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Working with family carers: towards a partnership approach

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Introduction

The use of the term 'family (informal) carer', as it is currently conceptualized, is recent and is largely the product of increased attention in the academic and policy literature over the last two decades.^{1,2} Despite their fairly late arrival on the scene, family carers now occupy centre stage in UK government policy, having been described by the Prime Minister, Tony Blair, as the 'unsung heroes' of British life, who are essential to the fabric and character of Britain.³ Such recognition stems from the growing realization that family carers are the lynchpin of community care,⁴⁻⁶ providing 80% of all the care needed⁷ at an estimated saving to the UK government of some £40 billion annually.⁸

Consequently, responding to carers' needs is a primary objective of health and social policy in the UK,^{9,10} with the aim of enabling carers to continue to care for as long as they, or the service user, wishes, without detriment to the carers' health and inclusion in society.^{3,9} In meeting this aim, recent policy rhetoric promotes an empowerment and partnership model,^{3,9,10} and while prime responsibility for meeting carers' needs rests with Local Authority Social Services, the Carers' National Strategy³ charges all organizations and individuals involved in the welfare services with assessing and responding to carers' needs.

The purpose of this review is to consider the implications of implementing a partnership approach with family carers within a rehabilitative context, with the main emphasis placed on carers new to their role. The limitations of exist-

ing practice are identified and suggestions for improvement made.

Working with family carers: the reality behind the rhetoric

The importance of family support is widely recognized in the rehabilitation literature¹¹⁻¹³ and involving carers has been actively promoted for some time in a range of disparate conditions such as multiple sclerosis,¹⁴⁻¹⁸ spinal injury,¹⁹⁻²¹ myocardial infarction²²⁻²⁴ and stroke.²⁵⁻²⁸

Notwithstanding such enthusiastic endorsements, it appears that families are rarely as fully involved in the rehabilitative process as they might be, and indeed are often marginalized.²⁹⁻³⁵ This situation is not unique to rehabilitation, but rather reflects the general failure to actively engage with family carers across the spectrum of health and social services. To understand fully how the present position developed, it is necessary to explore the historical context briefly.

The relative failure to support family carers adequately is paradoxical for, as noted above, community care *is* family care, with the presence of a supportive family member, particularly a spouse or partner, often being essential to maintaining morale and positive adaptation in disabled people.³⁶⁻⁴⁰ However, policy initiatives to support family carers have, until the recent introduction of the Carers' (Recognition and Services) Act (1995)⁴¹ been largely implicit and poorly developed.^{42,43} Consequently, the underlying rationale for supporting carers has been inadequately conceptualized, and services generally fail to respond to carers' changing needs over time.⁴³ This is particularly noticeable at key transition points, for example, when carers take on their role for the first time (often following a period of hospitalization) or alternatively, when they relinquish

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their role when the person cared for enters a residential or nursing home. The 'taking it on' stage of the caregiving career⁴³ is of particular relevance in the context of rehabilitation.

Until recently, little attention has been given to the way that carers 'take on' their role,⁴⁴⁻⁴⁶ but studies suggest that they usually do so without having exercised a genuine choice,⁴⁷ often being unaware of the extent and nature of their caring responsibilities.⁴⁸⁻⁵² There is little professional input at this time and carers are rarely fully prepared, either physically or psychologically, for their role, frequently lacking the necessary knowledge and skills.^{46,53-56} Subsequently, carers develop expertise largely by a process of trial and error, a situation which has been described as 'flailing about'.⁴⁶ Carers have a particular need for information which is often not met⁵⁷ and, according to Strauss *et al.*,⁵⁸ they are at the 'bottom of the institutional hierarchy of information'. If the needs of carers are assessed at all, they are often 'tacked on' at the end of the rehabilitation process,⁵⁹ reinforcing the suggestion of Waters and Luker⁶⁰ that carers do not figure prominently until the point of discharge.

This is unfortunate, as there is evidence to suggest that carers who are adequately prepared for their role in terms of possessing the relevant knowledge and skills not only provide better care, but also have improved physical and emotional health.^{54,61}

This lack of attention to carers' needs is largely attributable to the fact that carers occupy an ambiguous position in the welfare system, with assessment being based on a number of implicit and ill-defined models.⁴² The most common model is to see the carer as a resource, when the rationale for interventions is to maintain carers in their role. A further model regards carers as co-workers, giving greater attention to carers' individual needs. However, maintaining the caring role is still the primary motivation. Thirdly, carers can be seen as co-clients when it is difficult to determine who is the user. Finally, the aim may be for services to supercede (replace) the carer either in their own interests or those of the person cared for.

