

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

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Abstract

Background

Many people move in and out of hospital in the last few weeks of life. These care transitions can be distressing for family members because they signify the deterioration and impending death of their ill relative and forthcoming family bereavement. Whilst there is evidence about psychosocial support for family members providing end-of-life care at home, there is limited evidence about how this can be provided in acute hospitals during care transitions. Consequently, family members report a lack of support from hospital-based healthcare professionals.

Methods

The aim of the study was to implement research evidence for family support at the end-of-life in acute hospital care. Informed by Participatory Learning and Action Research and Normalization Process Theory (NPT) we co-designed a context-specific intervention, the Family-Focused Support Conversation, from a detailed review of research evidence. We undertook a pilot implementation in three acute hospital Trusts in England to assess the potential for the intervention to be used in clinical practice. Pilot implementation was undertaken during a three-month period by seven clinical co-researchers - nurses and occupational therapists in hospital specialist palliative care services. Implementation was evaluated through data comprised of reflective records of intervention delivery (n=22), in-depth records of telephone implementation support meetings between research team members and co-researchers (n=3), and in-depth evaluation meetings (n=2). Data were qualitatively analysed using an NPT framework designed for intervention evaluation.

Results

Clinical co-researchers readily incorporated the Family-Focused Support Conversation into their everyday work. The intervention changed family support from being solely patient-focused, providing information about patient needs, to family-focused, identifying family concerns about the significance and implications of discharge and facilitating family-focused care. Co-researchers reported an increase in family members' involvement in discharge decisions and end-of-life care planning.

Conclusion

The Family-Focused Support Conversation is a novel, evidenced-based and context specific intervention. Pilot implementation demonstrated the potential for the intervention to be used in acute hospitals to support family members during end-of-life care transitions. This subsequently informed a larger scale implementation study.

Trial registration n/a

Key words

- End-of-life care
- Family support
- Family-Focused Support Conversation
- Family Sense of Coherence
- Acute hospitals
- Normalization Process Theory
- Participatory Learning and Action Research
- Implementation

Background

For many, the end-of-life is characterised by movement between hospital and home or nursing home, particularly in the last few weeks of life¹. End-of-life care transitions can be practically and emotionally difficult for family members². They signify the certainty of impending death³ and evoke many uncertainties about the future, including care after discharge⁴. Thus, care transitions are a 'critical time' during which family members need additional support and information⁵ and an opportunity for health and social care professionals to identify and respond to this need.

However, family members rarely receive the support and help they need during end-of-life discharge planning. Qualitative research reporting their experiences demonstrate a focus on organisational needs rather than family concerns^{6,7}. As a result, families 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, once discharged⁶.

Whilst there is a growing body of research about effective family caregiver support interventions at the end-of-life⁸⁻²⁸ none of this evidence specifically addresses how to provide family support during hospital admission or during the transition of care from hospital to home or nursing home at the end-of-life. Despite this, the interventional content is considered potentially transferable to other contexts, providing consideration is given to the specific needs of family caregivers²⁹, and their broader circumstances over time³⁰. However, there is a paucity of research translating this evidence into realistic clinical applications^{31,32}.

We therefore undertook a Participatory Learning and Action Research study to implement support for family members (those important to a dying person, irrespective of relationship), during the transition between hospital and home or nursing home, at the end-of-life. This paper provides an in-depth account of intervention development and pilot implementation, of a unique, brief intervention, the Family-Focused Support Conversation.

Research approach

The study was informed by Normalization Process Theory (NPT), a structured and theoretically robust approach to understanding the factors that promote and inhibit implementation^{33,34}. NPT proposes that implementation is a dynamic interactive process, influenced by the social actions of those involved. This process is described by four constructs: coherence, sense making work; cognitive participation, relational work; collective action, operational work; and reflexive monitoring, appraising work.

NPT was integrated with a Participatory Learning and Action (PLA) Research approach, a combination previously demonstrated to positively influence the quality of intervention design and implementation, by ensuring inclusion of diverse sources of knowledge and expertise³⁵. In this paper we describe three PLA cycles concerned with intervention development and pilot implementation. These cycles broadly followed an intervention development process described by Hawkins and colleagues³⁶ consisting of: evidence review; co-production of a conceptual framework and interventional structure and process; and pilot implementation.

