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Connecting Health and social care to
Offer Individualised Care at End of
Life

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Summary

Background: In Scotland reduction in length of stay both in acute hospital and hospice (NHS Scotland 2012). Together with the national action plan for palliative care (NHS Scotland 2008), which sets out a commitment to equity of timely palliative and end of life care to all patients and their families, regardless of diagnosis and care settings including the patients home, prompts the need for care at home that is both effective and timely. Concurrently, the reform of health and social care in Scotland has placed emphasis on the integration of health and social care (NHS Scotland 2013). The aim is to support patients and families maintaining quality of life at home for as long as possible. While this presents an opportunity for community nurses and social care workers to work together, evidence from the literature and practice suggests care is fragmented with poor communication leading to social care workers in particular, feeling under supported and under-valued. They also feel unsure of what is expected of them.

Aim: To develop and pilot test an initial framework of integrated working to facilitate person-centred care for patients and families at the end of their life who are being cared for in their home.

Methods: Principles from different theories and approaches were adopted including participatory research, realist synthesis, person-centred practice, practice development and active learning.

Discussion: An evidence-based model was developed by adopting systematic rigorous processes. Multiple voices from research evidence, policy, community nurses, social care workers and most crucially family carers were incorporated. Through participation and inclusion of all stakeholders in the process and active learning, there was an indication of staff development at all levels. The processes of visioning and values provided direction for the project, whilst enabling the methodological principles to be developed. The outputs of the project included a shared communication sheet, draft person-centred end of life care questions for social care worker interviews, education sessions and informal drop-in sessions to address social care workers' development needs. Unfortunately it was not able to be tested during end of life care with patients and families.

Implications: This model has the potential to develop practice in an integrated, person-centred way, although further testing is required in practice. The implications for community nursing practice are considerable within the current integration agenda. The model has the potential to pose a way forward for delivering person-centred end of life care at home in an integrated way. The work is continuing in another project and is central in a research bid currently being developed.

Keywords:

End of life care, community nursing, home care workers, person-centred, integrated



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Glossary

CN: Community Nurse, Registered nurse who works as part of team delivering care to people in their own homes. NHS employee.

DN: District Nurse, Registered nurse who has a specialist practice qualification, leads a group of community nurses, HCA and clerical staff. NHS employee

HCA: Health care assistant: Employed by NHS

HCO: Home care organiser who leads a team of SCW, employed within Social work

MDT: Multi-disciplinary team

OOHs: Out of Hours

PD: Practice Development

SCW: Social care worker, employed by Social work

SG: Scottish Government

1. Introduction

Increasing life expectancy resulting in an increasing number of adults living with long term, often life limiting conditions, demands the need for a healthcare system that can adapt to meet the changing needs of populations and communities (Hardy et al 2014, (Scottish Government [SG] 2104). In 2008 The Scottish Government set out a national action plan, Living and Dying Well, to ensure equity of timely palliative and end-of-life (EoL) care to all patients and their families, regardless of diagnosis and across all care settings including the patient's home. In a response, innovative ways of providing better quality care and quicker responses for people at the end of their life who would like to return home to die are being explored. Within the new landscape of integrated care new ways of working are being sought. This report outlines a project funded by the Queens Nursing Institute Scotland which aimed to develop and test a model of integrated, person-centred care for people at end of life at home. This model, informed by current literature and through stakeholder engagement has the potential to develop practice in an integrated, person-centred way.

1.1. Background

In Scotland the reduction in length of stay both in acute hospital, 5 days in 2011 (NHS Scotland 2012), and hospice, e.g. 17 days in St. Columba's Hospice during 2013, means that more patients with palliative and EoL care needs are either discharged home or choose to be at home. Despite the vision produced by NHS Scotland in 2013 to enable *'everyone to live longer healthier lives at home, or in a homely setting'* the ability to be at home will often depend on the availability of care provision and equipment, as well as the suitability of the home circumstance. Both community nursing and social care services have seen an increase in the range and level of complex conditions being managed within an individual's home. This is attributable to the diversity of advancing technologies, social, demographic and legislative changes as well as a shift in public perception, beliefs and expectations about health and social care and how services are provided (Darzi 2008). In an effort to meet these changes to support patients and families maintain quality of life for as long as possible, the reform of health and social care in Scotland has placed emphasis on the integration of health and social care (NHS Scotland 2013).

Care provision at home, including symptom management, anticipatory care planning and emotional and psychological support, is usually coordinated by the district nurse (DN) with the delivery of personal care usually being provided by the social care worker (SCW). In spite of the significance of the integration of services to the provision of care at home, there was little underpinning research found in the literature. There is some reference made to the consequence of several social care workers being assigned to one service user and the mismatch of services resulting in fragmented care and poor communication between SCWs (Herber and Johnston 2013; Devlin and McIlfatrick 2009). Anecdotal examples from practice support this finding leaving SCWs feeling undervalued and unsure of what is expected of them. This ambiguity was highlighted by Herber and Johnston (2013). Despite this key role, varying levels of skill, experience and unmet training needs are seen amongst SCWs (Devlin and McIlfatrick 2010). This may be a reason for the DN taking over the personal care component when the patient's condition deteriorates into the last days of life. Research evidence ratifies this local anecdotal evidence and suggests the need for 'on the ground' supervision to enable the social care worker to be able to provide continuity of care, develop to cope with the demands of the role (Devlin and McIlfatrick 2010).

1.2. Community Services in Edinburgh

The Edinburgh District Nursing Service comprises over 300 predominately registered nursing staff with a small number of non-registered staff. The service is provided over a 24 hour period, 365 days of the year and often in collaboration with a wide range of primary, secondary, statutory and voluntary agencies. The DN team provides nursing care at home (or to those within a homely setting such as a care home) for patients who increasingly have complex multiple co-morbidities and life limiting conditions. The DN team also provides practical and emotional support to patients, their families and carers. They have a focus on prevention, anticipation and supported self-management and have expertise in palliative and end of life care including symptom management and pain control. Care is provided to the highest standards of quality and safety, with the patient at the centre of all decisions where at all possible.

The City of Edinburgh Home Care and Re-ablement Service comprise over 1,100 front-line care workers. Working over a 24 hour period, 365 days a year, together these services provide

14,000 hours of care each week in 24,000 visits (1.2 million a year). Approximately 50% of referrals for care are made from hospital to enable discharge; the remaining 50% are made from community services. Within these services there is a commitment to improve outcomes for service users through close collaboration with colleagues from health, the third and independent sectors.

2. Aim

The overall aims of the project were to develop and pilot test an initial framework of integrated working to facilitate person-centred care for patients and families at the end of their life who are being cared for in their home.

2.1. Project objectives:

1. Identify principles of integrated working through a rapid review of best practice models of integrated working in the community and ways of developing effectiveness in this
2. Engage with the steering group who have a variety of expertise, in verifying the literature findings and consider the implications for framework development
3. Explore patient, families, Community Nurse (CN) and care workers' values and beliefs of integrated working in providing end of life care
4. Work in partnership with key stakeholders to develop an initial framework of integrated working to facilitate end of life care at home
5. Adopt practice development methodologies to introduce and test an initial framework
6. Identify any ethical issues for consideration in the project delivery and seek the necessary ethics and governance approvals
7. Address learning needs to facilitate the pilot site work and consider future wider workforce needs
8. Explore process and outcomes of the development of the integrated care framework
9. Enhance leadership within both health and social care teams through the development and implementation of an initial framework of integrated practice
10. Enhance research capability of the community nursing team through engagement and involvement in this project

3. Project Methodology

The project drew on a number of principles from different theories and approaches: participatory research, realist synthesis, person-centred practice, practice development and active learning. The emphasis of these approaches is participatory, collaborative and inclusive approaches to research and development (McCormack et al. 2008). This broad-based approach to researching practice or work in health care includes all stakeholders (Manley et al 2013). The aim is to bring about change together with the generation of new knowledge arising from the processes.

