

Receiving specialist welfare benefit advice within Social Services: a qualitative interview study of older people and their carers

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Abstract

Benefits uptake in the older population is low compared to other age groups, and improving access to, and uptake of, welfare benefits advice is a key goal of UK health and social policies around active ageing. As there is little information on older people and/or their carers' experiences of receiving specialist welfare benefits advice within social services, we undertook a qualitative interview study with service users and staff.

Interviewees described difficult life circumstances around the time of referral. The complexities of accessing advice and of understanding the benefits system were recounted. Participants felt the advice was beneficial regardless of whether it resulted in additional income. The majority receiving additional benefits described a positive impact on life choices and control, quality of life, independence and health. Awareness of eligibility and availability of benefits and benefit advice remains low, and many older people and carers still feared the intrusion of benefit provision and advice. Whilst these findings confirm the valuable role of specialist benefits advice workers, more anticipatory rather than reactive approaches are needed to identify vulnerable adults who are not already known to the social care system.

Keywords: Welfare benefit advice, older people, social care intervention, qualitative

Introduction

In recent years, increasing focus has been placed on providing effective and accessible welfare benefits advice within the community for the older population as one means of tackling material deprivation and its associations with poor health status (Paris & Player, 1993; Acheson, 1998; Hoskins & Carter, 2000; McConaghy *et al.*, 2003; House of Commons Committee of Public Accounts, 2004; Abbott *et al.*, 2005). Although accessing benefit advice can lead to increased benefit income (Abbott & Hobby, 2000; Toeg *et al.*, 2003; Campbell *et al.*, 2007), the complexity of the benefits system may pose a considerable challenge for an older person or carer, and benefit uptake amongst older people remains relatively low (Great Britain National Audit Office, 2002).

Benefits advice is increasingly being provided within health and community settings and particularly within primary care (Abbott & Hobby, 2003). In some instances, dual-purpose teams have been set up within social services to take on the role of calculating client contributions for social services, as well as providing financial advice to maximise the individual's income (Audit Commission, 2000; Department of Health, 2001). Such an approach aims to be user-focussed, often has an advocacy role, and adopts holistic strategies. Older users' and carers' views on obtaining benefits in this way and of the less tangible associated effects, such as the potential impact of benefit advice on health, independence and well-being, have not been widely explored.

Using qualitative methods, this study examined the experiences of older people, carers of older people and officers from a specialist, social services-based, home-visiting advice team, regarding the provision and perceived impact of obtaining welfare benefit advice. This study was run in parallel to an associated longitudinal observational study examining the impact of welfare benefits advice on client health and well-being, whose findings are reported elsewhere (Campbell *et al.*, 2007).

Methods

Ethical and research governance approval was obtained in June 2003. Older people (age 60 years or over) and their carers (spouses and relatives, all ages) were identified through social service records of recent referrals to the welfare benefit advice service. Potential participants were purposively sampled to include individuals with a range of physical and mental health needs who either lived alone or with others, and who had been newly or previously referred to the service. Permanent nursing home residents and any participants taking part in the associated longitudinal observational study (Campbell *et al.*, 2007) were excluded. Trained welfare benefit advisors from the financial advice team, who ranged in expertise and experience, were also invited to be interviewed.

Older people and carers were approached by a brief covering letter from the welfare benefits team, with an accompanying letter, information sheet and reply slip from the research team. The information sheet reassured potential participants that the welfare benefits team would not know who took part in the study, and that their participation was voluntary and would not influence any advice, support or benefits received through statutory services both now and in the future. Invitations for interview were sent to 63 older people and 42 carers (including 19 pairs). Five invitees died before or during the mail shot period.

Non-responders were sent a reminder letter after two weeks. Individuals who indicated that they were willing to take part in the study were asked to provide written consent.

The tape-recorded interview took place in the participant's own home. The interviewer (RW) used a topic guide during the interview that was developed from relevant literature, respondents' free text and verbal reports from the associated longitudinal observational study (Campbell *et al.*, 2007), and was further refined during the course of the data collection period. Participants' experiences of the referral process and financial assessment, and its perceived effects (positive or negative) were explored. Interviewees' views on the processes involved in obtaining benefits advice for older people and their carers were discussed. A second interviewer interviewed the benefits advice team members as RW had some personal involvement with the team over the study period.

