

Reconsidering the term ‘carer’: a critique of the universal adoption of the term ‘carer’

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ABSTRACT

This critique of the term ‘carer’ argues that, although developed as a result of well-intentioned and socially-engaged research, it fails the people with whom it is most concerned, that is ‘carers’ and those who are cared for. The paper considers the historical and political development of the term ‘carer’ before examining research in various ‘carer’-related settings in the United Kingdom, namely mental health, physical and intellectual impairment, cancer and palliative care and older adulthood and dementia. The article concludes that the term ‘carer’ is ineffective and that its continued use should be reconsidered. This conclusion is based on the consistent failure of the term ‘carer’ as a recognisable and valid description of the relationship between ‘carers’ and those for whom they care. Furthermore, use of the term may imply burden and therefore devalue the individual who is cared for and in this way polarises two individuals who would otherwise work together. Consequently, this commentary suggests that descriptions of the caring relationship that focus on the relationship from which it arose would be both more acceptable and useful to those it concerns. Furthermore, a more accessible term may increase uptake of support services currently aimed at ‘carers’, therefore inadvertently meeting the original aims of the term, that is, to increase support for ‘carers’.

KEY WORDS – carers, terminology, critique.

Introduction

The term ‘carer’ (or care-giver in the United States of America (USA), Canada and elsewhere) is used profusely in health- and social-care research and practice (Fine 2004).¹ Despite its conception as a well-intentioned label to promote the recognition and support of these individuals, the current article argues that it is no longer a useful term. Instead it is a mark of bureaucracy, turning what was a normal human experience into an unnecessarily complex phenomenon (Foster 2005). Furthermore, the term

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is a 'socio-political construct whose currency is much more closely tied into rights to practical support than to the feelings and relationships which motivate care-giving' (Netto 1998: 223). Additionally it is a term that is unnecessary in Asian languages (Gunaratnam 1997), which suggests that it is a product of a specific cultural way of conceptualising this facet of a relationship.

In addition to the ineffectiveness of the term, the current critique contests the implication of burden that so often accompanies the term 'carer'. On the contrary, caring can be a socially-admired role embedded in the relationship between the 'carer' and the cared-for (Fine and Glendinning 2005). Furthermore, it is in terms of this relationship that 'carers' prefer to describe themselves (Arksey, Heaton and Sloper 1998); that is, as 'being within the traditional responsibilities expected of a parent, grandparent, partner' (Cleary, Freeman and Walter 2006: 190). Furthermore, definitions of caring that imply burden can result in the needs of 'carers' being prioritised over those of service users (Barnes 1997), thus 'devaluing' and 'blaming' the people originally targeted for care (Calderbank 2000: 530; Warnes 1993). In addition, the implication of burden associated with the term 'carer' ignores the experience of the person being cared for (Morris 1991). Consequently, people who are cared for would sooner deny the existence of their 'carer' than accept this presumption of dependency (Cleary, Freeman and Walter 2006).

This lack of identification with the term 'carer' has repercussions for the utilisation of 'carer' services (O'Connor 2007) which, for example, United Kingdom (UK) government initiatives are keen to provide (Department of Health 2008). Additionally, identification with the term is complicated by its association with the role of paid professionals employed to provide support beyond that of informal or family 'carers' (Cleary, Freeman and Walter 2006). In addition, debate continues regarding the 'definitions and nature' (Henderson 2001: 149) of the term 'carer'. For example, O'Connor (2007) reflects on the lack of any standard definition on which to base inclusion criteria for empirical research and hence studies vary on defining factors such as co-habitation and amount or type of care provided. Furthermore, the term 'carer' is used so indiscriminately in some research that it has 'lost contact' with its true meaning to participants (Adams 2000: 792).

