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Coordination of care for individuals with advanced progressive conditions:

a multi-site ethnographic and serial interview study

Abstract

Background
Coordination of care for individuals with advanced progressive conditions is frequently poor.

Aim
To identify how care is coordinated in generalist settings for individuals with advanced progressive conditions in the last year of life.

Design and setting
A mixed methods study of three UK generalist clinical settings producing three parallel case studies: an acute admissions unit in a regional hospital, a large general practice, and a respiratory outpatient service.

Method
Ethnographic observations in each setting, followed by serial interviews of patients with advanced progressive conditions and their family carers in the community. A spectrum of clinicians and healthcare workers were also interviewed.

Results
Ethnographic observations were conducted for 22 weeks. A total of 56 patients, 25 family carers and 17 clinicians yielded 198 interviews. Very few participants had been identified for a palliative approach. Rapid throughput of hospital patients and time pressures in primary care hindered identification of palliative care needs. Lack of care coordination was evident during emergency admissions and discharges. Patient, families, and professionals identified multiple problems relating to lack of information, communication, and collaboration at care transitions. Family carers or specialist nurses, where present, usually acted as the main care coordinators.

Conclusion
Care is poorly coordinated in generalist settings for patients in the last year of life, although those with cancer have better coordinated care than other patients. A model to improve coordination of care for all individuals approaching the end of life must ensure that patients are identified in a timely way, so that they can be assessed and their care planned accordingly.

Keywords
cooperative behaviour; end-of-life care; general practice; palliative care; primary health care.

INTRODUCTION

Improving end-of-life care is a health priority.[1] Individuals worldwide spend most of their last year of life at home being cared for by family, GPs, community nurses, voluntary sector services and as hospital outpatients.[2–6] Access to well-coordinated care for all individuals approaching the end of life in all settings is advocated in policy standards internationally.[7,8]

The need for palliative care for individuals with cancer and other long-term conditions is well established, and can improve outcomes and costs, but service responses remain inadequate.[7,9,10] Although many non-cancer conditions such as organ failure and dementia cause significant morbidity and mortality, these patients receive little proactive, end-of-life care compared with patients with cancer.[11,12] Coordination of care for those with multimorbidity is particularly fragmented, yet this population is rising.[13] Lack of coordination is commonly cited as causing poor quality care and increased burden on family carers.[14,15] However, 'coordination of care' is rarely explicitly defined, leading to difficulties in specifying how to improve it in diverse populations.

Effective coordination of care requires services to respond to changing needs, coordination between multiple agencies and settings, coordination within individual care settings, within institutions and across organisational boundaries. This has to be underpinned by clear information for patients and families.[16]

As coordination of care is frequently absent or ineffective for individuals approaching the end of life, a multi-site investigation was undertaken. The aim was to identify how and to what extent end-of-life care is coordinated in generalist care settings for a range of individuals with advanced progressive conditions in the UK.

METHOD

Ethnographic observation, qualitative interviews, and professional and service user consultations were employed across three different generalist care settings

