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## **From Dawn to Dusk: a temporal model of caring: adult carers of frail parents**

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## **From Dawn to Dusk: a temporal model of caring**

### **Abstract**

Caregiving is not a short term commitment. Of the estimated 6 million carers in the UK, almost a third of co-resident carers have been caring for at least 10 years (Rowland and Parker 1998). Yet our understanding of how relationships and caregiving evolve over time is limited. Many of the existing temporal models of care are based on studies of service users who suffer from dementia and their carers. These models have a tendency to map the experiences of carers in line with the progress of this degenerative condition. This focus means that existing models overlook the care provided for non-users of services such as older people without dementia, whose progress towards frailty and dependence is uncertain. The study on which this paper is based was a longitudinal, qualitative one which used a grounded theory methodology. Over a period of 28 months, it explored the experiences of unsupported carers of older people who were not known to service providers. This study provides a unique insight into the lives of unsupported carers and reveals how the dynamics of caregiving relationships change over time.

### **Introduction**

This paper draws on data gathered during a longitudinal, qualitative study which used a grounded theory methodology. It outlines a temporal model of caregiving, which illustrates the evolutionary nature of family caregiving. The model is based on the experiences of adults caring for their frail elderly parents. It describes nine stages in carers' caregiving careers, each of which encompasses a particular process. It illustrates how caregivers are confronted with the changing realities of caregiving as they deal with increasing levels of dependency, the changing nature of relationships with the care recipient and service providers.

In this paper I argue that unsupported caring is simply one of many dynamic stages; that the ongoing nature of caregiving disrupts family relationships, and that carers are more receptive to service intervention during particular stages of their caregiving trajectory. The paper will begin by briefly describing the research study which informed the development of the model. It will then discuss each stage of the model, the processes involved and the implications for caregiving relationships and service provision.

### **Methodology**

The aim of the study in its broadest sense was to explore why, when caregiving is portrayed as being stressful, do caregivers continue without support from formal service agencies? The term 'unsupported' is used in this paper to describe carers who when first contacted, were not in receipt of any type of formal support services. Support is taken here to mean any service whose purpose is to provide either practical or emotional support for caregiving. Formal services are taken to mean those that may be provided, funded and /or arranged by statutory and voluntary agencies, such as home, day or respite care, or community nursing. Although GPs and pharmacists are examples of formal services, for the purposes of this study they are not regarded as providing a service that is designed specifically to support carers.

#### *Participants*

Purposive sampling was used to identify a suitable sample of carers. Participants were selected because of their status as carers of older people aged 65 and over without dementia or other existing physical or cognitive disabilities, and who received no support from formal service agencies but were caring for 20 hours a week or more.

A total of 41 carers were approached of whom 26 were interviewed in the first phase of data collection, 21 in the second phase and 17 in the third and final phase. Data were collected

over a period of 28 months. Interviews were held in the homes or workplaces of carers who ranged in age from 36 to 83 years. Of these 8 were spouses, 15 were daughters, 2 were sons and 1 was the sibling of care recipients. The majority of carers lived in the same household as the person being cared for. The length of time they had been caring varied from 6 months to 20 years with the average being 6 years 10 months. While the sample cannot be said to be representative the data generated provided considerable insight into the responses of caregivers.

#### *Data collection and analysis*

The in-depth, unstructured interviews, which lasted between one and two hours, were recorded and fully transcribed. The computer software programme ATLAS<sub>t</sub>i (Mhur 1996) greatly facilitated the management and analysis of data, which were coded according to the principles of grounded theory. Common themes were identified and 'open codes' ascribed. Open codes and categories that linked together in some sort of relationship were then given an 'axial code'. The purpose of 'selective coding', the final step in the coding process, was the deliberate selection of categories, which illustrated major themes that emerged during axial and open coding. Once data analysis was completed, respondents were provided with a summary of the study's main findings. Where names appear in this paper, they have been changed in order to protect the identity of carers and their associates.