Methods

The aims were to:

- Critically review the research evidence base for supporting family members caring for a dying person, to identify the theoretical and therapeutic mechanisms of effective interventions (PLA cycle 1);
- Design a conceptual framework, theoretically modelled on the evidence review, and from this co-produce the structure and process of an intervention suitable for the acute hospital context (PLA cycle 2);
- Undertake a pilot implementation, to assess the potential for the intervention to be used in acute hospitals and understand whether it created unexpected work or disruption for family members and staff (PLA cycle 3).

PLA participants comprised:

- *Patient and public involvement [PPI] participants*, (n=5) members of the public with experience of caring for a dying relative, recruited through National Institute of Health Research (NIHR) networks;
- *Clinical co-researchers* (n=7), specialist nurses and occupational therapists, working in palliative and end-of-life care teams in 3 acute NHS Hospital Trusts in England (one in the South of England and two in the North). The teams were recruited through the National Nurse Consultant (Palliative Care) Group;
- *Social care experts* (n=6), members of local and national carers groups and social workers with expertise in end-of-life care, recruited through palliative care networks.

All PLA participants were involved in the co-construction of the intervention in PLA cycle 2. Clinical co-researchers led implementation in PLA cycle 3. All PLA participants were involved in the interpretation of implementation results for PLA cycle 3.

Evidence review (PLA cycle/aim 1): The evidence review focused on research reporting interventions to provide family caregiver psychosocial support during palliative and end-of-life care. Psychosocial support was defined as support concerned with the emotional and relational wellbeing of family members³⁷.

There are a growing number of systematic reviews assessing psychosocial interventions for family caregivers during palliative and end-of-life care. However, systematic reviews rarely provide enough detail about interventions to allow implementation³⁸, but they do provide rigorous assessment of the methodological quality of studies. We therefore identified studies to review from these sources. Systematic reviews were identified from the meta-review by Thomas et al⁹, and from a search for systematic reviews published subsequently. All studies included by the review authors were assessed for relevance (box 1). They were included if focused on caregiver support during palliative and end-of-life care, if graded by the systematic review authors as being of good methodological quality and if the intervention was amenable to delivery by hospital-based registered practitioners. Identified studies were analysed to identify the theoretical framework(s) underpinning the reported interventions and the interventional mechanisms identified by authors responsible for the reported therapeutic outcomes.

Insert box 1 here

Co-production of conceptual framework and intervention design (PLA cycle/aim 2): The outcomes of the evidence review were synthesised into a conceptual framework from which the structure and process of the intervention was co-constructed with PLA participants. There is very little guidance about how to undertake this process in healthcare^{39,40} but we previously found participatory theatre techniques^{41,42} valuable in drawing out participants' cultural, clinical and social knowledge to inform the translation and synthesis of evidence into healthcare processes⁴³. We integrated these approaches in the following steps:

1. Workshop with PPIs, clinical co-researchers and social care experts: 'theatre of language' and 'forum theatre'⁴¹ techniques were used to discuss the evidence and from this identify key principles for the conceptual framework and then map the identified intervention mechanisms onto to the structure of a typical clinical conversation⁴⁴.
2. The mapped clinical conversation was refined by developing conversational prompts through simulation and rehearsal of the intervention. The PI (SD) acted as clinician, an educational performative theatre expert as family member and the Senior Research Fellow (NC) as observer, providing reflective comments to guide simulation. The simulation was video-recorded and transcribed into a description of the interventional process.
3. The transcribed interventional process was discussed with PLA participants and mapped to a theoretical framework. This process resulted in a conceptual framework and intervention.

Pilot implementation (PLA cycle/aim 3): Following ethical and local site research governance approvals (REC ref: 16/SC/0330) pilot implementation was undertaken over a three-month period by seven clinical co-researchers (described above), most of whom were involved in intervention development. In preparation, clinical co-researchers attended a half-day workshop where the intervention was reviewed, discussed and rehearsed. Given one of the purposes of pilot implementation was to assess potential disruption caused by implementation, each clinical co-researcher was asked to limit intervention provision to five interventions.

Data collection was informed by NPT and collected via reflective records of intervention delivery, detailed records of telephone conversations between the research team and clinical co-researchers discussing implementation progress and detailed records of evaluation meetings.

Data analysis was undertaken by three members of the research team (NC, SL, SD), following a Framework Analysis approach⁴⁵. Data were initially coded, using the broad constructs of NPT, followed by a more detailed analysis, using NPT-generated questions designed by Murray et al⁴⁶ as an analytical framework. A workshop to discuss interpretation of data analysis was held with PLA participants.

