

Getting in Touch: Reflections on Clinical Attentiveness

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Though physical contact is a common element in many clinical encounters, this chapter is about the extent to which our minds can match our hands, and get in touch with the patient's experience.

PATIENT JOURNEYS: PRACTICE AND THEORY

Group discussion of clinical narratives is a powerful method of learning. Members have to put themselves in the patient's or parent's shoes and at the same time accept that their peers see it differently. Unlike in a classroom, there are no right answers. All perceptions are equally useful for exploration by the group. When this kind of reflection is encouraged, students discover just how expert they can be at identifying with other people. This is not technical knowledge such as 'psychology' or 'communication skills', it is a capacity we all began to learn before we could talk.

Your experience of being looked after as a child strongly influences the way you relate with and care for others: your friends, colleagues, partner, children and patients. Identification is a basic and necessary human skill, without which our contact with patients and families would be very limited. Patient journey seminars activate ordinary personal qualities that can then be integrated into clinical work. How did we acquire these? Until the twentieth century, there was little scientific understanding of child development. Then rival theories began to argue over the relative importance of learning on the one hand, and of love and hate on the other. This was a great step forward, but it was not until the 1960s that biology and psychology were brought together in attachment theory^{1,2} which began to demonstrate the primary drive for protection in all mammals, which is quite distinct from the need to be fed. We can readily see it in farm

animals, such as lambs, who always rush to the ewe when someone approaches.

Seeking help from health services highlights our life-long attachment needs. At birth, humans are the most immature of all mammals and have a much longer period of helplessness. During this time, mind and brain develop according to the experience of care that the child receives. At first, the child is totally unable to look after herself, and has no sense of time, only of the presence or absence of a caregiver whom she attracts with smiles or by crying. Despite the absence of predators in most modern human settings, a tiny child is fearful of abandonment and very sensitive to how you handle her. The people doing the looking after – parents, grandparents, childminders and others – are most helpful once the child gets to know and trust them, and this works best when they know and trust each other too.

The term ‘good enough mother’³ was coined to highlight the fact that a caregiver cannot possibly be in perfect sync with a baby. She may be too close or too far away, speak too loudly or be too hurried or too slow, and has to learn by trial and error how best to be in touch with the child. This is how infants learn about time, and about hope. If the people looking after you in the early years take you seriously as a person in your own right, with a mind – and a sense of humour – of your own, then your brain gets wired up to be curious about and interested in others’ experiences, precisely because that has happened to you.⁴ A secure attachment sets the body’s psychology and physiology in balance, protecting the child from overreacting to the normal stresses of life and preparing him or her for future relationships of all kinds. If caregivers are too often out of touch, then the child’s development adapts to that, and he or she grows up either denying any need for help (‘I’ll just have to manage on my own’) or anxiously seeking it but then not being able to receive it.

Both patient and clinician bring their attachment experiences to the consultation. The patient has learned over a lifetime how much hope and trust it is safe to put into anyone who is trying to help. In turn, using your own life-long learning, the best you can achieve is to be a good enough practitioner. It is not patronising to think of clinical care in terms of attachment. Whatever their age, anyone who needs help will show

something of their habitual way of seeking it. In every clinical encounter, we have to find the right emotional distance to understand and be understood.

Being ill or in need of help activates attachment behaviours at any stage of life.

Patients' expectations of you are conditioned by the kinds of care they received in the past in their own families and when seeking help from others.

The kind of care you are able to give is conditioned by how you have been treated by parents, teachers and trainers.

If you have been a patient yourself, you might be aware of the powerful expectations that become evident when you need expert help. You make a quite rapid judgement about whether this professional person is in touch with you. This is based more on their ability to see things from your point of view than on their knowledge, status or skill.

We are trained to be objective about disease and its treatment, yet almost everything about the patient journey narrative is just the opposite. It is about the subjective experiences of patients, their parents and their siblings: anxiety, relief, fury, gratitude, terror and grief. Technique and objective knowledge are always necessary, but never sufficient. These days, clinical training makes more of the clinical relationship, but there is still little awareness of the barriers between professional and patient.

The doctor is telling you something about your child who is seriously ill. Your head is spinning. He gives you a leaflet and says that it's all explained there. You wonder if you are going to faint, his voice seems far away. He does not seem to have noticed, so you sit down and look intelligent while feeling quite strange and disconnected.

Here, 'information' means something quite different to the giver and to the receiver, who cannot take it in. A doctor who does not notice that is out of touch.

USING YOUR IMAGINATION: UNDERSTANDING AND BEING UNDERSTOOD

The key to getting in touch as a clinician is to use your imagination and to be observant – about yourself as well as others. What might it be like to be that patient or parent? What do you see in the faces and movements of the people you are talking to? What is your emotional reaction to this particular patient's story?

One junior doctor I worked with in a discussion group was very shocked by her own violent feelings in the presence of a mother who was being cruel to her child. We don't have to accept everything that patients do, but we must be aware of our own reactions. Young clinicians often think they are meant to be kind even to people who abuse them. Some people are just too rude and you have to find a way of saying no.

There is a common theme of gratitude in the parents' narratives when staff make them feel understood, when they don't look away or brusquely send them off to another specialist somewhere else, with no clear idea of when or where the appointment will be. Even polite and obedient patients can feel disorientated, guilty or angry when they don't know what is going on. Just as in giving directions to people who are lost, you cannot assume that patients have the same map in their heads as you have. Making yourself available – for example, via email – to clarify queries or explain results can make a huge difference to families who are in the midst of a stressful time. This is not about being nice, it's about being aware of the bottomless anxiety that 'not knowing' causes.

