Sampson et al 2013
So what did we know about safety in palliative care?

- Population with reduced resilience to unsafe care
- Specific known risks for adverse events
  - Strong opioids and sedatives including use of syringe drivers
  - Care outside of specialist settings
  - Reliance on informal carers
  - Promoting patient choice
- Conflicts in applying ‘standard’ safety measures
  - Pressure ulcers (~25% ‘hospice care’)
- Potential harms wide-ranging: failure to provide good care before a good death
  - Suicide risk heightened
How is mixed methods research deepening understanding of safety and risk in palliative care?

Data from National Reporting and Learning System, stakeholder perspectives and published literature

New understandings of safety and risk in palliative care
- Being safe and feeling safe are intertwined for patients, carers and professionals
- Negotiating safe care that remains sensitive to patients’ priorities can create tensions with safety standards
- Failure to consider risks can result in avoidable harms
- A holistic approach to interpersonal patient safety in palliative care can be developed using social theories to analyse multi-voiced perspectives of safety and generate ‘real world’ learning
Mixed Methods

- Modified systematic review searching techniques
- Cross-sectional quantitative descriptive analysis
- Interpretative qualitative meta-syntheses

Data from National Reporting and Learning System, stakeholder perspectives and published literature

Illumination from cumulated ‘snippets’ of professional views found in big incident reporting data sets

Moving analysis from description to interpretation

Adding value through identifying important nuances and context-specific constructions of safety in the messiness of frontline clinical practice

New research questions about human factors in palliative care patient safety
New understandings of safety and risk in palliative care
Shortfalls in care or care planning

Lack of palliative care experience

Under-resourcing of health services

Poor service coordination

Communication

System failures versus individual caregivers? (anticipatory prescribing)

Equipment failures
Serious incidents requiring investigation, NHS, April 2002 – March 2014, n=475

- 91 medication errors
- 266 pressure ulcers
- 46 falls
- 21 healthcare associated infections
- 14 allegations against healthcare professionals
- 6 suicides
- 8 transfer incidents
- 18 other instances of disturbed dying
- 5 other concerns
Table 2. Location of patient care by report type.

<table>
<thead>
<tr>
<th></th>
<th>Patient's home, N (%)</th>
<th>Hospice, N (%)</th>
<th>Acute/secondary care, N (%)</th>
<th>Community hospital, N (%)</th>
<th>Care/nursing home, N (%)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pressure ulcer</td>
<td>92 (34.6)</td>
<td>74 (27.8)</td>
<td>72 (27.1)</td>
<td>11 (4.1)</td>
<td>17 (6.4)</td>
<td>266</td>
</tr>
<tr>
<td>Medication error</td>
<td>54 (60.6)</td>
<td>10 (11.2)</td>
<td>8 (9.0)</td>
<td>8 (9.0)</td>
<td>9 (10.5)</td>
<td>89</td>
</tr>
<tr>
<td>Falls</td>
<td>1 (2.2)</td>
<td>24 (52.2)</td>
<td>12 (26.1)</td>
<td>9 (19.6)</td>
<td>0</td>
<td>46</td>
</tr>
<tr>
<td>Healthcare-associated infection</td>
<td>2 (9.5)</td>
<td>2 (9.5)</td>
<td>15 (71.5)</td>
<td>2 (9.5)</td>
<td>0</td>
<td>21</td>
</tr>
<tr>
<td>Disturbed dying</td>
<td>4 (22.2)</td>
<td>7 (38.9)</td>
<td>0 (0)</td>
<td>4 (22.2)</td>
<td>3 (16.7)</td>
<td>18</td>
</tr>
<tr>
<td>Allegation against health professional</td>
<td>8 (57.1)</td>
<td>4 (28.6)</td>
<td>2 (14.3)</td>
<td>0</td>
<td>0</td>
<td>14</td>
</tr>
<tr>
<td>Inadequate transfer</td>
<td>3 (37.5)</td>
<td>0</td>
<td>2 (25.0)</td>
<td>0</td>
<td>3 (37.5)</td>
<td>8</td>
</tr>
<tr>
<td>Suicide</td>
<td>3 (50.0)</td>
<td>1 (16.7)</td>
<td>2 (33.3)</td>
<td>0</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>Other</td>
<td>1 (20.0)</td>
<td>1 (20.0)</td>
<td>3 (60.0)</td>
<td>0</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Total</td>
<td>168 (35.6)</td>
<td>123 (26.0)</td>
<td>116 (24.5)</td>
<td>34 (7.2)</td>
<td>32 (6.8)</td>
<td>473</td>
</tr>
</tbody>
</table>

