



IDEAS AND INFLUENCES

Learning for carers as a means to empowerment: a Welsh vision

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Submitted for publication: 24th October 2016

Accepted for publication: 3rd November 2016

Published: 16th November 2016

<https://doi.org/10.19043/ipdj.62.012>

Keywords: Social reform, empowerment, social justice, leadership, drivers, co-production, influence, learning

Introduction

I have thought about how this reflection on my experiences could help other nurses who feel they have an idea that may make a difference to their practice or to patient experience, yet are hesitant to act on it. During my career I have often spoken out for what I or other Royal College of Nursing (RCN) members believe is the right thing to do, and always reflect to ensure that my actions are underpinned by positive intent and consideration of the greater good. Some might see this as leadership in action. In many arenas of care provision, we can be influenced by the latest trends. Recently the buzz words of 'integrated care', 'prudent healthcare' or 'co-production' are being applied to 'cross-professional boundary working', or 'working in professional silos'. I would like this reflection to show how these buzz words can really lead to positive action and win-win outcomes.

An area I am most passionate about is enabling carers to have the opportunity to sustain as 'normal' a family life as possible while meeting the daily needs of those they care for. To realise this, I believe it is necessary for nurses to think outside our usual arena of care provision. I was passionately reminded about this at a conference about 12 months ago.

At this conference, I spoke informally with representatives of a carers' support group, who told me about the problems they had maintaining any personal quality of life. Their daily routines were wholly focused on the care they afforded to the person they were responsible for. They had no real personal time, insufficient respite, no time for a career or to gain employment, few if any holidays and certainly no idea how long their work at home would continue or how their future life would unfold. Some of the complex care needs they were dealing with surprised me and my thoughts turned to ways in which nurses or nursing could contribute.

As nurses, we generally still undertake most of our preregistration education in the acute care environment, with a team of professionals working together and in support of one another and ready access to help and advice when needed. We can also share a coffee and quiet moment to talk through an experience with a colleague when things get tough. I reflected on the need for preregistration nurses to gain experience by working alongside carers and patients in the community. Yet I am well

aware of the claim that nursing placements are in short supply and the numbers of nurses we prepare cannot exceed the number of clinical placements, as we have to comply with the EU regulations by ensuring that of the minimum 4,600 hours of theory and practice in a nursing degree, 50% must take place within the clinical environment.

After this encounter, I visited the carers support group. It was an emotionally charged meeting for me as I listened to their selfless commitment and dedication to people for whom they provided continuous, unrelenting and challenging care, often in the lonely, isolated setting of their home. I discovered that carers were mainly females aged between 18 and 60 (the years in which a person's working life usually occurs), with some being the sole care provider. In many cases their marriages had succumbed to the pressure of providing care. A few group members had two family members to care for, and I met one woman who had six disabled children at home, another who had three children - one of whom needed ventilation and full-time care. Their lives were a constant balancing act of caring for a family member and trying to maintain as normal a family environment as possible for their other children or family members. This left no time at all for themselves. While challenging, this meeting was a truly inspiring experience, as each of the carers was so eager for someone to help them learn how to care to their best of their ability.

Through the support group I met a young, married mother, who told me that she had a disabled son and her husband was away for extended periods (see Box 1). Her story about undertaking a college course to improve her care for her son led me to identify an opportunity: if nurses could be part of the provision of care and if we could free up more time for more carers to undertake such courses and have them recognised as accredited training, this would give them greater confidence, improve care and also provide a medium for social interaction and group support – similar to that which we experience in an acute care environment.

Box 1: Case study – benefits of healthcare training for a carer

A young, married mother told me that she had a disabled son and her husband was away for long periods with the forces. While her extended family was able to look after her son a couple of times a week, she had to use this time to attend a local college course to help her improve the care she was providing for her son.

This was hugely difficult for her; she was left with feelings of guilt for leaving him, albeit for a short time, and for having to depend on her elderly parents. I explored this with her and realised that, despite the added pressure of the course, the more knowledge she gained, the more confident she became and the less frequently she had to contact the health and social care services for help.

She knew there were health and social care certificates and if she could complete them this would improve the care she could give to her son. Thankfully, her husband's job meant he was eventually able to come back home for a period of time, giving her space to concentrate on completing her training modules. She ended up getting a certificate in social care, and her coping mechanisms improved, meaning fewer trips to the hospital as she was better able to recognise the warning signs of detriment in her son's condition. An increased understanding of the complex nature of the condition enabled her to cope with her son better in their own home and, as a consequence, she gained confidence, which meant less frequent calls for help to NHS care providers.