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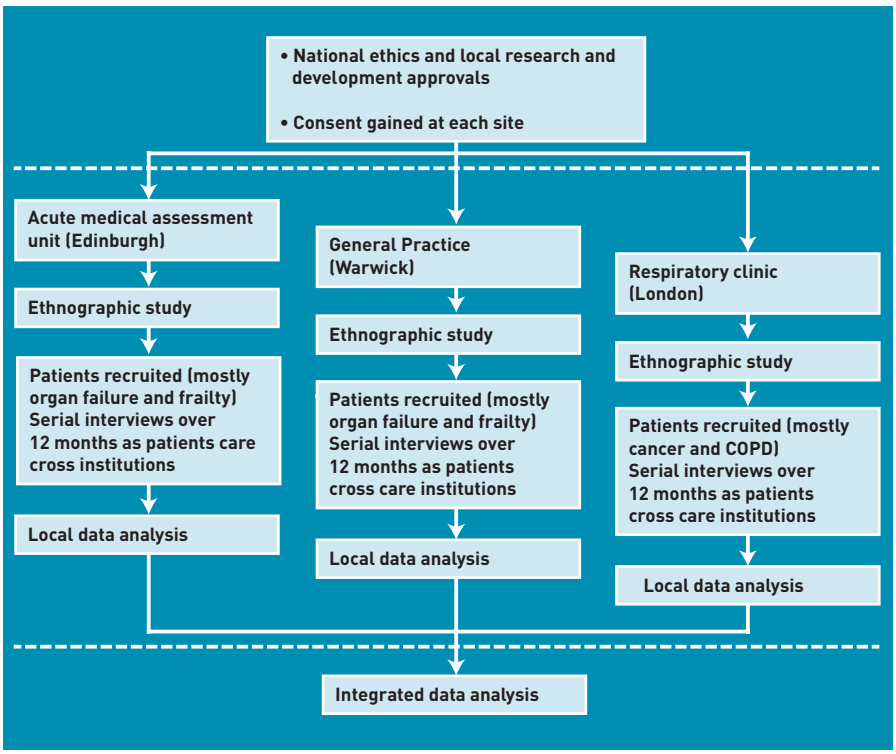
How this fits in

Coordination of care for people with advanced progressive conditions is frequently poor. A key benefit of generalist palliative care is enhanced communication and information sharing, but patients in the last year of life are rarely offered palliative care, unless they have cancer. Patients in the last year of life without a primary diagnosis of cancer were more likely to have multiple long-term conditions. Consequently, patients with the most need for coordinated care may be those least likely to receive it. This study reaffirmed that family carers and specialist nurses are important facilitators of coordinated care for patients in the last year of life, and that patients with conditions other than cancer were rarely identified for generalist palliative care. Findings also highlighted a lack of knowledge of the benefits of early supportive and palliative care. Patients, carers, professionals, and the wider community need to be better informed about the benefits of talking about end-of-life choices; greater openness can help ensure that appropriate care is received.

in the UK, producing three parallel case studies involving the most common settings where care coordination may be challenged. Using mixed methods in multiple sites has become prevalent in health service research and can address the complexity of healthcare provision.[17]

Figure 1. Project flowchart.



(A detailed account of the theoretical orientation and further methodological and other information can be found in the full study report at http://www.netscc.ac.uk/hsdr/projdetails.php?ref=08-1813-258.) Figure 1 outlines the design.

Settings

The acute admissions unit was in a Scottish teaching hospital. The general practice, with around 11 000 patients, extended over multi-ethnic urban and rural locations in the Midlands, England. The respiratory outpatient department was in a London teaching hospital.

Data collection: ethnography

A focused ethnography (short-duration fieldwork balanced by collaborative data collection and analysis)[18–20] was carried out at each site by experienced, postdoctoral, qualitative researchers who had no previous involvement with the participants. They obtained data from shadowing healthcare workers (spending all or part of a working shift with that professional), informal conversations with clinicians and from observing consultations, ward rounds, telephone conversations, and multidisciplinary meetings.

Recruitment: interview participants

At each site, the clinical staff identified eligible patients with advanced progressive conditions who were likely to be in the last year of life. They were guided by clinical criteria as detailed in the Supportive and Palliative Care Indicators Tool (SPICT™ at www.spict.org.uk)[21,22] and whether they would be surprised if the patient died within a year. The staff then sought permission to give the patient's name to the researcher who then approached them as a potential participant. A diverse sample of individuals were recruited for interview according to diagnoses, age, types of need, and social criteria. Patients with advanced dementia were excluded.

Data collection: interview participants

Semi-structured interviews lasting between 30 and 90 minutes were conducted with patients and linked family carers at 8–12 weekly intervals, using a longitudinal, multi-perspective approach.[23,24] Interviews with professionals were mostly single and shorter. The interview guide was used flexibly to explore experiences of care coordination (a full version of the serial interview guide is available on request from the authors). Each patient was followed for 5–9 months or until death.

