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Consequences of ‘conversations not had’

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Published in:
Journal of Health Services Research & Policy

DOI:
10.1177/1355819619898229

Publication date:
2020

Citation for published version (APA):
Redwood, S., Simmonds, B., Fox, F., Shaw, A., Neubauer, K., Purdy, S., & Baxter, H. (2020). Consequences of ‘conversations not had’: Insights into failures in communication affecting delays in hospital discharge for older people living with frailty. *Journal of Health Services Research & Policy*, *25*(4), 213-219. https://doi.org/10.1177/1355819619898229

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Online Supplement 1

Summary of themes, categories and illustrative interview excerpts

Theme 1: Uncertainty compounded by lack of information	
Categories ***Definition***	**Interview excerpt**
Identifying patients appropriately *Uncertainty around when a patient living with frailty is nearing the end of life*	People are frequently more comfortable at [recognising someone's last days] when they've got something such as a cancer, when someone's got a clear decline in their cancer, they've got a clearer trajectory. (…) But when someone's got complex, frail multi-morbidity, sometimes it's not really recognised until quite late. Participant 13, Consultant in elderly care
Fluctuating conditions *Physical and mental functioning that varies rapidly over time*	I think variability is often quite key. (…) When the difficulty prognosticating undermines everything else and everyone involved, no one's too sure how things are going to pan out, and therefore the decision maker might be relying on other people to have a stab in the dark at what might happen, and sometimes that's not forthcoming and so there's so much uncertainty that a decision can't be taken. Participant 13, Consultant in elderly care
Importance of 'collateral information' *Importance of key facts about a patient's usual functioning and abilities, their social circumstances*	That type of information is really useful for us, because then we know as clinicians how much we need to investigate acutely, what's caused the admission, or whether actually a number of factors are already in the history that clearly show why the patient's ended up in hospital, and then it speeds up the process of investigation and discharging the patient, definitely. That collateral information is vital. Participant 6, ED Consultant
	It's getting the right information to make the right plan. (…) Everybody should be able to get lots of history from patients, but it's probably not done in the right way. There's not time. If AMU [Acute Medical Unit] are turning out 200 patients a day, the doctors aren't going to be able to speak to 200 relatives. Participant 22, Senior Nurse
	We don't have the time to talk to people. They're very quickly through the admissions ward, they hit here [the ward], we're very clinical, we're trying to move things forward (…) We're so acute on this ward that we're dealing with our medications and our IVs [intravenous drugs and infusions] and our PEGs [percutaneous endoscopic gastrostomy, or feeding tube for patients who are unable to swallow] and our tracheostomies and our oxygen, and all that stuff; the rest of it has to come secondary, (…) we have to prioritise what we do, and our patient care comes first and the other bits have to come after. Participant 5, Senior Nurse
	One of the things that always annoys me as a consultant on ward rounds is if the members of the team who I'm with, the nursing team, the junior doctor team, don't know about a patient's social circumstances. I expect my team to know whether the bath is upstairs or downstairs, whether they've got a commode, whether they can manage the stairs, what their

	mental state was before they became unwell, because I think those are very fundamental things to the process of care, and if the other members of the team who spend more time with the patient than I do as consultant don't know that then I think they're not asking the right questions, thinking on the right lines. Participant 23, Consultant in respiratory medicine
	You need to pool that information, combine it with the medical information, co-ordinate that and make sure you've got a safe discharge and you know that would work. My junior doctors do a lot of that but they have to be told to do it, because they don't know, because they are junior, (…) it's not a natural thing for them to do and at the same time they are also doing medical stuff. Participant 7, Consultant in elderly care
	We are trained to look at the numbers, values, parameters and we are trained to look at 'oh that's going up - that's bad and that's going down - that's good', or whatever it is. It is not in our psyche, it is not in our skillset, it is not in our ethos to say Granny Jo didn't wash herself today - it just does not come into our thought process. Participant 11, Consultant physician
	As a profession as a whole, the default setting for medics is to do things and it is going to take a bit of time to work out actually not doing things is equally good. Participant 11, Consultant physician The main thing is that you have the conversations [about end of life] and I think there is a real problem with our health system at the moment that the default is to treat and these conversations are not had. Participant 7, Consultant in elderly care I think that a lot of other [clinicians] working in other specialties seem to pretend that death will not occur. (..) We have a lot of patients who have been looked after for a long time by the oncologists with some cancer that was inevitably going to kill them, and no one had ever had that conversation. I find that really strange. Participant 8, Doctor in training in elderly care
Theme 2: The hospital as an unsuitable place for end-of-life conversations and care	
Pressurised environment *A busy clinical setting where life-sustaining treatment and clinical tasks have to be prioritised*	End of life care is not usually our conversation. (…) Those conversations are quite difficult and I think palliative care are the experts in those. (…) I'm sure we've all been in with somebody who's at the end of life and they've said, "I want to go home" or "I'd like to go to the hospice," but I don't think we've actually sat down like palliative care (…) with a patient talking about where they want to be, what treatment they want, who they want to be there. It sounds awful but we haven't got the time for that. Participant 2, Senior Nurse
	When we have to have [end-of-life conversations], it's often in a very acute environment where there's a lot of emotional stress for the patient, the family, the staff – and we're making decisions with limited information sometimes … I don't think it's always appropriate that we're having to do that.

