

Careful Thoughts: Recognising and Supporting Older Carers in Intermediate Care

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Abstract

Recognition and support for carers has become an increasingly important part of government policy over the past decade. This paper draws on data from a national evaluation of intermediate care. It describes patterns of informal caring relationships among older people who were using intermediate care services and considers the issues which affect how the carers perceived their caring roles, the service interventions which they found helpful during intermediate care, and the negotiations and decision-making processes as people moved from intermediate care to mainstream services.

Keywords

Older people, carers, family relations, interpersonal relationships, social networks, intermediate care, mixed methods, case studies.

Introduction

Intermediate care may have important implications for carers, and careful thought should be given as to how best to involve them.

(Department of Health, 2001, Para 13)

During the past decade, carers have become the focus of considerable government attention in the UK (Department of Health, 2005; Her Majesty's Government, 1999; Social Services Inspectorate, 1998), resulting in new legal rights and benefits such as the *Carers (Recognition and Services Act (1995)*, *Carers and Disabled Children Act (2000)* and the *Carers (Equal Opportunities) Act (2004)*. This reflects growing recognition of the economic and social significance of caring in the context of an ageing population (Pickard, L. *et al.*, 2000; Wittenburg *et al.*, 1998). The definition of carers in UK policy has been described as 'promisingly broad' (Keating *et al.*, 2003), and the title of the first carers' act, *Carers (Recognition and Services)*

Act 1995, encapsulates the twin themes around which support has been developed.

Many service user and carers' groups welcomed such policy recognition, though some concerns have been raised about its underlying conceptions. Heaton (1999) commented that:

Patients' social contacts have been transformed into and made visible as 'carers' by the discourse of informal care.

(Heaton, 1999, p. 763)

Others have pointed to the state's interest in carers as an alternative or complementary provider of support (Dean & Thompson, 1996; Twigg & Atkin, 1994). Caring relationships have been perceived in fixed, often stereotypical, roles, such as that of a single carer looking after a 'dependent' person (Keating *et al.*, 2003). Historically, emphasis was on carers' 'doing for' or 'tending to' activities rather than recognition of emotional and social aspects of caregiving (Nolan *et*

al., 1996; Qureshi, 1986). Furthermore, the notion of 'hidden carers' has gained increasing currency, begging the question of hidden from whom (Heaton, 1999)? Sometimes the term is used to describe people whose activities have hitherto been unrecognised by professionals, such as children or men); sometimes importantly, to people who themselves do not relate to the term 'carer' as a description of their personal relationships such as parents supporting young disabled adults (Arksey *et al.*, 1997), carers from minority ethnic groups (Godfrey & Townsend, 2001) or couples, one of whom has cancer (Morris, 2001).

Issues around carer recognition are especially pertinent in respect of older people. First, while there are clear links between advanced old age and increasing dependency (Henwood, 1992), being old does not in itself mean that you have a carer; indeed nearly two million people in England aged over 60 are actually providers of care. Of these, 20 per cent are aged 75 or over and 40 per cent live in the same household as the person for whom they care, which means that they are likely to be providing more intensive types of care (Milne *et al.*, 2001).

For many older people, giving and receiving care occurs in the context of reciprocal relationships, involving family, friends and neighbours, offering a sense of meaning and purpose in life (Godfrey *et al.*, 2004; Phillipson *et al.*, 1998). However, the nature of these social and support networks shifts with increasing frailty and ill-health (Keating *et al.*, 2003). In spousal relationships, the onset and boundaries of caregiving, in the sense of a shift into a self-defined caring role where care had previously been mutual and interdependent, are often ambiguous (McGarry & Arthur, 2001; Pickard, S. *et al.*, 2000). Such

care may thus be hidden from or unsupported by health and social care agencies (Milne *et al.*, 2001). Yet, modelling of future carer supply indicates that spouse carers are likely to become increasingly important (Pickard, L. *et al.*, 2000).

