

The 'Palliative Paediatrician'

Understanding the Doctor-Parent Relationship in Paediatric Palliative Care

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Doctor-patient relationship

- ◆ Improved patient and doctor satisfaction
- ◆ Improved adherence to treatment regimes
- ◆ Therapeutic in its own right (Balint)

Aim

To explore the needs of families whose children require palliative care, from the perspective of the parents and the doctors who cared for their child

Methodology

- ◆ Qualitative: In-depth interviews with 69 bereaved parents of 45 children and 42 paediatricians
- ◆ Sampling to ensure representation across
 - Diagnostic groups
 - Geographical location
 - Service utilisation

Key finding

The quality of the relationship between parent and paediatrician is a key determinant of quality of care

- Intrinsic human value
- Correlation with measures of quality clinical care

The Palliative paediatrician

'... I think it's very ironic because in many ways you think we should have anger towards him (the paediatrician) because he didn't save our son. But it's the way he treated our son and helped us along the way that makes us trust in him.'

'It's not so much because of the disease. It was because of how it was handed to us.'

The 'caring' paediatrician

- 'Beyond clinical'
- 'Like family', 'Like a friend'
- Humanity
- Genuine concern
- Simple acts of human kindness

‘...and (paediatrician) came round...during the afternoon, and sat on the floor there, and he just- I said, “No, I’ll get him up, I’ll get him up”. “No,” he said, “No, I can sit on the floor”. And I just looked at him and I thought, here is (paediatrician) who is of very high standing, you know, who’s going to sit on the floor with my little boy there, you know, just like he would with his grand kids, you know, that was him.’

Parents who felt the paediatrician 'cared' ...

Were more likely to have

- Received adequate information
- Had their concerns acknowledged
- Felt empowered
- Trusted the clinician
- Reflected positively on the experience of care

Parent and doctor expectations

- ◆ As a group, paediatricians were far less likely to focus on the quality of the relationship
- ◆ More likely to focus on clinical facts of the case

But

Congruence

- ◆ Doctors described as ‘caring’ were more likely to emphasise the importance of the relationship
- ◆ Doctors who *appeared* not to care were more likely to express concern about becoming emotionally involved

Challenges for the paediatrician

- ◆ Confronting the fallibility of modern medicine
- ◆ Seeing that something good can be salvaged from very sad circumstances
- ◆ Grief
- ◆ Inadequate training
- ◆ Unit, hospital and professional values - concepts of medical professionalism
- ◆ Finding the right balance between patient needs and doctor needs

Confronting fallibility

'...it's having the extent of your abilities or your limitations made obvious to you, that you can't fix this one. That's confronting and difficult to deal with.'

Palliative care is a poor second

‘I think perhaps one of the more gratifying aspects of the job is that we can support a family through a horrible situation... (but) as good as it has been and as thankful as they are, we still haven’t delivered what they wanted and that was to take home a well baby... there is still somehow a sense that you’ve let them down.’

‘...that’s another year off my life.’

Many paediatricians found this work emotionally difficult

Parents expressed concern for doctors

‘It must break his heart.’

