

## Abstract

**Theoretical Principles:** Pragmatic Children's nursing theory draws on the theory principles of North American Pragmatist including the work of William James, Richard Rorty, and John Dewy and incorporate Margaret Urban Walkers work on expressive collaborative feminism.

**Phenomena Addressed:** In this discussion paper I explore how the role of parents is framed in Pragmatic Children's Nursing theory. In setting out Pragmatic Children's Nursing theory I detailed a rebuttal of family centred care. However, working with the theory I have come to realise how the arguments against family centred care do not exclude involving parents in children's care. Indeed, Pragmatic Children's Nursing recognises the vital role parents and other carers play in children's access and experience of childhood. Who accepts and who rejects the parenting role for children living with illness is discussed in terms of the gendered politics of societies and of nursing. Before considering the pragmatics of parenting children living with illness

**Research linkages:** This is an emergent theoretical approach to children's nursing with a challenging research evidence. However, I draw on existing children's nursing studies to explore the potential of Pragmatic Children's Nursing theory to assist children, parents and nurses in negotiating care. The conclusion drawn is that as childhoods and parenting are continually evolving in time. In certain physical, as well as cultural and political spaces and contexts, in which children's nursing using the pragmatic theory will evolve to meet these ever changing intergenerational challenges.

## Introduction

Pragmatic Children's Nursing is the first attempt to design a theory of nursing for children and their childhoods (Randall 2016). In order to urge nurses to adopt the new theory it was necessary to argue why the predominate philosophy, namely Family Centred Care (Smith and Coleman 2010, Mikkelsen and Frederiksen 2011), was no longer appropriate. To summarise Randall's rebuttal of Family Centred Care (Randall 2016, p.14-18) it is a philosophy, not a theory of nursing, Family centred care is a rather ill-defined concept, there is little evidence that nurses put it into practice so while Family centred care is a successful idea it is more of a professional concept than one recognised by children or parents. More importantly in the modern world of divided and reconstituted families, Family Centred Care seems impossible to deliver and it allows nurses to focus more on the concerns of adults (mostly mothers) rather than the rights of children.

However, on page 17 it is made clear that moving away from Family Centred Care is not a manifesto to ignore parents. It is this relational aspect of childhood and the role of a child's main carer when they are living with illness which is further explored in this paper.

Do we then throw parent carers out with the bath water? No as Berry Mayall (2002) has described childhood is relational- it is dependent on the relationships children have with members of their community, primarily with their main carers.

(Randall 2016, p.17)

## Accepting and rejecting responsibility

Berry Mayall (2002) describes the relational ways in which childhood is experienced by children which is dependent on the relationships they have with others. In particular, children have a relationship with an adult who provides a stable relationship over time. The experience of childhood is influenced by this relationship both if it is positive and if it is negative. Mayall does not suggest that the relationship has to be with a mother, but rather that an adult in the child's life has to provide this stability. In describing Pragmatic Children's Nursing I have drawn on the ideas of the feminist moral writer Margaret Urban Walker (2007) (Randall 2016, p. 99). She puts forward an expressive collaborative model where the theoretical judicial model is rejected (this would assign parental responsibilities according to a court ruling, made by judges, based on principles). While the theoretical judicial model may be required in extreme cases, in general on a day to day basis deciding who takes responsibility for a child's care, or who rejects such responsibilities occurs in negotiation between people (Sarajärvi, et al 2006). There is a collaboration between children, their carers (parents) and nurses who can express the outcome, the agreement. Thus this is an expressive collaborative model. Carers discuss who will do what, they talk, express their views and collaborate. Who accepts responsibility may be based on many issues, aspects and contextual details, but it is rarely based on a principle or theory. We might characterise this as "families just work it out for themselves", but what is happening here is that parties in the family unit negotiate who accepts and who rejects responsibility.

In a recent study we undertook (Randall 2017a) it was clear some mothers accepted the role of main carers and that fathers rejected the role of carer. This was not done with anger or disappointment, but rather as a positive aspect of the shared care. The mothers accepted the role not because they had a gendered principle that women should care for children, but because they recognised that their partners used work as a coping mechanism, they could go to work and not think about the child and the terminal illness, and this meant the fathers could cope and were more useful when they were at home. It has to be said not all the women accepted this, others were angry that they had to bear the care work alone, or that it was added to by unhelpful partners. The relationships and the contexts people found themselves in had an effect on the negotiation of care.

This rejection and acceptance of the care roles with expressive collaborative morality fits well with the ideas of pragmatism (Randall 2016). In classical Peircian pragmatism what works is good and what is good works (Murphy 1990). Thus if the negotiated acceptance "works" in a couple's relationship then it is good. As Richard Rorty (1996b) has pointed out the contextual and relativist aspects of pragmatism can cause some confusion and frustration. Thus Rorty suggests that we should divide the ideas from how ideas are used by people in a time and space (Rorty 1996a,b). In the case of who is the child's main carer, what this might mean is that the negotiation of who accepts the role of main carer in an illness occurs in a gendered political context influenced by when that negotiation takes place and where. The negotiation of parental roles would be different if they occurred in an Islamic country and might be different if they took place in the 1950s as opposed to in the 2010s. Rorty points out that in this time and space we cannot judge what might have been "good" for others at a different time, in a different space. The highly patriarchal views of a different culture at a different time may not be "good" for us (nurses perhaps) now, but would have been "good" for men during that time.

