



The University of Manchester

Parental ethical decision making and the implications for advanced care planning:

Results of a systematic review and secondary analysis of qualitative literature

Veronica Neefjes
School of Social Sciences
University of Manchester
veronica.neefjes@postgrad.manchester.ac.uk

Background

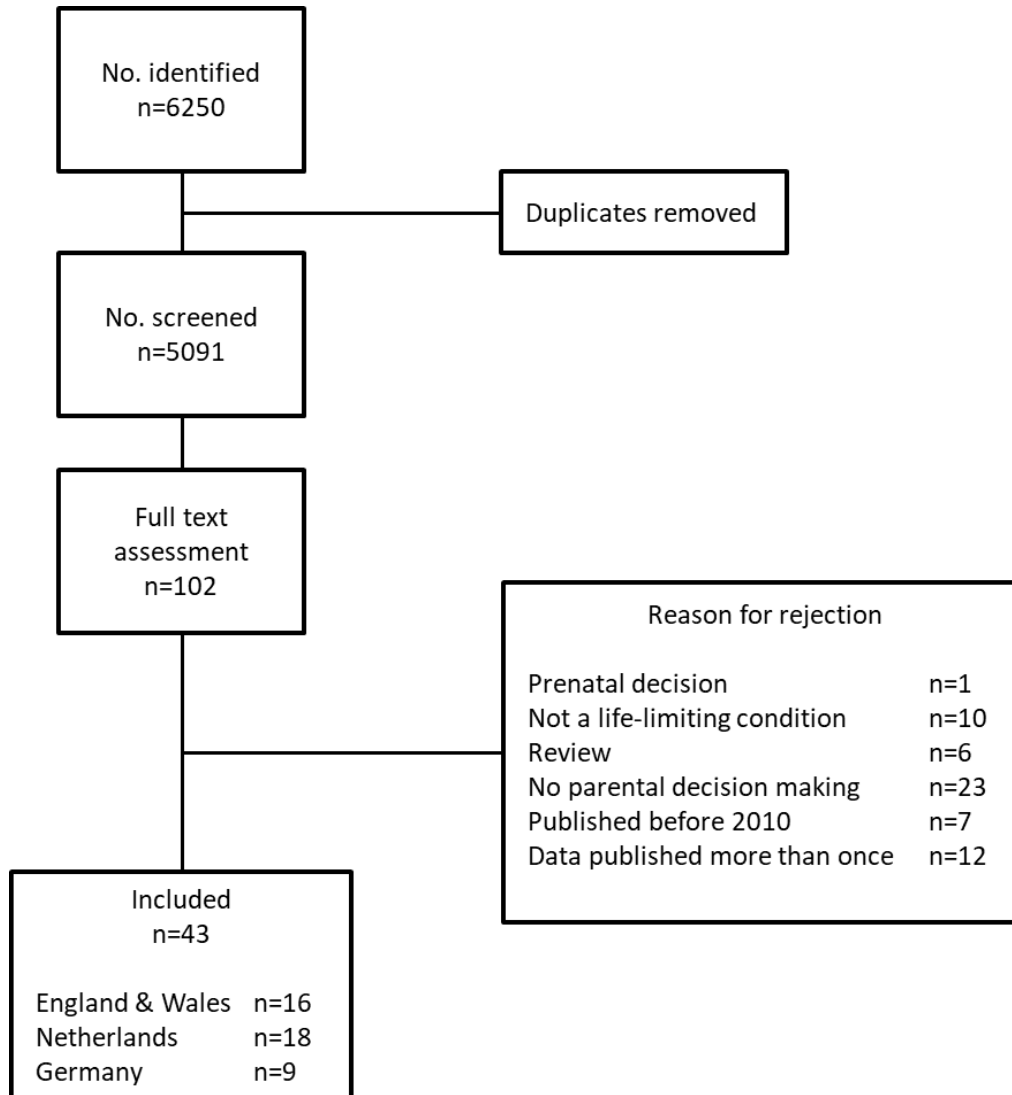
- Limited knowledge on how parents make decisions
- Some North-American literature, e.g. ‘good parent tool’
- ‘[...] that the weight of the evidence spells out the futility of Alfie’s situation he is, as a father, unable to relinquish hope. It is a facet of F.’s grief’