Realist synthesis methodology is an approach to research and synthesis which enables synthesis of evidence about complex implementation interventions (Rycroft-Malone et al. 2012). Realist synthesis was developed by Pawson (2006) as a method of studying complex interventions in response to the perceived limitations of traditional systematic review methodology which aims to assure reliability through a highly specified and intentionally inflexible methodology. Realist synthesis views 'context' as critical to determining outcomes steering away from failed 'one-size-fits-all' ways of responding to problems (Pawson, 2006; Rycroft-Malone et al 2012). Drawing on realist synthesis, multiple sources of evidence were analysed and synthesized and then used to inform model development. Additionally, evidence was sought from existing models of integrated working. This was then further refined and tested using practice development and active learning approaches.

Person-centredness is concerned with all persons including those being cared for as service-users, their supporters and colleagues. McCormack and McCance (2010) define person-centredness as:

“an approach to practice established through the formation and fostering of healthful relationships between all care providers, service users and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development”. (p 31-32)

There are four constructs: pre-requisites, care environment, person-centred processes and outcomes. To achieve positive outcomes for service-users and staff, McCormack and McCance (2010) suggest attention must be given to pre-requisites and the care environment. This will in turn enable person-centred care processes. Care processes highlighted in the person-centre practice model and evident in the literature are shared-decision-making, being sympathetically present, providing holistic care and working with patients' beliefs and values.

Practice development (PD) is a systematic approach to improving practice aiming to help practitioners and healthcare teams to look critically at their practice and identify how improvements can be made (McCormack et al 2009). Achievement through active learning where learning takes place in the workplace and involves the multiple use of the senses and intelligences. It also includes reflecting and engaging in an internal dialogue with self and an ongoing dialogue with others (Dewing 2008). Practice development and active learning aim to develop person-centred cultures with the intention of finding new ways of working (McCormack 2013). Key to these activities is participation and involvement of all stakeholders – patients, clients, families and staff. McCormack (2013) and Dewing (2009) suggest change will only occur if the culture and context of care is addressed.

Ethical approval was granted by Queen Margaret University Ethics Committee. NHS ethical approval was not required, although ethical principles were adopted by the researchers at all times.

3.1. Research approach

An inclusive approach to developing the framework was adopted, allowing an iterative process of examining evidence from existing literature and focus groups with key informants to address the review question.

“In maintaining person-centred care for patients at end of life and their families, what aspects of integration work, for whom do they work, in what circumstances and why?”

The process adopted was in three stages.

Stage 1

The first stage of the review was to refine the purpose of the review. Questions asked were developed by the project team and endorsed by the Steering Group. Current literature, including policy was scoped and existing models of integrated working were analysed to establish:

What does the evidence tell us about the nature and content of integrated working?

What circumstances or context help or hinder the effectiveness of integrated working?

What are the policy intentions or objectives?

What are the expected outcomes or impacts of effective person-centred integrated EoL care?

Stage 2

Following an initial scoping of the literature and piloting focus group questions with service-users, key theoretical principles that underpin integrated working in the community were identified and brainstormed by the project team. Realist syntheses are concerned with theory development and refinement (Pawson 2006). As interventions are complex, causal mechanisms: what may work and what may not work, in what contexts, how and in what circumstances are uncovered, rather than best practice (Pawson et al. 2011). Pawson and Tilley (1997) represent this as context + mechanism = outcome. By outlining programme theories, according to Rycroft-Malone et al. (2012) evidence can be interrogated to find out whether and where these theories are pertinent and productive. Draft programme theories were taken to the steering group and refined. These were then used to develop key search terms and shape the analysis of the literature and data synthesis. Data included findings from focus groups.

Stage 3

Data collected in four focus groups with service-users, community nurses and social care workers contributed to the development of programme theories. One focus groups was with community nurses, one with social care workers and two with family carers. The questions for the focus groups were piloted with two family carers. Data captured from these groups can be

found in Appendix 1. Findings were discussed within the framework of Pawson and Tilley's (1997) m,c,o configuration.

Mechanisms

Important to community nurses included anticipatory care planning and early intervention, providing holistic care, ongoing assessments interagency working and coordinating care. Social care workers also felt care coordination was important and identified the necessity of a key worker. Family carers identified this as organised care. Social care workers also identified support for themselves during care delivery and after as well as the need for team identity, whereas family carers also considered individualised approaches as a mechanism for integrated, person-centred care at EoL.

Context

Community nurses highlighted the need for a supportive environment, adequate time and valuing relational aspects of their role as well as tasks. Social care workers identified integrated organisational structures, whereas family carers emphasised the importance of one point of contact and appropriate preparation and key attributes of care workers. Social care workers highlighted cultures of person-centredness and anticipatory care as key contextual factors.

Outcomes

Given the mechanisms and context highlighted by the three groups participating in focus groups, anticipated outcomes for community nurses included quality care, anticipatory care, seamless care and dignity. This was echoed by the other groups. Family carers added reduction in anxiety, time and constraints.

The resultant programme theories are presented in Fig. 1

Fig 1: Programme Theories

- **A Person- centred approach drives integrated working for patients at end of life at home.**

(Key words: Person-centred, relationship, patient-centred, safety or risk, equity)

- **A holistic person-centred model of end of life care will be enhanced by effective collaboration.**

(Key words: communication, holistic model, collaboration, shared systems, multidisciplinary, interagency, patient pathway, shared documentation.

- **Working in partnership with patients and families will enable self-management and improve the patient and family experience of end of life care at home.**

(Key words: patient/carer expectations, appropriateness, anticipatory, therapeutic relationships, partnership, trust, family/patient/carer experience.

- **Good case management features effective leadership supported by integrated organisational structures.**

(Key words: leadership, case manager, key worker, organisational structures, out of hour services, early intervention, resources, continuity,

3.2. Search strategy

3.2.1. Databases

The focus of the rapid literature review was to identify relevant papers through a systematic search strategy. A limited number of electronic databases were utilised due to the nature of the literature review, namely: ASSIA, CINHALL, MEDLINE, PROQUEST, PsychINFO SCOPUS

3.2.2. Search terms

A variety of search terms were used to ensure full exploration in the different databases:

'District nurs*' OR 'Community Nurs*'OR ' Home health nurs*' AND integration OR inter-agency AND care*

AND person-centred* OR patient-centred* OR family centred*

AND relationship OR therapeutic

AND safety OR risk

AND equity

AND culture OR values

AND role* OR responsibilities*

AND teamwork* OR partner* OR multidisciplinary*

AND patient OR pathway

AND expectation OR appropriate*

AND anticipatory

AND trust

AND family experience

AND leadership

AND case manag*

AND organisation OR system

AND out of hours OR unscheduled care*

AND early intervention

AND resource

AND continuity

AND communication

AND holistic

AND shared documentation

AND end of life

With the assistance with the Divisional Librarian, all retrieved studies were entered into *Refworks*, a software package useful in managing data.

