

Who cares wins? Carers' experiences of assessment since the introduction of the Carers (Equal Opportunities) Act 2004

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Abstract

This paper examines the views of carers who have received a carer's assessment following the introduction of the Carers (Equal Opportunities) Act 2004. The Act ensured for the first time that a carer's desire to take part in paid work, education or training, and leisure opportunities was considered. Semi-structured interviews were undertaken with carers to illuminate their lived experiences. Six themes emerged from data analysis: finding out about entitlement to an assessment; gaining recognition as a carer; partnership working with service professionals; carers' awareness of support availability; desired outcomes; carers' unmet needs in relation to education, work and leisure. Some carers were knowledgeable about the support that was available to them and others were quite unaware. This affected their ability to access help in order to cope with their roles. Carers welcomed the opportunity to discuss their individual needs and wanted to be treated in a holistic way by practitioners. The complexities around partnership working with care organisations permeated several of these themes and thus carers' experiences may be defined as a 'wicked issue' requiring creative responses to the issues that concerned them. Solutions offered should be tailor-made and not delivered from a menu of 'what is available'.

Keywords: Informal carers, assessment, qualitative research

Introduction

This article investigates the experiences of working age carers who have undertaken a carer's needs assessment and explores whether legislation has had a positive effect on their ability to lead a life beyond their caring responsibilities. Currently there are around 5.2 million carers in the UK, including 4.4 million of working age (ONS, 2003). Fourteen per cent of working age women and 11% of working age men have caring responsibilities. Pakistani and Bangladeshi Asian men and women living in England and Wales are more likely to be carers than their White British or Black Caribbean counterparts (Buckner & Yeandle, 2005). The likelihood of becoming a carer increases with age, with most carers aged 45-64 years (Arksey *et al.*, 2005). Carers are not a homogenous group, they reflect the diversity of the wider society in which they live (Lloyd, 2006). However, they share a

sense of moral responsibility towards the person they care for (Baldwin & Twigg, 1991). They require support in order to maintain their own health and well-being.

Population projections show that the number of older people is due to grow as a proportion of the UK population. The latest projections show an 81% increase in people aged over 65 years from 9.3 to 16.8 million between 2000 and 2051. The population of over 85s is predicted to rise from 1.1 to 4 million and the 'elderly support ratio', the number of working-age people for those of pension age, is projected to fall from 3.3 in 2002 to 2.4 in the 2050s (Dini & Goldring, 2008). Thus, caring for older people is likely to be performed by a smaller segment of the adult population. The growth in the older population is due to increased birth rates, better survival rates, improvements in public health and socioeconomic factors. Nevertheless, people aged over 85 years are

more likely to experience mobility problems and poor health in later life and thus to increase demand for health and social care providers, as well as informal carers.

The 2004 Act extended the provisions for carers contained in two previous Acts of Parliament. The Carers (Recognition and Services) Act 1995 gave carers a statutory right to receive an assessment of their needs. This provision was largely rhetorical since entitlement to an assessment was not accompanied by a right to services to meet identified needs (Baggott, 2004). The Carers and Disabled Children Act 2000 extended the right to receive an assessment to the parents of disabled children and gave carers access to an assessment in their own right for the first time. Prior to this, carers' needs may have been assessed but only during an assessment of the cared for person. Official recognition of carers has taken much time and effort:

'Carers' did not exist as such prior to the development of the discourse of informal care in policy and other discursive domains. (Heaton, 1999, p.769)

Under the legislation, a carer is entitled to an assessment if they "provide or intend to provide a substantial amount of care on a regular basis" (Section 1, Carers (Recognition and Services) Act 1995). Implementation of carers' assessments continues to be patchy. For example, Keely and Clarke (2005), who surveyed 2,790 carers in England, found that 50% had not heard of assessment, a quarter had received an assessment and, of these, 14% said that the assessment had delivered a positive outcome. Carers provide practical and emotional support. As this reflects a regular pattern within family relationships, it is often difficult for carers and others to draw the line between *normal* family life and a *carer/cared for* relationship.