Pickard (2001) identified dual perspectives within UK policy on how to provide services to support carers. On the one hand, the National Strategy for Carers (Her Majesty's Government, 1999) aimed to provide support to carers to enable them to continue caring; its main mechanisms being carers' assessments and respite breaks. On the other hand, the Royal Commission for Long Term Care (1999) recommended that the:

Government ensure services become increasingly 'carer blind', offering flexible support services where carers currently take on caring unaided by publicly provided services.

(Royal Commission on Long Term Care, 1999, p. 90).

In its response to this report, the government held with the Carers Strategy as its main vehicle for carer support but also announced significant investment in new services for older people, such as intermediate care.

In this article, we explore issues of carer relationships and support in the context of intermediate care. The stated purpose of intermediate care is to:

Support older people to make a faster recovery from illness, encouraging independence rather than institutional care and... to enable the NHS to operate more efficiently by helping to release acute hospital beds.

(Secretary of State for Health, 2000, pp. 125-126)

Intermediate care services are diverse in location, duration and purpose; provided at home or in a residential facility; for a

very short time (that is, three days for emergency services); for up to and beyond six weeks. Such diversity under the umbrella of intermediate care means that it is used by a wide range of older people. In providing care to prevent admission to or support discharge from hospital, it is located at a point of crisis and transition for older people where many people encounter formal service assessments for the first time. Discharge from hospital has been seen as a site of tension for service users, carers, health and social care agencies (Hill & Macgregor, 2001; Holzhausen & Clark, 2001; Social Care Institute for Excellence, 2005). Intermediate care guidance (Department of Health, 2001), as the opening quotation to this article shows, requires that services should be designed to seek the best possible outcomes for users and play a supporting role for carers and advises that carers should be closely involved in assessments and in drawing up individual care plans. However, little has been written about carers' experiences in intermediate care, although a number of studies have included carer satisfaction in particular service settings, see for example Wiles and colleagues (2003) or Clegg (2003). Lindhardt's (2006) study of relatives of older people in hospital demonstrated how the history of the caring relationship offered a frame of reference in which the hospital stay of the older person was reflected and understood, while Daff and colleagues (2006) consider the value to carers of a transitional unit in giving them time to reflect on future options. Here, we take forward these approaches by focussing on the nature of informal caring relationships and interactions between service users, carers and formal services.

Methods

Our study adopted a mixed-method, case-study approach across five English localities to evaluate intermediate care at system, service, and service user levels. The range of data included routine annual admission data ($n=6,970$ admissions), tracking data for a cohort of service users over six months ($n=153$), interviews with key staff and managers, observation of operational and strategic meetings and service delivery and in-depth qualitative interviews with service users and carers (Godfrey *et al.*, 2005).

We interviewed a sub-sample of the tracked cohort ($n=64$) selected purposively to reflect a range of experience of different types of services (crisis intervention, enabling support, rehabilitation) and personal characteristics. Service users interviewed were typically older (mean age 79 years, range 56-94 years) and predominantly women. Seventy two per cent lived alone, 25 per cent lived with a spouse and the remainder with other relatives, such as an adult child or grandchild. These interviews were conducted following discharge from intermediate care and twice subsequently up to seven months later, to obtain perspectives of change over time. The interviews explored service users' views on service experiences and outcomes, lifestyles and networks, including help received from and given to family and friends.

Where the service users identified a single person on whom they relied for substantial support during intermediate care, we asked permission to interview those people.

Table 1: Relationships and residence of carers

Relationship of carer to service user	Lives with service user (n)	Lives close by service user (n)
Spouse	10	
Daughter/son	3	5
Daughter in law		1
Sibling		1
Grandchild	1	

We conducted 21 carer interviews, using a semi-structured interview guide to discuss their involvement in and views of intermediate care, prior and current support to service users and from formal and informal services. The carers ranged in age from 29-82 years, with 14 aged over 60. One carer was of African Caribbean origin. The remainder were white British.