Aims

- Values European parents use in medical treatment decisions for children with life-limiting conditions
-
- How parents use their values
- Implications for advanced care planning

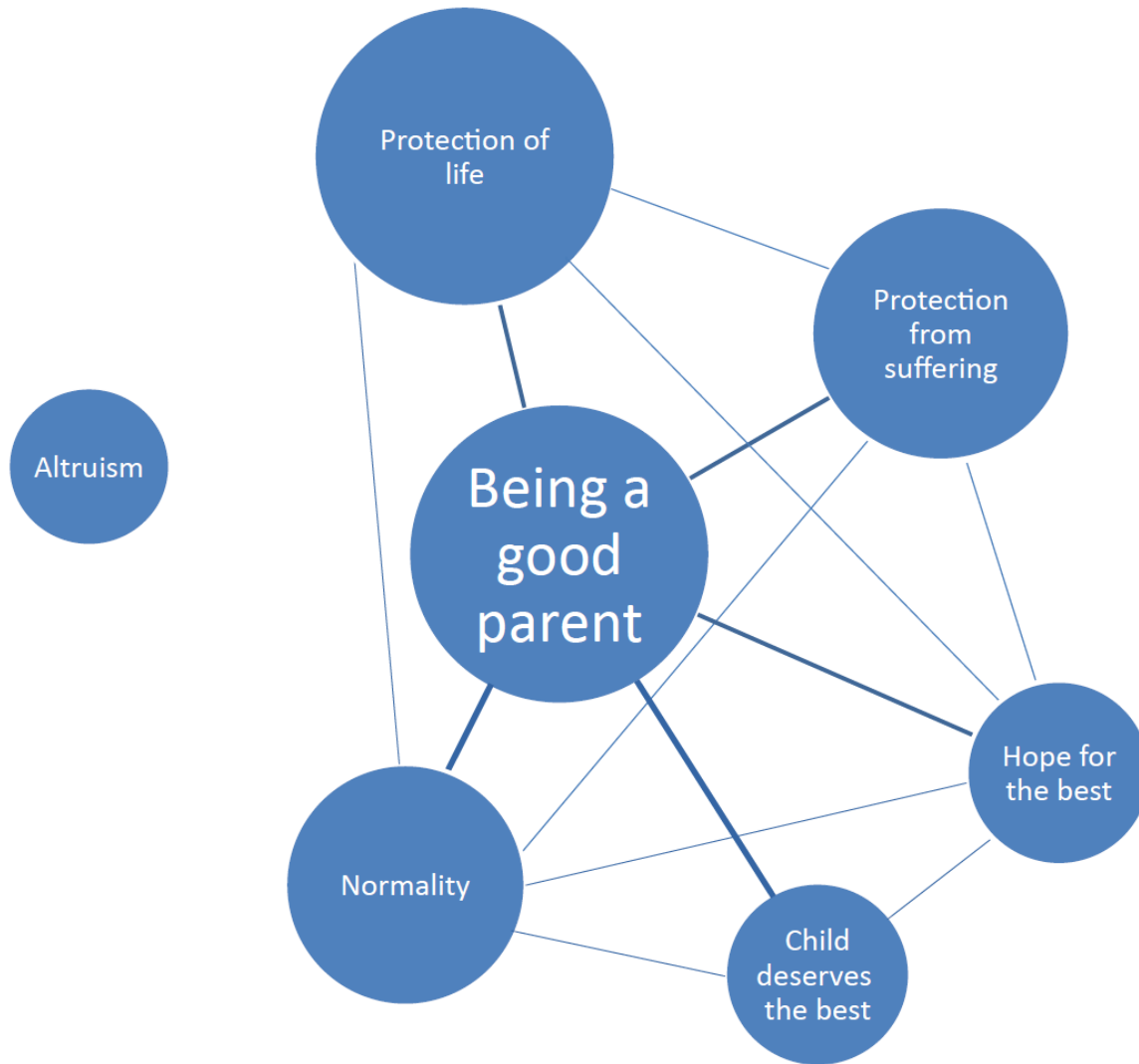
Method

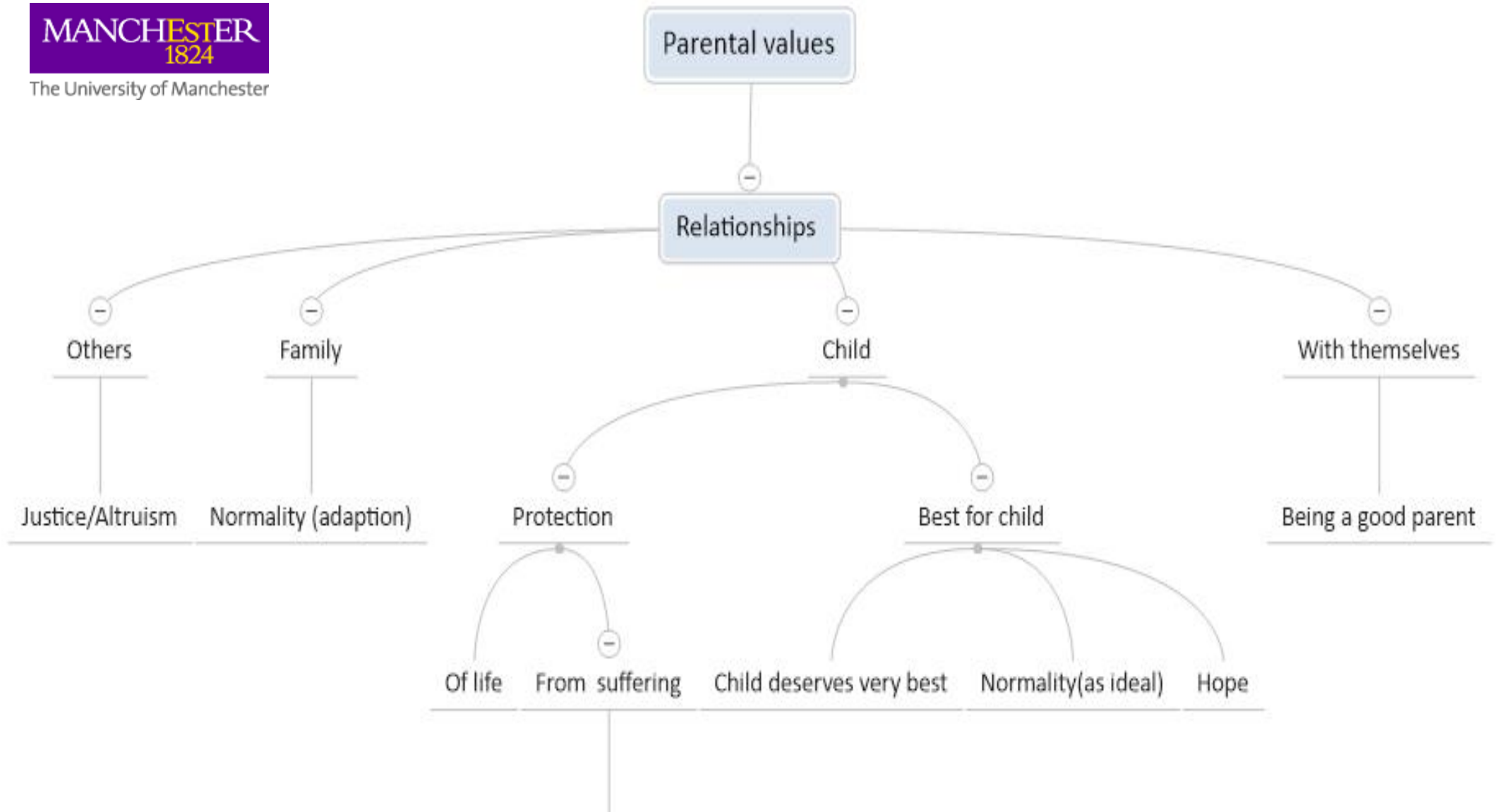
- Systematic review of qualitative literature
 - England & Wales, the Netherlands, Germany
- Published between 2010 - 2020