Assessment may highlight the lack of availability of appropriate services to meet carers' preferences. The Wales Carers' Alliance *Carers' Assessment Survey* (Bowen, 2004) found that 54% of carers refused the

support they were offered post-assessment because it was not what they wanted. On the other hand, help they wanted to improve their lives - such as respite care, training on the best ways to perform intimate tasks or advice to improve job prospects - was often not available.

Caring involves engagement with providers of health and social services (Nicholas, 2003). Responsibilities between informal care, statutory, private and voluntary providers should be shared, negotiated and re-negotiated. Arksey *et al.* (2000) stated that carers whose assessments did not lead to an ongoing relationship with service providers felt ambivalent about making contact again. This conflicts with policy imperatives to create person-centred initiatives to support carers' needs. A facilitative approach involving a 'carer as expert' model has been suggested by Nolan *et al.* (1996). Such a support model helps carers to sustain their caring relationships with the people they support. Practitioners who did not recognise carers' knowledge failed both the carer and the cared for person (Bucknall & Holmes, 2001). However, not all carers need or want to be seen as 'experts'. Some carers will gradually progress towards achieving the status of expert. Practitioners should consult carers at each stage of their caring careers as to whether they want to participate in decision-making and support those who wish to and not pressurise those who do not (Byrt & Dooher, 2003). Twigg and Atkin (1994) outlined a framework to investigate how service providers interface with carers which includes four models: carers as resources; carers as co-workers; carers as co-clients; and superseded carers. They suggested that service providers implicitly adopted one of these models, tending to see 'carers as resources' more often than not (Twigg & Atkin, 1994, p.13). Each model of support has consequences for the partnership formed with the carer.

Caring has both positive and negative effects on the well-being of carers. There may be:

- *Financial costs* due to reduced working opportunities and lower entitlement to pensions, transport and care costs;
- *Emotional costs* due to increased isolation and social exclusion, depression, time pressures, anxiety caused by supervising a vulnerable person full-time and stress caused by changing relationships, for example, from husband or wife to carer or cared for (Edelmann, 2000);
- *Health costs* due to lack of sleep, unmet personal health needs or injury caused by lifting an adult incorrectly. Carers are twice as likely to suffer poor health as those without caring responsibilities, 21% compared to 11% of the general population (Carers UK, 2004).

On the positive side there may be:

- *Emotional rewards* including gratitude and affection from the care recipient (Grant *et al.*, 1998), a sense of providing a worthwhile and meaningful service (Cohen *et al.*, 2002), the development of coping strategies to manage the day-to-day challenges of being a carer (Kinney *et al.*, 1995; Pakenham, 2005);
- *Social rewards* such as being seen as a 'good citizen', having a social identity as a carer (Graham, 1984) and being recognised as an expert in the care recipient's condition;
- *Financial rewards* including carers' benefits, access to subsidised transport and career opportunities using their caring skills.

The care sector is changing, with an emphasis on personalised provision based on individual needs and choices. Personalisation, including a strategic shift towards early intervention and prevention, will be the cornerstone of public services and will affect assessment and commissioning of services. Many people prefer to live in their own homes with informal and formal support and direct payments may sustain this. The government's aim is to transform social care and to increase

the take up of direct payments and to pilot the introduction of personal budgets (DH, 2006). The new system offers 'opportunities and threats' to providers and the social work profession including scarcity of funding and resources for care, together with cultural shifts towards a less profession-dominated system (Sawyer, 2008, p.41). Self-directed care should be focussed on the outcomes that service users and carers wish to achieve and the impact that services they prioritise will have on their lives.

Methods

The aim of this small-scale research was to undertake an in-depth study of carers in order to understand whether assessment led to improved access to work, leisure and education. Criteria for inclusion in the study were that carers had undertaken a carer's assessment in the previous six months and to be of working age. Written information and invitations to participate were sent to voluntary sector carer organisations in three local authority areas for distribution to carers. The sampling approach was therefore purposive (Patton, 2002) in order to recruit carers who would have in-depth, recent experience relevant to the aims of the study. Semi-structured, face-to-face interviews were undertaken with carers in their own homes, or at a carers' centre. Eight carers were approached by written invitation through the carer organisations and six agreed to participate. Interview questions were informed by the Social Care Institute for Excellence's practice guide to implementing the 2004 Act (SCIE, 2005) including:

- Availability of clear, published eligibility criteria and ease of access to an assessment;
- Provision of information to carers;
- Whether the assessment focussed on the desired outcomes of the carer;
- Identification of gaps in services and actions taken in partnership with carers to address these; and

- Awareness of and signposting to the multiple agencies involved in supporting caregivers and recipients.

