Experiential learning:
Lessons for (community) palliative care

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Overview

• Experiential learning – theory and practice

• Learning in workplaces: a socio-cultural experience

• Why does this matter in palliative care?
  – Education as an improvement science
  – Public health approaches to palliative care
  – Co-production of learning
  – Need for applied research
A little bit about me…

• Consultant in Palliative Medicine
  – UCL lead for Palliative Care

• PhD in Medical Education Research
  Understanding authentic early experience in undergraduate medical education

• MA in Medical Ethics and Law
  Are people in developing countries too vulnerable to be included in research? A critique of the application of autonomy and vulnerability models to inclusion of participants in pharmaceutical trials

A collector of stories – what do these mean and how does this meaning effect and create learning?
What is medical education research?

...research concerning the education of healthcare providers...

• ‘Real life’ learning experiences

• Workplace/informal learning

• How do social processes promote or prevent theory from translating into practice?
  – why clinical educational interventions do not match intended outcomes
  – how to mitigate unintended consequences of workplace learning
The world of medical education

Theories of educational and clinical practice

Intended learning outcomes

Quality assurance, evaluation and research

Contested methodologies and approaches

Contested knowledge, meaning, roles and identities

Discourse of what should happen

Socio-cultural and other theories accounting for “human factors”

Holistic understanding of what does happen

Hands-on traditions and practice

Policy imperatives

Complex social interventions for learning
Experiential learning – theory and practice

WEB PAPER
AMEE GUIDE: THEORIES IN MEDICAL EDUCATION
Experiential learning: AMEE guide No. 63

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Abstract

This Guide provides an overview of educational theory relevant to learning from experience. It considers experience gained in clinical workplaces from early medical student days through qualification to continuing professional development. Three key assumptions underpin the Guide: learning is situated; it can be viewed either as an individual or a collective process; and the learning relevant to this Guide is triggered by authentic practice-based experiences. We first provide an overview of the guiding principles of experiential learning and significant historical contributions to its development as a theoretical perspective. We then discuss socio-cultural perspectives on experiential learning, highlighting their key tenets and drawing together common threads between theories. The second part of the Guide provides examples of learning from experience in practice to show how theoretical stances apply to clinical workplaces. Early experience, student clerkships and residency training are discussed in turn. We end with a summary of the current state of understanding.

Learning from experience
- Lived experience
- Situated learning
- Social interaction

Authentic practices
- Workplace-based teaching
- ‘on the job’
- ‘hands-on’
- Meaningful exposure
Figure 4. Transitions in experiential learning.
Theoretical principles

- Individual people learn individual things in individual ways - reaction to individual perceptions of experiences

- Education - process of individual transformation
  - competing perspectives – even if there are some absolute truths our knowledge of these is partially perceived
  - research aims at understanding how people create (different) versions of reality and how this can be influenced
  - Socio-cultural perspectives on learning…
Learning in workplaces: a socio-cultural experience

• The subject matter of learning and the processes by which people learn are not uniform; they are as diverse as the people who learn (Wertsch 1991).

• Peoples’ higher mental functions are strongly influenced by the activities of social milieus in which they develop (Wells 1999).

• Learning is mediated by artefacts, which have cultural and historical significance, and sign systems, of which language is the most prominent and important.

• Action, which can be defined as a goal-directed joint activity, has a central place in learning.

• Learning is situated within the context in which it takes place; the subject matter, content and process of learning are inseparable from one another.

• If interactions are perceived to be adversarial (with either people or institutions) then this will lead to a different sort of ‘learning’ and risks marginalisation of the learner rather than gradual integration into the practice community (Wenger 1998).
Why this matters

• Context and potential for participation
  – opportunities and type of participants when designing an experiential learning intervention

• Need to distinguish between
  – theoretical concepts which describe ideal learning circumstances (and aspire to reproduce these)
  – experience in practice, in order to address the realities of education in complex workplaces

• Previous learning influences future learning
  – Assimilation: the organisation of experiences into increasingly complex schemata for future use
  – Accommodation: modification of these schemata in the light of new experiences

• Development of transferable knowledge
  – Difference has greater impact than similarity
  – Socially mediated: ‘culture beats strategy’
  – Psychological fidelity between ‘education’ and ‘real world’
Human factors

‘The law of unintended consequences states that ‘actions of people – and especially of government [institutions] – always have effects that are unanticipated or unintended’ (Merton)
Language and stories of learning

