

# **INTRODUCTION**

## **BACKGROUND**

The redefinition of community care from care *in* to care *by* the community combined with the demands of an ageing population has led to increased recognition of and research into the needs of informal carers. The material costs of their role have been highlighted, both in terms of day-to-day expenses and lost employment opportunities (Nissel and Bonnerjea, 1982; Glendinning, 1992). The influence of social divisions has also been well recognised, especially in the large body of feminist literature examining the extra costs incurred by women as a result of their ascribed caring role (Finch and Groves, 1983). However, as Arber and Ginn (1992) point out, relatively little is known of other ways in which caring responsibilities are socially structured with much research tending to adopt a classless analysis serving to ignore the influence of pre-existing material inequities on the role of informal carers. The limited research, which has taken place into this area, has tended to focus on the impact of poverty on younger carers, especially the mothers of young children (Graham, 1992). However, due to the close association between disability, older age and poverty (Townsend, 1981) many older people are likely to be involved in caring for a disabled person, especially within the spousal relationship, and the influence of material deprivation upon this role is likely to be especially significant, with households headed by an older person or a disabled person being more likely to be poor than any other group (Walker, 1981; Oppenheim and Harker, 1996). The review of existing literature tends to indicate that poverty is likely to significantly exacerbate the demands on informal carers. This is not only due to the increased incidence of disability found amongst deprived social groups (Office of Population Censuses and Surveys, 1990). It is also due to the role of poverty in promoting the dependence of disabled people while at the same time reducing the capacity of informal carers to cope with this dependence (Borsay, 1990).

It is therefore the aim of this research to help to redress the ageless and classless analysis of informal care research by examining the influence of material circumstances on the role of older co-resident carers, the ways in which these circumstances are actively managed as well as other factors that may mediate the influence of these circumstances. In focusing specifically on older carers, attention is given to a large and, due to

demographic trends, potentially growing group, many of whom have disabilities of their own but whose needs have often been neglected by the carers movement and by welfare providers in favour of other groups such as those of 'young carers' (Olsen, 1996). As Walker and Walker (1998) recognise, in spite of the close association between ageing and disability, this neglect of older people has also been apparent within the disability movement with recent measures such as the Disability Discrimination Act focusing specifically on the needs of younger disabled people. This research aims to counter this neglect and helps to challenge the traditional problem orientated approach towards older people by recognizing the positive social contribution, which they make (Arber and Evandrou, 1993).

Not only has research into informal caring overlooked the influence of ageing upon the caring role, it has also tended to portray the experience of caring in generally negative terms (Olsen, 1996; Newman, 2002). Similarly negative connotations have been attached to the experience of care receiving which has been regarded as a dependency-creating concept, with the achievement of independence widely being regarded as an ideal to which all disabled people should aspire (French, 1997). As Barnes (1997) observes, such negative perceptions of the experience of care-giving and receiving serve to neglect the many positive benefits to be gained within the caring relationship as well as the essential interdependence of this relationship and the reciprocal exchanges taking place within it. Barnes (1997) maintains that this neglect has been exacerbated by the development of campaigning user groups such as those for disabled people and informal carers. For while such exclusive groupings facilitate the collective identities of their members, they also impose a one-dimensional analysis on complex and overlapping identities and fail to recognize the way in which the interests of different groups may coincide (Newman, 2002). It is a purpose of this thesis to explore these issues by highlighting the material, practical and emotional interdependence between care giver and care receiver and the often-blurred distinction between their respective identities.

## **ORIGINS OF THE IDEA**

Social research can never be value free but is inevitably influenced by the perspectives of the researcher. In accordance with this, as subsequent chapters highlight, the theoretical perspectives from which this research is approached are broad and this reflects the similar broadness of my academic and professional background. This incorporates professional qualifications in both health and social care and degrees in sociology (Manchester Polytechnic), social policy (University of Nottingham) and social work (University of Warwick). The origins of the idea for this research are also broad and can be seen as a synthesis of three interests incorporating poverty, informal caring and older people:

### **Poverty and material circumstances**

My interest in this area originated in a more general interest in Marxist perspectives, which were themselves developed when, as an undergraduate I became a student cadre for a Marxist organisation. Subsequently, through my extracurricular activities and through taking Marxism and Political Sociology options as part of my first degree, I became familiar with the basic principles and theory of Marxism and I have subsequently retained my commitment to Marxist perspectives, going on to pursue this interest in subsequent degrees. Thus, while I no longer have any political affiliations, I still wish to help to reassert the importance of class and poverty in social research, an importance which I feel has been neglected in recent years due to theoretical trends such as postmodernism. This is not to say that I discount the validity of such theories. Indeed, I see many aspects of the 'post-modern' in my own life. I do, however, feel that the emphasis placed by such theories on diversity, meaning and lifestyle neglect the impact of structural constraints on the lives of individuals.

### **Informal caring**

My interest in informal care originated from a broader academic interest in theories of the family which can be traced to the time when as an A level sociology student I wrote an essay critically evaluating Parsons' theory of the nuclear family norm. I went on to develop this interest when, as a student psychiatric nurse, I evaluated Grad and

Sainsbury's research into the burdens experienced by families of psychiatric patients. During this time I also became interested in broader issues of community care which are, of course, of great contemporary relevance within psychiatry due to the large-scale closure of psychiatric hospitals. However, it was not until I was a student social worker that I came upon the idea that research into informal care was characterised by a classless analysis, an idea I believe I originally derived by reading the work of Hilary Graham (1993). I pursued this interest in the class basis of informal care in my MA dissertation at the University of Warwick, which involved examining the influence of material circumstances on the informal carers of older people (Argyle, 1997). This represented a synthesis of my long-standing work with adults, especially older adults, combined with my academic interests in poverty and caring.

### **Older people**

For the purpose of my PhD, investigation has focused specifically on older carers, rather than on the carers of older people. This gives the topic a more original slant and helps to counter the traditional 'burdensome' concept of older people who tend to be seen as the passive recipients of care rather than the active providers of it. Such a focus also helps to counter the considerable publicity that has been given, particularly within social work, to the issue of 'young carers'. For my professional experiences have suggested to me that, contrary to media portrayals, such carers are in fact tiny in number as compared to their older caring counterparts. This has been upheld by recent research, which has found that there are around two million older carers in Britain (Milne et al, 2002) as compared to around 10,000 'young carers' (Newman, 2002). Indeed, while the 1996 General Household Survey included questions on care giving by children, the figures remained unpublished as they were considered to be too low for statistical analysis.

### **RESEARCH AIMS**

After I acquired my original idea, a literature review followed, both in preparation for my original application to undertake PhD study and as part of the research training programme in my first year of research. As starting point for my literature review, I used references with which I had become familiar during work for previous degrees, especially

on topics relating to the general areas of poverty and informal care such as Becker and MacPherson (1986) and Abrams (1978). I also used the technique of ‘cascading’, which involved scanning the reference lists of relevant publications in order to identify further relevant material. The reference lists of books such as *The Caring Relationship* (Qureshi and Walker, 1989) were useful in this respect. However, the literature gained by these methods was not only likely to be out of date but was unlikely to relate to my specific area of interest, that is, the influence of poverty on the role of older carers. In order to locate references specifically relating to this area, I used the reference list on ‘carers and care giving’ given to me by my supervisor. As this was a very long list including over two hundred references, I selected only those with titles relating to older people, poverty or class, for example, *Class, Caring and the Life Course* (Arber and Ginn, 1993). I also selected from the list, authors who I knew from previous experience, tended to focus on the issues in which I was interested, for example, Hilary Graham.