Analysis

The interviews were recorded, transcribed verbatim and depersonalised and each transcript assigned a unique identifier (letters A-Z) to identify the origin of the quotes selected. An Interpretative Phenomenological Analysis (IPA) framework (Smith *et al.*, 1999) was used to capture the interviewees' perceptions and understanding of the benefits assessment, its outcome and its effect on their everyday lives, their health status and well-being.

Validation of the analysis

Steps were taken to maximise the validity of the findings (Elliott *et al.*, 1999). Recruitment continued until saturation of themes had occurred. Each transcript was read alongside the recording, re-read several times and individually coded. The emergent coding framework was checked against original transcripts for confirmation or contradiction of the coding categorisation

identified. Five transcripts were also independently coded by a second researcher and compared for convergent and divergent themes. Key themes identified by each of the independent coders were compared and discussed and any conflicts were resolved through discussion within the research team. A summary was sent to each participant who was invited to comment on its accuracy from their perspective. Feedback forms were reviewed for conflicts in theme interpretation. Key themes were also checked for credibility against free text and telephone notes from the concurrent quantitative study. The role and influence of the researcher in this process were recorded in a reflexive diary.

Results

Thirteen older people and ten carers expressed an interest in participating. Four additional people who accompanied the invited respondent and wished to contribute to the study also consented to interview. Twenty-seven people were thus interviewed in twenty separate interviews (Table 1). A further six interviews were conducted with benefits advice officers.

The distinction between older people and their carers was found to be somewhat arbitrary as the majority of carers were themselves past retirement age and were

often in a vulnerable state of health. ‘Older people’ were defined as those older people referred to the service who did not have a carer role, while ‘carers’ were people of any age who provided some regular support or care to an older person. Here we provide contextual information regarding the life circumstances of the study participants, before describing our four key themes of (i) the complexities associated with accessing welfare benefits, (ii) awareness of benefits and advice existence – concerns versus interference, (iii) the importance of forming relationships to facilitate the assessment process and, (iv) perceptions of impact of assessment on health and well-being.

Describing the life circumstances of carers and older interviewees

Many interviewees reported a recent change or deterioration in their own condition or of the person they cared for (e.g. had been hospitalized, could no longer cope alone) which had occurred at the time of their referral for benefits advice. Many interviewees had also recently been introduced to, or had received an increase in social service provision. For example, one 82 year-old lady who had suffered a heart attack, two falls, hip replacement and dislocations in recent months and lived with her husband recalled:

Table 1 Socio-demographics of older people and carers participating in interviews

		Older person (n)	Carer (n)	Total (n)
Gender:	Female:	6	9	15
	Male:	7	5	12
Living situation:	Lived alone:	7	1	8
	Carer lived with older person:	4	7	11
Age group:	40-50:	0	1	1
	51-60:	0	3	3
	61-70:	2	5	7
	71-80:	6	0	6
	80+:	5	2	7
	Not known:	0	3	3
Interview situation:	Interviewed alone:	7	6	13
	Interviewed with others:	6	8	14
Total		13	14	27

I definitely need the help at home. I mean Mr [name of husband]'s 87 and you can't expect an 87 year old man to start housework and cleaning when he's not used to it. ... And, and I couldn't do it. And still I'm not able to do these and that's very frustrating to me. ... I've led a very active life and kept fit and well and to suddenly find myself in this, has not gone down very well. We've had to take the brunt of all of this. (A)

A 65 year old carer (suffering from a chronic condition herself) supported her husband (aged 77), who has Parkinson's disease. A recent head injury had left him confused and less mobile. He attended a day centre once a week and she reported:

You can't leave him for a couple hours ... that's 24 hours a day. I can't go out except for on a Wednesday when he goes to [Name of day centre]. I mean I can't even go round to the shops and say 'sit in the car while I go in the shops' because by the time I come out he would be out of the car and wandering up the road and not knowing where he is. (C)