People construct knowledge, meaning, and understanding through social interactions and ‘talk’ including story-telling
Receiving a diagnosis of lung cancer: patients’ interpretations, perceptions and perspectives

SJ Yardley, CL Davis Courmess Mountbatten House, Moorgreen Hospital, Southampton and F Shalton Department of Social Work Studies, University of Southampton Highfield, Southampton

Abstract: Lung cancer has a higher incidence than any other type of cancer and more than 60% of sufferers die within a year of diagnosis. An important aspect of caring for cancer patients is the breaking of bad news, something that most doctors admit to having difficulty with. Only a few publications on this issue adopt the patients’ perspective. This study aimed to document patients’ views on delivery of lung cancer diagnoses, their attitudes to methods used and ideas for improvement.

Patients were selected from medical, surgical and general practitioner clinics to provide insight into patients’ perceptions of care in different environments. Those who gave informed consent completed a taped semi-structured interview. Transcripts were analysed qualitatively using a phenomenological approach. Recruitment was stopped when saturation summary of results was achieved by independent researcher reliability.

Thirteen patients were recruited in nine practices using the six questionnaires. Factor analysis and theoretical concepts were used to frame the data. The experience of patients with lung cancer is shaped by the perspectives of healthcare, family and friends.

Keywords: lung cancer

Improving training in spiritual care: a qualitative study exploring patient perceptions of professional educational requirements

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Healthcare professionals express difficulties in delivering spiritual care, despite it being a core component of palliative care national policies. The patient perspective on professional training to address difficulties has not previously been sought. The aim of this study is to describe patient suggestions for development of training to deliver spiritual care. Qualitative semi-structured in-depth ‘palliative patient’ interviews (n = 20) were analysed thematically. Training suggestions encompassed practical care delivery. Patients supported staff who introduced questions about spiritual needs, and they expected opportunities to engage in spiritual care discussions. The ‘right’ attitude for spiritual care delivery was defined as being non-judgemental, providing integrated care and showing interest in individuals. Training issues included patient perspectives of boundaries between personal and professional roles. This study provides ‘palliative patient’ perspectives to strengthen recommended models of spiritual care delivery. It shows that user opinions on training can be helpful not only in deciding objectives but also how to achieve them.

Keywords: continuing education; delivery of health care; needs assessment; palliative care; qualitative; spirituality

‘The nice thing about doctors is that you can sometimes get a day off school’, an action research study to bring lived experiences from children, parents and hospice staff into medical students’ preparation for practice

Jessica Spalding, Sarah Yardley

ABSTRACT

Patient and public involvement in healthcare is seen as a prerequisite for ensuring that services meet their needs. Little is known about patients’ views on patient experiences are healthcare, their perceptions of the role of parents using supportive care at home, and the needs of children and families. This article reports on an action research study that explored the views of parents and families as well as the perceptions of healthcare professionals working with children and families. The study aimed to develop collaborative working relationships between healthcare professionals and families and to improve the care of children and families. The study included five stages of action research: a review of the literature, a focus group with parents, a survey of healthcare professionals, an audit of practice, and a workshop with parents and healthcare professionals. The results of the study showed that parents and healthcare professionals had different perceptions of the role of parents in the care of children and families. The study also showed that there was a need for improved communication between parents and healthcare professionals. The study had the potential to improve the care of children and families and to enhance the professionalism of healthcare professionals.

INTRODUCTION

Patient involvement is important to ensure services meet patient needs and priorities and can result in improved service delivery. In order to develop a shared understanding of the needs of parents and children, it is important to consider the perspectives of both groups. In this study, we aimed to explore the views of parents and healthcare professionals about the care of children and families. The study involved the following stages: a review of the literature, a focus group with parents, a survey of healthcare professionals, an audit of practice, and a workshop with parents and healthcare professionals. The results of the study showed that parents and healthcare professionals had different perspectives on the role of parents in the care of children and families. The study also showed that there was a need for improved communication between parents and healthcare professionals. The study had the potential to improve the care of children and families and to enhance the professionalism of healthcare professionals.
How does authentic early experience ‘work’ for students?