Table 1 shows the relationships between carers and service users and their residence to each other. Fifteen carers (10 spouses, four daughters and one grand-daughter) were interviewed with service users also present in their own homes, followed by telephone contacts with seven of these carers during the tracking process. Six individual carer interviews were undertaken by telephone ($n=5$) or face-to-face ($n=1$).

Data analysis

Interviews were transcribed and analysed using a grounded theory approach. The first stage involved familiarisation of the whole data set: team members read and re-read transcripts of their interviews to identify patterns and themes through open coding (Emerson *et al.*, 1995). Then, discussion within the team and further exploration of each other's interviews generated broad themes, coping with personal transitions and negotiating pathways of care, that were subject of a more focused

analysis developing codes and categories. The analyses were carried out manually, using a word processing package. The study had ethics committee permission; participants were assured of confidentiality and names used are pseudonyms.

Findings

Patterns of caregiving relationships

For service users, intermediate care interventions came at a critical point in their illness pathway; with the process of recovery extending considerably longer than the intermediate care episode. For some older people, the event precipitating intermediate care led to or exacerbated chronic illness and disability, disrupting previous lifestyles. Two consequences arose for relatives and friends: first during the process of recovery, they took on caregiving tasks, if only for a limited period. Second, where the issue was less about fully restoring independence than managing life with increased disability, there were implications for changing relationships and roles for close relatives and friends.

From our analyses, we identified five 'types' of caregiving relationships, within which the balance of reciprocity can be seen as a seesaw. For many older people and their relatives and friends, the seesaw sways gently up and down but remains broadly in balance

(*temporary carer*). For some, the event that led to intermediate care causes a dramatic fall of the seesaw, jolting both partners (*shared disrupted lives*). In some relationships, the seesaw is beginning to tip more consistently in one direction (*reciprocal supporter through gentle decline*) and others have moved through this process to the point where the seesaw is constantly dipped towards dependency (*long term carer*). Some long term carers themselves became ill and needed support (*caregiver as care receiver*). The vignettes below offer illustrative examples of each type.

The temporary carer

Mrs Crawford, aged 82, and her husband were generally fit and able to enjoy an active social life, which was becoming restricted by her immobility. Her elective hip replacement surgery was followed by support on discharge from the rehabilitation-at-home team. Mr Crawford took charge of domestic tasks (cooking, shopping and cleaning). Mrs Crawford was worried that he might overdo things 'because he has a heart condition', but he did not want her to pick up her normal jobs too quickly. They said of their relationship, 'We look after each other'. At the six months follow-up, life for the Crawfords was back to normal.

Reciprocal supporter through gentle decline

Mrs Faraday, aged 87, and her younger sister, aged 75, had visited each other daily for years. Mrs. Faraday's intermediate care episode to help her recover from a diabetic coma was preceded by a year of medical crises (fall, heart attacks) and succeeded by investigations of further problems. When she went home, her sister helped out with housework for a fortnight. Six months later, she lived contentedly at home, surrounded by 'good neighbours',

doing her own housework and enjoying frequent social visits from her extended family. However, she spoke of feeling 'very dependent' on her sister, relying on her support to walk out to town or deal with new pension arrangements. Her sister emphasised their shared support and made light of her own input:

Constance is a wonderful person; she's always done everything for us. I tell her we take a copy from her...I go down every day and ask if there is anything to do but I don't do anything now. I just keep her company to walk out, keep her on her feet but some days she's tired out.

Shared disrupted lives

Mr and Mrs Partridge, both aged 80, were active members of the golf club, enjoying life despite his well-controlled Parkinson's disease. When a serious stroke impaired his mobility, the couple felt that their lives had been 'turned upside down'. Home-based intermediate care services helped Mr Partridge to relearn basic skills such as dressing and offered Mrs Partridge support and advice in coping with new demands, like helping her husband in and out of bed. Reduced contact with friends was a great blow to the couple. Over the following six months, they worked to come to terms with their new, restricted life: Mrs Partridge spoke of 'settling into a routine that appears to work quite well', though Mr Partridge still yearned to go out independently. Their care package gave Mr Partridge social time at a day centre and his wife a break to play golf with friends. Important in coping with disability was the frequent support of their family who lived nearby.