Participants were also invited to discuss their own views and the topics they prioritised were given attention (Green & Brown, 2005). Qualitative research seeks to capture respondents' perspectives and experiences (Silverman, 2005).

Data management and analysis

Tape recordings of interviews were transcribed. Participants were offered copies of the tapes but all declined. Familiarity with the data was developed by reading and re-reading and data coding was undertaken manually (Lofland & Lofland, 1995; Coffey & Atkinson, 1996). A coding framework identified themes emerging from the data (Patton, 2002; Richards, 2005). Contradictory evidence and anomalies were searched for and noted (Silverman, 2001).

Ethical issues

Ethical approval was granted by the Swansea University School of Health Science Research Ethics Committee. Participants were given written information about the study and signed consent forms. Taped interviews and transcripts were anonymised and data that could identify participants were stored separately. Pseudonyms were used to protect participants' confidentiality. The researcher undertook a Criminal Records Bureau check.

Findings

Four women and two men took part in the study; they were all of White Welsh ethnicity which reflected the majority group of the local population - further research with minority ethnic groups is required to find out whether they have benefited from the 2004 Act. All carers requested additional services so that they could have more free time. Jane cared for her elderly mother, worked full-time and also had a young family. She had limited

support from family members and provided care 5 days a week. She wanted extra home care for her mother and emotional support from social services to persuade her mother to attend day care. Kath worked full-time, was undertaking a college course and had school-age children. Her elderly mother had moved in with her 12 months before because of increased frailty and ill-health. She had limited help from family members. The local authority provided a home help and she wanted a sitting service for her mother to give her more free time. Theo provided full-time care for his elderly father who had Alzheimer's disease. He had some support from a local church. He required day and night sitting services several days a week. Social services had suggested he contact gardening and shopping services but he could not afford the charges. Gary had given up paid work to become a full-time carer for his wife. Both his parents were also frail. Eve had three disabled children in their teens and early twenties. She did not work and her husband had given up employment to be a full-time carer. She had requested support with education and training for her children. Anne cared for her severely disabled daughter, with some support from her sister. She wanted paid carers for her daughter so that she could return to work when her daughter left school to attend day care. Anne, Gary and Theo were, or had been, treated for depression. All carers had been caring for at least one year and, in some cases, for many years before they received an assessment.

Five main themes emerged from analysis of interview data:

- Finding out about entitlement to an assessment;
- Gaining recognition as a carer;
- Partnership working with service professionals;
- Carers' awareness of support availability;
- Did the assessment meet carers' desired outcomes?;
- Carers' unmet needs in relation to education, work and leisure.

Finding out about entitlement to an assessment

The most common source of information about entitlement to an assessment came from voluntary sector carers' organisations or disease-specific charities. Nevertheless, information about assessments was not always clearly written, understandable or easy to access. Despite having had an assessment one carer still did not understand what entitlement to an assessment meant:

I learned about them through the autistic society, but I didn't understand what it meant. I still don't know exactly what it means. (Eve)

The best informed were two carers who had work-related links with social services but this source of contact did not necessarily lead to acceptable outcomes. Five out of six carers were assessed following a crisis situation, with only one of these five carers having an assessment soon after the crisis arose. Only one carer, who had cared for another elderly relative in the past, had her needs assessed at an early stage in her new caring role. Gary cared for his wife for six years and received a Department of Work and Pensions (DWP) carer's allowance before his needs were assessed by a social worker. He found the information he had been given confusing:

Carers Wales sent me a booklet, it was confusing really, lots and lots of information and I still didn't really know where to go, it was a bit too much. I wasn't aware I could have my own assessment until six weeks ago and I've been officially registered as a carer for six years.

