Central and North West London NHS
NHS Foundation Trust

Experiential learning:

Lessons for (community) palliative care

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Wellbeing for life
London | Milton Keynes | Kent | Surrey | Hampshire

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

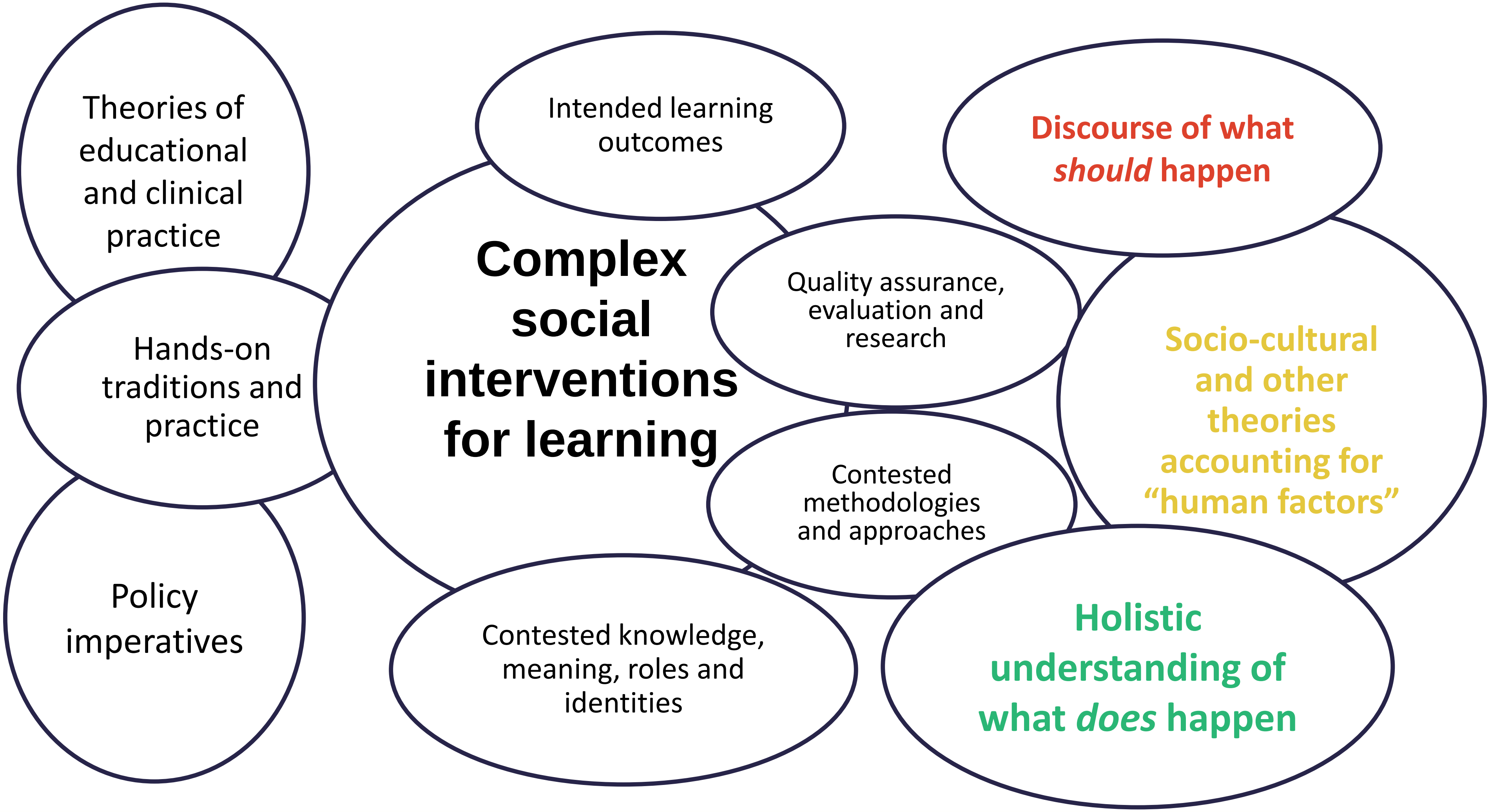
A collector of stories – what do these mean and how does this meaning effect and create learning?

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

Discourse of what *should* happen

Hands-on traditions and practice

Complex social interventions for learning

Quality assurance, evaluation and research

Socio-cultural and other theories accounting for "human factors"

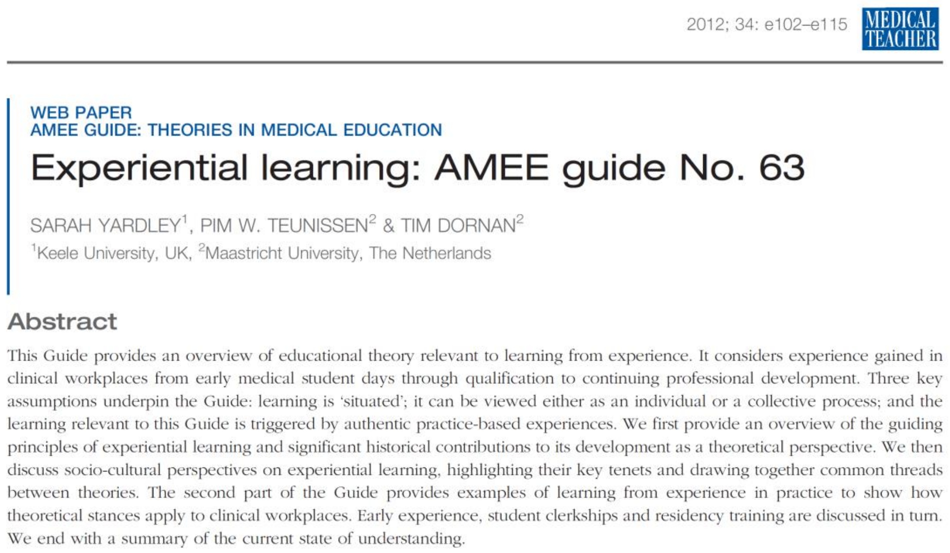
Contested methodologies and approaches

Policy imperatives

Contested knowledge, meaning, roles and identities

Holistic understanding of what *does* happen

Experiential learning – theory and practice



2012; 34: e102–e115 MEDICAL TEACHER

WEB PAPER
AMEE GUIDE: THEORIES IN MEDICAL EDUCATION

Experiential learning: AMEE guide No. 63

SARAH YARDLEY[1], PIM W. TEUNISSEN[2] & TIM DORNAN[2]
[1]Keele University, UK, [2]Maastricht University, The Netherlands

Abstract

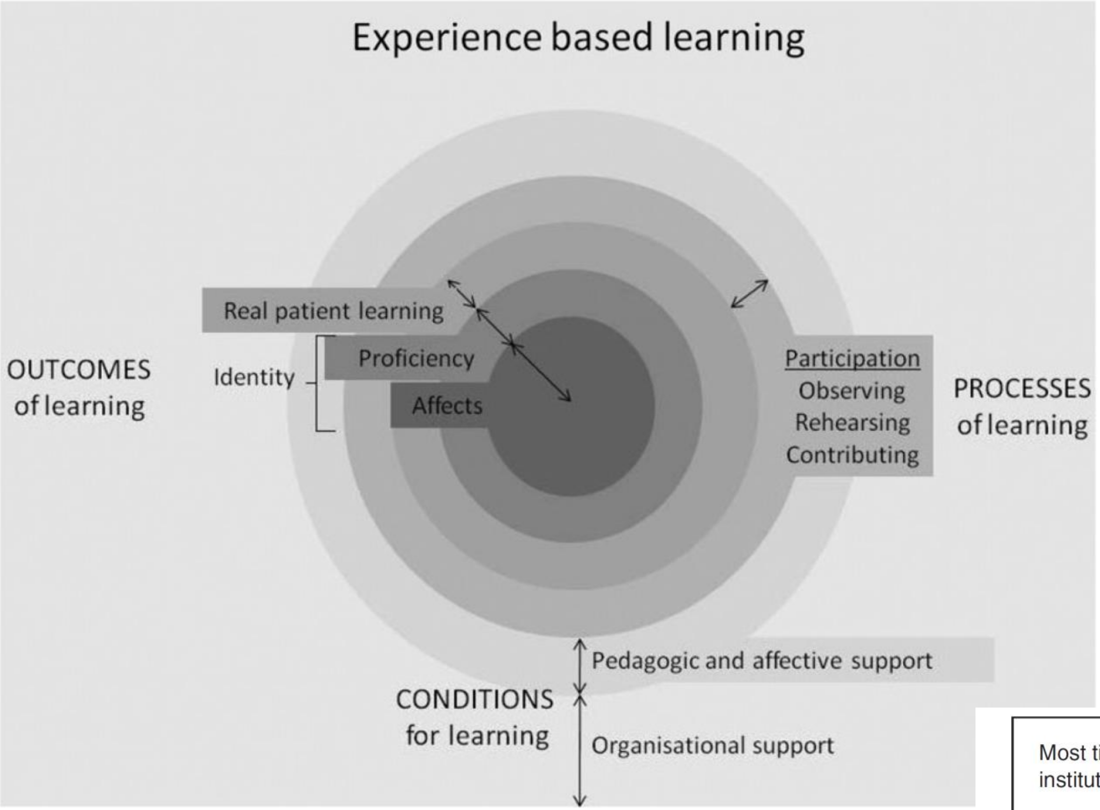
This Guide provides an overview of educational theory relevant to learning from experience. It considers experience gained in clinical workplaces from early medical student days through qualification to continuing professional development. Three key assumptions underpin the Guide: learning is 'situated'; 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



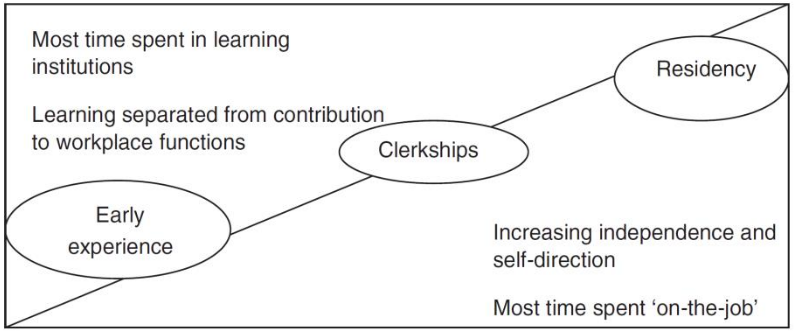


Figure 4. Transitions in experiential learning.

