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Redefining the carer-patient dyad at end of life

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Abstract

Context. Whilst the patient-carer dyad has been broadly described, there is little exploration about carer-patient models in use.

Aims. To explore types of carer-patient models in use for those with advanced and progressive disease.

Methods. Qualitative interviews were undertaken with patients at risk of dying in the next year and their carers across three sites (residential care home, medical assessment unit, general medical unit). Thematic analysis was undertaken.

Results. Four models of patient-carer dyad were identified. In these, the provision of care and of coordination of care services were important areas and organised differently across the patient, the carer, and alternative sources of support..

Conclusion. A 'one size fits all' carer-patient model is outdated and a new understanding of different types of carer-patient models are required to fully inform care delivered at end of life.

Key words: end-of-life, carer, carer-patient dyad, palliative care, advanced disease

Introduction

Due to increased life expectancy, people with advanced and progressive disease are living longer and with increasing numbers of comorbidities. This leads to end-of-life (EOL) care being recognised as occurring over months or even years (Hanratty et al., 2012). Policy and practice seek progressively effective ways of meeting the needs of this population (Robinson et al., 2014), with emphasis on supporting people to living independently in the community (Cohen-Mansfield and Frank, 2008; Davey, J, 2006; Wiles et al., 2011). Carers are acknowledged as essential enablers (Mason et al., 2013; Stoltz et al., 2004) however, the transitions occurring across healthcare settings at end of life are complex (Lawson et al., 2006). Additionally, recognised deficiencies in care planning and care coordination (Mason et al., 2013), have intensified pressure on both patient and carer. Literature reports a lack of recognition for the carer role (Daveson et al., 2014), that the carer voice is ignored (Hanratty et al., 2012), and that healthcare professionals (HCP) assume carer needs to be synonymous with the patient (Bee et al., 2009; Heaton et al., 1999).

Whilst traditional definitions of carers identify relatives as undertaking informal caregiving responsibilities (Mason et al., 2013), patients are finding new models of carer provision (Mason et al., 2013). Perhaps influenced by a societal shift away from the traditional nuclear family (Jack and O'Brien, 2010), a standardised carer-patient model no longer exists and the wider social networks used by patients requires acknowledgment (Procter et al., 2001). Although literature has explored carer-patient relationships in dementia care (Heaton et al., 1999; Oetzel et al., 2015), little is known about the types of carer-patient models in use, specifically for people with progressive disease in their last year of life. For the purpose of this paper, 'carers' are defined as non-professionals or lay carers.

Methods

Aims

This paper presents one aspect of a larger longitudinal ethnographic study, occurring over 9 months (2015) exploring practices and processes by which transitions in care in the last 12 months of life were managed across three study sites. During data analysis we identified a number of clearly defined models of care delivery with patients and carers each holding different roles and functions.

Sample and setting

Site 1: Residential care home

A 150-bed unit providing 24-hour registered nursing care to respite patients and permanent residents.

Sites 2 and 3 were located in a tertiary hospital offering a range of specialist and regional tertiary medical and surgical services for a population of 1 million people.

Site 2: Medical assessment unit

A 24-bed assessment unit for patients expected to remain in hospital for less than 36 hours. In 2014 there were 5,707 admissions with an average length of stay of 2.9 days per admission.

Site 3: General medical unit

A 36-bed general medical ward providing services for a range of medical specialities. In 2014 there were 1,501 admissions with an average length of stay of 5.1 days per admission.

Procedures

Four weeks of field observation were conducted in each site. At this time, people with advanced and progressive illness, who were at high risk of dying in the next year, were recruited using purposeful sampling and tracked for 3-4 months. Participants were identified by senior medical and nursing staff using the validated Supportive and Palliative Care Indicators Tool (Highet et al., 2013). Written consent was obtained at the time of recruitment and a process consent model was adopted (Dewing, 2007). After 3-4 months, the researcher contacted each patient and asked whether they would like to participate in a second interview in which case consent was obtained again.

Interviews were conducted at a mutually agreed time and place. The first interview focussed on diagnosis, prognosis and care journey to date. The second interview focused on experiences of care and transitions. Carers were present and interviewed at the patients' request and the same consent process was used. The nature and function of the carer role was explored across interviews.