### **Temporal Model of Care**

The temporal model of caregiving illustrates the evolutionary and dynamic nature of family caregiving. For many people caregiving is not a short term commitment. It is an active process which can vary in length of time from a few weeks to many years. Existing temporal models of care (see for example Bowers 1988, Wilson 1989, Willoughby and Keating 1991, Keady and Nolan 1993, 1995) have emerged from the literature on dementia, a degenerative condition with a recognised pathway. So while these models map carers' experiences in line with the progress of dementia, they fail to address the temporal and dynamic nature of caregiving for older people without cognitive impairment and whose descent into frailty and increasing dependency is uncertain. Furthermore, these models of care are based on the experiences of carers who are also service users. This focus on service users mean firstly, that existing models tend to overlook the circumstances that lead to service provision. Secondly, it means that the experiences of non-users remain little understood.

The model presented here however, reflects the experiences of non-users; unsupported carers of older people who have no cognitive impairment and no diagnosis of dementia. The model comprises nine stages which each reflect a particular process. These stages are:

- Increasing awareness,
- Accepting responsibility
- Going it alone
- Developing expertise
- Sinking or swimming
- Pathways to service providers
- Carers: clients or partners?
- Supported caregiving
- New Opportunities

Although this model is presented as being linear it is not experienced as such. Some stages can overlap and the time taken to reach a specific stage varies depending on individual circumstances. Similarly, the time spent in any one stage varies. Moving through and across these stages had important repercussions for caregiving relationships – some survived intact but others became virtual battlegrounds for control.

#### ***Increasing awareness***

Without exception, carers can recall the events, which led to them becoming a carer. Caregiving begins with this embryonic phase of increasing awareness – when it takes time

for individuals to appreciate their status as a carer. This stage is characterised by carers' realisation that their relative needs to be looked after. The realisation that their relative needs to be cared for more than usual can happen either suddenly or slowly depending on the nature of events. In situations where a sudden injury or illness is the catalyst for becoming a carer, the realisation is swift. On the other hand, where the older person experiences a gradual deterioration in their health, realisation is slow and gradual.

Mother fell. She was still active at that time and she had gone into town to buy some wool and the bus turned the corner and she fell and broke her leg. I had just retired and I just had to take over. I had no choice (Betty, 67 years)

My dad died and I've really taken care of my mother since then...It's just over the last couple of years that's she's got slower.. It was so gradual. You know I just started doing things for her and you never really noticed it and then – suddenly you realise that your doing everything (Pam, 47 years)

I felt as if - before you knew it, you were doing it - I can't remember when I started doing it or any specific day or what had happened. I think just over the years my mum was getting weaker and I just started getting her messages for her and from there it just went on (Wilma, 62 years)

When my father died I took on this role, it was just circumstance. At the time it didn't really sink in, the responsibility you had...It wasn't my choice it was just circumstance, just because I was there at the time. (Katy, 36 years)

The pace of this stage is not necessarily determined by residency, although many carers, who shared a household with the person being cared for, reported a gradual awareness of how they were increasingly doing more for their relative. In terms of relationships – those who had good relationships tended to be more alert to their parent's state of health and need for care. Comments from others suggested that they deliberately tried to delay the moment when it had to be acknowledged and steps taken to address the situation.

### ***Accepting responsibility***

This second stage is characterised by carers' acceptance of their relative's need for care and of their responsibility for providing it. This is an important stage in the caregiving career. The most crucial aspect of it is the decision-making process. In accepting the caregiving role, people tend to build on past relationships.

Where caring represents the continuation of a good established affectionate relationship then rarely are questions asked about alternative care arrangements. This is particularly pertinent for co-resident adult children. They tended to take on responsibility for caring almost 'by default' and were not conscious of having been offered the opportunity to make a fully informed decision. Their willingness to take on the caring role was simply taken for granted.

When my father died I took on this role, it was just circumstance. At the time it didn't really sink in, the responsibility you had...It wasn't my choice it was just circumstance, just because I was there at the time. (Katy, 36 years)

Sons and daughters who did not live with their parents were in a different position. They had the opportunity to make an informed choice of whether or not to become a carer and their positive choice was based on love and affection. In few cases, adult children who had an existing close relationship with their parent actually changed their living arrangements in order to accommodate their caregiving responsibilities. As we shall see, this change in living arrangements ultimately had serious consequences for the caregiving relationship and indeed the quality of care provided.

