Title: Valuing carers: rhetoric or reality?

Carers provide an invaluable service particularly in caring for adults and children with long term health challenges. However the annual State of Caring survey commissioned by Carers UK (2018) indicates not only that many do not feel their contribution is valued but that the impact of long-term stress on their health and wellbeing is not being adequately recognised. In a climate of increasing demand for hospital beds, there is considerable pressure on nurses and other health care professionals to discharge patients to care in the community as soon as possible (NHS 2017). Clearly patients have to be medically fit but for care continuity outside hospital, informal carers must be adequately supported. Unfortunately the carer survey indicates a gap between what is needed and what is provided: the NHS according to one carer needs to: ‘Accept equal responsibility for patients and their care after hospital stays, rather than putting all the responsibility on the carer’ (Carers UK 2018: 8). Person-centred care is at the centre of the NHS and nurse education; what do nurses need to know to ensure that care is person-centred for carers as well as patients?

The survey is based on responses from 6828 carers, the majority of whom were female, from a mixed age range although the largest group (33%) was aged 55-64 (Carers UK 2018). 38% were in paid work but most were not, with consequent financial difficulties; the poverty rate is 22% amongst carers. 47% spent up to 90 hours a week in caring activities. It is therefore not surprising perhaps that many reported deteriorating mental and physical wellbeing. 72% reported suffering mental ill-health as a result of caring and 61% reported physical ill health. 57 and 58% respectively thought their health status would get worse and 50% expected their quality of life to deteriorate in the coming year. These figures are shocking as carers contribute significantly to society as informal, largely unpaid carers; if we do not care for their health, clearly they will be unable to care for others. Carer commitment is very apparent in this survey although some feared the impact of lack of support especially when unwell themselves: ‘I will have to carry on as a carer, regardless of my mental and physical health. The thought of being unable to cope, frightens me’ (Carers UK 2018:21).

Five major areas of recommended changes are advocated, one of which is ‘to deliver an NHS that recognises, values and supports carers’ (Carers UK 2018:22). This short report makes salutary reading for practitioners and educators alike as we may well have been under the impression that we did value carers. Specifically the report asks for ‘a new duty of the NHS to put in place policies to identify carers and promote our health and wellbeing. Ensure that all staff are trained to know about carers and how to support us’ (Carers UK 2018:22).

Nurse education for undergraduate nurses needs to review the curriculum in the light of this report. Some elements of programmes support the aim of the report. For example, since 2010, 50% of the programme hours is for practice experience of which 50% is allocated to hospital experience and 50% to primary health care/community experience (NMC 2010). This differs markedly from my nurse training which was entirely hospital based. The advantage is that students are now far more aware of the patient/carer experience before and after hospital admission. Further, interprofessional education (IPE) is now part of the curriculum and so students may have a better insight into the role of other professionals when planning discharge for example. However clearly this is not enough or has yet to significantly influence practice. It is evident that some students do not value their community
experience as much as their hospital experience however and indeed this is sometimes reinforced by some mentors who would prefer students have a longer grounding in hospital care. Moreover whilst IPE is common, the mix of students varies; many health students do not mix with social work students for example due to logistical timetabling issues. This is a pity as both groups could contribute a lot to each other’s insights into carer needs, health and assessment. Increased use of IPE web-based case studies might help and assignments based around patient and carers needs could need to be mandatory.

In clinical practice, opportunities for discharge planning are usually offered. This is invaluable as planning a smooth transition between secondary and primary care sectors under the supervision of a mentor enables students to develop the necessary coordination and relationship skills required. Mentors are constantly updating their knowledge and skills and so including elements of a carer assessment in discharge planning would be very valuable both for service users and the learner, as over half the carers in the survey said that their ability and willingness to provide care was not considered or reflected in the care plan offered (Carers Uk 2018: 11).

To conclude, the imperative to reduce hospital stay especially for older people in order to prevent hospital acquired complications is strong but discharge can only work if authentically negotiated in conjunction with carers. Children’s and Young People’s nursing use the term family centred care as opposed to person-centred; maybe that approach would be more inclusive and therefore responsive to the needs of carers, many of whom are family members.

References


Dr Janet Scammell, Associate Professor (Nursing), Bournemouth University