Box 1. Factors that affected coordination at each site

Acute admissions unit

The dominant issue was the need to accept a constant throughput of patients. The speed and pressure of the work meant that palliative care needs were not identified unless a patient was in the last days, or hours of life. The specialist palliative care team were called only if there were complex, symptom control or psychosocial issues. Staff generally considered palliative care as a specialty associated with the treatment of pain and ascertaining cardiopulmonary resuscitation status. Staff routinely considered themselves to have only a partial understanding of patients' long-term conditions and circumstances. Coordination within the site was managed through internal communications and the computer tracking system, but coordination with professionals in the community was challenging and time consuming.

General practice

Presenting symptoms or conditions were addressed within the context of family and social circumstances. Some of the patients and doctors had been with the practice for many years which facilitated continuity of care and strong relationships. The practice had adopted some aspects of a framework to identify and coordinate care for people at the end of life. There was a monthly practice meeting attended by a specialist palliative care nurse. There was no formalised process of identifying patients for inclusion on the practice palliative care register. This usually occurred as a result of information given in a hospital discharge summary or from a team discussion. There were between 15 and 20 patients (about 0.2% of the practice population) on the register during the research period; most had cancer. As with the acute admissions unit, the greatest challenges to coordination were between settings: in this case the practice and two local hospitals. Coordination with the district nurse team was initially observed to be excellent but came under strain when the team was reorganised along geographical lines and previously strong professional relationships were fractured.

Respiratory outpatient unit

All patients with lung cancer had access to a nurse specialist who explained what was happening and their treatment plan, and sometimes suggested referral to a community palliative care team. At the general chest clinic, a nurse specialist provided some coordination of care but there was less nursing input in the interstitial lung disease clinic. Different amounts of coordination were observed at these three clinics with different levels of resources and channels of communication.

Analysis

Interview transcripts, observations and fieldnotes were imported into NVivo software for thematic analysis (version 9). The data set from each setting was analysed separately by the local research team. Thematic analysis was chosen because of its flexibility in handling complex data.[25] Each research team identified patterns in relation to effective or poor coordination. These patterns were coded and then grouped into categories to create themes and sub-themes. Cross-case analysis of this large and rich qualitative data set was then conducted by all three multidisciplinary teams to produce an integrated, multi-level understanding of coordination of care across settings and in different contexts. The study also utilised longitudinal analysis to ensure that the themes captured experiences over time.[24]

RESULTS

Ethnographic observations

The 22 weeks of observations enabled the researchers to gain an in-depth understanding of working practices at each setting during normal hours and out-of-hours (Box 1). At all three sites, there were problems when patients moved between services, particularly in the exchange of information between service providers. Tensions arose between processes intended to promote efficiency and the desire to deliver patient-centred care. There was considerable variability in knowledge about palliative care among healthcare staff.

Serial interviews

Fifty-six patients and 25 case-linked carers were followed through serial interviews with patients alone (n = 125), or as joint interviews with their carer (n = 56) (Table 1). Single interviews were also conducted with 17 clinicians. Four key challenges were identified as hindering effective coordination of care.

Patient identification as a prerequisite for coordination of care. All participants were recruited as being appropriate for a palliative care approach according to current policy criteria, but few had actually been formally identified as such. Only patients with advanced cancer were likely to have been identified. They appeared to receive well-coordinated care and had a good understanding of their illness. Other patients lacked a clear understanding of their health problems, often regarding themselves as simply 'getting old'. Patients with multiple non-cancer conditions tended to focus on living in the present and self-managing, sometimes actively resisting additional help:

Patient (W2): *'I keep saying there's nothing wrong with my heart. Well you would expect some pain or something, surely? I was tired and I still am a bit tired. But I'm getting old, you can't do what you did.'*