A 76 year old woman had fallen and broken her knee cap, could not get up the stairs at home and had made a temporary bedroom downstairs with a commode, was needing daily support from a care worker and said:

I couldn't manage to take the commode upstairs to empty it. I couldn't have done that. Well, you couldn't ask a neighbour to do it. (O)

Participants varied in terms of the type and amount of benefits received as a result of receiving an assessment from the welfare benefits advice team officer. Some individuals obtained additional financial benefits which they could spend as they liked (e.g. carers allowance), whilst others received the additional benefit necessary to pay for the social services input (for example, home care). Some participants

were unclear about which benefits they had received or were waiting for the outcome of their assessment, whilst a few participants received no additional benefit following their assessment.

The analyses identified four overarching themes, each encompassing a number of minor themes relating to: the complexities of accessing welfare benefits; awareness of benefits and advice services; forming relationships between clients and services and the impact of benefits advice on the health, well-being and quality of life of recipients.

Complexities associated with accessing welfare benefits

Many participants found it difficult to describe the route that they had taken or the chain of events that resulted in a visit by the welfare benefits team. Some were unclear about how the benefits advice service had been accessed, in part because many individuals who had received visits from various health and social care workers (often in quick succession) were often unclear as to the type of professional (e.g. social worker, occupational therapist, home care team leader, etc.) and the service being offered. Similarly, the advice team thought that some people saw them as commensurate with social services, despite the team emphasising their own identity and purpose. One lady caring for her husband commented:

She [the social services home care-co-ordinator who visited] said you have to be assessed by a financial person so she sent somebody round about that. ... Well I don't know who it was. It was - I thought it was somebody from social services. But I mean you say the [name of financial advice team] team are connected with social services? ... But that's, that might be who it was, I don't know. We only had one person come round about the financial side of it. (H)

Older people and carers reported feeling “pretty swamped” (Q) by the sheer quantity of paperwork associated with claiming benefits. Some found difficulty in completing forms because hands were “so unsteady” (N) or perceived the forms to be “scary” (C). Benefit officers were very aware of these stresses and often completed the necessary paperwork, something that was universally appreciated by the participants. One officer commented:

But for most people regardless of their status, education, class, background, anything like that, people get to a certain point in their lives, where they just can't cope and they see a brown envelope come through the door and it really is a huge thing for them. I know a lady who shouts to her husband “is there any brown envelopes?” and she doesn't even want to come down stairs. I mean she's a lovely, lovely lady, articulate, intelligent, very funny, educated, And I think people worry about what they put down on official forms in case they're going to get into a lot of trouble. (Z)

Older people, carers, and officers alike, emphasized the value of a specialist home visiting service, feeling that older clients “prefer someone to come round and visit” (Z). Some interviewees described their surprise when they were advised that they were eligible for a benefit, having previously felt they were “struggling” (U) for years, in a system that had felt “very daunting” (D). One benefits assessment officer noted:

But the elderly ones which are the majority of our cases tend to you know, they haven't claimed pension credit, they've not claimed income support. They don't even know what it is or the Attendance Allowance. They get muddled up with another benefit or they don't want to claim but you know they're, they're frightened that it might stop something else that they're getting. (W)

Awareness of benefits and advice existence: concern versus interference

Older people, carers and benefits officers described friends, relatives, neighbours and clients in the local community who had been unaware of the available benefits or the existence of the benefits advice service. Some felt more could be done to “flag up” (D) those who reached retirement age to provide information and welfare checks:

I don't know, not a criticism of them [the welfare benefits team] really but how, how is Joe Public supposed to know about them? ... The main thing I think erm is being aware of their existence. ... There are people who need them [the welfare benefits team] and they exist but the two don't know about each other. (D – Carer)

One carer felt that “prevention is better than cure” (E) and suggested involving the general practice surgeries systematically in identifying older people “above a certain age” (E) who could be in need of welfare and benefit advice. However, one officer commented on the pragmatic and ethical difficulties of identifying those in need of advice:

