Contextualising disability and dentistry: challenging perceptions and removing barriers

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Key points

Argues the relationship between disability and oral health is manifested in material, social and cultural barriers that disabled people face when accessing health care.

Suggests there is a discrepancy between theory and practice within dentistry when considering disabled people and services.

Assimilating a social model approach to dentistry and drawing on research insights from other disciplines will support the provision of person-centred, empathetic, responsive oral health care.

Abstract

This paper explores the contextualised relationship between disability and oral health, locating questions about the oral health and oral health care of disabled people within wider debates about the material, social and cultural barriers that disabled people face when accessing health care. Sociological and disability studies research is drawn on to highlight potential barriers to oral health for disabled people and outline alternative ways of looking at, thinking about and challenging these barriers. Starting with a brief look at definitions and understandings of disability and the impact of this on attitudes, research on the multi-level barriers faced by disabled people within oral health care is then highlighted. The article concludes with some thoughts on how research from other disciplinary traditions can be useful in helping to make dentistry more prepared to appropriately and successfully meet the needs of disabled people, both in a special care setting but also, more crucially, in a general dental setting.

Introduction

Current research suggests that disabled people and people living with long-term disabling conditions, such as a mental illness or a learning difficulty, have poorer oral health than their non-disabled peers.[1,2] Broadly speaking, disabled children and adults experience the same common oral diseases and conditions as non-disabled children and adults. There is evidence, however, that they experience poorer outcomes. Caries rates among people with learning disabilities, for example, are comparable to those in the general population, but the decay is significantly less likely to be treated,[3,4] and when treated is more likely to result in extractions. This in turn can lead to poorer oral health outcomes,[5] and may also have wider implications, impacting negatively on self-esteem, quality of life, nutrition, communication and general health.[2]

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Poorer oral health outcomes from similar population level experiences of disease suggest that the problem may lie within dentistry itself,[6] and the barriers encountered by disabled people when using dental services, rather than in the nature of the impairment *per se*. Research suggests that disabled people face a range of barriers, such as inaccessible buildings or inflexible appointments, when using health services, causing dissatisfaction and potentially deterring health service use (see, for example, Lawler *et al.*, 2013; Allerton and Emerson, 2012).[7,8] According to the 2011 World Report on Disability, these barriers discriminate against disabled people when trying to access health care.[9] In this paper, the term barriers is derived from the social model of disability, where it denotes any feature of the material, social or cultural world that excludes or discriminates against a disabled person.[10] In the UK, the Equality Act 2010 requires health care providers to identify and remove barriers by making 'reasonable adjustments'. This means a change must be made to any feature of a building, practice or policy that would otherwise cause a disabled person to be treated unfairly.

Set within the context of a growing population of people living with long-term disabling conditions and widespread, often unconscious, deficit-based approaches to disability, this article explores the contextualised relationship between disability and oral health, drawing on sociological and disability studies research to highlight potential barriers to oral health and to outline alternative ways of looking at, thinking about and challenging these barriers facing disabled people. The article starts with definitions and understandings of disability, and the impact of this on attitudes by outlining the medical and social model approaches to disability. This leads to a discussion of the barriers identified within the dental literature and the implications of these multi-level barriers for the oral health care of disabled people. We then conclude with some thoughts on how the approaches outlined here can help to make the dental team more prepared to appropriately and successfully meet the needs of disabled people, both in a special care setting but also, more crucially, in general dental practice.

Definitions and perceptions of disability

In order to identify and challenge barriers faced by disabled people, the terms surrounding disabilities and their meanings need to be challenged and redefined. In his work on the politics of disablement, Mike Oliver suggested

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that definitions are important because we orientate our behaviour towards people according to how we define them.[9] If we see disabled people as tragic victims then we seek to 'care' for them. If we see them as oppressed, then we fight for their rights. The Equality Act 2010 in the UK, and equivalent legislation in the US and Europe, is part of this process of empowerment. While acknowledging that the picture is more nuanced than often presented, it is nevertheless useful to set the parameters of the debate by outlining these two opposing viewpoints.

