Professional attitudes towards disability in special care dentistry

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Abstract

Aim: To use a theoretical framework to explore attitudes of staff within a Community Special Care Dentistry Department towards disability, disabled people and the provision of dental care for disabled people.

Design: Qualitative data from interviews and focus groups of community special care dentistry staff (n=30) working across hospital and community sites. Respondents were asked about attitudes towards disability and disabled people, the provision of dental care for disabled people and to design an ideal service. Data were analysed retroductively using a theoretically derived framework modelled on the key tenets of the social model approach to disability.

Setting: Data were collected from one large salaried dental service based in inner south-east London, as part of a Pacesetters Project through King’s College Hospital and the Department of Health.

Results: An awareness of the underlying ethos of the social model approach to disability was demonstrated by community special care dental staff in relation to both the ethos of care and in practice. Disability was seen as an issue to be dealt with by the clinic rather than as an individual problem. Patient centred care, adapted to ensure that the needs of all patients could be adequately met, was at the heart of the model. Specific issues around communication, time, the need for trust, and specialist training were raised. It was also suggested that many of the skills needed to provide care for patients with complex needs were honed over time.

Conclusions: There is evidence that community special care dentistry staff hold attitudes in support of the social model of disability and will provide an important resource to the profession. Future training needs for dental professionals are discussed.

Key words: Disability, SCD, social model, equality

Introduction

Historically, it has been found that those with a disability or other impairment (such as a mental illness or a learning difficulty) have worse oral health than those without such disabilities or impairments (Melville, 1981; Scott, 1998; Cumella et al., 2000). Not only can this cause physical problems, but it could potentially have a wider reaching impact. For example, it has been found that good oral health can have a positive effect on self-esteem, quality of life and general health (Health of the Nation, 1991, Section C, p.81, HMSO). Improving the levels of oral health in those with impairments or disabilities is consequently a major issue for the dental care services.

Special Care Dentistry (SCD) has evolved from the former community and salaried dental service (General Dental Council, 2008) in response to identified need for a specialty (JASCD, 2003; Gallagher & Fiske, 2007). SCD aims to cater for those with “a physical, sensory, intellectual, mental, medical, emotional or social impairment or disability or, more often, a combination of a number of these factors” (Fiske, 2006, p97). It was established to provide care for people with complex special needs and support primary care practitioners in providing the majority of routine care (Gallagher and Fiske, 2007). This is potentially a large proportion of the population. For example, recent figures show just over 24.5 million people registered for Disability Living Allowance (DLA) in the UK (Summerfield, 2004). There are just under one million people in England with a learning difficulty (Emerson and Hatton 2004) and approximately six million people with a mental illness (McManus et al., 2009). Gallagher and Fiske (2007) estimated that in the UK, over 200,000 adults have profound learning disabilities and/or complex medical conditions.

Although SCD offers a service that is much needed, there is some evidence that not all those who should be able to,
or want to, access dental services can do so (Oliver and Nunn, 1995). This can be for a variety of reasons, including a physical inability to access the premises (caused by a lack of wheelchair access or inadequate facilities for those who are blind or deaf), a lack of knowledge regarding the service and how to access it or a fear of the treatment (British Society for Disability and Oral Health, 2000). Whilst some of these issues stem from difficulties experienced in accessing the services, others stem from the adoption of the medical model approach to disability and disabled people prevalent across dentistry (Locker, 1988). Awareness of the alternative social model approach is slowly emerging, but to date most dentistry remains highly dependent on the medical model of disability with its focus on the impairments and disabilities experienced by the individual patient and the ways and means in which the dentist can ensure that the patient receives the best possible care. Teaching which incorporates critical analysis of the social and medical models of disability, and special care teaching more generally, has recently emerged as a key component of both undergraduate and postgraduate dental training (Nunn et al., 2005; Thompson, 2008).

