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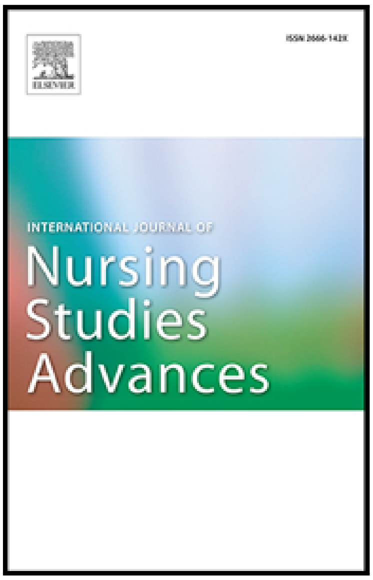

Evaluation of the usability, accessibility and acceptability for a family support intervention (Family-Focused Support Conversation) for end of life care discharge planning from hospital: a participatory learning and action research study

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Evaluation of the usability, accessibility and acceptability for a family support intervention (Family-Focused Support Conversation) for end of life care discharge planning from hospital: a participatory learning and action research study

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Abstract

Background: Family support is internationally recognised as integral to palliative care. However, during end of life care discharge planning from hospital, families report a lack of opportunity to discuss their concerns or contribute their knowledge of the ill family member and consequently feel unheard and unsupported. To counter this experience, we co-produced the Family-Focused Support Conversation, a novel research-informed intervention, to guide discussion of family concerns about the meaning, implications and manageability of end of life caregiving following discharge.

Objectives: To qualitatively evaluate the usability, accessibility and acceptability of the Family-Focused Support Conversation in hospital and factors which promote and inhibit implementation.

Design: Participatory Learning and Action Research design, guided by Normalization Process Theory, a social implementation theory.

Settings: Implementation was undertaken by 45 clinical co-researchers, specialist nurses (n=42) and occupational therapists (n=3,) working in specialist palliative care teams in twelve hospitals (within seven NHS Trusts) across England, over a six-month period.

Methods: During implementation clinical co-researchers collected reflective data about intervention delivery (n=110), participated in regular in-depth conversations of implementation with the research team (n=26 meeting records) and in a final evaluation meeting (n=11 meeting records). Data from family members who had received the intervention, comprised brief questionnaires (n=15) and in-depth semi-structured interviews (n=6). Data were qualitatively analysed, informed by Normalization Process Theory and Family Sense of Coherence Theory.

Results: Clinical co-researchers found the intervention eminently usable and accessible. They reported a shift in family support from informing family members about patient healthcare needs, to family concerns such as how they made sense of the meaning of discharge, and how to provide family-orientated care. Family members found the intervention acceptable, they felt supported and able to make informed decisions about their role in providing end of life care. Implementation was positively influenced by coherence between the intervention and value placed on family care by clinical co-researchers. Once incorporated in their practice intervention delivery took no longer than usual practice and could be divided across consultations and collectively delivered with ward and discharge teams.

Conclusions: The Family-Focused Support Conversation is usable, accessible and acceptable. It enhances family support by facilitating discussion of family concerns about end of life caregiving and results in family members making informed decisions about their role in end of life care following discharge.

Trial registration n/a

Keywords by MESH headings

Palliative care

Patient discharge

Caregivers

Hospitals

Family

What is already known about the topic?

- During transfer between care settings, family members are pivotal to continuity of end of life care and their involvement reduces the risk of readmission, but they are often excluded from discharge planning because of an organisational focus on patient need, and ambivalence towards their role by healthcare professionals.

- Families need information and support during the discharge process to make informed decisions about their role in providing end of life care but often feel unsupported, unheard, have little control or opportunities for effective advocacy for their ill family member and want more time to discuss their concerns.

- Conversational tools can help hospital staff to explore family expectations of end of life care and increase the likelihood families will be able to draw on their own resources, receive the services they need to support care and know where to find help and information after discharge.

What this paper adds

- The Family-Focused Support Conversation provides a usable, accessible and acceptable process to facilitate family involvement in discharge planning which results in family members contributing knowledge about the patient and what is important to them as a family.

- Implementation of the Family-Focused Support Conversation reportedly changed the focus of support from that of patient health care needs to family concerns about caregiving at the end of life, and enabled family members to make informed decisions about their role in end of life care.

- By being involved in discharge planning family members were able to harness family resources for care after discharge and practitioners tailored health and social care resources to patient and family needs.

Background

Family support is a key principle of palliative care, reinforced internationally through national health polices and palliative care mission statements, yet family members report unmet support and information needs (Wang et al, 2018). Hanratty and colleagues (2014) found professional support was rarely provided to family members of dying people during discharge planning. Yet, for many patients and families, the end of life is characterised by a succession of movements between care settings as ill health progresses (Van den Block et al, 2015). These care transitions are tangible indicators of the deterioration and impending death of an ill family member (Penrod et al, 2012) and consequently a source of family distress (Payne and Morby, 2013).

Family distress is further exacerbated by the discharge process, which is typically focused on organisational needs (Hanratty et al, 2014; Ewing et al, 2018) and experienced by family members as haphazard and disjointed (Waring et al, 2014; Hanratty et al, 2014). In addition, hospital practitioners typically conceptualise family support during discharge as providing information about a patient's health needs (Ewing et al, 2018), rather than about family concerns and helping family members to plan how they might provide care and support each other (Hanratty et al, 2014). Consequently, family members often feel marginalised and excluded from decision-making about discharge, lack the information and support they need to make informed decisions about their role in end of life care and how to harness family and community resources to provide and sustain care for their ill family member (Hanratty et al, 2014; Waring et al, 2014).

In contrast, when family caregivers are involved and supported during discharge planning, readmission is less likely, discharge is more sustainable, resource utilisation is optimized (Bret et al, 2016; Rodakowski et al, 2017) and caregiver burden reduced (Smith et al,2019). Whilst there is a paucity of research about caregiver support interventions during discharge (McLeod-Sordjan et al, 2011), those commenced in hospital prior to discharge, are more effective than those commenced after discharge (Bauer et al, 2009; Bret et al, 2016).

