

GUEST EDITORIAL

Ambitions for palliative and end of life care: a relentless focus on the person

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Introduction

Many countries are grappling with the dilemma of a growing gap between healthcare need and resource available. This gap is compounded by our collective and growing success in finding new treatments and potential interventions, many of them costly. There is no obvious solution for this conundrum. There is growing acknowledgement that simply pouring resources into this gap is not going to solve this dilemma on its own. Increasing life expectancy and a fall in fertility rates means that the cohort of older people within the population is growing at a faster rate than younger people, projected to grow from 8% in 1950 to 21% by 2050 [1]. The Office of National Statistics for England and Wales project a rise in the proportion of people dying over the age of 85 years from under 39% in 2014 to over 53% in 2040 [2].

As people age, they become more likely to develop chronic conditions, often concurrently. Barnett *et al.* [3] found that 30.4% of people aged 45-64 years had at least two conditions, increasing to more than 80% in those aged over 85 years, with the mean number of comorbidities in this latter age group being 3.62. Moreover, the onset of multimorbidity occurred 10-15 years earlier in people living in the most deprived areas compared to the most affluent. The increasing subspecialisation in healthcare may have helped to increase the rate of discovery of new treatments, but it may now hinder our ability to help people with multiple comorbidities in a whole-person approach. Optimum treatment of one condition may have a detrimental effect on another condition, all happening within the one person. This makes it even more important to focus on individualised person-centered healthcare.

The English National Quality Board has published a revised definition of quality [4]. This describes five

domains essential to achieving 'high quality person-centered care for all': (1) safety, (2) effectiveness and (3) positive experience, for people who use the service and (4) well-led and (5) sustainable use of resources for those providing services. In an effort to improve efficiency and performance, we turn to measurement, particularly of the processes of care. In an effort to improve effectiveness, we look to statistics around mortality, complication rates for different treatments and disease-free intervals. In an effort to improve safety, we turn to checklists which help to avoid major omissions, but risk depersonalising healthcare. The measurement that continues to elude us is that at the centre of these domains, that is, of person-centered care. National Voices, a coalition of charities that stands for people being in control of their health and care in England, concluded that a strategic review and overhaul of person-centered care measures across health and care is necessary if person-centered care is to become mainstream practice [5]. Their report found that while some aspects of person-centered care have improved, for example, the provision of information, communication and personalisation in adult social care, there remains little evidence of personalised care and support planning, with coordination of care appearing to have deteriorated and family involvement being not sufficiently central to person-centered care.

Enablers for person-centered healthcare

An important early and necessary step in our effort to promote person-centered healthcare is to understand the person better and their motivation and capability in terms of managing their own health and care. The concept of

patient activation has gained traction in recent years and, despite general acknowledgement that the term ‘patient’ may be somewhat disempowering, for the time being patient activation remains a widely employed term to describe the knowledge, skills and confidence that a person has in managing their own health and care. The Patient Activation Measure is a validated self-reported measure which provides a consistent and accurate measure of changes in activation over time [6]. This matters, because people with low activation levels are less likely to play an active role in staying healthy and less good at seeking help when they need it. Hibbard *et al.* found that activation levels were particularly low for people with low income, less education, Medicaid enrollees and people with poor self-reported health [7].

Health literacy is another closely linked concept. Health literacy skills are ‘the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health’ [8]. Smith *et al.* [9] argue that this is a skills-based construct and does not include the motivational elements that are part of the patient activation measure. But importantly, clinicians need to appreciate that patient activation and health literacy can fluctuate in the same individual over time, depending on circumstances. For example, faced with a diagnosis of a life-shortening illness, perhaps with rapid progression, it is easy to imagine how the person’s health literacy skills may suddenly take a ‘nosedive’. Equally, somebody with a higher patient activation measure at baseline, perhaps living with a complex condition, may find their activation levels dropping when suddenly confronted with multiple other adversities, for example, a dying parent, a child acting out in school and a partner’s redundancy happening at the same time. The challenge for doctors and other health professionals is that they need to be able to adapt their style and substance of communication to meet people at their current level of health literacy in order to achieve the real partnership that person-centered healthcare requires.

