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Open communication strategies between a triad of 'experts' facilitates death in usual place of residence: A realist evaluation

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Abstract

Background: In order to meet policy drivers on death in usual place of residence, it is key to understand how shared decision-making can be facilitated in practice. An integrated care pathway was implemented in primary care in the North East of England to facilitate death in usual place of residence.

Aim: To understand how, for whom and in which circumstances death in usual place of residence is facilitated.

Design: A mixed method realist evaluation was employed. Local primary care practice death audit data were analysed to identify outcomes using a mixed effects logistic regression model. Focus groups and interviews with staff of the integrated care pathway and bereaved relatives were analysed to identify the related contexts and mechanisms.

Setting/participants: Death audit data of 4182 patients were readily available from 14 general practitioner practices. Three focus groups were conducted with primary and secondary care staff, voluntary sector organisations and care home representatives. Interviews with bereaved relatives were carried out in participants' homes ($n=5$).

Results: A mixed effects logistic regression model indicated a significant effect of year on death in usual place of residence when compared to a model without year using an analysis of deviance ($p=0.016$). Qualitative analysis suggested that this outcome was achieved when a triad of 'experts' (comprising patient, family members/family carers/formal carers and healthcare professionals) used open communication strategies.

Conclusion: An empirically supported theory of how, for whom and in which circumstances death in usual place of residence happens is provided, which has important implications for both policy and practice.

Keywords

Advance care planning, decision-making (shared), palliative care, end-of-life care, death in usual place of residence

What is already known about the topic?

- Increasing patient engagement in healthcare has become a health policy priority.¹
- National Voices² suggest involving people who are important to the person with palliative needs in their care.
- Practical ways of implementing this in practice are vast, yet variable in use and efficiency; those that target both the healthcare professional and the patient show more promise.³

What this paper adds?

- This paper contributes to significant literature based on the effectiveness of open communication strategies in health-care, specifically in palliative care.
- This paper demonstrates the value of including three 'experts' in palliative care: the patient, the healthcare professional and the main carer.
- A refined programme theory of achieving death in usual place of residence is provided.

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Implications for practice, theory or policy

- In practice, where possible and with patient consent, healthcare practitioners should involve family members and/or the patient's main carer in palliative shared decision-making.
- In order to move care into the community in line with national drivers, we must strengthen the community workforce and also ensure healthcare professionals have the necessary tools and skills in order to engage patients and their families or main carer in open communication strategies.
- Internationally, shared decision-making could move beyond a process that takes place between two experts (patient/professional), to include close family members or main carers where appropriate.

Background

Patient centredness entails focusing on the whole person beyond their healthcare needs,^{4,5} including consideration of their feelings, experience of illness, psychological and social factors.⁴ Shared decision-making has been referred to as the crux of patient centredness,⁶ promoting the right of patients to be involved in decisions concerning their health.^{7,8} It has considerable research and policy support^{1,9,10} and has been described as the meeting of two experts – the patient as an expert in their own life, values and circumstances and the medical expert.^{6,11}

Involving patients in care decisions makes a potentially significant and lasting difference to health outcomes;^{12,13} the Five Year Forward View¹⁴ provides clear direction for improvement of the UK health service and stresses the importance of patients having greater control. Despite this, the literature indicates that quality shared decision-making occurs only about 10% of the time,^{6,15} adoption in practice has been slow⁹ and there is a lack of evidence about how to successfully implement shared decision-making.¹⁶

Shared decision-making is essential in palliative care in order to elicit preferences about care, including place of care; however, recent research indicates mixed implementation,^{17–19} which may be due to particular difficulty of using shared decision-making in integrated care sites such as palliative care, where decisions need to be negotiated between, and shared with, multiple health and social care practitioners, employed carers, patients and their family carers.²⁰

It is important that patient preferences are discussed in advance of end-of-life care, before lack of capacity sets in, to avoid unwanted, futile, aggressive and costly medical treatment, avoid the cessation of treatment when continuation is preferred and to ensure that preferred place of care or death is clear to all.^{21,22} In 2010, 60% of adults stated that they would prefer to die at home, making home the most preferred place of death; hospital was the least preferred place of death across all government office regions.²³ Despite this evidence,^{23–25} Public Health England²⁶ indicates that only 45.7% people died in their usual place of residence in 2015–2016. This points to a mismatch between desired and actual outcome, which could arise

from a multiplicity of causes including complex symptoms, lack of support or fear of death. Death in usual place of residence has been highlighted as an important proxy marker for quality²⁷ and is reported in the most recent Public Health England statistics;²⁸ death in usual place of residence forms the outcome of interest in this study.

The integrated care pathway evaluated in this study has been described in detail elsewhere,²⁹ but in brief, it was implemented in 2009 and was based in one locality in primary care covering 14 general practitioner (GP) practices.²⁹ The aim of the integrated care pathway was to meet palliative patients' preferences by engaging in shared decision-making and advance care planning, including preferred place of death. In order to do this, the integrated care pathway used several 'tools', such as palliative registers, traffic light systems of wellness and advance care planning, including preference discussions. Advance care planning includes advance statements: Do Not Attempt Cardiopulmonary Resuscitation form; Emergency Health Care Plan and the Lasting Power of Attorney for Health and Welfare. All the component parts of advance care planning can be considered as open communication strategies that promote discussions about care with patients, such as what care they would like to receive and where they would like to be cared for. Discussions should be open and aim to ensure that patients and their family members are involved in, understand and accept their palliative care plan.

