Working with carers in the next decade: the challenges

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Unpaid carers are the backbone of community care, therefore supporting unpaid carers is essential to the success of community care (Aldred and Gott 2005). The need for the National Health Service (NHS) to support carers is recognised in key health policy documents in both Scotland and the rest of the UK (Scottish Government (SG), 2007; Department of Health (DH), 2008a). These share an emphasis on shifting from hospital-based care reflecting reactive management, to preventative, anticipatory care alongside the need to work with carers as partners in caregiving. It is estimated that unpaid carers provide £87 billion worth of care, which is more than total UK Government spending on the NHS, and is several times the spending on social services (Buckner and Yeandle, 2007). When a monetary value is placed on the contribution of carers to the economy, it is clear that without carers, the NHS and social care systems could not survive. Therefore, the role of, and support for, unpaid carers have become central to the debates surrounding community care across the UK. The health and welfare of the patient and their carer are closely linked, although professionals have to recognize that, while both will have needs, they may not always be the same and indeed may sometimes be in conflict (Williams and Robinson, 2001).

Social exclusion of carers

Across the UK policy documents highlight the needs of carers and explicitly state that carers' health is a public health issue. Glendinning (2009) found that the provision of regular and substantial amounts of care to an elderly or disabled relative or friend is linked to a reduction in participation in the labour market, poverty and negative psychological and physical health. There is consistent evidence of the social exclusion of carers (Carers Wales, 2006; Carers Northern Ireland, 2008). Additionally, there is increasing evidence of the invisible, emotional consequences of caring (Cheung and Hocking, 2004; Jarvis and McIntosh, 2007) which may, over time, affect a carer's ability or willingness to continue to support the person they care for. Poor health in carers (particularly those caring for an older person) can often, in itself, lead to greater use of health services (Hirst, 2005). Despite this, many health professionals continue to focus only on the service user and neglect carer issues (Hervey and Ramsay, 2004).

A shift towards outcomes focus

Within current financial constraints, the level of funding that has been awarded to health over recent years will no longer be available and it is going to be increasingly important to ensure that users and carers have the right solutions rather than what a service has historically offered (Appleby, 2009). The measuring of public services, both health and social care (DH, 2005) are increasingly moving from that of service inputs to an outcomes-based approach to care. Glendinning et al (2008: p55) suggest that:

'outcomes are defined as the impact, effect or consequence of a service or policy. Outcomes-focused services are therefore those that meet the goals, aspirations or priorities of individual service users.'

Outcomes are therefore not just about measures of safety or clinical effectiveness but also about patients' and carers' views on the quality of their experience of receiving health care. This shifts the focus away from 'the service' to what the service user and carer say they need the service to achieve.

Nurses would all assert that they are patient or client centred and, generally, clients and their unpaid carers have positive experiences of community nursing services (Kennedy et al, 2009). However, there is an abundance of literature, for example Bauer et al (2009) and Power (2009), that suggests that services continue to fail to provide what users and carers say they want and need. In the focus groups undertaken as part of Scotland's review of nursing in the community (Jarvis, 2007), carers identified their needs as:

- Appropriate nursing services when they need them
- A nurse who helps them to co-ordinate care
- Consistency in the advice offered to them by nurses
- Nurses who identify carers early in their caring 'career' and signpost them to appropriate support
- Care provided by competent, appropriate practitioners who know them and the communities they live in
- Nurses who support them by working with them
- Nurses with excellent communication and relationship skills.

ABSTRACT

This paper outlines two challenges to community nurses as they work with unpaid carers. These reflect a changing culture in the way that health care will be delivered in the coming decade. The first of these challenges is a shift towards focusing on outcomes for both service users and adult carers. Outcomes evidence the impact a service has on a person's life. The second is the increasing focus on the concept of carers as partners in care.

KEY WORDS

Carers ◆ Partnership ◆ Service ◆ Outcomes

As health funding is inevitably going to be squeezed over the next few years, people will increasingly be looking for information on both effectiveness and quality of care.

Patient-reported outcome data

Lord Darzi points out that 'while a surgeon may deem a hip replacement successful because the procedure has been performed perfectly on the day, the patient will rightly disagree if they are still in pain and continue to have a poor quality of life some months down the line' (quoted in Nursing Times, 2009). From April 2009, in England and Wales, as part of the NHS Standard Contract (DH, 2008b), there is now a requirement for all primary care trusts and hospitals, including independent sector organizations supplying care to NHS patients, to collect data on patient-reported outcome data (PROMs). Initially the data will be collected for four areas – surgery to hips, knees, hernias and varicose veins. PROMs employ short, self-completed questionnaires which measure the patient's health status or health-related quality of life (HRQoL) at a single point in time which can be repeated to get a measure of the impact of health care interventions. A number of PROMs already exist, such as the EQ5D, which is a standardised instrument for use as a measure of health outcome, and the longer SF-36, which is an instrument used to assess multidimensional HRQoL. Other instruments are now in development but, arguably, will be more difficult to develop for long term conditions or mental illness rather than more discrete episodes of care such as a knee replacement (Appleby 2009).