Aims and rationale

In view of the above debates, the current article is timely in its critical examination of the term 'carer'. Although these controversies are touched

upon in the 'carer' literature, they are not addressed explicitly, as intended in the present discussion. This critique therefore draws the arguments together into a coherent contestation of the term 'carer'. Specifically, this paper argues for the abandonment of the term 'carer' and claims that the term fails the people it purports to help. In demonstrating this case, the current article considers the historical development of the term 'carer' and the experience of being a 'carer'. Although the term 'carer' is perhaps most commonly associated with care provided for older people, it is also pertinent to other groups that provide care. Therefore, the experience is examined across different caring contexts including mental health, cancer and palliative care, older adulthood and dementia and physical and intellectual impairments. The article concludes that the term 'carer' is no longer effective and considers the impact of this on health- and social-care research and practice. The paper considers alternative descriptions of the caring relationship and their implications for clinical psychology and policy makers.

Historical development of the term 'carer'

The term 'carer' is widely accepted and used not only in social- and health-care settings and research but also by, for example, the government of the UK (Heaton 1999). It may sometimes be preceded by words such as 'informal' or 'family' but, whether this is the case or not, it is used to describe people who care for others in a non-professional context (Thomas, Morris and Harman 2002) as well as those who are paid to 'care'. The first recorded use of this definition (1978; *see* Fine 2004) coincided with the feminist research of the 1970s and 1980s that examined the experience of caring (for review, *see* Fine and Glendinning 2005).

At this time caring was a role expected of women, undertaken within the privacy of their family and consequently largely ignored. The emerging feminist literature exposed the type and amount of unpaid care work performed by women and challenged the social norms and relations that resulted in women being obliged to care. Thus, caring came to be viewed as a responsibility that is forced upon (in the most part) women (Montgomery 1999), and it became impossible to overlook caring as an unproblematic phenomenon. As a result, and given that 'carers' are considered a vast economic resource (Guberman *et al.* 2003), 'carers' have received increasing recognition within social and political arenas.

Most notably, support for 'carers' comes from social and political organisations galvanised by the renewed interest in 'carers' brought about by the feminist literature (Heaton 1999). One such organisation, Carers

UK, promotes the needs of 'carers' and influences government policies that enforce the assessment of and provision for these needs. In the UK, the *Carers (Recognition and Services) Act 1995* (Department of Health 1995), followed by the *Carers and Disabled Children Act 2000* (Department of Health 2000) and the *Carers (Equal Opportunities) Act 2004* (Department of Health 2004) were the first to recognise the needs of 'carers' in their own right. Most recently in the UK, the Department of Health (2008) published a revised *Carers' Strategy* that makes a long-term financial commitment to the care of 'carers', placing them at the forefront of government policy.

The historical development of the term 'carer' shows that it was born out of a concern for women and the unappreciated care work they carry out. The aim of bringing the experience of 'carers' into the social and political arena by adopting this comprehensible term was to allow and demand significant improvements to the support provided for 'carers' and, in turn, the people they care for. Currently, the term 'carer' remains a gateway through which services are accessed. This critique, however, will consider research which suggests that the term has failed to meet these original aims. Firstly, the experience of caring will be examined in the context of mental health.

Findings from the field of mental health

Caring for someone with a mental health problem is considered to be intrinsically more complex than caring for someone with a physical illness (Karp and Tanarugsachock 2000). While the latter are presumed to share motivation to recover with their 'carer' and be compliant with treatment, mental health needs may follow a more turbulent and unpredictable course, making caring a more disruptive process (Karp and Tanarugsachock 2000). Consequently, the impact of caring for people with mental health needs is studied extensively (Schneider *et al.* 2001). In an attempt to understand this experience, Henderson's qualitative study with people with bipolar disorder and their partners described a 'rejection of the "carer" or "cared-for" identity' (2001: 152), whereby participants failed to associate with either term. Both people with bipolar disorder and their partners saw the person as caring for themselves with no role for their partner other than as their husband or wife. In fact, the two roles (of 'carer' and partner) were seen as mutually exclusive; for example, one participant commented: 'my husband. [He is] Not a "carer" at all. I don't think you can be both, not and have a proper relationship' (2001: 153).