Ethics

In addition to research ethics and site governance approvals required for implementation (REC ref: 16/SC/0330), PLA raises ethical concerns about the location of 'power' in researcher and participant relationships and how this is managed to achieve the collaborative relationship intended³⁵. Detail of how we approached these concerns is provided in supplementary information 1.

Results

Evidence review results (PLA cycle/aim1): Full details of the evidence review is provided in supplementary information 2. The process is summarised in fig 1.

A total of 20 systematic reviews were identified; 18 reviews graded as good or medium quality by Thomas et al⁹, focused on end-of-life care or cancer care^{8,10-26} and 2 systematic reviews published subsequently^{27,28}. Nine reviews were excluded because they focused on evaluation of services^{10,11}, bereavement interventions¹², communication¹³, or interventional approaches not amenable to hospital provision, such as art therapy¹⁴, physical activity¹⁵, web-based delivery¹⁸ and mindfulness^{27,28}. The remaining 11 systematic reviews^{8,17-26} comprised 103 studies of which 96 were excluded.

Insert fig 1 here

The seven papers identified for analysis, related to 6 studies focused on psychosocial support for family members, during end-of-life care⁴⁷⁻⁵³. Two of these studies related to the FOCUS^{49,50} and COPE^{51,52} interventions and therefore manuals for these interventions were obtained from the authors.

Insert table 1 here

Four studies explicitly stated the theoretical framework(s) adopted⁴⁷⁻⁵⁰, in one it was implicit^{50,51} and in another not stated⁵³. Five studies were underpinned by stress and coping frameworks derived from the work of Lazarus and Folkman and aimed to mitigate uncertainty, distress and carer burden, enhance family communication and increase access to resources⁴⁷⁻⁵². One study also drew on Horowitz's work⁴⁷, which emphasised the importance of meaning-making in adaptation to difficult life events (table 1). Thus, collectively, the reviewed studies were theoretically modelled on stress, coping and meaning making, and focused on quality of life.

The interventional processes identified from the review included the provision of information, sense-making, problem-solving, resource networking and self-care. All interventions were delivered over successive consultations, for example FOCUS and COPE were provided in three structured visits of at least 30 minutes each. There was insufficient detail in the reviewed studies to assess the effectiveness of proposed therapeutic mechanisms on outcomes. Therefore, in consultation with PLA social care experts and clinical co-researchers, we considered it prudent to adopt recommendations from Northouse and colleagues¹⁷ to focus intervention processes on mitigating uncertainty and from Candy and colleagues⁸ to at '*the very least healthcare practitioners should enquire about the concerns of family and friends caring for a loved one*' (p23) and incorporate information and problem-solving coaching processes, to buffer psychological distress.

Conceptual framework and intervention structure and process (PLA cycle/aim2):

PLA participants stressed the importance of the intervention being equally applicable to any family member, irrespective of their role in future care, and deliverable as the opportunity arose. Use of a pre-existing intervention such as FOCUS or COPE was therefore considered impractical and inappropriate. Therefore, to ensure the intervention could be delivered flexibly, depending on family and clinical circumstances, we used a structured conversation

design, a brief intervention design considered clinically feasible for provision of evidence-based psychosocial support⁵⁴.

In addition, PLA participants emphasised the importance of involving family members in end-of-life care decisions, recognising their knowledge of the ill person and 'how they do things as a family'. Therefore, the intervention was theoretically modelled on Family Sense of Coherence⁵⁵. Family Sense of Coherence is theoretically congruent with the stress, coping and adaptation theories underpinning the reviewed studies, but rather than focusing on ill health (distress) and quality of life, it focuses on family strengths, resilience (coherence) and salutogenesis (wellness). Coherence is influenced by whether life events are considered comprehensible, manageable and meaningful and congruent with 'how we do things as a family'⁵⁵. Family Sense of Coherence was also theoretically consistent with the interventional processes of meaning-making, problem-solving and harnessing resources, identified in the evidence review.

Importantly, the meaningfulness component of FSC is considered key to family coherence⁵⁵. Meaning focused approaches are particularly helpful in situations characterised by uncertainty⁵⁶ by helping to realign priorities and create or renew a sense of purpose⁵⁷. This approach therefore suited end-of-life care transitions where family priorities move towards the care of a dying member, when there is limited time to make decisions about place of care and where there is uncertainty about care provision and the future. Thus, addressing uncertainty by focusing on meaningfulness is likely to strengthen family coherence. Family members with strong family coherence are likely to have positive caring experiences⁵⁸⁻⁶⁰, and confidence in end-of-life care provision⁶¹.

