

Patient and relative involvement in raising concerns about deterioration: a qualitative case study approach

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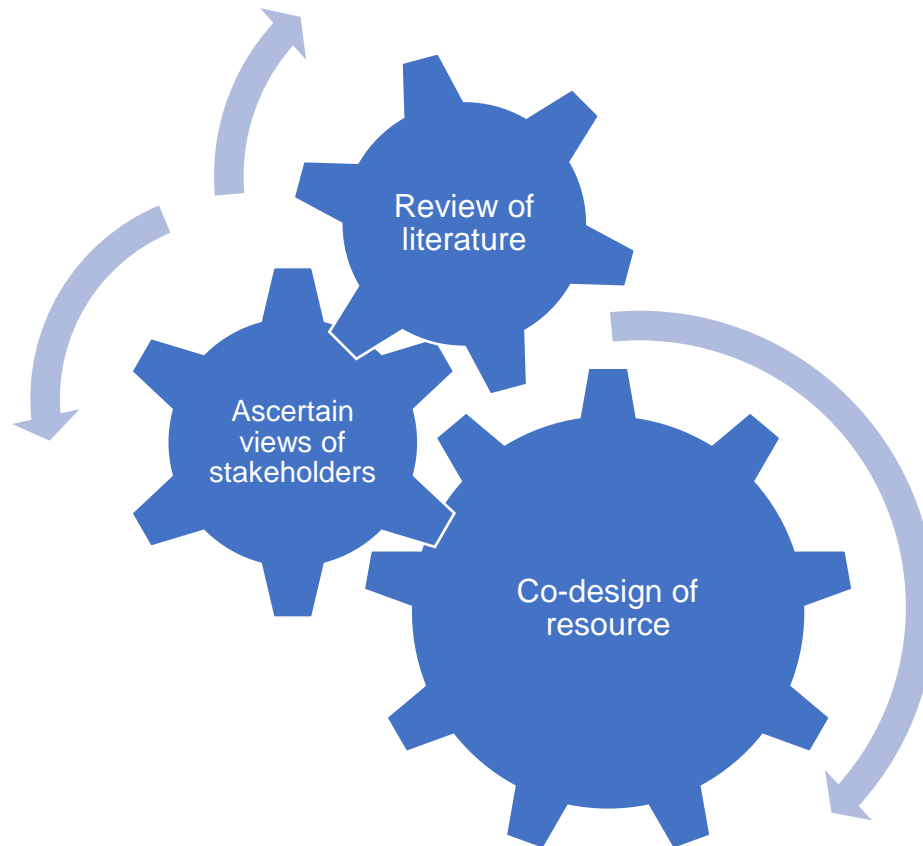
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Background

- Patient deterioration is not always identified early enough in clinical ward settings
- Contribution that patients and relatives can make to this process is increasingly being recognised
- There is a limited robust research in this area
- Need to design and develop an evidenced based family-initiated escalation of care scheme

Study Design

Aim: To co-design an All-Ireland resource that will enable patients and relatives to call for help if they become concerned about deterioration in adult hospital wards



Phase 2 – Qualitative Phase

- **Aim** – To explore patients', relatives' and healthcare staffs' experiences of deterioration and perceptions of a patient and family-initiated escalation of care scheme
- **Design** – Collective case study
- **Setting** – An acute adult hospital in NI and ROI
- **Participants** – Patients, relatives and healthcare professionals
- **Methods** – 1:1/ focus group interviews, review of case notes
- **Ethics** – Approval March 2019
- **Analysis** – Thematic analysis (Braun and Clarke,2006), NVivo 11

Themes and Sub-themes

<i>Themes</i>	<i>Sub-themes</i>
Experiences of deterioration	Knowing the patient Being heard
Challenges in calling for help	Knowledge/skill deficits Personal and role conflict factors Resource/organisational deficits
Ways to support	Signposting Enhancing engagement
Benefits and burdens of involvement	Ownership and empowerment Safety and control Resource/organisational impact

Experiences of deterioration

Some unable – e.g. due to extent or suddenness of deterioration

Other patients, and even more so, relatives, can recognise changes

Value of knowing... “know patient best”, “intuition”, “gut feeling”
(Relatives, A and B)

“Relatives often know a patient much better than we know them. We see them for a snapshot of fifteen minutes.... Whereas a relative will know what a patient is like ...and probably more readily sense that something is changing, potentially before parameters and NEWS and things we look at to see if someone is changing” (Ward Doctor, A [04])

Challenges in calling for help

Knowledge/skills deficit

*“It is kind of lacking. Who do you turn to? ...especially if the nurse isn’t listening to you”
(Ward manager, B [20])*

Personal /role conflict factors

“Some people won’t be confident enough to raise it.... and it is probably slightly older patients in general” (Critical Care Doctor, A [02])

“Dr knows best”, “Not my place” (Relatives, A and B)