How and why do students construct useful knowledge and meaning-making from authentic early experience?
Spectra of workplace variables:
cultural competencies
Student understanding of professionalism

Lay perspective
Uncertain personal perspective
Professional perspective

Student understanding of 'medical' work
‘you will be professional and you will be polite and you will speak to people in a certain way and people will react to you in a certain way... whenever you mention you’re a medical student to anybody... you’re not a person anymore.’ (M1110)
Placement provider expectations and actions

Exclusion  Legitimacy  Participation

Developing practical workplace knowledge
‘Some of them just put theatre blues on over their normal clothes…and you just think ‘no, come on’…You’re changing into theatre get up, you have to take your clothes off –that’s the whole point… well it keeps us amused… that’s just being young and naive… it’s simple things like… how to behave and what… you do in certain environments –maybe they haven’t been told, …we always get them putting on the lead coats the wrong way round, so what I always do is teach them.’ (PP9)
Performing / simulating

Generic objectives

Integrated / holistic learning

Student

Context specific learning

Separate / parallel learning

Specific objectives

Reality

Transfer of learning

Spectra of educational variables: Learning opportunities
Student able to link learning

Separation  Parallel  Holistic

Explicit links offered by faculty
‘Um, I think some of the placements help and some of the placements are just a bit annoying. You... could have been doing work in that time...’ (M2I6)

although they’re obviously important and you can get an OSSE score on them, which we did –interviewing a patient which no-one was expecting for that reason, because we didn’t think it would come up because we didn’t think it was, you know, sort of related to what we’d done.’ (M1I3)
Understanding of current utility

Context specific

Locus of real learning

Transferable learning

Understanding of future relevance
R6: ‘You almost park it [knowledge]. You do almost it park it at times and just kind of think right, this is something I need to know; it is important but it’s not relevant for the minute now and you kind of just almost park it away knowing that you will come back to it later…you might even have notes …that you just don’t look at them for the moment.’

R4: ‘But how often do you park it and then never find the car again?’ (DGM3PP)
Consequences of educational interventions

<table>
<thead>
<tr>
<th>Intended consequences</th>
<th>Predicted consequences</th>
<th>Unpredicted consequences</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intended learning outcomes</td>
<td>Intended learning outcomes</td>
<td>‘Soft’ outcomes</td>
</tr>
<tr>
<td>Unintended consequences</td>
<td>Expected negatives</td>
<td>Unknowns (use spectra to investigate)</td>
</tr>
</tbody>
</table>
Stories of survival: creation of Mētis

• Practical knowledge
  – necessary skills and intelligence acquired through interacting in real life circumstances
  – created in response to the need to make the circumstances work for the agent concerned

• Not limited to positive or negative, benevolent or oppressive intent

• Creation of meaning to ‘handle’ learning, so that it ‘works’ for students in social interactions
Mētis in social interactions

- Adjustment to and negotiation of difference
- Serving two masters: chameleon identity
- ‘Spontaneous’ meaning-making and knowledge construction
- The ‘allowed’ myth
- The identity of a ‘medical student’ and bargaining tools
Patient-centred?

‘…with regards to pharmacology it doesn’t apply as much on placements… when you are talking about medication with patients they’ll just hand you a list of medications and… because I’m trying to focus on the patient, I don’t necessarily have the time to write down the list or really even pay very much attention to it, so I move on… Yes [laughs], they give me the list and then I look at it and go “Thank you” [laughs] and give it back to them.’ (S8)
Key findings

1. Expectations simultaneously too high (cultural competencies) and too low (educational potential)
2. Social interactions fundamental to meaning and knowledge
3. Social processes described through dyads of variables which form intersecting workplace and educational spectra
4. Unpredictable and unintended consequences
5. Students do not align locus of ‘real learning’ with locus of ‘real practice’
6. Students create Mētis - how to handle knowledge and meaning to make experiences work for them
Secondary analysis

Perceived differences between simulated and authentic patient interactions

- Competitive contrast or constructive comparison?
- Opportunities to increase educational value
Tensions in guidance

‘real patients... a lot easier in a way... you wouldn’t normally go through, confidentiality with them and then consent...’cause they just, they don’t see it as being important, whereas simulated patients will – that’s only probably because they’ve been told to by the medical school’ (M1I3)

‘you’ve got experienced clinicians telling you what to do, how well you’ve done it, how well they feel you can improve... which way to go – and if you listen and just try and understand what they’re telling you’ (M2I11)
Comparing and contrasting