Nolan *et al.*⁴³ argue that although these models may reflect the current situation, none is entirely adequate. 'Carers as resources', whilst undeniably the most prevalent, is essentially exploitative and not supportable on moral, ethical or even prag-

matic grounds. 'Carers as co-workers' is possibly the most appropriate, but as it is still basically motivated by instrumental aims,⁴² the requisite balance is not achieved. 'Carers as co-clients' and 'the superceded carer' may be relevant in certain circumstances, but neither model is satisfactory as the primary basis for determining relationships between family and professional carers. Currently, a partnership and empowerment model of working is being actively promoted by both policy makers^{3,9,10} and academics.^{7,62-64} If this is to be achieved, there is a need for considerable remedial action, requiring among other things, a consensus on the nature and purpose of carer support and the development of practical approaches to realizing a partnership model which responds to carers' changing needs over time.

Widespread concern about the plight of carers, coupled with consistent lobbying from various pressure groups, resulted in the introduction of the Carers' (Recognition and Services) Act.⁴¹ This, in principle at least, affords family members 'providing, or intending to provide' substantial care on a regular basis, a statutory right to an assessment of their needs (see Wood and Watson⁶⁴ for a good, non-technical account of the Act). Assessment lies at the heart of the Act and is seen as the key to appropriate and sensitive support.⁶⁵ However, several major studies conducted over the last four years have demonstrated that the Carers' Act has had a very limited impact and has been introduced in an arbitrary and piecemeal fashion. Consequently, assessment is largely a 'matter of chance',⁶⁶ with limited evidence of a separate assessment of carers' needs,^{2,6,67} and little consistency in who gets an assessment.⁶ Furthermore, even when their views are sought, carers frequently report that they are not listened to and that their input is rarely acted upon.^{4,68} Therefore, despite the avowed intentions of both the Carers' Act and the subsequent Carers' National Strategy,³ it appears that a user perspective continues to dominate,⁶⁹ with the rights of carers still not being embedded within the mainstream thinking of service agencies.⁶

Many of the above difficulties are exacerbated at the time of hospital discharge, when major limitations in the way that the Carers' Act has been implemented become apparent.^{5,68-69} Carers still report feeling ill-prepared for their role, lacking essential information and basic caring skills.^{4,5,68-69} Henwood,⁶⁸ for example, found that

only 38% of carers considered that their needs had been assessed, 40% felt unprepared for their caring role at the time of discharge, 72% had not been given a discharge plan and 70% had not been informed of other potential care options. These findings are a cause for considerable concern, as not only do they raise questions about the ability of new carers to provide support that is safe and competent, but they also violate one of the fundamental principles of the Carers' National Strategy, respecting an individual's right to opt not to care.³ Whilst the majority of family members are usually only too willing to care, many feel apprehensive about their ability to care adequately.⁷⁰ Conversely, there are some family members who may not wish to, and indeed should not be encouraged to become carers.⁴³ Exercising a choice not to care is, however, increasingly difficult due to the strong moral imperative to care, the implicit pressure that professionals often place on family carers,⁶⁴ the increasingly rapid throughput from hospital settings⁷¹⁻⁷² and carers' lack of knowledge of alternative arrangements.⁶⁸ As Wood and Watson⁶⁴ note, some family members need active support in their decision not to care. Fortunately most wish to care, but it is essential that they are adequately prepared to do so.^{4,5,62,68,73} This means implementing a more holistic model of carer support, thinking clearly about intended goals and actively promoting a more equitable relationship.

The goals and purpose of carer support

As Twigg and Atkin⁴² argue, the service system views carers largely as resources and, as a consequence, support mechanisms have been inadequate

quately developed, focusing mainly on instrumental needs.^{6,43} Askham,⁶² summarizing a symposium on supporting family carers held at the 1997 World Congress of Gerontology, called for a more catholic approach which viewed carer support as any intervention which assists carers to:

- take up (or not take up) the caring role;
- continue in the caring role;
- give up the caring role.

However, to date, the main aim of the limited support that carers receive has been to ensure that they continue in their role, with little attention given as to how they take up, or relinquish, caring.^{43,74,75} A number of authors have suggested a range of goals for carer support (see Table 1) but in relation to adopting the caregiving role, two aims appear pre-eminent: to enable family members to exercise a genuinely informed choice as to whether to become a carer or not; to ensure that those who opt to care are adequately supported and fully prepared from an early stage, and that they receive ongoing support sensitive to the changing demands they face.

Many commentators focus on the importance of carers having the necessary information, knowledge and skills to provide appropriate and safe support.^{5,63,69,70,73,76-78} The challenges this poses should not be underestimated and the impact of resource constraints and pressure for rapid hospital discharge must be fully acknowledged. However, notwithstanding these difficulties, for progress to be made there needs to be a cognitive shift in the way that professionals perceive carers.