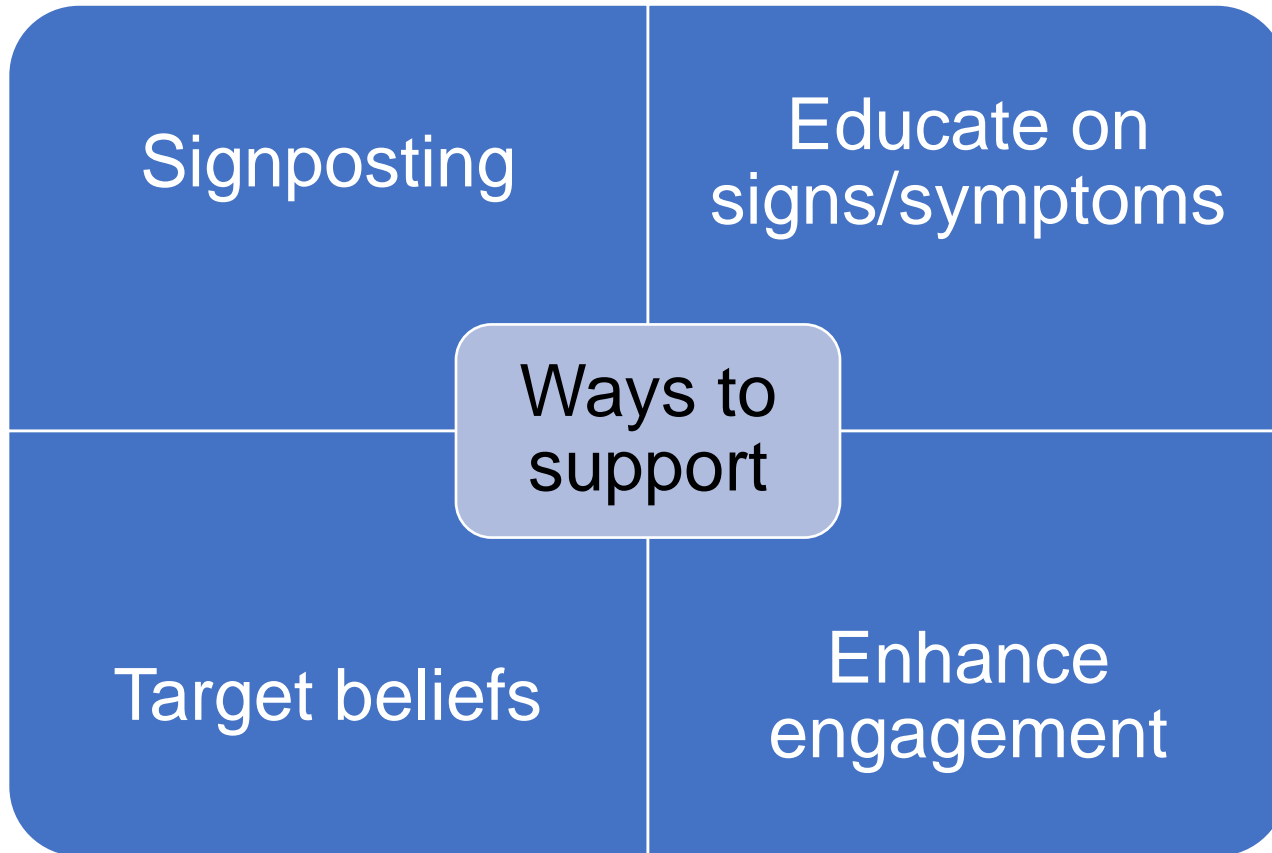
Resource/organisational deficits

“Better not bother the nurse, she looks busy” (Ward manager, B [20])

“An uphill battle.” (Relative 6, A [44])

“Coming from a person who saw an acute deterioration in a family member, I was met with a wall. And I kind of had to scramble up over the wall, scramble down again and say, somebody has to listen. And I was almost like a kindergarten, stamping my foot. ...it took... barrier breaking to say, can somebody listen?” (Ward nurse 2, FG2, B [30])

Ways to support



Benefits and Barriers of involvement

Ownership and empowerment

“Would make people feel it is kind of permitted...Might persuade you” (Patient, 4, B [48])

Safety and Control

“It would provide reassurance that their family isn’t just deteriorating in front of their eyes and they have no control over it” (Ward Manager, A, [03])

Enhance partnership in care

Resource / Organisational impact

“I think current structures don’t particularly support a very constructive engagement of family members in their loved ones’ health” (Critical Care Doctor, A [02])

Conclusion

- Patients and relatives are able to detect deterioration
- Calling for help can be challenging
- Need to better facilitate patient/family involvement
- Deeply embedded socio-cultural, organisational and cultural constraints limit patient-family escalation of care
- Support and buy in from decision makers at local, national and organisational level required to effect change.

Thank you

Any Questions?

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