



‘Care’: Research, Policy and Practice Briefing Paper 1

In post-industrial societies many issues about the delivery and resourcing of care remain unresolved. Debates on care have highlighted the growing tensions concerning the links between care services and economic participation, and the provision of formal and informal care. Attempts to develop policies that consider caring needs of adults and older relatives have had limited success. Services appear over-stretched, with demographic trends indicating that tensions around the nature, organisation and resourcing of care services will remain centre stage in social and public policies and political debates.

The aims of the seminar series include:

- a review of new theoretical work and empirical studies on the various aspects of care over the lifecourse and across nations.
- the generation of debates on how to develop, implement and evaluate policies and practice. These debates will involve policy makers, researchers, practitioners and representatives from relevant organisations. Further, by ensuring that we bring together those at earlier and later stages of their careers we can share experiences and ideas.
- a range of outputs, including a website, briefing papers, articles and an edited book.
- the establishment of networks and support for continued developments within a lifecourse perspective. The topic of care is of relevance to the quality of life and social inclusion of those in need and/ or in receipt of care, alongside those providing and organising care.

Seminar 1: Professional Discourses and Practices of Care

The starting point for this seminar is contemporary evidence on caring services and professional perspectives on the changing needs for care, and the professional and resource implications of these shifts. The values placed upon work, and care, are ‘still determined by who does them and where they are located’ (Land, 1999: 28). Given changes in morbidity and demography, in particular changing trends in chronic illness and longevity, what is the potential to shift research, and policy debates and practice, to consider the range of care needs and issues? Can discourses and practices acknowledge the multiplicity of demands that arise from the simple desire to ensure that care needs are met in a quality and cost effective manner? And what are the issues in training, professional development and practices ‘to meet these ends’? In this seminar the inter-face and inter-weaving of paid and unpaid care will be explored.

The Interface of Formal and Informal Care

Primary care in transition: a professional perspective on changing practices

Lewis Ritchie, Mackenzie Professor of General Practice, University of Aberdeen

Over the last twenty years general practice has undergone remarkable and relentless change as part of an increased prominence for primary care services. The patient consultation remains at the hub of clinical practice but is now being delivered in different ways, in new settings and by a growing team of health professionals. Primary care in the UK is multiprofessional, multidimensional and evolving rapidly.

Primary care is the usual point of first contact into the health care system and its remit has been defined as the provision of comprehensive, coordinated, continuous, accessible and high quality care. In the UK, 85% of all episodes of ill health are self-treated. Of the remainder, 90% are treated by primary care and 10% (or ~1% of the total) by secondary care. By contrast, self-care accounts for 5%, primary care 30% and secondary care 65% of the total costs.

Many of the observed changes in resources, workforce and patterns of primary care activity have been clearly influenced by government policy – for example the dramatic increase in GP practice nurses. Delegation and role substitution will continue for many of the current clinical activities in primary care with a differing skill-mix, including nurses, pharmacists and allied health professionals. Government policies have influenced change, but are not sufficient to explain away all of the observed differences. Other significant drivers have been: a rapidly ageing population, with increasing co-morbidity, the availability of new treatments and technologies, a heightened awareness of health promotion and the pursuit of unmet need. In turn, all of these are underpinned by increasing patient expectations. The crucial role and aspirations of health professionals in determining the changing shape and substance of primary care should not be overlooked.

In this seminar, the growing importance and ramifications of patient-centred care will be discussed, including the potential tensions between the community dimension of primary care and the needs of individual patients. Key enablers and constraints for progress will be outlined, including universal electronic patients and effective partnerships between patients and social, health, and voluntary care providers.

What are patient centred outcomes? A review of the literature

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There is increasing emphasis placed upon the development of patient centred care and involving patients and members of the public in health care. There is a large literature on the development and use of a range of different outcome measures, often termed 'subjective measures', but the results obtained when using these instruments may not actually reflect what the patient actually thinks. A number of authors have claimed to take the patient view into consideration, but the terminology used is very confusing and there are no standard definitions of terms used or concepts being measured.

This study reviewed the published literature to identify how and when authors were using the terms 'patient centred', 'patient based' etc, to see if trends in the existing literature would lead to suitable definitions of terms. Eighty-three papers were uncovered and sorted into three categories, based upon how the authors involved patients. Authors used a wide range of terminology, with no consistency whether the main focus of the paper was using patients as sources of data (35 papers), measuring quality of life (21 papers) or where authors stated that they were identifying what was important to patients (27 papers). Additionally there was confusion about what was actually being measured; many authors used health status, quality of life and patient centred outcomes interchangeably. There was a focus on the design and evaluation of standardised measures and less attention placed on the individual and their response. For outcome measurement to become patient centred, measurement needs to be iterative and the results fed back into the subsequent clinical processes. A definition of patient centred outcomes is proposed to stimulate debate and as the basis for future research

Psychotherapies, care and relationships

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Counselling and other psychotherapies (including psychoanalysis, arts therapies, family therapy etc.) have become increasingly widely used as responses to a diverse array of issues and conditions, from mental health problems, through work-related stress, to the impacts of ordinary life events such as bereavement and relationship difficulties. These practices draw on a variety of theories to conceptualise what they do, but common to all is the idea that the relationship between practitioner and recipient is of fundamental importance as both the medium and the substance of therapeutic work. Relationships are integral to human life, including 'ordinary' and 'professionalised' care, a point that has certainly not escaped the attention of psychotherapy practitioners. Thus, in addition to promoting what they do as distinctive practices in their own right, proponents have sought to influence and inform how people involved in numerous other fields, and the general public, conduct and conceptualise interpersonal relationships.