This article addresses whether, how and under which circumstances the integrated care pathway was successful in eliciting and adhering to patients' preferences.

Methods

Realist evaluation

The integrated care pathway is a complex intervention with varying outcomes that could be affected by numerous compounding factors. Realist evaluation is a theory-driven approach which seeks to understand not only whether an intervention works but also what it is about it that works,

for whom, in what circumstances and why.^{30,31} It acknowledges that interventions take place within complex social systems³² and is therefore well suited to studying interventions, such as the integrated care pathway, with complex and potentially multiple pathways from implementation to impact. In a realist approach, the research begins with a programme theory, which is refined using relevant evidence to provide a more precise programme theory, with greater explanatory potential.³³ A realist programme theory details how the programme or intervention is supposed to work and is formulated as a Context–Mechanism–Outcome Configuration (CMOC).^{33,34} Mechanisms are understood as being a combination of the often multiple resources offered by an intervention and the reasoning this enhances in an individual, in a particular context.³⁵ This alters the behaviour of participants, which leads to measurable or observable outcomes. Empirical data are used to test programme theories to identify how the intervention works in practice.³⁵ The initial programme theory (developed through a literature review and familiarisation with the study setting)²⁹ stated, ‘The Integrated Care Pathway can facilitate preferred place of death and prevent emergency admissions (outcome) through identifying patient preferences (context) and using the locality advance care plan (mechanism)’.

Data collection

In keeping with realist evaluation, this theory was ‘tested’ using empirical data. Quantitative data analysis in the form of routinely collected locality death audit data from 14 GP practices (including 4078 patients who died) explored variations in death in usual place of residence in the locality over time 2007–2012. The dependent variable was the rate of ‘home’ deaths, here expressed as a fraction of total deaths for each practice in each year with year itself being the sole independent variable. Variation across practices was accounted for by including practice as a random effect. A mixed effects logistic regression model was used to investigate the hypothesis of whether death in usual place of residence, as measured by the rate of ‘home’ deaths, had changed over time in the locality.

It is acknowledged that the statistical tests performed are at odds with the realist notion of generative causation,³⁶ meaning that outcomes of interest are generated by relevant mechanisms which are triggered by context.³⁷ Yet these analyses demonstrate tangible outcome patterns over time and therefore complement the realist explanatory endeavour.

Qualitative data were collected to explain any variations in outcomes: three focus groups and semi-structured interviews with bereaved relatives and carers. Consent to contact eligible staff to participate in focus groups was obtained through research and development (R&D) approval and letters to relevant organisations. The date and time of the focus group were arranged and emailed to all

the relevant potential participants (GPs, community matrons, social care workers, out-of-hours (OOH) staff, ambulance service, urgent care staff, voluntary organisations and relevant hospices including the locality palliative care unit). Focus group 1 took place in May 2012 ($n=12$; three GPs, two community matrons, two ward staff nurses, one social care team lead, one junior doctor, one palliative care unit project manager, one palliative care unit deputy manager and one team leader for the OOH nursing service). It aimed to understand how the integrated care pathway functioned in practice. Focus group 2 took place in October 2012 ($n=8$; two GPs, one Macmillan nurse, one ward staff nurse, one community matron, one social care team lead, one district nurse and one palliative care unit deputy manager) with a focus on refining Soft Systems Methodology maps of the integrated care pathway created from Focus group 1. Focus group 3 took place in October 2013 ($n=6$; four GPs, one care home manager and one social care team lead) and acted as a final round of refinement for the CMOCs (programme theories) created from Focus group 2. Each focus group was located at a central GP practice in the locality for ease of access, was an hour and a half in length and was audio-recorded.

Population and recruitment

Semi-structured interviews were conducted with bereaved relatives ($n=4$) and palliative care patients ($n=3$). Patients and bereaved relatives were identified by GPs in Practice D (data collection was spread among the 12 practices²⁹). All bereaved relatives were 4 months post bereavement; this was an inclusion criterion of the study. Once a potential participant was identified by a GP, they were discussed with the founder of the integrated care pathway (retired GP with an interest in palliative care) to ensure that they were suitable and psychologically stable to participate in the study. Once confirmed, they were sent a study invitation letter, which they returned to the principal investigator (PI) with contact details if they wished to participate. Palliative care patients were more than 18 years of age, had cancer and non-cancer illnesses and were not excluded due to frailty. All interviews were located at the patient and bereaved relatives’ homes and all participants were given pseudonyms. Participants were provided with contact details of the founder of the integrated care pathway in case of distress and were assured of anonymity and confidentiality throughout the research process. The interviewer was fully prepared to discuss sensitive issues and had attended training on qualitative data collection techniques. Interviews used realist interviewing techniques³⁸ which focus on testing the programme theory and use a teacher–learner approach to interviewing where both parties take an active role in informally refining relevant programme theories. Data analysis was conducted using a realist approach, identifying CMOCs using an iterative approach.