Last year it was becoming increasingly obvious that she needed care... I decided to move back. It was purely my own decision. It wasn't a spur of the moment thing. I don't think of it as a sacrifice. She was on her own and I didn't want my mother going into a home because I thought she would go down hill faster. With me being here all the time I know she is being well looked after. (Diane 47 years)

'It was my choice to look after mum. Well it had to be. You couldn't let your mother go to a home, could you? No, I'd feel guilty because she was a good mother. Then she took the blindness. So then she fell and she phoned, she'd broken her arm, then it was her ankle. So then I decided we'd be better with the one big house and we'll all be together,, because I used to go up and clean as well and my mum would be here, If maybe you'd phone her and not get a reply and I'm saying oh mum will be behind the door. So this is how, we came here. And she could never have managed sheltered [housing] because she needs attention... It's quite a lot of hard work now (Maggie, 63 years)

In other cases, carers who have poor relationships with the person requiring care, accepted the role with reluctance. This acceptance was often based on the belief that no one else was available or able to provide the care required. In other words, they were motivated more by a sense of obligation and duty rather than affection.

I took over after mum died. She knew that I would look after my father. ...We were close. I was round every day or I phoned every day...What else can I do? I can't put him into a home...I don't like my dad basically. The reason I'm here is because it is what my mum wanted. It's what she wanted, not what I ... (Wendy 38 years)

I had a wee miniature of whiskey and I drank it and I thought whit the hell do I do. It was a take it or leave it situation. If I left it then she would end up in a home or hospital or something. It was down to me really. I wouldn't see her going into a home, I knew what that meant so I thought it's not really on so I'll just do it. (Paul, 63 years)

I have always had a difficult relationship with my mother – because I had always had to do for her all over the years. But when you are dependent on someone – you will favour someone else who is doing nothing, but the one who is doing it all has all the faults. I do what I have to do instead of getting on with my own life. (Vera, 69 years)

### ***Going it alone***

'Unsupported caring' represents the period after individuals have accepted their role and identified themselves as a carer. This, the third stage to emerge from the data, was the period in which carers looked after their relative without support from formal service providers. Some had limited support from their social networks but it tended to be short-lived. Carers reported that family and friends soon left them to 'get on with it' and expressed regret at the loss of friendships, some of which were long established relationships.

If you take over the care of another person, you take over their life and they in turn overtake your life, you don't exist any more. Your friends that used to be your friends don't come. The true friends that you have got get fed up asking you out because you have to end up saying I can't go. (Theresa, 68 years)

Having an adult to look after differs from having kids to look after. I remember when I had my son and if my friend phoned and asked me did I want to go out - my mum would say away you go, I'll watch him. If my friend phones now and says do you want to go out, nobody jumps and says they'll watch my dad. That's the difference. (May, 45 years)

Friends dwindle. The only thing I do miss is my friends. I grudge losing a lot of my friends. You find your true friends but they get fed up with you and then eventually the phone calls don't come. And it's not their fault and it's not your fault. It's just a fact. It's one of the things that happen. You're just a carer. It's just the 'caring syndrome' (Susan, 53 years)

Many individuals became carers in a state of naivety in which they generally had no idea what caregiving would entail. They were not prepared for what was essentially hard work – making sure that their parent was clean, well fed and in an optimum state of well being. Once the reality of the daily grind started to become clear – doubts arose about their ability to cope.

I do everything for my dad. Everything. Get him up, shower him, toilet him, dress him, cut his hair and see to his catheter - everything because he can't do it himself.

Some tried to seek help from service providers once they encountered difficulties, but if their attempts were unsuccessful, they were discouraged from trying again. Others were offered a referral to health and social care agencies but refused the opportunity for various reasons. Thus for the majority, their caregiving activities went completely unacknowledged by formal service providers and their GP.

This was also the stage when subtle changes in relationships first became evident. For example, some carers had difficulty in coming to terms with the role reversal that was taking place. This role reversal occurred when parents through ill health or frailty lost their independence and some became very childlike and demanding and the carer who was once the child found this process perplexing. Demanding behaviour within the context of once close relationship created tensions that were not easily eradicated.