3.2.3. Inclusion criteria

To be considered for inclusion in the literature review, papers had to meet the inclusion criteria.

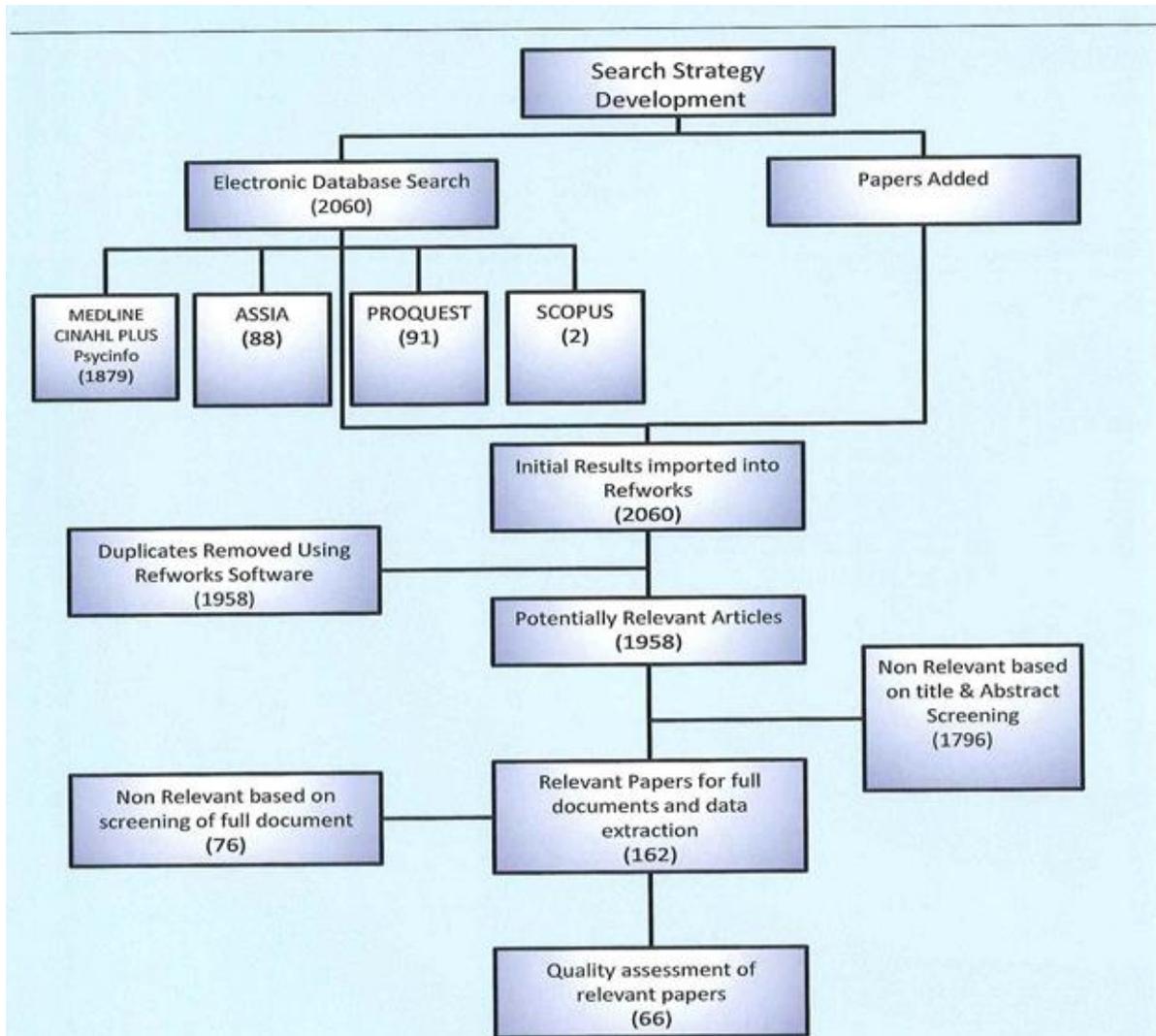
Inclusion criteria	Exclusion criteria
English language only	Hospice care
Dates 2009-2014	Hospital care
Community nursing	Care homes
Home care	Nursing Home
Community setting	Dates Pre-2009
Social care involvement	Opinion pieces
Research papers	
Practice developments	
Policy documents	
Peer-reviewed	

Search limits were 2009-2014. A total of 66 relevant papers were found (Fig 2). Papers revealed in the initial search were screened for relevance by two reviewers. The abstract of each paper was read and independently by each reviewer and assessed against the inclusion criteria.

3.3. Quality assessment

Data were extracted using and adapted data extraction forms from Elliott et al. (2012) and Garrard 2007). While the data extraction forms highlighted the focus of the studies and the quality of the methodology adopted, inclusion of programme theories ensured the theoretical framework was adopted. This is a unique feature of realist reviews. Studies included in the review were inserted into a literature matrix and themed.

Fig 2: Search strategy



4. Data synthesis; Literature Review

4.1. A Person- centred approach drives integrated working for patients at end of life at home

The Healthcare Quality Strategy (NHS Scotland 2010) sets out three Quality Ambitions, safe, effective person-centred care. This strategy underpins all Scottish healthcare policy. An

integrated approach is required for implementation to improve service planning and delivery. For example the 'Routemap to the 2020 Vision for Health and Social Care' (Scottish Government (SG) 2013) advocates the person at the centre of all decisions in 'mutually beneficial partnerships' between patients, families and those delivering healthcare. The national action plan Living and Dying Well (SG 2008), the Scottish Palliative Care Guidelines (NHS Scotland 2014) and National Institute for Clinical Excellence (NICE) (2011) echo the Healthcare Quality Strategy ambitions. Living and Dying Well advocates assessment and review, planning and delivery of care, communication and information sharing for people at end of life in an integrated way (SG 2008). The Scottish Palliative Care Guidelines (NHS Scotland 2014) emphasise the importance of caring for the family as well as the patient.

The National Institute for Clinical Excellence (2011) specifically highlighted the need for effective, collaborative, multidisciplinary working across all care settings, including home, to be able to achieve quality, person centred end of life care. However, from a person-centred perspective, the literature reviewed focused mainly on the importance of relationships with patients and families in community nursing. Only two studies were found around unqualified care workers. The impact of person-centred relationships in CN practice was identified as promoting autonomy and choice (Bowers ET AL. 2010; Senior and Hubbard 2010; Karlsson and Berggren 2011; Adamson and Cruikshank 2013). This was achieved through relationships which foster openness and honesty, conserving dignity, good, timely communication, anticipation, preparation, comprehensive assessment and symptom control (Senior and Hubbard 2010; Karlsson and Berggren 2011). Bergen (2011) and Adamson and Cruikshank (2013) highlighted the importance of having a vision for providing a good death while Adamson and Cruikshank (2013) specifically emphasised the need for equitable, individualised care that offers patient choice. Senior and Hubbard 2010) claimed information to promote understanding and decision-making empowered the patient, with the family included as far as consent would permit. Bowers and Arnold (2010) suggested that as death approaches, people often changed their mind. They proffered the preference for dying at home can sharply decline, often because of factors such as no longer believing their symptoms can adequately be controlled and being too much of a burden for their family.