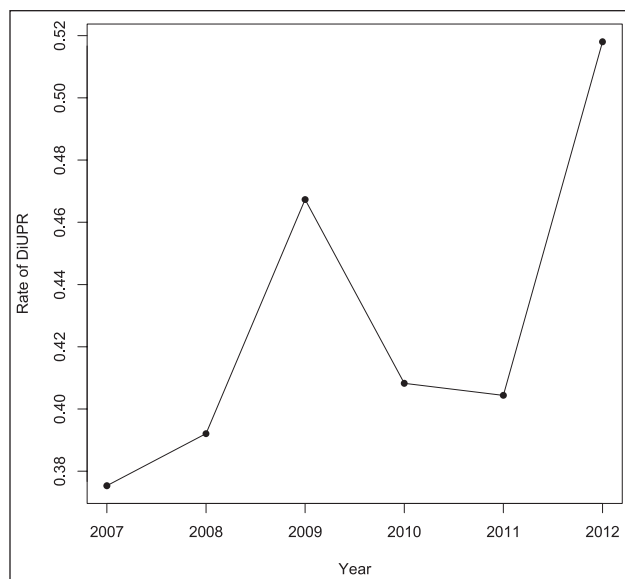


Figure 1. Mean rate of death in usual place of residence in the 14 GP practices with complete data between 2007 and 2012, using death audit data.

The data from both the focus groups and interviews were used to test and refine the programme theory.

Ethical approval

The study was granted full ethical approval from the National Health Service (NHS) Research Ethics Committee (REC) on 13 December 2011. Permission was sought to use GP practice data from 14 GP practices and the manager of R&D at NHS North of Tyne Primary Care Trust (PCT). Written informed consent was obtained from all participants. RAMESES II reporting standards for realist evaluation have been adhered to throughout the article.³⁷

In section 'Results', data used to understand and test the programme theory are presented, which then form a CMOc as part of a refined programme theory. Outcomes are presented first in the Results section as this echoes the analysis procedure.

Results

Outcome: increase in death in usual place of residence

The effect of year was significant when compared to a model without year using an analysis of deviance ($p=0.016$). Inspecting the coefficients for each year showed that the significance was driven by the large increase in the rate during 2012 (the other years were largely similar). During 2012, the odds of death in usual place of residence were 40% greater than in 2007 with a 95% confidence interval indicating that this increase could

range from a 12% increase to a 73% increase (Figure 1). Analyses were carried out using the R 2016 package lme4 (Bates et al., 2015).⁶⁴

Mechanisms: open communication strategies and access to palliative expertise

Open communication strategies. Preference discussions within advance care planning are integral to avoiding emergency admissions and facilitating a home death. A Macmillan nurse (Focus group 1) describes how advance care planning leads patients to have a better understanding about their care and feel more competent in directing it:

So if it's (advance statement) in the house it gives them a chance to sit and read through it as well you know? Often people don't like to look through things when someone's, a professional's there, but if they've got it to look at you can encourage them, and if they've got more questions they can understand more about what's going on. (Macmillan nurse, Focus group 1)

Comprehensive communication strategies were also seen as an anticipatory mechanism that reduces patient and family stress:

It's what we expect to happen, this is what we, this is what we can do, if it's like this, if it's like that, and it takes the pressure off them, you've talked to the families, you've said remember when we talked about the plan, and remember when we said if, and they go, ah yeah, yeah. (GP1, Focus group 2)

Patients' understanding of their illness their preferences and their palliative care is enhanced through open communication strategies with primary care providers to complete advance care planning, potentially leading to less emergency admissions and facilitating home deaths. However, if an emergency admission occurs, this three-way open, honest and comprehensive communication between the GP, patient and carer may break down. Primary care health teams are not significantly involved in hospitalisations, patients are very unwell and families can become emotional, scared and disempowered. Ned and Caroline (bereaved relatives) explained how their elderly mother had gone into hospital after a brain haemorrhage and had remained there for some time having futile investigative tests, against their will:

If you like that's a bit like what they (hospital staff) were doing with (Ned's mother), to say well we know this lady's had a brain haemorrhage, we want to know what's happening, well we know there is something going on in her head that involves blood pressure and, so probably this, but we need to prove, we need to prove what's happening so we can do nothing. (Caroline, bereaved relative)

Caroline and Ned were distressed by their mother's extended hospital stay and tests but felt that they did not

have the experience, knowledge or empowerment to request a discharge:

(You have less experience) than the medics do, and so inevitably you are going to be slightly shocked, and not certain whether there is going to be the possibility of, erm, some form of effective treatment [...] and, it was, it was clear when she came out four days later that no one had done anything, apart from, apart from find out what was happening. [...] Perhaps we weren't strong enough (to take her out of hospital). (Caroline, bereaved relative)