These are aspects of person-centered healthcare which are not explicitly taught in undergraduate professional education, yet are akin to clinicians’ ‘life skills’. The teaching of communication skills, now widely in place within most professional undergraduate curricula, provides a great opportunity to embed the exploration, understanding and approaches to patient activation and health literacy within clinical practice.

Shared decision-making is a process which most clinicians would regard as being fundamental to how they practise, yet a recent report found that only 56% of inpatients said they were definitely as involved as they wanted to be in decisions about treatment, 39% said their GP was very good at involving them in decisions and 37% said that of their practice nurses [5]. Clearly, what clinicians think they do and aspire to do, does not always translate into the same outcomes for patients. Elwyn *et al.* argue that the focus needs to shift from assuming that decisions must be guided predominantly by scientific consensus about effectiveness, to a position whereby the major factor in decision-making are the person’s informed preferences [10]. They suggest a three step model for

shared decision-making consisting of team talk (eliciting goals and providing support), option talk (task of comparing alternatives) and decision talk (task of arriving at decisions together).

The Point of Care Foundation argues that ‘seeing the person in the patient’ is critical to patients’ experience of care, which they define as the totality of events and interactions that occur in the course of episodes of care [11]. Their report provides examples of ways in which institutions can support this happening, including Schwartz Rounds which are structured forums for clinical and non-clinical staff to come together to discuss the emotional and social aspects of working in healthcare. Another tool which has grown in popularity because of their ease of use and practicality in any setting is the one page profile, originally developed by Helen Sanderson [12]. This captures on one page the most important information about the person under three headings: ‘what people appreciate about me’, ‘what’s important to me’ and ‘how best to support me’. It helps to remind staff of the ‘person in the patient’ (or ‘client’, when used in social care).

Enabling person-centered care: through the lens of palliative and end of life care

In their editorial within the *European Journal for Person Centred Healthcare* in 2016, Miles & Asbridge explored the vital role of person-centered healthcare in chronic disease trajectories [13]. In their opening editorial for that journal in 2017, they moved the conversation on to the ‘why’ and ‘how’ of person-centered care, by moving from rhetoric to methods, to implementation and outcomes [14]. In this, the guest editorial for the final issue of the year, I describe how we approach the ‘how’ and ‘what’ of person-centered healthcare through the lens of palliative and end of life care, using an example from England, UK.

In 2011, over 29 million people globally died from diseases requiring palliative care [15]. Each year, around 377 adults out of 100,000 population over 15 years old and 63 children out of 100,000 population under 15 years old across the world require palliative care at the end of life. No matter how good we get at improving treatments, death and dying are not things that any of us can avoid. For some, the processes of dying may be obvious for a while, enabling conversations, preparation and anticipatory decision-making. For others, death may come with little, if any, warning. Person-centered healthcare is brought into sharp focus when somebody is facing the prospect of death in the foreseeable future, whether it is their own death or that of a loved one. It seems completely intuitive that enabling person-centered healthcare is even more urgent in these circumstances, yet there are many challenges to achieving this for a frail, vulnerable group of people whose energy and time are rapidly diminishing. Family and staff alike tend to be more protective at such times, yet this may make it more difficult for the person they care for to indicate their own views, preferences and priorities. At times, people may express wishes that are clearly

unattainable - skilled and sensitive clinicians, working closely with family members, can gently steer people away from unrealistic expectations while offering alternatives that make reality as close to those wishes as possible.