Data analysis

Field data and interview recordings were transcribed, verified against original recordings, anonymised, read and re-read, coded and thematically analysed (Braun and Clarke, 2006; Thomas, 2006). NVivo was used to support data management. Once coding was complete, two authors (MC and RP) discussed the findings. Data addressing relationships between patients and their carers underwent separate analysis. Different carer-patient models were identified as carer-patient dyads described changes in care circumstances over time. All authors discussed and agreed the final models.

Ethics and governance

This study received approval from the Regional Advisory Group - Maori (Ref. no. RAG-M 2014/346), the Health and Disability Ethics Committee (Southern Health Region) (14/STH/180) and Victoria University of Wellington Human ethics committee (RM 21627). Local approval was given to access and collect data at each site. Site specific research governance procedures were upheld.

Results

Of the 29 patients recruited into the main study, 17 patients noted different models of carer-patient activity. All 17 patients had a first baseline interview at enrolment, seven participants had a second interview giving a total of 24 interviews. Of these, eight were conducted with the carer and patient, and three solely with the carer. Carers were identified as: spouses (n=5); siblings (n=1); adult children (n=9); and alternative carers (n=2). Patients aged 60-98 (mean 84.1) and had a range of medical diagnoses. See table 1 for demographic information.

[Insert table 1]

Findings identified that, contrary to the literature, there was not one, but four carer-patient models for patients with advanced and progressive disease in the last year of life. In these, the responsibility for different functions, namely for coordination of care services and for provision of care, was held by different individuals. The four models identified were: dependence on carer for care and co-ordination (community based); dependence on carer for care and independent for co-ordination (community based); independent for coordination with dependence on alternative help for care (community based); dependent on carer for coordination whilst in an organisational care settings for care. The patient-carer model in use was dynamic and changed over time to meet patient need as the patient's illness trajectory shifted.

Dependence on carer for provision of care and coordination of care

This model described circumstances where patients were dependent on their carers for both provision of direct care and coordination of care services in the last year of life. Caring duties included providing food, meeting hygiene needs, and managing medications. Coordination duties included liaising with HCP, managing patient finances, and making decisions about the health care services. Carers in this model took full responsibility in providing care and coordination:

"It becomes virtually 24 hours care and then gradually down, down...but you're a nurse, you're a physiotherapist, you're a runner around in the car, you're appointments...you're absolutely everything."

[Wife: Res M]

The patient position here was one of compliance with and trust in their carer and HCP. These patients were often so reliant on their carer that they were unaware of what their treatment plan was:

“I can't remember most of it, my daughter knows more about it than I do...my daughter will give you all the technical side. My technical knowledge is nil.”

[Patient: Gen H]

Dependence on carer for provision of care and independent for coordination of care

In this model, whilst the patient was dependent on their carer for caring responsibilities, the patient was independent in their ability coordinate their care services. Some carers used hospital admissions opportunity for respite, because the carer could rely on hospital staff to do the caring and did not need to be present for the coordination as the patient was independent in that regard. These patients based the decision to come into hospital on their perception of their carer's ability to cope. Below is an example of a patient-carer model where a husband had been providing direct care (*“things he's been asked to do lately”*) but was clearly not coordinating care as the patient made the decision regarding hospitalisation:

“Interviewer: ... the ambulance had decided to bring you here to give your husband a break?”

Patient: Well they made me make the decision.

Interviewer: How did you feel about making the decision yourself...?

Patient: Well it was important, my husband's comment, he said to me 'give me a break'. Yes. You know he's 96. It's not fair, with things he's been asked to do lately."

[Patient: M12]

HCPs did not always realise the patient had taken responsibility for care coordination and assumed that if patients were unable to undertake direct care, they were also unable to undertake care coordination. Consequently, patients' in this model wanted to be informed about their care services and were often dissatisfied with HCP communication:

"So I thought oh why didn't you tell me this. To you it's all just clinical, just want a body on a slab...they don't tell you something unless you ask. So you have to already know that these things are available...You have to ask the right questions...It's communication things it all comes out in the communication...the other problem is I actually am one of those people that even though I'm crook I like to know what's going on."