Secondary care is characterised by a dominant curative culture, which can be obstructive of palliative care discussions. In emotionally charged circumstances and with less technical knowledge than medical staff, families rarely feel confident to challenge a consultant's decisions about investigations and request a discharge. Families may not be given the chance to engage in decision-making (as above with Ned and Caroline). This difference in the place of patient centredness between primary and secondary care is paramount. Although shared decision-making is an aspiration in secondary care, it can be more challenging to deliver within a dominant curative culture. This results in difficulty using resources such as open communication strategies, therefore leaving patients and their carers disempowered. GP1 highlights the curative culture of secondary care; the GP did not challenge the consultants when her own father was ill, thus questioning how families with no medical knowledge might find a voice in the same setting:

Well once you're in a technical setting it's very difficult to keep your brain straight. My dad was on ITU for 6 weeks with an open abdomen, that's crackers isn't it? That's crackers. But I lost the plot as well because you're in such a technical setting that you lose the plot. I mean, I look back and I think, he was a corpse, for goodness sake what was anybody thinking, but you're in a high tech setting where everybody's doing things constantly for 6 weeks. You lose the plot, you really lose the plot. So I wish somebody would have given me some, some sort of common sense, but you do lose the plot yeah. I think families do that. (GP1, Focus group 2)

Focus groups with the integrated care pathway staff and interviews with bereaved relatives identified that open communication strategies were an essential mechanism in facilitating a home death.

Access to expertise and responsibility. Qualitative data highlighted that open communication strategies needed to involve a person with significant health expertise and palliative knowledge to effectively facilitate a home death.

Rachel (bereaved relative) was provided with an OOH district nursing service telephone number after she expressed anxieties about caring for her husband at night. This ready access to palliative and end-of-life expertise at all times eased her anxieties:

And that was better because then I knew I could ring them at any time, through the night, because everything's always worse through the night. And it was, you felt, alone, you know, on your own. [...] I didn't need to ring it on the Thursday night but definitely on the Friday night when he was pulling the drip out. (Rachel, bereaved relative)

It was not loneliness that caused Rachel anxiety; she explains that contacting her family did not help as, '... they couldn't diagnose anything or tell us what to do'. Her reasoning changed when she had access to palliative expertise at all times: GP surgery during the day and OOH telephone number. This allowed Rachel to care for her husband at home, thus facilitating a home death.

In care homes, palliative expertise was not always readily available. Qualitative data suggested that often death in usual place of residence was more difficult to achieve in care homes, due to carers' lack of palliative expertise. This was exemplified when a care home staff member explained how he felt it was safer to call an ambulance in case of future questioning about their decision. A GP also reinforced concerns about staff expertise and responsibility:

In some of the patients in care homes the reason it (emergency admission) happens is because of, erm, staffing levels on the weekend, and it can simply come down to that confidence and grade of staff in a nursing home who are not prepared to take responsibility and not paid to ... (GP1, Focus group 2)

Family support was also considered pivotal in allowing care home staff to manage death in a care home, as opposed to calling for an ambulance, often leading to the patient being admitted to hospital:

I mean, it is part of the education we do with them (care home staff), but ... they can be just teenagers and it's a hell of a responsibility isn't it to ring up someone's family and say your patient, you know, your mums deteriorated but we're not doing anything, you know it's very difficult for them ... It's the family that need to be saying to the staff, please do not, you know, we've already discussed this and this is what we want to happen. Your protection is the family. (GP1, Focus group 2)

Fear of litigation and responsibility for death were also commented upon by one of the bereaved relatives, Ned. He referred to recrimination being not only institutional but also public, through the media:

... you've got this terrible fear, you know of, of, I'm gonna get sued or am I going to get in the newspapers you know, somebody died at (care home) that should have gone to hospital and that, also the impulse of the carers to ... To worry ... to care ... Ring an ambulance! (Ned, bereaved relative)

In 2011, local care homes implemented a separate end-of-life care planning form as a requirement of the county

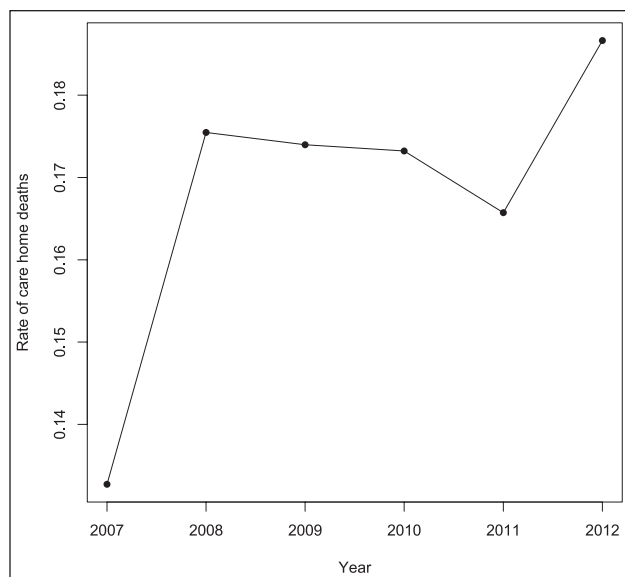


Figure 2. Mean rate of care home deaths in the 12 GP practices with complete data between 2007 and 2012, using death audit data.