Long term carer

Mrs Keating, aged 89 years, blind and with little mobility, lived opposite her daughter, Denise, who had helped her daily for several years. After months of ill health and pain and several GP consultations, in desperation Denise rang

for an ambulance one evening and took her mother to A&E where she was admitted because of 'carer distress'. Mrs Keating was subsequently diagnosed and treated for a stomach ulcer. At discharge, Denise sought out a hospital social worker who referred Mrs Keating to an intermediate care unit to develop coping and confidence skills. Twice daily home care was arranged when she left the unit, mainly to relieve Denise, whose husband had recently suffered a stroke. Mrs Keating recognised how much she needed Denise's support to remain at home but was adamant that Denise's husband came first. For her daughter, the issue lay in balancing both sets of needs.

Caregiver as care-receiver

Mrs Smith, aged 79, had 'done everything for her husband' with multiple health problems for eight years, without 'realising how much of a task it was'. When she fell and fractured her fingers, she told the nurse in A&E that she looked after her husband and was referred to the Emergency Response Team.

It was unbelievable...my husband had collapsed really because he realised how dependent he was on me...when I walked in with a sling...It affected him dreadfully...They organised everything ...helped us get up, dressed, organised a meal...You don't realise what you can't do when you have lost the use of your right hand - nothing. Looking back, we'd have been in care...

This help continued until she felt well enough to resume caring, without accepting home care support. At six months Mr Smith had moved into a nursing home after another stroke, when Mrs Smith realised she could no longer manage to look after him. She was living temporarily with her son to recover from the strain.

The extent and nature of support needs identified by carers was affected by several interacting factors. A key issue was whether this was a temporary breakdown, creating short term anxieties and stresses but with a prospect of returning to previous normality or a more permanent or significant disruption to people's lives. For example, two adult children gave up their jobs to provide twenty four-hour care for their parents; a son moved in with this mother after her return from hospital. Several spouses coped with big changes in their daily routines and in their homes, which became transformed into care environments.

As people talked about their lives, it was also clear that personal relationships and networks affected the support they required from formal services. The extent of mutuality and interdependence, especially apparent in spouse and sibling relationships, affected how far people saw themselves as undertaking a distinct carer role, which required support in its own right. Spouses were more likely to talk about the help *we* need rather than that *I* need.

Beyond this, however, were the wider social networks; sons, daughters, grandchildren, friends and neighbours offering a range of practical, social and emotional help and support (or otherwise). Some were supportive to both service user and carer, for example, the Partridges' children. Others were especially protective towards the carer. One daughter, who had given up her job to continue to care for her disabled mother at home, remarked about her own son's concern:

This morning my son told me off, because he reckons I've gone down so fast since mum's come out. I haven't...It's just a fluke with this ulcer.

Some carers like Mrs Keating's daughter, balanced dual responsibilities; other were dealing with conflicting family loyalties. Mr Harris's daughter had a son with learning disabilities who recently moved into care but her husband felt 'they still were not free to enjoy their retirement' because of long term caring for her father. A daughter in law exemplified weariness resulting from a long career of family caregiving:

I'm a pensioner myself, I'm 61, and she is the fourth one I've looked after. I looked after her husband for a year, then my stepfather had a stroke, and my mother had Alzheimer's. She died six years ago and I've been looking after Florrie ever since. My friend sometimes says, 'Who is going to look after you?' and I say, 'Don't worry. I'll be dead by then'.