[Patient: Gen K]

It was unclear whether patients had chosen to take responsibility for coordination of care services, or whether this had been taken out of necessity, secondary to the limited capacity of their carer.

Independent for coordination of care with dependence on alternative help for provision of care

Here, patients coordinated their own care during the last year of life and, due to the absence of an appropriate family member or friend, made alternative arrangements to support their care needs. This included advertising spare rooms in their home for rent to 'flatmates' whose presence enabled them to remain in their own homes as opposed to transitioning to a residential care home. The caring responsibility was shared between flatmates and professional health services based in the community. Depending on the health status of the patient, care needs could vary from simply having someone present in case of emergencies to daily assistance with personal hygiene. It was challenging for patients to communicate the nature of their carer relationship and this became problematic when establishing patient eligibility for funded support. In the quote below, flatmates provided the patient with a safety-net for emergencies and assistance in daily tasks. However, their presence meant that the patients' entitlement to funded support was questioned:

“And they [flatmates] came to stay with me on the undertaking that we all look after ourselves and they weren't any way playing nursemaid to me...that's why they came there and I don't want to lose them. And yet [care agency] more or less takes the attitude, if I've got flatmates there they should be able to help me.”

[Patient: Gen L]

Although the coordination responsibility for patients was burdensome at times, and even though some patients struggled with taking responsibility for this activity, patients were determined to maintain this independence:

"I've developed about making phone calls and fronting up to counters and so on... just the merest suggestion that anything's official, so just making an appointment is more than I can cope with, but that's just a psychological problem that I have and I have to manage...And no one else is going to do it."

[Patient: Gen L]

Dependent on carer for coordination of care whilst in an organisational care settings for care provision

The final model identified where carers were actively involved in the coordination of health care, even though patients were cared for in organisational health care settings e.g. residential care home. In this environment, carers were observed organising outpatient appointments, updating on medication changes, etc. For some carers, whilst their coordination role continued, they found it challenging to relinquish previous caregiving responsibilities:

"I found it difficult to come up here because I felt that the staff weren't just quite aux fait with [medical condition]...tending to some of the things that I did that I felt that they should have done because they're professionals...it took me nearly that first year to actually get at what was needed to be done, what cares [Patient] needed."

[Wife: Res M]

Carers felt that their involvement with the patient was essential and were concerned for what would happen to the patient if they did not undertake this function:

“[The] elderly need someone to speak up for them even at the rest home, patients are neglected because they don’t have someone to speak up for them.”

[Field notes from an informal conversation with a patients’ daughter]

Discussion

Of those models identified, the one most explored in literature is where carers took full responsibility for care and coordination to maintain the patient in the community. This is clearly a complex and demanding role for carers with carer burden and potential for carer fatigue well documented (Daveson et al., 2014; Jack and O’Brien, 2010; Mason et al., 2013). We suggest given this risk for carers, HCP need to monitor and work to prevent carer burnout, cognisant of the many recommendations made for supportive carer interventions (Heaton et al., 1999; Jack and O’Brien, 2010; Laugaland et al., 2012; Oetzel et al., 2015; Procter et al., 2001; Thomas, 2004).

The second model outlined for patients in the last year of life described where patients care needs were met by carers yet patients continued to hold responsibility for, coordination of care services. Interestingly, whilst it has been suggested that carers of this population risk exclusion from discharge planning (Bee et al., 2009; Heaton et al., 1999; Procter et al., 2001; Rowe, 2012), in this study it was patients who needed more communication from HCP than was being offered. This may be resultant from HCP assumptions that carers were responsible for care coordination (Hanratty et al., 2012; Murphy et al., 2015). We suggest that HCP recognise that this model is distinct from the traditional model of carer-patient relationship and ensure patients are kept informed, even with their dependence on carers for care provision.

Patients who utilise alternative models for care and coordination during the last year of their life, reflect increasingly complex care circumstances (Mason et al., 2013; Procter et al., 2001) and the changing nature of caregiving in society (Fine and Glendinning, 2005). Whilst innovative and resourceful, these patients do not 'fit' current health care services and may be disadvantaged with regards to available community services. These novel and emerging care arrangements need wider and formal recognition.