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

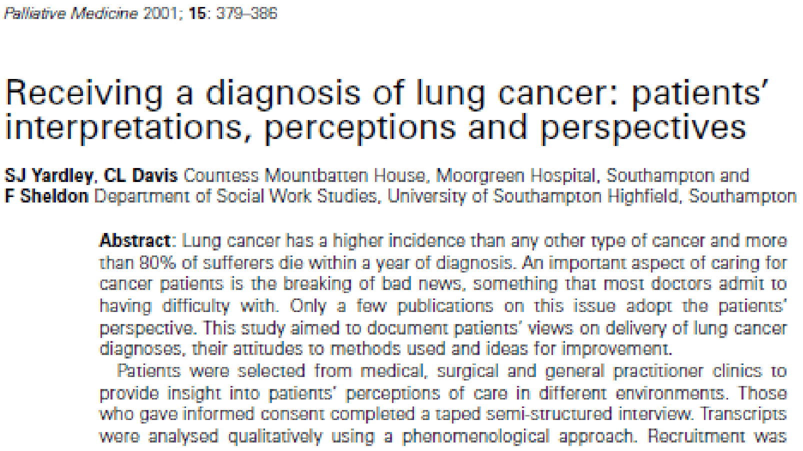
- Context and potential for participation
  - opportunities and type of participants when designing an experiential learning intervention
- Need to distinguish between
  - theoretical concepts which describe ideal learning circumstances (and aspire to reproduce these)
  - experience in practice, in order 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



Palliative Medicine 2001; **15**: 379–386

Receiving a diagnosis of lung cancer: patients' interpretations, perceptions and perspectives

SJ Yardley, **CL Davis** Countess Mountbatten House, Moorgreen Hospital, Southampton and
F Sheldon Department of Social Work Studies, University of Southampton Highfield, Southampton

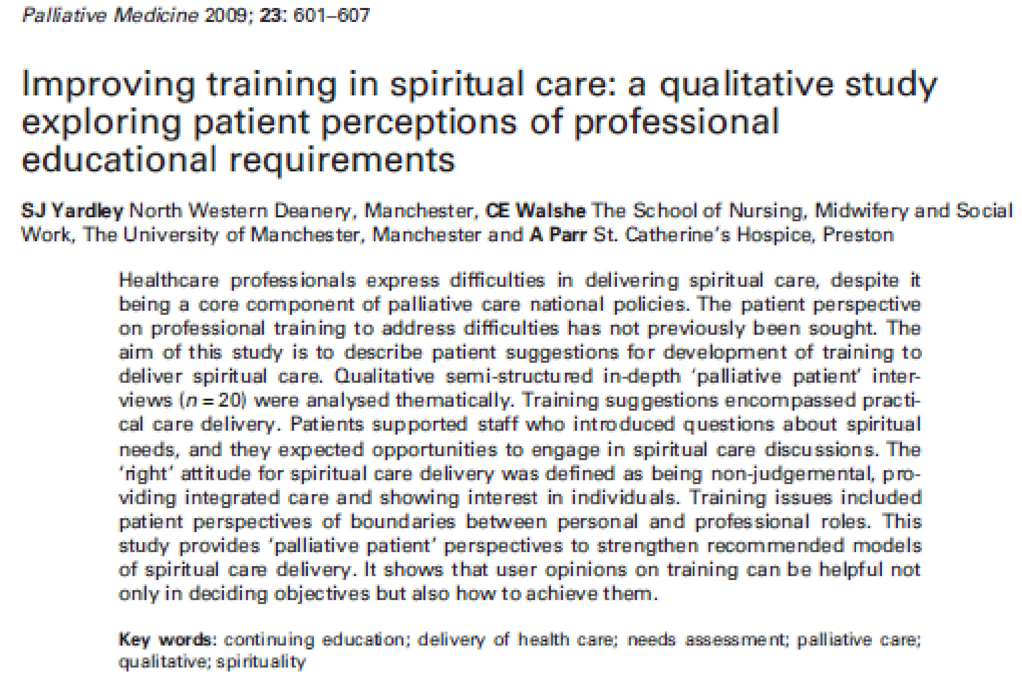
Abstract: Lung cancer has a higher incidence than any other type of cancer and more than 80% of sufferers die within a year of diagnosis. An important aspect of caring for cancer patients is the breaking of bad news, something that most doctors admit to having difficulty with. Only a few publications 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 se
independent researcher co
reliability.

Thirteen patients were rec
the use of words such as
to diagnosis, views on tre
and suggested improvem
bronchoscopy in the patient
PIL is being revised.

Factors including family s
yet they influence patients
interpretation of this and tl
underline the need to contir
care tailored to each patien

Key words: lung cancer/nec
truth disclosures



Palliative Medicine 2009; **23**: 601–607

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

SJ Yardley North Western Deanery, Manchester, **CE Walshe** The School of Nursing, Midwifery and Social Work, The University of Manchester, Manchester and **A Parr** St. Catherine's Hospice, Preston

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.

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

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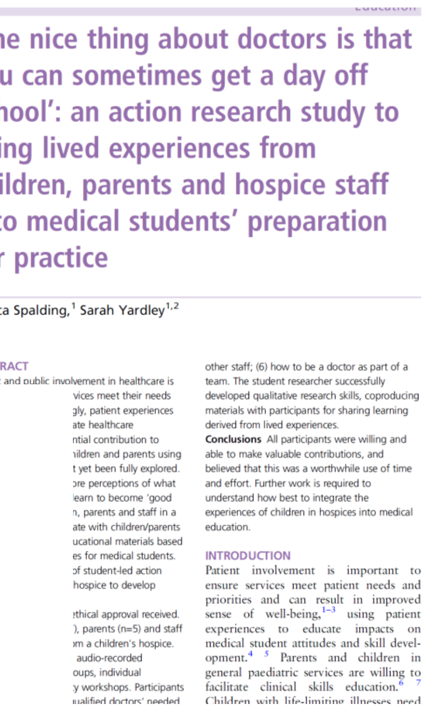

'The nice thing about doctors is that you can sometimes get a day off school': an action research study to bring lived experiences from children, parents and hospice staff into medical students' preparation for practice

Jessica Spalding,[1] Sarah Yardley[1,2]

ABSTRACT

Patient and public involvement in healthcare is
vices meet their needs
gly, patient experiences
ate healthcare
ntial contribution to
ildren and parents using
t yet been fully explored.
ore perceptions of what
learn to become 'good
n, parents and staff in a
ate with children/parents
ucational materials based
es for medical students.
of student-led action
hospice to develop

ethical approval received.
), parents (n=5) and staff
om a children's hospice.
audio-recorded
oups, individual
y workshops. Participants
ualified doctors' needed

other staff; (6) how to be a doctor as part of a team. The student researcher successfully developed qualitative research skills, coproducing materials with participants for sharing learning derived from lived experiences.

Conclusions All participants were willing and able to make valuable contributions, and believed that this was a worthwhile use of time and effort. Further work is required to understand how best to integrate the experiences of children in hospices into medical education.

INTRODUCTION

Patient involvement is important to ensure services meet patient needs and priorities and can result in improved sense of well-being,[1–3] using patient experiences to educate impacts on medical student attitudes and skill development.[4 5] Parents and children in general paediatric services are willing to facilitate clinical skills education.[6 7] Children with life-limiting illnesses need

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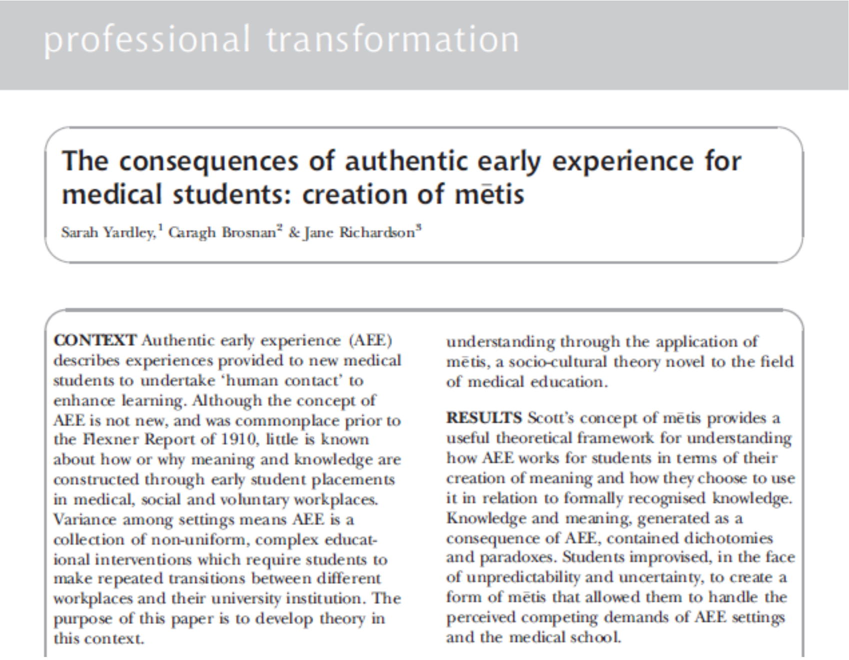
Authentic early experience in Medical Education: a socio-cultural analysis identifying important variables in learning interactions within workplaces

Sarah Yardley, Caragh Brosnan, Jane Richardson, Richard Hays

Abstract

This paper addresses the question 'what are the variables influencing social interactions and learning during Authentic Early Experience (AEE)?' AEE is a complex educational intervention for new medical students. Following critique of the existing literature, multiple qualitative methods were used to create a study framework conceptually orientated to a socio-cultural perspective. Study participants were recruited from three groups at one UK medical school: students, workplace supervisors, and medical school faculty. A series of intersecting spectra identified in the data describe dyadic variables that make explicit the parameters within which social interactions are conducted in this setting. Four of the spectra describe social processes related to being in workplaces and developing the ability to manage interactions during authentic early experiences. These are: (1) legitimacy expressed through invited participation or exclusion; (2) finding a role—a spectrum from student identity to doctor mindset; (3) personal perspectives and discomfort in transition from lay to medical; and, (4) taking responsibility for 'risk'—moving from aversion to management through graded progression of responsibility. Four further spectra describe educational

How and why do students construct useful knowledge and meaning-making from authentic early experience?



professional transformation

The consequences of authentic early experience for medical students: creation of mētis

Sarah Yardley,[1] Caragh Brosnan[2] & Jane Richardson[3]

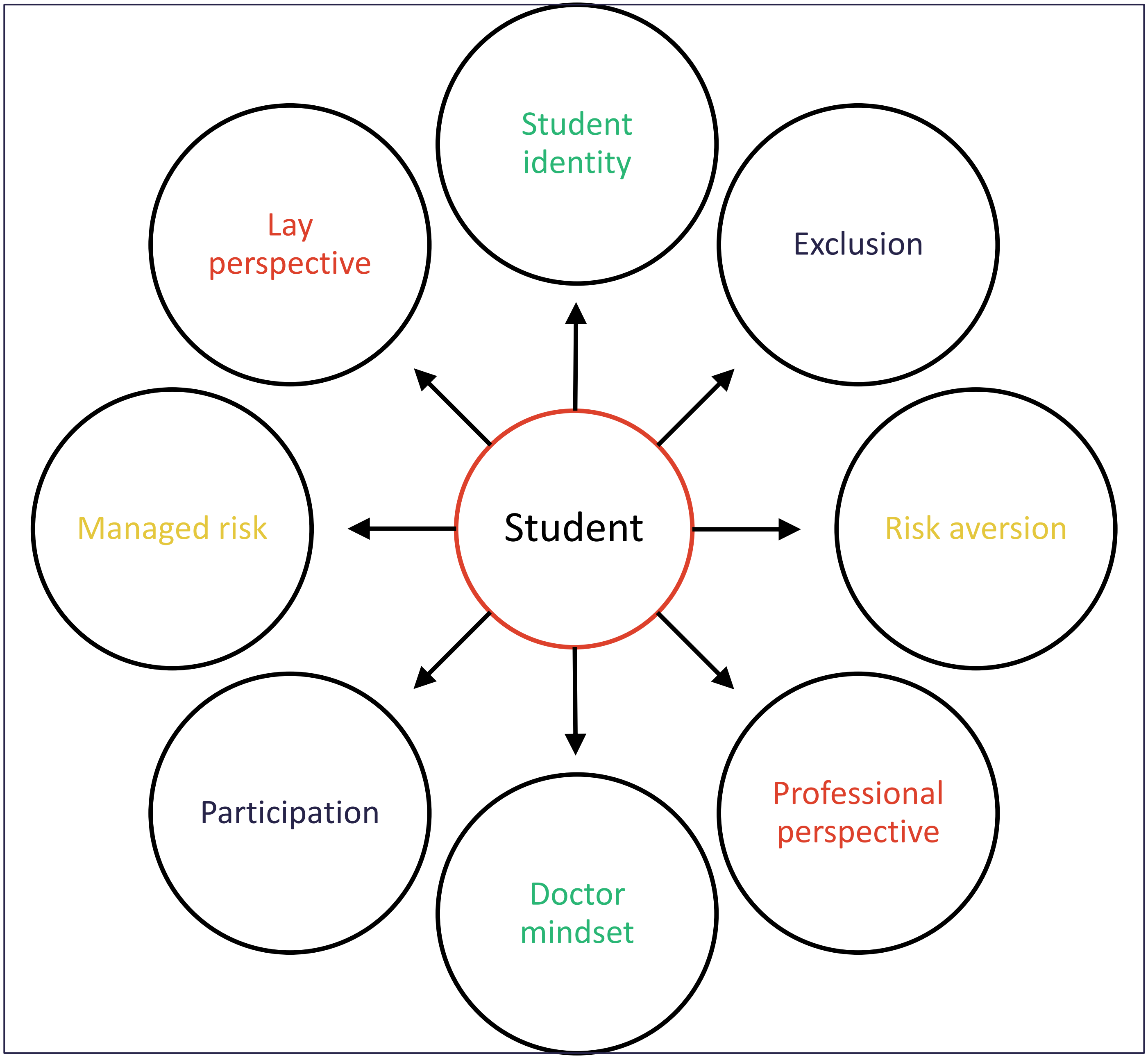
CONTEXT Authentic early experience (AEE) describes experiences provided to new medical students to undertake 'human contact' to enhance learning. Although the concept of AEE is not new, and was commonplace prior to the Flexner Report of 1910, little is known about how or why meaning and knowledge are constructed through early student placements in medical, social and voluntary workplaces. Variance among settings means AEE is a collection of non-uniform, complex educational interventions which require students to make repeated transitions between different workplaces and their university institution. The purpose of this paper is to develop theory in this context.

understanding through the application of mētis, a socio-cultural theory novel to the field of medical education.

