Supporting shared decision making for older people with multiple health and social care needs: a realist synthesis

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Background

Shared decision making (SDM) involves patients and health and social care practitioners jointly selecting treatment, care and support packages to reflect and accommodate the patient's preferences, priorities and goals. SDM is seen as a central organising principle of integrated care. SDM may be particularly difficult in integrated care sites where decision making and communication need to be negotiated between, and communicated to, multiple health and social care practitioners, as well as patients and their family carers. Moreover, for those most reliant on health and social care support, such as people who are very frail and those with severe disabilities arising from long-term conditions, decision making may be particularly complex involving matters such as resource availability, polypharmacy, consent, concordance, the capacity of patients to attend to health care demands, support networks, safeguarding and the appropriateness of treatment in people with multi-morbidity.

Aims

The overall aims of this synthesis are to provide a context relevant understanding of how models to facilitate shared decision making (SDM) might work for older people with multiple health and care needs, and how they might be to applied integrated care models.

Methods

The synthesis draws on the principles of realist inquiry, to explain how, in what contexts, and for whom, interventions that aim to strengthen SDM between older patients, carers and practitioners are effective. We used an iterative, stakeholder driven, three phase approach. This included:

Phase 1: Development of initial programme theory/ies

The purpose of Phase 1 was to develop candidate theories about why programmes that seek to promote SDM do, or do not, work. This involved scoping the SDM literature (n=39 reviews and 35 primary studies) and interviews with 13 stakeholders. Stakeholders included user/patient representatives, commissioners and service providers in Vanguard sites and

health care professionals. The purpose of the stakeholder consultation was to explore key assumptions about what needs to be in place for effective SDM and identify relevant outcomes. The initial programme theory was discussed at a workshop attended by research team members and at the first Project Advisory Group meeting.

Phase 2: Retrieval, review and synthesis

In Phase 2 we undertook systematic electronic and lateral searches of the evidence to test and develop the theories identified in phase 1. There were 11 separate searches which were focused on areas relevant to the theory identified in Phase 1 (e.g. person-centred care and coaching). Data sources included: Medline (PubMed), SCOPUS, Cochrane Library (incl. the Cochrane Database of Systematic Reviews), DARE (Database of Abstracts of Reviews of Effects), the HTA Database, NHS EED (NHS Economic Evaluation Database), Google and Google Scholar. Data were extracted into a specially developed ACCESS database. The database was used to identify prominent recurrent patterns of contexts and outcomes in the data and the possible means (mechanisms) by which they occurred.

Phase 3: Testing and refining of programme theory

In Phase 3 we tested the programme theory via interviews with 11 stakeholders and through discussions with the research team and Project Advisory Group.

The review was supported by two well established public involvement groups based at the University of Hertfordshire and Kings College London. Members of these groups were involved in the Project Advisory Group, took part in stakeholder interviews and attended project team workshops. As such they contributed to the development of our programme theory.

Results

We included 88 items which included 26 evidence reviews, 46 primary research studies, seven guidelines, case studies or reports and nine discussion or opinion papers. Twenty-nine items focused on older people or participants with complex health and care needs (e.g. multimorbidity). The included literature either focused specifically on SDM or on aspects of care, such as person-centred care or personalised care planning, in which SDM plays an essential if not specified part with the patient or their proxy.

Despite the constraints of the current evidence base we were able to develop an explanatory account of what SDM should look like for older people with complex health and care needs. The theory draws on four context-mechanism-outcome (CMO) configurations that together provide an account of what needs to be in place for SDM to work for older people with complex needs. They highlight the importance of understanding patient and carer values, the organisation of systems to support SDM, the need to support and prepare patients and family carers to engage in SDM and the need for wider cultural changes of which SDM is a part. The CMOs are grounded in evidence from the literature and stakeholder perspectives.
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CMO1: Reflecting patient and carer values

The evidence shows how systems that enable health and care professionals to develop relationships with patients/ service users and their family carers trigger feeling of trust, engagement, and respect that can lead to improved outcomes such as patient and carer satisfaction with services and decisions. The quality of individual clinicians' communication skills, and their ability to foster trusting relationships with older people and their families, is fundamental to SDM. In addition, there is also a need for systems that foster continuity of care both through ongoing relationships with one clinician (relationship continuity) and through system based approaches that develops ways of working whereby the patient is linked to multiple professionals (management and informational continuity). SDM with older people with complex needs is likely to increase appointment length and whilst it is thought to

improve adherence to treatment regimens there is currently little evidence to suggest a link to health outcomes or service use.

CMO2: Systems to support SDM

There is evidence that organisational support, appropriate training and system based aspects, such as longer appointments, lead to health care professionals feeling more supported and having the confidence to engage with SDM. It can also lead to increased patient satisfaction with decision making because they feel that service providers are attentive to them and their concerns. There is a lack of studies addressing interprofessional approaches to SDM or the training needs of providers other than doctors.

CMO3: Preparing for the SDM encounter

Older people with complex health needs are likely to need support to participate in SDM. Whilst the evidence suggested that interventions such as decision aids and coaching can improve involvement in SDM the impact on adherence or health outcomes is not proven. Moreover, most tools were not designed (and have not been tested) for the oldest old. Evidence suggests that if tools are used they need to be brief, designed for use within a consultation and focused on facilitating discussion between the patient, family carer and professionals involved in their care. The right culture, that allows people time to ask questions and to discuss options, and staff with positive attitudes towards SDM are likely to be more important than tools for older people with complex health and care needs.

