

'Take nothing on its looks; take everything on evidence. There's no better rule'.

Charles Dickens: Great Expectations

## **In the first person: A body of clinical evidence**

### **Abstract**

Clinical evidence is written on the body but how do people read it? In considering the nature of evidence, this paper examines how people who have developmental disabilities give their [clinical] evidence and (for some) examines the nature of their relationships with others in order to make it seen. Such an examination brings to light the evidence of developmental disability nursing in a series of vignettes.

English literature and developmental disability nursing on the same page; some things really do come full circle. A literary excursion into the ways of nursing.

George Gissing (1898) said of **Great Expectations** that 'no story in the first person was ever better told'. When I read that, I immediately thought of the fact that developmental disability nursing is full of stories told in the first person ; here I mean by you (a person who has a developmental disability) or by me (a developmental disability nurse). These stories culminate in a body of evidence – taken from moments over time, telling of lives lived and of extraordinary relationships that may be needed for the telling – that belong to ordinary people and to nursing work. **You**: you plural, a collective 'you' when necessary that embraces all that individualism. I will not keep talking about 'people who have developmental disabilities'. You and I know who you are. It is the best I can do right now; we here will think of you, each of you, in the first person. We are in this together; it is a joint venture of sorts.

### **The vignette**

My plan was to examine this body of evidence – call it clinical, because that is what we are about here – in some sort of engaging, creative way (developmental disability nurses are nothing if not creative, as are you, in so many ways). I had decided to look at evidence of developmental disability nursing in a reflective way, through a series of vignettes. Reading about the history and meanings of the vignette in photography and writing, it seemed a suitable framework for this paper.

### **Photographic and literary**

From old French, diminutive of 'vigne', vignette, originally a picture with a decorative border, typically based on foliage, applied to medieval manuscripts, illuminations. The vignette later transferred to the pictures themselves. In the 19<sup>th</sup> century, the vignette described a head and shoulders photograph which was clear in the centre and faded off at the edges (Ayto, 2001). Today it can be any image, the brightness or saturation of which reduces at the periphery, compared to the image centre. We have 'vignetting', a clear example of which can be seen in the photographs of Eugene Atget : a circular shadow around the edges of the image ( Cartier-Bresson., & Sirven, 2011). I was lucky enough to see some of Atget's superb photographs of old Paris at the NSW Art Gallery exhibition last month.

In literature, a vignette can mean a strong impression about an idea, character or object; a brief evocative description; a short, impressionistic

scene that focuses on a moment (Ayto, 2001). As nurses, we have our work structures, with the weight of the profession and government bodies pressing on us; shaping what we do and how we do it. The activities and interactions of moments; they are what defines clinical nursing practice. For the world can be contained in a moment. These moments which define practice, that are your life; each such moment is that central image (you; being bathed, having breakfast, going to a medical appointment, being talked to for the last time, smiling, going to work, breathing easier), right there, with the greater, outer context of life and nursing practice constituting the blurry edges of the vignette. So it seems to me.

### **Preface to an examination of the nature of evidence**

When I was eight and nine years old, and living in Stockholm, a charming lady lived a few houses away on Hockertsvagen. Her name was Mary Dickens Lindberg and she was a direct descendant of Charles Dickens, writer and social critic. She loved her Siamese cats, and was a terrible driver.

'There's no art  
To find the mind's construction in the face'.  
Macbeth Act I Scene IV 11-12 (Rowse, 1978)

### **Evidence**

Origin: middle English via old French. From Latin 'evidentia'.  
Evident: obvious to the mind or eye (Ayto, 2001). Historical evidence in a word.

Available body of facts or information indicating whether or not a belief or proposition is true or valid (Ayto, 2001). Take the Mona Lisa. Everyone knows her face. Probably painted between 1503 and 1506. Reliably thought to be Lisa Gherardini, wife of Francesco del Giocondo, a Florentine cloth merchant. Source: most reliably Giorgio Vasari, author of the first commentary on the Mona Lisa, probably written in 1547. By then Leonardo da Vinci had been dead for twenty eight years, Francesco for eight. Lisa was still alive (Lucas, 1915; Sassoon, 2002). Solid evidence?

Decipherment: 'The problem of decipherment is always theoretically capable of solution provided that enough evidence is available (Pope, 1975). Your body as code. The mind that cannot be read in the face, or anywhere, come to that. For me your 'differences' are as anyone's 'differences'; they do

not demand a second look for all that they conceal. You are just one of the 'teeming mass', the 'anonymous hero'. You are one of the 'multitude of quantified heroes who lose names and faces as they become the ciphered river of the streets (de Certeau, 1984).