Carer: *'I personally don't want anybody to come in because we cope ourselves and the way we cope is because we cooperate with one another you know. The way I look at it is it's for better or worse isn't it?'* (Carer of E2)

There was a clear mismatch between policy and guidance around identifying patients systematically for palliative care and the actual practice observed:

GP: *'The usual threshold we have got for our register is: "Would you be surprised if this person died within the next year?" And I can't say I was altogether surprised. I mean, he did have a pretty extensive vascular history and peripheral vascular disease. So, he is probably one of those patients who quite commonly slips through the net, when it comes to palliative care needs.'* (GP of patient E32)

Another barrier to identification for palliative care support was that many (but

Table 1. Summary of patients for serial interviews

ID	Age	Sex	Main conditions	Int#	Carer?	Status
E1	82	M	COPD; heart failure, renal failure	1	No	Deceased
E2	76	F	Heart failure, renal failure, diabetes	1	Yes	Deceased
E4	85	M	Heart failure, IHD, mild dementia	3	Yes	Alive
E5	86	F	Pulmonary fibrosis, IHD, Paget's disease, hypothyroidism	2	No	Deceased
E6	66	F	Liver failure, diabetes, IHD	3	No	Alive
E8	56	F	Neurological illness, polio, COPD, epilepsy	3	No	Alive
E13	89	F	Unresponsive episodes, atrial fibrillation, hypertension,	3	Yes	Alive
E15	58	M	Pancreatic cancer	1	Yes	Deceased
E17	75	F	Diabetes, hypertension	2	No	Deceased
E20	75	F	IHD	3	No	Alive
E25	70	F	Multiple sclerosis	2	Yes	Alive
E26	71	F	Parkinson's disease, asthma	3	Yes	Alive
E27	68	M	Alcoholism, prostate cancer, peripheral vascular disease	3	No	Alive
E28	87	M	Renal failure, diverticular disease, mild dementia, prostate cancer	3	Yes	Alive
E32	75	M	Mitral valve disease,	1	No	Deceased
E33	71	M	Hypertension, atrial fibrillation, heart failure	3	Yes	Alive
E34	85	M	Hypertension, motor neurone disease, arthritis	1	No	Alive
E37	69	M	Peripheral vascular disease, IHD	3	Yes	Alive
E39	60	M	Multiple sclerosis	3	Yes	Alive
E40	87	F	Renal failure, metastatic melanoma	1	Yes	Deceased
W1	67	M	Diabetes, Charcot's arthropathy, cellulitis	3	No	Alive
W2	79	F	Diabetes, heart failure, osteoarthritis	3	No	Alive
W3	79	M	Renal failure, heart failure, IHD, hypertension , osteoarthritis	3	Yes	Alive
W4	82	F	Lung cancer, stroke, ischaemic heart disease	2	Yes	Deceased
W5	56	M	Pulmonary fibrosis, cerebral aneurysm, hyperlipidaemia	2	No	Deceased
W6	82	M	Renal failure, heart failure, anaemia, osteoarthritis	3	Yes	Alive
W7	92	M	Respiratory failure, heart failure, renal failure, osteoarthritis, glaucoma	3	Yes	Alive
W8	80	M	Prostate cancer, mild dementia, osteoarthritis	1	Yes	Deceased
W9	71	M	Multiple sclerosis, osteoarthritis	3	No	Alive
W10	73	M	Prostate cancer, mild dementia, hypertension	2	Yes	Alive
W11	71	F	Multiple sclerosis	3	No	Alive
W12	67	M	Peripheral vascular disease, renal failure, COPD	3	Yes	Alive
W14	41	M	Metastatic melanoma	1	Yes	Dead
W15	81	F	COPD	1	No	Alive
W16	58	M	Multiple sclerosis	2	No	Alive
W17	90	F	Stroke, osteoarthritis	1	No	Alive
K1	61	F	Lung cancer, metastatic to adrenal glands	3	Yes	Alive
K2	68	M	Lung cancer, emphysema	3	Yes	Alive
K3	76	M	Lung cancer, asbestosis	3	No	Alive
K4	82	M	Lung cancer with leg metastasis, IHD	1	No	Dead
K5	54	M	Lung cancer with bone metastasis	3	Yes	Dead
K6	78	M	Pulmonary fibrosis, IHD, emphysema,	2	Yes	Alive
K7	55	F	Pulmonary embolism, dermatomyositis, breast cancer, hypothyroidism	2	No	Alive
K8	70	M	COPD	3	Yes	Alive
K9	90	F	Lung cancer, COPD, osteoporosis	2	No	Dead