RESULTS Scott's concept of mētis provides a useful theoretical framework for understanding how AEE works for students in terms of their creation of meaning and how they choose to use it in relation to formally recognised knowledge. Knowledge and meaning, generated as a consequence of AEE, contained dichotomies and paradoxes. Students improvised, in the face of unpredictability and uncertainty, to create a form of mētis that allowed them to handle the perceived competing demands of AEE settings and the medical school.

How does authentic early experience 'work' for students?

Spectra of workplace variables: cultural competencies



Student

Student identity

Exclusion

Risk aversion

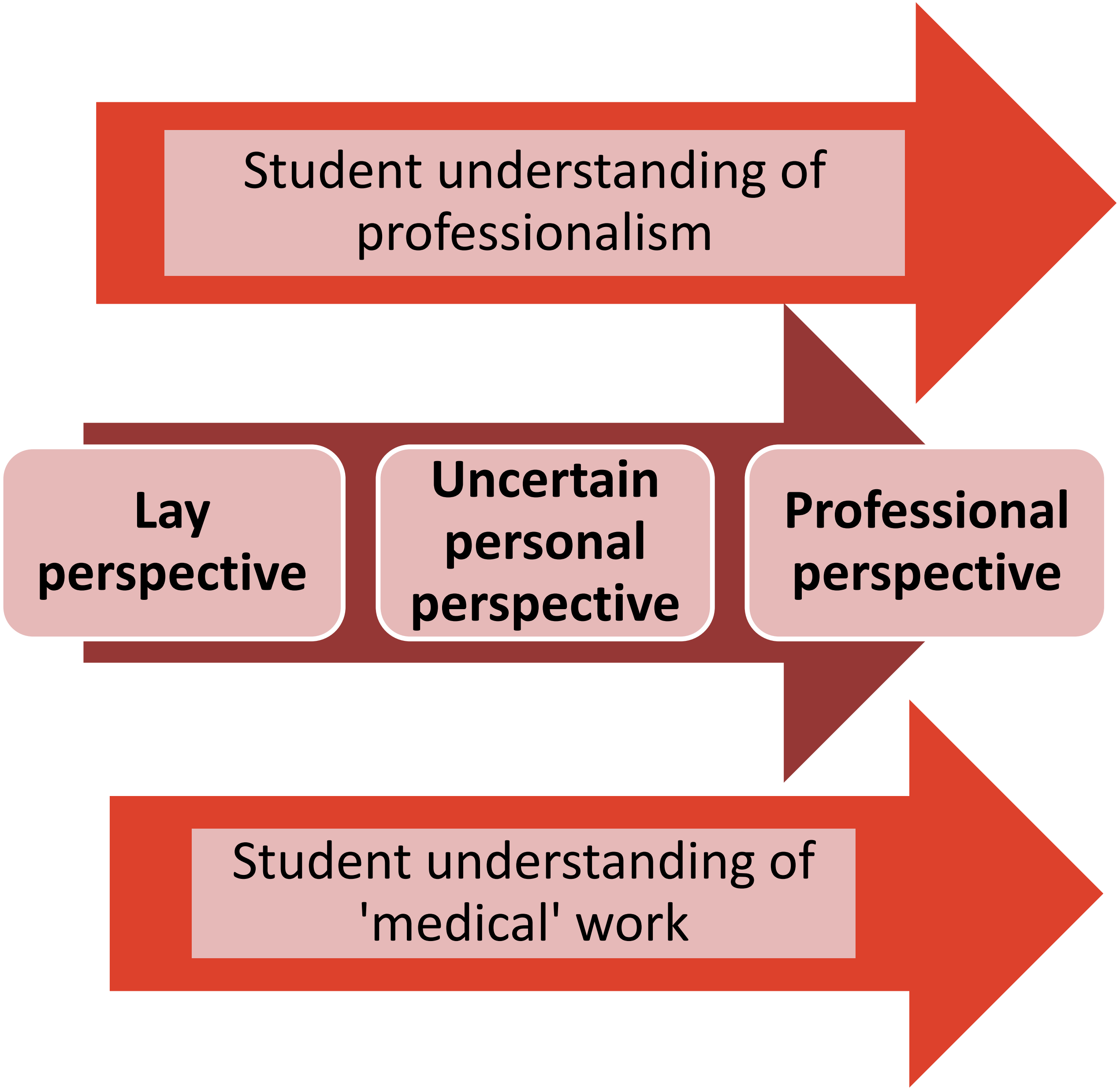
Professional perspective

Doctor mindset

Participation

Managed risk

Lay perspective



Student understanding of professionalism

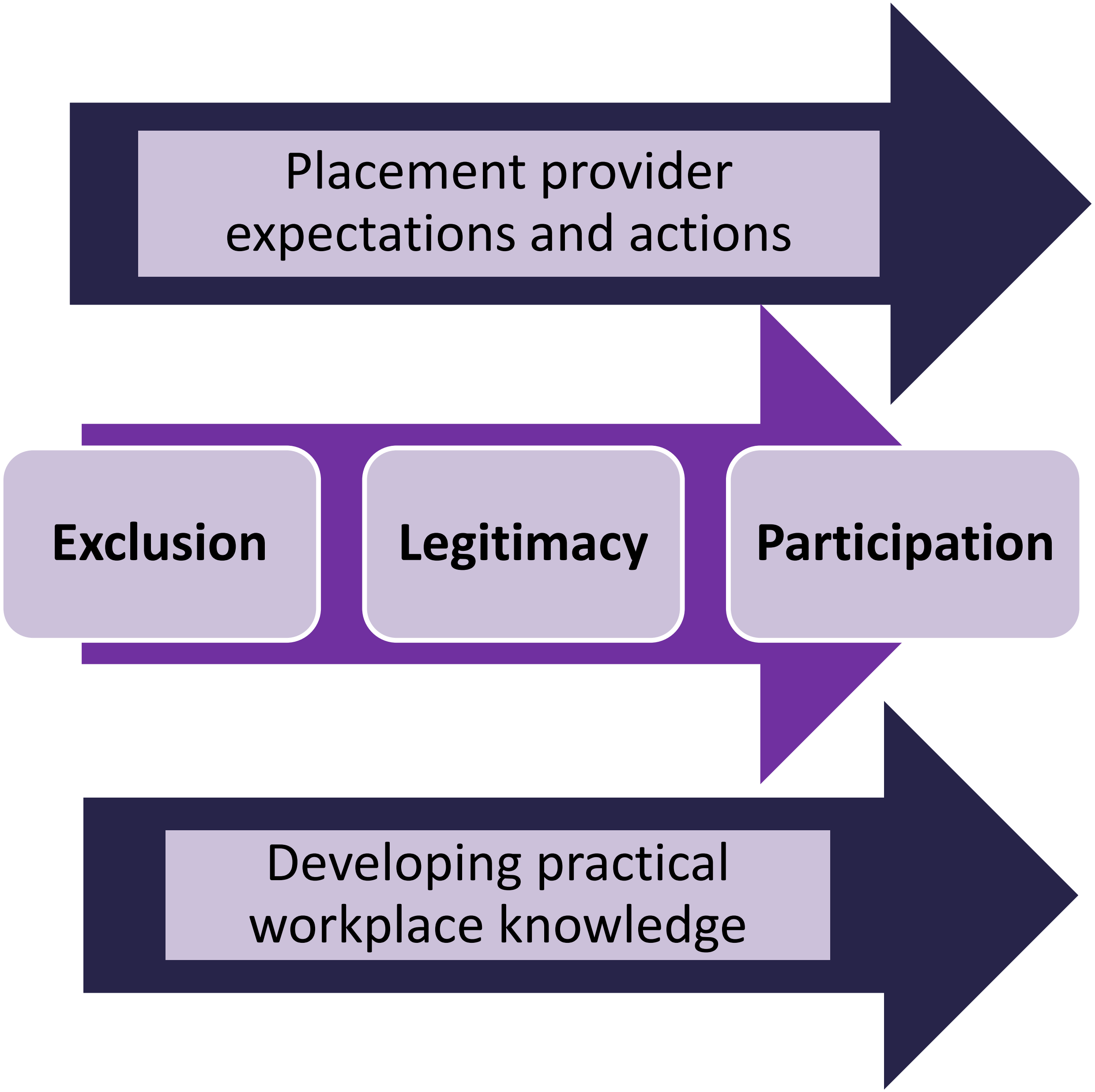
Lay perspective

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.’ (M1I10)



Placement provider expectations and actions

Exclusion

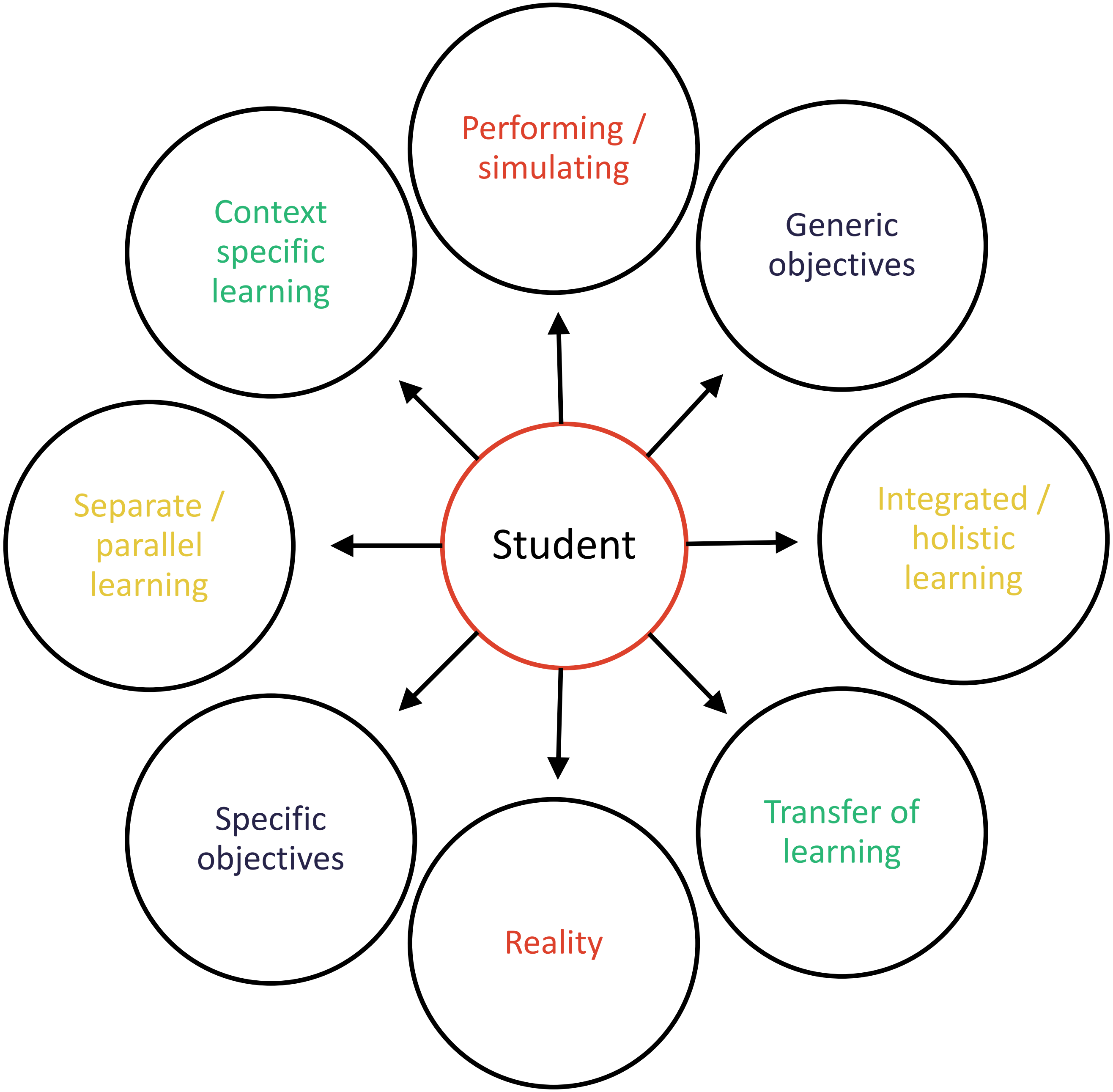
Legitimacy

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)