Little consideration has been given to the nature of the carer-patient dyad once the patient is in a formal care setting. Carers of patients in such settings perform a vital role in care coordination, patient advocacy (Bridges et al., 2010; Li et al., 2004) and in maintaining continuity on admission to residential care (Davies and Nolan, 2006) and as end of life approaches (Shield et al., 2010). This also has implications for patients who live in residential care homes but who do not have a carer. It raises questions as to who does provide this coordination role.

The models developed from data in this study illustrate carer-patient dyad structures that expand on traditional carer-patient models. Some of these arrangements are beginning to be recognised, for example, the New Zealand Carers' Strategy Action Plan recognises that patients may have care needs outside the scope of traditional health provision (Ministry of Health, 2014; Ministry of Social Development, 2014) and in the UK, concerted effort has gone into raising HCP awareness of the contribution of carers (Bee et al., 2009; Department of Health, 2010).

Findings from this study suggest inflexibility remains within the health system for patients using alternative care arrangements in the last year of life. There is evidence that hospital-based HCP may not fully understand the complex and dynamic needs of carers and community service provision for patients at end of life.

Limitations

The sample size may be insufficient to capture all potential models of carer-patient dyad currently used by patients in the last year of life and a larger study is required to either strengthen or dispute these models. However, the purpose of this paper is to challenge the concept of a singular model of carer-patient dyad and to suggest alternative models which may exist. Further work is required to identify what factors influence the transition from one model to another, and offer guidance to HCP on the tailored assessment of care needs and coordination of services in use in each patient carer model.

Data collection took place in just one tertiary hospital and one residential care home in New Zealand and may not be transferable to other settings. To assist in making transferability judgements, we have provided detail on the population, data collection and data analysis.

Conclusion

Four carer-patient models for managing provision of care and coordination of care services were identified in use for patients likely to be in the last year of life. In each model, the responsibility varied between carer, patient and other support sources, and flexed to meet the changing needs of the patient. This refutes the 'one size fits all' definition of the carer-patient dyad model. Historical models in this area are outdated and a new understanding of the carer-

patient dyad is required. By taking a tailored, flexible approach that is cognisant of the trajectory of the patient's illness, HCP may be able to work with carer-patient dyads to instigate care provision systems preferable to patients and carers, as well as being more efficient use of resources (Stoltz et al., 2004).

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Table 1

Patient ID	Gender	Age	Diagnosis	Status at 3/4 months	Carer	Type of model*
<i>Residential care home n=5</i>						
Res B	M	92	MS	Alive	Care home, previously wife	1
Res C	F	80	MS	Alive	Husband	1
Res D	F	90	Frailty	Withdrew	Daughter	1
Res K	F	98	Cardiac, oncology	Alive	Son	4
Res M	M	80	Parkinson's	Alive	Care home, previously wife	1, 4
<i>Medical assessment unit n=6</i>						
M4	M	91	Heart failure	Deceased	Daughter	1, 4
M6	M	61	Parkinson's, COPD	Deceased	Alternative	3
M9	F	86	Heart disease	Deceased	Daughter	1
M12	F	86	Respiratory	Deceased	Husband	2
M13	F	83	COPD	Alive	Daughter	2
M14	F	97	Heart failure, liver disease	Deceased	Daughter	4
<i>General medical unit n=5</i>						
Gen B	M	91	Oncology	Unable to contact	Son	1,3,4
Gen H	M	77	Oncology	Deceased	Daughter	1
Gen I	F	83	COPD	Unable to contact	Daughter	1
Gen K	F	60	Oncology	Deceased	Sister	2,3
Gen L	F	81	Heart failure	Alive	Alternative	3

* Key for models of care provision

1 = Dependence on carer for provision of care and coordination of care

2 = Dependence on carer for provision of care and independent for coordination of care

3 = Independent for coordination of care with dependence on alternative help for provision of care

4 = Dependent on carer for coordination of care whilst in an organisational care setting for care provision