



Sharing Knowledge,
Sharing the Load



**Modern medicine is a
negation of health. It isn't
organized to serve
human health, but only
itself, as an institution. It
makes more people sick
than it heals.**

Ivan Illich

QUOTEHD.COM

American Sociologist

Man's consciously lived fragility, individuality, and relatedness make the experience of pain, of sickness, and of death an integral part of his life. The ability to cope with this trio autonomously is fundamental to his health... Medical Nemesis is the negative feedback of a social organization that set out to improve and equalize the opportunity for each man to cope in autonomy and ended by destroying it.

Ivan Illich. *Medical Nemesis*, 1975

When Patients and Their Families Feel Like Hostages to Health Care



Leonard L. Berry, PhD, MBA; Tracey S. Danaher, PhD; Dan Beckham, MBA;
Rana L.A. Awdish, MD; and Kedar S. Mate, MD

Abstract

Patients are often reluctant to assert their interests in the presence of clinicians, whom they see as experts. The higher the stakes of a health decision, the more entrenched the socially sanctioned roles of patient and clinician can become. As a result, many patients are susceptible to “hostage bargaining syndrome” (HBS), whereby they behave as if negotiating for their health from a position of fear and confusion. It may manifest as understating a concern, asking for less than what is desired or needed, or even remaining silent against one’s better judgment. When HBS persists and escalates, a patient may succumb to learned helplessness, making his or her authentic involvement in shared decision making almost impossible. To subvert HBS and prevent learned helplessness, clinicians must aim to be sensitive to the power imbalance inherent in the clinician-patient relationship. They should then actively and mindfully pursue shared decision making by helping patients trust that it is safe to communicate their concerns and priorities, ask questions about the available clinical options, and contribute knowledge of self to clinical decisions about their care. Hostage bargaining syndrome is an insidious psychosocial dynamic that can compromise quality of care, but clinicians often have the power to arrest it and reverse it by appreciating, paradoxically, how patients’ perceptions of their power as experts play a central role in the care they provide.

REALISING REALISTIC MEDICINE

'REALISTIC'

1. HAVING OR SHOWING A SENSIBLE AND PRACTICAL IDEA OF WHAT CAN BE ACHIEVED OR EXPECTED.
2. REPRESENTING THINGS IN A WAY THAT IS ACCURATE AND TRUE TO LIFE.

CREATING CONDITIONS

COMMUNICATE



CONNECT



COLLABORATE



CULTURE



THE VISION

BY 2025, EVERYONE WHO PROVIDES HEALTHCARE IN SCOTLAND WILL DEMONSTRATE THEIR PROFESSIONALISM THROUGH THE APPROACHES, BEHAVIOURS AND ATTITUDES OF REALISTIC MEDICINE

What am I really doing?

.....How well am I doing it?

.....Does it really make a difference?



If you can't
MEASURE it
you can't **MANAGE** it.

What am I really doing?

.....How well am I doing it?

.....Does it really make a difference?

Box 4. The ten core competencies in palliative care

1. Apply the core constituents of palliative care in the setting where patients and families are based
2. Enhance physical comfort throughout patients' disease trajectories
3. Meet patients' psychological needs
4. Meet patients' social needs
5. Meet patients' spiritual needs
6. Respond to the needs of family carers in relation to short-, medium- and long-term patient care goals
7. Respond to the challenges of clinical and ethical decision-making in palliative care
8. Practise comprehensive care co-ordination and interdisciplinary teamwork across all settings where palliative care is offered
9. Develop interpersonal and communication skills appropriate to palliative care
10. Practise self-awareness and undergo continuing professional development

