CARE MANAGEMENT AND SOCIAL WORK: WORKING WITH CARERS

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This second paper on care management and social work examines the ways in which practice can reflect the special circumstances of carers. Using the findings from a research project established to develop partnership in social services work, it is argued that social work values, skills and techniques provide the core elements of a care management approach, but that further work is needed to develop a practice which fully reflects the principle of treating the client as a user and as a citizen. In particular, practice must recognise the ambivalent feelings of carers, extend information to clients and opportunities for participation, reinforce choice, resolve conflict between carer and client in ways which safeguard the rights of each and co-ordinate the services of a wide variety of providers to the benefit of the client.

In the first of these two papers on care management and social work, it was argued that the advent of care management as a practice model for social work requires a re-examination of the working relationships between social workers and their clients. The first paper focused on practice with older people with dementia, since this provides a severe test of the consumerist principles underlying care management. In this second paper, it will be argued that social work skills, techniques and values are essential to underpin care management with carers, but that more development is required if social work is to address fully the practice issues in work with carers. Again, the proposed guidelines will draw heavily on a research and development project investigating agreement-based work in social services (Social Work in Partnership, see Fisher et al., 1989).

The urgency to focus on work with people suffering dementia and with their carers arises both from the intensity of the dilemmas in work with these clients, where the limits of a consumerist approach to service recommended in Caring for People will be tested, and from the likely concentration during the first year of operation of care management on clients with high dependency needs.

Much of our understanding of caring has been shaped by an analysis which emphasises the disproportionate burden which falls on women (see, for example, Finch and Groves, 1983; Finch, 1989; Qureshi and Walker, 1989). The results of a study carried out for the Equal Opportunities Commission in 1980, which reported that 75 per cent of carers were women (Equal Opportunities Commission, 1980), had an important influence on this research and policy initiative. Relying on a small-scale survey of a self-selected sample of 116 carers in one geographical area, the research was, however, unrepresentative of the national picture and more recent and accurate evidence is available from the 1985 General Household Survey (Green, 1988). This survey estimated that there are some six million carers in the UK, of which some 3.5 million (58%) are women (Green, 1988). Information from the General Household Survey (GHS), 1985, shows that 76 per cent of the carers were caring for someone over 65, suggesting an estimated figure of about 4.56 million carers of older people.

The survey confirms that women take the main burden, particularly in respect of being the main carer, caring for more than 50 hours per week, being expected to care if single and between 45-64 and
receiving less informal help from outside the household. However, the GHS also shows that there are many more men carers than previously assumed. In the peak age group for caring (45-64), men represent 47 per cent of the total numbers. When looking at the numbers of carers in the older age range, men represent only 40.8 per cent of the total. However, it should be remembered that there are more older women than men in the population, so if we want to understand the influence of gender on becoming a carer, we have to examine the proportions of men and women caring. Of all men over 65, the GHS indicates that 14 per cent are carers compared with 12 per cent of women over 65. Of all carers over 65, proportionally more men than women care for a dependant in the same household (27 vs. 24%); care for a dependant in another household (16 vs. 14%); are main carers (24 vs. 18%); devote 20+ hours per week to caring (30 vs. 24%).

It is clear from this and other re-examinations of the issue of gender and caring (e.g. Evandrou et al., 1986; Arber and Gilbert, 1990) that one critical factor overlooked in previous analyses was that of spouse caring: while it remains generally true that women are expected to take a disproportionate share of the total burden of caring, the response to disability in an older spouse appears to depend on the obligations of marriage rather than of gender. Previous analyses had also suggested that men get a disproportionate amount of help from formal services. The General Household Survey shows that, although it is true that men carers get more informal help from outside the household than women, formal help from the health and social services is given equally to both sexes of carer.