‘with simulated patients you’ve got... the other ten people in the group watching you – it’s really awkward, it’s the first time you’ve done it ...the adrenalin rush and you’re not... thinking on your feet – like you are...in a real situation...so it’s a little bit forced. It’s good to practice ‘cause you just get to go through the motions’ (M1I10)

‘They [real patients] might come out with... a lot of things which you don’t expect or which you never asked but somehow it came out... they came out with something totally unrelated but still a good insight to their lives.’ (M1I11)
Responsibility

‘You can’t harm simulated patients… you can’t really make them upset… whereas a real patient… they perceive us as doctors’ (M1I4)

‘there’s a lot more to think about when you’re with a real patient…you really are delving into their personal, private lives… whereas the simulated patients are told to react in a certain way, these patients could act any which way they want to… and you have to…go…a bit more cautious’ (M1I9)
Legitimacy

‘approaching more sensitive issues I tend to shy away in the real... not so much because I was scared to delve into them, I just didn’t think it was that necessary at the moment. These people are on a ward, they’re obviously ill, they don’t want me coming along and asking them about other sensitive issues... I asked “do you have any other illnesses you would mind talking to me about” and... didn’t ask that much about whether you were married or had kids or... just because it wasn’t directly relevant’ (M219)
Interpreting educational evidence for practice: are autopsies a missed educational opportunity to learn core palliative care principles?

Sarah Yardley

**ABSTRACT**

**Objectives**

UK policy requires undergraduate medical curricula to equip students to care for dying patients. The educational potential of autopsy attendance during authentic early

**INTRODUCTION**

In the late 1960s, as Kübler-Ross was identifying problems in medical institutions from the perspective of dying patients, Cicely Saunders was pioneering
‘You’re used to... seeing a dead person...but you’re not used to seeing a fresh dead person,— I know it sounds terrible to say but I mean these people have died, say, the night before and ... she’s just been opened up and he just scooped everything out and slapped it on the bench... this was someone who was alive yesterday and to see all her organs just out on the bench ... Massive carving knife, just doing sections through and then it all gets whacked in a bag and put in the cavity and sewn up, so it was just... I don’t know it’s... I suppose it’s going from something... someone that was alive yesterday to basically a piece of meat the next day – which is something that if you... see it for the first time it’s something that’s quite new... ‘cause that could be me, tomorrow,... It was a good experience. I mean... You get used to it but I was a little, um...a little nauseous ....I’d say to start with. But the more and more you experience it, the less and less that gets and then you walk into a situation and it’s just normal.’ (M2I1)
Why does this matter in palliative care?

– Education as an improvement science

– Public health approaches to palliative care

– Co-production of learning

– Need for applied research
Education as an improvement science

The learning of professionals and patients today will affect the healthcare outcomes of the future.

Whole task learning theory

- ‘Real world’ problems
- Linked components of complex tasks including communication skills, practical support and clinical knowledge
Jeroen J. G. van Merriënboer and Liesbeth Kester

Learning Tasks
- Task description (e.g., worked-out example, completion task, conventional task)
- Guidance

Part-Task Practice
- Practice items

Supportive Information
- Domain models (illustrated by case studies)
- Systematic approaches to problem solving (illustrated by modeling examples)
- Cognitive feedback

Procedural Information
- How-to instructions (exemplified by demonstrations)
- Prerequisite information (exemplified by instances)
- Corrective feedback

Figure 35.1 A schematic overview of the 4C/ID model and its main elements.
Study day: structure and content

**Plenary**
- Transitions
- Competencies FY1
- Diagnosis of dying
- Care of the dying

**Small groups: sim. patient/relatives**

1. Patient with bowel obstruction
   - Bad news / CSCI
   - Discharge home / DNAR
   - Care of the dying

2. Frail elderly patient with dementia
   - Diagnosis of dying/ appropriate care
   - Shared decision making
   - Certification/coroner / bereavement
Thematic analysis of reflective writing

- Value in practicing challenging and realistic complex tasks
- Knowledge gained and applied including critique of role models
- Community team working
- Patient and relative perspectives
- Self-awareness, emotional intelligence
- Reluctance to mention actual deaths
- Preparation for foundation year 1
Preparing to prescribe: How do clerkship students learn in the midst of complexity?