There is a growing evidence-base about effective support interventions for family members providing end of life care, published in several systematic reviews (for example, Candy et al, 2011; Thomas et al, 2017). However, there is a paucity of implementation research translating this evidence into realistic clinical applications (Ferrell and Wittenberg, 2017; Ugalde et al, 2017). Moreover, none of the tested interventions reported in systematic reviews address caregiver support during hospital admission or during the transition of care from hospital to home or nursing home. All were developed for provision in outpatient or community settings, designed to be delivered over successive consultations, each lasting 30-90 minutes. This pattern of delivery is unrealistic in acute hospitals because of the unpredictability about the length of time needed to organise end of life care discharge (Benzar et al, 2011). In a systematic review of intervention design for supporting caregivers during palliative care, Applebaum and Brietbart (2013) concluded structured interventions which are time-limited and goal-orientated are likely to be feasible and effective.

In an earlier phase of the study reported here we co-constructed a brief intervention, the Family-Focused Support Conversation, a structured conversation to provide family support during discharge planning for end of life care (Duke et al, 2020). The intervention was co-constructed from a critical review of interventions reported in randomised controlled trials, reviewed in systematic reviews and meta-analysis of caregiver support during end of life care. Table 1 outlines the structure of this intervention and examples of conversational prompts designed to guide the process.

Table 1: Family-Focused Support Conversation – theory, context, intervention processes and interactional practice

	Theory – Family Sense of Coherence	Context – Care Transitions at the end of life	Intervention Process - change mechanisms	Interactional Practice – Conversational Prompts for Practitioners
Meaningfulness	Meaningfulness is the motivational dimension of FSC, concerned with desire to resolve difficulties and invest energy to get through a stressful situation	The sense the family is making of discharge for end of life care and its significance to the family	Empathetic statement followed by a pause	'*We are beginning to plan/think about discharge/next place of care and wanted to talk to you as a family. We recognise this can be a difficult time for families*' (pause)
Comprehensibility	Comprehensibility is the cognitive dimension of FSC – the ability to organise and sort information	The implications raised by discharge for EoL care for the family	Asking about concerns	*'Have you talked as a family about the plan for [relative] to [go to next place of care]? Have these discussions raised any concerns for your family'*?
Manageability	Manageability is the instrumental or behavioural dimension of FSC – whether you feel you have the resources to meet challenges and the willingness to solve problems faced	How the family might manage the implications of discharge and how they can harness necessary resources	Problem-solving coaching	'*Have you had any thoughts as a family about how you might manage those concerns?'* *'Are there things that we can help you with?'*

The Family-Focused Support Conversation is a structured conversation, guided by the components of Family Sense of Coherence Theory (Antonovsky and Sourani, 1988): *meaningfulness* of the care transition at the end of life; the *comprehensibility* of implications of the current situation; and the *manageability* of responding and harnessing resources to support the ill family member and each other (table 1). Each component is explored using intervention mechanisms identified from the evidence review: identifying concerns, providing information, and coaching problem-solving. A full description of the Family-Focused Support Conversation intervention is provided using the TIDieR criteria (Hoffman et al, 2014) in supplementary material 1.

Pilot implementation of the Family-Focused Support Conversation was undertaken in three acute hospital NHS Trusts in England, to assess the potential for the intervention to be used in acute hospital practice. The results of the pilot implementation demonstrated the intervention was readily implemented in practice and had potential to be adopted in acute hospitals (Duke et al, 2020). In this paper we report a qualitative evaluation of a larger scale implementation in 12 NHS acute hospitals (within seven NHS Trusts).

Method

Aims

Our aims were to:

1. Assess usability and accessibility of the Family-Focused Support Conversation in acute hospitals
2. Assess acceptability of the Family-Focused Support Conversation - how roles, relationships and resources were influenced
3. Understand factors which promoted and inhibited implementation of the Family-Focused Support Conversation

Implementation - theoretical approach

The study adopted Hawe and colleagues' (Hawe, Shiell and Riley, 2009) definition of interventions as time and space bounded activities and patterns of behaviour, determined by the relationship between features such as roles, people, time, funds and physical resources. Thus, implementation was considered a dynamic relationship between the Family-Focused Support Conversation (intervention) and implementation context. Hawe and colleagues argue this dynamic influence whether '*something significant happens*' which positively '*change[s] the future trajectory of the system's dynamic*' (p274). Thus, this dynamic influences how an intervention is operationalised, accessed and its consequent effectiveness (Zamboni et al, 2019). Understanding this dynamic is crucial to explaining variability between implementation sites.

Therefore, the study was guided by Normalization Process Theory (May and Finch, 2009), a robust social implementation theory, which explains the implementation work undertaken by practitioners to embed an innovation in practice and the dynamic between the innovation and organisational context. Normalization Process Theory consists of four constructs. *Coherence* describes the work of making sense of an innovation; *cognitive participation* describes the relational work involved in implementation; *collective action* describes the operational work involved; and *reflexive monitoring* describes the appraisal work undertaken to understand how an innovation influences practice. These constructs provide a means of analysing implementation work to illuminate the organisational and relational factors that promote and inhibit implementation (Murray et al, 2010; May et al, 2013; May et al, 2018).

In addition, May and colleagues (2016:7) describe two restructuring processes, consequent to implementation work, indicative of organisational change. The first, normative restructuring, refers to '*modifications in the conventions, rules and resources'* that guide *'everyday behaviour and action'* (May, Johnson and Finch; 2016:7). The second, relational restructuring, refers to '*changes in the structure and conduct of the interpersonal interactions and group processes'* and in '*accountabilities to each other*'.

Moreover, Normalization Process Theory provides understanding about interventional factors influencing implementation (Murray et al, 2010; May et al, 2016). To be embedded in practice an intervention has to have traction or purchase in practice. The potential traction of an intervention is influenced by how tightly the interventional components are coupled to each other. An innovation is more likely to be embedded if there is some flexibility in the order or timing of interventional components (loose coupling). In addition, implementation is influenced by the degree of discretion available to clinicians. The more discretion clinicians have to use their expertise and available resources, the more likely an innovation is to be embedded (May et al, 2016). Combined, these two factors (loose coupling and clinical discretion) enable practitioners to shape the intervention to meet individual and contextual circumstances and this in turn influences the potential for an innovation to effect organisational change.

Thus, our approach to implementation focused on '*linkages, relationships, feed-back loops and interactions amongst the system's parts*' (Hawe, Shiell and Riley, 2009:269), rather than discrete factors such as individual or organisational attributes. We were concerned with the potential for the Family-Focused Support Conversation to be embedded in practice and to change or create new roles and relationships, re-distribute resources and influence system change.

Research approach – Participatory Learning and Action Research

The theoretical perspectives described above were integrated with the overarching study approach, Participatory Learning and Action Research (PLA) (de Brùn et al, 2016). In previous phases of this study we found this integration valuable to ensure inclusion of different kinds of knowledge from diverse groups of participants.