Although such conclusions are secondary to the main focus of Henderson's paper, these findings have implications for the utility of the

term 'carer', most notably with regard to the relationship within which caring takes place. If becoming a 'carer' means an end to the previous relationship, then caution should be taken when applying the term. Henderson questioned this in terms of the policy-driven use of caring which may exploit 'carers' as an economic resource, to the advantage of statutory services. Consequently, such services benefit from a 'carer's' acceptance of this role, perhaps to the detriment of their pre-existing relationship. Furthermore, Henderson examined the universal application of the term 'carer' in mental health services among whose clients family and social relationships may be extremely complex. For example, the person labelled as 'carer' may have mental health needs of their own for which the other person provides care, which again points to the need to avoid treating the term 'carer' in a simplistic and pervasive manner.

In strong agreement with these considerations, Pilgrim (1999: 15) suggested that we should 'abandon the notion of "carer" and use other words instead, according to specific roles and contexts, such as relatives, friends, supporters or advocates'. In his opinion piece on the appropriateness of the term 'carer' in mental health services, he argued that the label often implies blame on the part of the 'carer' either in causing or maintaining the other person's problems. Furthermore, Pilgrim reiterated the point that being a 'carer' does not necessarily mean that one person cares about the other. Rather, they may share an abusive history either from the 'carer' to the person they are caring for or vice versa. The basis of Pilgrim's article, the notion that 'carers' cause and/or maintain the mental health needs of their relative, is specific to mental health, but the article highlights the difficulties associated with the widespread application of the term 'carer' and its inappropriateness in such complex settings.

Findings from the physical and intellectual impairment literature

Involved in a similarly complex relationship with their 'carers' are people with intellectual and/or physical impairments. In the context of often lifelong conditions, most 'carers' for this group of individuals are parents. Consequently, 'carers' may find it difficult to accept their child's adult identity and therefore continue to exert parental control (Williams and Robinson 2001). Calderbank's (2000) analysis of the literature explored this vulnerability of people with physical impairment to abuse from others. She argued that the use of the term 'carer' is itself a form of exploitation, and suggested that focusing on the needs of the 'carer' neglects the needs of the person with an impairment and increases their vulnerability to

abuse. Calderbank therefore concluded that use of the term 'carer' is a 'disablist assumption' (2000: 530).

This position originates from the dissatisfaction of people with impairments over the power imbalance created by the appointment of a 'carer'. Furthermore, in quoting Morris (1993), Calderbank (2000) argued that the original development of the term was flawed; that is, it was developed to highlight the unrecognised needs of 'carers', but if the people they cared for did not belong to such a marginalised group, these unmet needs would not exist in the first place. Therefore Calderbank's analysis undermined the originally well-intended term, and instead recommended that the needs of 'carers' are ultimately better met by addressing the underlying social prejudices that create these gaps in statutory services. Adopting the term 'carer' and promoting 'carer' support needs therefore ignores this fundamental issue.

Robinson and Williams (2002) examined the impact of the *Carers Act 1995* on people with intellectual impairments and their 'carers'. In addition to interviewing people with an intellectual impairment, their 'carers' and the professionals who conducted the assessments, they conducted a case note audit which identified that of 157 assessments carried out, only 35 of the 'carers' received their own, full assessment as recommended by the *Act*. They attributed this poor uptake to the terminology of the *Act*. The participants linked the term 'carer' with a paid professional from outside the family, and specifically to those who took responsibility for and carried out the physical aspects of care. Robinson and Williams argued that among parents, caring tasks are seen as part of the parental role and they do not wish to relinquish this role and designation in favour of the 'carer' role. For example, one participant preferred to call herself 'just a general mum' rather than a 'carer' (2002: 173). Moreover, these findings add weight to Calderbank's (2000) argument that the needs of 'carers' are a symptom of service users' unmet needs. For example, one of Robinson and Williams' participants said that, 'time and resources were wasted in trying to look separately at the carer's needs, when a properly conducted user assessment would in fact meet all their needs' (2002: 181). The authors concluded that the solution is more effective service delivery with improved and consistent communication rather than replacing the term 'carer', as the current critique suggests.