Moreover, for some, the intermediate care episode was revelatory in bringing caring, often long term and of high intensity, into focus for the carer and for service agencies. People like Mrs Smith recognised themselves as carers for the first time. Others suddenly had an opportunity to take stock of their situation as a social worker remarked:

We do find...family are going in four times a day though when they get here it's like a crisis situation and when I speak to the family, they are telling me, 'We can't possibly carry on'. But had that person not come in here, they would carry on giving that care.

The 'careful thought' suggested by guidance on meeting carers' needs requires that the interplay of these factors is recognised and acted upon to optimise carer support. We go on to consider service responses within intermediate care and in handing over to longer-term support.

Intermediate care

As indicated earlier, a unifying feature of intermediate care services was that their service users were at a point of

transition; recovering from a crisis in which services had intervened, often a time of high anxiety. What caring relatives were looking for in these first few days or weeks, was help to cope with and understand changed circumstances. Four common features could be identified across all types of caregiving relationships, though the level and intensity of support they needed varied. Generally, carers were positive about intermediate care although there were clear variations across services.

Getting the service user going again

In general, service users' needs to resume the functional aspects of normal life or manage increased disability were met fairly consistently, while the social and emotional elements were more patchily addressed. All carers were very concerned that their relatives should be safe in getting on with day-to-day life but this assumed high priority where service users lived alone or where carers went out to work. Thus, Mrs Keating's daughter praised the way occupational therapists enabled her mother to make herself a cup of tea. Some couples valued such help provided in a way that also recognised their shared lives. For example, Mr Udall, aged 80, who had multiple health problems, was taken to A&E after collapsing with a urinary tract infection. He was admitted to the rehabilitation unit, convenient for his wife to visit, after she made it clear that he had to regain his former mobility before he returned home:

I said I can't have him home until he can walk because I'm nearly 80. I couldn't move him to the toilet.

Here therapy was geared towards enabling 'normal life' which for this couple meant continuing their shared social activities. During his stay, therapists arranged for Mr Udall to join his wife at choir practice nearby and for

membership of an accessible swimming pool, where the couple could continue to swim together.

Reassurance and confidence-building

Most carers had worries about their relative's condition or prognosis and sought reassurance from knowledgeable staff. A wife praised the support of rehabilitation-at-home team after her husband's knee operation:

With the support that you get. If you're wondering if this is alright, you've always somebody there, you're not sat at home worrying... because there's somebody there to say, 'Oh yes, this is normal.' I think it's a good idea.

Personal communication

Good practice here could be seen in several ways. In one unit, an old friend was invited to review meetings as well as relatives, because staff recognised how significant he was to the service user's life. Carers valued a range of opportunities to talk to staff; thus the chance to chat, to check up on things informally was seen as helpful as well as involvement in assessments and reviews:

The nursing home really was a wonderful place... I went in at different times - popped in during the morning or the afternoon and there was the same care...Once or twice I had a word with the nurses just to make sure she wasn't covering anything up because if you ask Constance how she is, she'll always say, 'Fine'.

For one caregiver who was receiving daily home support after she fractured her arm, chats with her support workers gave her the chance to express her concerns about looking after her husband, which led to a carer's assessment and ongoing support.

Carer education

Those who had to learn how to support relatives with increasing dependency

needed help to understand how to undertake new tasks of personal care, to make judgements about risk and to assess what progress was or was not possible. The wife of an amputee had four days' home support after her husband's discharge:

[It was helpful] until I could see what needed to be done, until he could do it for himself. Because when you've never had to cope with it before, it's all new.

Mrs Carter was supported at home by a community rehabilitation team, rather than going into hospital after her stroke but her granddaughter found that learning how to help her grandmother involved difficult judgements.

The therapists didn't particularly like [that I did everything for my grandmother]... but they wanted to encourage her to be independent and do things on her own because I think she was a bit scared.

She took their advice to stand back:

...And leave her to get on with it and if she really couldn't manage it, that's when I would go to help her...Now, when I leave her on her own, I do get a bit worried but usually she is OK. I don't feel as worried any more, now I can leave her and she will be all right.