EAPC, 2013

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EAPC, 2013

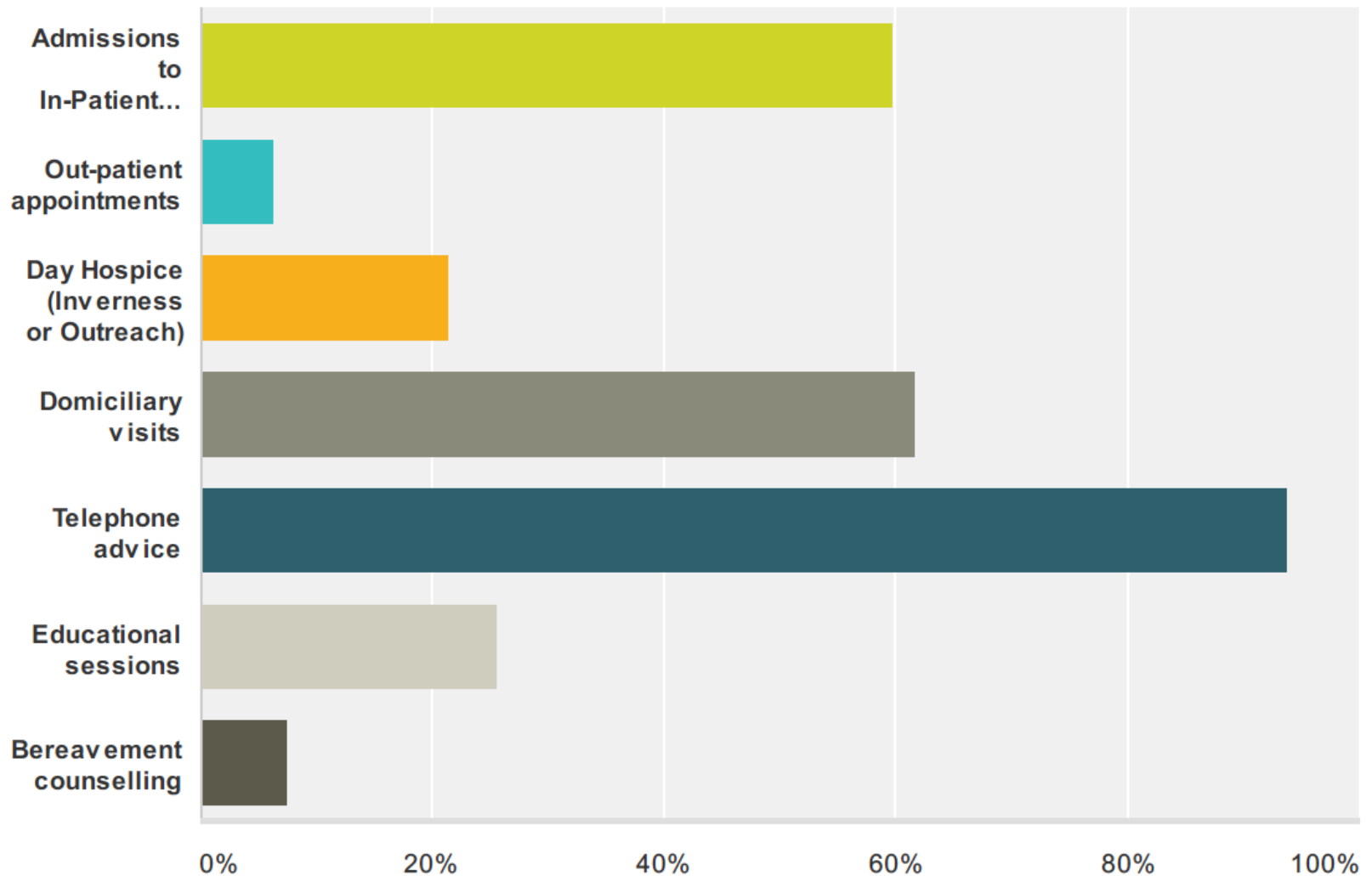
?11. Be understanding of incompetence

“Dying is active. Dying is not what happens to you.
Dying is what you do.”

Stephen Jenkinson

Q3 To which of the clinical services that the Hospice provides do you most value having access? (Choose up to 3)

Answered: 94 Skipped: 0



Supporting and improving community health services—a prospective evaluation of ECHO technology in community palliative care nursing teams

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ABSTRACT

Introduction Project ECHO (Extension for Community Healthcare Outcomes) uses teleconferencing technology to support and train healthcare providers (HCPs) remotely, and has improved care across the USA. A 6-month pilot was trialled in a community palliative care nursing setting to determine if ECHO would be effective in the UK in providing education and support to community hospice nurses (CHN).

Methods The pilot involved weekly 2-hour

INTRODUCTION

Project ECHO (Extension for Community Healthcare Outcomes) was developed in New Mexico to improve access to specialised care through supporting and training primary healthcare providers (HCPs) in rural areas to better manage patients with complex health needs.¹ ECHO does this by engaging HCPs in an ongoing learning system and partnering them with peers and specialist

Evaluating the Role of Key Learning Theories in ECHO: A Telehealth Educational Program for Primary Care Providers

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Abstract

Background: ECHO (Extension for Community Healthcare Outcomes) is a telehealth educational program that uses videoconference technology to train community-based primary care providers (PCPs) on the management of complex, chronic diseases. The main components of ECHO are didactics, case presentations, and case-based learning. ECHO was developed using the key principles of Social Cognitive Theory, Situated Learning Theory, and Community of Practice Theory.

Objectives: In a prior study, we implemented an ECHO curriculum to improve management of resistant hypertension. The goals of the current study were to determine the extent to which the learning theories served as the foundation of the ECHO curriculum and identify opportunities to more effectively incorporate key principles of these theories into the ECHO program.

Methods: We conducted semi-structured interviews with the nine clinicians who participated in the pilot curriculum. A community-based PCP assisted with question develop-

ment, analysis, and manuscript preparation. We analyzed the interview transcripts using Directed Content Analysis.

Results: Transcript analysis supported the contention that ECHO is based upon Social Cognitive Theory, Situated Learning Theory, and Community of Practice Theory. Comments from study participants highlighted benefits of each theory's principles. Conversely, they also suggested we could improve our implementation of ECHO by adhering more closely to specific learning theory strategies.

Conclusions: Our results indicate that ECHO indeed reflects the key tenants of Social Cognitive Theory, Situated Learning Theory, and Community of Practice Theory. Several aspects of our ECHO curriculum can be improved by more complete application of these learning theories.

Keywords

Medicine, Community-based Participatory Research, Health Disparities, Cardiovascular Diseases, Urban Health



ECHO and Palliative and End of Life Care

So What is Project ECHO?