Interventions still focus predominantly on the patient/client⁶⁹ and, while many might argue that

Table 1. *Typology of Carer Support*

Askham 1998	Schmall 1997	Schumacher <i>et al</i> 1998
<ul style="list-style-type: none"> • Training and preparation • Equipment and technical support • Empowered to use services • Information • Direct help • Respite care • Financial support • Relaxation services 	<ul style="list-style-type: none"> • Knowledge of medical condition • Coping skills • Family/relationship issues • Communication with cared-for people • Community services • Dealing with emotions • Long-term planning 	<ul style="list-style-type: none"> • Knowledge and skills about condition • Providing technical care safely • Meeting needs safely • Attending to social care • Attending to personal care

this is legitimate, there is a greater need to ‘think carer’,⁶⁴ and to provide information and support to carers proactively rather than waiting until it is sought.⁷⁸ This rarely happens as relatively little thought has been given to the role of families in hospital, other than as visitors and occasional helpers,^{72,79} but there is evidence to suggest that an experienced and expert carer can be threatening to some professionals.⁷⁹ Allen⁷⁹ argues that because both professionals and carers claim to possess expert knowledge of the patients’ needs, tensions can arise. Rather than conflict, what is required is recognition of differing forms of expertise, with Harvath *et al.*⁵⁴ suggesting a balance between what they call ‘local’ and ‘cosmopolitan’ knowledge. Local knowledge refers to a carers’ unique insight into the experiential world of the patient, with cosmopolitan knowledge representing expertise of a more technical and general nature, usually held by professionals. However, a skilful blending of the two is essential to ensure optimum care.⁵⁴ Achieving this synthesis requires a different way of working, a fact which is increasingly recognized in a range of disciplines.

For example, the therapy literature has paid growing attention in recent years to the interaction between therapists and family carers, with a number of useful models emerging. Hasselkus,⁸⁰ for instance, suggests that in the acute stages of an illness, the professional assumes the lead but that, as discharge approaches, carers become far more actively involved and that, as they gain sufficient confidence and expertise, the role of the professional should shift to that of facilitator and enabler. Brown *et al.*⁸¹ also provide a comprehensive framework delineating the potential levels of interaction between family and professional carers as follows:

- No involvement relationships based on a traditional medical model with a focus on the patient only
- Family as informant a passive role for the family, purely as a source of information
- Family as therapy assistant traditional role in rehabilitation where the family is seen as a resource useful in facilitating the rehabilitation process

- Family as co-client with the family playing a much more active role in goal planning, but not a full member of the multidisciplinary team
- Family as collaborator included as a full member of the multidisciplinary team
- Family as director where the family takes the lead role, with the OT acting as a resource and facilitator

It is models such as these that require further elaboration and testing in a practice context, in order to determine the most appropriate relationship at a given point in time.

One approach that broadly reflects the ethos of empowerment and partnership is the ‘carers-as-experts’ model,⁴³ which is based on the following principles:

- The primary purpose of the ‘carers-as-experts’ approach is to help carers to attain the necessary competencies, skills and resources to provide care of good quality without detriment to their own health. In this context, helping a carer not to take up or to give up care is a legitimate aim.
- It is essential to consider both a carer’s willingness and ability to care. Some family members may not really want to care but may feel obliged to do so. Conversely, while many family members may be willing to care, they may lack the necessary skills and abilities.
- A comprehensive assessment will include not only the difficulties and demands of caring, but also the quality of past and present relationships, the satisfactions or rewards of caring and the range of coping and other resources, for example, income, housing and social support that carers can draw upon.
- The stresses or difficulties of caring are best understood from a subjective rather than an objective perspective, with the circumstances of care being less important than a carer’s perception of them.

‘Carers as experts’ recognizes the changing demands of care and that skills and expertise develop over time. A temporal dimension is therefore crucial, and this suggests varying degrees of ‘partnership’. For carers new to their role, pro-

professional carers are likely to be 'senior partners' in possession of important knowledge of a 'cosmopolitan nature', which is needed to help the carer understand the demands they are likely to face. Conversely, experienced carers, many of whom will have learned their skills by trial and error, often have a far better grasp of the situation than professionals, and acknowledgement of this is vital to a partnership approach. At a later stage, the balance may shift again so, for example, if it is necessary to choose a nursing home, carers may go back to a 'novice' stage, probably never having had to select a home before. They will therefore need additional help and support. Recognizing and achieving such a balance is the crux of the 'carers-as-experts' model.

Accepting a 'carers-as-experts' approach can be difficult for professionals as in many ways it challenges their traditional power base; that is the possession of unique knowledge.⁸² On the other hand it can be liberating and open the way for new, and more appropriate, relationships. Schumacher *et al.*⁷⁰ argue that if the aim is to help carers to 'care well', then we need a better understanding of concepts such as mastery, competence and self-efficacy, and how carers can be helped to acquire them, and also to recognize the power differentials that exist between family and formal carers and that mediation and negotiation are essential components of mutually supportive relationships.^{83,84}

Conclusions

Most practitioners working in a rehabilitative context would fully endorse the importance of supporting family carers and on an individual basis many probably feel that they already do so. However, the bulk of the empirical literature suggests otherwise, and whilst there are undoubtedly pockets of good practice, much needs to be done if genuine partnerships are to be created. At the very least there is a need to 'think carer'⁶⁴ and to be proactive in offering sufficient information and training, so that family members who enter a caring role have exercised a fully informed choice and feel confident in their ability to provide the standard of care that they would wish.

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