Having selected appropriate references, I followed them up through the author/title search on the STAR catalogue in the university library. From subsequent reading of this material, I discovered authors such as Sara Arber who specialised in my areas of interest but whose work I had not previously encountered. I therefore used the author search facility on the STAR catalogue in the university library to attempt to locate any other relevant publications by this author. I also carried out a keyword search to see if I could find any new references on the influence of poverty on the role of older carers. The fact that the author and keyword search failed to yield any relevant references could partly be attributed to the specificity of my area of interest but it could also be due to the shortcomings of the STAR catalogue in that it does not always include the most recent publications and neither does it include all available material such as journal articles. The Bath Information Data Service (BIDS) was useful in this respect providing information on such things as individual journal articles as well as having an abstract facility, which allows the researcher to check the contents of publications before attempting to locate them in the library. I used this facility to conduct an author and keyword search and by doing this located some new material such as *Class and Caring – a forgotten dimension* (Arber and Ginn, 1992). However, like my STAR search, my

BIDS search yielded limited relevant literature. For example, while my keyword search for literature relating to poverty and informal care produced texts of general interest, most referred to the way in which caring caused poverty rather than to the impact of poverty upon such care. This served to reinforce my belief that my area of interest was neglected and in need of further research.

This review led me to further modify and refine my original idea. For example, in view of the relatively high incidence of co-resident care amongst older people and the possible role of material deprivation in influencing the assumption of this care (Arber and Ginn, 1992), it was decided to focus specifically on older carers within a co-resident rather than extra-resident setting. Such specificity of focus also helped to facilitate consistency and comparability in the roles of respondent carers. This process of review and modification culminated, at the end of the first year, in my departmental upgrading from MPhil to PhD study and my successful application to the ESRC research studentship competition for funding, under the thematic priority of social integration and exclusion. Four broad areas of investigation were identified in this theoretical proposal:

**The influence of material circumstances on the caring role**

In their secondary analysis of General Household Survey statistics, Arber and Ginn (1992) found that older people and poor people were much more likely to be involved in demanding co-resident care than their younger and more affluent counterparts amongst whom extra-resident care was more common. In order to explain this, they use the term 'leverage' to refer to the way in which the possession of cultural and material resources can reduce the need for informal caring involvement and also promote choice in caring strategies employed. It is a purpose of this research to 'look behind' these statistics by investigating the way in which carers access to material resources goes on to influence their caring role and the potentially positive as well as negative aspects of this role

**The way in which older carers manage and control material resources.**

The issue of the social construction of dependency in older age has been well recognised and addressed. In spite of this, little corresponding attention has been given to the way in which older people actively manage and negotiate their financial situation or the influence of the distribution of household resources on the caring role, especially within the spousal relationship (Askham, 1995). For example, little attention has been given to the distribution of financial resources between older married couples and to the influence of retirement on this distribution. It is an aim of this research to help to redress this neglect by exploring these issues both with regard to money management as well as to other material resources.

**The relationship between the objective and subjective experience of caring**

The objective and subjective costs of caring have tended to be seen as being largely unrelated, the former depending on measurable factors such as financial sacrifice with the latter derived from arbitrary or individually derived factors such as the quality of the caring relationship. A third aim of this research is to challenge this assumption by examining the hypothesis that not only are poorer carers more likely than their better-off counterparts to experience greater levels of 'objective' caring responsibility due to their limited access to resources with which to resist this role, but they are also more likely to subjectively experience this responsibility in a negative way. This may be due not only to unfavourable environmental factors but also due to the role of material deprivation in undermining the spontaneity and choice which have been found to be important influences on the subjective experience of caring (Abrams, 1978).

**Access to external sources of support**

As Arber and Ginn (1991) recognise, the material circumstances of carers are not only influenced by their access to personal and household resources but also by their access to formal and informal resources. Consequently, this research explores the way in which the recent transformation of community care and the adoption of a 'bottom-up' perspective in welfare provision has served to exacerbate the costs of poorer carers and reduce the choices available to them, in spite of rhetoric to the contrary (Williams, 1992). Access to informal support is likely to be similarly restricted, with recent research suggesting that, contrary to popular belief, many poorer people may have very limited access to such support (Graham, 1993).

In the light of these research aims, a research design was also formulated, that is, a structure that guided the execution of research method and the analysis of subsequent data. (Bryman, 2001). For the purpose of this research, it was decided that an emergent design would be utilised incorporating a main stage of semi-structured interviews and follow up interviews in which significant themes would be identified and pursued. From these interviews, transcripts, statistical data, case studies and analytical memos were produced. This was followed by a small amount of secondary analysis of official statistics, which helped to further illustrate and illuminate issues emerging from the qualitative data.