CMO 4: SDM as part of a wider culture change

SDM is likely to be most effective when it involves service providers who have the right skills, attitudes and tools, working in systems that are structured to support service providers and users to engage in SDM. Key to this is a culture that involves person (and family) centred approaches. This CMO incorporates components from the previous CMOs, such as organisational resources (time and space), systems to support SDM and skills development

through continuous practice development. These wider changes are important to trigger mechanisms such as familiarity and confidence. This familiarity, which develops over time, is necessary for both health care professionals and patients and their families and includes an understanding that patients and (where appropriate) their family carers have responsibility for their health and the decisions which affect them. The evidence suggests that such approaches may lead to improved service user and provider satisfaction with services and with the quality of decisions but there is currently little research on the impact on health-related outcomes.

Conclusions

Programmes that are likely to be successful in creating shared understanding and shared decision making between service users and providers are those that create trust between those involved, that allow service users to feel that they are respected and understood, and that engender confidence to engage in SDM. Confidence is likely to take time to develop as, we suggest, it is related to the development of a shared understanding and expectation of SDM between service users and service providers. The cultural shift that is needed to embed SDM in practice may require new ways of working for health care professionals and a shift away from a biomedical focus to a more person-centred ethos that goes beyond the individual patient encounter. To achieve this health care professionals are likely to need support, both in terms of the way services are organised and delivered and in terms of their own continuing professional development. This cultural shift also involves an expectation that patients and their family carers will take a greater responsibility for their health and the decisions that affect them, and they too may need support to engage in SDM. How this support might best be provided needs to be further explored, although face to face interactions and ongoing patient-professional relationships are clearly key. Support needs to ensure that well-meaning attempts to focus on patient goals do not increase health inequalities.

Models of SDM for older people with complex health and care needs should move away from thinking about SDM purely in terms of one encounter between a doctor and a patient. Rather SDM should be conceptualised as a series of conversations that patients, and their family carers, may have with a variety of different health and care professionals. Such an approach relies on continuity of care fostered through good relationships between service providers and users, and systems that facilitate the communication of information, including that about patient goals and preferences, between different health and care professionals.

The literature on SDM involving older people or those with complex needs is largely qualitative or descriptive and there are very few evaluations of interventions specifically designed to promote SDM with this group, and with their family carers. This review suggests there is need for further work to establish how organisational structures can be better aligned to the needs of older people with complex needs. This includes a need to define and evaluate the contribution that different members of the health and care team can make to SDM for older people with complex health and care needs.

Implications for practice

The following implications for practice have emerged from the review.

Systems and culture

- The evidence suggests that SDM is only likely to become embedded if it is regarded as an essential component of 'good' healthcare and is a linked to a culture of person-centred approaches throughout an organisation.
- The evidence suggests that a culture that allows people time to ask questions and to discuss options, and staff with positive attitudes towards SDM are likely to be more important than decision support tools for older people with complex health and care needs.

- The evidence suggests that there is a need for visible organisational support in order for SDM to become embedded. This includes visibility in internal policy documents, through financial and organisational support (e.g. enabling longer appointments when necessary, providing appropriate administrative support) and through the inclusion of SDM in continuing professional development.

- The evidence suggests that systems that foster continuity of care both through ongoing relationships with one clinician (relationship continuity) and through system based approaches that develops ways of working whereby the patient is linked to multiple professionals (management and informational continuity) are important for SDM.

- It appears likely that in instances where choices are constrained by resource limitations, health care policies or evidence based recommendations it is still valuable to explore patient's choices and reasons.

- Whilst properly conducted SDM may increase the length of consultations (such as those in primary care) there is evidence to suggest that this may be ameliorated by involving other members of the multidisciplinary team in the SDM process.

- It is important that service providers and service users have shared expectations of, and familiarity with, SDM for it to become properly embedded. This is likely to take time to develop.

Education and training

- Our findings suggest that SDM education and training should be focused on all members of the multidisciplinary team and not just doctors or lead clinicians. It should be part of undergraduate training programmes but also part of ongoing professional development.

- Evidence points to a need for SDM and communication skills training to include the task of exploring what matters to patients and how to elicit their goals and priorities.

- SDM training should include information on risk communication.

Preparation for SDM

- Evidence suggests that many older people with complex health and care needs, particularly those with lower health literacy or conditions such as depression, are likely to need support to take part in consultations involving SDM.
- The evidence indicates that patient decision aids for older people with complex needs are likely to be most effective when used as part of a face to face interaction with a health care professional, for example for facilitating discussion between the patient, family carer and professional.

Suggestions for future research

Several potential areas for future research were identified by the review. These are listed in order of priority and include the following:

- How can interventions be tailored to the SDM needs of older people with complex health and care needs and how effective are such approaches? For example, would longer consultations in primary care facilitate SDM and improve patient outcomes?
- How can family members be involved in SDM and what is the impact of this? For example, what is the impact of making it the default option (with consent from the older person) to involve designated family members in consultations and discussions about treatment options? What models work best, what would be the uptake and how would it impact on satisfaction and patient outcomes?
- What service models are most likely to support SDM? For example, does moving away from disease related checks in primary care to a more holistic and team based regular review increase SDM and improve patient outcomes?
- How can health and care professionals other than doctors be involved in SDM?

- What is the impact of training members of the multidisciplinary team to act as decision coaches for older people with complex health and care needs? Who should act as a coach and at what stage should coaching be provided?

- What is happening in SDM conversations involving older people and how are patient decision aids being used andto what effect? Can modes of communication, other than face to face, be effective?

- Can decision aids be developed for use with older people with multiple health and care needs? For example, rather than focusing on individual conditions can SDM be used to look more generally at the overall treatment burden for the older person and their family members?

- How can patient decisions, goals and preferences be best recorded and communicated between different team members in integrated care sites?

- What would be the impact of overt discussions about prognosis? Would knowing more about an individual's views about coming to the end of their life shape decisions?

- How does working in a more patient centred way, with a focus on SDM, impact on health care providers experience and satisfaction?

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