Baton-passing to mainstream services

Few intermediate care users were fully recovered in the sense of return to their previous state within the six weeks and many needed ongoing support. Over half of the 153 people tracked said they had more family help six months after intermediate care than they had before admission. Intermediate care offered a gateway to access mainstream services, most commonly homecare. Here we observed an intricate and complex process of negotiation between service users, carers and professionals.

For some frail or disabled older people, return to their own homes depended primarily on the willingness of their relatives to provide extensive care, usually supported by a substantial package of homecare. Mrs Acton's daughter was delighted at the positive partnership work to achieve her mother's return home despite staff's earlier reservations. Mr Harris's daughter, on the contrary, was concerned about her father's future safety at home, after his second fall and hip fracture at the age of 92 and wanted him to move into residential care. He was strongly supported by staff in his desire to return home, while his daughter felt that no one listened to her.

They never asked me about things - just told me ways that they could make it easier for me, like the pension being put in the bank.

However, she conceded that 'it is his choice, I couldn't do anything else but let him come home' and was relatively positive six months later, despite Mr Harris's further fall and readmission, although she still felt burdened by her responsibilities. Mr Harris for his part accepted home care because 'it's time [my daughter] was having it a bit easier'.

Several other service users accepted services primarily to reduce the burden on their relatives. Mrs Robinson continued to have a home care evening visit, which she felt served little purpose other than to reassure her daughter.

Mrs Keating similarly believed that by accepting home care she was reducing demands on her daughter, who was ambivalent about its value:

It is a hundred times easier [now that I have help] I feel quite content waking up in a morning, thinking, 'Right, I know mother has had her tablets and someone's given her breakfast and a shower'. But these little things [carelessness with medication, not heating meals properly]

are a worry. They take away the reassurance. I feel I need to keep popping over to keep an eye on things.

However, acceptance was by no means universal. One service user typified the struggle to balance her own independence with her desire not to be a burden. She initially refused both domestic help and a Careline, because:

I am a bit independent. [Although] I feel I just don't want to be a bother to anybody, yet I depend on my sister. Strange, isn't it?

Her sister agreed that there was no need for domestic help, which she happily fitted into daily social visits. However, later Mrs Faraday arranged for a Careline to be installed when she realised that her sister was delaying her holiday because of concerns for her safety.

Some married couples mutually refused home care. These decisions involved balancing the help offered against a desire to return to normality. Several wives said that they 'could do what was necessary' and 'that others need the help more'. Mrs Smith and her husband initially accepted home care but cancelled on the first day when the care workers arrived late. One important factor here was the close, trusting relationship built up with intermediate care support workers and the difficulty of transferring to another service but she also spoke of her relief at getting away from what she called the 'Grand Central Station caring response'.

However, service users frequently refused help without consultation because 'my family will do it'. In some cases, this provoked exasperation, frustration, or even desperation in caring relatives:

Intermediate care was brilliant but with all services, it is a case of Dad agreeing to use them. If he won't, there is no

alternative.

They offered home help when he came out but my husband wasn't interested in that. Between us, we manage it. We had to fight with him to go to the day centre for one day. We begged him to go to respite.

For me just once, a fortnight a year isn't much. I've got arthritis myself – but I have to keep my issues to myself so I can keep going.

In these cases, staff might act as advocates for relatives, sometimes without avail.

There were also service users who needed practical or social support, for whom either no service was available or who did not meet eligibility criteria so that by default, support devolved to family carers.

All our carers were involved in the discussions about cessation of the intermediate care service, either in joint meetings with the service user or independently. Yet continuing support for them was dependent on continued service receipt by users. Several, whose relatives had substantial care packages, spoke of valued ongoing support from social workers and three had organised respite breaks based on carer assessments. However, where service users refused offers of services, carers faded from the view of statutory agencies. Thus, we found some providing regular and frequent care, who needed information about benefits, equipment, and services but were uncertain where to access it. We also met carers, stressed by their responsibilities, simply soldiering on. Discharge from intermediate care appeared in these cases to mirror earlier findings about hospital discharge, with carers as forgotten partners (Hill & Macgregor, 2001).