Lucy McElhinny1,2 · Sarah Yardley3 · Ben Norris4 · Antigue de Bruin5 · Mary P. Tully6 · Tim Dornan1,2

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Abstract Prescribing tasks, which involve pharmacological knowledge, clinical decision-making and practical skill, take place within unpredictable social environments and involve interactions within and between endlessly changing healthcare teams. Despite this, curriculum designers commonly assume them to be simple to learn and perform. This research used mixed methods to explore how undergraduate medical students learn to prescribe in the ‘real world’. It was informed by cognitive psychology, sociocultural theory, and systems thinking. We found that learning to prescribe occurs as a dynamic series of socially negotiated interactions within and between individuals, communities and environments. As well as a thematic analysis, we developed a framework of three conceptual spaces in which learning opportunities for prescribing occur. This illustrates a complex systems view of prescribing education and defines three major system components: the “social space”, where the environmental conditions influence or bring about a learning experience; the “process space”, describing what happens during the learning experience; and the intra-personal “cognitive space”, where the learner may develop aspects of prescribing expertise. This conceptualisation broadens the scope of inquiry of prescribing education research by highlighting the complex interplay between individual and social dimensions of learning. This perspective is also likely to be relevant to students’ learning of other clinical competencies.
Symptom perceptions and help-seeking behaviour prior to lung and colorectal cancer diagnoses: a qualitative study

Sarah McLaughlan, Gemma Mansell, Tom Sanders, Sarah Yardley, Danielle van der Windt, Lucy Brindley, Carolyn Chew-Graham and Paul Little

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**Correspondence to Sarah McLaughlan, Arthritis Research UK Primary Care Centre, Research Institute for Primary Care & Health Sciences, Keele University, Keele, Staffordshire ST5 5BZ, UK. E-mail: s.mclaughlan@keele.ac.uk

Abstract

Background: Lung and colorectal cancer are common and have high UK mortality rates. Early diagnosis is important in reducing cancer mortality, but the literature on lung and colorectal cancer suggests many people wait for a considerable time before presenting symptoms.

Objective: To gain an in-depth understanding of patients’ interpretations of symptoms of lung and colorectal cancer prior to diagnosis, and to explore processes leading to help-seeking.

Methods: Semi-structured interviews were conducted with patients diagnosed with lung (N = 10) or colorectal (N = 10) cancer within the previous 12 months. Patients were asked about symptoms experienced in the period preceding diagnosis, their interpretations of symptoms, and decision making for help-seeking. Thematic analysis was conducted and comparisons drawn within and across the patient groups.

Results: Patients were proactive and rational in addressing symptoms; many developed alternative, non-cancer explanations based on their knowledge and experience. Discussions with important others frequently provided the impetus to consult, but paradoxically others often initially reinforced alternative explanations. Fear and denial did not emerge as barriers to help-seeking, but help-seeking was triggered when patients’ alternative explanations could no longer be maintained, for instance due to persistence or progression of symptoms.

Conclusions: Patients’ reasoning, decision making and interpersonal interactions prior to diagnosis were complex. Prompting patients for additional detail on symptoms within consultations could elicit critical contextual information to aid referral decisions. Findings also have implications for the design of public health campaigns.

Keywords: Diagnosis, symptoms, primary healthcare, qualitative, referral and consultation.

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Figure 1. Model of symptom perceptions and help-seeking behaviour prior to cancer diagnoses, based on data from 20 patients with lung or colorectal cancer.
Modelling successful primary care for multimorbidity: a realist synthesis of successes and failures in concurrent learning and healthcare delivery

Sarah Yardley, Elizabeth Cottrell, Eilot Rees and Joanne Protheroe

Abstract

Background: People are increasingly living longer with multimorbidity. Medical education and healthcare delivery must be re-orientated to meet the societal and individual patient needs that multimorbidity confers. The impact of multimorbidity on the educational needs of doctors is little understood. There has been little critique of how learning alongside healthcare provision is negotiated by patients, general practitioners and trainee doctors. This study asked what is known about how and why concurrent healthcare delivery and professional experiential learning interact to generate outcomes, valued by patients, general practitioners and trainees. The patients with multimorbidity in primary care?

Methods: This realist synthesis is reported using a framework. Relationships between learning and care were the primary outcome of interest. Healthcare, social science and philosophical approaches were reviewed. Data extraction focused on context, mechanisms and outcome on data which might assist understanding and explains the configurations; it is their role and place in evolving programme theories arising from data synthesised from evidence. Meetings were used to aid interpretative analysis.