Ross (2013) highlighted the skills DNs have in providing holistic care to patients in their own homes, and their importance in patient and families' lives. He suggested DNs knew and understood the whole picture and helped patients join up the dots when patients were moved from one service to another. Kennedy et al (2011) suggested to do this, DNs adopted person-centred approaches with patients and their families, although this required time which was often unavailable to them. Building rapport and trust (Stajduhar et al 2011), openness and honesty (Adamson and Cruickshank 2013), centering care around patients' wishes (Alsop 2010; Vanderboom et al 2013), dignified care (Karlsson and Berggren 2011; Johnston et al 2012) are all relational aspects of DN and CN practice highlighted. Middleton-Green (2014) drew attention to the need for nurses specifically, to maintain clear, sensitive and honest communication with families about what was happening. The importance of avoiding euphemisms rather using clear words, the need for the plan of care to be communicated to the whole family, were highlighted by Middleton-Green (2014).

Only one study found specifically focused on care workers in the community (Devlin and McIlfratrick (2010), although another was conducted with nursing assistants in a care home by Beck et al (2012). Both studies focused on relational aspects of caring. Health Care Workers in Devlin and McIlfratrick's (2010) study reportedly played a central role in supporting family carers and in relation to palliative care, HCWs mostly talked and listened to clients in addition to providing personal care. Health Care Workers felt clear about their role, although sometimes carried out additional tasks, despite time being identified as a barrier to this. Three quarters of HCWs found this aspect of their role important although somewhat stressful and rewarding. They found providing care particularly difficult if patients' symptoms were uncontrolled and there was physical deterioration. Some of the participants found it difficult to cope with their own sense of loss. Community Nurses meanwhile thought HCWs only provided physical care, with some reassurance to families although they felt the standard of care was variable. They also felt there could at times be overlap of roles, particularly in the final few days when HCWs' role became obsolete. Variability in HCWs' role in reassurance to families was highlighted. This was put down to a range of experience and a lack of training. Regular updates provided by the multidisciplinary team was recommended. They recognised the support they could offer might be difficult because of the challenges of meeting up in patients' homes.

In a study by Beck et al (2012) nursing assistants in care homes reported, while they too focused on physical tasks although they wanted also to focus on relationship aspects of care. The organisational expectation was they would focus on tasks because this was how care was measured. It was also easier for some than talking about death and dying. This however led to feelings of guilt. As in Devlin and McIlfatrick's (2010) study, despite some of the nursing assistants feeling they had little time to 'be relational', others managed this aspect in a variety of ways. In the last days of life by staying close to residents and being available, they felt they gave them a sense of 'being in control'. The HCWs however described feeling 'out of control' when residents required symptom relief and they needed the help of registered nurses. It was also found during the last days of life they paid more attention to the needs of the family, making time to be with relatives, giving information and support whilst doing practical things. Health Care Workers saw their role as safeguarding but described this aspect of their work as being invisible.

4.2. A holistic person-centred model of end of life care will be enhanced by effective collaboration.

Senior and Hubbard (2010) stated EoL care is a discrete specialty using patient and family need as the basis of holistic care. The Scottish Palliative Care Guidelines (Scottish Government 2014) point out that palliative and EoL care must focus on the person, not the disease, and through a holistic, person centred approach can identify the physical, psychological, spiritual and social needs of patient and their family. The ethos of Living and Dying Well, (NHS Scotland 2008), is a cohesive and collaborative approach to the availability of person-centred palliative and end of life care to those patients and families requiring it.

Key aims within Gold Standards Framework (2014) are the upskilling of staff involved in end of life care and the improvement of 'coordination and communication across care boundaries'. Ross (2013) emphasised the need for a workforce who can work in teams, collaborate on care planning, and manage ambiguity and uncertainty of service reorganization, if integration is to move forward. There was however, little consistency in the literature around integrated teams or services, and little that identified how EoL care is enhanced through effective collaboration

between health and social care. In the main, integration was reported between primary and secondary or tertiary care. The benefits of effective collaboration was reportedly improved joint working, including integrating relevant specialists in a position of influence, integrated policy, promoting integrated assessment on patient care, reducing anxiety and isolation for patients and streamlined care (Bowers et al. (2010; Cioffi et al 2010; Clarkson et al 2011; Pender and Pearce 2012). Bowers et al (2010) also suggested inter-professional working allows quicker referral processes and same day service provision (Hospice at Home service) if patients suddenly deteriorate.

There are a number of aspects of collaborative working that reportedly enhanced integrated working although Clarkson et al (2011) suggested integration between generalist and specialist services is concerned more with inter-professional team working than about shared organisational cultures. The study which surveyed 700 specialist clinicians, found effective integration was achieved by a shared vision, robust informational technology infrastructure, shared record systems with social services which promoted information sharing. Bowers et al. (2010) reported the implementation of a patient register linked to the Gold Standards Framework which led to an increased frequency of meetings from three monthly to 8 weekly. It also increased awareness of people with complex needs before they had a crisis in the last few weeks of life, empowering community nurses (CNs), General Practice Nurses and General Practitioners to add patients with any illness requiring palliative care needs. They suggested the benefits of the team meetings included identifying care issues, group problem-solving and joint action planning. The improved communication with Out of Hours (OOHs), also a feature of improved joint working, was demonstrated in information in the front of the (multi-disciplinary) patient-held record about what to do if the patient's condition deteriorated.

Cioffi et al (2010) also advocated regular team meetings and documentation systems, but also suggested joint premises, centralised IT and health professionals being aligned to specific care needs are required. They suggested inefficiencies reduced continuity of care leading to increased difficulties tracking patients' progress. They emphasised the need for centralised documentation being available to all staff. The need for shared documentation was also highlighted by Craftman et al. (2012) and Smith (2012). Smith (2012) highlighted the

significance of communication amongst various professionals in relation to patient safety. Although focusing on patients with heart failure, it was suggested using a shared folder kept in the patient's home for all organisations to use in order to document patient care. Craftman et al. (2012) emphasised the need for communication in terms of physical working practices. District Nurses and HCWs working in different locations caused difficulties in working in an integrated way. In their study exploring DNs' perceptions of delegation of administration of medicines to HCWs, DNs believed that opportunities to communicate with and supervise HCWs on a daily basis would make it easier to collaborate in administration medication. Craftman et al (2012) however warned the risk of miscommunication between nurses and unlicensed personnel, may be because of language barriers. To ensure positive inter-agency working Webber et al (2011) emphasised the need for professionals to be clear about their roles as well as the need to have positive interpersonal relationships (Webber et al 2011). They claimed joint protocols could clarify lines of communication between services, however protocols may only be effective if professionals were confident in communicating beyond their own service boundaries. Pender and Pearce (2012) suggested a one stop referral hub for EoL care coordination as a solution to streamline the referral process and ensure an accessible consistent approach in service provision.

According to Admi et al (2013) patients placed great importance in continuity of care and communication between providers of care (on both sides of the hospital and community interface). In a small qualitative study exploring patients with cancer and health care providers' experiences, patients felt they were at the mercy of a bureaucratic system as there was no overall integrated plan for their management. Nor was their continuity of care (Admi et al 2013). Communication was highlighted as the key difference in reducing role confusion and maintaining care continuity and addressing patients' needs in a person-centred way. From the perspectives of healthcare providers in the community, reciprocity and collaboration across the interface, as well as amongst themselves was highlighted as necessary to provide continuity of care.