Mind Your Language

When you want to explain something, you have to mind your language. 'Cerebral palsy', for example, may have quite a specific meaning to *you* because you know your anatomy, physiology and pathology, but very little to a child or parent. If they do happen to have a relative with cerebral palsy or have seen someone with it on television, they may still have a very different image in their mind to the one that you are trying to give them. You can also talk about risk but (unless they are gamblers) it's just numbers to most people. The words you use, such as 'probably' or 'might', can be seriously misinterpreted.⁵

Just like a parent or teacher, it is part of our task to notice if what we are saying is making sense. If you think you are not getting through, the best thing to do is to say something like, ‘Maybe I have not explained this clearly enough,’ or, ‘Perhaps this is too difficult to take in at the moment,’ then stop talking and wait a few moments.

The most difficult thing to impart is a diagnosis of a long-term or fatal disease. I think it is wrong for beginners to have to break bad news, yet many are left to do so.⁶ Trainees should first observe their seniors doing it,⁷ to see that it is not about telling people you know how they feel (you almost certainly don’t). It’s about being able to find genuine, normal words to show your respect for their suffering. All you might be able to say is, ‘I am so sorry.’ You might feel like crying, which is not a terrible thing to do provided you can carry on working. But it is not good practice to switch off just when you need to be paying attention. One mother’s narrative recorded her fury with a doctor: ‘She asked a few questions and told us he [her son] was delayed without even looking at him.’

We can learn to tap into and improve reflective skills during training. Though role play⁸ helps real clinical settings are the best places to learn some of which can then be reviewed in case discussions.⁹

WORKING WITH THE SYSTEM AROUND THE PATIENT

In the patient narratives, we often hear about a ‘breakdown in communication’. It seems so obvious that if there are people working with your patient (say, in another clinic), then they need to be told about what you have been doing. So why does this link-up so often not happen? First, it may not be clear who is responsible for making that connection, but secondly, there may be a failure of imagination. The boundaries of any case extend beyond the walls of your department. Unless you are conscious of the health and related systems around to this patient, you can easily forget about the other people upon whom the family also depends; people they assume you are in communication with. Then the patient goes to another clinic and wonders why they have hardly any information about his or her case:

No 21st century health system should require parents and children to go from place to place or even worse to go to multiple appointments to tell the same story.¹⁰

In effect, this leaves the patient or parent in charge of coordinating their own care; a dereliction of our professional duty. Just as in the care of children, there is more security for patients if helping professionals keep in touch with each other. The more complex or disturbing the case, the less likely this is to happen.

Chronic Disease

Most of the patient narratives are about children with disabilities or other long-term conditions. Nothing better illustrates the need for integrated and stable health services in which different organisations keep in contact with one another. In general, disability and chronic disease can turn family life upside down,¹¹ with the parents having to fit in frequent clinic appointments while trying to run a family with other children who also need looking after. It's not unusual to hear of parents who have split up under the strain.¹² Although all chronic diseases have a significant impact on family life, when the brain is involved, there is likely to be still more distress. In children with epilepsy, for example, rates of emotional and behavioural problems are four-times greater than in the general community.¹³ Many more children with chronic and complex disorders could benefit from mental health services that are integrated with medical ones,¹⁴⁻¹⁶ but this sensible idea is frequently forgotten.¹⁷

Parents make heroic efforts to keep the siblings¹⁸ of their sick child in focus (and the siblings themselves may be heroically patient), but it is a herculean task. Brothers and sisters of any age will feel excluded by the necessary attention lavished on the patient. They might also feel guilty about their own good health and by the fact that they can do so little to heal their ill sibling. Most families in this situation do not get the chance to explore these emotions, and because they are so busy, some may not even think that such an opportunity is necessary.

Patient narratives show how a lack of authority and imagination within teams or mistrust between them undermines integrated care.

However expert patients and parents become^{19,20} they cannot possibly lead the professional network.

In every case in which there are several agencies involved it must be clear to everyone who is the care coordinator.

HOSPITALS

Being in hospital is disturbing for anyone. Everything is unfamiliar; you are expecting some treatment that may be painful and are often utterly dependent on others, like a tiny baby. Just imagine, then, how much more unsettling this is for a child patient.²¹ More than anything else, a child in hospital is helped by the presence of one or both of his or her parents, but they themselves will feel insecure because they are not at home and have very little authority to organise anything without asking, even begging for it. Very young children often want to bring their special toy or blanket – ‘transitional object’²² – with them, which is a comfort. Hospital staff need to understand children’s anxieties. Our resistance to doing so comes from not wanting to be reminded of how frightening and confusing childhood can be. Cheerful reassurance, such as making jokes, may be tempting, but is unlikely to have any useful effect for more than a moment. Getting paediatricians and children’s nurses to allow parents to visit their children in hospital at times that suited them, and then to stay the night with them if they wanted, was an enormous struggle that lasted from the 1950s until the 1980s.²³

CONCLUSION

Making an accurate judgement about another person’s state of mind has nothing to do with sympathetically feeling sorry for them, which can be sentimental and patronising. This chapter is about learning to pay thoughtful attention to your own perceptions and reactions in clinical situations, which then becomes a professional skill.²⁴ If you can reflect on your emotional capacities as you do your intellectual and technical work, you will be a better clinician. Patients notice that.

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