She's like a baby now, aye, like a baby and I'm the mother. That's it in a nutshell. They rely on you and you alone and nobody else. And if you say one wrong word to them it's like scolding a baby. There's nothing you can do about it except grin and bear it... You got to stay within sight of her. She's got to be able to see you. It's like being chained to somebody, chained really. I never knew it could be like this. It makes you browned off actually. Browned off! (tears welling up) (Beatrice, 51 years)

She has tantrums and screams or stamps about muttering under her breathe. I just treat her like one of the kids to a certain degree. That's the only way to deal with her. (Catherine, 43 years)

For carers who had moved into the parental home in order to provide care, changes in the dynamics of relationships were particularly challenging. They perceived themselves as being powerless and lacking control of the caregiving situation. The care situation was determined by their parent who exercised control through ownership of resources such as the house and money. In some instances, tensions in the relationship led to carers adopting distancing techniques and this in turn meant that older people were not necessarily having their care needs met.

'I think it gets more difficult. You have your own coping methods and mine I'm afraid is taking to my bed. I mean Sheila [friend] will come in and say are you resting or are you hiding? And most of the time I am hiding. It's the only way. I have to say that my back is sore today, I have to go to my bed. And I'm just hiding upstairs, because when I am in my bedroom I don't have to do anything for her. It's the only place where I don't do anything for her. (Betty, 67 years)

Mum used to come and stay most weekends and when I had to move out of the flat, mum suggested that I come and live with her. I felt that because we got on well together coupled with the fact that mum needed more care, that it would work out ok. But it's been a disaster. I wish I had never agreed to it. (Clark, 50 years)

My husband said what have I let myself in for. As the time was getting nearer, it was getting harder to leave our own house. My husband said – this is your father's house as far as he's concerned, it's not anybody else's, it's his and that's it. It's his telly, his remote control, it's his furniture, according to him, everything is his. I says oh that will all change – but it's not changed at all. He still rules the telly, and if any of our friends come in he'll ask what are they doing here? It seems that it's only him that's got rights. There was a fight here on Monday night and at half past seven at night I got Susan (child) ready and went out and left him. Now I am now talking to him and I'm refusing to wash him too. (Wendy, 38 years)

### ***Developing expertise***

This stage was characterised by carers' ability to learn from their experience and eventually to carry out routine procedures that were once unfamiliar, in a competent and proficient manner. During the course of the study, carers' appeared to develop a degree of expertise that led to an increase in confidence in their own abilities.

Most carers took on their role without fully appreciating the nature or the extent of the care they were expected to provide. The majority were ill prepared, had limited caregiving skills

and were given little information or advice even when caregiving followed on from a planned discharge from hospital. Those who had previous experience, either of caring or of having worked as a nurse, were more likely to adapt quickly to the practical aspects of the role.

I think it is easier for me because I was a nurse for thirty years. At least I am used to moving and handling patients and know how to get him sitting up the bed and things like that. (Roberta 62 years)

We have a routine now and we stick to it. Now she gets washed and has his breakfast before she gets dressed. Then I don't get so annoyed when she spills tea or porridge on her clothes because I know they are still to get changed. I used to get her washed and dressed and then give her breakfast and by the time she'd finished eating she needed changed again. I used to tear my hair out! (Mary, 48 years)

Many quite rightly, regarded themselves as experts in the care of their relative. Isobel for instance, having cared for her father for six years felt that although caregiving did not get any easier, she had now adapted to her role and to the routine that it instilled in her life. Her view was that:

You just get used to it I think. I don't think it gets easier as time goes on but I think you learn the best way to wash him or get him into the bath, and you know how hard it is to get his socks on when he is sitting up – so you soon get to know to put them on before he gets out of bed. Wee things like that can make a difference. I think you have to learn to adapt. I'm so used to it now – it's just part of your life' (Isobel, 63 years)

Carers gain experience and develop skills in caregiving through a process of trial and error. When faced with a problem they considered the range of resources available and decide on a particular action. If that strategy was effective then it was used again if and when required. If it was found to be ineffective, consideration was again be given to the problem and another possible solution identified. This almost unconscious process continued until effective strategies were identified and used routinely. Thus through a continuous process of trial and error, carers progressed from being relative novices to being competent and proficient in the activities and management of caregiving. Those who gained a great deal of expertise and felt competent were more likely to perceive themselves as coping with caregiving.