But there are probably individuals within that category who we could be helping and we could increase their income, we could put some assistance in to make their life easier, but then they may not want it, they may not want interference, so it's (a) how do you identify (b) do you want to identify ... or do they want to be identified? (Y)

Some older people and carer interviewees felt that there was still a widely held view in the community that receiving benefit was “almost degrading” (E) and that there were those who would not want interference from advisors or to receive additional benefits. Welfare benefit advisors were also aware that for some clients having to disclose their

financial situation was disconcerting and indeed some chose not to do so. However, most older people interviewed had accepted the input of the service and the necessary disclosures, and were “not worried so long as I am assured that it’s confidential” (J). Conversely, several younger carers (who had not needed to disclose their own finances) felt that if they had to provide detailed financial information of their own or their parents’ situation they “would have to think seriously about it” (D) prior to agreeing to go ahead:

I think maybe it might be a bit secretive because our generation if you can understand really don’t want to talk about it [receiving benefits]. (O - Older person)

The word ‘means tested’ does mean quite significant things as I said. A lot of people will remember what it was like many, many years ago when it was a case of ‘well you look as though you could sell that’. I think it can be a very distressing period if they’re needing help they’re obviously quite vulnerable anyway. (Z - Officer)

Forming relationships to facilitate the assessment process

The welfare benefits advice team viewed their ‘core business’ as involving visiting clients in their own homes, and “generating income for the Council but also ensuring that the individual is getting the best out [of] their benefits and income” (V). In this way, the team acknowledged that there were tensions arising from their dual purpose role, seeing it as a “a double-edged sword” (Z). However, all the officers emphasized the importance of putting clients at their ease, gaining client’s trust, and their extended caring role (e.g. helping with small tasks such as posting a letter) which not only enhanced the relationship with their clients, but also helped to provide the

widespread “feel good factor” (V) amongst officers towards their job.

... It’s a very fine line [when visiting a client] but you cannot go out and meet people and go into their homes and listen to their lives and their circumstances without giving something of yourself. ... And I think that’s probably why the team’s been successful because you do give something of yourself. It’s, it’s not an impersonal service. ... There’s nothing like it. I have come - I’ve come away from visits erm and felt oh just so incredibly happy. (Z - Officer)

I gave them the information they wanted and this lady who came was very pleasant and I got on very well with her. She seemed to be very understanding and sympathetic and so on. (J - Older person)

Older people and carers described their impressions of the welfare benefits officers as generally very good (“efficient”, “clued up” (wife of M)), and the process was described as “a satisfying procedure” (Q) once people had met with the officer. There was a sense of confidence and security knowing that the team involved were able to negotiate their way through the system on behalf of their clients:

... So you know I’ve passed their [the welfare benefits team’s] existence on to, to others who didn’t know, didn’t know about them. ... And the wife [of a neighbour], had been looking after him for 9 years and he’d never heard of Attendance Allowance. Erm so I, I said to him ... “phone social services and just ask for finance and benefit team and you know they’ll come and just talk about anything and everything”. (D - Carer)

Officers were very aware of the range of attitudes surrounding their visits, with some clients being initially “very defensive” whilst others “just want to have you in and have a cup of tea” (Y).

Perceptions of impact of assessment on health and well-being

Choice, control and security

Most interviewees who received a benefit felt that the money gave them extra choice or control over important, practical aspects of their lives. One couple, for example who both received Attendance Allowance, commented “we don’t have to be so careful”, adding it had “made a big difference to our lives” (M), choosing to have higher quality meals from a private meals company, and being able to purchase services and equipment:

They (name of firm supplying meals) do some nice things. ... I mean, we’re not extravagant and we make one meal do for two of us because we haven’t got big appetites. But, they have more... some more expensive meals which are quite a big improvement. But umm, you know, we feel now, well we can have one of those between us. Whereas before we would probably have thought, “Oh-oh”. (M – Older person)

For some it enhanced financial security and reduced anxiety: it could be used “in an emergency (for repairs)” (S), whilst it allowed others to use taxis or to go on outings or:

I don’t worry if anything goes wrong like the cooker or the washing machine. (S - Older person)