Extension of
Community
Healthcare
Outcomes



HIGHLAND HOSPICE
SCOTLAND

ECHO and Palliative and End of Life Care

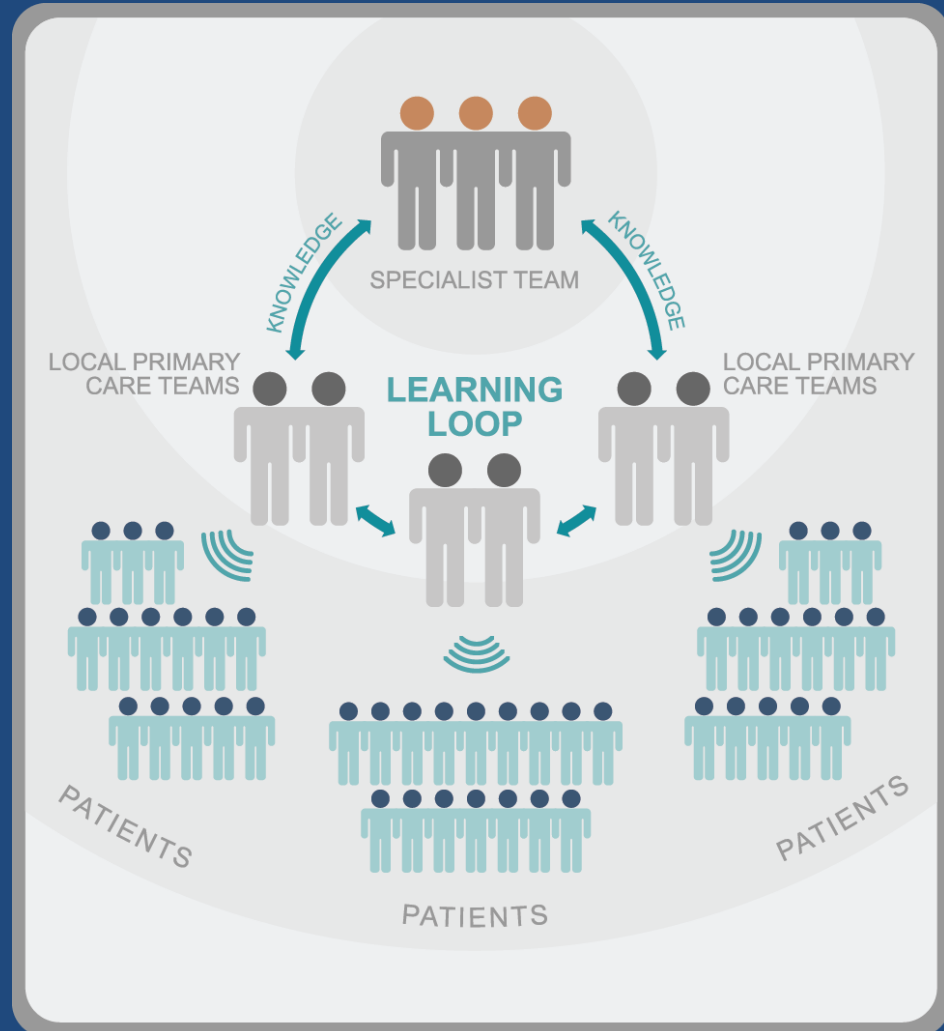


ECHO is.....Telementoring



HIGHLAND HOSPICE
SCOTLAND

Project ECHO – a 'Force Multiplier'