### ***Sinking or Swimming***

The term 'sinking or swimming' was derived from carers' references to coping. Sinking refers to feeling overwhelmed and unable to cope, while swimming implies coping by being on top of things.

It either makes you sink or swim. Well I did sink but then I swam and now – I have come out of the deep and am still standing here. I've come through it! (Theresa 41 years)

As caregiving progressed it became more stressful, even although carers became more competent and experienced. Stress had an accumulative effect in that one stressor like incontinence or demanding behaviour by the cared-for person would beget another, such as tiredness in the carer. Although carers clearly developed a range of coping strategies, such as the use of routines, they took different approaches to problem solving.

There comes a point when you just give in and give up and just go with the flow. I don't know how to describe it .... It is like a never ending river, it just flows and there's never a ripple and then - if you get the ripple that's when it all blows up, that's when your stress really hits the high level. But you are always in constant stress

When faced with crises or critical incidents carers either sink or swim. Swimming was associated with an active response to crises, the presence of positive outcomes from which carers derived satisfaction, and caregiver control. Strategies such as seeking information and planning in advance were indicative of an active approach.



*I could cope with anything but you have to be practical. I mean you can't live in airy fairy land. You have to deal with situations as they arise. Every day has a different problem. You have to take it a day at a time. (Rita 56 years)*

In contrast, sinking was associated with a passive response, the presence of negative outcomes, which caused carers to feel depressed and overwhelmed by caregiving, and a lack of control. Examples of passive responses include using music or alcohol to escape from the stress of caring.

*I had a pretty bad time and I just felt that the world was caving in. I felt that I had got older and I couldn't cope...suddenly I was feeling miserable and thought I was going to end up a nervous wreck. It was like I had reached a peak and I remember saying to myself – I can't take much more of this. I can't even say what I was feeling. I felt that I had had enough. I found that I had to get it right in my head and I put everything down on paper and kept a journal – it helped to get it out of my head. (Susan 50 years)*

Moving on from this stage to the next depended on the extent to which carers felt they are coping or not. If they felt they were coping and in control, then they were more likely to continue for longer without service intervention. On the other hand those who felt overwhelmed and unable to cope were more likely to seek and accept support from service providers.

### ***Pathways to service providers***

This stage is characterised by attempts to access services. These attempts were usually triggered by crises, which forced carers to seek and accept help, although the process was anything but straightforward. A number of pathways were used to access services, the most effective of which was via GPs. The least effective was self-referral. Those who tried but failed to seek help directly from providers were left feeling bitter and disillusioned with the system.

*Dr Lance changed my life in that he made me see sense and that's why I go to him if I need support. He helped me get my act together and got dad into a day centre. (Theresa 41 years)*

*The Carers Association contacted them. I have had Mandy who runs it out, she came into see my mum. I must admit after that they weren't long in coming out...It's all the fighting you have to do. You're on the phone, you're down at the office and still nothing gets done. That's what makes you so angry. I mean what's the point in all this red tape? I'm a pensioner looking after a pensioner and I thought help would come easily. But it doesn't. (Susan 68 years)*

*I knew I needed help from somewhere. So I phoned everywhere and eventually I got to onto social work. He came out and I didn't really know what they could do to help. I just knew I needed something but it took three months (Iris 69 years)*

Sometimes the decision to accept service intervention was taken out of the carer's hands. If the care recipient was admitted to hospital, services could be arranged as part of a planned discharge procedure. In these cases, referral was sometimes made without consultation with carers. Yet this stage provided the ideal opportunity for service providers to view carers as 'partners in care' and in this way support their efforts to cope and continue caring.

Carers experienced access as a lengthy protracted process fraught with difficulties, which they refer to as 'a fight' or 'a battle'. This process highlighted the power of service providers,

who control carers' access to services by exercising the authority vested in them by law. These interactions with service providers confirmed carers' perceptions of them as being authoritarian in nature.