Paradoxically, there were also those participants for whom receiving extra benefit caused some anxiety, as they felt that they would “get used to living as you do at a different level” (V), which could cause concern if the benefit amount was reassessed due to changing circumstances or if the benefit ceased:

But if you used it [the Attendance Allowance] for every day living [rather

than spending it on care] and then something happened to your husband then you suddenly would be, I mean you’d be on a lower income anyway and then you’d be that much lower as well, and that would be stressful. ... We’re financially not rich but average, but if anything happens to my husband I will be on a very low wage. (C - Carer)

Quality of life, independence and health

Perhaps related in part to increased choice and control, a number of people described improvements in their quality of life or health following benefit receipt. Increased options for transport were common (use of taxis, maintaining their own car) which enabled easier access to their general practitioner or hospital, allowed more regular trips to social events and made visiting relatives and friends and shopping easier. Some participants had also set up or maintained private services (e.g. gardening, cleaning services) with the extra benefit:

We belong to a luncheon club which we go to on a Tuesday morning and we didn’t want to give that up, erm, so we have a wheelchair taxi, you know a taxi that takes a wheelchair, ... It’s booked every Tuesday morning. Erm, and that costs £10, erm so that, you know, comes out of the attendance allowance. (H - Carer)

Affording taxis is a big thing for erm a lot of the older people. A lady up in [town name], her son was really concerned because he was in London and she kept saying “the hill’s like that [steep] to walk down”, really steep and she took something like an hour and half to get back from the local shop. It was only about 200 yards down the hill and erm but she wouldn’t pay for a taxi ... I got her the Attendance Allowance which was near on £40 a week and she was whizzing down to (town name) town centre a couple of times a week to meet

her friends for coffee and said it completely opened her life up because she didn't feel so cut off at the top of this big hill. (W - Officer)

Tangible effects were described regarding physical and mental health for some receiving additional benefits. A new 'scooter' had encouraged one couple to take turns in exercising alongside it, whilst another participant used the additional money to pay for alternative therapies. The positive impact on mental well-being was also reported by interviewees. For carers in particular, there were clear benefits as the extra income allowed them to buy in services, which in turn gave them greater freedom and reduced the strain of caring:

We get very nice meals at the (name of local town 1) Club and, er, they are not overly expensive. We just walk down, er, and it relieves me. It is a help. [Name of husband] likes to go to chat, or, just being the ambience of, you know, nice people. (L - Carer)

I got into this sort of phase where we get these depressions and you can't be bothered and you lose interest in things. But you see suddenly things started to change and I think a lot of it was worrying about things. ... What's going to happen, are we going to be able to keep this car going, ... and all these things. They all build up. (A - Older person)

A few participants found that they were not eligible for specific benefits; however this did not appear to negate their experiences of the assessment. One carer who found she was ineligible for a benefit felt that:

It didn't put me off. As I said my expectation was very, very low anyway because I thought it was just too good to be true. We're not entitled to anything else I know. (D)

This carer had gone on to recommend the service to others. Conversely, three participants who had received benefits did not believe the additional money had any tangible effect. All three individuals described their health and functional status as so poor that by the time the allowance had come through it had little or no impact:

No, I've no desire to do anything more darling. I just want to, if I can just walk to the kettle every day and cook my vegetables and be steady I'm grateful. It really is like that when you have been bad. ... I mean you have to focus on the basics. ... I've no aspirations for anything. (Q - Older person)

Negotiated feedback

Eleven of the twenty interviewees completed feedback forms asking for their views on each of the main themes arising from the analysis as well as providing any additional comments about their experiences. Most participants either made no further comments or said that the themes were an accurate reflection. Those that made comments gave support to the researchers' interpretation of the interviews and some offered further illustrative examples of their experiences relating to one or more of the main themes (Box 1).