Results: The final synthesis included 14 articles of which 14 contained models of practice and patient care. Models of experiential learning for practitioners and for patients frequently referenced theories of transformation and socio-cultural processes as key themes. Key themes included the perceived impossibility of recording personal experience, clinical challenges in adherence to guidelines, and the need for greater recognition of roles and tasks including the complexity of shared responsibilities. A model of concurrency for learning and healthcare delivery in the context of multimorbidity supporting evidence is presented.

Conclusions: This study is novel in considering empirical evidence from patients, concurrent learning and healthcare delivery. The findings should inform future in medical workforce to provide multimorbidity care.

Keywords: General practice; Health service delivery; Medical education; Multimorbidity; Socio-cultural theories.

Table 4 Key constructs of success and failure

<table>
<thead>
<tr>
<th>Health care delivery</th>
<th>Key constructs of success</th>
<th>Key constructs of failure</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>- Collaborative working practices</td>
<td>- Repeated/prolonged hospital admissions</td>
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<tr>
<td></td>
<td>- Holistic and transparent goals developed through negotiation</td>
<td>- Clinician reluctance to look beyond biomedical markers</td>
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<tr>
<td></td>
<td>- Integration of medical and experiential knowledge regarding diseases and impact</td>
<td>- Negative corollaries of the described constructs of success [1, 13, 24, 26, 37, 44, 48, 51, 52, 57, 61, 63-69]</td>
</tr>
<tr>
<td></td>
<td>- Professional sharing of best practice</td>
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<tr>
<td></td>
<td>- Transformative learning through trusted relationships between patients and practitioners to enable self-management</td>
<td></td>
</tr>
<tr>
<td></td>
<td>[1, 10, 12, 24, 26, 28, 37, 44, 48, 51, 52, 57, 61, 63-69]</td>
<td></td>
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<tr>
<td></td>
<td>- Learning to engage in and benefiting from collaborative working</td>
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</tr>
<tr>
<td></td>
<td>- Reciprocal learning: viewing learning as a shared social process</td>
<td>- Contexts which reduced students and patients to passive roles</td>
</tr>
<tr>
<td></td>
<td>- Learning from direct interaction with patients</td>
<td>- Negative workplace cultures</td>
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<tr>
<td></td>
<td>- A supportive environment for the appropriate mix of responsibility, challenge and scaffolding to permit a safe but legitimate role in practice</td>
<td>- Lack of exposure to multimorbidity with excessive focus on single-disease frameworks</td>
</tr>
<tr>
<td></td>
<td>- Physical space to allow interactions between patients and trainees</td>
<td>- Overreliance on guidelines often not developed on evidence applicable to patients with multimorbidity in primary care [27, 28, 50, 65]</td>
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<tr>
<td></td>
<td>- Patients and practitioners needed to learn how to make personalised trade-offs between risks and benefits in multimorbidity and to manage competing priorities which could change over time</td>
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<tr>
<td></td>
<td>[10-12, 26, 27, 47, 48, 50-53, 56-59, 64, 68-75]</td>
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</table>
Key findings

• Concurrency of education and care delivery
• Non-linear nature of transitions for patients and trainees occurring during social interactions
• Active engagement and meaningful roles by legitimising participation and providing a safety net which balances challenge with appropriate support
• Create contexts in which patients, GPs and trainees can discuss challenges, concepts of success and failure and develop shared goals.
• Recognition of different sorts of knowledge and practice (including experiential expertise) as valuable for development of new in-practice knowledge
• Trusting relationships must be cultivated
• Interventions should be designed to take account of the dynamic systems in which people work, accounting for breakdowns and work-arounds in interventions (and learning from these) as well as targeting education at individuals
• A reduced emphasis on index condition and diagnosis models in long-term conditions is needed
Lived experiences of multimorbidity: An interpretative meta-synthesis of patients’, general practitioners’ and trainees’ perceptions

Elizabeth Cottrell and Sarah Yardley

Abstract
Objectives: Multimorbidity is an increasing challenge of patients, general practitioners and trainees. This interpretative meta-synthesis sought to identify themes regarding multimorbidity and how they should shape future solutions.

Methods: Empirical studies containing qualitative research (PROSPERO 2013) were identified through a systematic literature review. Data were extracted from key papers from remaining studies were utilised to expand the themes within and between perspectives.

