

EDITORIAL INTRODUCTION

Carers - vital partners in increasing the person-centeredness of health and social care systems

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Introduction

The Oxford English Dictionary defines a carer as ‘a family member or paid helper who regularly looks after a child or a sick, elderly or disabled person’. As a basic descriptor, the OED definition is a good starting point, broadly differentiating carers, as it does, into two types - ‘informal’ (family/friends/volunteers, unpaid) and ‘formal’ (health and social care professionals and also care workers, paid). In this Editorial we concern ourselves with the former. We reflect on the carer function, the differing types of ‘informal’ carers, the difficulties carers face in undertaking their work and the political response to the increasing visibility that carers have achieved over recent decades. We concur with the carer advocacy charities that there is a need to care for carers if they are to maintain their physical, emotional and social wellbeing in order to undertake their functions effectively. We assert that health and social care professionals should aim to acquire a far greater understanding of the role of carers in the day to day support of the person who is disabled or ill and that carers should be involved as expert partners in shared clinical decision-making and the construction of the Care Plan. Carers, we argue, are vital partners in increasing the person-centeredness of health and social care systems.

The caring function

The assistance carers provide is broad and wide ranging. Typically, it involves practical tasks such as shopping, cooking, eating, housework, assistance with going to and getting up from bed, use of the toilet, washing, dressing, lifting, helping with the ascent and descent of stairs if there

are any and, perhaps, even physiotherapy. Carers also assist in household management, managing finances, processing and collecting benefit entitlements and settling domestic and other bills. If there are young children, they may also help with taking to and picking them up from school.

In addition to such valuable, often indispensable, physical and domestic assistance, carers also offer psychological, emotional and existential/spiritual support to the one who is disabled or ill, listening carefully to worries, anxieties and concerns and responding to them when necessary. Equally importantly, they act to ensure medication adherence and adherence to other therapeutic regimens and are often the first to observe a deterioration in the health status of the person, having the potential to act as an ‘early warning system’ in alerting health and social care professionals of the need for a rapid assessment and a modification of the Care Plan accordingly. In so doing, they help maximise health outcomes and can decrease the frequency of hospital admissions, directly enabling the maintenance of the person’s autonomy, dignity and social routine and precluding the unnecessary use of secondary care resources as part of this process. They will often provide continuity of care and support when formal clinical and other interventions cease [1].

Young carers

It is typical to consider the carer a mature individual, a spouse, a parent or a ‘grown up’ son or daughter. But this is far from automatically the case. Indeed, there is another type of category into which carers fall - that of the young carer [2]. Young carers are typically described as children and young people under 18 years of age. The tasks they

undertake and the level and frequency of caring they provide differs as a function of the disability or illness of the one cared for. It is typically unpaid. It might focus on a family member who is physically or mentally ill. It might focus on a family member who engages in alcohol or substance misuse. Certainly, there are large numbers of such carers in existence. In the UK, for example, data derived from the most recently analyzed Census [3] was able to identify in excess of 200,000 such carers, but this figure may well be an underestimate, given the findings of research by the British Broadcasting Company (BBC) which indicates that the number, when properly calculated, may in fact approximate 700,000 [4].

Hidden carers

Of the carers we have discussed and who can be identified as such, there are many who are described as ‘hidden’ [5]. Hidden carers may simply not want to be identified as a carer, given its association with substantial responsibility and the implication that if they cease to exercise such a function, they may, *ipso facto* be considered as having stopped caring, which is to say that they may be perceived as having become ‘uncaring’. A spouse, in particular, may object to the descriptor in that it detracts from or minimises the solemn responsibility to care and love in sickness or in health as part of matrimonial vows or other expressions of long term commitment. In these circumstances, the term ‘carer’ may be considered inappropriate or even profoundly unpalatable. It is likewise for young carers. Often, they do not realise that they are a carer *per se*, a factor especially likely to be the case if the cared for does not appreciate or understand that their child is actually acting in this role. Others, external to the family, may not realise that the child is functioning in this way, perhaps as a result of the parent’s condition not being particularly visible, so that the child’s status and needs for help are not immediately recognised. The child may not wish to be considered a carer, not wanting to be seen as ‘different’ by their friends and worrying, perhaps, that if such a status and situation became known, the family would be broken up and the child or children taken into care. They may remain hidden for these reasons and sometimes also because nobody is available to hear their story. Many do not wish to communicate their story or plight, seeing little benefit in doing so [5].

Caring for carers

Carers UK, a major charity dedicated to assisting carers [6], estimates that there are 6.5 million carers in the UK, representing, at current population estimates, 1 in 8 adults. The Charity reports that 45% of carers have given up work to care and that many more are “stretched to breaking point”. Sixty one per cent are reported to have faced depression as a consequence of their caring role, feeling unable to maintain ‘a life of their own’. Forty nine percent describe themselves as struggling financially because of

their caring role, with constant worries of their own as well as having worries about the one cared for. In terms of young carers, many are reported to experience problems with their own physical health, especially if the type of caring in which they are involved entails caring throughout the night and lifting a heavy adult, with sleep disturbance/deficit and physical strain being experienced as a consequence. Moreover, young carers are commonly reported to experience a lack of emotional wellbeing, stress, fatigue and even frank mental ill health. A feeling of being different from their friends or being effectively isolated from social interaction as a function of their caring is also reported. Of major relevance here too is the effect of the loss through bereavement of the person cared for, the breakup of the family, the loss of income or housing and of having seen the effects of an illness or addiction. The effects of these experiences on carer’s education, employment and wellbeing cannot therefore be underestimated and impact on their role in facilitating the person-centered care of the ill or disabled person. There is, then, a need to care for carers.