Consequently, the internal logic of the resulting conceptual framework proposed that family members' uncertainties about end-of-life care could be reduced by identifying and addressing their concerns, by providing information and coaching problem-solving. As a result, family members would make informed decisions about their role in care and harness family and community resources. Thus, the intervention would foster family coherence (resilience) (fig ii).

Insert fig ii here

The structure and process of the intervention, resulting from the participatory theatre workshops, are outlined in table 2 and fig iii. This description includes a revision made by clinical co-researchers during implementation training, to use an empathetic phrase at the beginning of the intervention to orientate participants to the family focus of the conversation, followed by a pause. This combination of empathetic statement and pause, increases the likelihood that concerns are raised and addressed in clinical consultations⁶².

Insert table 2 and fig iii intervention process here

Implementation results (PLA cycle/aim3):

Data consisted of n=22 reflective records of intervention delivery (site 1: n=5; site 2: n=10; site 3: n=7), n=3 records of discussion of implementation progress and n=2 records of evaluation meetings.

Table 3 provides a summary of analysis, constructed from data coded against NPT-generated questions for intervention evaluation⁴⁶. The table provides the source of data quoted in italics below. All quotes were provided by clinical co-researchers - specialist nurses and occupational therapists in palliative care.

Insert table 3 here

- a) The potential for the intervention to be used in acute hospitals

All clinical co-researchers implemented the intervention. Some needed to see the intervention delivered or to deliver it themselves, *'to get it'*. Most needed to practice how to phrase the interventional prompts so that the intervention *'flowed'* and was consistent with their communication style and patient population. Some approached implementation by delivering the intervention whenever they spoke to a family member about discharge care plans, irrespective of circumstances. Others initially selected opportunities to use the intervention, starting with more straightforward discharge situations. As co-researchers gained confidence, the intervention was incorporated into practice, irrespective of the complexity of discharge.

Some clinical co-researchers were initially concerned the intervention would take more time than normal care but found it enabled focused discussions and quickly identified family concerns, and thereby saved time. As they gained confidence they moved backwards and forwards between the comprehensibility and manageability components of the intervention to address family concerns. Nevertheless, implementation was influenced by contextual challenges such as resource constraints and organisational pressures on their work, for example when organisational pressures resulted in *'late referrals'* and insufficient time to meet with family members before discharge. Some managed these pressures by splitting delivery over successive consultations, introducing the focus of the intervention (meaningfulness) in the first meeting (in person or by telephone) and completing delivery at a second meeting.

- b) Did the intervention create unexpected work or disruption for family members and staff?

Co-researchers described how the intervention disrupted and *'pulled apart their practice'* by *'flipping conversations to focus on the family'*. They described a shift in their understanding of family support as something professionally focused and *'done to families'* to practice centred on *'the meaning for the family and their concerns'*. They also discriminated the intervention from *'discharge itself'* or *'bits of kit'* or *'a checklist'*. They reported a deeper understanding and respect for family care and increased satisfaction with discharge work and provided examples of how the intervention enhanced family care (see table 3).

Implementation was also influenced by the local working arrangements for discharge between specialist and ward teams. When discharge was considered a ward team responsibility, clinical co-researchers were worried the intervention would disrupt these arrangements and create ambiguity about their role. Some clinical co-researchers therefore restricted use of the intervention to occasions when discharge conversations had been commenced with family members by ward staff. Others used the intervention to clarify concerns family members had previously raised with ward staff or by delivering the intervention in collaboration with ward staff.

Discussion

In the three PLA cycles reported above, we co-constructed and implemented the Family-Focused Support Conversation. This structured conversation is underpinned by a robust review of research evidence, family members' experiences and clinical expertise, and theoretically informed by Family Sense of Coherence, a theory which emphasises family strengths and resilience.

The evidence review identified the importance of modelling interventions for family support on uncertainty¹⁷, and therefore asking family members about their concerns⁸. Consistent with other reviews we found a lack of interventions adopting a family centred or family systems approach² and a lack of translation of research evidence into feasible clinical interventions^{31,32}. Similarly, with respect to intervention reporting, we found inconsistent detail about the theoretical frameworks underpinning interventions⁶³ and insufficient evidence about the effectiveness of intervention mechanisms on outcomes^{8,9,29,63}.