Carer outcomes

Although much of the focus has been on patient outcomes, there is also a drive to explore outcomes for carers. In Edinburgh, VOCAL (Voice of Carers Across Lothian) has implemented an outcomes approach and agreed four key carer outcomes which can often be themed. These are that carers will have:
- Increased self-esteem and increased confidence in managing their caring role
- Improved physical and mental wellbeing
- Greater confidence in their ability to shape the services and support available to them
- More confidence in their ability to combine caring responsibilities with work, social and learning opportunities.

Carer outcomes have been developed in Scotland in conjunction with service user outcomes by the Government's Joint Improvement Team (2009). The challenge is to ensure that a focus on outcomes is more than simply a 'tick-box' exercise and a change in the use of language, but properly reflects moving away from concentrating on problems to what it is the person wants to achieve. *Table 1* contrasts the current service led approach to a more outcomes-focused approach.

To date, there is limited research evidence of how well this is working for service users, let alone carers, apart from the work of Glendinning et al's (2008) early investigations that explores the development of outcomes with older adults using social services. However, it is suggested that the difficulties identified are likely to be similar for both service users as well as for carers. Glendinning et al (2006) identify a number of barriers and particularly highlighted the assessment process within the Single Assessment Process (Single Shared Assessment in Scotland) continuing to be service led and devoid of choice. They found that assessments often emphasized dependency or overlooked psychological and emotional needs and did not challenge low expectations of services or the limited range of help older people think it is legitimate to request. It is, of course, recognized that the assessment process is important in establishing eligibility and is used as a way of rationing resources (Ellis, 1993). However, it is also acknowledged that staff want to move from a perceived bureaucratic model to spend more time with people but still find it difficult to shift from a deficit or dependency approach to one which is not service led.

Underpinning many of the outcomes is the concept of carers as key partners in providing care.

Carers as key partners

Carers as partners in care is an underpinning principle of many of the policy documents across the UK (SG, 2007; DH, 2008a). However, if true partnership is to come about, there needs to be a radical shift in the relationship between the professionals and the carer where there is an inherent tension in terms of the status and power imbalance. Arskey and Glendinning (2007: p55), using Twigg and Atkin's (1994) seminal typology of carer-service provider suggest that service providers continue:

'to regard carers instrumentally, as resources or co-workers, but with some concern for carers' well-being in order to sustain their care-giving capacity.'

Clements (2004) goes further and suggests that while it is now no longer acceptable to talk about 'the elderly' or 'the handicapped' it remains acceptable to talk about a 'carer', with the term 'informal' carer often being used, with the implicit assumption 'that caring is considered an elective and noble quality' and carers as 'bearing heroic burdens' (p6). Gray et al (2009:p128) quote a nurse who says:

'If you're a carer for a disabled child, if you're a carer for somebody with a learning disability, if you're a carer for someone with cancer, the instinctive reaction is 'Oh, you must be an angel, you're having to deal with that, poor thing', you know, it's a tragedy.'

Clements (2004) suggests that the term 'carer' implies that they are not seen as decision makers, but as people who must defer to experts (Gillies, 2000). Allen (2000: p155), referring to a ward setting, illustrates how nurses found the expert carer:

'presented important challenges to the ward nurses' ability to control the work, their claims to expertise and their licence to define standards of care.'

This resulted in fear, feelings of exposure and undermined

Table 1. Comparing a service-led to an outcomes-focused approach

Service led	Outcomes focused
Current tools encourage information gathering through standardized question and answer approaches to assessment, support planning and review	Decision making informed by semi-structured conversations with individuals in assessment, support planning and review
Tick box approach to assessment	Analytical skills involved in assessment
The person's views may be included in decision making	The person's views/preferences are central to decision making
The person is viewed as a client, service user or patient	The person is a citizen with rights and responsibilities
Where needs link to strict eligibility criteria, the assessor is required to maximize individual difficulties to access services	Involves consideration of difficulties, limitations and aspirations or goals. The priority is to identify what to work towards
Where needs are tied to eligibility criteria, preventive work with people with low level needs may be excluded	Outcomes allow preventive work to take place while services and resources are prioritized for those most in need
Focusing exclusively on deficits and difficulties, and how needs are to be met, results in a focus on tasks and in services which do things **to** people	By focusing on strengths, capacities and goals, while mindful of limitations, the role of the person is maximized. Services do things **with** people
Where outcomes are identified, these tend to be professional or organizational outcomes, e.g. delayed discharge	Outcomes are what matter to the person, though often consistent with professional and organizational outcomes, e.g. being able to get out and about

Source: Abbreviated from Joint Improvement Team, 2009

their sense of professional status, occupational identity and expertise. Clements argues that in the same way that there have been challenges regarding the social exclusion of disabled people, there needs to be an equivalent move to ensure that carers are similarly not excluded.