... continued

not all) GPs understood palliative care as meaning terminal care. GPs therefore struggled to articulate when someone might have palliative care needs:

GP: *'But in some ways, she has got palliative needs, but they are not quite palliative, if you know what I mean. So I don't have her on a palliative care register, because to me that's more people where there are obvious end-of-life issues.'* (GP of patient E5)

When asked about 'palliative care', most patients and carers associated it with care where there is no cure possible and death is imminent. This often led to resistance to engaging with a palliative care approach:

Lung nurse specialist: *'You have patients who live for years and yet people with mild or moderate* [disease] *who unfortunately, that one exacerbation causes pneumonia and they end up being the ones to go. So no, I, I think it's the prognosis ... if end of life,* [means a] *need to know how long you have, or estimated date unfortunately before you pass away, then I'm not sure how we can get around that in COPD.'* (Outpatient case study)

Patients and their family carers showed little understanding of the benefits of palliative care. Their response to questions about future planning was that they preferred to 'stay positive.' It seemed that they perceived talking about dying as negative in itself:

Patient (E6): *'Nope, nope nobody has ever ... said anything to me about that and I've never broached the subject cause I think like I'd rather be positive. I think "I'm not going to get worse".'*

However, some patients with cancer had been offered the opportunity to discuss the future and appreciated being able to do so:

Patient (K5): *'Well the hospice people, they're supposed to be coming next week to talk about the future, what preparations I make should things go worse and things like that ... I have already, my daughters they already know my wishes if things don't go right and how I would like it to go.'*

A final barrier to identification was limited contact time with the same professionals despite multiple attendances at different health services. In secondary care, the imperative to move patients rapidly through the hospital system and the focus on acute,

Table 1 continued. Summary of patients for serial interviews

ID	Age	Sex	Main conditions	Int#	Carer?	Status
K10	72	M	COPD, emphysema	3	No	Alive
K11	59	M	Lung cancer, with stomach, throat and bone metastasis	1	Yes	Dead
K12	65	M	Lung cancer	3	No	Alive
K13	69	M	Lung cancer , COPD, emphysema	2	Yes	Deceased
K14	63	M	COPD	3	No	Alive
K15	66	F	COPD	2	No	Alive
K16	52	F	COPD	1	No	Alive
K17	46	M	Lung cancer (small cell) with brain metastasis	2	No	Alive
K18	64	F	Lung cancer, diabetes, hyperthyroidism	1	No	Alive
K19	74	F	COPD	1	No	Alive
K20	79	M	Lung cancer, COPD, asthma, heart failure	2	No	Alive

Int# = number of patient interviews. Carer? = family carer present. Status = whether the patient was alive or deceased at the conclusion of the case study. COPD = chronic obstructive pulmonary disease. IHD = ischaemic heart disease.

presenting clinical problems mitigated against identification of patients who would benefit from a palliative approach:

Palliative care specialist: *'they're in an acute situation where you're managing the acute problem. ... So really the only other decision they'd make down there is whether they're for CPR or not, which is an important decision if they don't come with a form in case they do have an arrest, they need to decide that.'* (Hospital case study)

Patient experiences of short consultations in primary care and lack of knowledge about the potential benefits of palliative services meant that neither patients nor family carers had considered initiating a discussion themselves:

Patient (E13): *'I remember a time when you could go to a doctor and talk to him and you know, just give him your worries and what did he think? Can't do that now because they haven't got time. You know, you get your 2 minutes or 3 minutes or whatever, and then you are out.'*

Patients, family carers, and specialist nurses as coordinators of care. In most cases a family carer or the patient took on the primary coordinating role. The family carer kept track of medication, collaborated with professionals and shared information as well as giving physical care. This role was demanding and crisis admissions were often triggered when the carer could no longer cope:

Patient (E33) [talking about his carer]: 'She was exhausted [looking after me]. *By the time I went to hospital, she was needing the hospital as well, just about.'*

Patients without a family carer often struggled but there were exceptions:

Patient (K14): *'But when I am ill I don't go to the hospital I stay in the house, I do everything myself, take my medication ... I have everything here, I've got a nebuliser, I've got oxygen ...'*

Family carers often found coordinating care to be frustrating, because communication was inconsistent or information about the patient was not available. However, this improved as they gained experience:

Carer: *'So we're continually having to tell them, and the frustration of saying, but surely you must now have that on records?'* (Carer of E13)

Patient (W14): *'I know Dr X is on the phone on a Thursday so if I've got any quibbles I just phone up on a Thursday. She tells you how it is, you know, she doesn't mess about. It's a good doctors' up there.'*

Patients with a nurse specialist involved were more likely to indicate that they felt well cared for:

Patient (K12): *'I can ring* [nurse specialist] *up and she could ring me up, you know, she rings me up now and again and asks me "How are you getting on?" and everything else, you know. But, you know, she's good as gold.'*

Carer: *'The heart nurse is great, her and her colleagues, I can say nothing but good about them, they know what they're doing, they're better than the doctors actually. You can say what you want and they listen ... and I think that listening is important.'* (Carer of W6)

The GP was sometimes recognised as playing a key role but usually the GP was only consulted for an acute problem with patients 'not wanting to bother' a busy doctor:

GP: *'I think our involvement has been quite peripheral. But if he, you know, if he has got a problem or he needs us, he uses us. But if he doesn't need us, then he doesn't bother us. That seems to be the way he wants it to be.'* (GP of patient E1)

Patient (E17): *'You can phone in and the doctor will talk to you or you can phone a nurse and they will talk to you. "Please don't make an appointment unless it is absolutely necessary." Well, what do you know is absolutely necessary? I have been rushed into hospital because I have left it too long, because I won't bother them.'*

Sometimes reluctance to call a GP was matched by a patient perception of reluctance of the GP to visit when requested:

Carer: *'I don't believe in calling doctors out if there is no need but I do feel that sometimes when I've rung up you have to discuss things over the phone and I think "why don't you come out". But they don't you see.'* (Carer of W12)

Transitions and communication between care settings can challenge coordination. Unplanned hospital admissions and discharges caused frequent problems in coordination. Admissions could bring unexpected medication changes, unmet patient and family distress, and a feeling of being in an institution that was too busy to offer adequate care:

Patient (E20): *'I mean, they took me off morphine tablets that I had been on a long time. And they made me so 'doolally' that my family thought I was going to end up in a nursing home. And at the back of my mind, I knew there was something happening to me, and I know that I wasn't right, I couldn't speak right to my family.'*

After discharge, patients reported difficulties in re-establishing support at home and many were disturbed by a lack of follow-up in primary care. When there was contact, patients felt that the GP had little recent information. Patients and carers were frequently unsure of whether a GP or nurse would visit and whether they needed to act themselves:

Patient (K6): *'There is no follow-up. I mean I get a copy of the letter and I've never been asked to go to my GP surgery to discuss my medication or the recommendations the consultants have made.'*

Patient (E2): *'Well I would have thought that a doctor would be up right away, but no he* [patient's carer] *had to phone. And he* [GP] *had a letter for it, but I think maybe they expected me to go down but I couldn't.'*