The purpose of clarifying the evidence about caring and gender is that there is a tendency for services to reflect assumptions about gender roles. A care management practice model, one feature of which is responsiveness to the consumer, cannot function on the basis of assumed roles imposed upon the clients. In the past, it is clear that services expected women to care because they are women and social policy commentators rightly drew attention to this injustice. The possibility now is that the necessity for care managers to adapt services to recognise the amount of care undertaken by men is overlooked precisely because previous policy analysis has made their contribution almost invisible. The point about assumptions and service provision will be returned to later.

It is also important to note that older people are more likely to be known to the domiciliary care section than to social work. One study showed that 85 per cent of older people in touch with social services were known to the Domiciliary Care service (Sinclair et al., 1988). Other studies show that cross-referral between the two services is relatively rare (Fisher and Cohen, 1988). The GHS showed that 23 per cent of carers had contact with the Domiciliary Care service, and seven per cent with Meals on Wheels service, compared with six per cent having contact with social work. Clearly this places a responsibility on social work to reconsider its relationship with domiciliary care workers, with a view to sharing social work skills in care management but also in recognising the contribution that domiciliary care staff will make to service to older people and their carers.

There are many issues unique to the lives of carers which will have important implications for the approach care managers take. Carers have usually been doing the job a long time. One study of elderly people admitted to short term residential care showed that 20 per
cent of carers had been looking after their dependent relative for ten or more years, and 50 per cent for five or more years (Allen, 1983). These long periods can give rise to very complex caring arrangements, finely tuned to meet the dependent persons needs and the carers abilities and patience. Where the dependant is living with the carer, 68 per cent of carers had help from someone else in the household and 42 per cent from outside (GHS). Altering these arrangements, even those which seem to be minor, can upset the system. It follows that carers must often be regarded as experts - experts in their own caring arrangements, in communicating with a dependent relative, in balancing competing demands, in interweaving practical and emotional care, and in surviving. Another characteristic of caring is that it is of indeterminate duration. Carers may take on a dependent relative without any real conception of the time span that may be involved. Nor do carers always actively decide to care. A study of daughters caring showed it was rather a drift into a caring relationship (Lewis and Meredith, 1988).

The experience of caring can depend a lot on the quality of the relationship before care 'started'. Caring for a person the carer did not much like can be extremely stressful, whereas previous affection can see her or him through bad times (Marsden and Abrams, 1987).

Caring is often intensive, especially for women living in the same household as the dependent person. The General Household Survey showed that 59 per cent of carers aged 65+ worked 50 or more hours per week. Apart from the heavy labour and the time input, carers have often no way of getting a substantial break: the GHS showed that half of those looking after someone in their own household could not get a two day break, and that 57 per cent had not had such a break since caring began. Another study showed that 25 per cent of carers never left the dependent person alone (Levin et al., 1988).

It almost goes without saying that caring is stressful, but it is easy to overlook how acute the distress can be. One study showed that carers' mental health suffered in 68 per cent of cases where they were caring for a person with dementia: social services workers were aware of these problems in only a third of the cases (Cohen and Fisher, 1988). Caring can involve reaching the point of physical abuse of dependent relatives: some studies indicate that ten per cent of dependent older people are at risk of abuse (Cloke, 1983). Furthermore, carers may not know when they need outside help: the study of daughters caring (Lewis and Meredith, 1988) showed that the gradual way that stress accumulated made it very difficult for carers to become aware of a breaking point or to decide that something must change.

Lastly, carers often know little about available services, particularly if a member of a minority group and the relevant agencies have unclear policies or practices on translation and interpretation. There may also be confusion about the responsibilities of health and social services helpers and about which problems to take to which service.

Agreements about carer stress

It can be difficult to hit the right note with carers, who are in one sense partners with the care manager in caring but in another important sense may be clients in their own right. The goal for the worker is to offer the client recognition of the stress of caring in a way which does not impose on the client role. The issue for the
care manager is that the practice model calls for explicit negotiations to agree a set of problems and to write them down as the basis for service.