His 'officially registered' status also highlights the lack of communication between agencies when carers' needs are identified. Despite having regular contact with primary and community mental health services over a five year period, Theo had not been told of his right to a carer's assessment:

I've looked after dad for five years and it wasn't until now that I found out I could have an assessment myself, it was the Carers' Centre who told me.

Carers' legislation advocates multidisciplinary working but there was little evidence of partnership working between health and social care in the experiences of this study's respondents. As most carers have regular contact with health services, this is a weakness in the current working of the 2004 Act and reflects the evidence provided by the Audit Commission of the lack of GP referral to social services (Audit Commission, 2004). However, some progress has been made since 1999 when Seddon (1999) found that local authorities adjusted eligibility for assessment according to the resources they had available. Since then, Seddon *et al.* (2008) have also reported that local authorities are taking a more consistent approach to eligibility for an assessment.

Gaining recognition as a carer

Carers reported that the assessment process confirmed their status and identity as carers. Carers did not always acknowledge the role they had 'slipped into' or believe they deserved the label 'regular and substantial carer', as these extracts illustrate:

It's the way you slide into it. I'd have humorous arguments with the Carers' Centre saying 'I'm not a regular and substantial carer, no, I'm not a carer.' (Jane)

Well, first of all he's my dad, he always will be, and he doesn't want to be like he is. It's very difficult but I don't complain. I try and cope the best I can without bothering people. (Theo)

Until they contacted their local authority social services departments, Jane and Theo were 'hidden carers' unacknowledged by health or social services. Those who had accepted the label of 'carer' voiced how they had come to identify with the role:

I'd taken on that duty. (Kath)

They're my kids. What else can I do?
(Eve)

Maybe I should have started asking sooner for help rather than wait until it got really to a head. (Gary)

Coming to terms with the label 'carer' may involve a complex re-evaluation of one's own identity and the impact of caring on the relationship with the care recipient (Henderson, 2001). Four carers appreciated the opportunity the assessment offered them to discuss their own needs with a professional, in contrast to discussing their relatives' needs with health and social care staff over many years:

What I wasn't expecting ... was how amazing, how wonderful it was just speaking to somebody for two hours about me, and how it was affecting me. (Jane)

The psychosocial benefits of having a carer's assessment are demonstrated by the value Jane placed on the recognition the assessment process gave her. She appreciated the exploration of her own needs and feelings. She valued 'being listened to' and the recognition of her work by social services.

Partnership working with service professionals

The results in this section explore carers' experiences of the process of negotiating an assessment with social services and provide feedback on services that were put in place following the assessment. Some carers expressing mixed feelings about relationships with the professionals they routinely came into contact with. Others found partnerships worked well - for example with health professionals - but barely worked in contacts with social care. Five out of six carers were frustrated by the length of time it took to secure an assessment. Four carers were able to access some services as a result of the assessment and two received no ongoing

support. Reasons social services gave for refusing support included lack of resources and a perception that the carer's needs were not high enough. None of the carers who received services as a result of the assessment were satisfied that their needs had been met. The following extracts demonstrate the range of experience of the carers interviewed. Initially, Eve telephoned the local authority adult services team to request an assessment but she was unsuccessful:

They said they couldn't do anything for me because he [her son] wasn't disabled enough so we ended up with the complaints officer. (Eve)

The local carers' support group advised her and she eventually secured an assessment for herself. Gary was also frustrated by delays:

Then social services when I rang them said, 'Oh, we'll get someone out tomorrow.' But then my wife was admitted to hospital so they then said that it will have to be done through the social worker at the hospital. That then took two weeks before I could get hold of anyone.

When his wife was admitted to hospital, Gary spent several weeks worrying about what would happen when his wife was discharged from hospital because of the lack of communication between social care and health. Partnership working around carers' needs has to be intra-agency (within social services departments) as well as inter-agency (between social services and health services). Shortcomings emerged in the approach to partnership working in Jane's case. Her mother's social worker knew that Jane was providing extensive care but did not recommend a carer's assessment for several years:

A lot of the discussion was with me so at the end the social worker went away knowing that I'd got two dependent children, I did have a partner, full-time job, I was cooking all my mother's meals, I was doing all of these various things for

her and was visiting at least three times a week and having her round at weekends and one wasn't offered.