This paper used data from a Department of Health and KCH NHS Trust funded Pacesetters study on disability and dentistry (Scambler et al., 2010). The aim of the paper was to use a theoretical framework to explore attitudes of staff within a Community Special Care Dentistry Department towards disability, disabled people and the provision of dental care for disabled people. This was in line with the aims of the original study informing the development of patient-centred oral and dental care for disabled adults. Focus groups and interviews with clinical, allied and administrative staff across the department were used to make the case that the social model approach to disability is neither widely understood nor acknowledged within discourses around practice. Clear instances of (unconscious) social model influenced behaviours and beliefs could be distinguished suggesting that a social model ethos exists at least amongst some staff. It is posited that this is due both to the nature of the patient group and of the type of work involved in community special care dentistry and also to the types of professionals attracted to working in this area. This paper makes suggestions as to how this ethos can be expanded and how a more formalised knowledge and understanding of the social model approach to disability and to the provision of care for disabled people can be fostered in dentistry to further improve the provision of patient care. The paper outlines the key tenets of the social model of disability in relation to the medical model and the practice of dentistry. A brief explanation of the methodology for the study is given before the results are presented. Finally, the implications of the empirical data and the theoretical model are explored in relation to the future development of community and hospital based Special Care Dentistry and dentistry in general.

Models of disability

The term disability has been defined in a variety of ways over the past quarter of a century. The definitional frameworks and their critiques are complex, hinging on the interface between the bio-medical and the social and the role of bio-medicine in defining and ‘treating’ disability and the role of society in shaping the ‘experience of disability’. The approach of dentistry towards disability and the provision of care for disabled people has been shaped, at least in part, by the conceptual framework for measuring oral health status which was developed by Locker in 1988. This emerged from the ‘International Classification of Impairment, Disability and Handicap’ which defines disability as “a restriction or lack (resulting from an impairment) of ability to perform an activity in a manner or within the range considered normal for a human being” (WHO, 1981).

Locker’s model made the link between impairment and a whole range of functional and psychosocial outcomes of oral disease (Locker, 1988) and has been ‘pivotal’ in the development of dental research on the impact of oral disease and disorders on daily life (Allen, 2003). Locker moved beyond the ‘impaired body as the cause of disability and handicap’, however, to suggest that handicap is both a product of society and is dynamic in nature:

“The extent to which functional limitations and activity restrictions cause a problem, or are otherwise handicapping, is not only variable historically and culturally but is also somewhat dependent on more immediate contexts: their meaning is not the same across different social and environmental settings.” (Locker, 1983: 5)

This acknowledged the socially contextual nature of functional limitations whilst stopping short of questioning the nature of disability itself. More recently, studies have looked to utilise ICIDH-2, the International Classification of Functioning, Disability and Health (WHO 2001) as a way to calculate the number of people in need of special dental care, acknowledging the role of the environment in the creation and perpetuation of disability (Allison et al., 2001). Again, however, the assumption that disability hinges on an impaired individual is not questioned.

The social model of disability developed alongside the ICIDH as an alternative, suggesting that disability is caused solely through the inadequate adaptation of the environment to the needs of people with impairments. The clearest version of this definition, which is in wide use in the areas of disability studies and politics, is as follows:

**Impairment** - lacking part or all of a limb, or having a defective limb, organ or mechanism of the body.

**Disability** - the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or lit-
The ICIDH/ICIDH-2 is still widely used within dentistry and a whole range of other medical and non-medical professions, either implicitly or explicitly. Amongst a number of criticisms it has been pointed out that the ICIDH placed the emphasis on the impairment as the cause of disability and handicap. The environment was seen as neutral and the onus was placed on the individual, with the use of medical aids, to fit in to the environment (Oliver, 1990; Swain et al., 1993). Rather than being viewed as the result of an inadequate social environment, as may originally have been intended, a number of researchers have suggested that the ‘handicap’ category gives the impression that handicaps are merely complex disabilities’ (Birkenbach et al., 1999), a view echoed by Grimsby et al., (1988) and Orgogozo (1994). Birkenbach et al., went on to suggest that:

“Although identified as a classification ‘of circumstances in which disabled people are likely to find themselves’, there is never any reference in the handicap classification to features of the social world that create those circumstances. It is a classification of limitations of people’s abilities.” (1999; p1175)

This growing awareness of the limitations of the medical model of disability (ICIDH/ICIDH-2) led to calls for the dental profession to challenge negative attitudes towards disability within dentistry. In a recent editorial in this journal, Goss (2007) called for dentistry to adopt the social model approach as 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.