In an adjunct study, Williams and Robinson (2001) presented findings from the same data regarding the mutuality of care between people with an intellectual impairment and their family members. A focus group of people with intellectual impairments with little understanding of the term 'carer', upon explanation, preferred the word 'support' rather than 'care'. Furthermore, the focus group's primary understanding of a caring

relationship was of a partnership in which both partners work to support one another. Consequently, the distinction between ‘carer’ and ‘cared-for’ was arbitrary when multiple occasions of emotional, practical and physical care being provided by the participants with intellectual impairments are also identified, most often for an older or frail parent. Despite these caring acts being recognised by both the people with intellectual impairments and their ‘carers’, neither party identified the actions as caring, or labelled the person with intellectual impairments as a ‘carer’. In comparison, the roles undertaken by the person without intellectual impairments were readily identified as caring. In this case the term ‘carer’ is discriminatory in application. While neither group identified with it spontaneously, further discussion of caring exposed that people with intellectual impairments are fixed in the cared-for position regardless of any caring roles they fulfil. The authors argued for the adoption of a broader view of caring, one that recognises that people with intellectual impairments may have more than one ‘carer’ or be a ‘carer’ themselves.

Keith (1992) further condemned this polarisation of people with impairments and their ‘carers’ in a paper based on her experience of having an acquired physical impairment. The author considered how the popular depictions of ‘carers’ create a sense of uselessness and burden among people with impairments, portraying them as passive and devalued. Keith critiqued the original feminist research which similarly separated women from disabled women, further contributing to the dehumanisation of people with impairments. In this way, ‘carers’ and the cared-for are unhelpfully seen as taking opposing sides rather than as people sharing a relationship of care. Consequently, Keith considered that proponents of the term ‘carer’ are ‘taking the same patronising stance to disabled and elderly people, which they have justifiably accused men of doing to women for years’ (1992: 172). It is therefore necessary to develop a term that unifies the needs of ‘carers’ and the people they care for rather than continuing to use one that polarises and pathologises.

Findings from the cancer and palliative care literature

The needs of ‘carers’ in palliative and cancer settings differ again from those discussed thus far. In the case of a terminal illness, this is because the focus may shift from the needs of the patient to the bereavement of the ‘carer’ and their survival without the cared-for person (Harding and Higginson 2001). In addition, caring may be of shorter duration than in the other contexts discussed presently, while conversely many cancer patients remain in remission for extended periods, which creates an additional

challenge for 'carers' who continue to worry about the patient even when physical care is not required (Thomas, Morris and Harman 2002). As a result, 'carer' support is treated with the same importance as, for example, the patient's pain management (Harding and Leam 2005). Despite these differences, however, once again in the cancer context the boundary between 'carer' and cared-for is blurred. This results from the high levels of psychological distress this group of 'carers' experience (Higginson, Wade and McCarthy 1990) and creates their dual role as 'carer' and patient. Regardless of these levels of identified need, Harding and Higginson found this group of 'carers' to be ambivalent with regards to undertaking support. Their qualitative exploration of the roles of 'carers' indicated that they did not see themselves as a 'real caregiver' (2001: 643) but instead felt that they performed care tasks as part of their relationship with the patient. Moreover, the study argued that their entire identity is diminished by the caring situation. For example, one participant said, 'I lost my own identity; I was the girl whose fiancé was dying of cancer and I didn't know who I was any more', which suggests that being labelled as a carer can damage a person's sense-of-self. Furthermore, 'carers' do not recognise themselves as a group of individuals who require support and are 'unaware of their eligibility and the appropriateness of such interventions' (Harding and Higginson 2001: 643). Consequently, the authors recommended that 'carer' interventions should address this lack of identification using education and skills building to encourage 'carers' to adopt the role.