The lack of recognition of Jane's needs demonstrates the ambivalence of some social workers towards carers' assessments. Statutory legislation may raise carers' hopes but does not guarantee entitlement to any service provision (Janlov *et al.*, 2006; Seddon *et al.*, 2006). This can leave social workers in an impossible situation. Jane felt overlooked during her mother's needs assessments:

And I think that because cases are then closed there isn't really anybody to go back to discuss it with.

Five out of six carers did not have a review of their needs following the initial assessment, leaving them feeling isolated and without a continuing relationship with a social worker. Eve was critical of the lack of ongoing support from social services to meet her needs, although she described her relationship with health professionals as excellent. Kath valued the assessment process itself but did not receive any services because of lack of availability of staff and funding. As a result, she made private arrangements with a care agency to sit with her daughter. Theo did not develop rapport with the social worker who assessed him:

I have grave doubts about the social worker that came to see me. She seemed to resent having to give me the assessment, it was as if she thought she had more important things to do, and I shouldn't be wasting her time.

Core to the concept of partnership is the idea of collaboration (Carnwell & Carson, 2005). Anne's experience of partnership working was successful. In her case, trust and understanding had been established between partners so that she was confident that the arrangements around her daughter's transition from education to day care would enable her to return to paid work.

Did the assessment meet carers' desired outcomes?

Just two of six carers (Anne and Jane) had their needs for practical support fully or partially met. Jane's requests had been partially met when her mother's needs were reassessed. However, the offer of a day care place was refused as transport and help to get ready was not available. Kath, Gary and Theo had been promised support but only when it became available. Eve despaired of receiving appropriate support to enable her to continue to care for her adult, autistic sons. The interview extracts in this section summarise the tensions around lack of flexible provision – the emphasis on 'what was available' rather than 'what carers needed' to enable them to improve the overall quality of their lives – and the conflict between meeting the needs of care givers and the cared for person:

It's so stressful babysitting my father twenty four hours a day, seven days a week ... if I don't get a break soon I don't know what will happen. Some of his friends from church call in and will sit with him for me to pop out. I need more time to be able to do little things like going to the dentist and the doctor's by myself, taking my father with me is very difficult. I hope he'll get on with the sitters they send.
(Theo)

Kath was promised the possibility of services in the future:

The outcome of the assessment was, when the staffing situation allowed there might be sitters.

In these examples, services are rationed that are available to others. Arksey (2002, p.15) termed this situation 'rationing by delay'. Eve was frustrated by delays in the assessment process and the lack of provision for autistic adults with social rather than health needs:

Up until now, I haven't had anything, I'm still waiting to hear months later.

On the other hand, Anne was content with the services put in place for her daughter as they were built around her work schedule. She looked forward to the opportunity to return to work while her daughter was cared for before, during and after day care attendance:

It was me having assistance for [daughter] really. I plan to go to work when she leaves school. Carers have got to put her on the bus to day services and then be here, to work around my schedule. We've started to introduce carers now in the mornings with [daughter]. It's worked really well. I am confident that everything is going to work out.

The interviews also revealed that, although carers like Anne welcomed support, they were also reluctant to give up some caring tasks. Anne bathed and changed her daughter, even though it was difficult for her to manage single-handed. In this way, Anne was self-rationing the care package available to her regardless of the impact on her own health (Arksey, 2002).

Carers' unmet needs in relation to education, work and leisure

A common experience reported by carers was that their assessments focussed more on the needs of the cared for person than themselves. Some carers agreed that their primary motivation was to obtain services for the person they cared for in order that their participation in work, education or leisure was not jeopardised, in the cases of Kath or Jane, or to give them opportunities denied to them in the examples of the other carers. The interviews revealed the practical and emotional support required by carers. Even though the main reason for an assessment may have been to ask for practical support with caring tasks, carers felt let down if the assessment did not enable them to express their felt needs for emotional competence to deal with the demands of caring (Twigg & Atkin, 1994). These were needs they struggled to express explicitly. For example,

Jane wanted emotional support to help her negotiate her caring role with her mother:

But there was never, there was no suggestion of sort of, I mean I know there's issues with time, but with going back to my mother and in a nice way saying 'Well, you know, I really think it would be worth your while going to day-care for an extra day, now I know it might be a bit of a burden to your daughter to take you but you know £10 a week [for her mother to pay for a taxi to attend day care rather than relying on her daughter to take her] isn't a lot and we'll find someone else that can share it'. There was no possibility of negotiation which was what I would, that's what I would have liked most.