Spectra of educational variables: Learning opportunities



Student

Performing / simulating

Generic objectives

Integrated / holistic learning

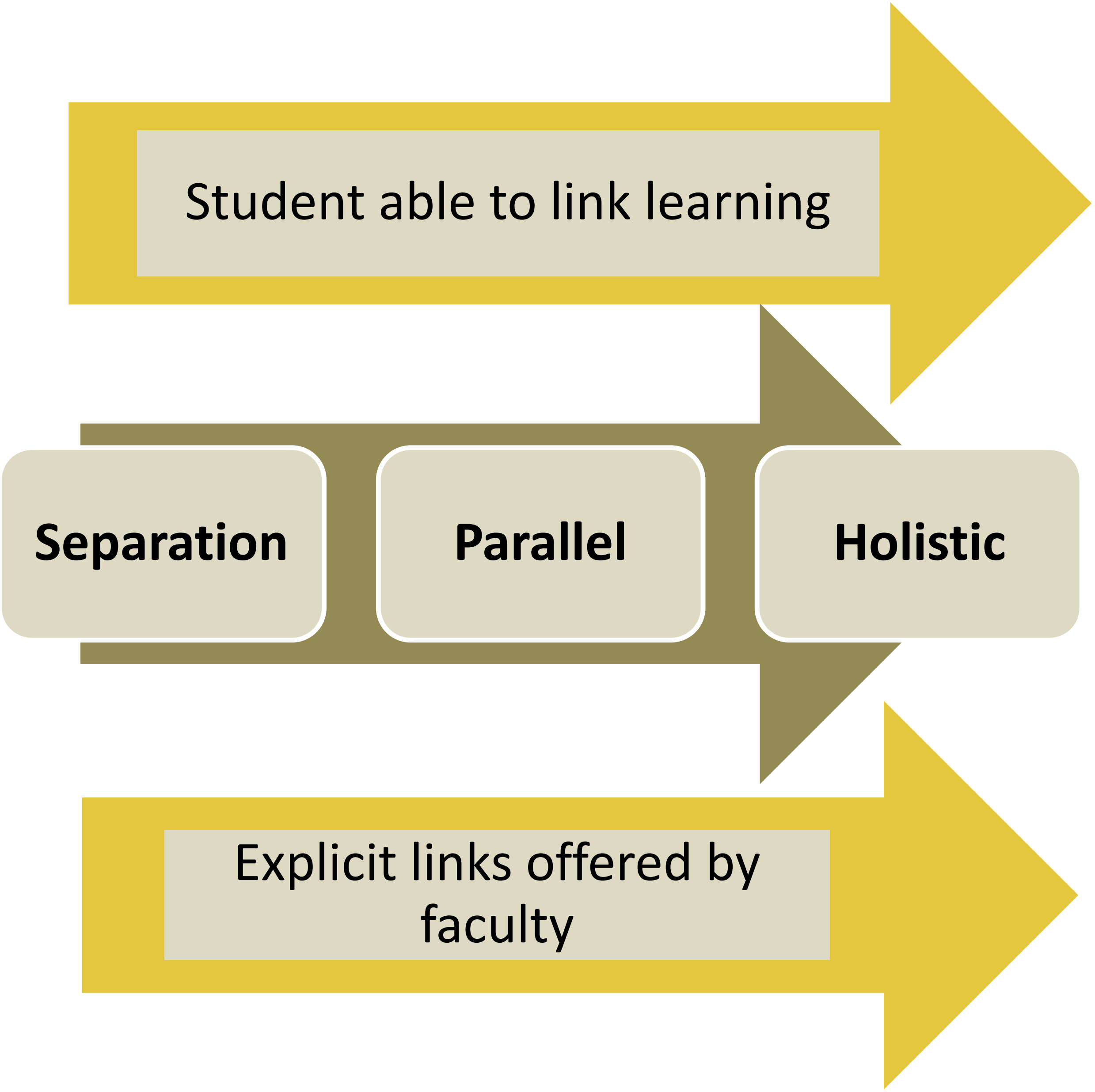
Transfer of learning

Reality

Specific objectives

Separate / parallel learning

Context specific learning



Student able to link learning

Separation

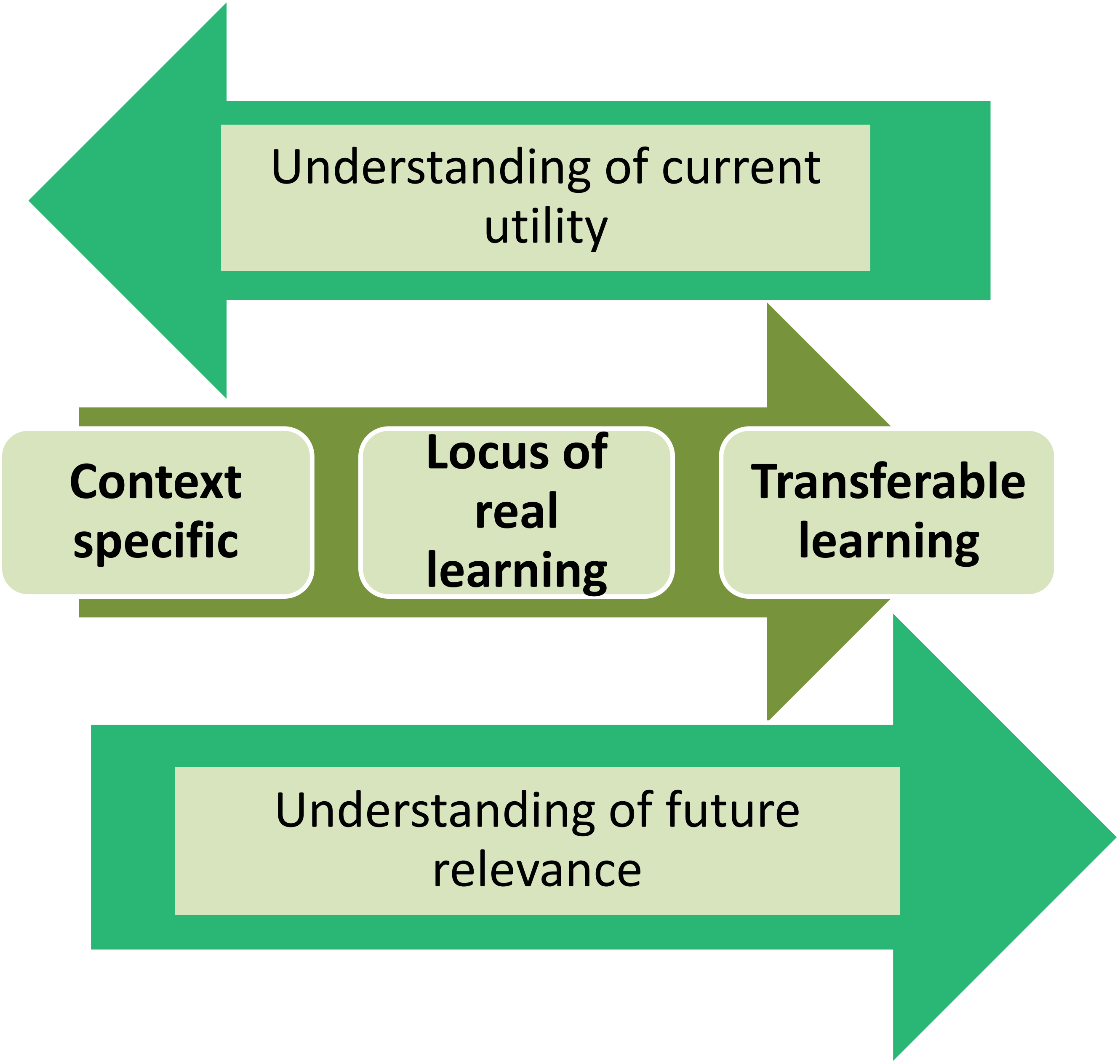
Parallel

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

	Predicted consequences	Unpredicted consequences
Intended consequences	Intended learning outcomes	‘Soft’ outcomes
Unintended consequences	Expected negatives	Unknowns (use spectra to investigate)

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

original article

Minding the gap between communication skills simulation and authentic experience

Sarah Yardley,[1] Alison Irvine[2] & Janet Lefroy[2]

CONTEXT Concurrent exposure to simulated and authentic experiences during undergrad- … single UK medical school with an integrated curriculum.

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)

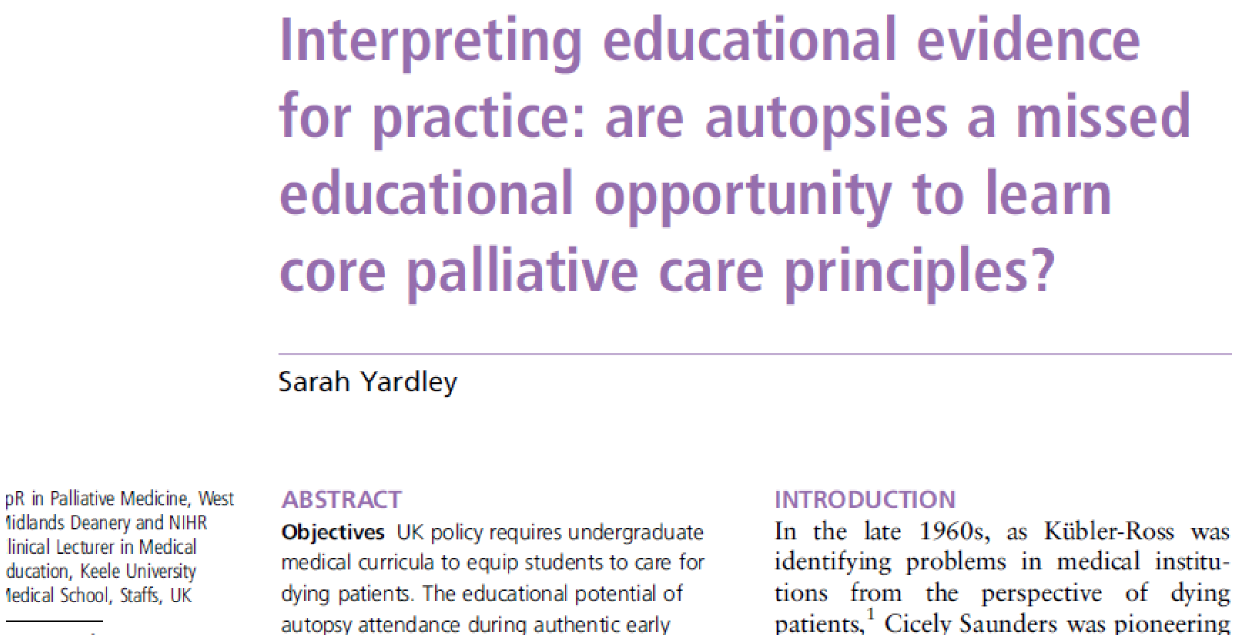
Responsibility

'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’ (M2I9)



Interpreting educational evidence for practice: are autopsies a missed educational opportunity to learn core palliative care principles?