The emphasis that psychotherapies attach to relationships is often presented and understood in terms of the need to distinguish and separate one's self and one's own needs from those of others. In the context of the rise of psychotherapies and their wider influence, this generates concern about their role in the 'psychologization' of social and political life, the valorisation of self-oriented consumerism, and the consequent devaluing of care. Notwithstanding such risks, and drawing on some of the theoretical formulations advanced by practitioners, I will advance a more radically relational interpretation of psychotherapies. In so doing, I will argue that psychotherapies offer potentially important resources for debates about care, capable of facilitating politically and practically useful and respectful links between professional and lay practices.

Disability: Research, Theory and Practice

Exploring the ethics of care through the implementation of direct payments: findings from across the UK.

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The implementation of direct payments across the UK has been met with varied success over the past eight years, with availability to only a small minority of disabled people. Campaigning from the Disabled People's Movement from the late 1980s centred on the need to replace many existing structures of social service provision by promoting personal assistance alternatives through cash payments. Although initially rejected by the UK government, legislation for direct payments eventually emerged on the statute. In April 1997, this came into force as enabling legislation and then was shifted to a mandatory requirement in 2003.

Clearly, the original goals of the disability movement have been important in terms of securing policy change both at local and central government levels. However, implementation has also been caught up in other competing agendas whereby policy across the UK has been strongly linked with wider changes in community care and the promotion of mixed economies of provision within these structures. Indeed, although some local authority/health and social service trust planners have worked with disabled people to develop independent living options through their schemes, others have only enabled restricted access and limited payment use within a rigidly defined notion of personal care. It is therefore clear that the availability and coverage of direct payments is influenced by several factors. These include locality within the UK, local planners' and councilor's commitment to more traditional modes of service provision, cash limited budgets, contracting systems within social care services, trade union concerns and restrictive assessment systems.

Drawing on data from a two year UK comparative study of direct payments funded by the Economic and Social Research Council, this paper explores the competing discourses impacting on local authority/health and social service trust service development. This raises a number of questions surrounding the ethics of care and their intersection with direct payments as an exemplar of service provision.

Problems and solutions: perspectives on 'care' for people living with disability and chronic illness in medical sociology and disability studies.

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This paper examines the contrasting ways in which writers associated with two academic disciplines - medical sociology and disability studies – have approached 'care needs' and 'care provision' associated with chronic illness and disability. Though sociology is the parent discipline in both cases, medical sociologists and disability studies scholars formulate 'the problem of care' very differently, and seek incompatible solutions.

In *medical sociology*, the older discipline, chronic illnesses and other impairments are seen to cause disability – that is, limitations in 'normal' functioning and restrictions in social activity. Disability brings dependency (to varying degrees) and generates individual care needs in excess of those expected given a person's age. Thus the 'problem' is that chronic illness and disability create a significant demand for care. Academics study and critique the 'social solutions' that are offered in contemporary society in the form of formal and informal care services. Feminist writers, for example, have critiqued the shift in the 'burden' of care from state services on to the shoulders of unpaid female carers; the gendered nature of care together with the 'deviant' status of people living with chronic illness and disability have meant that carers and care work are accorded low social status. Others focus on 'unmet needs' and critique the social, political and cultural constraints that place limits on the volume and quality of formal care services.

In *disability studies*, contemporary social arrangements and cultural practices are understood to be the source of disability – a social reaction that results in the marginalisation and oppression of people with impairments. In the last two centuries, the provision of institutionalised or community-based 'care' in society is thought to have played a key role in the oppression of disabled people. Thus 'the problem' is 'care' itself – especially systems of formal care. Health and social care professionals and workers have controlled the lives disabled people and created dependency. Drawing inspiration from disabled people's struggles for self-determination, writers in disability studies see the dismantling of contemporary systems of formal and informal 'care' as the solution - to be replaced by schemes for independent living and personal assistance.

Theory and practice with reference to disability

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Professional policy and practice has taken insufficient account of ideas and perspectives on disability from disabled people themselves. Although there has been some change with regard to this in recent years, Disability Studies is still marginalised in the education of health, social care and education professionals and practitioners. Roles are slow to change and inertia within institutions persists.

In this paper Sally French will draw upon her experience of teaching social science to a variety of health and social care students to illustrate the difficulty of influencing their ideas and practice. The possibility that 'a little knowledge is a dangerous thing', inasmuch as complex issues such as the social model of disability have very limited space in the curriculum and can easily be distorted, will be discussed.

Findings from various pieces of small-scale qualitative research will be drawn upon to illustrate the conflict between the theories and models of disability that professionals use in their practice and those of disabled people themselves. This will include research on user involvement in residential homes, disabled people's experiences of physiotherapy and occupational therapy, disabled people's experiences of housing, disabled people's and health professionals conflicting ideas about health promotion and the experiences of educational inclusion by visually impaired young people. It will be argued that the voices of disabled people need to be central to the education and practice of all workers in health, social care and educational settings if meaningful change is to take place.

This is the first in a three part series of briefing papers produced in this ESRC seminar series. Please contact Dr Arbory McNulty, Glasgow Caledonian University (a.mcnulty@gcal.ac.uk, 0141 331 8503) for more details.