Participants in the phase of the study reported here, consisted of:

- clinical co-researchers (n=45): nurses (n=42) and occupational therapists (n=3) working in hospital palliative care teams (n=9), providing specialist palliative care services to n=12 hospitals in n=7 NHS acute hospital Trusts in England (involved in implementation, data collection and interpretation of findings).
- family members who participated in the intervention (n=15)
- health and social care experts (n=7), consisting of palliative care social workers and carer organisation leaders, hospital and community care experts, recruited from local and national networks (involved in interpretation of findings);
- patient and public involvement participants (PPIs) (n=5), members of the public with experience of caring for a dying relative, recruited through local research networks (involved in interpretation of findings).

Ethical considerations – participant recruitment and consent

Ethical approval was gained via the NHS Health Research Authority South Central - Hampshire A Research Ethics Committee (16/SC/0330). Research Governance approvals were gained from each participating NHS Trust (IRAS: 208275).

Family members were recruited via an invitation within a research information pack given to them by the clinical co-researcher who had provided the intervention. The research pack consisted of a participant information sheet, consent form, short questionnaire, and request for contact details if willing to be interviewed and a freepost return enveloped. Clinical co-researchers explained to family members the pack contained details of an evaluation and they were under no obligation to participate. Family members were invited to return a short questionnaire to the research team and to indicate on the questionnaire if they were willing to participate in an interview. Those who agreed to participate in an interview, were contacted by the researcher to arrange a date and time for interview and offered an opportunity to discuss the study. Participants gave informed consent before the interview was conducted.

The clinical co-researchers were recruited in the following ways. Co-researchers from three teams involved in previous phases of the study (co-design of the intervention and pilot implementation) were invited to participate in the roll out phase; all agreed. Co-researchers from six other teams were recruited via an invitation letter outlining the study, sent by the principal investigator (SD) to clinical leads of hospital specialist palliative care services in

England. We selected teams from those who replied and voiced interest to participate (n=32), across England (from four NHS Trusts in the South England, one in the Midlands and three in the North) to facilitate provision of support from the research team and to ensure a mixture of district and teaching hospitals in rural, urban and inner-city areas, serving populations with differing demographic and deprivation characteristics. Thus, four of the teams worked in NHS Trusts serving urban populations, three serving inner-city populations and two serving rural populations. The NHS Trusts were situated in some of the least deprived places in in England (n=5) and some of the most deprived places (n=4). All of the specialist palliative care teams selected provided palliative care services to people with any diagnoses. None of the invited teams declined to participate. Once teams were recruited, team members self-selected.

Participatory Learning and Action research raises particular ethical concerns which principally revolve around the location of 'power' in researcher and participant relationships and how this is managed to achieve the collaborative relationship intended (de Brùn et al, 2016). Our decision to refer to the clinicians implementing the intervention as co-researchers relate to these concerns. The term co-researcher attempts to recognise the participating practitioner’s role in researching their practice, implementing the intervention and critically reflecting on this process. Explanation of this research approach was included in the training provided to clinical co-researchers prior to implementation.

One of the key challenges of participatory learning and action research is the changing expectations that occur as research progresses. Therefore, information provided at the beginning of the study, on which consent to participate is based, may change over time. We managed this challenge by outlining expectations for each cycle of the study and these expectations were part of the ethical approval gained for the study (Duke et al, 2020).

Thus, prior to implementation, clinical co-researchers were informed about the purpose and process of the study, their role, expectations of their involvement and of the core research team.

Implementation

Implementation was undertaken by the clinical co-researchers described above over a six-month period (March-Sept 2017). Prior to implementation clinical co-researchers were trained in the use of the Family-Focused Support Conversation in a two-hour face-to-face interactive group discussion and demonstration, provided by members of the research team (SD, NC, SL, NL). Training was organised regionally, one in the north and one in the south of England. The same educational delivery plan was used and delivered at both events. In addition, the training was supported by a training pack, which detailed the intervention process, rationale and underpinning premises and provided worked examples of intervention delivery. Clinical co-researchers provided the intervention to family members of patients on their caseload being discharged home or to a nursing home for end of life care.

Data collection

Data were collected with family members who had received the intervention and clinical co-researchers implementing the intervention.

Family member data (designed to address research aim 2) consisted of:

- Questionnaire comprising 3 items about the intervention process (whether they had been asked about their concerns; whether they had discussed these concerns as a family; and what would help to address these concerns) and 1 item about their view of the intervention (whether there was anything else they would have preferred or not preferred to have discussed).
- Semi-structured interviews exploring family concerns about transfer of care and the perceived helpfulness of the intervention. Interviews were conducted by telephone, by NC and SL, both experienced qualitative researchers in end of life care (NC and SL), digitally recorded and transcribed verbatim. Interviews lasted 45-60 minutes each.

Clinical co-researcher data (designed to address all three research aims) were collected through discussion with co-researchers during and at the end of the implementation period. Guided by Normalization Process Theory, data included

- Reflective records of intervention delivery. Each clinical co-researcher was asked to reflect on a minimum of five interventions during the implementation period in a reflective record. The purpose of these records were to provide an aide memoire for support call and evaluation discussions about implementation, to address the research aims, rather than to record of the total number of interventions provided, as might be needed in an impact and scalability evaluation.
- Support call records, of team-based telephone conversations between clinical co-researchers and members of the research team (SD, NC, SL), to discuss implementation progress, guided by common questions reflecting Normalization Process Theory. Detailed notes of these conversations were made by a member of the research team. The duration of support calls were typically 30-45 minutes;
- Evaluation meetings were held at the end of the study (facilitated by SD, NC, SL) with clinical co-researchers in each hospital palliative care team, in a venue of their choice (usually a team office). The reflective records and support call discussion were used as a prompt for discussion, in addition to Normalization Process Theory generated