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linical Lecturer in Medical
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ıedical School, Staffs, UK

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,[1] Cicely Saunders was pioneering

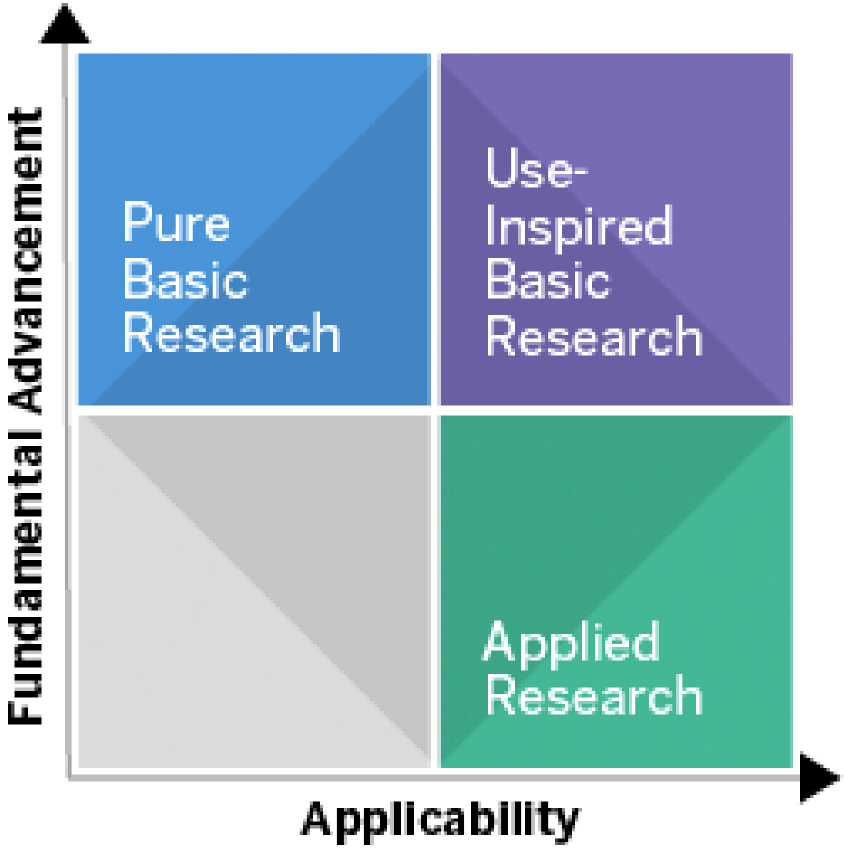
'You're used to... seeing a dead person...but you're not used to seeing a fresh dead person,– I know it sounds terrible to say but I mean these people have died, say, the night before and ... she's just been opened up and he just scooped everything out and slapped it on the bench... this was someone 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



Stokes, Donald E. (1997). Pasteur's Quadrant – Basic Science and Technological Innovation. Brookings Institution Press. p. 196. ISBN 9780815781776.

Whole task learning theory

- ‘Real world’ problems
- Linked components of complex tasks including communication skills, practical support and clinical knowledge

Education for Primary Care (2013) **24**: 436–43

Designing whole-task learning opportunities for integrated end-of-life care: a practitioner-derived enquiry

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Academic Clinical Lecturer in Medical Education

Claire Hookey MBBS MSc MRCP
Consultant in Palliative Medicine and Medical School Tutor

Janet Lefroy MBBS, FRCGP, DCH, DRCOG, MMedEd
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Primary Care and Health Sciences, Keele University

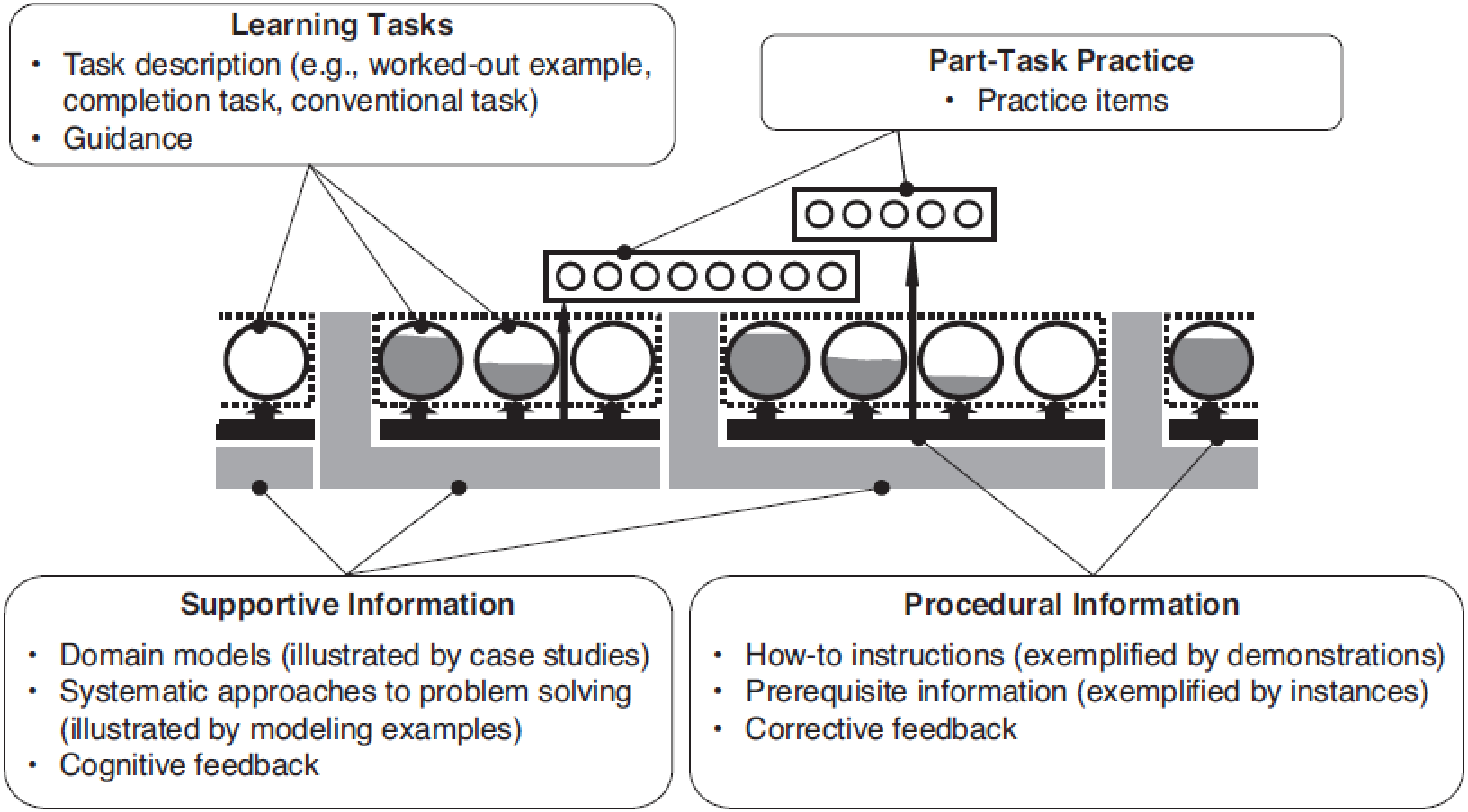
WHAT IS ALREADY KNOWN IN THIS AREA
- An aging population who are living longer with chronic diseases and greater morbidities places increasing emphasis on the need for good medical practice to support patients who are ‘living with dying’.
- Newly qualified doctors feel unprepared to care for patients at the end-of-life, and lack understanding of end-of-life care outside of hospitals.
- The reality of practice places doctors in busy complex environments where they must integrate learning and multitask to provide individualised patient-centred care.

WHAT THIS WORK ADDS
- Whole-task theories can be applied to develop strategies for integrating learning in complex areas of practice such as end-of-life care.
- Final year medical students are keen to engage in opportunities to develop high-quality approaches to end-of-life care when they can perceive relevance and utility within foundation posts.
- Role modelling and exposure to patient experiences are perceived as crucial mechanisms for learning end-of-life care. Despite this only a few students explicitly reflected on the actual death of their patient so it may remain a taboo subject.

SUGGESTIONS FOR FUTURE RESEARCH
- Investigation of longer-term impact (e.g. after commencing foundation training) arising from experiential learning with study day support in the final year of medical school.
- Investigation of ‘what really happens’ when students meet with professionals and patients engaged in end-of-life care processes, e.g. how and why do they interact in certain ways.
- Development of understanding with respect to reluctance to ‘name death’ and refining of learning opportunities to address this appropriately.

Keywords: education, end-of-life care, medical, primary healthcare, undergraduate

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

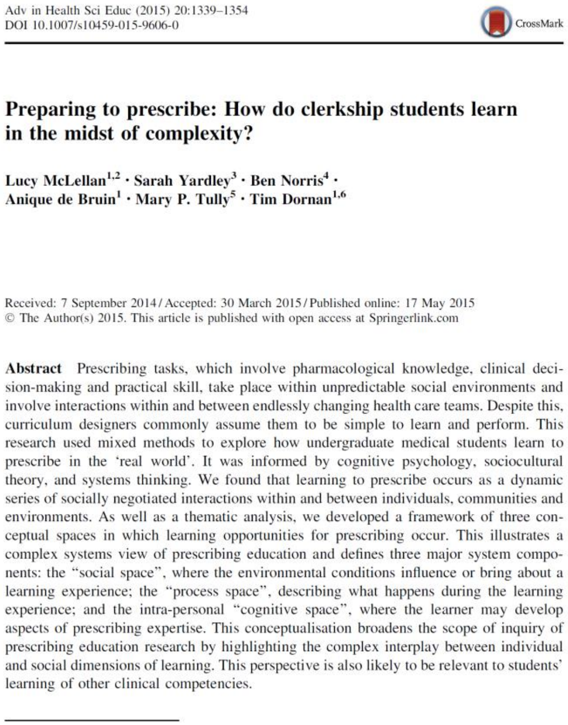
- Transitions
- Competencies FY1
- Diagnosis of dying
- Care of the dying

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



Adv in Health Sci Educ (2015) 20:1339–1354
DOI 10.1007/s10459-015-9606-0

CrossMark

Preparing to prescribe: How do clerkship students learn in the midst of complexity?

Lucy McLellan[1,2] · Sarah Yardley[3] · Ben Norris[4] · Anique de Bruin[1] · Mary P. Tully[5] · Tim Dornan[1,6]

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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 health care 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.