**Evidence:** signs, indications of something (Ayto, 2001).

Pip (Dickens, 2001), not having much in the way of expectations; inexplicable, humiliating visits with the strange Miss Havisham's beautiful, manipulative niece Estella; his unexpected rise to riches by way of an anonymous benefactor. Miss Havisham – reasonable assumption, on the face of it?

No finding the mind's construction in the face. Everyone knows William Shakespeare's name. His writing is second to none, down the centuries. No-one knows his face. There are two portraits generally accepted as authentic, both created after Shakespeare's death: the bust by Geraert Janssen in the Holy Trinity church, Stratford upon Avon, and the engraving for the First Folio by Martin Droeshout. There is little reliably known of his life (Nolen, 2002).

In the shadow of Sacre Coeur there is a window, wooden shutters open. The interior is hidden by a lace curtain. A cat lies on the window sill, asleep. A suggestion; something to pursue in a foreign place. Use that nursing intuition. It has its place. I use what I think I know of you. Signs and symptoms, that lead and mislead.

**Evidence in law:** information drawn from personal testimony (Ayto, 2001). Documents, objects, the body; used to establish fact. Written on the body (Winterson, 1992) or the mind misleading. Insufficient evidence. What is easily seen is only the half of you. It takes all our nursing knowledge and skill to find what needs to be found.

**Body of evidence.** Christopher Nolan. Under the Eye of the Clock (1987). 'Joseph (in the third person) is accused of being a fraud by a journalist, and it is only by supplementing his text with his body that he is able to prove its authenticity. He invites journalists to cup his chin as he types "in order that they could feel the undercurrents of electricity running and molesting his attempts to strike a letter"' (Nolan, as cited in Coogan, 2012).

## **Florence Nightingale**

God made the world and runs it by laws, which we can discover by research in the biophysical and social spheres (McDonald, 2001; Nightingale, 1860).

How nursing practice is brought to light; the picture that plays in my mind is one of your lives going on, the everydayness of it. While we theorise and analyse, this goes on (you take another , because he is blind, by the hand when you go for your daily walks. It becomes something that you both do. One day, you are not there. He doesn't want to go for walks any more). It is clear, a central, focused image and also the long exposure – 'pedestrians passing by slowly, surviving as smeared vestiges of themselves, blurred, incorporeal'(Cartier-Bresson., & Sirven, 2011) – this is the effect of time and my having to remember too much, but I'm there, sharp in the moment as needed. Your lives, you work with what you have, with me. What matters most; what is most important for you? How is that determined? It is not necessarily the response to your health crises; that is part of the everydayness of nursing work, in ways. It does not matter that there are more questions that answers; things change constantly, internally and externally. Surely it has to be enough to effect change in one's own corner (the doctor looks for and finds that sparkle in your eyes that directs your treatment outcomes. Not only you taking the lead, but someone seeing it and acknowledging it. Evidence too that developmental disability nursing work is paying off, for you).

Florence Nightingale had the world, literally, to play with, in terms of nursing change; had the connections to take on the establishments; had the passion to keep going. Taking to her bed might have been a physical necessity, but what a tactical manoeuvre (Mathieson, c. 1918). Look at the work she got done.

Look at the work that we (developmental disability nurses) have been getting done, in all its complexity. Go back to the vignette, the image centre. It is you, getting through your lives, taking what support you need from us in order to do so; at the same time us giving, gauging your levels of support need (watching you perform on stage, there was no doubt as to who was in control; your helpers were as extensions of you and so unseen in the moment).

### **The empirical, the actual and the real (Nairn, 2012)**

Some observations on evidence-based practice from the literature (since I am talking about our evidence, yours and mine), in the context of the position on the debate today. A quick summary.

The debate seems to centre around the meanings and interrelationships of evidence and knowledge; positivist – developing robust methods of inquiry so as to access precise knowledge about the world, and identifying levels of such

knowledge to inform practice; and hermeneutic – dealing with interpretation and therefore the endless play of language, as meaning is never total or complete (McQueen & McQueen, 2010; Tarlier, 2005; Nairn, 2012). There is argument for knowledge from qualitative inquiry to have validity as evidence upon which to base practice; critical reflection on evidence derived from the experience of nursing practice as a sound basis of knowledge (Leeman & Sandelowski, 2012; Avis & Freshwater, 2006).