These are, by no means, always explicit or deliberate but can, sometimes, be borne out of low levels of disability awareness, which can result in anxiety and, at worst, a lack of enthusiasm and or willingness to treat disabled people (Goss 2007). It is from this starting point that attitudes towards disability and disabled people within Special Care Dentistry can be explored.

Method

The empirical data for this paper came from a Department of Health and King’s College Hospital NHS Trust funded qualitative study on disability and dentistry which is part of the Pacesetters Programme. The aim of the Pacesetters Project was to inform the development of patient-centred oral and dental care for disabled adults. Data were collected through focus groups and in-depth semi-structured interviews with dental and allied professionals and administrative staff working within a Community Special Care Dentistry Department and covered attitudes towards disability and disabled people, and issues around service provision and the composition of an ideal service. The sample consisted of consultants, senior house officers, dentists, dental nurses, hygienists and administrative staff and in total eight focus groups and three interviews were conducted with 30 staff across the department. Ethics (08/H0802/56) and Research & Development (KCH429) approvals were obtained for the study prior to commencement and informed written consent was obtained from all participants. All interviews and focus groups were recorded and transcribed verbatim. The original data analysis was conducted using a thematic content analysis (Silverman, 2006; Low, 2007), a four stage process involving: familiarisation; development of the coding frame; coding and compiling themes and exploring the depth and breadth of talk on each theme (Green, 2007). The data were then reanalysed retroductively (Blaikie, 2000) to test the fit between the data and the social model of disability using a theoretical framework derived from the extensive literature on the social model approach presented above.

The theoretical model

Theoretical modelling of empirical data is one way of illustrating the potentially wider implications of views and opinions expressed within the data. Retroductive analysis was conducted using a theoretically derived framework modelled on the key tenets of the social model approach to disability (UPIAS 1976). This incorporates: The Social Cause of Disability (Oliver, 1990; Swain et al., 1993):
• Disability is caused by society not impairment
• Services should be adapted to meet the needs of the patient not vice versa
• Focus is on accessibility of clinic, personnel, information, treatment options and communication.

Patient centred care (Charlton, 1998):
• Patient needs are prioritised over convenience, cost or time, the best treatment for a patient may not be the most comprehensive. Avoiding GA/Sedation unless absolutely necessary
• Disability as secondary to dental care needs.

Equality of care (Galipeault, 2004):
• Disability as secondary to dental care
• Disabled people receiving the same quality of care and treatment as non-disabled people.

These themes were developed to reflect the underlying ethos of the social model of disability rather than relating to the semantics of the definition itself. This allowed for the charting of attitudes and working practices COMPLICIT with the social model approach even where a direct knowledge of the key arguments and debates were not known or presented.

Results

The data presented here reflect the attitudes of the dental and allied professionals and the ethos of the service provided to disabled people. The results are presented according to the four aspects of the framework described above.

The Social Cause of Disability

There was no direct reference to the social model approach by any of the participants in the study and none had been on recent training incorporating these ideas and debates. There were, however, a number of references to the importance of designing services that allowed full participation and treatment for all patients regardless of disabilities or special needs. A number of dental and nursing staff talked about the fact that the ‘disability’ is ‘our problem and not the patients’. In other words the patient should expect and receive the same quality of care and treatment as any other patient and it is up to the dental team to work out the practicalities of how to make that happen.

“In Community we do the same thing for every patient because it is as if...well every patient who comes through our door has say HIV for instance so we don’t do anything different for anyone.” (S005:FS2:9)

“This attitude suggests there is understanding that the disability is a hurdle to be overcome by the service and not the patient. It is worth noting, however, that this attitude was most common amongst clinical and allied staff and there was markedly less awareness of the specific importance of inclusion amongst support staff.

Many staff, at all levels, also stated that they would often find themselves treating people whom they felt could and should be treated in primary dental care by GDPs but appeared to be referred inappropriately through fear, lack of expertise or time-related issues, which was a source of frustration.