council. This was part of the assessment of new residents, under a scheme called ‘Future Wishes’. This care home-initiated end-of-life care planning may be a more effective way of achieving a statement of preferences that are active in the minds of (care home) carers. GP4 (Focus group 3) felt that the use of end-of-life care planning by care home staff may provide them with more ownership of the plan and avoid crises of confidence when medical emergencies occur, as they have a familiar, care home completed plan to refer to:

That’s kind of giving the carers (care home staff) more ownership of this instead of being just medically driven. (GP4, Focus group 3)

Families are a strong source of support for care home workers when a resident is dying. This end-of-life care plan is carried out with family members and thus may provide care home workers with the reassurance of their support and more ownership over the end-of-life process than if it is only discussed with medical staff. This increased sense of ownership may reduce care home staff’s fear of reprimand and also increase their feelings of expertise in the patient’s and family’s wishes, thus reducing emergency admissions. Use of this care planning was introduced in 2011, prior to the increase in death in usual place of residence in 2012. Figure 2 indicates an increase in care home deaths from 2011 to 2012, thus supporting the theory that the newly introduced end-of-life care plan in care homes may have had an impact on death in usual place of residence. However, statistical analysis did not show a significant change between 2007 and 2012 with the overall effect

of year deemed non-significant in an analysis of deviance ($p=0.14$). However, there is less power to detect a change in the care home death data since the numbers involved are necessarily smaller.

Context: triad of ‘experts’. Having informal preference discussions and advance care planning as part of the integrated care pathway encourages discussions about care, making the patient’s preferences explicit not only to themselves but also crucially to those involved in their care. These discussions can take place between a triad of people: healthcare professionals, the family or main carer and the patient. Each member of the triad can be considered as ‘expert’ in their own right, as if one of them is omitted from the decision-making process, death in the usual place of residence becomes less likely. For example, if a patient wishes to die in their own home but family members are not involved in this decision-making process, necessary arrangements cannot be made to avoid emergency hospital admissions. When admission does occur, secondary care is not a favourable context for open communication, as it is not set up to use end-of-life primary care resources (preference discussions and advance care planning).

In summary, preference discussions and advance care planning are integral in the community setting when used with a triad of experts who are aware of and adhere to the patient’s preferences; they can prevent emergency admissions, which can break down a palliative approach.

Discussion

Refined programme theory

The evidence detailed in this article suggests that the initial programme theory can be refined to better reflect how the integrated care pathway facilitates home deaths. When a triad of experts (context) are able to use open communication strategies, such as advance care planning, preference discussions or emergency palliative care access (resources), this leads to expert (informed) carers (reasoning), whether these are family members or care home staff. This leads to increased confidence to care and retain the person in their usual place of residence (reasoning), resulting in an increase in death in usual place of residence (Figure 3).

This mixed method study used GP locality practice data in combination with qualitative data to understand how death in usual place of residence is achieved, through the testing of a realist programme theory. Quantitative data indicated a significant increase in death in usual place of residence over the time of data collection from 2007 to 2012. Qualitative data highlighted the importance of open communication strategies and expertise in palliative care. The integrated care pathway facilitated death in usual place of residence through use of open communication strategies with a triad of ‘experts’, who were informed in

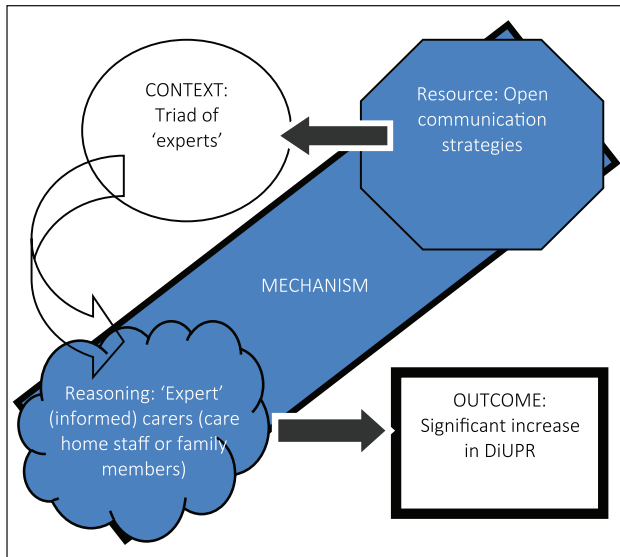


Figure 3. Refined programme theory; open communication strategies used with a triad of experts to increase knowledge of the patient's wishes and increase in death in usual place of residence.

the patient's care. A realist review on engaging older adults in healthcare decision-making identified few studies that considered involvement of patients' family members and friends in shared decision-making.³⁹ However, supporting our findings, shared decision-making has been described in the literature as a series of conversations that patients and their carers should have with several healthcare professionals,^{40–42} although not specifically in palliative care. However, others have highlighted that older people with complex care needs are often reliant on family members and carers to make decisions on their behalf.⁴³ Bunn et al.²⁰ indicate that models such as the triangle of care and patient-centred approaches support involvement of families for both quality and safety and should be routinely involved in shared decision-making for older people with complex health needs, with their agreement.^{44,45} Yet evidence has indicated that although this contribution is accepted, in practice it does not result in routine engagement of family members and carers.^{46,47}