There were also two isolated reports of medication errors, one relating to care in a general practice surgery and another to a patient receiving care in prison.
Admitted to [hospice] due to uncontrolled pain, confusion and diarrhoea … Impression was that the patient had overflow diarrhoea secondary to opiate constipation … The C. difficile toxin positive result was communicated [five days later]. (Hosp05)

The medical and nursing assessment of [the patient] did not indicate a patient with suicidal ideation; however this was apparently a concern of the MacMillan nurse … Communication between the Acute team and the Macmillan nurse here leaves …

Prescribing error occurred when general practitioner incorrectly converted oral morphine to diamorphine for a syringe driver. Three times recommended dosage was prescribed … Patient was administered the syringe driver and became drowsy, so duty nurse contacted duty doctor and it was identified that incorrect dose had been prescribed. Ambulance called and patient was admitted to hospital. (Home86)
What do we know about out of hours palliative care?

Quality improvement priorities for safer out-of-hours palliative care: Lessons from a mixed-methods analysis of a national incident-reporting database

Huw Williams¹ ID, Sir Liam Donaldson², Simon Noble³, Peter Hibbert⁴, Rhiannon Watson¹, Joyce Kenkre⁵, Adrian Edwards¹ and Andrew Carson-Stevens¹,⁴,⁶
Community out of hours palliative care

- 2%–3% consultations prone to patient safety incidents
- ‘Out-of-hours’ services responsible for approx. two-thirds of the week
- 30% of patients have contact with the OOH service in the last days of life
- Additional risks:
  - Lack of prior knowledge of patient
  - Remote consultations
  - Lack of access to records
  - Difficulty identifying services

Out-of-hours care

Unsafe care arises from
- Medication provision
- Timely access to care
- Information Transfer
- Nursing care

Harms include
- Increased pain
- High levels of psychological distress
- Avoidable admissions

Contributing factors
- Failure to follow protocols
- Lack of staff skills/confidence
- Use of syringe drivers
“almost two-thirds of reports described harm with outcomes such as increased pain, emotional and psychological distress featuring highly”

Table 1. Harm severity n (% of incident type).

<table>
<thead>
<tr>
<th>Incident type</th>
<th>No Harm occurred</th>
<th>Low Harm</th>
<th>Moderate Harm</th>
<th>Severe Harm</th>
<th>Death</th>
<th>Harm severity unclear</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medication related</td>
<td>71 (11%)</td>
<td>355 (57%)</td>
<td>45 (7%)</td>
<td>3 (0.5%)</td>
<td>5 (0.8%)</td>
<td>139 (22%)</td>
<td>618</td>
</tr>
<tr>
<td>Access to timely care</td>
<td>5 (4%)</td>
<td>63 (51%)</td>
<td>14 (11%)</td>
<td>–</td>
<td>3 (2%)</td>
<td>38 (31%)</td>
<td>123</td>
</tr>
<tr>
<td>Information transfer</td>
<td>14 (14%)</td>
<td>53 (52%)</td>
<td>12 (12%)</td>
<td>–</td>
<td>–</td>
<td>23 (23%)</td>
<td>102</td>
</tr>
<tr>
<td>Treatment (non-medication)</td>
<td>10 (10%)</td>
<td>51 (50%)</td>
<td>18 (18%)</td>
<td>–</td>
<td>1 (1%)</td>
<td>22 (22%)</td>
<td>102</td>
</tr>
<tr>
<td>Other</td>
<td>17 (13%)</td>
<td>44 (35%)</td>
<td>21 (17%)</td>
<td>2 (2%)</td>
<td>5 (4%)</td>
<td>38 (30%)</td>
<td>127</td>
</tr>
<tr>
<td>Totals</td>
<td>117</td>
<td>566</td>
<td>110</td>
<td>5</td>
<td>14</td>
<td>260 (24%)</td>
<td>1072</td>
</tr>
</tbody>
</table>