In the pilot phase of their more extensive study, Thomas, Morris and Harman (2002) made explicit their reasoning for using the term 'carer'. Their research aimed to understand the psycho-social needs of 'carers' in cancer contexts and, in contrast to the other research that has been discussed, the authors 'went to some lengths to explain our "carer" inclusion criteria to [the] questionnaire pack recipients because we recognised that the term "carer" was problematic' (2002: 531). In addition, their findings identified that 'some people do not immediately associate a close companion through cancer with the term "carer". Newly diagnosed patients and their close companions are most likely to express uncertainty about the "carer" label because patients do not usually have physical care needs' (2002: 531). Despite these reservations, the study continued to use the term 'carer' because no alternative was identified and the recurring explanations are considered to be appropriate to limit further uncertainty.

Additional findings from the same large project focused on what being a 'carer' meant to people (Morris and Thomas 2001). Interview data from 79 participants (32 'carers' and 47 patients) suggested that 'carers' were hesitant to participate in the patient's health care because of their respect

for the doctor–patient relationship. This is in stark contrast to other contexts that can result in a highly enmeshed relationship, for example, when parents have been caring for their child with an impairment for many years. Furthermore, ‘carers’ view their own needs as secondary to those of the patient, which again inhibits them from identifying with a view of themselves as a client in need of support. Thomas, Morris and Harman’s papers carefully consider how to approach ‘carers’ with sensitivity and with detailed explanation of the term. Such a measured approach would benefit all who work in this area. Selecting ‘carers’ by asking the patient to pass on a questionnaire to the person they consider to be their main ‘carer’ appears to be effective with regard to the response rate achieved (64 per cent of patient questionnaires were returned with a ‘carer’ questionnaire), but it is of interest that the remaining 36 per cent of patient questionnaires were returned without an identified ‘carer’ questionnaire. Perhaps this same group of people are those who are missing out on other interventions designed for ‘carers’.

Findings from older adulthood and dementia research

The final caring context, older adulthood and dementia, is deemed to be one of the most stressful for ‘carers’ who are required to ‘cope with the individual’s cognitive and behavioural decline, as well as the loss of the relationship with that person as he or she used to be’ (Kneebone and Martin 2003: 2). Consequently, there is an abundance of literature regarding ‘carer’ burden in this area, but the present critique is limited to research on how ‘carers’ experience this label. O’Connor explored the process through which people identify themselves as a ‘carer’ by adopting the notion of caring as a ‘position’ rather than a ‘role’ (2007: 166) in order to highlight the fluctuating nature of the phenomenon and its associated difficulties. Qualitative interviews were conducted with 33 participants who had recently attended a family support group in addition to 14 partners of people with memory impairment who had not attended the support group. O’Connor suggested that all ‘carers’ experience a time when others describe them as a ‘carer’ when they do not themselves but instead describe their actions in terms of their relationship with the other person, as for example with ‘I mean, I was looking after my wife, I never gave myself a title or anything like that. She was ... I was her husband, it was up to me to look after her and I did the best I could’ (2007: 168). The author argued that this is partly due to ‘carers’ being preoccupied by the demands of caring rather than taking time to reconsider their role and also a result of resistance to the loss of a part of their relationship with the other

person. For example, one participant said, 'Maybe it's part denial on our part because we don't want to admit what's happening ... what we're losing. And so if we keep playing this dream that we have ... that this is only temporary ... because you see once you say "caregiver" then it's permanent' (2007: 168). Ultimately, however, it does not occur to 'carers' that they are 'doing something outside the bounds of their relational role', and those participants who identified themselves as a 'carer' did so in light of ongoing communications with health professionals through which they develop 'a new language for understanding what they were doing' (2007: 168–9). Positioning themselves as a 'carer' is, however, a transient act and the 'carer' position competes with their long-standing relational position regardless of time or context. O'Connor concluded that the 'carer' identity is very rarely 'sought, embraced or consciously taken on' (2007: 170). The only exception to this is when 'carers' require access to services for 'carers' and therefore identify themselves as such at this time.

Similarly, the 'carers' in Kutner's (2001) study revealed a lack of identification with the label care-giver. Telephone interviews were conducted with 4,037 adults in the USA. Unprompted, 69 per cent described a care-giver as someone who provides care for another, but when asked whether they were a care-giver (both directly and following a detailed description of care-giver activities), 44 per cent of those who met the criteria based on care-giver activities initially did not identify with the term. Given this high proportion, it is reasonable to question its appropriateness or at least its promotion within the USA.