Discussion

The study aimed to explore the experiences of older people and their carers in receiving welfare benefit advice through a specialist, social services-based team and its effects on health and well-being. Their accounts highlighted the perceived and real difficulties associated with accessing benefits and benefits advice, often at a stage of acute ill-health or difficulty in coping. Nevertheless, those who received an assessment viewed it as a positive and supportive process. The assessment often resulted in provision of increased welfare benefits which helped to pay for new

services and heightened feelings of improved security, control, independence, and the associated beneficial effects on quality of life and health. However, participants expressed concern for those unaware of the service or the benefits available. This was in contrast with the view expressed by a few participants that such a provision could be viewed as intrusive, or that the benefits arising were being provided too late to have much impact. These perspectives raise important issues about how a service provider might best target those at risk or in need.

Although the study was conducted through only one welfare benefits advice team, the validity and reliability of the study is supported and strengthened through feedback within and between concurrent studies. First, negotiated feedback from interviewees and interviews from the service provider viewpoint supported our interpretation of the findings. Second, an associated longitudinal observational study of older people and carers that was conducted concurrently also highlighted the vulnerability and general poor health status of those receiving benefits advice (Campbell *et al.*, 2007). Third, free text comments and telephone notes from the latter study also support these findings. Fourth, the primary and secondary coders (with different professional backgrounds)

were able to come to a consensus on how themes were categorised and interpreted.

This project explored the impact on older people of benefits advice provision and differed from similar studies because of the team's dual role, providing benefits advice as well as calculating contributions required to support the implementation of social services. In addition, this service was largely a home visiting service. Other services have focussed on the provision of benefit advice through providing a benefits advice officer located in a general practice surgery or in the offices of the Department of Work and Pensions. In both cases, calculating actual contributions to social care services is not normally conducted alongside the provision of advice around eligibility for benefits. In these situations, the older person has to deal with an additional social services agency to calculate any contribution to care provision, an issue which has been highlighted as time consuming and confusing (Mayor, 2003). One large longitudinal observational study (involving structured interviews) of clients of all ages receiving benefits advice within GP practices found improvements in health, however, clients were referred elsewhere for housing benefits and did not assess payments for social services alongside any increases that they received (Abbott *et al.* 2005).

Box 1 Negotiated feedback: Examples of comments

Barriers to the uptake of financial benefits and social services

E (Carer of mother): *Many older people are very proud and worry terribly about finances. My mother still regularly asks how she is paying for her residential home.*

Impact of accessing new financial benefits

P (Carer of husband): *Would not have had a clue of where to start and would probably not have bothered because of the emotional state you are in at the time.*

Suggestions for change:

M (Older person): *Would it be possible for someone to regularly check up to make sure that things are still satisfactory?*

Our study underlines the importance of specialist welfare benefits advice for older people and their carers where receipt of benefits may be linked to service provision. Respondents valued the home-visiting service and often reported improvements in well-being and health even though the high levels of ill-health were evident amongst those accessing benefits. Our findings emphasize the need to encourage the early awareness of benefit availability and to provide tangible help to facilitate access to benefits at the same time as payment for social services (House of Commons Committee of Public Accounts, 2004). Further research exploring the best means of targeting benefits advice to vulnerable older people is needed.