For decades, there has been an ambition to provide palliative care as equitably as possible. Almost ten years ago, the publication of a national end of life care strategy for England [16], followed by Scotland [17], Wales and Northern Ireland, all heralded an intention to systematically improve the provision of palliative and end of life care. There have been lots of advances, along with the appearance of many different approaches and tools, and many groups and organisations with different initiatives aimed at improving the care of dying people. So how can we piece these approaches and tools together into a cohesive model of care? How do we allocate tasks to the multiple stakeholders?

In England, we adopted a highly collaborative approach, using co-design and a 'new power' style of leadership. The latter acts like a current of energy; it is open, participatory and peer-driven; it taps into people's capacity and desire to participate [18]. We brought together twenty seven national organisations, all with a central focus, or partial interest, in palliative and end of life care. Together, we curated the multiple publications, recommendations and reports already in existence and identified a small set of high level ambitions which would, in our collective view, informed by the literature, transform palliative and end of life care in this country. These evolved around a central vision about what person-centered coordinated care meant, which had been previously generated for us by the organisations, National Council for Palliative Care and National Voices, working in partnership with patients and families: "I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carers" [19]. Our six ambitions were expressed as person-centered outcomes: each person is seen as an individual; each person has fair access to care; maximised comfort and wellbeing; care is coordinated; staff are prepared to care; each community is prepared to help. Each ambition has an 'I' statement, stating clearly what the realisation of that ambition would look like to the person. A set of building blocks were identified to help achieve each ambition. The message is clear and simple - together we built the framework; together we make it happen - focusing relentlessly on the person.

Since publication, the 'Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020' [20], has provided a focus and a framework for drawing together various tools and approaches at personal, organisational, system and societal levels, all sharing one purpose: to achieve the best possible person-centered care so that, despite a terminal diagnosis, the person can live as well as possible until they die and that they and those close to them can experience the type of care that puts them at the absolute centre of all clinical effort and attention. Far from simply allocating tasks to multiple stakeholders and running the risk that, at times of limited resources, everybody tries to offload their responsibilities onto

somebody else, the process of building the Framework together has generated a sense of co-ownership and a moral obligation to share the 'heavy lifting' that is required to enable an authentic person-centered palliative and end of life care across whole populations. Of course, we are a long way from achieving utopia, but the relational foundations have been strongly secured and should help us to weather the inevitably difficult times ahead.

Conclusion

So what shifts are needed to achieve high quality, person-centered healthcare for all?

First, we need to acknowledge the reality of what Berry *et al.* called a hostage bargaining syndrome [21]. They describe how patients and their families may hold back from open engagement and robust discussion with clinicians that is needed for genuine shared decision-making, behaving like hostages, negotiating from a position of fear and confusion. This is even more likely to occur in the context of serious, deteriorating illness, when the stakes of health decisions are high. Even though clinicians themselves do not wish patients to feel like hostages, they need to recognise and acknowledge that the hostage bargaining syndrome exists, so that they can actively work to minimise these feelings of helplessness before they become entrenched in the person.

Second, there needs to be recognition that in trusts where there are higher rates of staff health and wellbeing, as measured by injury levels, stress levels, job satisfaction and turnover intentions, there are higher patient satisfaction rates [22]. There is also an association between higher staff satisfaction rates and lower rates of mortality and hospital-acquired infection. This is why one of the six ambitions for palliative and end of life care explicitly focuses on staff *being prepared* to care, with the phrase 'being prepared' referring not only to education and training, but also to being physically and emotionally prepared to care, with attention paid to developing resilience [20]. As Ham *et al.* point out, improvements in the quality of care come from 'the intentional actions of staff equipped with the skills needed to bring about changes in care, directly and constantly supported by leaders at all levels' [23].

Finally, high quality person-centered healthcare can only be made a constant and consistent reality for patients and their families if they and their professional caregivers are supported by the wider system of service and education providers, commissioners and Society, who help to safeguard an environment in which a deeply respectful partnership approach flourishes between those who need healthcare and those who provide it and where measurement of person-centered healthcare outcomes drive improvements all of the time.

Acknowledgements and Conflicts of Interest

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