Original Article

PALLIATIVE MEDICINE

Palliative Medicine
1–9
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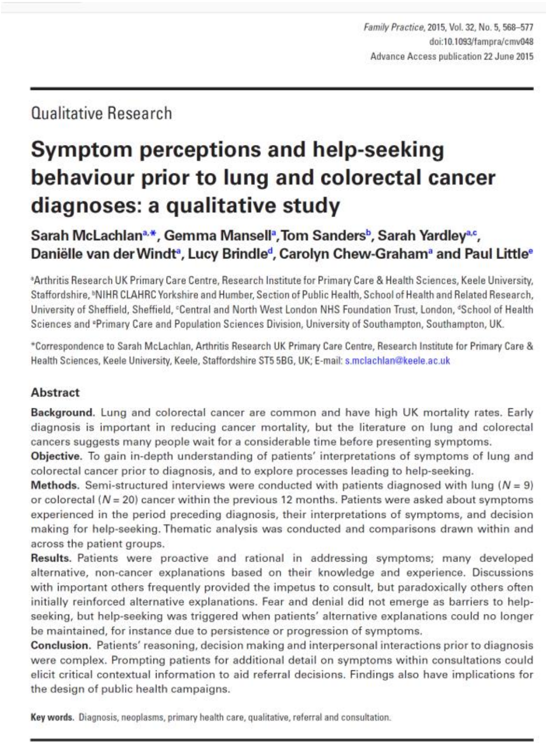
Hospital doctors' understanding of use and withdrawal of the Liverpool Care Pathway: A qualitative study of practice-based experiences during times of change

Sharon Twigger[1,2] and Sarah J Yardley[3,4,5]

Abstract

Background: The Liverpool Care Pathway was used in UK hospitals (late 1990s to July 2014) in an attempt to generate hospice-style high-quality end-of-life care in acute settings. Despite being widely established, there was limited research or contextual evidence regarding this approach or its impact. Growing criticism from the public, media, politicians and healthcare professionals culminated with a critical independent review (July 2013) and subsequent withdrawal of the Liverpool Care Pathway.
Aim: This research explores experiences of doctors using the Liverpool Care Pathway, prior to and during its withdrawal, to better understand shortfallings and inform future initiatives in hospital end-of-life care.
Design: Individual semi-structured audio-recorded interviews were transcribed verbatim and concurrently analysed using thematic analysis.
Setting/participants: Following ethical approval, volunteer participants from an acute UK hospital were sought ($n = 73$). A total of 18 specialist doctors were purposively selected.
Results: Seven themes shaped doctors' experiences of using the Liverpool Care Pathway: (1) changing perceptions according to length of clinical practice, (2) individual interpretation and application of the Liverpool Care Pathway, (3) limitations arising from setting, speciality and basic end-of-life care competence, (4) understanding and acceptance of medical uncertainty at the end-of-life, (5) centrality of communication and fear of discussing dying, (6) external challenges, including a culture to cure, role modelling and the media and (7) desire for reassurance in end-of-life care decisions.
Conclusion: Future initiatives in hospital end-of-life care must address doctors' fears, (in)abilty to tolerate medical uncertainty, communication skills and understanding of the dying phase, in order to provide optimum care in the last days of life.



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Qualitative Research

Symptom perceptions and help-seeking behaviour prior to lung and colorectal cancer diagnoses: a qualitative study

Sarah McLachlan[a,*], Gemma Mansell[a], Tom Sanders[b], Sarah Yardley[a,c], Daniëlle van der Windt[a], Lucy Brindle[d], Carolyn Chew-Graham[a] and Paul Little[e]

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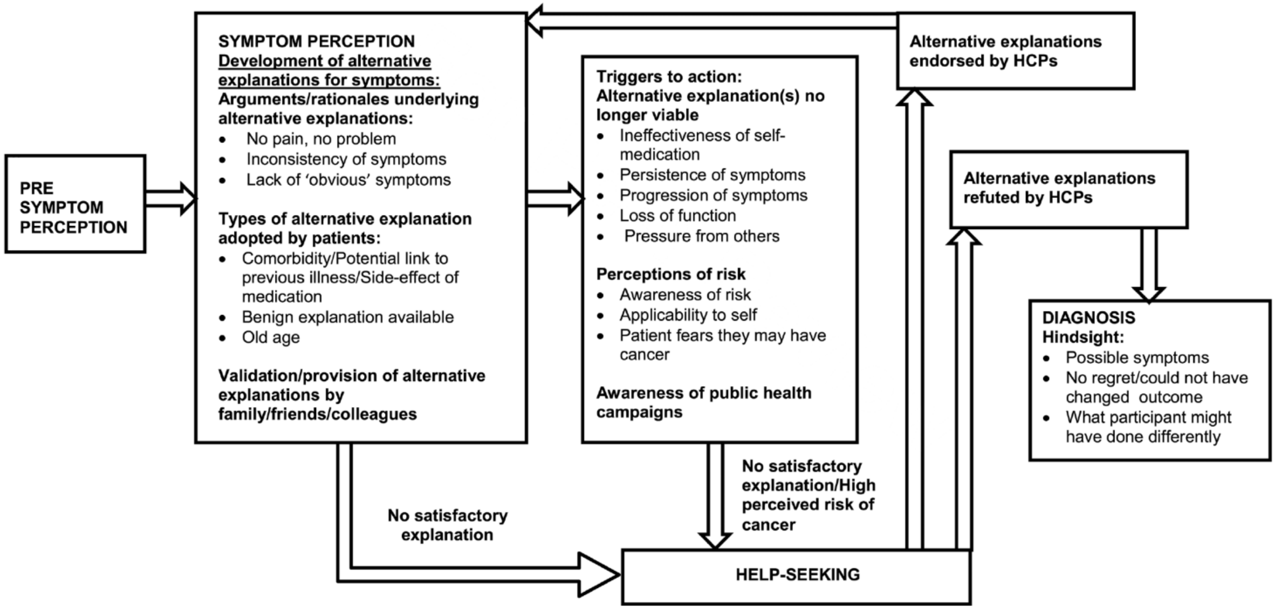
Abstract

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 cancers suggests many people wait for a considerable time before presenting symptoms.
Objective. To gain 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 ($N = 9$) or colorectal ($N = 20$) 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.
Conclusion. 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.

Key words. Diagnosis, neoplasms, primary health care, qualitative, referral and consultation.

570 *Family Practice*, 2015, Vol. 32, No. 5



PRE SYMPTOM PERCEPTION

SYMPTOM PERCEPTION
Development of alternative explanations for symptoms:
Arguments/rationales underlying alternative explanations:
- No pain, no problem
- Inconsistency of symptoms
- Lack of 'obvious' symptoms

Types of alternative explanation adopted by patients:
- Comorbidity/Potential link to previous illness/Side-effect of medication
- Benign explanation available
- Old age

Validation/provision of alternative explanations by family/friends/colleagues

Triggers to action:
Alternative explanation(s) no longer viable
- Ineffectiveness of self-medication
- Persistence of symptoms
- Progression of symptoms
- Loss of function
- Pressure from others

Perceptions of risk
- Awareness of risk
- Applicability to self
- Patient fears they may have cancer

Awareness of public health campaigns

No satisfactory explanation

No satisfactory explanation/High perceived risk of cancer

HELP-SEEKING

Alternative explanations endorsed by HCPs

Alternative explanations refuted by HCPs

DIAGNOSIS
Hindsight:
- Possible symptoms
- No regret/could not have changed outcome
- What participant might have done differently

Figure 1. Model of symptom perceptions and help-seeking behaviour prior to cancer diagnoses, based on data from 29 patients with lung or colorectal cancer

Yardley *et al. BMC Family Practice* (2015) 16:23
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BMC
Family Practice

RESEARCH ARTICLE **Open Access**

Modelling successful primary care for multimorbidity: a realist synthesis of successes and failures in concurrent learning and healthcare delivery

Sarah Yardley*, Elizabeth Cottrell, Eliot Rees and Joanne Protheroe

Abstract

Background: People are increasingly living for 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, for patients with multimorbidity in primary care?'

Methods: This realist synthesis is reported using RAMESES standards. Relationshi
learning and care was the primary outcome of interest. Healthcare, social science
sought as evidence. Data extraction focused on context, mechanism and outcom
on data which might assist understanding and explain; i) these configurations; ii)
iii) their role and place in evolving programme theories arising from data synthes
meetings were used to aid interpretative analysis.

Results: The final synthesis included 141 papers of which 34 contained models fo
and/or patient care. Models of experiential learning for practitioners and for patie
frequently referencing theories of transformation and socio-cultural processes as
Key issues included the perceived impossibility of reconciling personalised conce
clinical markers or adherence to guidelines, and the need for greater recognition
GPs and trainees including the complexities of shared responsibilities. A model fo
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 int
medical workforce equipped to provide multimorbidity care.

Trial registration: PROSPERO International prospective register of systematic revi

Keywords: General practice, Health service delivery, Medical education, Multimor
Socio-cultural theories