HIGHLAND HOSPICE
SCOTLAND

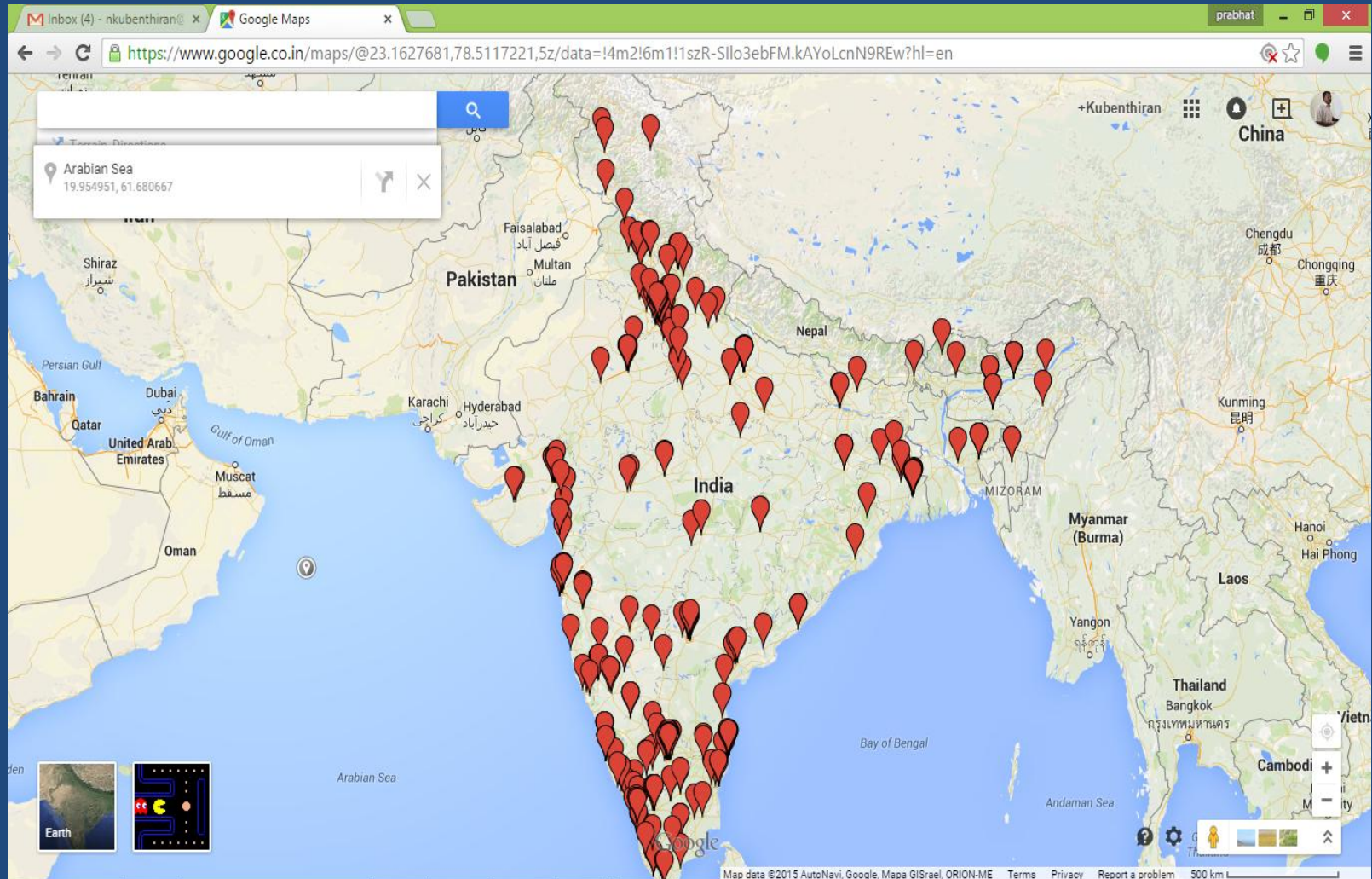
Project ECHO Global Impact



Project ECHO Global Impact

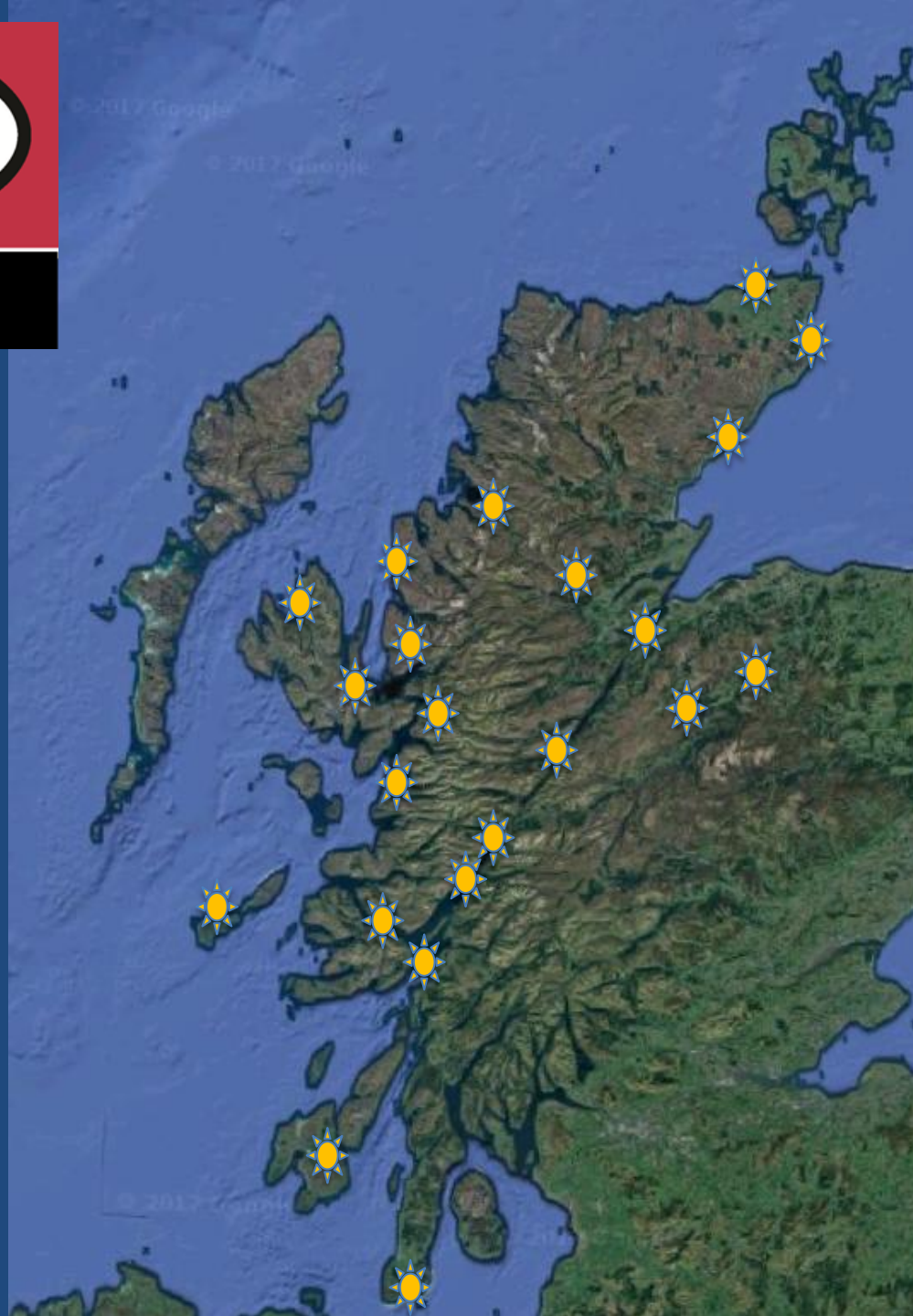


NIMHANS ECHO, India





HIGHLAND HOSPICE
SCOTLAND



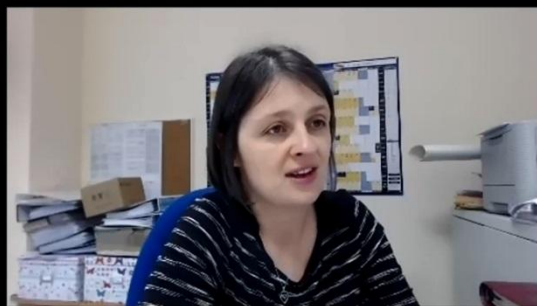


ECHO and Palliative and End of Life Care

How?