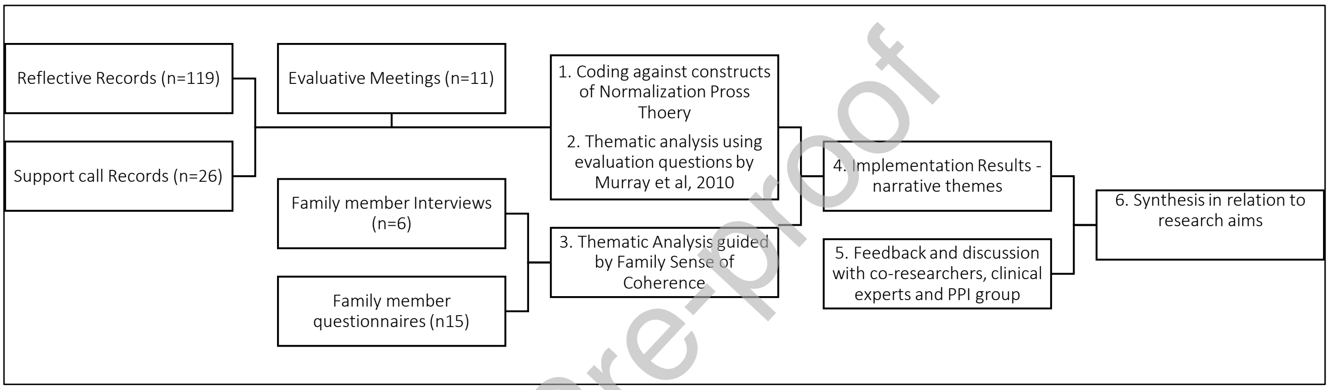
questions focused on reflexive monitoring, which were common to all meetings. Evaluation meetings typically lasted between 60-90 minutes.

Analysis

The analytical process was informed by Normalization Process Theory (all clinical co-researcher data) and Family Sense of Coherence (all family member data). Researchers have adopted several strategies for analysing data informed by Normalization Process Theory. Like others, we found it helpful to undertake analysis by hand in a small group (NC, SL, SD), so that analytical decisions and disagreements could be discussed to come to resolutions congruent with the data (http://www.normalizationprocess.org/how-do-you-use-npt/qualitative-research/coding-analysis/). We adopted the following analytical process (fig i):

1. Clinical co-researcher data were deductively coded against Normalization Process Theory constructs;
2. Data were then extracted, using this coding, and deductively organised against questions generated for evaluating interventions using Normalization Process Theory (Murray et al, 2010);
3. Family member data were inductively thematically analysed, guided by Family Sense of Coherence Theory, to provide an understanding of the process and impact of the intervention, from family members' perspectives;
4. Family member analysis was then synthesised with the clinical co-researcher data analysis, to provide an integrated account of implementation results. This was achieved by constructing narrative themes which described the data for each of the Normalization Process Theory generated questions (Murray et al; 2010);
5. Implementation results were revised following discussion of interpretation with clinical co-researchers, PPIs, and clinical experts;
6. The revised implementation results were mapped against the research aims;
7. The resulting narrative summary was cross-checked against the extracted data generated in step 5, to guide composition of the report text

Figure 1: Process of analysis



Results

Forty-one family members received an invitation to participate in the study, 15 family members completed a questionnaire (10 females, 5 males; age range 20-82, median age 60); 10 family members agreed to be approached to be interviewed, 6 were interviewed (3 females, 3 males; age range 48-81, median age 66) and 4 did not participate (3 accepted invitation but were unobtainable when contacted, and one declined to be interviewed, with no reason given).

Forty-five clinicians self-selected to be clinical co-researchers and recorded n=105 reflective accounts of intervention delivery. Co-researchers recorded interventions that 'stood out' in some way, to discuss in support calls and evaluation meetings. Twenty-six support calls and nine end of study evaluation meetings were recorded, seven face-to-face and two by telephone with individual co-researchers unable to attend an evaluation meeting.

Characteristics of the participating research sites and of co-researcher involvement are detailed in supplementary material 2.

All references to clinical co-researchers in the following results refer to the specialist nurses and occupational therapists who undertook implementation.

1. The usability of the Family-Focused Support Conversation intervention

By the end of the study, clinical co-researchers were positive about the Family-Focused Support Conversation, some reported it was now embedded into their practice, *'it would be hard not to use the intervention now'* (team A) and others were committed to continuing to use it in the future. Co-researchers found it *'straightforward to deliver, …not onerous'* (team H) and time effective, *'you're not going round and round with families'* (team A).

Clinical co-researchers described a variety of collective action strategies adopted (table 2). They stressed the importance of '*retraining their brains*' so that they did not slip back into their '*embedded habits*' (team H, both quotes). Strategies included rehearsing the intervention with each other and proactively planning opportunities to use the intervention in practice. A key focus of this performance work was attention to the phrasing used in the intervention, so that it was concordant with their interactional style and local vernacular. Most clinical co-researchers also described the conscious effort that was needed to leave a pause after the empathic statement and to resist the temptation to *'focus on professional solutions – what the team can offer the family…you want to blurt it all out'* (team H).

Table 2: Implementation strategies (collective action) adopted by clinical co-researchers

Skill-set workability - performance	
Situated learning strategies Co-researchers stressed the effort needed to absorb the intervention and to '*retrain their brains*' so that the intervention became '*second nature*' and they didn't '*slip back into old habits*' (team A and H, evaluation meetings)	- Reviewing training slides and rehearsing the intervention together - Seeing a family in pairs to enable joint feedback and reflection - Coming together as a group to undertake post-intervention reflection - Some practiced on 'straightforward' opportunities for delivery, so that they could become confident in using the intervention without worry of complex family issues, such as conflicting opinions about place of care (team H). Others practiced parts of the intervention as opportunities arose (team A). - Designing a crib sheet as an aide memoire (team B) or referring to the prompt card before seeing a family member (team A)
Interactional strategies	- Tailoring the wording of prompts to their role, or local language (Teams C and F) - To resist providing solutions, co-researchers used strategies such as pausing, or reframing the question and breaking it down into something more specific, such as '*what might you need help with*?' (Team D, evaluation meeting).
Skill-set workability – allocation	
Proactive planning '*anything that changes practice you need to remember (to do it) and be conscious of it*' (Evaluation meeting H)	- Identifying opportunities to use the intervention when reviewing caseload - Communicating opportunities to use intervention to other team members in board rounds or by marking the caseload board.
Phasing delivery strategies	- Phasing delivery across sequential consultations by the same or different co-researcher (A and J) to manage time pressures or to enable family members time to think through their concerns or so that other members of the family could be involved or when a family had numerous concerns, prioritising the concerns to address first and returning at another time to address others - Phasing delivery according to skill mix (team A and B). For example, dividing delivery between a nurse and occupational therapist, matching skill-set with family concerns, or between palliative care nurse and discharge liaison nurse, optimising skill-set resources. - Extending the medium of delivery from face-to-face to telephone, for some or all the intervention (Team A and J)

2. The influence of Family-Focused Support Conversation on roles, relationships and resources

Clinical co-researchers reported the Family-Focused Support Conversation facilitated a change in their approach to family support, from an orientation solely on patient needs to one that encompassed family concerns. They described how they had previously made assumptions about family concerns and been complacent about what was possible. One co-researcher commented *'the experience of delivering the intervention is characterised by receiving answers you did not expect…it changed how family members responded'* (team H). Another found '*[family members raised] little things that you would not have thought about*' (team D). Additionally, some valued the intervention for bringing *'complex [family] dynamics to life…the intervention really picked up on complexities'* (team E).