Brady (2013) analysed the concept of 'partnership' within the context of health and social care. He suggested the term is used inter-changedly with other concepts e.g. 'collaboration' and 'inter-agency working going on to'. adopted the definition,

'a voluntary or legally required alliance-like working arrangement between two or more people, departments, communities or agencies, help up as a valuable and evolutionary medium to bring together a diverse range of skills and resources to achieve improved service for users, where there is a commonality of interest or desire to achieve shared or compatible goals'.

This definition particularly emphasised the evolutionary nature of the concept which can grow and develop, but equally can diminish over time. Brady (2013) suggested the benefit of partnership was being responsive to user needs, particularly when multiple services were required. She suggested that partnership working promotes ownership, but may foster unrealistic expectations of care delivery. While partnership did facilitate holistic care, an increased skill mix team she claimed, may lead to role ambiguity. The changes in expectations of and from service-users who were active recipients of care were also acknowledged in the study. According to Brady (2013), partnership is cost-effective and can reduce care costs although there is little evidence to support this.

Care networks that facilitated coordination of arrangements between health and social care professionals and care pathways emerged as key to successful integrated care at EoL. A number of papers highlighted the benefits of patients being placed on a recognised pathway (Dundau 2009; Alsop 2010; Webber et al 2010; Bowers 2013; Johnston et al. 2012; Adamson and Cruikshank 2013). Until recently the Liverpool Care Pathway provided guidance for practitioners and patients but the report *More Care, Less Pathway* (Neuberger et al 2013) recommended it be suspended from use by July 2014 in England and December 2014 in Scotland. Johnston et al 2012 highlighted that care pathways have the potential to improve patient care at EoL, through raising the needs of these patients and their families. Clarkson et al (2011) and Pellet (2012) advocated the importance of this at the assessment stage however Bowers et al. (2010) highlighted that often CNs only meet patients in the last few days of life. This may lead to potential last minute crisis management and an increased risk of hospital or hospice admission when the preferred place of death is home. Alsop (2010) described the

development of patient pathways for working in an integrated way between primary and tertiary care. Although social care was considered, this was particularly care home personnel. Key issues of identified pathways and the importance of care coordination, clarity of concepts and principles, communication and decision-making were again highlighted. The pathway ensured clarity of roles and responsibilities and also highlighted enhanced relational communication. Johnston et al (2012) suggested it may also promote multidisciplinary training. However, Middleton-Green (2014) cautioned pathways do not replace or improve clinical judgment or effective communication.

Adamson and Cruikshank (2013) used evidence based clinical guidelines and action plans as a means of communication in guiding EoL care at home. They highlighted the key drivers in EoL care policy including service redesign, increased OOH support for carers, increased training and equity of service provision. Webber et al 2011 stated that interpersonal contact with multi-agency practitioners was important in promoting joint working and inter-agency collaboration. Joint protocols could provide procedures and guidance about practice in complex cases and could support decision making. However, they may remove personal initiative which is susceptible to criticism in the risk-averse culture of the UK public sector (Dundau 2009). Since most deaths occur OOHs, Middleton-Green (2014) emphasised patients' needs and plan of care must be communicated to providers of OOHs medical and nursing services. Carers within the Complex and Palliative Continuing Care Service (CPCCS) followed comprehensive care plans written by DNs (Ingleton et al 2011). The care plans detailed discrete activities including for example efficient movement and meal preparation. However Ingleton et al (2011) highlighted this additional work load as a potential barrier to prioritising key care issues. Senior and Hubbard (2010) suggested that different varieties of paper and electronic patient record systems between the agencies create barriers to communication, yet all these agencies need to work together and share information securely.

4.3. Working in partnership with patients and families enables self-management and improves the patient and family experience of end of life care at home

Little emerged from the literature around partnership working with patients and families despite partnership with people being acknowledged by as being central to achieving a truly person-centred service (NHS Scotland 2013). Equally, despite partnership enabling self-management being central to the 'Route Map to the 2020 Vision for Health and Social Care' (NHS Scotland 2013) and other policy drivers, little evidence was found. NHS Scotland (2014) suggested clear, open communication with patients and families allows not only understanding of the focus of care but the setting of realistic goals and consideration of priorities for the patient and family. The Scottish Palliative Care Guidelines (NHS Scotland 2014) emphasised the centrality of the family. In the study by Ross (2013), service users highlighted their appreciation of friendly professionals who were willing to give their time to listen and explain things to them in a patient, non-judgemental and respectful manner. The important role family carers had within the home was also recognised by Brady (2013) and Oldman (2014), although they claimed it was necessary they claimed at least in part, to reduce care costs. They advocated being responsive to user needs, engaging in partnership working to promote ownership, although Oldman (2014) indicated DNs were the professionals best placed to support them.

One study by Jarvis (2010) described the move towards family carers being viewed as co-workers having implications for both DNs and care support workers. She stated the move towards outcome-focused assessment and enabling self-management, service support would make a positive difference to someone's life. She claimed this was only possible if carers were considered as partners in care, allowing nurses to deliver truly holistic care. Vanderboom et al (2013) however stated, if patients were to understand

and maintain their role in self-managing their complex needs then self-management support was crucial. They also claimed carers could easily become burnt out when providing both physical and emotional support at EoL. They suggested therefore early intervention is key before symptoms become problematic reducing the emphasis on informal carer intervention. Informal carer burden was also cited by Jack and O'Brien (2010) as one factor affecting whether patients could die at home. The adequacy of service provision, could be influenced by unrealistic patient and carer expectation and have significant impact on the ability to provide individual care packages which could be compounded by unrealistic expectations of hospitals. This could result in delayed provision of services which in turn could increase strain on informal carers. O'Brien and Jack (2010) suggested exploring what services patients and carers understand is available.

Karlsson and Berggren (2011) used Chochinov's model to theme CNs care actions in EoL care. These were symptom distress, dignity conserving perspectives and social dignity inventory. Care actions included were establishing early contact in order to get to know the patient and their family well, using assessment tools and guidelines and collaborative working with the Multi-disciplinary Team (MDT). This helped patients set realistic goals and provided equipment as necessary; communicating with the family and patient in a way that kept everything normal and equal; giving permission to be sad; helping patients to articulate what is important; accommodating particular visit requests; being sensitive to patients' need for privacy; being respectful when providing care and; helping patients come to terms with their changing circumstances. However, in discussion around the development of quality indicators, Bowers (2013) suggested however, some patients and families do not want professional input until the terminal stages. In these situations, completing some process indicators can be counterproductive to building therapeutic relationships and results in 'tick box'

exercises. Clinical discretion and a realistic multidisciplinary team approach are needed.