ECHO – rooted in four ideas:

1. Multi point video technology
2. Based on best practice (Guidelines)
3. Case-based learning
4. Use of IT to monitor quality improvements





ECHO and Palliative and End of Life Care

Current ECHO 'Clinics'

- Community Macmillan Cancer Nurse Specialists
- Care Homes
- Emergency / Out of Hours Practitioners
- Community Pharmacists



ECHO and Palliative and End of Life Care

What?

Learning and sharing through regular ECHO Support meetings over a 'term' (10 in total)

- 15-30 minute teaching session
- 5-10 minute questions and discussion
- 2 case presentations and discussion with MDT

Sessions recorded and uploaded to secure, dedicated 'Moodle' site



ECHO Curriculum - Macmillan Cancer Nurse Specialists

- An ethical framework for decision-making
- Red and black – making sense of the lab report
- NIV and oxygen therapy
- Finding meaning in limbo
- Physical communication issues
- Hope and hopelessness in long term care
- Palliative care for those with renal disease
- Financial anticipatory care
- Palliative care for those with head and neck cancer

ECHO Curriculum – Care Homes

- Breathing difficulties
- Useful drugs for end of life care
- Drugs – when enough is enough
- Prognosis: death and dying
- Depression and delirium in those with dementia
- Difficult conversations
- Pain assessment
- Team work
- Hole-istic care

**Knowledge is knowing a
Tomato is a fruit.**

**Knowledge is knowing a
Tomato is a fruit.**

**Wisdom is not putting it
in a fruit salad.**

**Knowledge is knowing a
Tomato is a fruit.**

**Wisdom is not putting it
in a fruit salad.**

**Philosophy is wondering
if that means Ketchup is
a smoothie.**



Benefits and costs of Project ECHO

Costs: Training
 Equipment
 Time: Clinical, Admin, IT

Benefits: Knowledge, wisdom and philosophy (& CPD!)
 Community of practice, Confidence
 Competent incompetence



“As an oncologist, I can’t heal another. The most and the least we can do as caregivers is hold the space where healing can happen. The person, the sufferer, has to discover that within themselves. But we can be catalysts through good symptom control and through presence.”

Balfour Mount



The demands of palliative care work

Remen 1996:

‘the expectation that we can be immersed in suffering and loss daily and not be touched by it is as unrealistic as expecting to be able to walk through water without getting wet’

Ways of reducing stress in the carer

Mason 2002: bringing the self of the practitioner into the process by:

- Empathetic listening
- Sharing our humanity
- Living with uncertainty
- The power of love, unconditional positive regard
- The power of stories
- The dot theory: Oliviere 2002

- May I offer my care and presence unconditionally, knowing that I may be met with gratitude, indifference, anger or anguish.
- May I offer love, knowing that I cannot control the course of life's suffering and death.
- May remain at ease and let go of my expectations.
- May I view my own suffering with compassion as I do the suffering of others.
- May I be aware that my suffering does not limit my good heart
- May I forgive myself for things left undone.
- May I forgive those who have hurt me.
- May those whom I have hurt forgive me
- May all beings and I live and die in peace.

Joan Halifax at the 'Art of Dying III' Conference, the Open Centre and Tibet House New York City 2000

What causes our stress?

The demands of Palliative care

- Breaking bad news
- Coping with the inability of the medication to palliate
- Repeated bereavements of patients with whom relationships have been formed
- Involvement with emotional conflicts
- Absorption of anger, grief, despair
- Multi-professional role blurring
- Challenges to one's personal belief system
- Living with uncertainty and mystery

Rokach A. *caring for those who care for the dying: Coping with the demands of palliative care workers*, Pall and Supp Care, 2005 3325-332



ECHO and Palliative and End of Life Care in Care Homes

Why

What

How



ECHO and Palliative and End of Life Care in Care Homes

Why?

- Ageing population
- Complexity of care
- Expectations
- Uncertainty
- Isolation
- No new money



ECHO and Palliative and End of Life Care in Care Homes

Why?

Twenty years ago residents parked their cars

Today average life expectancy < 18 months

Multiple morbidities

Multiple medications



ECHO and Palliative and End of Life Care in Care Homes

Why?





ECHO and Palliative and End of Life Care in Care Homes

Why?

- Up to 20 Care Homes
- Huge experience and skill base
- Limited opportunities for collaborative working