I did find one study (from the UK) of particular interest to us here today, exploring as it does decision making in intellectual disability nursing practice and how that is influenced by evidence. A literature review highlighted a lack of application of concepts such as knowledge transfer, evidence-based practice and research utilisation in the field of intellectual disability nursing. Methods such as life history accounts and participatory research are gaining some validity towards evidence for practice (Williams, Roberts, Irvine & Hastings, 2012).

“The findings from this study regarding nurses’ understanding of EBP, and faith in colleagues to verify decisions is comparable to other research reviewed. However, this study has identified that within practice, the ID nurses consider evidence from the client as ‘gold standard’” (Williams et al., 2010). We should be researching evidence used for developmental disability nursing practice here, if not already happening; or even so.

### **The vulnerable body**

I talked earlier about your levels of support needs. My reflective interest here lies with those of you who use high levels of support, and how we negotiate moments of intimacy, let’s call them, in the context of an extraordinary relationship – so called because it is needed at all. The challenge for me is to be present and to stand back in the moment – there is an art to this I believe.

Photographic evidence. Your evidence – the smiles, the fun, the outings, the birthdays, the family moments. Beautiful scrapbooks testimony to lives well lived.

‘It is a cruel, ironical art, photography. The dragging of captured moments into the future...that should exist only in memories...’ (Morton, 2007).

Captured moments. Captured body? So little movement; so much life. How do we deal with the vulnerability – and who is vulnerable here? Let’s say that the

physical, the obvious, is a given for my reflective purpose here. In the plane it's night; you see dotted lights. It's over Russia or somewhere – unknown – you couldn't possibly identify with it, imagine people's lives down there. Then there is you; so familiar in so many ways, so foreign. I look at your shape, your skin (that undamaged skin that doctors commented on, testimony to our care for you). I see it all, I do things for you, always judging how much is right, or too much. You look at me, or don't; smile at me, or don't. You make sounds. What do I really know of you? You look at me; what do you think of me; why should you think anything of me? You are unfathomable. Is this what should make you safe? That makes me vulnerable? I have to take cues from you; you are in charge (I remember when I felt a fool talking to you, with no words coming back. Look at me now). I do what I know you need, what I think you need; and this changes in the moment. A bath is not just a bath. (I see the look in your eyes today, that was not there yesterday, and I know that you are hurting somewhere before you cry. Please let me be able to help).

You don't have language in the form accessible by the majority to give that sort of expression to thoughts and desires; to the complexity of you. There is the perception of otherness that you are almost expected to answer to, it seems to me. Actually the body resonates with its own evidence. You become master of 'aphasic enunciation' (de Certeau, 1984).

The writer Christopher Nolan said that he wanted 'to highlight the creativity within the brain of a cripple', to 'dwell upon his life, his laughter, his vision, and his nervous normality' (Nolan, cited in Coogan, 2012).

My body now denies me the ability to have many of those 'moments of Intimacy' with you; dressing you, moving you in the bath, tying up your shoelaces. This is loss.

I graduated from the University of Sydney in March 1981, only three weeks or so after I started my mental retardation nursing training at Marsden Hospital. We were gathered in the main quad afterwards and people were saying what work they were doing. When I said what I was doing, all but one literally looked down their noses at me. I have not forgotten that, but I am so the winner.

### **Points of conclusion**

Through the process of writing this reflective piece, it seems that the evidence remarked upon (yours and mine) is that of the ordinary, the practice of everyday life (de Certeau, 1984). The body is a complex, dynamic entity from

any point of study, and here I have given 'the body' the meaning of life in its fullness, with evidence, in the first person, as activities and memories, relationships, wellness, illness and death.

The people with whom I work, as a clinical nurse consultant now (so I still do get to negotiate moments of intimacy in the first person), will soon be experiencing a major life change; for many in their later years – that of moving home. Nurses have been working tirelessly to put together your body of evidence: of the everyday, the difficult, the special, the relationships, It is my greatest expectation that your support will continue to be based on evidence; yours, and that of nursing practice.

My brother Michael, who has Down syndrome and lives in the Netherlands, moved from the large residential centre he had been living in for the last forty three years on the 17<sup>th</sup> of January this year, to a house in the local community. I finally had news of him last week. He has not been happy; his 'obsessive' behaviour has increased. Michael has moved to another house. I am sure that the nurses supporting him are doing their best; for Mike and for the people he was sharing a house with. I will find out more when I visit him in December.

### **The last word**

'Life's but a walking shadow, a poor player  
That struts and frets his hour upon the stage  
And then is heard no more; it is a tale  
Told by an idiot, full of sound and fury,  
Signifying nothing'.

Macbeth Act V Scene VI 24-28 (Rowse, 1978)



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