The recognition of the difficulties faced by carers has led to an increasing number of studies aimed at investigating how these can be successfully addressed. At the time of writing, the European Federation of Associations of Families of People with Mental Illness (EUFAMI), in collaboration with the LUCAS Centre of the University of Leuven [7], is currently completing the Caring for Carers Survey (C4C). The C4C is an international survey aimed at understanding the particular needs and challenges that are faced by the carers of those living with a mental health illness and is the first investigation of its kind, being conducted in 25 countries in total, principally in the European Union, but with the inclusion in addition of Canada, Australia, Israel and Russia. The preliminary results of the study released on 10 October 2014 derived from responses from over 400 carers in Australia, Canada, France, Germany, Italy, Spain and the UK are clear in demonstrating what has been described as an “immense and unspoken burden on people caring for those living with schizophrenia ... (highlighting) ... the contribution they make and the overwhelming impact this has on their own lives”. Indeed, while the Survey documents that approximately one third of carers experienced positive experiences of providing care, it reports that almost four out of ten feel unable to cope with the constant anxiety of caring, with one third experiencing depression. Equally notable is the finding that over 10% of carers reported feeling a sense of isolation and had experienced strains in their social lives as a consequence of the caring function they exercise [7].

EUFAMI calculates that there are approximately 10 Million such family carers caring and supporting their child or sibling with a serious mental health condition on a day to day basis. This is an astonishing figure and illustrates the enormous contribution of this carer workforce, not only to the individuals they serve, but also to Society and to the financially strained nation states that would otherwise become faced with substantially increased health and social care expenditure. Indeed, we concur with Kevin Jones, Secretary General of EUFAMI, when he

emphasises that “This hidden workforce of family carers is a lifeline for society and we must take steps to ensure they are fully recognised for their contributions, their voices are heard and they are supported in order to allow them to continue caring effectively and safely for their loved ones, without putting their own physical and emotional well-being at risk” [7].

Political responses to the caring function and the rise of the status of the carer

Since the initial use of the term ‘carer’ in the late 1970s and its first dictionary entry in the mid 1980s [1], carers have become increasingly vocal about their work and its needs. A wide range of charities and advocacy bodies dedicated to the care of carers have been created across Europe and these have proved instrumental in increasing the political visibility of carers, resulting in a formal recognition of the caring function and an increasing allocation of resources. In the UK, for example, an important document in this context, The Carers’ Strategy, was published in 2008 [8] with five key objectives to be achieved for carers by 2018. The Strategy laid great emphasis on the need to recognise the carer as an expert care partner, that he or she should have the capacity to enjoy a life outside of caring and not to be financially disadvantaged, that he or she should be treated with dignity and have the resources available to remain mentally and physically well and that children present in the caring environment should be enabled to thrive and remain protected from inappropriate caring roles. In 2010, the UK Government ‘refreshed’ the Carers’ Strategy in the document ‘Recognised, valued and supported: next steps for the Carers Strategy in 2010’ [9], subsequently adopting measures to improve the awareness of the work undertaken by carers and improving support through formal legislation. Both the Care Act 2014 [10] and the Children and Families Act 2014 [11] mandate significant improvements to the processes through which carers of all ages are assessed and supported.

Other documents and policy statements are of relevance here. While the Care Act and the introduction of the Better Care Fund have been instrumental in providing new and significant opportunities for the integration of health and social care [12] and, as a function of this approach, facilitating a seamless health and social care support for individuals and their families, the UK Government has articulated an additional vision of progress which recognises the need to involve and support carers and which is set out in the document ‘Transforming Primary Care: Safe, proactive, personalised care [13]. An unequivocal aim is to implement the reforms set out in the legislation and to ensure good outcomes for carers of all ages in terms of their health, wellbeing and quality of life and to work closely with carer organisations in this task. Thus, the UK Government has had no difficulty in

formally recognising the “enormous contribution that carers make to Society” [14] and that “the country cannot do without the contribution of carers” [14].

Conclusion

While the role of a carer is well understood in general terms, more detailed descriptors that better illustrate the different types of carer and caring are needed and in a forthcoming Preliminary Lexicon and Dictionary of Terms for PCH [15,16] we suggest some possible examples. Despite the current lack of definitional precision, it is clear that people who act in this role perform a service of great importance and one which is directly related to the success of strategies to implement person-centered approaches within health and social care systems. Research has shown that in addition to their provision of direct, ‘hands on’ care, carers provide major economic benefits for the State. Indeed, it has been estimated that the caring function in the UK saves the UK State approximately £119 Billion *per annum*, funds that would otherwise need to be expended on formal carers, hospital admissions, care homes and other supportive services [6].

While the person who is disabled or ill remains the focus of care, the predicaments of carers can no longer be ignored as their needs and the needs of the one cared for are intertwined. But such recognition will also need the enthusiastic support of care professionals and this is not always forthcoming. The EUFMAI-LUCAS Survey [7] reports that carers’ positive experiences of their caring were eclipsed by dissatisfaction with the lack of support they received from care professionals, with 92% of carers surveyed needing additional support across several domains. Startlingly, 38% of carers reported feelings of not being taken seriously by medical and other care professionals and 44% were dissatisfied with their ability to influence important decisions in treatment and care planning [7]. Such findings indicate that in addition to greater political and Societal awareness of the carer function, changes are necessary in the informal carer - professional carer relationship in order to maximise the positive impact of carers’ work. We need, then, to enhance the ability of carers to care, by guidance and training, by political advocacy and by caring for carers themselves. Carers are crucial partners in the care process and should be fully recognised as such. The formal definition of their role and their inclusion by health and social care professionals, through shared decision-making, in the construction and delivery of the Care Plan is a vital step in efforts to increase the person-centeredness of health and social care.

Conflicts of Interest

The authors report no conflicts of interest

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