ECHO Whale



PCA Espanola



Baton Rouge



Pecos Valley MC



DOH Las Cruces



SBRT-First Choice South Va



Memorial HDX7000

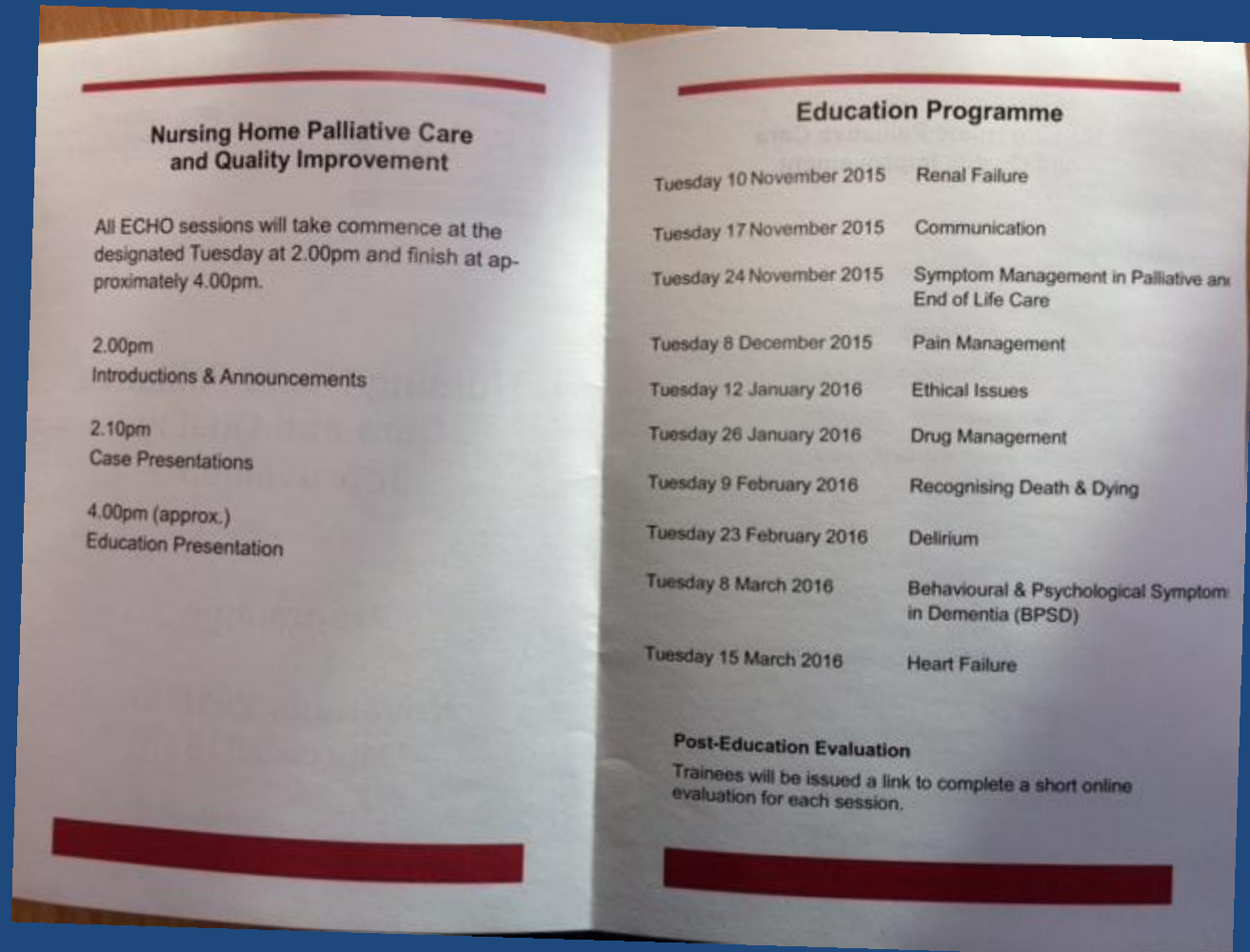


LAS VEGAS ECFH



ECHO and Palliative and End of Life Care in Care Homes

What?





ECHO and Palliative and End of Life Care in Care Homes

What?

- ECHO is based in the “cloud”
- The software through which we connect is ‘ZOOM’
- ZOOM is a highly secure environment
- Participants join the meeting using the invitation sent by our ECHO administrator – Sharan Brown





HUB

- Administrator
- Facilitator
- Presenter
- IT specialist

Spokes

- Case Presenter
(at least one case per term)





HUB

- Palliative Care CNS
- Palliative Care Consultant
- Pharmacist
- Social Worker
- Physio / OT
- Chaplain

Spokes

- Care Home teams





HIGHLAND HOSPICE
SCOTLAND

Care Home (Spoke) Set Up





ECHO and Palliative and End of Life Care in Care Homes

How?

Process needs

- Set time for each 90 minute session to suit
- Decide what teaching topics you want covered
- Commit to staff attending
- Commit to staff fulfilling responsibility to present two cases according to schedule



ECHO and Palliative and End of Life Care in Care Homes

How? Equipment needs

- Broadband connection (Ideally $>1.2\text{Mb/s}$)
- Computer with headphones or speakers
- Webcam appropriate for the numbers attending
- Software – Downloaded from *Zoom US* when you join first trial meeting

Trial



ECHO Network	Dates	Time	Didactic Teaching
Nursing Home Palliative & End of Life Care Facilitation Leads: Max Watson / Sue Foster HUB: NI Hospice Education & Research Department	Tuesday 3 rd November 1. Tuesday 10 November 2015 2. Tuesday 17 November 2015 3. Tuesday 24 November 2015 4. Tuesday 8 December 2015 5. Tuesday 12 January 2016 6. Tuesday 26 January 2016 7. Tuesday 9 February 2016 8. Tuesday 23 February 2016 9. Tuesday 15 March 2016	2:00pm – 4.00pm	Trial of ECHO and Evaluation in each home 1. Communication 2. Symptom Management in Palliative & EOL Care 3. Pain Management 4. Ethical Issues 5. Drug Management 6. Recognising Death & Dying 7. Delirium 8. Behavioural & Psychological Symptoms in Dementia (BPSD) 9. Heart Failure

Nursing Home ECHO Network

ECHO ID: (Your nursing home)

Key Questions For Case Presentation

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Background

Age		Gender	Please select
Diagnosis and Date		Metastases and Date (if applicable)	
Treatment and Significant Investigation to date:			
Past Medical History			

Holistic Assessment (Brief)

Physical (Drugs discussed only if related to key issue/issues)	
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ECHO and Palliative and End of Life Care in Care Homes

Anatomy of an ECHO

- Introductions
- Announcements
- Brief didactic (teaching presentation)
- Case presentation
- Hub ask spokes for questions and for recommendations and impressions
- Hub summarises recommendations and consensus on treatment plan



ECHO and Palliative and End of Life Care in Care Homes

Before.....

