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Authors	Bourke , Julie;Flynn, Angela V.
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Inclusion:

Key to quality of life in disability

For people with disabilities, full social inclusion is one of the most crucial components of quality of life, write **Julie Bourke** and **Angela Flynn**

PRIMARY care nurses often feel under-equipped or unprepared to handle the unmet needs of people with disabilities. Increasingly, primary care services are recognised as being vital to the essential healthcare for people with disabilities.[1]

The term 'quality of life' refers to the physical, social, psychological and functional components of happiness.[2] Being healthy is important for one's quality of life, personal growth and community involvement. While health is a basic human right, not everyone enjoys the same degree of health and happiness.[3] Maintaining quality of life is extremely important for people living with disabilities.

Having a good quality of life can be linked to the amount of social inclusion or exclusion a person with a disability feels in their everyday life. There are different definitions of social exclusion, but it typically refers to the condition of disadvantage experienced by specific groups who are perceived to be marginalised in society and unable to fully engage in regular life.[4]

This article will discuss the factors that affect the quality of disabled people's lives, as well as the importance of social inclusion in the context of health inequalities. In addition, it will specifically discuss the experiences of nurses with self-identified sensory disabilities.

Models of disability

When talking about quality of life and the social inclusion of disabled people, the models of disability are important and relevant. There are two main models of disability: the medical model and the social model. People with disabilities are defined and classified in the medical model based on their disability. It portrays the person as a 'victim' or a 'problem'. A disabled person is framed as having to adapt to the demands of society and the environment in which they live. In terms of growth and functioning, there are 'norms' against which the individual is measured. It becomes more about what people can't do rather than what they can do. The focus becomes attempting to 'cure' or 'repair' the disabled person.[5] The medical model can be seen to be damaging to a disabled person's quality of life and can affect their image of themselves.

Alternatively, according to the social model, it is the unfavourable attitudes of society, social institutions, organisations and individual people that create obstacles inhibiting people with disabilities from obtaining services and resources. In this approach, society must adapt to enable people with disabilities to participate in society.[5] The social model is far more effective in boosting disabled people's self-esteem and improving their quality of life.

Intellectual disability

Intellectual disability (ID) can have a significant effect on people's lives. It has been argued that there is a gap in ID nursing research, which may be due to the ID nurse's limited visibility among the community of healthcare workers. Traditionally, people with intellectual disabilities have been excluded from mainstream society, leaving them with restricted opportunities and independence. They typically don't get the chance to choose what happens in their own lives as much as those without an ID.[9]

This societal attitude is ludicrous and affects immensely the general health and happiness of individuals with intellectual disabilities. Only Ireland and the UK provide direct-entry specialty undergraduate ID nursing education programmes.[6] As a consequence, this influences the quality of life of people with intellectual disabilities as there may be a related deficit of specialised care and treatment in this area in many countries.

Health inequalities

Health inequalities in people with intellectual disabilities are triggered by a range of causes. Individual features include the degree of impairment and any accompanying hereditary disorders. Secondary health issues, as opposed to personal/biological risk factors, are other variables that contribute to lower health status in those with intellectual disabilities.[3]

These health inequalities have a major effect on the quality of life of people with intellectual disabilities. The secondary health issues, although for the most part treatable, still cause major disruption to one's life. Individuals with intellectual and developmental impairments appear to have more difficulty accessing and using healthcare services than the general population.[3] The unfortunate irony here is evident, as this population requires far more healthcare and support than average.

People with disabilities were named as a groups in society which faces the most social exclusion during a debate of the links between social exclusion and health ahead of the 2008 WHO Commission on Social Determinants of Health. The Social Exclusion Knowledge Network, a subgroup of this commission, was formed in 2006 to explore and report on this link.

This network's final report found that inequalities in access to resources (means to satisfy human needs), capacities (the relative power people must employ to access the resources available to them) and rights characterise social exclusion processes, resulting in a continuum of inclusion/exclusion.[4]

Inequities in health arise as a result of this continuum. Social exclusion has a direct impact on health through its expressions in the health system, as well as an indirect impact on health through altering

economic and other social inequities. These inequities exacerbate social isolation, resulting in a vicious spiral.[4] It is important to talk about social inclusion and exclusion in the context of healthcare because the sector of basic healthcare is a critical location to observe evidence of social exclusion and its impact on health.[4]

Nurses with disabilities

Recent research on registered nurses with impairments has shown that nurses with sensory disorders are resigning or are on the verge of leaving the profession.[7] This is most notably due to the discrimination and lack of social inclusion they face in the workplace. Healthcare workers experience being pushed out by co-workers and management who believe they are unable to operate properly or do not 'lift their weight'.[7]

Despite cultural and educational disparities, physicians and nurses' experiences as healthcare workers with self-identified persistent sensory disability have been found to be very similar. Both groups revealed that career options and trajectories were narrowed as a result of disability and that deciding whether or not to disclose their condition at work could be difficult.

They also spoke about how they were affected by a wide range of emotions as a result of their disability-related professional issues. Nurses and physicians felt that the interactions that they had with colleagues reflected the culture around disability in the workplace and as a result they seldom asked for workplace modifications.[7] This type of social exclusion in the workforce can leave people with disabilities feeling like outcasts in their working lives, which is extremely damaging for their self-esteem.

Healthcare professionals often experience a loss of self-confidence and self-worth as a result of attempting to compensate for what they couldn't accomplish effortlessly. Anger, contempt and sadness were frequently expressed as a result of their frustration at others not being able to grasp that they could still think critically and act safely.[7]

This sadness and frustration can lead to a lower quality of life for the person with an impairment. These experiences can also cause people's self esteem and self image to lower drastically. Lower self image and self esteem can lead to poor mental health and even mental illness, such as depression and anxiety.

This demographic is recognised to be more vulnerable to mental health risks. Those who are deaf and hard of hearing, for example, are more prone to experience feelings of isolation and poor self worth and are more vulnerable to the adverse effects of domestic violence, both in childhood and adulthood.[8]

Conclusion

There are many different factors that impact quality of life for people with a disability. They may face prejudice while seeking healthcare or while working in the healthcare sector. Communication may have an effect on their experiences and their inclusion in society by influencing perceptions and models of disability.[5]

For those with impairments, social inclusion is equally critical. When someone with a disability seeks employment, they can be discriminated against and can find themselves socially ostracised. There are various definitions of social inclusion and exclusion in use, and their extent varies substantially. While numerous instruments have been created to measure these ideas in healthcare settings, they are not primarily focused on healthcare. In primary care settings, the need is there for the creation of a method for analysing social inclusion or exclusion.[4]

There is still more work to be done to ensure that all people in our communities have equitable access to healthcare services, including the pursuit of research to inform access, use and quality of healthcare services, as well as the continued implementation of systemic initiatives.[3] Only when these kinds of initiatives are achieved will we see full social inclusion for people with disabilities – a crucial component to ensuring quality of life.

Julie Bourke is an undergraduate nursing student and Angela Flynn is a lecturer, both at the School of Nursing and Midwifery at University College Cork

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