From a qualitative study that investigated the views of ethnic minority 'carers' of older people in the UK about respite services, Netto (1998) argued that they were equally unaware of their role as a 'carer'. She suggested that people from these groups have a strong cultural link with caring, for example, describing caring as their 'duty' or 'obligation as her child' (1998: 222). Furthermore, they tended to see caring as a reciprocal relationship. As one respondent put it, 'I don't put it that way. She is my mum, [my life has been affected] the same as looking after me has affected her life' (1998: 222). The study concluded that greater efforts should be made to raise awareness of the rights of 'carers', not only in minority ethnic groups but also in the population as a whole. Ribeiro, Paúl and Nogueira's (2007) paper on older male 'carers' identified a comparable lack of identification with the label. Their respondents integrated their identity as a 'carer' with their sense of being male, and virtually all identified themselves as men and/or husbands rather than 'carers'. Caring is therefore viewed as a fundamental aspect of a couple's relationship, regardless of gender. As one of Ribeiro, Paúl and Nogueira's participants put it, 'It doesn't matter if you're a man or a woman, what

really matters is that there's a soul that helps the other. ... Just because I am a man it doesn't matter, we just forget it. She's my wife' (2007: 306). In addition, husbands take honour from their caring roles, particularly when noticed in social situations. Even when complimented by others, however, these admired actions are viewed primarily as the tasks of a husband rather than a 'carer'. Another participant said, 'People see me doing things and say, you're really one of those husbands ... one of those husbands like all should be!' Ultimately, people acknowledge that caring is 'a woman's role but that it was, first and foremost, a husband's responsibility' (2007: 308–9). However a small number disagree with this gender stereotype and also with the relationship-centred view of caring, but instead view caring as a basic human function and therefore not something that should be a threat to masculinity.

The last two cited studies exemplify the universal failure of the term 'carer' as an engaging term with which individuals identify. In the case of 'carers' of older people or people with dementia, this is widely demonstrated across ethnic and gender groups with remarkably analogous results. Likewise, the present critique repeatedly identifies this pattern across varied care settings. The ensuing discussion considers the implications of this failure and argues its support for the current contention, that the term 'carer' should no longer be regarded as an appropriate term.

Discussion

The unanimous failure of the term 'carer' as a role with which people can identify is evident across all contexts considered by the present critique. Regardless of why a person requires care, it is inappropriate to apply the term 'carer' to the person who provides this support. Furthermore, both parties are equally reluctant to make use of the term 'carer', which suggests that complex processes are involved in the positioning of individuals as either cared-for or 'carer' (O'Connor 2007). It is questioned whether or not this dichotomy between the cared-for and the 'carer' exists, or rather was created for the convenience of researchers and service providers (Keith 1992). Indeed, caring is often a reciprocal relationship (Williams and Robinson 2001). For example, an individual with a physical or intellectual impairment may begin to provide care in return as their parents age and experience ill health. Similarly, an older person caring for their partner with dementia may have physical health problems of their own for which they receive mutual support. Consequently, applying the label 'carer' creates a division between people who might otherwise work together. Firstly, its application is discriminatory in its exclusion of those in

receipt of care. Secondly, in creating this rift, those in receipt of care are left increasingly vulnerable to neglect or abuse (Calderbank 2000).

This phenomenon can be likened to the social model of disability in that the predominant societal view of people who are cared for is just as hostile and disempowering as it can be towards those who are disabled (Shakespeare 1993). Therefore, any of the impairments discussed in the current paper, particularly those considered untreatable, may be viewed as a tragedy rather than as diversity within the human condition. By taking this pessimistic stance, for example in dementia research that focuses on negative outcomes or which excludes people with dementia from participating (Nolan, Ingram and Watson 2002), these individuals are excluded from their full range of potential experiences. This pessimistic view adds further credibility to the current tendency to increase 'carer' support. That is, if an individual's impairment is viewed as a tragic disability for which nothing can be done, then the best alternative is to support the 'carer' rather than to include, as fully as possible, individuals with impairment in treatment and research (Lawthom and Goodley 2005).