The concept of organisational culture was identified as important within the study, specifically the differences between primary and secondary care. Definitions of organisational culture are wide ranging from simplistic, 'the way we do things around here'⁴⁸ to more detailed 'shared beliefs, norms and routines that a society can be interpreted and understood by'.⁴⁹ Secondary care professionals have reported that discussions about adopting a palliative care approach to patient management were not often held with patients, thus suggesting a curative culture. Primary care professionals confirmed that patients were often discharged from hospital with 'false hope' of cure because

this information had not been conveyed, thus suggesting a dominant curative culture in secondary care.³⁹ Barriers to ensuring a smooth transition to palliative care in secondary care included the difficulty of 'standing back', professional hierarchies that limited the ability of junior medical and nursing staff to input into decisions on care and poor communication,⁵⁰ all of which can be suggested to contribute to the organisational culture of secondary care. Furthermore, it has been found that the diagnosis of dying in secondary care is often made late; this was accredited partly to prognostic uncertainty but also by a curative culture that did not acknowledge death as a possible outcome until it was imminent.⁵¹

A limitation of the study was that the last year of data available for analysis was 2012; datasets of this kind are now unavailable due to locality restrictions. This is nevertheless a large dataset from 12 GP practices over 6 years, and the aim of the integrated care pathway under study is still strived for in today's care; to address patient preferences early in the illness trajectory and facilitate preferred place of death. The integrated care pathway is also still in use in the locality. Thus, the age of the dataset should not detract from the currency of the explanatory proposition drawn from it.

Another limitation of this article pertains to the balance between ensuring transparency of realist analysis process and exposing the findings in a way that is substantiated and engaging. An alternative option would have been to present a set of alternative explanatory theories for the increase in death in usual place of residence and expose the process of disconfirming some, while substantiating others. However, the emphasis of the article would have then been on the process of analysis rather than the findings, somehow distracting from our key message for this particular readership.

The study found open communication strategies to be essential in facilitating a home death. These included shared decision-making in terms of preference discussions and advance care planning, as reported in the literature,^{6,52,53} but also having immediate access to palliative care expertise, whether this be in the form of access to primary care staff or an OOH service. Both family carers and patients take reassurance from knowing that they can receive skilled support quickly if they need help OOH.^{54,55} In the integrated care pathway, as with most practice development efforts, interpersonal relationships between healthcare professionals and patients embody the intervention and have the ability to bring about change.⁵⁶ Accordingly, shared decision-making has been referred to as the crux of patient-centred care^{6,53} and appears throughout the findings of this research. It is known that most patients and their relatives prefer shared decision-making over strict autonomy or healthcare professional-directed decision-making.^{2,57–59} This study provides evidence to suggest that shared decision-making in palliative care is most effective when it consists of a triad of

‘experts’, the patient, healthcare professional and main carer, using open communication strategies. This has been previously alluded to by authors such as Godolphin;⁶ however, our research findings further stress the importance of family members, carers and care home staff. The palliative context complicates reflections on shared decision-making, in that illness progression, capacity and confidentiality are key influencing factors on each expert’s participation.

In the United Kingdom, over 10 years ago, the Department of Health White Paper recognised that additional investment was needed to improve end-of-life care in the community and to facilitate death in usual place of residence.⁶⁰ Subsequently, the 2010 White Paper highlighted the importance of increasing patient engagement in medical decisions.⁶¹ Furthermore, in 2011, death in preferred place of care was highlighted as a quality indicator in the Community Indicators for Quality Improvement.⁶² Yet in 2012, the Royal College of General Practitioners⁶³ found that on average each patient will have three crisis admissions in the final year of life, costing £3200 on average. Using shared decision-making as a triad may help in the prevention of these emergency admissions and meet current policy initiatives for patients to have more control over their care.¹⁴ Thus, in order to facilitate the move of end-of-life care into the community, not only must investment be made to strengthen the community workforce but also in ensuring healthcare professionals have the necessary tools and skills in order to engage patients and their families, carers or care home staff in open communication strategies where appropriate.