“My feeling is that if you are a special care dentist, you are treating special care groups. Therefore the people that we should be treating, spending more of our time on, should be those people that really do need our services.” (S008:18)

These patients were often treated by the SCD team as a means of ensuring that they received the care they needed rather than because of a specific need for this type of specialist service. The idea of a shared responsibility towards disability was also reflected in the idea of services provided and tailored to the needs of individual patients at the service delivery level. Again this was raised by dental, nursing and allied staff and related to service delivery and design and included domiciliary services, community clinics and mobile clinics. Services were also provided for care homes it was broadly felt that this was an important and delicate area, requiring proactive, sensitive handling.

“Let’s get some care plans going for them, dental care plans, trying to make them as simple as possible so they are actually achievable. I have every sympathy with care homes who might end up having, they may cater for people with, perhaps, more Alzheimer’s or learning disabilities, and if you have 20 clients and three people or four people to get them up in the morning and it takes 10 minutes to sort out their oral needs for each person, you know that’s a considerable proportion of the morning actually just sort of brushing teeth and stuff like that. Let alone getting them out of bed, sorting them out to get them in to the day room or whatever, ...you know it’s not easy sometimes, but it doesn’t, you know that doesn’t mean to say that we should have, you know, supervised or unsupervised neglect. We should be being a little more proactive in going in there.” (S008:27)
Services were provided in locations appropriate to the needs of patients to address issues of access. There were also comments about the timing of appointments, the length of appointments and a variety of practical issues around parking and accompaniment by families or carers and specifically for treatment under sedation. There was also awareness that some of the facilities and treatments were not fully accessible and that there was a lack of funding from the NHS (local Primary Care Trusts (PCTs)) for the modification and redevelopment of facilities.

**Patient-Centred Care**

The second theme related to the ethos that, wherever practicable, the needs of the patient take precedence over everything else. Awareness of the specific and individualised needs of patients was reflected not just at a macro level in the organisation of the service itself but also on a micro level in the pre-eminence placed on patient-centred care. This involved a holistic element to the care being provided:

"...I think when you’ve got to take into consideration somebody’s capacity to consent, their medical issues, how they actually have dental treatment, can they cooperate…… you know, you’ve got lots of things to consider.” (S007:5)

It also incorporated the idea of tailoring treatment specifically to the patient:

“Sometimes it might be your decision is not to treat, because that’s in the best interests of the patient or because they’re old and frail and bed bound or whatever…you don’t always dive in there and do what a dentist should do, you know; filling and taking out teeth and whatever; you, you’re acting in the best interests of the patient as a whole rather than just the mouth.” (S007:5)

“Because of cover you ask when the best time of day is as well don’t you, so if somebody is better in the morning...” (S005:FS5:5)

And providing appropriate information and support:

“...the whole fact that we are special care we have had to, we have to know how to go about that, giving those instructions of patient oral health dependent on their disability and so forth…these are tailor made, you know; even to the point where brushes have been sent and made a special handle with putty so that it fits that person’s hand” (S005:FS2:17)

“We got to know all the carers, the multidisciplinary team and links we were able to transfer. So, for example, patients with severe autism or severe learning difficulties weren’t having, just to get to know the faces, but just the environment. One of the things that we did was to make up photo albums and sort of a diary about ourselves and the environment and although some of those clients have moved house and they don’t necessarily live close to the general, they have stayed on and they’ve kept the same carers they had before. So we’re trying for continuity of care.” (S001:FS4:7)

Time came up as a major issue, often related to remuneration where staff were aware of the opportunity that their salaried service provided to shape care to focus on the patients’ needs rather than a business model established for mainstream services:

“I never felt that I had to make a set amount each month and I think that’s very good because it allows you to do the treatment that you should do.” (S008:24)

“I don’t think the patients we see you could treat and make a living doing it if you were dependent on say rules as a general practitioner; and that’s the bottom line really.” (S004:FS3:2)

But also solely in relation to the amount of time needed to best treat patients and the opportunity to build relationships over time:

“A number of our staff have known their patients from when they were little, you know, so there’s, there’s a relationship, erm, that has built up that patients want to come in to see those……these patients with, erm, really sort of special needs because they’ve seen that face it’s become familiar.” (S009:17)

“When you got people with bad learning difficulties you do have to have a lot of time and patience.” (S003:FS5:3)

This theme came up repeatedly and time is a crucial factor on a number of levels. Even before clinical work commenced, time was invested in building up relationships and confidence to allow the work to be carried out, preferably without the need for sedation. There was then, extra time needed in the clinic when treating patients with complex needs or communication needs. Considerable time was also spent chasing referrals and expert advice from a range of health professionals when providing care for patients with multiple conditions or complex medical histories.

**Equality of Care/Disability as Secondary**

Perhaps unsurprisingly in a service dedicated to providing dental care for people with a range of special care needs; there was no direct suggestion from any of the participants in the study that the disabilities of the pa-
patients were secondary. They were clearly a central concern in the care. This being said, the focus on patient-centred holistic care, suggests an acknowledgment that, whilst the disability cannot be ignored in this setting, it is still secondary to the person. The general and universal belief in equality when related to disabled patients was not explicitly stated either, but nevertheless visible in ethos, attitudes and the passion with which the staff, at all levels, spoke about the importance of special care and the roles that they carry out. This was illustrated through the desire to reach out to particularly vulnerable groups

“I think the ideal service has got to be a combination of reaching out to people, so it’s not just a question of waiting for people to come to you. You have to have an element where people are going out to find the people that need your services. And the one group particularly springs to mind are the people for instance who are in care homes. Because they often, especially if they’ve got Alzheimers or something like that, and older people are renowned for being stoical, they don’t complain. And it’s probably true that most dental problems actually don’t hurt them until it’s too late, but their mouths could have a big impact on their life you know, as regards as enjoyment for chewing or just how they feel, look, laugh, and everything else...” (S008:26).

And also through the continued fight for accessible clinics:

“I think that the PCTs really do need to look at the services that are being provided for our patients, erm, I mean it’s fine saying about, erm you know, making our services accessible for the disabled when we’ve still got clinics that are not, clearly not accessible and haven’t been accessible for a number of years” (S009:18)

And for greater access generally:

“...a lot of the things I have done have been to do with trying to encourage access for adults with special needs and also families with children with special needs and including things like doing group work, using things like the ways of drama and things to try and build up, erm, some work that they have in the centre which shows photographic stuff and things like that that gets them more prepared to access services.” (S003:FS2:1)

There was a widespread feeling that the work being done in this department was worthwhile and important and made a real difference to the lives of those treated within the service and for the wider community.

**Discussion**

The results from this study suggest that there are significant elements of current practice within this special care team that are in line with the ethos and aims of the social model approach to disability. There was little argument explicitly based on the social model; (understanding of the model was not tested), but a generalised acceptance/practical examples of the fundamental ethos of equality and an awareness of the role played by poorly designed, funded or organised services and inadequately trained staff in propagating inequality and the socially disabling effects of impairments. There is little work that reflects an explicit social model approach to disability within dentistry. There is, however, some evidence that rights and inclusion are prioritised by some members of the dental team and not others (Bedi et al., 2001), and that attitudes expressed by the dental team, and society more widely, can be a barrier to the use of dental services. This has been demonstrated in studies exploring barriers to dental care for older people, where perceived negative attitudes perpetuated by dentists, poverty, and a lack of social support can create barriers (Kiyak and Reichmuth 2005; Borreani et al., 2010). Current work by Owens et al. (2011) takes this to the next level and uses an explicitly social model framework to suggest that the social model may be used to enable people to actively participate in their oral healthcare by exploring the wider determinants, rather than focusing on impairment and deficit. This echoes the work of Nick Goss (ibid) who highlighted the need to challenge negative attitudes towards disability within dentistry through adopting 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. For dentistry to rise to this challenge it is important to assess where current attitudes and understanding lie before seeking to raise awareness through the implementation of training programmes or service developments.