“Contributory factors were failure to follow a protocol, lack of skills/confidence of staff and patients requiring medication delivered via a syringe driver”
Medication related  
Example 1. Staff nurse reflected on the incident, and she stated that she administered a dose of hyoscine which was prescribed for a syringe driver–1.2 mg–as a stat dose. She realised after giving the injection. She contacted out-of-hours GP, but patient’s breathing worsened and she called 999 after giving adrenaline. No ‘Do not Resuscitate’ order was found in the patient’s home, and so CPR was performed by the ambulance crew. At [time] I contacted A&E and spoke to Sister in Resus. She informed me that the patient was critical and called back [30 min later] to state that the patient was ventilated … A + E sister informed me that patient was transferred to a ward. Ward sister stated that they were trying to send patient home as this was their wish. Telephone call received from Dr [Staff Name] at GP OOHs stating that the patient had died.

Example 5. Called to see patient who is in pain and under palliative care. Patient in pain and very distressed heading towards last days of life. Passed over to unplanned care department at [time]. [3 h later] GP still had not visited. Contacted unplanned care at this time and they said they had a busy night and that the GP who [had just stated work] would see the patient first.

Example 9. Elderly patient … at home was being treated for sub-acute bowel obstruction. Despite maximal treatment via syringe driver including octreotide, hyoscine butylbromide, haloperidol, and morphine, [the patient] experienced a gradual accumulation of GI fluid every 48 h which resulted in severe pain … Palliative-care team advised use of a Ryles tube on free drainage. In evening of [date] after visiting, I requested that the DNs insert the tube. After a period of confusion (staff were under impression that he had to go to hospital to have a tube inserted) … it became apparent that the nurse on duty did not feel they had the competency to insert any form of NG tube … The patient did not get a drainage tube at any time that evening, he eventually vomited but remained agitated throughout his last night. Why was no nurse with this basic competency on duty? Does the trust have a policy for this basic nursing procedure in line with the document appended?

Example 6. Patient’s wife phoned out-of-hours service at [time], and GP decided that a syringe driver needed to be put up. OOH failed to contact DN with appropriate information regarding the patient and at the right time. Insufficient time span for adequate provision of care with a patient at end stages of life. Inappropriate use of DN time.
Figure 2. Driver diagram to show potential interventions to improve the safety of out of hours primary care for patients at the end of life.
Out of hours care: context, mechanisms, outcomes

- How do perceptions and lived experiences compare to reported incidents?
  - Stakeholder data
- Which issues should be priority areas for improvement efforts?
  - within the local OOH service
  - feasibility and acceptability of existing interventions identified from a scoping review
- A mid-range theory for driving quality improvement
Is everything just worse at night?
Significant concerns:

- Lack of empirical evidence to support many interventions that professionals believe in
- Professional fear of consequences from not admitting/escalating
- Differential in speed of response times
- Sense of safety, taking risks, support and holding of anxiety for patients and carers
- Lack of pre-existing relationships between professionals
  - trust, autonomy, giving and receiving advice, lack of understanding of practical constraint on each others working practices
- Autonomy of non-medical practitioners to act on discussions around ceilings of care
Can planning ahead help?

- 70 reports across three error categories:
  - ACP not completed despite being appropriate (23%, n=16).
  - ACP completed but not accessible or miscommunicated between professionals (40%, n=28).
  - ACP completed and accessible but not followed (37%, n=26).

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Patient safety incidents in advance care planning for serious illness: a mixed-methods analysis

Toby Dinnen, Huw Williams, Sarah Yardley, Simon Noble, Adrian Edwards, Peter Hibbert, Joyce Kenkre, Andrew Carson-Stevens

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Advance Care Planning

Safe ACP requires
- theoretical knowledge and acceptance of socially constructed roles and responsibilities
- applied metacognitive skills and emotional intelligence

Errors occur due to
- Lack of ACP when appropriate
- (Mis)communication with lost documentation or inaccurate handover
- Failure to follow ACP

Underling causes
- Lack of staff knowledge, confidence or trust to enact ACP

Harms
- Inappropriate treatment and admissions
These interventions are graded according to United States Department of Veterans Affairs (USDVA) Strength of Intervention scale. [24] Weak interventions are mostly human-dependent, intermediate interventions rely on people but systems can limit choice and variation or offer guidance, strong interventions eliminate chance and force replication in choices with minimum supervision needed (i.e. are system controlled). This driver diagram is a visual summary of our research paper, developed as a tool to guide quality improvement. Primary and secondary drivers are hypotheses derived from our mixed methods analysis. Ideas for change are interventional options proposed by our research team. A focused literature search was performed to identify empirical evidence of efficacy for these interventions and relevant studies cited.