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References

1. Durand M, Carpenter L, Dolan H, et al. Do interventions designed to support shared decision-making reduce health inequalities? A systematic review and meta-analysis. *PLoS ONE* 2014; 9: e94670.
2. National Voices. Every moment counts: a narrative for person centred coordinated care for people near the end of life. *The National Council for Palliative Care*, 2014, https://www.nationalvoices.org.uk/sites/default/files/public/publications/every_moment_counts.pdf
3. Légaré F, Stacey D, Turcotte S, et al. Interventions for improving the adoption of shared decision making by healthcare professionals. *Cochrane Database Syst Rev* 2014; 9: CD006732.
4. Wagner E, Bennett S, Austin B, et al. Finding common ground: patient-centeredness and evidence-based chronic illness care. *J Altern Complement Med* 2005; 11(1): S7–S15.
5. Manley K, Hills V and Marriot S. Person-centred care: principle of nursing practice D. *Nurs Stand* 2011; 25(31): 35–37.
6. Godolphin W. Shared decision-making. *Healthc Q* 2009; 12: e186–e190.
7. Straub C, Nebling T and Muller H. Translating research into practice: a German sickness fund supporting patient participation. *Patient Educ Couns* 2008; 73: 544–550.
8. Légaré F, Ratté S, Stacey D, et al. Interventions for improving the adoption of shared decision making by healthcare professionals. *Cochrane Database Syst Rev* 2010; 5: CD006732.
9. Joseph-Williams N, Lloyd A, Edwards A, et al. Implementing shared decision making in the NHS: lessons from the MAGIC programme. *BMJ* 2017; 357: j1744.
10. Coulter A. *Engaging patients in their healthcare: how is the UK doing relative to other countries?* Oxford: Picker Institute Europe, 2006.
11. Tuckett D, Boulton M, Olson C, et al. *Meetings between experts: an approach to sharing ideas in medical consultations*. New York: Routledge, 1985.
12. Stewart M. Studies of health outcomes and patient-centered communication. In: Stewart M, Brown J and Weston W (eds) *Patient-centered medicine: transforming the clinical method*. Thousand Oaks, CA: SAGE, 1995.
13. Elwyn G, Edwards A, Kinnersley P, et al. Shared decision making and the concept of equipoise: the competences of involving patients in healthcare choices. *Br J Gen Pract* 2000; 50: 892–897.
14. NHS. Five year forward view, 2014, <https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>
15. Braddock C, Edwards K, Hasenberg N, et al. Informed decision making in outpatient practice: time to get back to basics. *JAMA* 1999; 282: 2313–2320.
16. Elwyn G, Scholl I, Tietbohl C, et al. ‘Many miles to go ...’: a systematic review of the implementation of patient decision support interventions into routine clinical practice. *BMC Med Inform Decis Mak* 2013; 13(Suppl.2): S14.