This carer decided to go further by completing an access course and then undertaking training to become a registered nurse. She now has the full skillset to look after her son at home, and the social interaction she experienced helped her to cope with the psychological trauma she faced by diminishing her feelings of isolation. It also gave her a source of income as she was able to work two nights a week while her parents looked after her child. In her opinion, the whole family benefited as a result these opportunities.

My thoughts went back to my time as an academic teaching students. When a student nurse completes year one at university, they attain a certificate in health and social care and following success at the end of year two a diploma is awarded. Surely if we sought to place student nurses with carers at home, once each risk assessment and supervision package was gained, then it would be a win-win. We gain an increased number of placements and more students trained to meet our service delivery plans, and the students gain experience working in the community within an integrated health and social care setting. This would serve to meet the integrated environment of delivery in Wales and carers would get support to undertake accredited training, which would offer the additional benefit of offering a career training profile for a time when circumstances may permit them to return to paid employment.

Of course, I needed to establish if this was feasible for significant numbers of carers but the young mother's story made me start to believe my idea really could work.

A major concern among the carers looking after their children was that their whole life was engulfed in round-the-clock care and that their children have relatively short lifespans. They had spoken with others who had given up everything to care for their loved one and when they experienced the inevitable loss, life felt like it was no longer worth living. They felt isolated, lonely and of no use to anyone. Yet alongside their need to feel valued, they had so much experience and such compassion, and when I asked for their views on what difference training and qualifications could bring, they responded positively.

Although the idea is not suitable for everyone, qualifying as either a healthcare support worker or as a nurse would offer a paid and potentially empowering career that they would be able to focus on, and something that would enable them to re-engage and have a sense they were still able to provide care and to help others following this upsetting period in their lives.

I have since discussed the subject of carers having a career alongside their substantive care work with the Chief Nursing Officer for Wales and the director of human resources at the Welsh government and this agenda has now received a higher profile. It was agreed that widening access to health and social care training in Wales would have government agreement. However, what I really need to see is that support being taken forward into action. So onwards to influencing further...

Importantly, I've also spoken to deans and heads of healthcare schools at universities in Wales to see if they would be able to provide student nurses with carer placements during their training – offering some relief and support to individuals who are 24/7 carers, in order for them to study for their own qualifications. I also met with directors of nursing and chief executive officers of health boards. I purposefully chose to discuss this initiative with them as I knew they could enable solutions to be operationalised and we could then work on the advancement together.

So, what about the carers themselves? The co-production of influence continues. They have been involved in a cross-party discussion, with all National Assembly parties represented, where our carers, the Carer Support Group and I spoke about this work. It was received well, with an outcome being an agreement to continue to work together to make it happen.

In summary

When student nurses complete their first year of university, they qualify with the equivalent of a certificate in health and social care work, similar to what could be achieved by carers. If student nurses were to undertake placements working with carers in their own homes, then when they have completed two years of nurse training they will have achieved a diploma in health and social care. This would benefit both student and carer, with carers gaining in confidence and students gaining experience in the community and in caring for an individual in their own home, and then being suitable for placement in homes that require higher skills with higher-risk clients.

This strategy could have multiple positive outcomes: it could enable universities to increase student intake, increase student placements for healthcare providers and, most importantly, offer carers vital respite time to enable them to undertake healthcare training. It's an all-round winner.

I strongly believe in social justice and social reform, giving everybody the chance of a fair and equitable outcome, and the buy-in I have experienced from all parties is a real driver for change. Ultimately, with this you are setting people up to succeed, enabling them to live their lives and realise their full potential.

I always look for solutions to problems and challenges, with optimism being key. If you believe nothing is going to develop, then what gets you up in the morning? In challenging situations, I believe I can make a difference. However, it's important that I remember I can't do it alone; what's needed is a multidisciplinary, community approach where we are co-dependent on other people and on parts of a larger system. That's why it is important to know the people and networks to work with in order to have influence and make real change happen. And once movement starts and there are shared values and a shared goal or shared needs, this co-production is a vital driver.

The Chief Nursing Officer for Wales has to be able to build a nursing workforce that will deliver high-quality care. She can't do that if demand outstretches resource. Currently, directors of nursing know they can't get patients into hospital because they can't get patients out. If you've got patients with complex needs there is a need for them to be admitted but keeping those who don't need inpatient care in their homes, with the right care in place, is key to easing this problem.

People would rightly be sceptical if I claimed this plan could be implemented overnight – but we are working on it bit by bit. If we can ensure that all the co-producers are in it for the long haul, then there is no reason why we will not achieve success together, producing the results needed with the right systems in place. We have more than 130,000 carers in Wales that stand to benefit.

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