- All participants will have the curriculum and session dates before term starts
- Completed Case Presentation templates to be forwarded to Sharan by Friday of the week prior to the session
- The agenda, Case Presentations and a web link to enter the session will be emailed by Sharan to the nominated individual from each Care Home team, 2-3 days before each session



ECHO and Palliative and End of Life Care in Care Homes

Afterwards.....

Evaluation

- After each ECHO there is a short evaluation form to be completed on line - Survey Monkey
- Once the on-line form is received participants become eligible for CPD for each session of ECHO attended - Certificates issued at the end of 'term'



ECHO and Palliative and End of Life Care in Care Homes

Afterwards.....

Access to ECHO resources

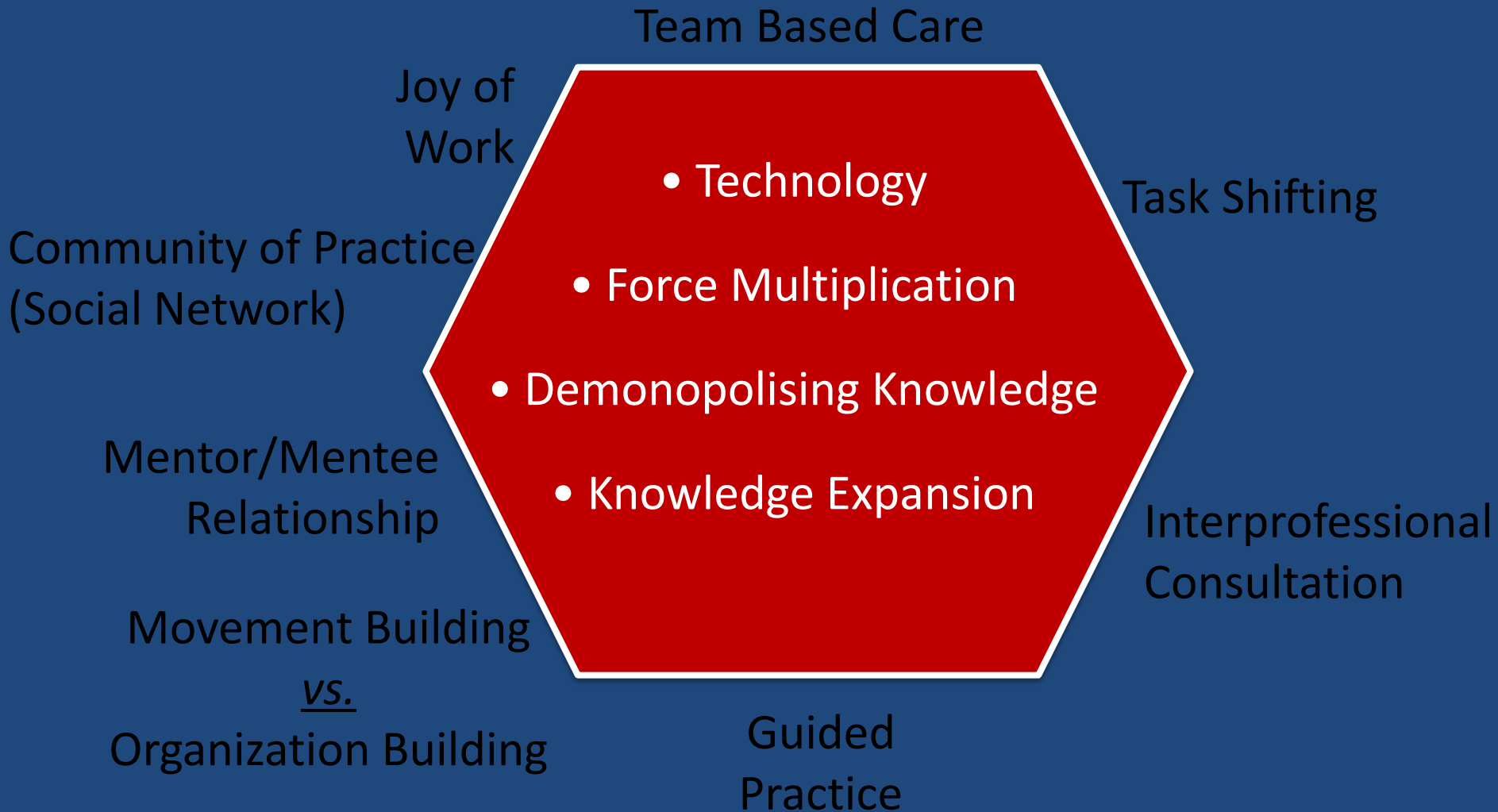
- Each ECHO session is recorded and the recordings (and presentation slides) will be posted on a secure website that is only accessible by participants
- Additional resources that may be helpful to learning related to the topics discussed (articles , web links etc) will be posted on the secure site.



To do.....