Due to this emergent research design combined with the iterative nature of qualitative research (Bryman, 2001) fieldwork findings and analysis led to a slight shift and elaboration in the of the original research aims. For while the research started out as a materialist exploration of the way in which material resources went on to affect the caring

role, as fieldwork and analysis progressed, further dimensions were added. Thus the materialist perspectives on which the initial four aims were based were modified, with issues of physical pathology, attitudes and culture achieving greater prominence than was initially anticipated and with the role of respondents as active social agents being given greater recognition. This in turn was reflected in the literature review into which research on cultural and attitudinal factors in older age as well as on post-modern issues such as consumption were incorporated in the light of emergent findings. It was also reflected in the accounts of research findings in chapters three, four and five. For while chapter three focuses largely on the influence of material circumstances on respondents and their role, chapters four and five adopt a multi-causal approach with the issue of 'resources' being interpreted more broadly to include culture and disability as well as financial well being. However, in the concluding chapter, the significance of material issues is reasserted.

### **THESIS OUTLINE**

This thesis makes an original 'contribution to knowledge' in three main ways. Firstly, by exploring the role of older carers and the influence of material circumstances upon this role, it helps to redress the neglect of older age and class in existing research into informal caring. In doing so, it also aims to challenge post-modernist perspectives and their tendency to neglect the constraining influence of structural factors such as poverty. The fact that the concept of these structures is broadened to incorporate aspects of culture and physical pathology as well as material circumstances helps to supplement the economic focus of structural theories of poverty and older age. For in their emphasis on material circumstances, situational constraints theories of poverty and political economy approaches to ageing have underplayed the physical and cultural factors, which can have an important influence on the lives of individuals. Secondly, while most studies of informal caring address either the subjective or the objective aspects of this experience, this thesis explores both these components and the way in which these experiences are socially constrained on one hand and actively negotiated on the other. In doing this, the thesis addresses the ongoing sociological debate between structure and action. For example, while the social construction of poverty and dependency in older age has been well recognized and addressed, in this thesis attention is also given to the way in which

these circumstances are actively managed by respondents. Moreover, its focus on the role of respondents as active social participants rather than passive victims helps to challenge the traditional problem-orientated approach to older people, recognizes the positive social contribution that they make and provides a unique commentary on their experiences. Thirdly the thesis helps to unify diverse theoretical themes relating to poverty, older age and informal caring and their relationship to contrasting perspectives on society and the state. As such it considers the implications of research findings for existing social, social policy and gerontological literature and recommends that theoretical synthesis is required if future progress in these areas is to take place. Thus drawing on the insights of Marxist-feminist theory, it is suggested that the 'relative autonomy' of the age dynamic should be recognized and responded to. This breadth of focus is, in turn, reflected in the breadth of the findings yielded from this research, being of potential relevance to literature on poverty, caring and older age alike.

Chapter one, *Poverty, Caring and Older Age*, reviews existing literature relating to the key themes of poverty, caring and older age and the location of these themes within contrasting perspectives of society and the state. Chapter two, *Research Methods*, considers the research methods used in the study, including practical issues of sample selection, gaining access, questionnaire design and data collection as well as a consideration of the ethical and methodological issues associated with these methods. Commencing the discussion of fieldwork findings, chapter three, *Material Resources and the Caring Role*, examines the various ways in which carers' access to and management of resources, goes on to influence their experience of caring. It will thus be suggested that contrary to materialist assumptions, issues of culture and physical pathology as well as material circumstances have an important impact on the caring role. These themes are further pursued in chapter four, which focuses on *The Experience of Caring* and the way in which this is evaluated. It will be maintained that, contrary to oppressive portrayals of caring, many respondents gained positive benefits from their role and experienced a practical, material and emotional interdependency in the caring relationship. Moreover, contrary to individualistic concepts of caring these benefits were

not arbitrary and incidental but were integral to the experience of caring. The final findings chapter, chapter five, explores respondents' '*Access to External Sources of Support*' and the way in which this access is mediated by both material and non-material factors. The thesis concludes with chapter six, '*Constraint, Culture and Caring*', which considers the implications of the preceding findings for existing literature, social policy and research. |