Carers did not unquestionably accept service providers' recommendations for particular services. The least intrusive services such as day or respite care and aids and equipment, are the ones most acceptable to carers. Whilst home care services were not widely used, once the benefits were recognised, it was usually appreciated by carers who accepted it.

This stage can also overlap with the previous one of 'sinking and swimming'. Although service intervention is thought to help carers cope, some still have difficulty in doing so. But service intervention could create problems as well as resolving them and so the cycle of sinking or swimming continued.

### ***Carers: clients or partners?***

This stage refers to the status of carers, which changes once contact is made with service providers. This stage was characterised by carers' acceptance of service intervention in order to prevent the breakdown of care. 'Carers as clients' are one of the ways in which carers are conceptualised by service providers (Twigg 1989). But here in Scotland carers are now supposed to be seen as 'key partners' in the provision of care. The status of partner is significant in this context and has implications for the way in which services are experienced by carers.

It's easier if you live in separate house. It becomes easier to get someone in to help. Because I don't need a home carer or a nurse. I just feel why should I have someone coming into my house going through my stuff when I don't need it. (Maggie 63 years)

I'm kind of funny about accepting help and having strangers into my home. I don't need or want their help. Carers don't want help because it is the cared-for person who needs the help. (Rita 56 years)

We talked about splitting up. It was just far too much. So that is when I started putting her in [to respite] and I tried to keep going because it was working...It was of course of mum wouldn't accept help. She was a bit nervous of it but the fact the doctor said to mum that she might need to go into a home, she thought it best to accept help. (Katy 37 years)

Although many carers would like to have continued without service support, for many there came a point when they realised it was not in their best interests to continue without help. Acceptance of formal services was often accompanied by feelings of failure and relinquishing control of the caregiving situation. It was also in some cases, determined by the wishes of the care recipient and took place only with their co-operation.

Interactions with service providers evoked passionate responses from carers. They resented being treated as a client and were emphatic that it was not they that needed help but rather the person they were looking after. They did not view themselves as clients and were aware that services were traditionally, designed to meet the needs of carer recipients.

This was one reason why carers are reluctant to admit service providers into their homes. They did not want strangers coming into *their* home and intruding on *their* privacy when it is not they who was the client in need of help. Paradoxically, a service such as respite care was often arranged because carers were regarded as clients in need of a break.

### ***Supported caring***

Service intervention marked a new stage in carers' careers. Caregiving continued but now with support from service providers. Carers had successfully (if traumatically) negotiated the pathway to providers and for some there was a steady increase in the level of support they received and accepted. Thus carers had increasing levels of interaction with providers such as paid care workers who came into their homes or staff in day or respite care facilities.

It's just amazing the difference it makes. You know just with that bit of help in the morning, it just makes things so much easier. Just having that space, the rest of it has all fallen into place. (Katy 37 years)

I'm not awfully keen on social services. I got what I wanted but it took a lot of hard work and I didn't like asking for help. (James 54 years)

This stage was also marked by the adoption of new routines, which were developed to take account of service intervention. For example, ensuring that the care recipient was up and dressed in readiness for day care required a change to existing routines. Similarly, ensuring that clean equipment and laundry was available should community nurses or careworkers needed it, required a change to household routines.

Yes, it is a help but I've got to make sure there's always clean sheets and towels ready and I've got to be here. Sometimes when I take the girls to school I have to run down the road to be there to let her in. If I'm too late back she'll just go away again and I have to get my dad out of bed. (Ellen 58 years)

But service receipt also created tension. Carers reported that interactions with service providers could be frustrating and stressful. Criticisms of service providers were based on their apparent disregard for carers' specialist knowledge about the needs of care recipients. Carers were at times regarded by service providers as partners and in some instances clients, but rarely as 'experts'.

### ***New opportunities***

New opportunities refers to the stage when, for what ever reasons, carers are no longer required to provide care. The end of caregiving might be due either to the death of the care recipient, an alternative caregiver taking over or admission to long term care. Interactions with service providers also tended to end at this stage because the immediate caregiving situation is over.