However, some hospitals and primary care teams did provide good coordination:

Carer: '[at discharge] *they gave me a letter for the doctor and they gave me a letter for the district nurse and they gave me a discharge letter and I took them along that afternoon. The district nurses are marvellous and they arrived the next day, but I haven't heard from the doctor at all.'* (Carer of patient E4)

Patient (K3): *'I think my own local doctor, my GP, who I went to see, he's kind of pushed it on a bit, you know. He's an extremely good doctor.'*

Service organisations and reorganisations challenging coordination. Professionals universally experienced difficulties in communicating across institutional boundaries and found information sharing to be inconsistent. In an individual locality, several different systems for delivering care and ensuring continuity operated simultaneously, with clear potential for confusion:

Palliative care nurse: *'It was very difficult to get information from the* [hospital without electronic record sharing]. *It needed faxes to be sent, secretaries to be contacted and so on. There was one oncologist there who was very good at sending detailed information to the Macmillan nurses.'* (GP surgery case study)

Issues of professional autonomy made coordinating care between services challenging. Hospital doctors were sometimes reluctant to suggest that a patient might have palliative care needs or direct a GP to visit a seriously ill patient being discharged home for fear of imposing their views on GPs.

Initiatives such as shared registers and electronic records were considered by clinicians to have improved information sharing between primary and secondary care. However, communication between services was often inconsistent with staff unsure of whom to communicate with, and what information should be shared. During the general practice study, the community nursing service was reorganised into geographical zones with a central telephone hub. A major impact of this was that district nurse participation at the monthly palliative care, multidisciplinary team meeting decreased significantly and sometimes GPs, patients and carers were uncertain about how to contact the appropriate district nurse.

Carer: *'Every time I ring, when I eventually get through because apparently it goes through ambulance or fire places, I think it's over in Birmingham, and then it has to come back here, but the clinic is only down the road. It's crazy, if I could lift him and get him down to the nurse ... You know, it's complicated now.'* (Carer of W6)

DISCUSSION

Summary

Patients and family carers frequently experienced problems in coordination of care because they were simply not recognised as approaching the end of life and needing coordination. Without such identification, their care was reactive unless a particular initiative was in place or a key worker was present. Some patients regarded themselves as simply 'getting old', while others were ambivalent about seeking support. Patients with multiple non-malignant conditions appeared less likely to receive coordinated care. This appears to be an instance of the 'inverse care law.'[26]

Strengths and limitations

The involvement of three research teams, each implementing a shared protocol enabled data integration and analysis to highlight both diversity and commonality while maintaining a flexibility that allowed each team to focus on emergent local issues. The diversity of centres allowed the study to sample a range of services across different settings and draw up a sampling frame with a wide range of conditions. The project also allowed the study to collect perspectives from GPs and hospital doctors that are rarely accessed in palliative care research.[27] However, the variety of data sources occasionally caused difficult decisions about which areas to prioritise. The use of longitudinal data allowed the study to recognise dynamic changes such as how increasing familiarity with the local system facilitated patients and carers in coordinating their care, only for this to be compromised when service reorganisations occurred.

Comparison with existing literature

Throughout the study, patients met a wide range and large number of healthcare providers, with implications for costs and efficiency. This study supports recommendations that patients with multimorbidity are more likely to require continuity of care that can best be delivered by primary care teams.[28] A large proportion of healthcare spending is in the last year of life, yet patients did not receive the integrated care that can reduce costs.[29] An ageing population means that we must coordinate care better to prevent unnecessary and sometimes unsafe treatments and ineffective care transitions.

This study describes experiences of providing and receiving care in real world situations where access to enhanced coordination is contingent on health condition, local initiatives, and informal arrangements. The findings support Henderson's call for mainstreaming a small number of widely available services that focus on patient-centred goals and needs rather than diagnoses.[30] Such public health approaches can promote equity and better generalist care in the community.

