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Background: Older adult patients now often: have a shorter length of stay; leave hospital with complex health & social needs; require a period of ongoing recovery at home; require involvement of multiple agencies. This means that the transition from hospital into the community can be risky, and some older people are readmitted shortly after discharge.

Aim: To capture the **experiences** of older patients and their families during the transition from hospital to home; and identify opportunities for patient **involvement** in care.

Methods: **Interviews, observations and 'go-along' interviews** captured patient/carer experiences at 5 timepoints from admission up to 3 months post-discharge. Inductive analysis of transcripts and field notes were used to create case histories. Themes were identified through within- and between-case analyses of the case-histories.

Findings

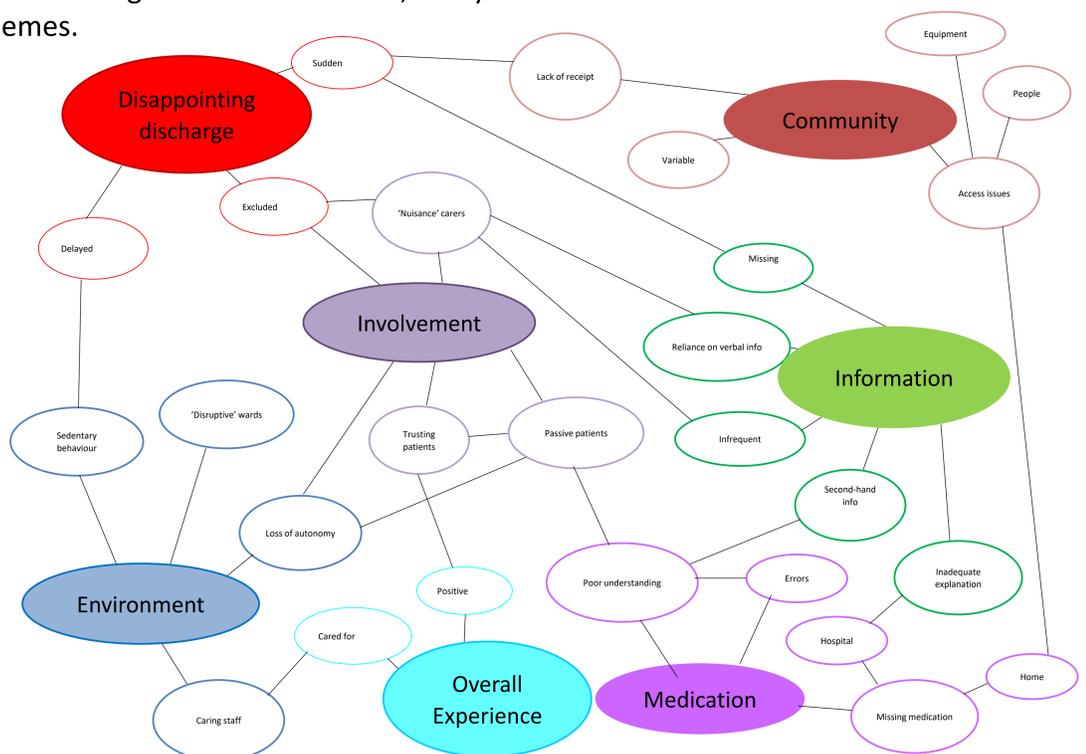
- We recruited **32 patients** (aged 75-99), and 15 carers, from two NHS Trusts across various wards (acute medical wards, elderly care, stroke respiratory).
- Participants **did not experience a 'transition'**, instead they experienced a 'discharge.' Once back home, many felt in between services.
- Seven themes were identified. Involvement and information are key themes.

Involvement

- Participants wanted to be informed about their care and share information, but saw themselves as non-experts regarding treatment decisions. They trusted staff and knew they were busy, so they often didn't speak up even when asked if they had any questions.
- Family involvement was crucial for some, although they described getting information and staying involved as confusing and difficult.
- Participants wanted more control over things like using the toilet, washing themselves, and moving about in hospital.
- Many participants did not understand their medication. This was exacerbated as participants placed trust in staff, who managed medications on the patients behalf. Patients went home out of practice in managing their own medications.

"If you're a Dr in terms of medical conditions you do know more than me, but you don't know more when it comes to my Mother's health... I interrupt, I ask questions, I've got to know the inside out, I cause problems because I need the information."
Serena, 92 (daughter)

"[My medication] that's a medical decision isn't it, I have nothing to do with it... They'll make a decision without me, not in my earshot, and I know they'll be correct." Leslie, 84



Information

- Participants wanted more information. Information was often missing, infrequent, uncertain, contradictory, or lacking detail.
- Verbal information was valued but difficult to remember, sometimes leading to unintentionally non-compliant behaviour or readmission.
- Written information such as the discharge letter was often 'second-hand' – participants struggled to understand it, and did not value this.
- Once home, participants often were unsure what would happen next or who was now responsible for their care.

"Yeah, I know nothing, unless somebody tells me, I don't know. I mean I've grabbed that doctor to say what's happened and he said no you can't go home, he says, I think you've got trouble with your heart and I couldn't believe it, I never knew I had anything wrong with my heart."
Katherine, 84

"[they send you home] with carrier bags of medication and papers beyond me... I've gone through and read the pamphlets, but there's that much, I'm not medically minded...am I supposed to understand it?...I don't know why they give you, it just upsets you." Jasmine, 78

Summary

- A number of barriers and opportunities for improving transition and increasing patient involvement have been identified (eg information about changed medications, follow up appointments, a sense of 'receipt' into the community).
- Receiving information is a welcomed form of involvement. People struggle or are reticent to seek information. Being involved requires effort, knowledge and skills. Information needs to be accessible and more frequent.
- Involving the patient is important – the patient is the only constant through the transition journey. Their involvement has the potential to improve experience and positively contribute to safety (eg knowledge transfer between services, being more informed about medications)

This study reflects the first workstream within a programme of research, and will be used to help develop an intervention to support patient transitions. For more information follow our work on www.YQSR.org/PACT or on Twitter: @PACT_YQSR