The medical model of disability is encapsulated in the *International Classification of Impairment, Disability and Handicap*.[11] In this model the environment is seen as neutral and the limitations faced by disabled people are caused by their impairment and the resulting acts they are unable to perform (such as walking, seeing or hearing). Underlying this is the assumption that disabled people should be willing to adjust themselves to become more 'normal' (for example, through the use of medical and animal aids, artificial limbs or cochlear implants),[12] and adjust their expectations to make the best of their 'diminished circumstances', perpetuating the idea of disabled people as tragic victims of the circumstance of their impaired bodies.[13]

An alternative way of understanding disability is provided by the social model.[14] This definition rejects the idea that the body, and any impairment it may have, has anything to do with an individual's experience of disablement. Disability is caused by a social environment which fails to take account of the needs of people with non-normative bodies. This results in disabled people routinely encountering barriers to full participation, whether in the form of a lack of physical access to a building, discrimination, or policies which encourage inflexible working patterns. The social model approach was designed to politicise the disability movement's struggle for equality,[15] suggesting that it is social oppression which prevents individuals from participating fully in society.

Acknowledging the polarisation of debates around disability, and after consultation, the WHO published the International Classification of Functioning and Health (ICF) in 2001.[16] Starting from the presence of a health condition (widely interpreted to include everything from disease or injury to health issues associated with natural phenomenon such as pregnancy), the ICF distinguished three levels of human functioning. Functioning can be classified at the body level (body functions and structures/impairment); the level of the whole person (activity/activity limitation); and incorporating the lived experience of health (participation/participation restrictions). In addition, both environmental and personal factors are included in the model, which advocates suggest is both multi-dimensional and interactive. The ICF is in wide use as a standard epidemiological tool in research across medicine and many allied fields.[17] Critics suggest that the focus of the ICF remains on people with a (biomedicalised) health condition while advocates suggest that this is a misinterpretation of a model that is intended to be applicable to every human being and not solely to a pre-selected, or minority, group.[17]

It is the interface between the bio-medical and the social that is at the heart of debates about disability. Disability activists say disabled people are consistently discriminated against, oppressed and stopped from achieving their potential in a world designed for non-impaired bodies.[12] These debates can be used to contextualise poorer oral health outcomes for disabled people and the implications of what disability activists would call the 'social oppression' of disabled people in relation to their oral health and their access to and use of oral health services.

Barriers to oral health

A study by Scully *et al.*[18] suggested four categories of barriers which prevent people accessing oral health care. These are: individual; dental profession; societal and governmental barriers. Individual barriers include a lack of perception of need by individuals;[19] or their carers;[3] difficulty following instructions with relation to oral self-care;[20] and access problems including those relating to travel to and from the dental surgery.[21] Barriers relating to the dental profession include a lack of training specific to the requirements of the job;[22] poor communication skills;[23] high staff turnover which results in a lack of trust and continuity of care;[22,24] and a lack of time and resources.[22] In addition, cramped and inappropriate clinical environments and a lack of funding were identified.[25,26]

Societal barriers include a lack of awareness of the importance of oral health care and oral health promotion,[4] a lack of appropriate service planning and provision and a lack of research into the oral health needs of disabled people.[2,26] Finally, governmental barriers include a lack of resources for oral health services and the resulting inability to put planning and policy into practice and ensure good quality oral health care for everyone.[21] This suggests that there are significant, multi-level barriers to ensuring that the oral health needs of disabled people are met and that they receive good quality care.

By categorising research on the barriers to accessible oral healthcare for disabled people, using the categories set out by Scully *et al.*, it is possible to discern the micro-, meso- and macro-level responses to the problem of poor oral health outcomes among disabled people. What is clear from this is that the majority of research that has been undertaken focuses on disabled people as the source of the problem and their 'inability' to use general dental services.[4] Thus, the evidence base used to teach the dental care team and design services perpetuates an implicit medical model approach, potentially reproducing the attitudinal (and other) barriers faced by disabled patients accessing oral health care. To contest these barriers this, often subconsciously, embedded approach needs challenging.