Discussion

This article explores carer recognition and support within intermediate care, currently an under researched area. Our sample had limitations in being focused mainly on traditional dyadic relationships, and on carers who were immediately 'visible'. The perspectives of others providing informal support, notably friends and neighbours, distance carers and the wider extended family have not been explored. All the service users in this sample remained in their own homes after intermediate care; so that the complex decision-making around moves into residential care has not been discussed here.

The majority of our carer interviews took place jointly with service users. Arksey (1996) cautioned that such data differed qualitatively from that obtained in separate interviews. Morris's study of the lived experience of people with cancer and their carers found real positives in joint interviewing in terms of enabling understandings of relationships and shared/different perspectives (Morris, 2001). Our joint interviews were supplemented in several cases with individual follow-on contacts, which were included in the analysis.

It is clear that intermediate care occurs at a critical juncture for many carers as well as users. In particular, adjustment to serious or on-going illness affects both service users and their relatives, especially where they are taking up new caring responsibilities or 'moving up a gear'. Carpentier and Ducharme (2003) offer the concept of a 'caregiver career', mirroring Corbin and Strauss's 'illness career' or 'trajectory' (1985; Corbin & Strauss, 1988), which identifies ways in which people manage their lives and adapt to ill-health and disability. The shifting balance in mutual relationships has particular implications for spouses

and requires sensitive service responses geared to supporting the relational aspects of caring. For many the crises which precipitated intermediate care brought people into the gaze of formal services and revealed to them, as well as to service providers, the extent of caring which had been going on for some time.

The experiences of service users and carers in this study shed light on practice issues to meet carers' needs. Understanding the prior lifestyle of the user and his or her significant others, particularly in terms of exchanges of care and support, is essential to a holistic assessment of needs. Recognising changing needs over time is also key, and reinforces the importance of information and support at different points and of access loops back into the system. In ongoing, high-level caring situations, good assessment and care-planning to meet carers' support must determine whether this is more appropriately provided as a shared service, as in the example given earlier of the Udalls, or separate activities to rebuild a social life or provide a break, such as that experienced by the Partridges).

Carers and service users' stories also offered insight into services along the pathways of care. Within intermediate care, much positive work was undertaken with carers by staff from a range of backgrounds as part of a holistic service. In many services, there was specific support to carers to educate and support them and to facilitate their adjustment in serious illness. This was patchy both in that it depended on the skills and attitudes of individual staff and because practical, functional support appeared to have more emphasis than social and emotional needs.

Potential tensions in supporting aspirations and needs of users and carers

and the consequent processes of negotiation within families at the interface with formal services were revealed. Intermediate care is typical of recent older people's policies, which promote independence and control (Department of Health, 2001; Her Majesty's Government, 2005): a vital corrective to historical perceptions of older people as dependent recipients of care. However, tensions may occur, especially around acceptance of formal help for carers whose own lives are significantly affected by providing support. These could be seen in some spousal relationships but were most clearly articulated by daughters, often with long experience of supporting older relatives. In this respect, guidance gives little attention to the complexities of duties, rights and affection, through which service users, carers and staff are constantly negotiating their way. The issues merit more attention if we are to support informal care for older people effectively.

Conclusions

To conclude, we found that within the arena of intermediate care, valued support for many relatives and carers was provided as part of holistic care to service users. There is a need, however, for additional focus, particularly at the point of handing over to mainstream services, on appropriate responses to the differing relational aspects of caregiving: for spousal relationships; where informal care is prolonged and on going; and where user and carer views diverge. For practice and policy, a consistent twin-pronged approach is important, to offer user-centred services, which recognise and enhance their social networks and to support carers.

Acknowledgement

This paper is based on data collected as part of a national evaluation of

intermediate care funded by the Department of Health and the Medical Research Council.

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