Findings from Social Work in Partnership suggest that carers and workers can sometimes reach an agreement, unspoken and unwritten, which allows for the issue of personal support for the carer to be legitimately on the agenda without the carer explicitly having to acknowledge and name this as a problem for which service is sought. Although this sort of understanding falls short of an agreement in care management terms, it represents good practice with carers. The difficulty of recording this as an agreement can be resolved by the worker noting on the joint records a general phrase, such as that the carer needs support to continue caring, but omitting details of carer stress unless the carer wishes to have this recorded and worked on explicitly. Care management calls for a review of the care plan and so this provides the mechanism for the carer to raise this if s/he requires a more formal agreement. During any such review, the worker must be sensitised to the potential for carers to choose to make their problems a more explicit focus, and could prompt this by asking whether they are happy to leave the statement (carer needs support to continue caring) at the general level or wish to put more detail on it. A tactful focus on the stress of caring may also allow workers to identify situations where older people are at risk of abuse. The net result of this strategy is that the care manager may achieve a quasi-agreement in which the focus on carer emotional support is legitimised and clarified without explicitly casting the carer in the client role.

Care management calls for carers to be given information about relevant services and to be involved as far as possible in decisions about how those services are allocated. However, findings from Social Work in Partnership suggest that carers may edit their problem reporting in line with what they see as available, in a context where most know very little about relevant resources. The attempt to elicit problems may therefore be of limited use because carers do not raise problems for which they cannot see a solution. If the care manager is to work with informed clients, information about available resources will need to be introduced and the agreement-making phase delayed until carers can assess the information available to them. Thus the care manager must be prepared to take sufficient time during the assessment phase not only to give information but to ensure that it is understood and that carers can see the relevance of resources described.

This in turn implies the availability of up-to-date and accurate written information, translated where necessary, and an organisational readiness to make eligibility for services explicit and to give information on services for which there may be substantial waiting lists. It is critical that carers understand eligibility criteria and how decisions will be taken. If domiciliary or day care is in the carer’s mind, is it clear whether they are entitled to this service and who will make the decision? The care manager should therefore attempt to clarify entitlement to clients and where decisions about the allocation of resources are taken. Carers should be invited to participate in decision-making, with proper preparation and support, and they should know clearly the outcome of any decisions affecting them as soon as possible.

If a service is agreed, carers need to know how it is to be given and
who is responsible for arranging it. Previous evidence suggests that carers are often given a service on a 'when you need it' basis (such as a sitter service), placing the responsibility on the carer to ask for service. Given the evidence about carers’ difficulties in knowing when a breaking point has been reached and ambivalence about making their needs a focus, the care manager should check that carers have a sufficiently strong sense of entitlement to use the service without feeling guilty and without leaving it until they are desperate. If a service is not going to be given (or is going to be delayed), carers should know the reasons and where to lodge their views if they wish.

Service based on agreements

Caring arises out of affection, obligation and chance (such as being the only geographically close relative). The principles underlying care management imply that services should reinforce wherever possible the carer’s sense of choice and minimise the sense of imposition. This means that workers must be careful to avoid making assumptions about the role of a carer and must be alert to the need to help the carer to resist others’ assumptions. ‘Choosing’ to care is a complex idea. Many carers retain a sense of ‘choosing’ to care, despite a clear, socially constructed obligation and little evidence that there was any alternative. Some policy analysts quoted earlier suggest that caring contributes to women’s identity, because of the link between concepts of femininity and caring (see Graham, 1983). The care manager therefore has a delicate path to tread between respecting this sense of choice and the identity it may confer and yet not losing sight of the stress and restrictions involved in being a carer. In view of the evidence about male carers presented earlier, there is no space in service provision for any assumption that men cannot, will not or should not care.