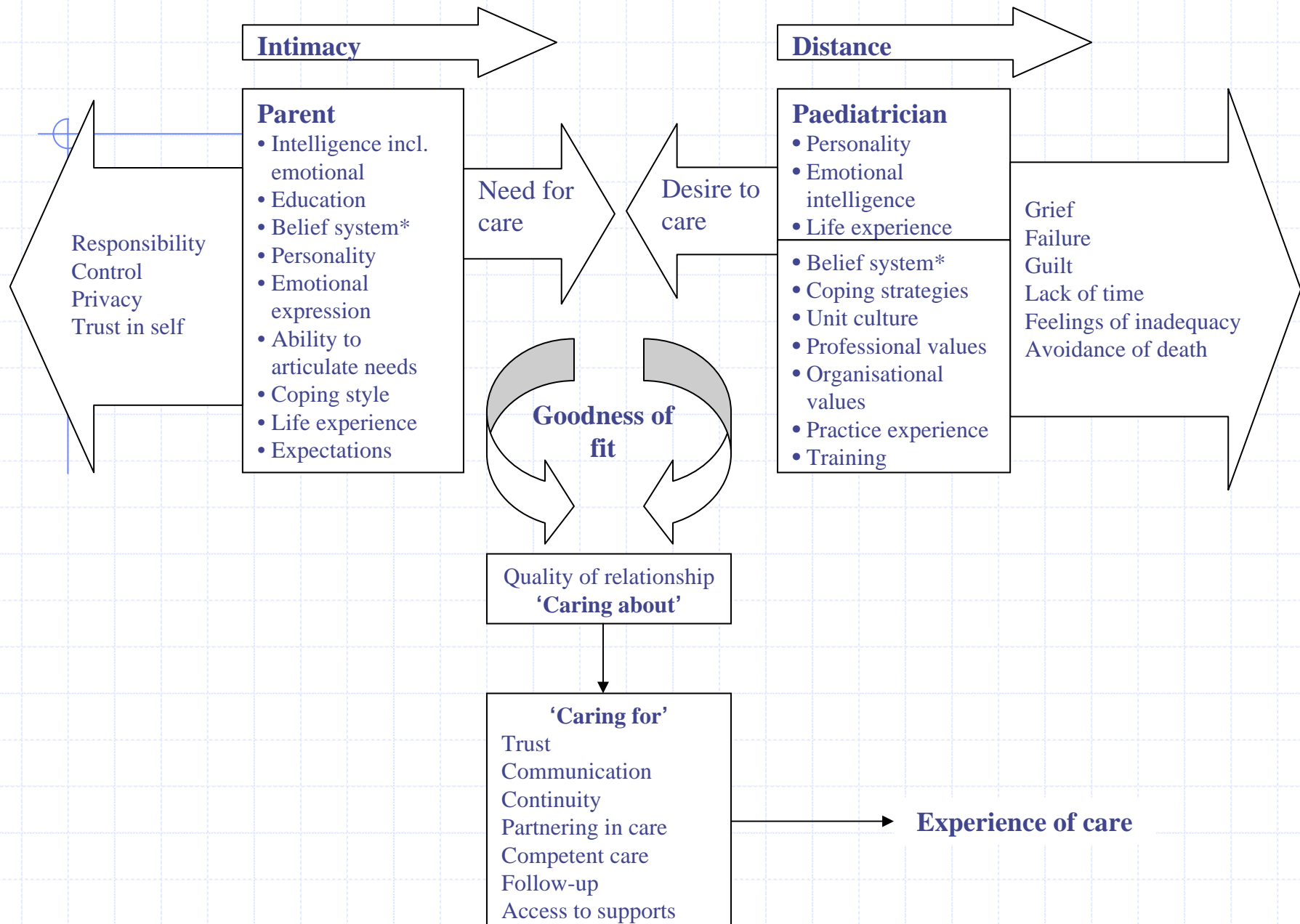
Concepts of medical professionalism

‘... you can care for them but if you get emotionally involved then you’re up the creek I reckon, you can’t do it... it can be very sad for them and you might feel the sadness yourself as well but, at the end of the day, you’ve still got to be effective for them as a physician.’

Inadequate training

'...you spend an enormous amount of effort acquiring skills that are of bugger-all use to you down the track, and you do that because that's the easy thing to learn. What's hard to learn is how to sit down with a family and tell them that their child is dying.'

A Proposed Model of Interaction



Summary

- ◆ A doctor who ‘cares about’ a family is better able to ‘care for’ that family
- ◆ The human connection has intrinsic value for families but also seems to be the font from which the more practical elements of care naturally flow
- ◆ Parents understand this and many work hard to strengthen the relationship
- ◆ Some doctors may create too great a distance thereby compromising care

Implications

- ◆ **'Fit for Purpose'** – some doctors may have a greater capacity for this work than others
- ◆ **Education and training** – must be more than a mechanistic approach to communication
- ◆ **Organisational and professional values** must reflect the importance of human relationships in this work
- ◆ **Caring for doctors** so they may care for others