- Set the curriculum
- Decide on Duration, Frequency and Day / Time
- Log contact details (name, email and phone no.)
- Agree evaluation methodology

What makes ECHO work?

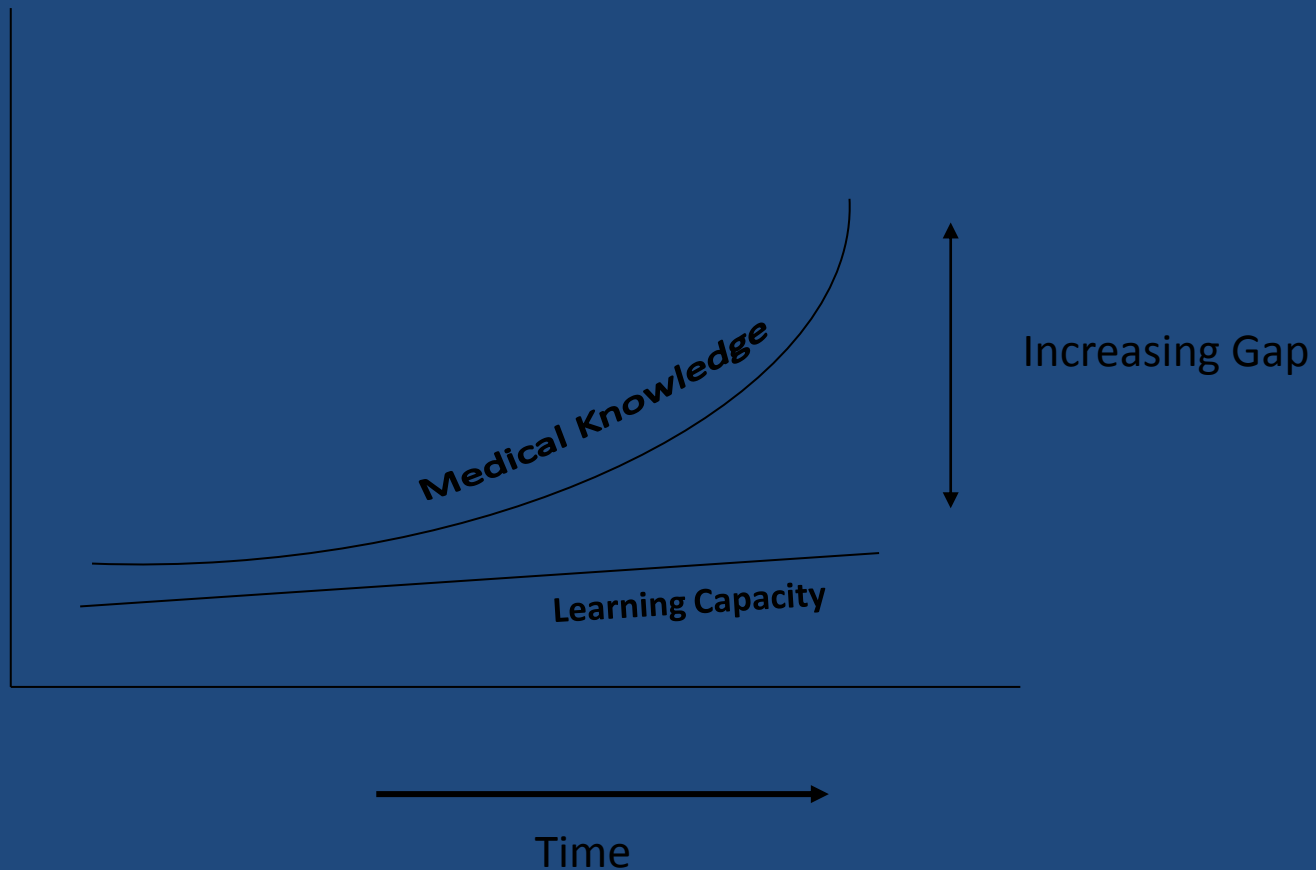








'Keeping up' in Primary Care



I suspect although taken at face value this means putting people through tests etc can make folk worse – there is also the way in which the very term patient and acquiescing to the ever present need for a diagnostic label (whether from clinical staff needing reassurance or from google... are the actual harms

But, as a product of this medical system I deep down still measure my outcomes by my role as a scientific paternalistic decision maker

And possibly some patients also judge me in those terms – if they are the product of a system that has put pressure on them to behave as patients

Realistic medicine is in part a response to the way in which we judge our contribution / performance

Even last week through twitter I believe JULIET SPILLER WAS TALKING ABOUT hostage and learned helplessness

I suspect that even in palliative care this search for personal justification and outcomes has lead to more and more 'research that I'm afraid has little impact on our day to day activity ..



ECHO and Palliative and End of Life Care

Extension of **Community Healthcare** Outcomes

- Locally delivered care by well trained and supported staff provide the best patient outcomes
- Peers & MDT input provides holistic framework of care
- Teams sharing real practice and challenges allows for increased learning, confidence and clarity in handling complex holistic interventions
- Educational Governance Model



ECHO and Palliative and End of Life Care

Extension of Community Healthcare **Outcomes**

- Opportunity to monitor progress in future
- Process effective? - Attendance & Feedback
- Impact on staff knowledge and skills
- Impact on patient care



ECHO and Palliative and End of Life Care

Extension of Community Healthcare Outcomes

- To build up the strength and capacity of our teams
- To increase support for each other
- To learn practically from case examples of complex care
- To reduce stress for our patients and ourselves by providing care which is informed by peer and multidisciplinary learning and sharing