4.4. Good case management features effective leadership supported by integrated organisational structures

The importance of effective leadership surfaced as a means to coordinate, rather than to case manage EoL care. Additional influencing contextual factors that emerged were resources, networks, roles and responsibilities and effective team working. NICE (2011) recommended that teams should promote clinical continuity for patients through identifying a key worker as coordinator of care and partnership with the patient and family in the delivery of holistic end of life care. Bowers et al (2010) and Cioffi et al (2010) echoed the need for leadership in coordinating the multidisciplinary team, particularly when EoL care was initiated. Senior and Hubbard (2010) suggested this was key to clarifying roles of team members, thus optimising team efficiency and keep family intrusion to a minimal. Bowers et al (2010) suggested lack of clarity around leadership may contribute to lower levels of team effectiveness leading to poorer quality of care. However, O'Brien and Jack (2010) suggested resources rather than leadership may impact on whether patients' needs could be met realistically with the services available. Within their study, DNs highlighted that while packages of care could be requested, they were not always available due to lack of capacity within care agencies or funding. They also discovered that funding was not the only issue but the lack of suitably skilled staff available could jeopardise the situation for patients. This, they suggested could result in disappointment from families when the care is not available as they assumed. A different resource issue, according to Vanderboom et al (2013) was community services. They stated while these are available to address patients' social needs, most healthcare systems did not partner effectively with the available community services, leading to the under use of existing services and fragmentation of care.

According to the Scottish Care Institute for Excellence (SCIE) (Webber 2013) care networks enable joint working and information sharing, the provision of the same familiar staff for patients and a single nominated contact person. They suggested key features of health and social care

professionals was the ability to work flexibly, being responsive to the needs of patients and carers. According to Adamson and Cruikshank (2013) it was the DN's unique role in both coordination and provision of EoL care at home that would allow family carers to undertake enhanced roles. They used what Cramm et al (2014) identified as 'relational coordination' in their study exploring meeting the needs of community-dwelling frail people in a coordinated way. Using Gittell's theory (2002) which suggests specific dimensions of relationships are integral to coordination work. The effectiveness of coordination was determined by the quality of communication among professionals providing care. Thus effectiveness was determined by the strength of the relationships. Concurring with Weick and Roberts (1993; Crowston & Kammerer 1998; Faraj & Xiao 2006) the relational process in Cramm et al's (2014) study involved a shared understanding of the work and the context in which it was carried out. An important aspect of the inter-dependencies was the iterative nature of the relationship requiring feedback as new information arises. They suggested the importance of was to enhance task integration, improve care delivery and professional satisfaction among a diversity of professionals. The implications of this work were the need to strengthen relationships, focusing on high-quality communication supported by relationships, shared goals, shared knowledge and mutual respect between professionals. Cramm et al. (2014) suggested CNs have an important role in strengthening connections and should therefore be selected for their relational competence as well as their functional competence.

In addition to leadership, Ross (2013) suggested team effectiveness would be achieved through optimum skill mix and 'the right professional behaviours'. Vanderbook et al. (2013) suggested team working is achieved by integrated care planning, with each discipline assuming responsibility for the task, within their domain of experience, within a specified time frame. In addition to defined roles, Cioffi et al (2010) suggested integrated team members must be appropriately trained with clear delegation and have obvious structures and processes of communication in place. Clarkson et al (2011) identified that difficulties in integrated working could arise from differences such as professional identity, roles, status and professional accountability, particularly in assessment. Cioffi et al (2010) went on to suggest both blurring and misunderstanding of roles could inhibit integration, stating that guidance around developing trust and encouraging a deeper understanding of each professional's contribution to care was

required. According to Pitt et al (2014) this could be achieved through networking between staff and by understanding each others' professional roles. Brogaard et al. (2011) suggested this would also avoid confusion for patients and family carers and keep patients informed along their journey.

According to Ward et al (2010) strong support systems also needed to be available for professionals working with patients at end of life to maintain morale Little was found in the literature around education training and support of CNs although Pitt et al (2014) suggested to prepare health and allied health professionals to work collaboratively and facilitate and manage seamless person-centred care, integrated professional learning was essential. The CPCCS service (Ingleton et al 2011) which aimed to promote and support integrated working between health and social care emphasised careful selection of potential carers. This research highlighted the importance of ensuring that potential applicants realised the type of work they were entering with regards to caring for people at end of life. In the study, support was provided by an identified qualified nurse for ongoing training and development. Month-long training was provided to enable carers to assist with personal non-medical caring tasks such as: personal care, medication administration, meal prep and emotional support. The initiative included shadowing of existing team members, and spending time within a hospice. In this study the consequences of training and support included a low turnover of staff and DN perceptions of the carer's professionalism and quality of care. Edge and Smith (2008) also advocated training and time given to the newly recruited care workers. Senior and Hubbard (2010) suggested it may also encourage young people to become home carers.

However, in their mixed methods study of 236 home-care workers and 6 CNs, Devlin and McIlfatrick (2010) identified a lack of training and variable support for HCWs caring for people at EoL. They found HCWs in their study felt they had adequate supervision from home-care officers, 'on the ground' and from colleagues (but who had not been trained). They felt previous support from CNs was becoming less available and more supervision on the ground was needed. This was for HCWs, as well as support from home-care officers and CNs. In the study there was also a call for induction, preceptorship, ongoing training and clearer roles and responsibilities. They did not have a nationally recognised qualification and over one third had

no training for their role despite the majority indicating they would be willing to work towards a relevant qualification. They identified their training needs in communication skills, EoL care, dealing with death, dying and loss, information on specific conditions and subsequent care required and palliative care awareness (Devlin and McIlfratrick 2010). Stefanou and Faircloth (2010) highlighted that nurses involved with EoL care at home would also benefit from advanced communication training.

5. Conclusion from the realist review

Testing of the programme theories through the literature review identified what works for whom, in what circumstances and why. Drawing on the work from Rycroft-Malone et al. (2012), hypotheses were generated by theming the literature into m,c,o formations, linking these to the chains of reference and then hypothesis (Fig 3). The emergent model would go on to be further refined by the practice development (PD) group.

Fig 3 Generation of tentative hypotheses

Hypothesis	Chain of reference	Themes
A person-centred approach (m) underpinning integrated working (c) with patients at end of life at home can result in more patient autonomy and choice (o)	M: Communication Person and family at the centre Comprehensive assessment and review C: caring Time Training O: relationships Autonomy	Mechanisms: Person at the centre, comprehensive assessment and review; planning; timely communication; information sharing; collaboration; multi-disciplinary working; relationships with patients and families; openness and honesty; conserving dignity; anticipation; preparation; symptom control; individualized care; inclusion; listening; reassurance; information giving Context: caring; time; coping; training; invisible Outcomes: relationships; autonomy; choice; having a good death