The demands on Kath's time were many so she could not always plan when she needed additional help and would have liked a flexible sitting service rather than the fixed one that was available. Her concerns to have a service in place to meet her mother's needs for dignity and personal cleanliness when she was not available were not therefore met. Soothill *et al.* (2001) found that carers with unmet needs were more likely to be in poorer health themselves. None of the carers were offered Direct Payments that may have enabled them to purchase tailor-made packages of care.

Discussion

Carers' needs display all the characteristics of a 'wicked issue' (Clarke & Stewart, 2000, p.377): they are messy, there are lots of issues combining to create a milieu impossible to navigate through in a classical, linear problem-solving mode. As Scourfield (2005) argues the relationship between practitioners and carers is 'problematic' with conflicting areas of confusion and ambiguity. Practitioners work in a 'maelstrom of competing discourses' including users' and carers' rights, abuse and efficiency, in times when resources are stretched to the limit (p.26). Solutions to perceived needs require a combination of imagination and service

provision. Suggestions to resolve carers' problems may have unforeseen outcomes, for example, a request for respite care may offer a break to the carer but can be seen as a threat to independence by the cared for person. In the experiences of carers interviewed in this study, no attempts were made to be creative with services to accommodate carers' requirements or to pursue the option of Direct Payments in order to provide a responsive solution. Stainton and Boyce (2002) found that family carers could benefit from the flexibility Direct Payments offered but this option has yet to be fully embraced by all Welsh local authorities. Innovative solutions do not necessarily need to cost more than existing services and working closely with voluntary sector agencies may offer opportunities for more creative results to be delivered.

In order to tackle 'wicked issues', thinking around carers' problems needs to be holistic and not cemented in old, linear patterns. Practitioners need to search for new ways of seeing issues as complex interactions that require new approaches to solving problems. All participants in assessments should be willing to learn, to take risks, and to challenge the status quo. Partial responses, from single agencies like social services, can lead to limited success, total failure or the creation of other problems arising from the unforeseen consequences of actions taken. A holistic approach is required that leads to the forging of partnerships between carers, the people they care for, employers, health, education and social services. The whole system should work seamlessly together if carers are to become fully socially included. The implication for social services departments is the necessity to facilitate partnerships with other agencies, with carers and care recipients at the heart of discussions and developments.

Conclusions

One of the requirements of carers' assessments, since the introduction of the Carers (Equal Opportunities) Act 2004, is to recognise carers' desires to take part in paid

work, education or training, and leisure activities. In practice, carers may not identify strongly with these aspirations but, when they do, their expectations are modest. Carers often subordinate their own needs, giving primacy to the needs of the cared for person, even though this adds to their stress. Carers identified the lack of emotional and psychosocial support available to them and were aware of the destructive effect this had on their own health and well-being. The practical support offered to them did not always meet their requirements.

Being assessed gives the carer an opportunity to discuss their hopes, wishes and fears for the future (Arksey, 2002). The carer's assessment validates the work that the carers do, according them social recognition. The findings of this study suggest that there is room for improvement in the provision of information to carers about carers' assessments. Primary care staff could provide a useful signposting service to carers well before they reach crisis point. The Carers (Equal Opportunities) Act encourages local authorities to work jointly with other statutory agencies.

Where carers have complex support needs, a more holistic and creative approach is necessary to address the 'wicked' nature of their concerns. Trying to fit carers into the existing service provision framework may be frustrating and unproductive. Direct Payments are an option to give carers more autonomy and the opportunity to participate in society through work, education, training and leisure activities on an equitable basis (Stainton & Boyce, 2002). More work is needed to identify innovative solutions to the needs of carers with the cooperation of carers themselves.

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