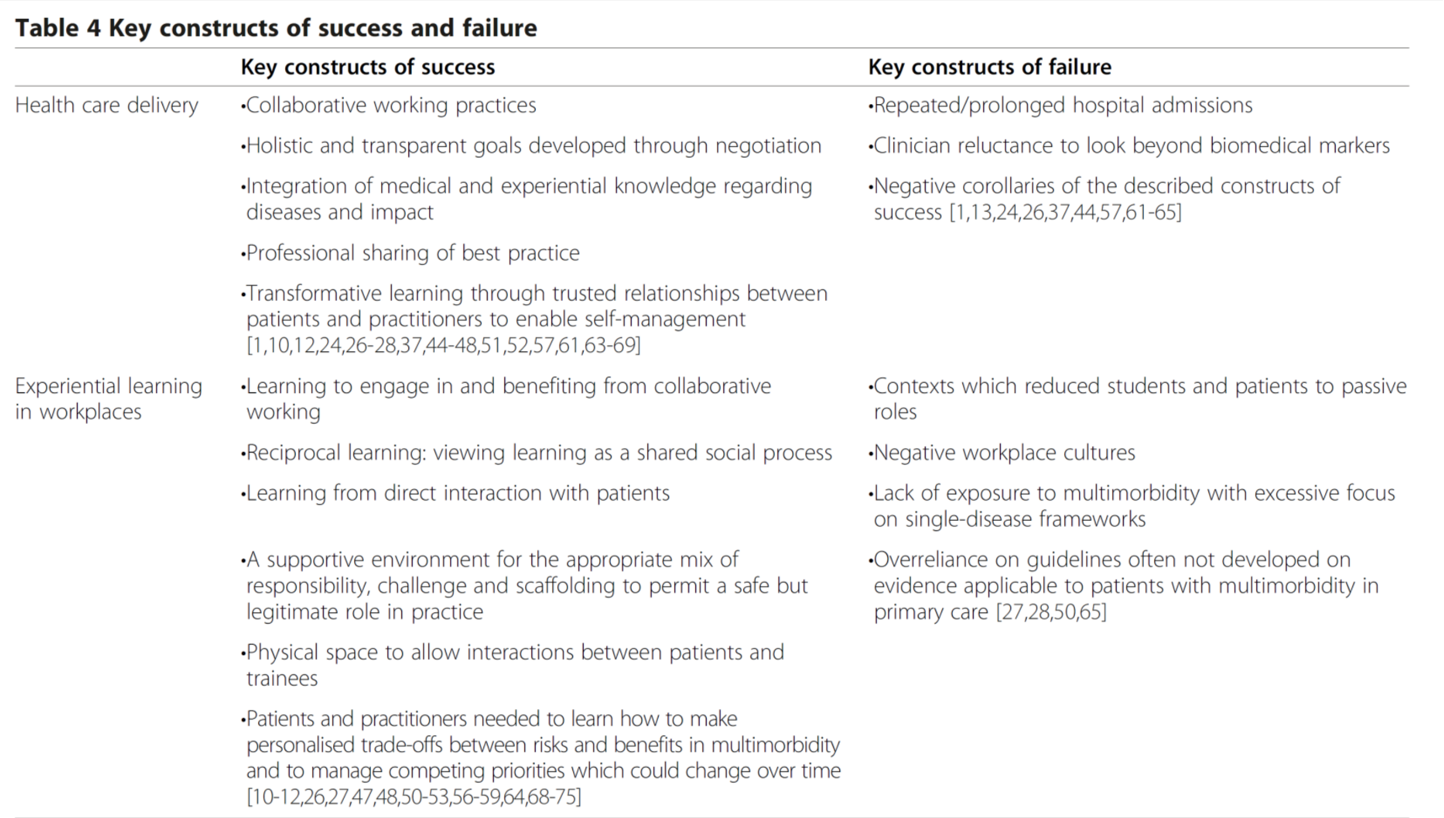
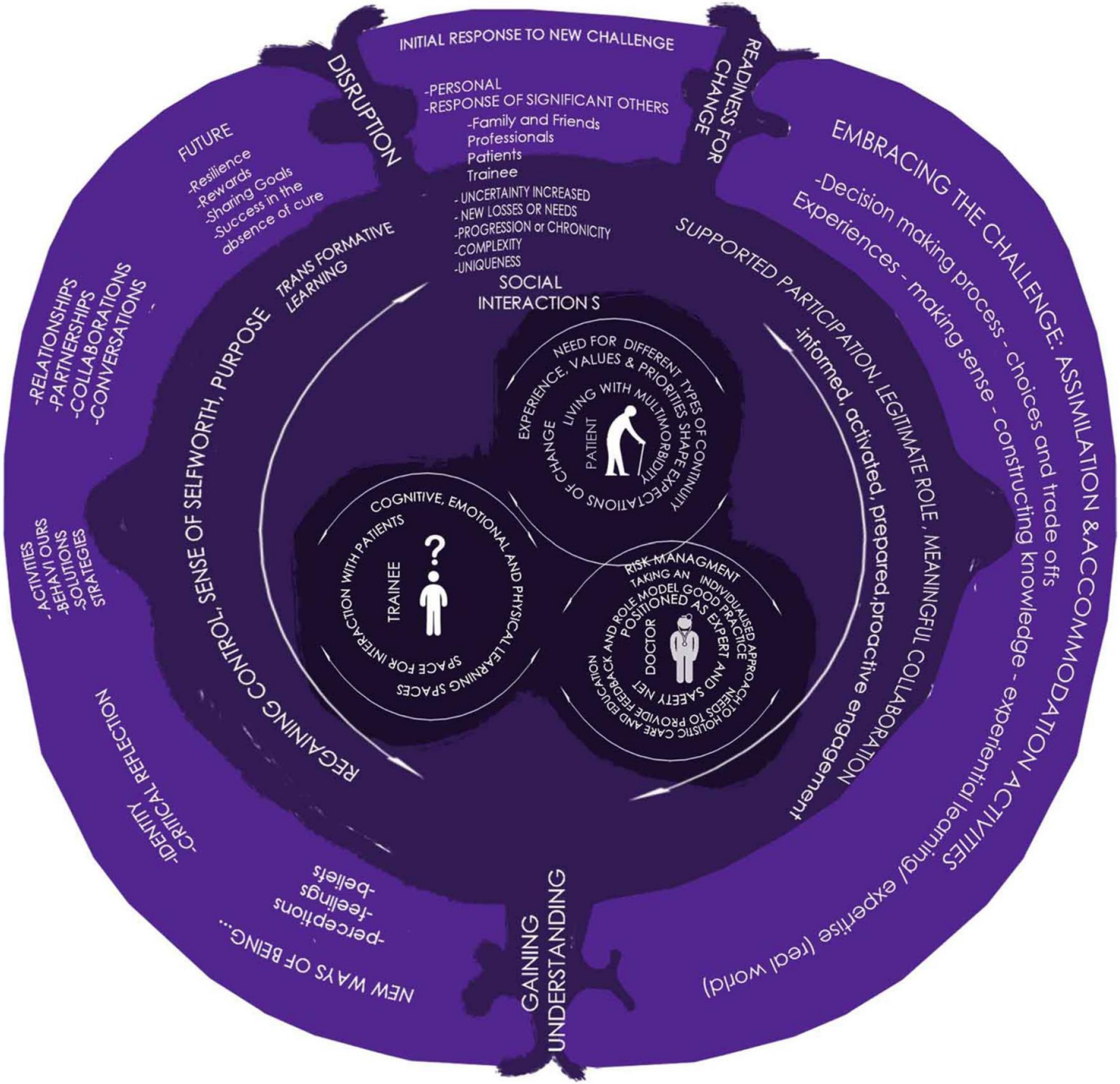


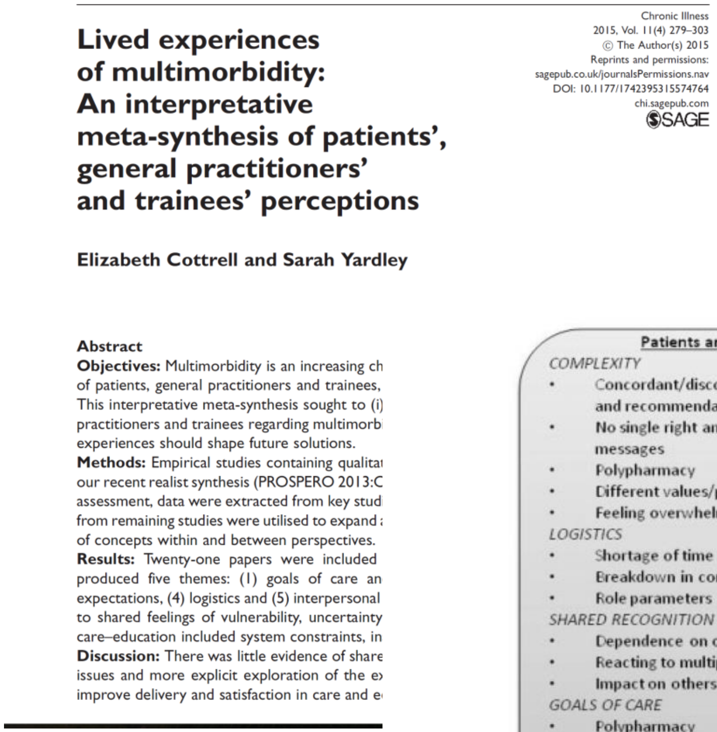
Table 4 Key constructs of success and failure

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


INITIAL RESPONSE TO NEW CHALLENGE
-PERSONAL
-RESPONSE OF SIGNIFICANT OTHERS
-Family and Friends
Professionals
Patients
Trainee
- UNCERTAINTY INCREASED
- NEW LOSSES OR NEEDS
-PROGRESSION or CHRONICITY
-COMPLEXITY
-UNIQUENESS
DISRUPTION
READINESS FOR CHANGE
EMBRACING THE CHALLENGE: ASSIMILATION &ACCOMMODATION ACTIVITIES
-Decision making process - choices and trade offs
Experiences - making sense - constructing knowledge - experiential learning/ expertise (real world)
SUPPORTED PARTICIPATION, LEGITIMATE ROLE, MEANINGFUL COLLABORATION
-informed, activated, prepared,proactive engagement
FUTURE
-Resilience
-Rewards
-Sharing Goals
-Success in the absence of cure
TRANS FORMATIVE LEARNING
REGAINING CONTROL, SENSE OF SELFWORTH, PURPOSE
-RELATIONSHIPS
-PARTNERSHIPS
-COLLABORATIONS
-CONVERSATIONS
- ACTIVITIES
-BEHAVIOURS
-SOLUTIONS
-STRATEGIES
-IDENTITY
-CRITICAL REFLECTION
NEW WAYS OF BEING...
-perceptions
-feelings
-beliefs
GAINING UNDERSTANDING
SOCIAL INTERACTION S
NEED FOR DIFFERENT TYPES OF CONTINUITY
EXPERIENCE, VALUES & PRIORITIES SHAPE EXPECTATIONS OF CHANGE
LIVING WITH MULTIMORBIDITY
PATIENT
COGNITIVE, EMOTIONAL AND PHYSICAL LEARNING SPACES
SPACE FOR INTERACTION WITH PATIENTS
TRAINEE
?
RISK MANAGMENT
TAKING AN INDIVIDUALISED APPROACH TO HOLISTIC CARE AND EDUCATION
ROLE MODEL GOOD PRACTICE
NEEDS TO PROVIDE FEEDBACK AND
POSITIONED AS EXPERT AND SAFETY NET
DOCTOR

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



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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 ch
of patients, general practitioners and trainees,
This interpretative meta-synthesis sought to (i)
practitioners and trainees regarding multimorb
experiences should shape future solutions.
Methods: Empirical studies containing qualita
our recent realist synthesis (PROSPERO 2013:C
assessment, data were extracted from key stud
from remaining studies were utilised to expand
of concepts within and between perspectives.
Results: Twenty-one papers were included
produced five themes: (1) goals of care an
expectations, (4) logistics and (5) interpersonal
to shared feelings of vulnerability, uncertainty
care–education included system constraints, in
Discussion: There was little evidence of share
issues and more explicit exploration of the ex
improve delivery and satisfaction in care and e

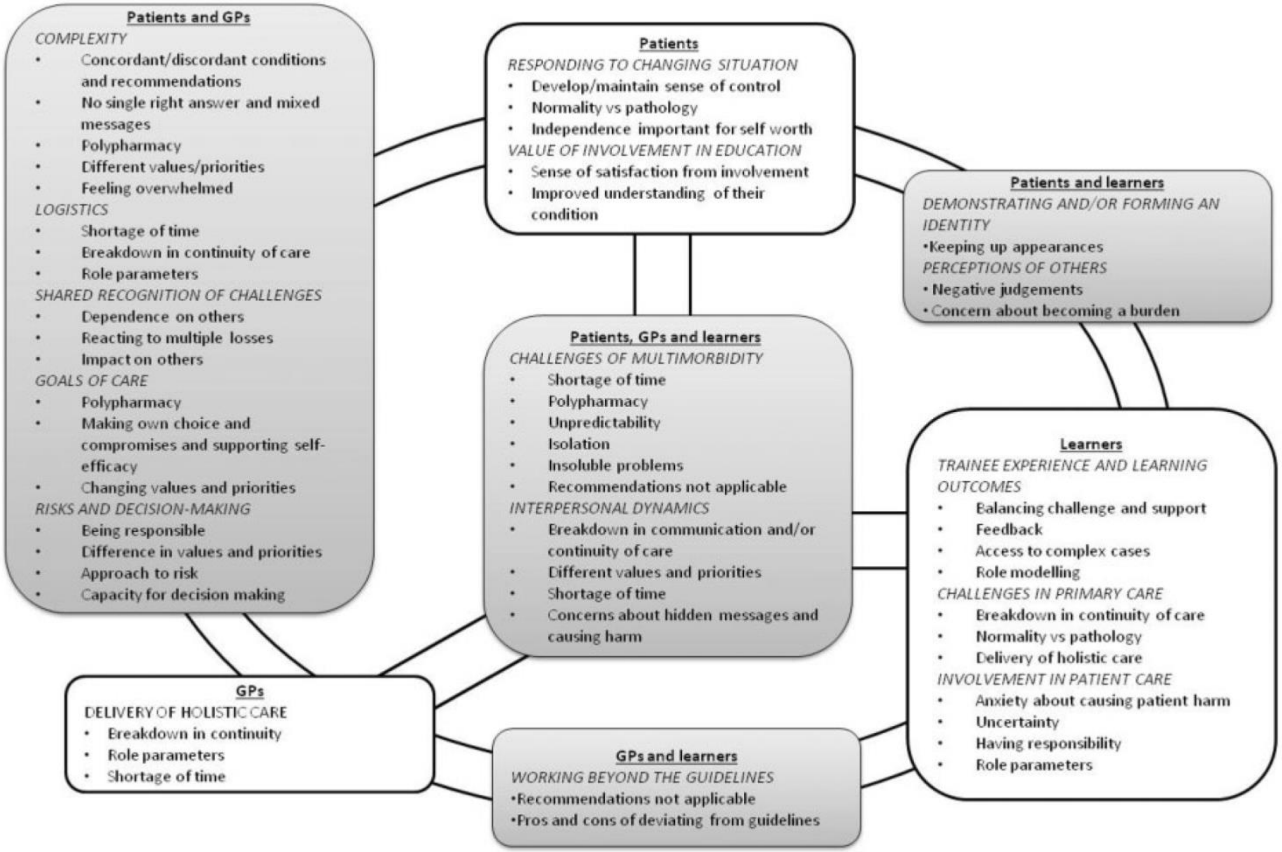

Figure 2. Initial 16 third-order themes (capitals) with summary of associated concepts.