References

- Abbott, S. & Hobby, L. (2000) 'Welfare benefits advice in primary care: evidence of improvements in health', *Public Health*, **114**(5), pp.324-7.
- Abbott, S. & Hobby, L. (2003) 'Who uses welfare benefits advice services in primary care?', *Health and Social Care in the Community*, **11**(2), pp.168-74.
- Abbott, S., Hobby, L., & Cotter, S. (2005) 'What is the impact on individual health of services in general practice settings which offer welfare benefits advice?', *Health and Social Care in the Community*, **14**(1), pp.1-8.
- Acheson, D. (1998) *Independent Inquiry into Inequalities in Health (Acheson Report)*, London: The Stationery Office.
- Audit Commission (2000) *Charging with Care*, London: Audit Commission.
- Campbell, J., Winder, R., Richards, S.H., & Hobart, J. (2007) 'Provision of welfare benefits advice and the health of older people: a longitudinal observational study', *Health and Social Care in the Community*, **15**(5), pp.454-63.
- Department of Health (2001) *Fairer Charging Policies for Home Care and other Non-residential Social Services. Guidance for Councils with Social Services Responsibilities. Local Authority Circular (2001)32*, London: Department of Health.
- Elliott, R., Fischer, C. T., & Rennie, D. L. (1999) 'Evolving guidelines for publication of qualitative research studies in psychology and related fields', *British Journal of Clinical Psychology*, **38**(3), pp.215-29.
- Great Britain National Audit Office (2002) *Tackling Pensioner Poverty: Encouraging Take-up of Entitlements: Report by the Controller and Auditor General*, London: Stationery Office.
- Hoskins, R. & Carter, D. (2000) 'Welfare benefits' screening and referral: a new direction for community nurses?', *Health and Social Care in the Community*, **8**(6), pp. 390-7.
- House of Commons Committee of Public Accounts (2004) *Improving Public Service for Older People: Twenty-ninth Report of Session 2003-2004*, London: The Stationery Office.
- Mayor, S. (2003) 'Better co-ordination is needed in services for older people', *British Medical Journal*, **326**(7391), p.680e.
- McConaghy, M., Hill, C., Kane, K., Lader, D., Costigan, P., & Thornby, M. (2003) *Entitled but not Claiming? Pensioners, the Minimum Income Guarantee and Pension Credit*, London: Corporate Document Services 197.
- Paris, J.A. & Player, D. (1993) 'Citizen's advice in general practice', *British Medical Journal*, **306**(6891), pp.1518-20.

Smith, J.A., Jarman, M., & Osborn, M. (1999) 'Doing Interpretative Phenomenological Analysis', in *Qualitative Health Psychology*, Murray, M. & Chamberlain, K. (eds.), London: Sage, pp.218-40.

Toeg, D., Mercer, L., Iliffe, S., & Lenihan, P. (2003) 'Proactive, targeted benefits advice for older people in general practice: a feasibility study', *Health and Social Care in the Community*, 11(2), pp.124-8.

Notes on Contributors

Rachel Winder is an Associate Research Fellow in Primary Care. Her interests include social welfare and housing for older people, and the management of chronic diseases and end-of-life care, using both quantitative and qualitative methodologies. She is currently involved in a randomised controlled trial examining the effectiveness of treatment of depression through the provision of exercise in primary care settings compared with usual care.

Dr Suzanne Richards is a Senior Lecturer in Primary Care specialising in research into the delivery of health and social care of older people. Current projects, using both quantitative and qualitative methods, include exploring the use of out-of-hours health care for patients with palliative care needs, the role of mentoring for socially isolated older people, and effectiveness of exercise programmes at reducing the risk of falling for people with Parkinson's Disease.

Dr Katrina Wyatt is a Senior Research Fellow in Child Health. Her research interests lie in developing and evaluating complex interventions, evidence synthesis and consumer involvement in research. She is currently involved in a trial looking at the effects of cranial osteopathy on cerebral palsy, developing and evaluating an intervention to prevent and reduce obesity in primary school children and a national cohort study looking at the effectiveness and

cost effectiveness of enzyme replacement therapy for lysosomal storage disorders. All of these projects have had patient and public involvement in the design and delivery of the research.

Professor John Campbell is the head of the Primary Care and General Practice Research Group of the Peninsula Medical School. With broad clinical and research interests across the spectrum of community medicine, he specialises in the development of measures to assess patients' and clinicians' views on the quality of health care, and trials of complex interventions.

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Young carers: still 'hidden' after all these years?

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Abstract

Although legislation and policy guidance within the United Kingdom provide a framework for intervention and good practice with young carers, children and young people caring for ill or disabled family members continue to remain 'hidden' or 'invisible' in our communities. This paper reports key findings from doctoral research which identify a group of children and young people within the population who have not been formally recognised in their caring roles nor formally assessed as young carers. It highlights, for the first time, the differences in the nature, frequency and time spent on caring tasks by this sub-group of carers, compared with known young carers and 'non-caring' children and young people. Indicating a high level of unmet need among parents and other family members who are ill or disabled, these findings have important implications for professional policy, planning and practice across adult and children's services. The paper concludes that greater professional awareness of the work that all children perform in a household, earlier intervention and effective collaborative practices could do much to ensure that children, young people and their families receive the services that they need.