Thus, most co-researchers reported the intervention changed their perception of family involvement in discharge planning, '*we have a greater appreciation of family work and the impact of this on everyday life'* (team D). One commented the intervention '*challenges the commonplace assumption that family work relates to once discharge has been achieved, and that for example the spouse can have a rest whilst the patient is in hospital'* (team B). As a consequence, they stated feeling more confident to counter colleagues' negative perceptions of family involvement.

Clinical co-researchers stated the orientation towards family concerns required a significant change in their interactional '*scripts'* and '*turn[ed] professional conversations on their head*' (team C). Thus, instead of providing information about patient needs and available resources, they described how the intervention facilitated tailored conversations focused on family concerns. One co-researcher described how their practice had changed from providing the same information to every family member, '*deliver[ing] lines like an actor*' (team H) to crafting conversations based on family concerns, *'it made [us] listen to what the family have been thinking about and to their thoughts about solutions'* (team H).

Clinical co-researchers reported these changes altered the dynamics of family support conversations, describing how their role shifted from an expert in patient care to a facilitator of family-orientated care. One explained:

> *'Previously [we] had focused on the patient, [we] had a paternalistic/arrogant approach of what [we] could offer as a team and professionals, and what the family needed to do. Now [we] ask family members their concerns'* (team G).

Thus, rather than providing professional solutions, co-researchers described how they guided and coached family members to voice their concerns and think through the implications of care. Family members welcomed this facilitative approach, comparing it favourably to previous experiences of informational approaches: '*people in our position* *don't really want all that information thrown at us…[because]… they're giving you the facts but you're like: what does this actually mean*?' (Family member 005).

Thus, family members valued the family-focused approach taken by co-researchers '*…it was like, you know, this is ---it's about all of you*' (Family member 004). They were positive about the opportunity to consider implications of care, describing how co-researchers sensitively encouraged them to consider how they would manage:

> *'[The co-researcher] was trying to get me to tell him how I felt about the subject of care and so we discussed that in quite intimate terms really…we discussed it quite openly. Problems like incontinence and so forth and, you know'* (Family member 004).

Family members described the benefit of these conversations in terms of equipping them to act, '*well, I think we need to know what to expect in the future and then we're--- we're prepared to deal with it'* (Family member 003). It helped them to prioritise what was important, as one family member explained:

> *'It's difficult to say but the fact that my mum was dying sort of wasn't in my mind anymore. What was in my mind was to get her home and start to look after her at home. I wanted her to be at home. I wanted her to be in her own bedroom' (*Family member 001).

Consequently, clinical co-researchers described the Family-Focused Support Conversation *'changed the colour of family work*', the depth, content and emotionality of family support conversations. Some clinical co-researchers experienced powerful emotional responses expressed by family members when their experience was acknowledged, or when they were asked about their concerns. They described how these responses conveyed the significance and emotional impact of their relative's illness and impending death. One co-researcher stated the intervention '*gives time for the penny to drop – that their relative is going to die'* (team F). Although some co-researchers were initially worried by the strength of emotional expression evoked, family members explained it expressed their experience in terms of feeling valued and included:

> '*A couple of times we…started crying when they…started to involve us and ask about us…that someone was caring for us*' (Family member 003).

Whilst there was no doubt from family member data that these conversations were emotionally significant, they were considered crucially important, as one family member eloquently summed up, '*…it's that awful torment, isn't it? You want to know what you don't want to know'* (Family member 004).

Thus, clinical co-researchers reminded us of the sensitivity and '*leap of faith*' needed by clinicians to use the intervention, one explained:

> *'People are putting their courage into your hands and you can't anticipate what is going to happen in the conversation…each explanation about what is likely to happen, or what help might be available, is a [potential] horror to a family member'* [team C].

The recognition of family concerns and family knowledge, combined with prompting and coaching about the implications of care, facilitated family members to make informed decisions about their role in care. Clinical co-researchers provided examples where this facilitated families to decide to provide care at home when initially they ruled this out, to collectively decide that care at home was not feasible, or to consider alternative care options. Family members described this decision-making process as supportive and comforting: '*I found [it] very, very comforting, that I wasn't made to think I was doing the wrong thing*' (Family member 004).

Discussions about the implications of family caregiving helped families to work out how best they could help each other to provide care on discharge. This enabled clinical co-researchers to assess the fit between patient and family needs and resources and thus, to tailor the provision of health and social care resources in a plan considered manageable by family members. Thus, some co-researchers described this changed their practice of offering standard care packages to every family and by tailoring resources to family needs, they made better use of scarce resources and positively influenced the sustainability of discharge:

> *'current professional practice often provides things families do not want or need, and can result in failed discharges because the professional has taken over with their own solutions, not family-focused ones'* (team A)

Clinical co-researchers described how this process helped them to take informed discharge risks, for example, discharging patients with less than ideal social care packages, because concerns were discussed, family members harnessed family resources and made an informed decision to compensate for resource shortages. Moreover, co-researchers found this prevented crisis situations and resulted in sustainable discharges (team A).

Whilst clinical co-researchers described the tailoring of resources as taking informed discharge risks, family members described it as making realistic and appropriate plans, which respected their knowledge of their ill family member:

> '*The [consultant told me] my mum wouldn't make the journey home…I thought you're not right…you're [not] telling me I can't take my mum home…[the co-researcher] was more realistic…as soon as I said I want to take her home, she said "well yes of course you can take her home" and arrangements were made'* (Family member 001)

3. Factors which promoted and inhibited implementation of the Family-Focused Support Conversation

Implementation was promoted by strong coherence between the purpose of the intervention and the value co-researchers' placed on family care: *'the intervention is very much what [we] do as a team – to support family members'* (team E). Clinical co-researchers initially described the intervention as the same as their usual practice, apart from subtle differences. Coherence was promoted by these subtleties being '*sufficiently different to warrant practice and thought'* (team B). However, differentiation between the intervention and usual practice became more distinct for co-researchers as they gained experience in its provision.