	choice	
A holistic, person-centred model of end of life care (m) enhanced by effective collaboration (c) can result in more streamlined care (o)	<p>M: relational communication Collaborative care planning Continuity and consistency Care pathways responding to patients needs</p> <p>C: training Support role clarity</p> <p>O: streamlined care improved care joint working reducing role confusion</p>	<p>Mechanisms: cohesive, collaborative approach; care coordination; relational communication; teamworking; collaborative care planning; shared vision; information sharing; patient register; regular team meetings; responding to care needs; continuity of care; centralized documentation; shared documentation; communication; joint protocols; consistency; integrated care management plan; partnership; pathways; clarity of concepts</p> <p>Context: coordination and communication; regular team meetings; documentation systems; inefficiencies; location of services; supervision of care support workers; role clarity; reciprocity; patient and family expectation; skill mix; collaboration at assessment stage; OOHs support for carers; equity of service provision; joint working; plan of care around patient needs; communication with OOHs; workload; electronic patient record systems</p> <p>Outcomes: effectiveness; joint working; information sharing; increased awareness of people with complex needs; empowered CNs; frequency of meetings; identification of patient need; group problem-solving; improved communication; continuity of care; reducing role confusion; improved service delivery; ownership; active recipients of care; supported decision-making</p>
Working in partnership with patients and families (m) at home (c) may improve self-management and the overall patient and family experience of end of life care (o)	<p>M: early intervention Partnership Being responsive Multi-disciplinary approach</p> <p>C: resources Families as co-workers Carer support Realistic goal setting</p> <p>O: person-centred service Ability to articulate</p>	<p>Mechanisms: partnership, open communication with patients; enabling self-management; being responsive to user needs; outcomes-focussed assessment; early intervention; early contact; assessment tools; guidance; collaborative working; communicating with the family; being sensitive to patients' needs; being respectful; multi-disciplinary team approach</p> <p>Context: understanding the focus of care; centrality of the family; time to listen and explain; families being viewed as co-workers; enabling self-management; service support; partners in care; carer support; adequacy of service provision; patient and carer expectation; realistic goal setting</p> <p>Outcomes: person-centred service; ability to articulate</p>

	what is important	what is important
<p>Effective care coordination (m) supported by integrated organizational structures (c) may improve team efficiency and effectiveness (o)</p>	<p>M: continuity Care coordination Leadership Communication Care networks C: understanding of roles and responsibilities Ongoing training and development Accountability Clear communication systems O: team efficiency and effectiveness Being responsive Improved care delivery</p>	<p>Mechanisms: care coordination; leadership; nominated contact person; care networks; work flexibly; communication between professionals; integrated care planning; support Context: effective leadership; clarity of roles and responsibilities; resources; suitably skilled staff; strength of relationships; optimum skill mix; right professional behaviours; assuming responsibility; clear delegation; appropriately trained; ongoing training and development; support and supervision; clear structures and process of communication; professional identity; professional accountability; strong support systems; inter-professional learning; careful selection of carers Outcomes: continuity; keep family intrusion to a minimum; team efficiency; meet patient expectation; being responsive; inter-dependence of teams; shared understanding of the work; enhanced task integration; improved care delivery; satisfaction among professionals; team effectiveness; avoiding confusion; seamless person-centred care</p>

6. Conceptualisation of a framework of care

Drawing on the work (McCormack et al. 2011; Manley et al. 2013) the process followed in the PD group was: Visioning, refinement, prioritising, action planning, and evaluation. The first question the group were asked to consider was ‘What will end of life care look like?’ demonstration being assisted by the use of Evoke cards, developing a vision of EoL care at home. The group collectively highlighted key areas they felt were essential at end of life. The person was considered to



Fig 4: PD project own initial model

be at the centre of everything, with time to care, choice, creating a strong bond with the patient, streamlined care and consistent teams surrounding the person.

The facilitator presented the visual representation of the evidence from the literature and focus



groups to the group (Fig 4) acknowledging the effort of the group in developing their own model of what end of life care might look like. The group was then asked to consider missing elements when several areas which were not represented including spiritual need, cultural difference, clear communication systems, signposting for help/resources and knowing the team were identified.

Fig 5: Refinement of model Once amendments

were made, the group collectively identified the strengths of their model as being person-centred, holistic, adaptable, and responsive with clear communication channels (Fig 6).

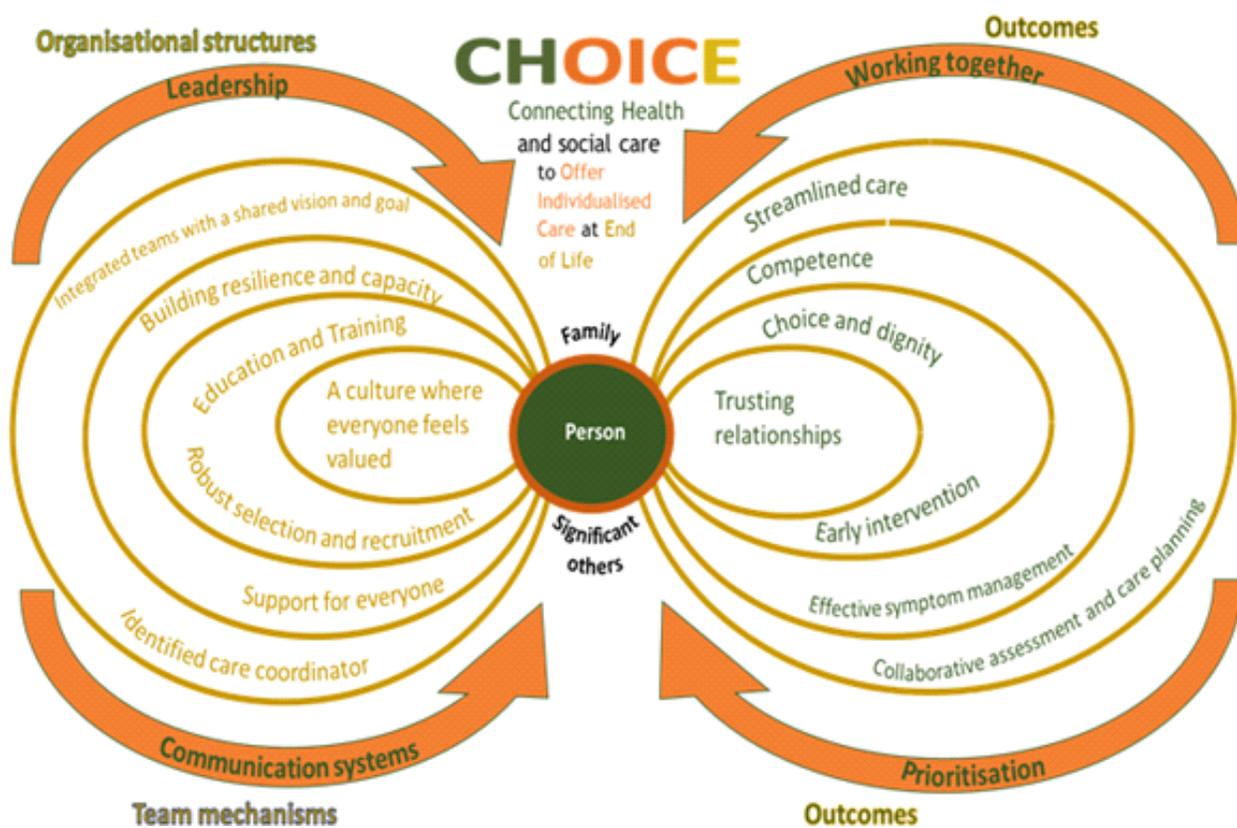
Fig 6: strengths and limitations of the model presented

Strengths	Equality between nursing and social care Person-centred Overall integrated approach Gives structure and reassurance
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Not happy with	All arrows should lead to the centre Centre-add end of life-not clear Competence rather than professional competence Integrated structures Key worker Don't like terminology Team mechanism
Similarities	All elements Emphasis on the patient interaction/streamlining Person in the centre Flexibility/adaptability
What is missing	Stronger emphasis on integration Streamlined care/continuity Support and being surrounded by significant others CHOICE

The groups were presented with the first draft of the project model. Comments and thoughts were encouraged by the facilitator particularly in relation to similarities to their model, was there anything they were not happy with, strengths and did they think anything was missing. Taking all of this valuable data into account the project team revisited the model. The newest version of the CHOICE model was presented to the group at the second PD session (Fig 56). The general consensus was positive and it was agreed this would be the model that would be tested in practice

Fig 6: CHOICE model



7. How can health and social care teams work effectively in an integrated way?

Following agreement about the model, the PD group focused on testing in practice. The group were encouraged to develop their own vision for the project to demonstrate, not only their shared values but also reflect their ownership of the model. They achieved this by splitting into two groups initially, then coming together to compare and contrast each statement and develop one strong integrated vision:



Integrated person-centred EOL Care at home is.....