Patterns of caring also vary between different ethnic groups: some black and ethnic minority groups make very little use of formal social services, partly because of the unsuitability of many services, but also because of a strong moral code in some communities requiring care of older dependants by kin. Again, the issue in care management is that service must be based on a negotiated agreement rather than on any assumptions by the service providers. The care manager will therefore need to recognise and respect different patterns of caring, but must resist the assumption either that the existence of a moral imperative to care removes stress or need for service, or that all members of a given minority group will automatically share this moral code.

In practice terms, the opportunity to examine the sense of choice experienced by carers should be taken during the initial assessment, where workers may need to prompt carers to clarify how far their caring represents to them a chosen or imposed activity. The care plan then provides the opportunity to he clear that any work to be undertaken meshes with the carers’ sense of choice.

Integrating with existing care

The emphasis on negotiated agreements helps to underline the need to explore with carers both the pattern of their caring day and the potential involvement of other carers. Care management dictates that services support rather than compete with informal care and this requires the worker to understand both the strength and the fragility of the caring network. It is important in this connection that any
services to be given are agreed in detail and written down: this allows for maximum clarity over what has been agreed and provides a reference point for future negotiations. Another consequence is that negotiations to introduce another carer or caring resource may need explicitly to recognise the carer's expertise and to allow the carer a controlling role. This requires that the worker obtains the agreement of others involved to allow the carer to retain primary control unless it is relinquished by negotiation. Any tendency for this to become inflexible can be controlled by regular review.

Carer and dependant: resolving different agendas

There will often be conflicts between client and carer, perhaps where the carer is seeking relief and the dependent person wishes arrangements to remain unchanged. At the extreme, there will be the outright conflict of carers seeking the client's admission to care against her or his wishes. Their different agendas may be very difficult to reconcile and both may be wanting the worker to take their 'side' and to legitimate their view. This is one of the key dilemmas for a practice model which emphasises the users rights to have their viewpoint respected, since the underlying consumerist model has no solution to the circumstance where one client's needs can be met only by giving them priority over those of another client.

The starting point for the care manager must be to view both the carer and the dependent person as adult clients with equal rights: workers have no right to decide between competing claims to have needs met, unless the legal framework is relevant (see next section). This does not mean, however, that workers stand by while clients are subject to undue pressure: workers have a role to explain to both clients that they each have the right to be treated as a competent decision-maker and that neither can impose a solution on the other. Subsequently, the care manager should highlight to each party areas of disagreement so that they are openly on the agenda. The legal framework may be of help if the dependent person attempts to block consideration of the carer's needs, since the Disabled Persons (Services, Consultation and Representation) Act 1986 requires that the worker make an assessment of the needs of carers of people with disability. Although it would be good practice to discuss this with the dependent person, s/he cannot insist that the worker should not consult the carer.

There will nevertheless be cases where no resolution of differing agendas is possible, and it will be important that the care manager resists the temptation to force a solution. The strategy should be to ensure that each party has as clear as possible an understanding of why a resolution is not possible. In doing so, there is a responsibility on the worker to ensure that each party is aware of the consequences of continued conflict, if necessary by using her/his knowledge of such circumstances to alert both clients to what the future is likely to hold. However, it should never become the worker's job to convince one party of the 'rightness' of another's view. The worker may well have strong advice to give, which may echo another's view, but it should be given as professional advice and not as added pressure to 'give in' to someone's view. This is particularly relevant where there is risk to an older person and the view is expressed that s/he doesn't have the right to take this risk. In this way, the worker reinforces each client as a competent adult. (The next section offers guidance in circumstances where an adult is mentally incompetent.)
Although this section has focused on conflicts between carer and dependant, there may also be conflicts between different carers. Essentially the same approach applies in which each person's view of the problems is taken as legitimate, but cannot form the basis for imposing a solution on others.

In trying to resolve differences between carers and clients, the care manager may eventually need to have recourse to the legal framework. The relevance of the Disabled Persons (Services, Consultation and Representation) Act 1986 has already been mentioned: under Section 8 the needs of someone caring for a person with disability must be assessed. If abuse between a carer and dependent person has been identified, the criminal law may be relevant in the same way as with other violence against the person. If the relationship between the carer and the dependent person involves emotional or physical risk and either is mentally disordered, then the compulsory treatment framework of the Mental Health Act 1983 should be considered.