There remain many reservations about the suitability of the term 'carer'. Despite achieving its original aim of increasing the recognition given to the care work of women (Montgomery 1999), the term defeats its purpose by pursuing this aim too narrowly. Indeed in some cases the needs of 'carers' are over-represented to the detriment of the person requiring care (Calderbank 2000). Thus services should address this imbalance by focusing on the fundamental care needs of the person requiring care. In doing so, the associated needs of 'carers' may be similarly met. If the needs of 'carers' and those who are cared-for are unified in this way, perhaps an equally unifying term can be developed to describe this phenomenon.

When such options are discussed with individuals involved in caring, they consistently view the caring dynamic in light of their pre-existing relationship. That is, the most widely understood view of being a 'carer' is in fact as being a typical task involved in being a husband, wife, parent, sibling, partner, friend or child (O'Connor 2007). Therefore using such relationship-focused labels is preferable to the term 'carer' (Pilgrim 1999). The possible pitfall is a return to the previous status quo in which care work was invisible and unvalued (Montgomery 1999). This could be avoided, however, by employing a thoughtful and considered manner and maintaining the same intent and level of resources. Using the term 'carer' may be appealing because it seems inoffensive, for example, if it is unclear to a clinician whom an individual brings along to an appointment with them, but the term is not innocuous and such uncertainties can be clarified readily by asking the people attending the appointment. Therefore, in the

spirit of individualised care, each caring relationship should be identified according to the relationship from which it arises.

In further support, Harding and Higginson (2001) stated that denying a previous role, such as that of a partner, in favour of a 'carer' role has a negative impact on an individual's sense-of-self. Identifying themselves as a 'carer' is therefore damaging for the relationship between the 'carer' and the person they are caring for (Henderson 2001). Given that 'carers' are a highly valuable resource, such a breakdown in their ability to care would be disastrous and should be avoided at all costs (Guberman *et al.* 2003). In contrast, however, if service providers acknowledge the pre-existing relationship through the terminology they use, it may result in improved care and reduce the level of need expressed. Furthermore, a relationship-focused approach to care may increase the uptake of 'carer' support services (Robinson 1994), targeting interventions at husbands and wives or service users and their children, for example, may be much more acceptable and inviting.

Implications

A successful change in terminology requires a universal adoption of this relationship-based description of caring. This necessitates top-down changes, as at government and policy formulation level, and bottom-up changes, as in the communications professionals have with and about service users. It requires clinicians and researchers to engage critically with the labels they employ rather than using them unquestioningly. Similar changes in terminology have been made successfully in other fields, as in intellectual impairment (*cf.* Eayrs, Ellis and Jones 1993), which suggests that a similar revolution could occur with regard to the term 'carer'. Notably, a number of studies have benefited from clarifying their usage of the term 'carer'. For example, Mackenzie and Holroyd's (1996) study of the perceptions of Chinese 'carers' stated explicitly their inclusion criteria for 'carers'. The article also defined other terms including family, dependent, dependency and long-term care. Kramer and Lambert (1999) included a defined sample of 'carers' by asking participants if they (or anybody living with them) required 'care or assistance because of a disability or chronic illness'. Furthermore, the participants were asked if they provided to anyone they lived with 'help or assistance because of their long-term physical or mental condition, illness, or disability' (1999: 661). McKee *et al.* (2003) defined 'carers' in terms of their relationship with the individual for whom they provided physical, emotional, domestic or financial support on at least a weekly basis. Such efforts to clarify or make terminology more inclusive allow greater identification of people who

require services which in turn places greater demands on service provision. If almost half of all 'carers' do not identify themselves as such (Kutner 2001), then new efforts to engage with this group of individuals may almost double the present demand. Although this creates pressure on resources in the short term, it will be advantageous in the long term for the individuals involved as well as for service development.

NOTE

- 1 Throughout this review, the term 'carer' is written in quotation marks to indicate the incongruity of the term.

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