Beyond the biomedical in dentistry

Locker's conceptual framework for measuring oral health status[27] made the link between impairment and a range of psychosocial and functional outcomes of oral disease, and has been pivotal in the development of dental research on the impact of oral disease and disorders on daily life.[28] Locker's framework, which explicitly drew on the ICIDH,[11] acknowledged the socially contextual nature of functional limitations while stopping short of questioning the nature of disability itself. More recent literature reflects awareness of the need to challenge the medical model approach, calling for a socially aware approach which focuses on barriers to accessing oral health care and ways to remove them.[4,22,26,29]

In 2007, Goss explicitly called for dentistry to adopt the social model approach as a means of focusing on the environmental barriers, including attitudinal and awareness issues, which prevent disabled people from accessing dental services or promote dependency and powerlessness.[30] This call to action tied in with the publication, in 2007, of *Valuing Oral Health: a good practice guide for improving the oral health if disabled children and adults,*[31] which advocated the promotion of choice and inclusive practice. More recently, Owens emphasised the fact that responsibility rests with the whole dental team, suggesting that 'the condition of being human means that we

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need to engage with diversity and treat people with disabilities with dignity, respecting and ensuring that they have a say in their health care and everyday lives'.[29]

When looking at dental and allied professionals' attitudes towards disability within a special care dentistry (SCD) context however, the picture is less bleak. Scambler *et al.*[22] carried out a retroductive analysis of a series of focus groups and interviews with dental and allied professionals (n = 30), using a theoretical framework modelled on the key tenets of the social model approach to disability. This incorporated the social cause of disability,[10,32] patient-centred approach, disability as secondary to dental care needs, and equality of care.[33] They found that the attitudes of community SCD staff supported the social model approach, with an underlying ethos of equality and awareness of the environmental, social and organisational barriers facing people with impairments but demonstrated no explicit knowledge of the social model itself.

Discussion

While some of the organisational, financial, skills-based and attitudinal barriers to accessing dental care services may be addressed through accessing a specialist (SCD) service run by a trained, disability-aware dental team, as a salaried service, a recent article[26] suggests that this is only a partial solution to the apparent widespread medicalised view of disability within dentistry. The vast majority of disabled people should be, and would prefer to be, treated by their local dental practitioners. Furthermore, barriers identified by disabled people in accessing dental care are often located in wider societal attitudes towards disability and disabled people; this supersedes the presentation of these barriers in the dental surgeries and among dental staff. Members of the dental team, unsurprisingly, reflect the views and mindset of the society to which they belong and are subject to health policies which provide insufficient funding to make the 'reasonable adjustments' necessary to provide good quality care for disabled patients.[26]

The rhetoric around disability is moving from a medical perspective towards a social model approach but there is a lag between the theory and practice within dentistry, which, we argue, is reflected in differential treatment outcomes. By failing to fully embrace the social model, the care provided to disabled people is at risk of not only holding back individuals' ability to achieve 'good' oral health but also exacerbating barriers to ongoing, effective care. Dentistry must move beyond biomedicine if it is to break through the explicit and implicit barriers highlighted here. By assimilating a social model approach, dentistry as a whole can contribute to barrier removal, and the provision of person-centred, empathetic, responsive oral health care. Special care dentistry is at the forefront of this and leads the way in barrier recognition and removal, but the medical model approach still underpins most dental practice.

Conclusion

In this article we have not sought to outline the structure of dental service provision for disabled people, nor the practicalities of providing dental care for people with a range of different impairments. The aim of this paper, rather, is to explore the oral health of disabled people and dental care provision in its widest context, exploring attitudes towards disability and disabled people and how these manifest themselves in the barriers, discrimination and social disadvantages that disabled people are forced to deal with on a daily basis. The slow move towards a social model approach to disability within medicine and dentistry is welcomed but it is worth noting that the poor oral health outcomes currently experienced by this group, when compared with their non-disabled peers, still exist and can be explained through the individual, professional, societal and policy level barriers encountered in accessing dental care. Any barrier is a potent reminder that disabled people are always excludable, as inclusion is conditional on someone else's perception of who belongs where.[34] The need to challenge the biomedical approach, and identify and remove barriers remains paramount to the provision of good quality, equitable dental care.

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