The provisions to arrange compulsory treatment or Guardianship of a mentally disordered person in order to protect the health or safety of others could be brought into use. If this is under consideration, it would clearly be essential to bear in mind that it may be convenient to describe poor relationships in terms of mental disorder and that, generally speaking, the carer would have greater power to define the dependent person's behaviour as mental disorder than vice versa. Another difficult area is where a carer must act on behalf of a dependent person in financial matters. If the dependent person is mentally competent and can appoint another to act on his or her behalf, this is straightforward. But it is extremely difficult for a mentally incompetent person to appoint another to act for him or her: under current UK law, the power of attorney granted to another normally lapses upon the mental incompetence of the person who granted it. Although there is provision under the Enduring Powers of Attorney Act 1985 for the power to continue, this requires substantial planning before the onset of mental disorder and is not a widely used provision. In cases where there is mental disorder and substantial sums are involved, the Court of Protection may be relevant (Mental Health Act 1983). Workers should note that Guardianship under the Mental Health Act 1983 cannot be used to control the finances of a mentally disordered person.

Collaboration in service provision

Meeting the needs of carers and older people typically calls for the skills of several professions, and there is a clear role for the care manager in involving appropriate professionals and in helping clients make sense of who is offering what service. Carers in particular may have little sense of the fine divisions between nursing and domiciliary care, or between the counselling offered by a social worker and by a nurse, and the care manager has a function to act as a guide to the carer.

Within social services, assessment should have the aim of allowing the carers to give their account of their problems and difficulties on just one occasion, rather than having to repeat the account in full to each service provider. Some repetition will be inevitable, if only to allow the service-provider to understand how the service needs to be adapted to the individual's unique circumstances, but starting from scratch with each new worker can be not only tiring but
can also appear to require the carer to justify the service request repeatedly. The onus is on the care manager to produce an agreed statement of needs understandable to each new worker.

The care manager will have a specific function to be alert to the need for a wide range of services, some of which will be outside the care manager's professional ambit. Evidence from other studies suggests that workers tend to assess within their own service rather than across services. Those undertaking initial assessments should therefore be aware of the potential relevance of all the activities of social services (social work, occupational therapy, domiciliary care and residential and day care), of the housing department and of the health service, and should actively cross-refer. The care manager must have a good working knowledge of others' practice, intake methods and possible waiting lists. The object is not that the care manager assesses on behalf of others, but rather that the care manager is able to know when cross-referral would be appropriate, to give the clients accurate information about the service and to be confident that an assessment will be made within a specified period. Co-ordinating the input of workers outside social services may require the care manager to undertake some advocacy on the carer's behalf. Health or housing workers may have very different ethics of practice, some of which may run counter to the underlying values of care management: workers will need to explain their own methods of practice to colleagues and attempt to get them to collaborate with existing agreements and style of work. The care manager will also have a role in helping carers assess the relevance of services offered by other service-providers.

If care management is to be enacted in such a way as to enhance the rights of clients as citizens, rather than promoting a false consumerism, the values, skills and techniques of social work will provide a firm foundation. In working with carers, however, this foundation needs to be extended to develop a practice which recognises the ambivalent feelings of carers, creates an informed and participating client, reinforces choice in a context of obligation, resolves conflict between carer and client in ways which safeguard the rights of each and, lastly, co-ordinates the services of a wide variety of providers to the benefit of the client.

Acknowledgements

Social Work in Partnership is a three and a half year research and development project (1988-91) funded by the Joseph Rowntree Foundation and undertaken by the Universities of Bradford and Sheffield in conjunction with social services departments in Bradford, Doncaster, Wandsworth and Westminster.

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