The data presented here demonstrated that, whilst theoretical knowledge may be sketchy, Special Care Dentistry professionals in the service studied were clear both on the ethos of equality and the removal of barriers for disabled people and on how this affected and shaped the services that they provided. Whilst not seen as socially caused, disability was acknowledged to have clear social implications and barriers, and one respondent did go as far as to say that the disability is a problem for the service but not the individual. The patient was considered to be at the centre of the care provided, both from a macro service development stance and from the micro organisation and delivery of individual care. Furthermore, there was some evidence that the disability was secondary both to the individual patients and their care needs.
Developing and running a service which accepts and adopts a social model approach to disability does not mean signing up to the extremes that are often portrayed in the theoretical debates. It does, however, involve designing and providing a service that believes in equality and that signs up to the idea that a well designed, organised and provided service can move a significant way towards removing the barriers faced by disabled people in accessing services which most non-disabled people take for granted. Conversely there is the tacit understanding that a poorly designed, non-accessible (physically, financially, and in relation to information and communication) service staffed by non-specialised staff may exacerbate existing barriers and further ‘dis-able’ people. It is clear that some excellent work is being done to this end, albeit not explicitly, and it would seem that Special Care Dentistry is ideally placed to provide an exemplar of practice in this area and leadership in taking this model forward both in the dental field and into wider medical areas.

A study carried out by Romer et al., (1999) found little training available in Canada and the USA at undergraduate level in the treatment of special care patients despite that fact that the vast majority of disabled people are treated within the community. The authors suggested that increasing the training would improve both access and quality of care for disabled people. Recognition of the need for specialist training is not new; however, the momentum to include it within the undergraduate curriculum has picked up pace over the last few years (Nunn et al., 2005; Thompson 2008), amidst arguments about whether the training is needed at pre- or postgraduate level (Thierer and Meyerowitz 2005). King’s College London Dental Institute has run Masters Programmes incorporating Special Care Dentistry (Little et al., 2004) for some time. Other countries have also taken this aspect of dentistry seriously with the Netherlands developing a three year postgraduate programme for dentistry for the disabled in 2004 (Broers & Meuwissen, 2001). The momentum for a Specialty of Special Care Dentistry grew through the 1990s with a Royal College Working Group (1999) recommending the establishment of the Joint Advisory Committee for Special Care Dentistry and a public health led Case of Need (JASCD, 2003; Gallagher & Fiske, 2007) with the necessary approvals in place for the GDC to open the specialist list in 2008 (GDC, 2008). Higher specialist training has been formalised. Furthermore, the opportunity for Dentists with a Special Interest in Special Care Dentistry has been created (Department of Health, 2009). These findings suggest there is evidence that special care services across hospital and community setting are working in line with the social role theory. Clearly there is a role for specialists to develop the wider primary dental care workforce either as generalists or DwSIs to support the care of people with a disability so that the community special care service is used most appropriately.

Conclusion

There is evidence that community special care dentistry staff hold attitudes in support of the social model of disability with an underlying ethos of equality and awareness of the environmental, social and organisational barriers facing people with impairments. As such, community special care dentistry can provide an important resource to the profession in demonstrating the ways in which services for disabled people should be provided not just within special care services but across dentistry. An explicitly theoretical take on disability awareness has also been introduced into both the undergraduate and postgraduate curriculum in Special Care Dentistry at King’s College London, further strengthening awareness of issues of oppression, discrimination and difference with the aim of strengthening implicit good practice with explicit understanding of the issues underlying it.

It is clear that any training pathway for dentist and allied professionals choosing to work in the field of special care dentistry should include training on approaches and attitudes towards disability. Disability awareness training should also be made available to support staff including reception and administrative staff as they are often the front line contacts for the service. In addition, this training should be rolled out to staff in general dental practice where the majority of disabled people receive dental care but also system changes to support their providing care for people with a disability – perhaps developing DwSIs in Special Care Dentistry is the way forwards (Department of Health & Faculty of General Dental Practice, 2009). The expertise of experiences Special Care Staff makes them ideal sources of information, training and practical help for the wider dental profession.

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