Quality appraisal

- Gate-keeping:
 - Eligibility criteria
 - Recruitment method → ‘vulnerability criterium’
- Participants
- Higher educated parents over-represented
- Non-western ethnic minorities under-represented
- Over-representation of mothers with children with high care needs





Ethics of care

- The core of moral action is human relationships
- The maintenance of the caring relationship is the ethical ideal
- The 'right thing to do' depends on circumstances at the time
- → contextual decision making

Contextual decision making

- ‘So, it was ok to DISCUSS this for the day when it would be necessary. But I did not want to commit myself. And I always said: We will see when it comes.’
- ‘The decision about mechanical ventilation was hard for me. I wish I could decide at the moment that mechanical ventilation has to be installed. If she gets a heart attack or something is wrong with her heart, I would say, “I don’t want that.” But if something else is wrong, something that has never been a problem before, in that case, it’s a pity not to try mechanical ventilation.’

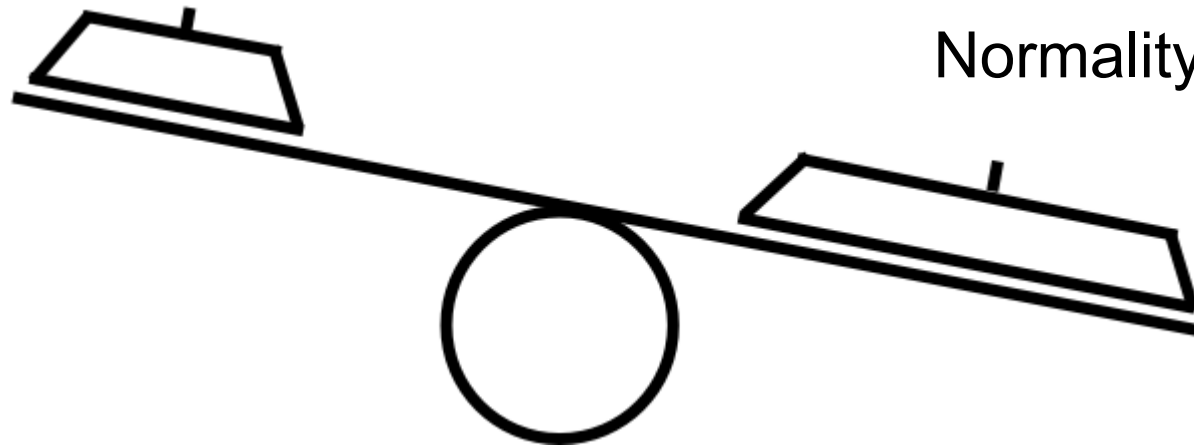
Protection from
suffering

Protection of life

Hope for the best

Child deserves the
best

Normality



Maintaining the relationship

- ‘We think she is suffering, and we discussed this with her treating physician. She is not in pain, but there is nothing that gives her a little joy in her life. [...] Together we made a decision that if something happens, for example if she gets pneumonia, she won’t be treated for that and the tube feeding will be stopped.

Maintaining relationship

- ‘Then he was given Dormicum®. That was a really horrible moment, because he (the doctor) just gave the injection in his leg and I thought he was really nonchalant about it. And Jonathan started to cry because it hurt. And shortly after that, he just, lost consciousness, so we didn’t have any time at all to comfort him. I found that... it felt like sort of as if you deserted him...

Conclusions

- Parental contextual decision making model fits less well with advanced care planning
- More research needed