Skilled health and social care staff working together, supporting each other to build a relationship with the 'cared-for person' and family and/or significant others to provide holistic care where everyone feels valued, has choice and dignity through open communication. We will work together with 'cared for persons' to assess, plan and evaluate care of their choice giving sufficient time to give streamlined, coordinated care with staff continuity to achieve a dignified death.

The group began to identify priorities from their shared vision and the model, to begin to formulate an action plan that could be implemented within practice. Following this action plan the group identified areas for development that smaller groups could work on until the next session. The main topics to be explored were Communication, Education and Integration (Fig 7).

Fig 7: Action Plan

Identified priority	Relationship to model	Progress
Identify social care workers interested/keen to engage with EoL care Ensure skilled staff (education and training) Shadowing opportunities	Organisational structures – robust selection and recruitment Education and training	Not possible to test the model in caring situation Drop-in sessions initiated for carers Education/training sessions initiated Shadowing opportunities available in St Columbas Hospice Draft interview questions for SCWs Dissemination of project
Integrated team meetings ? monthly Early intervention Effective care coordination Effective discharge	Organisational structures - integrated teams with shared vision and goals A culture where everyone feels valued Team structures – identified care coordinator	Team meetings not established No progress with early intervention, care coordination, effective discharge
Improve communications – systems, team and care plan Joint visits and joint communication (including documentantation)	Organisational structures – a culture where everyone feels valued Building resilience and capacity Support for everyone involved	Communication has improved within the PD group (sharing contact details) and health and social care managers within SE Edinburgh. No progress with joint visits

		Shared communication sheet developed and ready for testing
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8. How can education and development needs of social care staff providing care at end of life be met within existing resources?

The PD group identified perceived barriers in working in an integrated way with DNs. They felt apprehensive about approaching them and were unsure of how to go about this. There was a consensus from the group that participation with this project has contributed to these barriers being less visible with DNs appearing more accessible. Contact details were shared which was key to this process. Education and development needs were addressed during the project by DNs providing short, flexible education sessions for SCWs. These were informal and were considered to be a means of increasing confidence. Drop-in sessions for supporting SCWs were also planned by DNs and the Occupational Therapist. There is also an opportunity to have some educational sessions delivered by Janice Logan from St Columba’s Hospice. These were deemed to be the means by which education and development needs of SCWs could be met. Additionally, one of the SCWs wrote a blog for dissemination throughout City of Edinburgh Council’s staff newsletter.

9. What are the health and social care systems and processes required to work together openly and transparently?

Despite action planning and progress towards some of the identified outcomes, unfortunately the model could not be fully tested. This was due to the unavailability of patients at EoL in the care of those SCWs and CNs involved in the project. The group developed a joint communication sheet which they felt would be an achievable way to address the needs of shared documentation, but this was not implemented. In addition to evidence emerging from the literature, it was felt SCWs being recruited often were unaware the job included caring for people at end of life, pilot interview questions for SCWs relating to EOL care were created. Other ways of testing were not possible. To continue this work, extra funding has been secured from the Queens Nursing Institute Scotland which will support further testing of the model by

providing external facilitation. The results of this work will strengthen the findings of the initial work presented here.

10. Discussion

The overall aim of the project was met, with the caveat that initial testing in practice could not fully be carried out. The objectives have also been met with the successes of the project being threefold: the development of the evidence-based model, participation and inclusion of all stakeholders in the process which led to staff development at all levels, visioning and values processes which provided direction for the project, whilst enabling the methodological principles to be developed.

The chosen methodology was a systematic, rigorous approach to gathering, interpreting and applying evidence from research and stakeholders. Undertaking a realist review offered the opportunity to ask specific questions of the literature rather than gaining a broad overview. This allowed a rich understanding of the literature, not only different models of integration at EoL, but what worked, for who, in what circumstances and why. A solid foundation for model development was therefore possible. Additionally, multiple voices from the focus groups, the steering group and the project team enabled identification of mechanisms, contexts and outcomes and co-production of the model.

The participatory approach was not only to participants in the PD group, but also the project group. While developing confidence in the CNs' and SCWs' participation in the study also developed knowledge and skills of the research team. By embedding PD throughout the process participants at all levels were able to see the strength of the approach. For example, the importance of creating a safe environment (Manley et al. 2013) enabled relationship building within the group and created a space for innovative thinking. SCWs particularly were enthused by having the opportunity to be part of process, achieved through the use of a variety of PD tools e.g. 10 point portrait, imagery, creativity and 4th generation evaluation (Guba and Lincoln 1989). By capturing claims, concerns and issues of the PD group throughout the process, issues were addressed collectively, again enhancing ownership of the work and developing a sense of cohesiveness. Additionally, developing a shared vision in PD, achieved both at the

beginning of the project by the project team and the PD group enabled the successful outcome of the project. However, work undertaken by small working groups outwith the PD group presented some challenges, perhaps due to the limited skill in facilitating the work and an absence of the safe environment during the main PD group. This appeared to contribute to two members deciding to discontinue working on the project.

One of the key advantages and a key learning point was having a clinician within the project team which enabled the team to identify and access a PD group. Her reputation as a clinical leader within the practice area, established networks, together with her enthusiasm and passion for the project encouraged engagement and participation. Management support from both organisations was essential, not only as Steering Group members guiding the project, but to encourage and recompense staff for their involvement.

While visioning was identified as a key learning point, the challenges included inconsistency of PD team members, three joining the group after terms of engagement and visioning had taken place. This meant for them, there was some lack of clarity of the aim of the project and contributed to the failure of the evaluation to capture robust data. The inability to test the model with a patient and family in practice was however the main reason for poor evaluation results. This was not possible not due to any lack of commitment to the vision or the project, but circumstance. It may however have been unrealistic within the timescale. The ongoing 'critical companionship' mini-project will address this gap.

11. Conclusion

The overall aim of the project was met, with the caveat that initial testing in practice could not be carried out. The CHOICE model has the potential to develop practice in an integrated, person-centred way, although further testing is required in practice. The implications for community nursing practice are considerable within the current integration agenda. The model has the potential to pose a way forward for delivering person-centred end of life care at home in an integrated way. The work is continuing in another project and is central in a research bid currently being developed.

12. Next steps

The next steps of the project are to celebrate the achievements. There are plans for a local event where the team will be able to share the process and outcomes of the project and will be awarded certificates of participation for evidence of continuing professional development. In addition to this report being available on the Queens Nursing Institute, Scotland's website, there are plans to write up for publication and dissemination at national and international conferences. In addition to the ongoing testing of the model through the 'critical companionship' mini project, there may be further research opportunities for testing.

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14. Appendix 1