Pilot implementation demonstrated the potential for the Family-Focused Support Conversation to be adopted in acute hospitals. Clinical co-researchers made sense of the intervention (coherence), actively engaged in implementation (cognitive participation), worked together to provide the intervention (collective action) and reflected on its benefits and costs (reflexive monitoring).

The reported shift in co-researchers' practice, as a consequence of implementing the intervention, is notable. All co-researchers valued family support as part of their palliative care role but described how their practice was subject to the organisational constraints and priorities experienced by most hospital practitioners^{6,7}. Thus, some described how previously they focused on discussing discharge arrangements with family members rather than family concerns. The intervention enabled a shift in focus to family concerns about the meaning, significance and implications of discharge, and how family caregiving might be managed.

In part this shift occurred because of the strong coherence between the value co-researchers placed on family support and the purpose and design of the intervention. Co-construction meant co-researchers' values were integrated within the design of the intervention. However, because these values were combined with those of family

members, social care experts and research evidence, and integrated through theoretical modelling and clinical simulation, the intervention provided a structured communication process by which the inherent tensions in purpose between hospital organisational priorities and family support could be reconciled⁶⁴. Thus, the structured conversation weaves intervention components in a clinical conversation and provides a clinically feasible⁵⁴ means of providing family support and to optimizing family outcomes⁶⁴.

However, the results also demonstrated how organisational discharge priorities were embedded within the distribution of work between practitioners. Where ward teams had responsibility for end of life discharge, implementation threatened to disrupt previously negotiated roles between ward and specialist teams and co-researchers were concerned about creating role ambiguity. In these instances, the noted shift in practice was also due to the negotiation strategies used by co-researchers to implement the intervention, and sustain their relationships with ward teams, without causing ambiguity about their respective roles. However, it is important to recognise this account does not include the impact of implementation on ward staff or their experience of the negotiation strategies used by co-researchers.

Our decision not to involve ward teams in the study was a consequence of the role we wished co-researchers to play in the reported phases of the study. We considered it important for co-researchers to have palliative care expertise and communication, reflective and service development skills to influence the design of the intervention and lead implementation. The rich knowledge generated by co-researchers, discussed above, is testament to these skills and to their adaptation to a research leadership role, something which markedly contrasted with most co-researchers' previous experiences of research. This reversal of roles reinforced the importance of a research team having pedagogic skills to support co-researchers in this leadership role.

The knowledge generated in the three PLA cycles described in this paper was used to further implement the Family-Focused Support Conversation in 12 NHS acute hospitals in England and to qualitatively evaluate its usability, acceptability and accessibility and will be reported elsewhere.

Conclusion

Discharge from hospital at the end-of-life is complex and organisational priorities often result in family members lacking the support needed to make informed decisions about their role in end-of-life care on discharge. Through a process of co-construction, we designed an evidence-based structured conversation, the Family-Focused Support Conversation. Pilot implementation demonstrated the intervention has the potential to be adopted in acute hospitals, and addresses family concerns about the meaning and significance of discharge, implications about end-of-life care needs and how family caregiving can be managed and enhanced.

Abbreviations

FSC: Family Sense of Coherence

PLA: Participatory Learning and Action (Research)

NPT: Normalization Process Theory

Declarations

Ethics approval and consent to participate

Ethical approval was gained via the NHS Health Research Authority from the South Central – Hampshire A Research Ethics Committee REC ref: 16/SC/033; IRAS Number 208275

Consent for publication

Not applicable

Availability of data and materials

All data generated or analysed for this study are included in this published article [and its supplementary information files].

Competing interests

The authors declare that they have no competing interests

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Authors' contributions

Implementation was undertaken by the co-researcher group. Data collection and analysis was undertaken by NC, SD, SL. All authors contributed to interpretation of the data. The study was supervised by AR. SD drafted the paper, NC, SL, CM, NL and AR made significant contributions to its development and refinement and commented on subsequent drafts of the text. All authors have read and approved the final manuscript.

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Figure Legends

Figure 1 Evidence review process

Figure 2 Family-Focused Support Conversation: Conceptual Framework and Logic Diagram

Figure 3 Family-Focused Support Conversation – process

Table Legends

Table 1 Summary of review of intervention studies of family support during palliative and end of life care

Table 2 Structure and process of intervention and underpinning theoretical framework

Table 3: Implementation results – summary of analysis using NPT generated questions for interventions (Murray et al, 2010)

Box legend

Box 1: Inclusion and exclusion criteria for evidence review