In preliminary research undertaken to inform the DH Caring with Confidence programme (Caring with Confidence, 2009) societal attitudes towards caring were explored which may impact on people's experience of being a carer. They describe four categories outlined in *Table 2*.

Relevance to clinical practice

Across the UK it is recognized that preventative, anticipatory care, rather than reactive management, should be the aim of care delivery. The NHS needs to work with both statutory and non-statutory agencies and with patients and carers to provide continuous, anticipatory care to ensure that, where possible, health-care crises can be prevented. This will not happen without effective and sustained support of unpaid carers. However, with a shift towards outcome-focused care, if carers are to become partners in the delivery of care, there may be some tensions that nurses, and other health professionals, will need to resolve. Acknowledging and accepting the outcomes articulated by the user or carer may indeed pose challenges for nurses, particularly if those choices are thought likely to cause a poor health outcome (Hobden, 2006).

Millard et al (2006) point out that although there is an implicit assumption that community nurses, because they work in people's homes, involve patients in their care and treatment decisions, there are varying levels of client involvement in the decision making. In their observational study they found that involvement in decision making varied considerably from 'completely involving' to 'overt non-involving'. If there is evidence that professionals find it difficult to alter the way they relate to patients, there are

corresponding research findings that carers' dealings with professionals can be problematic. Ostman and Kjellin (2002) found that relatives who acted as carers had deep-seated feelings of inferiority to staff. Todd and Jones (2003), in their study of mothers of young people with intellectual disabilities, found that although they embraced the role of advocate for their children, they were much more hesitant and reluctant to raise any needs and aspirations concerning their own lives. They feared that in articulating these, they could be seen as 'selfish mothers'.

The 'Caring with Confidence' programmes (DH, 2008c) for carers have been devised as a way of empowering and enabling both patients and carers, acknowledging the inherent power imbalance. However, Kelly et al's (2009) evaluation of the Edinburgh programme found that although participants indicated that they felt more confident talking with care professionals about what they needed, there was not a corresponding change in their ability to work with care professionals as a key partner. Carers reported that they were better able to talk with professionals, they felt better informed and more confident in their abilities, but they did not feel any more able to work with professionals as partners. Though on one level this may seem a contradiction, on another there is a plausible explanation. Working with care professionals as a partner is transactional. It takes more than one person to make a partnership. Therefore, just because one side of the relationship is stronger that does not mean there will necessarily be a change in the other partner.

Conclusion

Many unpaid carers suffer from both stress-related illnesses and physical health problems with an increased risk of poverty (Carers UK, 2008). The shift towards consideration of carers as partners with a corresponding focus on both user and carer outcomes must challenge how nurses work with patients and carers, from the way they undertake an assessment, to the language they use and how they deal with

Table 2. Different societal attitudes towards caring

Category	Characteristics	Experience
Classic medical conditions	These diseases are not seen as part of the natural order and society views the impact of cancer, heart disease, stroke, etc as tragic They are medically easily defined They are more widespread and therefore more people the carer interacts with have experienced them	Less negative and more sympathetic
Part of the 'natural order'	Caree is considered to be ageing, rather than ill although they may have an illness Less sympathy from society, this situation is sad but inevitable (and not tragic) Carers are more likely to be occasional Most carers did not see themselves as a carer; 'just looking after dad!'	Carers showed the greatest level of acceptance of their situations
Mental illness	Illnesses are not well understood by society and there is considerable prejudice towards these illnesses Medical care is not as good as for the 'classic medical conditions'	In many cases carers found their situations harder than in either of the above groups
Socially nebulous situations	Includes a wide range of diagnoses for example ADHD, Asperger's, ME, etc There is much less sympathy from society and more of a fight to get an accurate diagnosis (and in some cases to even prove they are suffering from something) A greater proportion of carers in these situations were caring for a child	Carers find it a constant struggle to prove their situation valid which can lead to a devastating impact on carers' self-esteem

(Adapted from Caring with Confidence, 2009)

potential conflict in both care goals and intervention in the shared desire to see people optimize their health. Whatever the challenges, health providers will not be able to provide client-centred care that enables people to be supported at home without recognising the need to work in partnership with unpaid carers.

Shifting towards an outcomes-based approach for both service users and carers has the potential to help ensure that a service or support makes a positive difference to someone's life. It will be challenging for nurses and other service providers and will only be possible if carers are considered as partners in care, allowing nurses to deliver truly holistic, empowering care. Carers' self-perceived needs are often relatively modest (Yee and Blunden, 1995). What the majority of carers want is acknowledgement of their caring role, to be listened to, and gain access to other sources of support (Twigg and Atkin 1994, Gillies 2000). Ultimately, the nettle that must be grasped, is that service provision needs to be what the carer needs, not what service providers decide they can provide. **BJCN**

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