The collective action strategies used by co-researchers (table 2) were important to the success of implementation. Undertaking implementation as a team or subgroup of a team, was considered helpful and supportive, particularly during team changes and conflicting priorities, to manage doubt and hesitation about their role in family support and/or discharge. However, when teams experienced significant staff sickness or shortage, or role changes, implementation was hindered. In two teams these factors resulted in an individual rather than collective approach to implementation, or in one team a shared understanding of the intervention but reduced capacity to participate in implementation.

Implementation was also fostered by the malleability of the Family-Focused Support Conversation. Whilst all interventional components were experienced as inter-related, co-researchers described loose coupling between the first component (meaningfulness) and the second and third components (comprehensibility and manageability) and strong coupling between the second and third components. Thus, clinical co-researchers in six teams described dividing the intervention into two phases, the first phase introduced the intervention and signalled understanding of the significance of the situation (meaningfulness component) and the second addressed concerns and focused on planning (comprehensibility and manageability components). This helped co-researchers to manage caseload pressures and complex clinical circumstances and to involve additional family members. In addition, in teams with specialist nurses and occupational therapists, delivery was sometimes divided between team members according to the nature of family concerns. Co-researchers also described occasions, when they only delivered the first intervention component, for example, because a patient was discharged before they were able to complete the intervention.

Thus, loose coupling helped co-researchers manage the reported change in the meaning of discharge fostered by the intervention, the shift from family support being specific to provision of discharge information about patient needs, to working with family concerns about caregiving after discharge. Therefore, in several research sites, there was evidence of normative restructuring, (May, Johnson and Finch; 2016:7), through the reorientation of interactional work and organisation of caseload management.

There was also evidence of relational integration, in how clinical co-researchers perceived their role in discharge care and how discharge work was distributed between ward, discharge and specialist teams. If co-researchers regularly undertook family support during the discharge process, the intervention was considered congruent with their role, co-researchers negotiated and collectively provided family support according to family needs and concerns. In the minority of cases where discharge work, and related family support, was considered a discrete ward or discharge team responsibility, co-researchers voiced tension in delivering the intervention in case it was perceived as inconsistent with previously agreed division of labour and for fear of creating ambiguity between their role and ward and discharge team roles. This made them cautious about using the intervention when ward teams had already started conversations with families about discharge. In these cases, co-researchers suggested it would be better if ward and discharge teams were trained to use the intervention.

Nevertheless, family support and discharge planning was not considered '*mutually exclusive'* (team C), as one clinical co-researcher explained: '*to think about discharge as …distinct from palliative care …is a false division*' (team B). Co-researchers provided examples of where they had provided the intervention by working together with ward and discharge teams delivering the intervention components according to each person's expertise. Others described how they used the intervention to reflect on conversations family members had previously had with ward teams, providing family members with opportunities to raise doubts and review decisions, and considered this use of the intervention as consistent with teamwork.

Discussion

The results provide confidence the Family-Focused Support Conversation can be implemented in acute hospitals by nurses and occupational therapists. Clinical co-researchers readily learnt how to deliver the intervention, found it practical to use, and time efficient. Co-researchers reported the intervention fostered family-focused support, which enabled family members to make informed decisions about their role in end of life care after discharge and resulted in realistic care plans which optimised use of available resources. Thus, the Family-Focused Support Conversation has the potential to provide evidence-based family support during end of life care transitions from hospital to home/nursing home. To our knowledge this is first intervention developed and implemented with this purpose.

The implementation differences noted between research sites can be explained by normative and relational restructuring processes (May, Johnson and Finch; 2016). The intervention was embedded in contexts in which co-researchers established flexible boundaries between their roles and those of ward and discharge teams, and where they were able to compensate for changes in resources (e.g. staffing and workload). Implementation was less embedded in sites (n=3) where there was strong demarcation between roles, or where co-researchers provided a service across several divergent organisations, and where there were significant role changes, sickness or vacancies.

Overall, the results point to the potential of the Family-Focused Support Conversation to influence system-wide change, given the implementation changes described (Hawe, Shiell and Riley, 2009). Changes were reported in patterns of behaviour (suspending assumptions about family concerns, avoiding the temptation to jump in with professional solutions to family concerns); roles (co-researchers as facilitators rather than experts, family members as experts in 'how we do things as a family' rather than an extension of the patient); and in practitioner-family relationships (from paternalistic to inclusive). These changes resulted in family members being involved in care planning and making informed decisions about their role in end of life care provision. At a system level these changes have potential to mitigate professional ambivalence and marginalisation of family members, noted to occur in acute hospital settings by Hanratty et al (2014) and Waring et al (2014), and to counter the risk adverse approach to discharge planning by hospital staff, noted by Coombs and colleagues (2017). In addition, these changes have potential to enhance the quality of end of life care transition decisions, effective use of resources and the sustainability of end of life care discharges (Rodakowski et al, 2017).

Moreover, the way in which the Family-Focused Support Conversation was considered supportive by family members is important, because it helps reconceptualise the purpose of family support during end of life care transitions. Support was described in terms of galvanising motivation and capacity to care, and harnessing resources inherent in family networks. These results reflect the meaning-focused approach to coping inherent in Family Sense of Coherence theory, which underpins the intervention. Meaning-making realigns priorities and creates or renews a sense of purpose (Folkman and Moskowitz, 2007). As noted by Hanratty and colleagues (2014), the results demonstrated during end of life care transitions, family members prioritised organisation of care in the most appropriate place, rather than long-term consequences of care on themselves or the family system.

Thus, support during end of life care transitions is concerned with working with the capacity of families to care for a dying relative, aligning this with 'how they do things as a family' and available resources. This affirms the importance of the Family-Focused Support Conversation in facilitating informed, sustainable decisions about place of care, and the role of family members in this care, through discussion of the implications of care options and available family and social care resources. This has potential to foster the resilience of family networks to organise and provide the necessary care to a dying relative, and to care for and about each other (Payne and Morby, 2013). Indeed, Ewing and colleagues (2018) argue these conditions are pre-requisites for comprehensive carer assessment for future support needs, important for sustaining care after discharge. Therefore, the Family-Focused Support Conversation has an important place in establishing the pre-conditions necessary for identifying and supporting family carers in the community.