It was found that generalists could identify patients at risk of dying when they were asked to do so for the purpose of this study, but in their daily work practice identification was rarely triggered due to lack of time or rationale. These professionals will need time, support, training, and a systematic approach to enable them to identify more patients for palliative care. Hospital doctors in the UK are encouraged to identify such patients during routine ward rounds.[31] However, primary and secondary care clinicians will have to perceive that there is a clear benefit for patients in being identified. Currently this is not the case, especially for patients with non-cancer conditions.[32] For patients to request palliative care it must be presented positively. The word 'palliative' often meant giving up hope and preparing to die to the patients, family carers, and professionals interviewed in this study. This deterred most individuals involved from raising the subject. Current controversies over the Liverpool Care Pathway in the UK, and 'death panels' in the US indicate the potential for resistance to earlier palliative care if it is associated purely with managing 'dying'.[33,34] Offering 'supportive care' rather than palliative care might be a more acceptable way to trigger better coordinated care.

This study confirmed the importance of informal carers and patients themselves as care coordinators.[35] Inherent inequities were identified within the healthcare system for those that do not have access to informal carers, and in the reliance of the healthcare system on unpaid carers.[36,37] Initiatives promoting self-management in long-term conditions through collaboration between patient, informal carer, and healthcare providers have been effective and there is every reason to suspect that they can be applied to early palliative care.

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Ethical approval

The study was approved by the South East Scotland Research Ethics Committee 02 and research governance approval was obtained from NHS Lothian, Coventry Teaching PCT and King's College Hospital NHS Foundation Trust. Staff at each research site gave consent as a group at the beginning of the ethnographic observations and offered the option to withdraw individually at any time (details available from the authors). Written consent was obtained from patients in the serial interviews. Consent was also obtained from the informal and professional carers identified by the patient.

Provenance

Freely submitted, externally peer reviewed.

Competing interests

The authors have declared no competing interests.

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The study also confirmed that emergency admissions and discharges are often poorly coordinated.[29] Hospital staff perceived that professional autonomy could reduce continuity of care: they felt unable to ask a GP to undertake a home visit unless a specific task was required. It was found that service reorganisations aimed at increasing efficiency, in the face of increasing workloads and resource constraints, risked hampering informal communication mechanisms between key personnel.

Implications for research and practice

Identification is the key; for good care coordination to be delivered reliably, a system must be in place in primary care and hospitals to consistently identify individuals who would benefit. Patients who are at risk of dying in the next year are clearly such a group. Clinicians need training and support in tools such as the SPICT or the Gold Standards Framework prognostic indicator guide[38] to help them identify patients with advanced cancer, organ failure, or dementia, and especially the increasing numbers of patients with multimorbidity.[35]

Innovative communication strategies, such as the electronic palliative care summary in Scotland and 'Coordinate My Care' in London (where services target all those at risk of dying, regardless of age or diagnosis in a geographic area) have the potential to be nationally effective developments that can prevent crises and unnecessary care transitions.[39,40]

The role of the family carer or the patient in coordinating care needs to be fully recognised and acknowledged by professionals. Working more effectively within and across teams, and involving carer support groups, has the potential to empower and enable family carers to realise their own assets so they can meet the challenges of caring for someone who might die. This enabling approach can also be applied to help patients without family carers.

It is necessary to promote greater openness in society about death and dying and convey two key messages. First, that talking about end-of-life choices can be a positive experience that allows forward planning and a greater likelihood that wishes and preferences will be realised. Secondly, that the introduction of a palliative care approach does not mean that death is imminent.

Further research is required to establish how clinicians can reliably identify patients as soon as their health has deteriorated to a point where they would benefit from holistic, supportive care planning. There is a need to explore how best to overcome barriers associated with the term 'palliative care' and choose to either use an alternative such as 'supportive care' or to reclaim it in a positive, enabling manner.

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