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)."

National Palliative and End of Life Care Partnership
www.endoflifecareambitions.org.uk

06

Each community is prepared to help

The building blocks for achieving our ambition

Compassionate and resilient communities	Public awareness
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.	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.
Practical support	**Volunteers**
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.	To achieve our ambition more should be done locally and nationally to recruit, train, value and connect volunteers into a more integrated effort to help support people, their families and communities.

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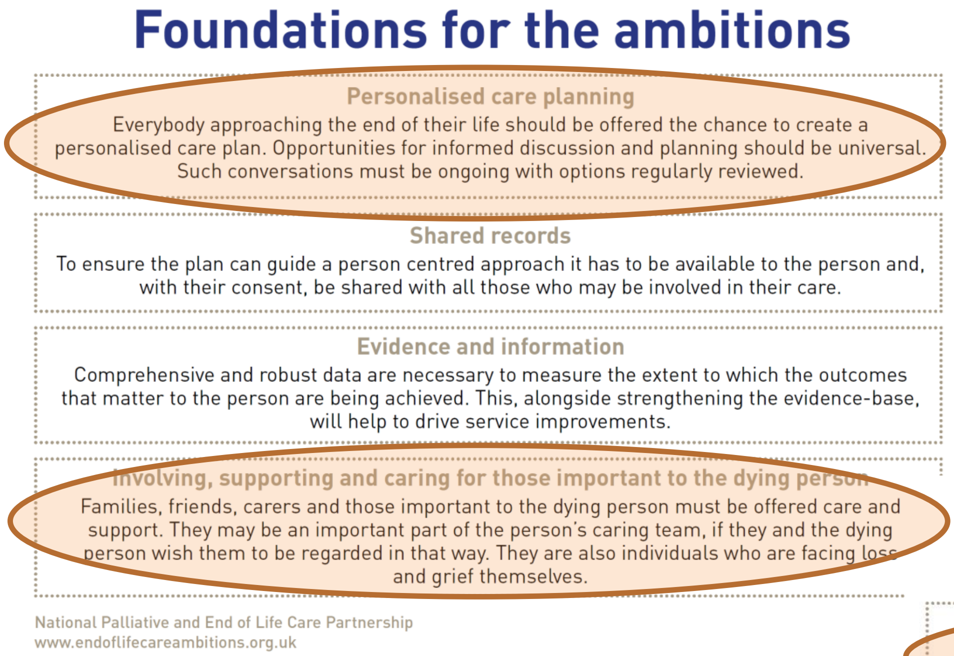

Foundations for the ambitions

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.

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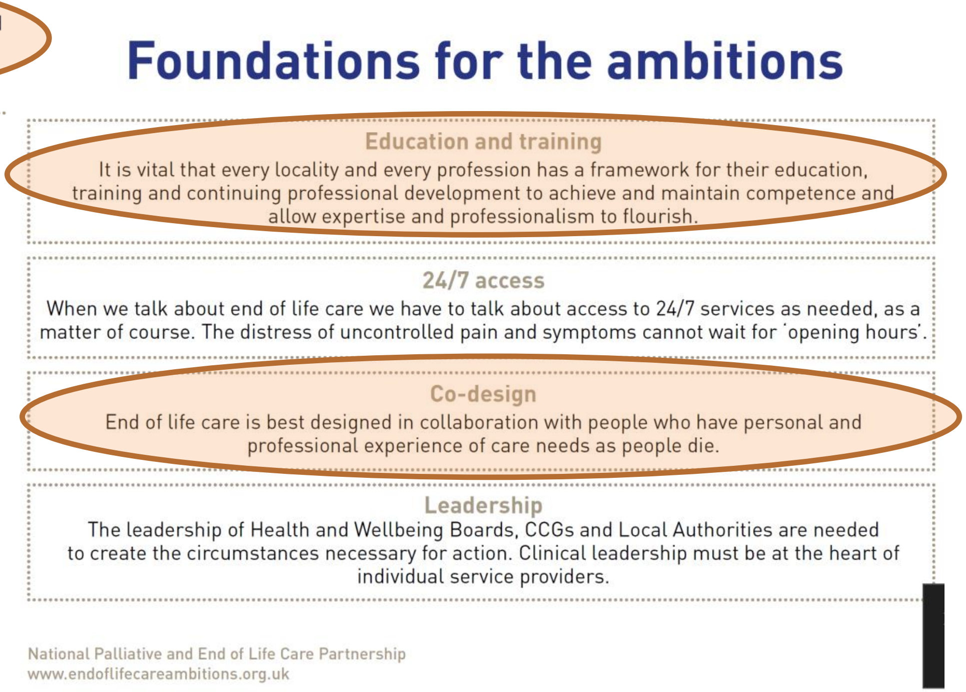

Foundations for the ambitions

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.

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www.endoflifecareambitions.org.uk

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

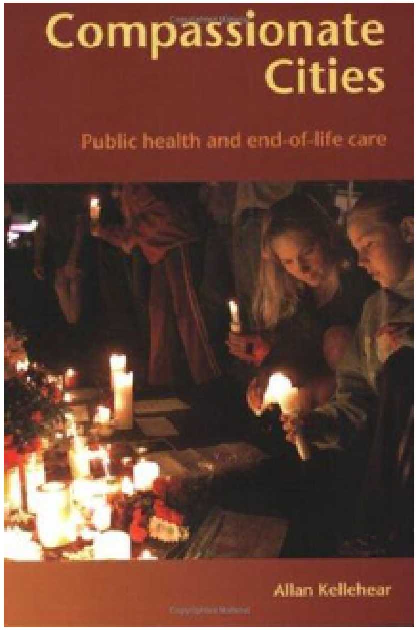
St Joseph's Hospice

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



Compassionate Cities

Public health and end-of-life care

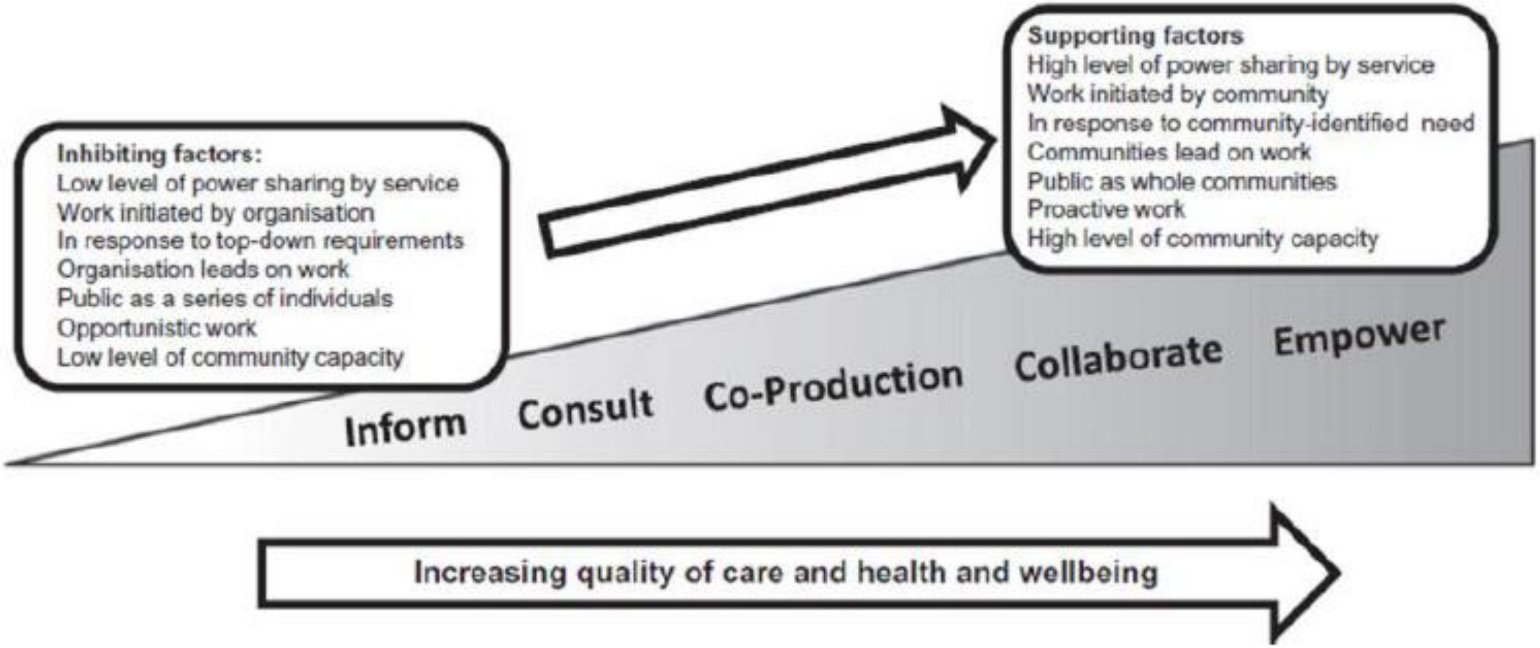
Allan Kellehear

Conceptual clarity

Understanding community engagement in end-of-life care: developing conceptual clarity

Libby Sallnow[a,b]* and Sally Paul[b,c]

Critical Public Health, 2015
Vol. 25, No. 2, 231–238,



Inhibiting factors:
Low level of power sharing by service
Work initiated by organisation
In response to top-down requirements
Organisation leads on work
Public as a series of individuals
Opportunistic work
Low level of community capacity

Supporting factors
High level of power sharing by service
Work initiated by community
In response to community-identified need
Communities lead on work
Public as whole communities
Proactive work
High level of community capacity

Increasing quality of care and health and wellbeing

Review Article

PALLIATIVE MEDICINE

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

Libby Sallnow[1,2], Heather Richardson[3], Scott A Murray[2] and Allan Kellehear[4]

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 PsycINFO) 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.

Conclusion: 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

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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

Poster 21

University of Edinburgh, Edinburgh, UK (L Sallnow MSc, S Murray MD); St Christopher's Hospice, London, UK (H Richardson PhD); and University of Bradford, Bradford, UK (A Kellehear PhD)

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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 peers 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. Ethics 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 compassion 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 passivity 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.

Funding None.

Contributors
All authors conceptualised and designed the study. LS undertook investigation and formal analysis of the data. LS, HR, SM, and AK contributed to data review and interpretation. All authors approved the 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

Rosenberg, J., Horsfall, D., Leonard, R. and Noonan, K. (2015), 'Informal caring networks for people at end of life : building social capital in Australian communities', *Health Sociology Review*, vol 24, no 1 , pp 29 - 37.

Co-production of learning
Need for applied research

UNIVERSITY of York
Centre for Reviews and Dissemination

PROSPERO International prospective register of systematic reviews

The influence of social networks on the function and impact of specialist/generalist interfaces in healthcare: methodology and protocol for a meta-synthesis

Sarah Yardley, Elizabeth Cotterell, Nigel Hart, Rachel Isba, Susan Jamison, Joelle Kirby

Citation
Sarah Yardley, Elizabeth Cotterell, Nigel Hart, Rachel Isba, Susan Jamison, Joelle Kirby. The influence of social networks on the function and impact of specialist/generalist interfaces in healthcare: methodology and protocol for a meta-synthesis. PROSPERO 2017:CRD42017054065 Available from http://www.crd.york.ac.uk/PROSPERO/display_record.asp?ID=CRD42017054065

Review question(s)
1. What is the literature on (triadic) relationships between specialist advisory services, other providers and patients? What is known about the influence of social networks within and across patient-professional boundaries?
2. Do boundary crossing networks/learning opportunities exist for patients and professionals in the context of specialist advisory teams working alongside generalist care providers?
3. Are there examples of (reciprocal) learning in the literature and if so in what context and by what mechanisms does this occur?
4. Are there any examples of interventions using social networks to promote formation of transient teams / boundary crossing practice / boundary crossing learning?

- 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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