17. Evans N, Pasman HRW, Payne SA, et al. Older patients' attitudes towards and experiences of patient-physician end-of-life communication: a secondary analysis of interviews from British, Dutch and Belgian patients. *BMC Palliat Care* 2012; 11: 24.
18. Eneanya N, Goff S, Martinez T, et al. Shared decision-making in end-stage renal disease: a protocol for a multi-center study of a communication intervention to improve end-of-life care for dialysis patients. *BMC Palliat Care* 2015; 14: 30.
19. Belanger E, Rodriguez C and Groleau D. Shared decision-making in palliative care: a systematic mixed studies review using narrative synthesis. *Palliat Med* 2011; 25: 242–261.
20. Bunn F, Goodman C, Manthorpe J, et al. Supporting shared decision-making for older people with multiple health and social care needs: a protocol for a realist synthesis to inform integrated care models. *Health Serv Res* 2017; 7: 2.
21. Detering K, Hancock A, Reade M, et al. The impact of advance care planning on end of life in elderly patients: randomised controlled trial. *BMJ* 2010; 340: c1345.
22. Silveira M, Kim S and Langa K. Advance directives and outcomes of surrogate decision making before death. *N Engl J Med* 2010; 362: 1211–1218.
23. Gomes B, Calanzani N and Higginson I. *Local preferences and place of death in regions within England 2010*. London: Cicely Saunders International, 2011.
24. Hoare S, Morris ZS, Kelly MP, et al. Do patients want to die at home? A systematic review of the UK literature, focused on missing preferences for place of death. *PLoS ONE* 2015; 10(11): e0142723.
25. National Audit Office. *End of life care*. London: National Audit Office, 2008.
26. National End of Life Care Intelligence Network. Data sources; place of death public health England, http://www.endoflifecare-intelligence.org.uk/data_sources/place_of_death (accessed 25 April 2017).
27. National End of Life Care Intelligence Network. Data sources: place of death, 2013, http://www.endoflifecare-intelligence.org.uk/data_sources/place_of_death
28. Public Health England. Number and proportion of deaths by place of occurrence. 2017. http://www.endoflifecare-intelligence.org.uk/data_sources/place_of_death
29. Dalkin S. The realist evaluation of a palliative integrated care pathway in primary care: what works, for whom and in what circumstances? Doctorial Thesis, Northumbria University, Newcastle upon Tyne, UK, 2014.
30. Pawson R and Manzano-Santaella A. A realist diagnostic workshop. *Evaluation* 2012; 18: 176–191.
31. Dalkin SM, Jones D, Lhussier M, et al. Understanding integrated care pathways in palliative care using realist evaluation: a mixed methods study protocol. *BMJ Open* 2012; 2: e001533.
32. Pawson R and Tilley N. *Realistic evaluation*. London: SAGE, 1997.
33. Wong G, Westhorp G, Pawson R, et al. Realist synthesis: RAMESES training materials, 2013, http://www.ramesesproject.org/media/Realist_reviews_training_materials.pdf
34. Greenhalgh G, Pawson P, Wright J, et al. Functionality and feedback: a protocol for a realist synthesis of the collation, interpretation and utilisation of PROMs data to improve patient care. *BMJ Open* 2014; 4: e005601.
35. Dalkin S, Greenhalgh G, Jones D, et al. What's in a mechanism? Development of a key concept in realist evaluation. *Implement Sci* 2015; 10: 49.
36. Pawson R. Evidence-based policy: the promise of 'Realist Synthesis'. *Evaluation* 2002; 8(3): 340–358.
37. Wong G, Westhorp G, Manzano A, et al. RAMESES II reporting standards for realist evaluations. *BMC Med* 2016; 14: 96.
38. Manzano A. The craft of interviewing in realist evaluation. *Evaluation* 2016; 22: 1–19.
39. Elliot J, McNeil H, Ashbourne J, et al. Engaging older adults in health care decision-making: a realist synthesis. *Patient* 2016; 9: 383–393.
40. Politi M and Street R. The importance of communication in collaborative decision making: facilitating shared mind and the management of uncertainty. *J Eval Clin Pract* 2011; 17(4): 579–584.
41. Gagliardi AR, Légaré F, Brouwers MC, et al. Protocol: developing a conceptual framework of patient mediated knowledge translation, systematic review using a realist approach. *Implement Sci* 2011; 6: 25.
42. Shay A and Lafata J. Where is the evidence? A systematic review of shared decision making and patient outcomes. *Med Decis Making* 2015; 9(4): 1–13.
43. Dixon-Woods M, Cavers D, Agarwal S, et al. Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC Med Res Methodol* 2006; 6: 35.
44. Conway J, Johnson B, Edgman-Levitan S, et al. Partnering with patients and families to design a patient- and family-centered health care system. *Institute for Patient and Family Centered Care and Institute for Healthcare Improvement*, 2008, <http://www.ipfcc.org/resources/Roadmap.pdf>
45. Hannan R, Thompson R, Worthington A, et al. *The triangle of care carers included: a guide to best practice for dementia care*. Carers Trust, 2013, <http://www.careinfo.org/wp-content/uploads/2013/02/Hannan-Ruth.pdf>
46. Bunn F, Burn A, Goodman C, et al. Comorbidity and dementia: a mixed-method study on improving health care for people with dementia (CoDem) *Health Serv Deliv Res* 2016; 4: 8.
47. Groot G, Waldron T, Carr T, et al. Development of a program theory for shared decision-making: a realist review protocol. *Syst Rev* 2017; 6: 114.
48. Lundy O and Cowling A. *Strategic human resource management*. London: Elliot and Thompson, 1996.
49. Rafferty A, Philippou J, Fitzpatrick J, et al. *'Culture of care' barometer*. London: King's College London, 2015.
50. Gott M, Ingleton C, Bennett M, et al. Transitions to palliative care in acute hospitals in England: qualitative study. *BMJ* 2011; 342: d1773.
51. Reid C, Gibbins J, Bloor S, et al. Healthcare professionals' perspectives on delivering end-of-life care within acute hospital trusts: a qualitative study. *BMJ Support Palliat Care* 2015; 5: 490–495.
52. Brighton L and Bristowe K. Communication in palliative care: talking about the end of life, before the end of life. *Postgrad Med J* 2016; 92: 466–470.
53. Ferrer R and Gill J. Shared decision making, contextualized. *Ann Fam Med* 2013; 11(4): 303–305.

54. Ellershaw J and Ward C. Care of the dying patient: the last hours or days of life. *BMJ* 2003; 326: 30–34.
55. Eyre S. Supporting informal carers of dying patients: the district nurse's role. *Nurs Stand* 2010; 24(22): 43–48.
56. The Health Foundation. Enabling people to live well, 2013, <http://www.health.org.uk/publication/enabling-people-live-well>
57. Shields CG, Morrow GR, Griggs J, et al. Decision-making role preferences of patients receiving adjuvant cancer treatment: a University of Rochester cancer center community clinical oncology program. *Support Cancer Ther* 2004; 1(2): 119–126.
58. Murray E, Pollack L, White M, et al. Clinical decision-making: patients' preferences and experiences. *Patient Educ Couns* 2007; 65(2): 189–196.
59. Coulter A. Do patients want a choice and does it work? *BMJ* 2010; 341: 973–975.
60. Department of Health. Our health, our care, our say: a new direction for community services, 2006. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/272238/6737.pdf
61. Department of Health. Equity and excellence: liberating the NHS (White Paper), 2010, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213823/dh_117794.pdf
62. Department of Health. Transforming community services. *Demonstrating and measuring achievement: community indicators for quality improvement*, 2011, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215624/dh_126111.pdf
63. Royal College of General Practitioners and Royal College of Nursing. Matters of life and death: helping people to live well until they die, 2012, <https://dementiaroadmap.info/blog/resources/matters-of-life-and-death-helping-people-to-live-well-until-they-die/#.WmBmx9SF7Dc>
64. Bates DM, Maechle M, Bolker B, et al. Fitting Linear Mixed-Effects Models Using lme4. *Journal of Statistical Software* 2015; 67(1), 1–48.