*Well I can put my head on the pillow at night and say I have done my best. The others, well they be for months saying going oh I should have done this or I should have done my wee bit*

*Maybe I'll be able to do it as a job...I'm now attached to the Princess Royal Trust for Carers so that's got me into a whole new field. I go to conferences, I've learned a lot about other people and aspects of training and caring...I want to use the knowledge I have for something*

Some carers experienced feelings of relief tinged with sadness and grief when caring came to an end through death of the care recipient. For others, the end of caregiving left a huge void in their life especially in cases where they had been providing a substantial amount of care over a number of years. Many carers were not quite sure what to do in this stage as it was taking more time than expected to adjust to their changed circumstances. 'New opportunities' therefore, represents new challenges for carers as they come to terms not only with the loss of a loved one but also the loss of their role.

## **Nature of caregiving relationships**

In the present study an important determinant of carers' experiences was the quality of their relationship with the cared-for person. It appeared that the quality of the caregiving relationship conditioned carers' perceptions of caring. For example, carers who had a strong and emotionally close relationship with the cared-for person were more likely to perceive the caregiving situation as unproblematic. The relationship with the care recipient was usually a positive one in which the cared-for person was treated with respect and viewed as a valued member of the family. This did not mean that these caregiving situations were completely free of difficulties, but rather that in the context of a good relationship, they were not perceived as being a problem. For example, some carers said that the hardest thing about caring was the constant feeling of responsibility.

*We've always been close, we always got on pretty well, even when I went to college and I suppose it's [the relationship] become closer - because your doing so many personal things for her. I mean it's hard, but you look at her sometimes and you think she needs you. So I'm there for her.*

This carer's relationship with her mother structured her perception of caregiving. Her mother had difficulty negotiating stairs but insisted that she be helped to the toilet upstairs rather than have to use a commode placed beside her bed downstairs. Yet despite facing problems such as these on a daily basis, Beth tended not to view caregiving as problematic because of the close and affectionate relationship she shared with her mother; a relationship she was committed to maintaining.

Rarely was the quality of relationships at the outset of caregiving maintained throughout the experience. Often the pressure and demands of caregiving led to a deterioration in the relationship between carer and care recipient.

*I've always been close to my mother. But she's like a baby now, aye, like a baby and I'm the mother. That's it in a nutshell. They rely on you and you alone and nobody else. And if you say one wrong word to them it's like scolding a baby.*

*I'm not his wee lassie anymore. He might still be the daddy but I'm a granny now and I'm old enough to tell him to go take a walk. I don't stand for his nonsense now.*

*We've always had a very close relationship. Even although I'd been away twenty odd years I still had a close relationship with her and I didn't want that to change. But it has. Sometimes I feel I just want to scream at her and run away from it all.*

Caring also created tensions within the carers' marriage, this was particularly true for carers in their 30 and 40s who had young children.

*My husband complains that I do too much for my mother. We've had a lot of rows and talked about splitting up. I have to split myself between so many people. I'm at everyone's beck and call. Yet every year she gets frailer and frailer and can do less for herself.*

*My husband and father don't get on. I think my father resents him actually. And well, I know for a fact that my husband resents him [father]. I'm piggy in the middle...There's a lot of resentment. My dad says I should give him a divorce so I can turn all my affection on to him*

## **Policy implications**

The provision of care can be very stressful and is said to have an adverse affect on caregivers' health. Policy has recognised the need to support carers and a key objective has been to improve service provision for them. However, whilst service intervention has been

shown to prevent the breakdown of care, relatively few carers use formal services. While this low uptake of services is documented, it is not fully understood.

The model of caregiving presented here is important for three reasons. Firstly, because it is based on the experiences of hidden carers who were initially caring without support, the model sheds light on the non-use of services by caregivers. Secondly, despite being based on carers who were looking after frail older people, it can be applied to other client groups and caring situations. Furthermore, it indicates that carers are more likely to accept service intervention only at particular stages in their caregiving career. This finding has important implications for policy and service design. .

In order to effectively improve support for *all* carers, policy needs to address more directly the complex issues surrounding the non-use or low take-up of services by carers. Service providers need to be aware of and understand the various stages that carers go through in order to tailor service interventions to particular stages in the caregiving trajectory. These stage specific interventions should aim to empower carers by enhancing their existing skills, competence and expertise.

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