Results: Twenty-one papers were included, producing five themes: (1) goals of care, (2) patients’ expectations, (3) logistics, (4) shared recognition of challenges, and (5) interpersonal issues. The integration of these themes provides a comprehensive framework for understanding and addressing the challenges of multimorbidity.

Discussion: There was little evidence of shared expectations and more explicit exploration of the importance of effective communication in care and education.

Figure 2. Initial 16 third-order themes (capitals) with summary of associated concepts.
Value?

‘The systematic recording of what actually happens in working circumstances can be a powerful political tool. The same can be said of studies of the ‘mismatch’ between what is textbook pedagogic ‘good practice’ and what actually happens’ (Coats et al 2005)

‘to produce a tested theory about what works for whom in what circumstances and in what respects. This end product is never a pass/fail verdict on an intervention but an understanding of how its inner workings produce diverse effects.’ (Pawson & Tilley 2004)
Ambitions

Six ambitions to bring that vision about

01 Each person is seen as an individual
02 Each person gets fair access to care
03 Maximising comfort and wellbeing
04 Care is coordinated
05 All staff are prepared to care
06 Each community is prepared to help

“I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s).”

06 Each community is prepared to help

The building blocks for achieving our ambition

<table>
<thead>
<tr>
<th>Compassionate and resilient communities</th>
<th>Public awareness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public health approaches to palliative and end of life care need to be accelerated and support given to people and communities who can provide practical help and compassion.</td>
<td>Those who share our ambition should work to improve public awareness of the difficulties people face and create a better understanding of the help that is available.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Practical support</th>
<th>Volunteers</th>
</tr>
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<tbody>
<tr>
<td>Local health, care and voluntary organisations should find new ways to give the practical support, information and training that enables families, neighbours and community organisations to help.</td>
<td>To achieve our ambition more should be done locally and nationally to recruit, train, retain and engage volunteers into a more integrated effort to help support people, their families and communities.</td>
</tr>
</tbody>
</table>

National Palliative and End of Life Care Partnership
www.endoflifecareambitions.org.uk
Foundations for the ambitions

Personalised care planning
Everybody approaching the end of their life should be offered the chance to create a personalised care plan. Opportunities for informed discussion and planning should be universal. Such conversations must be ongoing with options regularly reviewed.

Shared records
To ensure the plan can guide a person-centred approach it has to be available to the person and, with their consent, be shared with all those who may be involved in their care.

Evidence and information
Comprehensive and robust data are necessary to measure the extent to which the outcomes that matter to the person are being achieved. This, alongside strengthening the evidence-base, will help to drive service improvements.

Involving, supporting and caring for those important to the dying person
Families, friends, carers and those important to the dying person must be offered care and support. They may be an important part of the person’s caring team, if they and the dying person wish them to be regarded in that way. They are also individuals who are facing loss and grief themselves.

Foundations for the ambitions

Education and training
It is vital that every locality and every profession has a framework for their education, training and continuing professional development to achieve and maintain competence and allow expertise and professionalism to flourish.

24/7 access
When we talk about end of life care we have to talk about access to 24/7 services as needed, as a matter of course. The distress of uncontrolled pain and symptoms cannot wait for ‘opening hours’.

Co-design
End of life care is best designed in collaboration with people who have personal and professional experience of care needs as people die.

Leadership
The leadership of Health and Wellbeing Boards, CCGs and Local Authorities are needed to create the circumstances necessary for action. Clinical leadership must be at the heart of individual service providers.
Libby Sallnow

The principles of a new public health approach

• Focuses on equity, participation and a broad understanding of health and wellbeing
• Social capital, resilience etc. assessed along with mortality rates
• Acknowledges the limitations of the biomedical model
• Social determinants of disease recognised
• Interventions done with not to people
Community engagement and end-of-life care

- Kellehear first described the ‘public health approach to end of life care’ (1999)
- Aligned the two apparently paradoxical disciplines

**Compassionate Communities** are community development initiatives that actively involve citizens in their own end-of-life care

Build partnerships between services and communities to build on the strengths and skills they possess, rather than replacing them with professional care
Conceptual clarity

Understanding community engagement in end-of-life care: developing conceptual clarity
Libby Sallnow\textsuperscript{a,b,*} and Sally Paul\textsuperscript{b,c}

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The impact of a new public health approach to end-of-life care: A systematic review

Libby Sallnow1, Heather Richardson2, Scott A Murray2 and Allan Kellehear3

Abstract
Background: Communities play an increasingly significant role in their own health and social care, and evidence demonstrates the positive impact of this work on a range of health outcomes. Interest is building regarding the application of the principles of the new public health approach to those facing the end of life and their families and communities.