We described the Family-Focused Support Conversation as a brief intervention, a short, structured conversation, designed to be provided either in planned or serendipitous interactions with family members. Whilst the results suggest this an appropriate classification, it raises some important considerations in terms of who should provide the intervention. Brief interventions are often used by non-specialists to deliver opportunistic 'front-line' support or health promotion, as a pre-curser to specialist support and/or self-management (Heather, 1989). Our decision to work with practitioners in specialist palliative care teams is somewhat contrary to these purposes, but important to the outcomes of the study. As in the pilot implementation, clinical co-researchers' expertise in palliative care, and their leadership and service development skills, generated rich 'insider' knowledge, pivotal to understanding how implementation was negotiated, organised and actioned. However, the examples provided by co-researchers sharing intervention delivery suggest the intervention could be delivered by ward-based nurses, hospital occupational therapist team members and discharge co-ordinators, with appropriate skills, if family member concerns were treated as triggers for referral to other colleagues and services, when beyond their expertise.

Nevertheless, the results also reinforce the complexity of discharge at the end of life (Popejoy 2011, Benzar et al, 2011) and the consequent need for interdisciplinary participation. This often results in dispersed, sometimes ambiguous and overlapping responsibilities (Benzar et al, 2011). Therefore, whilst the Family-Focused Support Conversation might be appropriately classified as a brief intervention, it is intended for implementation in complex situations (May, Johnson and Finch, 2016) where integration, and therefore family support outcomes, will be determined by the ability of professionals to navigate these complexities, to negotiate how they use available resources and work with colleagues to address family member concerns.

Strengths and limitations

This study has provided a rich qualitative account of implementation of the Family-Focused Support Conversation in twelve hospitals (seven acute NHS Trusts) across England. As with the pilot implementation, the quality of these results are a consequence of the combination of the research design, Participatory Learning and Action Research, with Normalization Process Theory, which provided a powerful reflexive lens through which to conduct the research and interpret the data. Importantly, the quality of the research is influenced by the emic knowledge, the rich insider implementation knowledge, generated by clinical co-researchers through their skilled leadership.

Nevertheless, it is important to consider the results in context. We need to better understand implementation by clinicians with different expertise and roles, and to understand the effectiveness of the intervention in terms of outcomes such as sustainability of discharge and family resilience. In addition, whilst the overall dataset has provided a rich understanding of implementation, accounts of family member experience were provided by a small proportion of those who received the intervention. Whilst response rates of family members were typical of palliative care and carer research (Grande et al, 2009), the number of research packs distributed by co-researchers was lower than anticipated. Co-researchers explained this was because discharge happened sooner than expected (although some packs were posted to family members afterwards) and some felt uncomfortable asking family members to participate (and take on more work) when they had just spoken about the amount of work they were doing to support their ill relative and prepare for discharge. Thus, the results are influenced by decisions made by clinical co-researchers about which family members to provide with a research pack and in turn this will have influenced the range of experiences recounted by family members. Therefore, thought needs to be given to alternative recruitment strategies in future studies to broaden the voice of family members in the research outcomes.

Conclusion

Discharge at the end of life is complex and consequently focuses on patient needs and securing appropriate resources and services to meet these needs. As a result, the emotional impact on family members and their concerns and contributions to discharge plans are seldom acknowledged. This study provided confidence about the usability, accessibility and acceptability of the Family-Focused Support Conversation, a brief intervention specially designed for use in acute hospitals in end of life care discharges, where time is of the essence. Importantly, it provides an evidence-based conversational guide that can be used by hospital palliative care teams, and potentially by ward and discharge teams with appropriate support, to meet family members' support needs during the end of life care transitions from hospital to home/nursing home. To our knowledge this is first intervention developed with this purpose.

Clinical co-researchers and family members reported implementation made a positive impact on the roles and relationships between practitioners and family members, the decisions made by family members and on how health and social care and family resources were utilised. The normative and relational restructuring underpinning this impact appear fundamentally important to the sustainability of discharge and the future support of family carers in the community. Additionally, there is good indication that the Family-Focused Support Conversation has the potential to influence system-wide change, by changing practitioners' understanding of family care and consequently mitigating the professional ambivalence and marginalisation of family members which has been described in acute hospital settings.

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Conflict of interest

The authors declare that they have no competing interests.

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References

Applebaum AJ and Breitbart W (2012) Care for the cancer caregiver: a systematic review *Palliative and supportive care* 11(3): 231-52.

Antonovsky A and Sourani T (1988) Family sense of coherence and family adaptation *Journal of Marriage and Family* 50(1): 79-92

Bauer M, Fitzgerald L, Haesler E and Manfrin M (2009). Hospital discharge planning for frail older people and their family. Are we delivering best practice? A review of the evidence. *Journal of Clinical Nursing* 18(18):2539-2546. doi:10.1111/j.1365-2702.2008.02685.x

Benzar E, Hansen L, Kneitel AW and Fromme EK (2011) Discharge planning for palliative care patients: A qualitative analysis Journal of Palliative Medicine 14(1):65-69

de Brùn T, O'Reilly de Brùn M, O'Donnell CA (2016) Learning from doing: The case for combining normalisation process theory and participatory action and learning research methodology for primary healthcare implementation research *BMC Health Services Research* 16(346) DOI: 10.1186/s12913-016-1587-z

Braet A, Weltens C and Sermeus W (2016) Effectiveness of discharge interventions from hospital to home on hospital readmissions: a systematic review. *JBI Database Systematic Reviews and Implementation Reports* 14(2):106-173. doi:10.11124/jbisrir-2016-2381

Candy B, Jones L, Drake R, Leurent B and King M (2011) Interventions for supporting informal caregivers of patients in the terminal phase of disease *Cochrane Database Systematic Reviews* 15(6): DOI: https://doi.org/10.1002/14651858.CD007617.pub2

Coombs M, Parker R and de Vries K (2017) Managing risk when approaching care transitions at the end of life: A qualitative study of patients' and health care professionals' decision making *Palliative Medicine* 31(7): 617-624

Duke S, Campling N, May C, Lund S, Lunt N, Hospital to Home co-researcher group and Richardson A (2020) Co-construction of the family-focused support conversation: a participatory learning and action research study to implement support for family members whose relatives are being discharged for end of life care at home or in a nursing home *BMC Palliative Care* 19:146 https://doi.org/10.1186/s12904-020-00647-5

Ewing G, Austin LM, Jones D and Grande G (2018) Who cares for the carers at hospital discharge at the end of life? A qualitative study of current practice in discharge planning and the potential value of using the Carer Support Needs Assessment Tool (CSNAT) approach *Palliative Medicine* 32(5): 939-949