	Participant 6, ED Consultant There are clearly patients who should not be resuscitated, and it's a difficult discussion to have in the cold light of day, but it should be had and it doesn't. And then actually it's a very poor experience for people when it has to be had in here. And I just think it's not a good experience for the patient. Participant 19, Consultant physician
Consequences of conversations not taking place *Descriptions of situations resulting from end-of-life and advance care planning decisions not being made*	When I first came here (…) we were having 30 cardiac arrests in a month … 28 of them were people who have reached the end of their life. But the reason they [nurses] put the call out is because the sensible decision making around end of life and 'ceiling of treatments' haven't happened. So as far as they were concerned, the nurses on the ward were legally and professionally [obliged to do so]. If the conversation hasn't happened, and the patient has collapsed, they are not breathing, we've got to start resuscitation procedures. Participant 4, Senior nurse
	The junior doctor who (…) sees the eighty five, ninety year old coming in [via the ED], struggling to breathe with a nasty chest infection has only so much time, so the easiest thing to do is to start them on antibiotics, start the oxygen and then they get passed on to MAU where the junior doctor there says okay that looks like a good antibiotic, I'll do the blood culture, I'll do this, that, and then pass the patient on. Because the conversations take a lot longer and if done well, you need to have the time. (…) Typically it's quicker to do things and not have the talk, because everything has to happen quickly, you have got to get people out otherwise you hit the [waiting time] targets. (…) So there are perverse incentives that sometimes stop us doing the right thing. Participant 11, Consultant physician
	We think these [end-of-life and resuscitation conversations] should be happening on an outpatient basis with our outpatient colleagues for patients with chronic illness or with their general practitioners, ideally. (…) I think it would be better had they happened previously when the patient was well, but had obvious multiple chronic conditions that meant that cardiopulmonary resuscitation was not going to be appropriate for that patient. Participant 6, ED Consultant
Record keeping *Documenting conversations and decisions*	(…) I think [healthcare professionals] are not using the conversation path because they are very time consuming and one of the problems we have at the moment is we don't have a reliable health record where a lot of those discussions can go (…) sometimes the conversations are had and they don't go on the discharge summary and then nobody is any the wiser, this patient comes in again, and there are temporary notes. Our communication structures remain fairly woeful I would say in terms of co-ordinating this care. It is not because people haven't tried and it's just because it is fairly complicated, and we don't have a universal heath record'. Participant 7, Consultant in elderly care
Lack of planning for sudden deterioration	There is an issue with care homes and GPs so that the default is to send patients in to hospital and we should sometimes be more proactive about their future plans, so if we know we are not going to operate on

Admission to hospital and distress caused to patients at the end of life that could have been averted through joint planning	somebody and we have already made that decision, if so say they have got terminal cancer and that we know that their bowel might block off, if their bowel blocks off and they are in a care home, they will be sent to hospital even though there's nothing we can do about it, because we have already made that plan and we are not great at making really good care plans for people in the community and following them through, so there are a few patients where they should never come to hospital in the first place. Participant 15, Consultant surgeon
Inappropriate admission to hospital *Patients are admitted to hospital when this could have been avoided*	It's the worst thing for someone who's old and frail to be whisked into an acute building away from people who've been looking after them, people they know, to die alone in hospital. It's not kind. Participant 23, Consultant in respiratory medicine