Aim: To review the evidence relating to the impact of a new public health approach to end-of-life care, specifically as this applies to efforts to strengthen community action.

Design: A systematic review employing narrative synthesis. Both meta-ethnography and the use of descriptive statistics supported analysis.

Data sources: Eight databases (AMED, ASSIA, Bibliomap, CINAHL, Cochrane Reviews, EMBASE, MEDLINE and PsychINFO) were searched from the earliest record to March 2015 using set eligibility criteria.

Results: Eight articles were included in the analysis. Three main themes emerged from the meta-ethnography: making a practical difference, individual learning and personal growth and developing community capacity. The quantitative findings mapped to the meta-ethnography and demonstrated that engaging communities can lead to improved outcomes for carers such as decreased fatigue or isolation, increase in size of caring networks and that wider social networks can influence factors such as place of death and involvement of palliative care services.

Conclusions: Evidence exists for the impact of community engagement in end-of-life care. Impact assessment should be an integral part of future initiatives and policy makers should recognise that these approaches can influence complex issues such as carer support, community capacity, wellbeing and social isolation.

Keywords
Palliative care, public health, health promotion, community engagement, impact, outcomes

Understanding the impact of a new public health approach to end-of-life care: a qualitative study of a community led intervention

Libby Sallnow, Heather Richardson, Scott Murray, Allan Kellehear

Abstract
Background: Social isolation is recognised for its substantial impact on mortality, ranking above many established public health threats. The end of life can compound this problem; with escalating acute care costs due to poor social support and rising numbers of deaths, new solutions are needed. Examples of peer providing social support exist within end-of-life care but have not been well characterised. We aimed to understand the impacts and facilitative processes of a home visiting intervention.

Methods: A qualitative study with mixed methods of data collection (in-depth interviews, participant observation, documentary analysis) was done. Volunteers and beneficiaries matched for more than three home visits, staff members leading the project, and family carers were included. Data were analysed according to modified grounded theory. Participants were recruited by theoretical sampling, and recruitment was concluded when theoretical saturation was reached. Ethical approval was obtained.

Findings: Data included 21 in-depth interviews, 19 episodes of participant observation, and 19 documents. Three central impacts emerged from the data. Participants stated that peer support filled a gap in social support that neither professionals nor family could meet. Participants described becoming socially connected and linked this connection to increased wellbeing. Volunteers viewed themselves and those they visited as peers, despite differences in age or diagnosis. This view explained how connections could be expressed, instead of a more detached form of empathy. A key facilitative process was the development of a relationship based on mutuality rather than positivity and dependence. On this basis, the relationship could be reconstructed outside the professional domain and could develop a depth and sustainability beyond the formal intervention.

Interpretation: This study highlights the role of social networks in promoting wellbeing at the end of life. For sustainable changes to occur, relationships must be reciprocal rather than passive. These findings have important implications for how social care interventions are structured at the end of life. Peer support networks are a sustainable and appropriate care model, and this study provides evidence of their utility and sheds light on the fundamental components of compassionate care.

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Contribution: All authors conceived and designed the study. LS undertook investigation and analysis of the data. TS, HR, IM, and AR contributed to data review and interpretation. All authors approved for abstract.

Declaration of Interests: We declare no competing interests.
Debbie Horsfall

Re-orientation of Practice/s

• From protective and paternalistic service provision
• To negotiated care between providers and carers
• Where the role of the service provider is to understand and supplement the informal networks skills, knowledge and values with their own practice wisdom and resources

What will it take?

• respecting lay people as possessing agency, knowledge, skills understanding
• community capabilities and needs from the communities perspective
• believing that people learn best by doing, by being involved and engaged re-orientating from person centred to network centred care

https://www.westernsydney.edu.au/staff_profiles/uws_profiles/professor_debbie_horsfall

Co-production of learning

Need for applied research

- Social network influence on workplace-based learning and healthcare
- Role of social networks at patient-carer-generalist-specialist interfaces
- How learning at boundaries/interfaces relates to networks
- Palliative Care and Liaison Psychiatry
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