Grande G, Stajduhar K, Aoun S, Toye C, Funk L, Addington-Hall J, Payne S and Todd C (2009). Supporting lay carers in end of life care: current gaps and future priorities *Palliative Medicine* 23(4): 339–344. https://doi.org/10.1177/0269216309104875

Hawe P, Shiell A and Riley T (2009) Theorising interventions as events in systems *American Journal of Community Psychology* 43: 267-276

Ferrell B and Wittenberg E A (2017) review of caregiving intervention trials in oncology *CA A Cancer Journal for Clinicians* 67: 318-325

Folkman S and Moskowitz JT (2007) Positive affect and meaning focused coping during significant psychological stress Chapter 12 in *The Scope of Social Psychology* (eds Hewstone M; Schut H, de Wit J, van den Boss K, Stroebe M) East Sussex: Psychology Press pp193-208

Hanratty B, Lowson E, Grande G, Payne S, Addington-Hall J, Valtorta N and Seymour J (2014) Transitions at the end of life for older adults – patient, carer and professional perspectives: a mixed-methods study *Health Services Delivery Research* 2(17) NIHR

Heather N (1989) Psychology and brief interventions *Addiction* 84(4): 357-370

Hoffman T, Glasziou P, Boutron I, Ruairidh M, Perera R, Moher D, Barbour V, Johnston M, Lamb S, Dixon-Woods M, McCulloch P, Wyatt J, Chang A-W and Michie S (2014) Better reporting of interventions: template for intervention description and replication (TIDieR) checklist and guide *British Medical Journal* 348:g1687 https://doi.org/10.1136/bmj.g1687

Hudson P and Payne S (2011) Family caregivers and palliative care: current status and agenda for the future *Journal of Palliative Medicine* 14(7): 864-869

McLeod-Sordjan R, Krajewski B, Jean-Baptiste P, Barone J, and Worral P (2011) Effectiveness of patient-caregiver dyad discharge interventions on hospital readmissions of elderly patients with community acquired pneumonia: a systematic review. *JBI Library Systematic Reviews* 9(14):437-463. doi:10.11124/01938924-201109140-00001

May C (2013) Towards a general theory of implementation *Implementation Science* 8, 18 https://doi.org/10.1186/1748-5908-8-18

May C. & Finch T (2009) Implementing, embedding, and integrating practices: an outline of normalization process theory *Sociology,* 43(3): 535–554. https://doi.org/10.1177/0038038509103208

May C, Johnson P and Finch T (2016) Implementation, context and complexity Implementation Science 11(1): 141 ISSN 1748-5908 https://doi.org/10.1186/s13012-016-0506-3

May C, Cummings A, Girling M, Bracher M, Mair F, May C, Murray E, Myall M, Rapley T and Finch T (2018) Using normalization process theory in feasibility studies and process evaluations of complex interventions: a systematic review *Implementation Science* 13:8 https://doi.org/10.1186/s13012-018-0758-1

Murray E, Treewick S, Pope C, MacFarlane A, Ballini L, Dowrick C, Finch T, Kennedy A, Mair F, O'Donnell C, Ong BN, Rogers A and May C (2010) Normalisation Process Theory: a framework for developing, testing and implementing complex interventions *BMC Medicine* 8(64) https://doi.org/10.1186/1741-7015-8-63

Payne S and Morby H (2013) *Supporting Family Carers: report on the evidence of how to work with and support family carers to inform the work of the commission into the future of hospice care* London: Help the Hospices

Penrod J, Hupcey JE, Shipley PZ, Loeb SJ & Baney B (2012) A Model of Caregiving Through the End of Life: Seeking Normal *Western Journal of Nursing Research* 34(2), 174–193. https://doi.org/10.1177/0193945911400920

Popejoy LL (2011) Complexity of family caregiving and discharge planning *Journal of Family Nursing* 17(1): 61-81

Rodakowski J, Rocco PB, Ortiz M, Folb B, Schulz, R, Morton SC, Leathers SC, Hu L and James AE III (2017), Caregiver Integration During Discharge Planning for Older Adults to Reduce Resource Use: A Metaanalysis. *Journal of American Geriatric Society* 65:1748-1755. doi:10.1111/jgs.14873

Smith TO, Pearson M, Pfeiffer K, Crotty M and Lamb SE (2019) Caregiver Interventions for Adults Discharged from the Hospital: Systematic Review and Meta-Analysis *Journal of American Geriatric Society* 67:1960-1969. doi:10.1111/jgs.16048

Thomas S, Dalton J, Harden M, Eastwood A and Parker G (2017) Updated meta-review of evidence on support for carers *Health Services and Delivery Research* 5(12) https://www.ncbi.nlm.nih.gov/books/NBK425177/

Ugalde A, Gaskin CJ, Rankin NM, Schofield P, Boltong A, Aranda S, Chamber S, Krishnasamy M and Livingston P (2019) A systematic review of caregiver interventions: Appraising the potential for implementation of evidence into practice *Psycho-Oncology* 28: 687-701

Van den Block L, Pivodic L, Pardon K, Donker D, Miccinesi G, Moreels S, Alonso TV, Deliens L, Onwuteaka-Philipsen B (2015) Transitions between care settings in the final three months of life in four EU countries *European Journal of Public Health* 25(4): 569-575

Wang T, Molassiotis A, Chung BPM and Tang J-Y (2018) Unmet care needs of advanced cancer patients and their informal caregivers: a systematic review *BMC Palliative Care* 17:96 https://doi.org/10.1186/s12904-018-0346-9

Waring J, Marshall F, Bishop S, Sahota O, Walker M Currie G et al (2014) An ethnographic study of knowledge sharing across the boundaries of care processes, services and organisations: the contribution to 'safe' hospital discharge *Health Service Delivery Research* 2(29) NIHR

Zamboni K, Schellenberg J, Hanson C, Bertran AP and Dumont A (2019) Assessing scalability of an intervention: why, how and who? *Health Policy and Planning* 34(7): 544-522 https://doi.org/10.1093/heapol/czz068

Declarations

Authors' contributions

Data collection and analysis was undertaken by NC, SD, SL. All authors contributed to interpretation of the data. SD drafted the paper, NC, SL, CM, NL and AR made significant contributions to its development and refinement, commented on subsequent drafts of the text and approved the final version. The implementation phase of the study was supervised by NC. The PI (SD) was supervised by AR.