Figure 2: A driver diagram of data-driven hypothesis to improve the safety of Advance Care Planning to end of life patients.
ECP asked whether there was a living will and was told there was not. ECP informed family that he had an obligation to commence CPR [Cardiopulmonary Resuscitation] if needed but family adamant that this should not be done. ECP also stated would not give any analgesia as it would kill the patient and this could be seen as homicide. (report 3)

I looked at the will noting that it was drawn up in [date: 1 year prior] and that it was not signed by a doctor or medical professional. I stated that the document was not binding and that it would be illegal for me not to treat the patient [...] The daughter arrived and I was asked not to treat her mother. I informed her that I the patient had the mental capacity to stop. (report 20)

Patient with [neurodegenerative disorder] attended Accident & Emergency – DNACPR form and living will brought in from home but not returned when patient discharged, therefore when patient suffered cardiac arrest at home DNACPR paperwork not available and [ambulance service] forced to perform full ALS treatment. As a result patient suffered the indignity in death that he had taken every step to prevent. (report 10)
Priorities?

- “Better coordination of the delivery of palliative care and wider availability of specialist palliative care advice and support may make care safer”

- How will we know change is improvement?
- Multivoiced perspectives
- Evidence base for socially mediated interventions
  - (including the practical and pharmacological ones!)
- How to we represent and hold complexity well?

Identified need to compare professional reporting of risks and safety incidents with patient and carer perspectives
How is mixed methods research deepening understanding of safety and risk in palliative care?

- Being safe and feeling safe are intertwined for patients, carers and professionals
- Negotiating safe care that remains sensitive to patients’ priorities can create tensions with safety standards
- Failure to consider risks can result in avoidable harms
- A holistic approach to interpersonal patient safety in palliative care can be developed using social theories to analyse multi-voiced perspectives of safety and generate ‘real world’ learning

New understandings of safety and risk in palliative care

- Modified systematic review searching techniques
- Cross-sectional quantitative descriptive analysis
- Interpretative qualitative meta-syntheses

Serious incident Reporting
Incidents requiring investigation
- Pressure ulcers
- Medication errors
- Healthcare associated infections
- Disturbed dying
- Allegations against professionals
- Transfer incidents
- Suicides

Harms
- Worsened symptoms
- Disrupted dying
- Serious injury & hastened death

Underlying causes
- Lack of palliative care experience
- Under-resourcing and poor service coordination

Out-of-hours care
Unsafe care arises from
- Medication provision
- Timely access to care
- Information Transfer
- Nursing care

Harms include
- Increased pain
- High levels of psychological distress
- Avoidable admissions

Contributing factors
- Failure to follow protocols
- Lack of staff skills/confidence
- Use of syringe drivers

Advance Care Planning
Safe ACP requires
- Theoretical knowledge and acceptance of socially constructed roles and responsibilities
- Applied metacognitive skills and emotional intelligence

Errors occur due to
- Lack of ACP when appropriate
- (Mis)communication with lost documentation or inaccurate handover
- Failure to follow ACP

Underlying causes
- Lack of staff knowledge, confidence or trust to enact ACP

Harms
- Inappropriate treatment and admissions

Identified need to compare professional reporting of risks and safety incidents with patient and carer perspectives
What does good look like?

- ‘I want to be able to phone a person who picks up, listens, can make decisions and take action with me’

- Are we as good at relationship centred care as we think?
Future work

- Methods and tools
  - We need to understand the problem before we offer more of the ‘same’ solutions
  - Generating expertise through shared endeavours (mutual expansive learning)
  - Close to practice methodologies

- Thinking differently
  - “the development and use of knowledge to offer standardised responses to common needs, customised responses to particular needs, and flexible responses to emergent needs.”  
    - (Batalden 2018)
Acknowledgements

Our colleagues, in particular: Iain Yardley, Huw Williams, Toby Dinnen, Sir Liam Donaldson, Simon Noble, Peter Hibbert, Rhiannon Watson, Joyce Kenkre, Adrian Edwards

Key references


Closing Comments

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