Keywords: Children, disability, research with children, young carers

Introduction

Over the past thirty years, a combination of factors has made it more likely that children will take on caring roles. These factors include the de-institutionalisation of care, advances in medical care, reductions in family size, an increase in privatised family life-styles and the adoption of policies in the United Kingdom, which place emphasis on informal care within the community (Olsen, 1996). The development of legislation and policy guidance relevant to the needs of these children and their families has provided a framework for intervention and good practice which, in theory, should enable welfare professionals to define when and how to intervene to provide services and support to families. Much of the qualitative and quantitative research in this field, however, continues to highlight the failings of agencies to provide adequate support to these children and young people, commonly referred to as 'young carers'. In particular, the virtual invisibility of these children and young people, the ongoing lack

of recognition among agencies of the work that they do and the impacts of caring when children and their families lack appropriate care support, are well documented (see, for example, Aldridge & Becker, 2003; Cree, 2003; Thomas *et al.*, 2003).

Building on such literature, this paper seeks to highlight the experiences of a group of children and young people in the general population whose caring roles and responsibilities remain hidden. Drawing on findings from doctoral research undertaken in 2001, the paper presents a profile of this sub-group of carers: who they are, what they do and how their experience differs from other children and young people who do not adopt care-giving roles and those who are known as 'young carers'. This is the first study to provide a three way perspective of children and young people's care-giving, as shown in Figure 1. The study suggests that children and young people who show signs of being in a caring role are potentially more vulnerable than *known* young carers, in that they do not appear to have been formally

recognised in their caring roles, nor formally assessed as young carers. Unidentified and unsupported, children's voices continue to be unheard, and their care-giving remains as hidden today as it did in 2001 (see Barnardo's, 2006). It is hoped that the findings presented in this paper will be of practical use to a range of professionals working in children's and adults' services, informing developments in policy, practice and research, for the benefit of young carers and their families.

Background

Why do young carers remain 'hidden'?

Previous research and practice guidance have suggested a number of reasons why young carers' contributions to family life in the United Kingdom remain 'invisible' and their needs unmet. There can be a lack of recognition of the child's role as a caring one by both the child and parent (Aldridge & Becker, 1993). There may also be reluctance, by family members, to admit to the presence of a child carer within the family, for fear of professional interventions that might lead to family separations (Bilsborrow, 1992; Aldridge & Becker, 1994). The perceived stigma associated with

alcohol misuse, HIV/AIDS, mental illness or caring more generally, particularly among young black and South Asian carers, may also affect families' openness about child care-giving (see, for example, Imrie & Coombes, 1995; Shah & Hatton, 1999; Aldridge & Becker, 2003). Significantly, the lack of recognition among professional workers about young caring as a welfare issue, combined with the ongoing lack of awareness among professionals of the potential for children and young people to assume caring roles, can result in failure by many professionals to recognise the potential 'triggers' for young caring (Aldridge & Becker, 2003). Furthermore, the myths and racial stereotypes associated with black and South Asian communities, which may lead some professionals to assume that, because of extended family networks, families 'take care of their own' (Shah & Hatton, 1999), combined with the discrimination and institutional racism experienced by black and minority ethnic families in accessing education, social and health services (Shah & Hatton, 1999; Jones *et al.*, 2002) are also impacting on professional recognition and identification of young carers.

Figure 1 Classification of children and young people's care-giving

- **'Non young carers' ('non-caring')** - children and young people who do not look after, or give special help to someone at home who is ill, has a disability or other special needs. They undertake low levels of domestic and caring tasks considered appropriate for their age and level of maturity.
- **Known young carers** - children and young people who have been formally identified and recognised in their care-giving roles. They undertake a range of domestic and caring responsibilities which vary in amount, regularity, intensity and duration according to the context of care, and most importantly, the nature and effectiveness of services and support available from outside of their family (see Becker *et al.*, 1998).
- **Children 'showing signs of caring'** - children and young people who look after, or give special help to someone at home who is ill, has a disability or other special needs, and who undertake a range of caring responsibilities that are sometimes as substantial or more significant than known young carers, but who appear not to have been identified or recognised in their caring role.