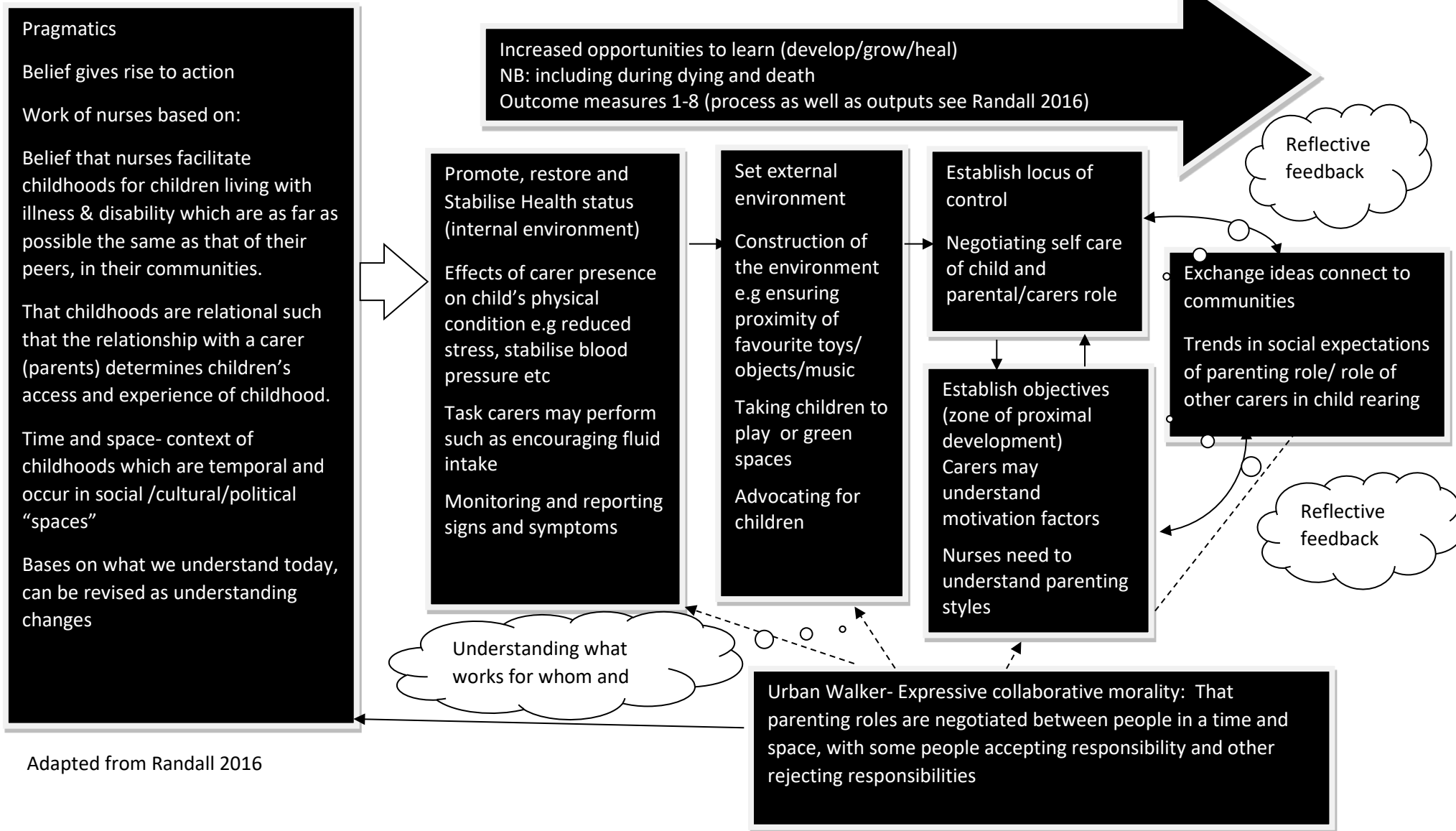
We might read the paragraphs above and say they reflect a patriarchal gendered politic of our day, that we want to reject. Rorty says that's fine, the idea of men using their work to escape their responsibilities may be deemed reprehensible, but such a judgement is a political one. Who accepts or rejects children's nursing care is one thing, whether that is socially culturally and or

politically acceptable to a community is something else, and the two should not be confused (I am of course re paraphrasing Rorty 1996a). This division allows nurses to accept and work with the negotiations that children's carers might agree upon (which might be good for them at this time and in this space) while campaigning to change the expectations put upon women and men as parents. Such that while accepting a mother may be the child's main carer we may still push for fathers to have parental employment rights to be with their children when they are ill. Further that other carers such as uncles, aunties or grandparents might be recognised and supported to deliver care and support children (Findler 2008).

We should also consider how the gendered politics of nursing as a profession interacts with the gendered politics of parenting in societies. In Northern Western cultures this is typically a feminist issue, women are assigned by communities the role of the care of children and of being children's nurses (Davies1995). These "caring and nurturing" roles are not valued and are therefore not recognised, and under resourced. Women's acceptance of these child care roles and men's rejection of them on a society level allows for women's career development and other employment opportunities to be curtailed, while men's are systematically privileged (British Council 2016).

As indicated above nurses may work to support women as women themselves (in the majority) while also taking action to oppose patriarchal hegemonic positions. Pragmatic Children's Nursing allow us as nurses to consider the political and the cultural as well as the physical care of children (see Figure 1). To be supportive to women who are victims of male aggression, to ensure children's physical and emotional safety and to consider if such support sets up systematic barriers to the involvement of fathers (who are not abusive), to advocate for more men to forge careers in children's nursing in order to allow children access to male role models, but also gender appropriate care. The temporal aspects of Pragmatic Children's Nursing also allows us to start to consider if this heterosexual role assignment is still relevant to the generation growing up in 2018.

Figure 1 Parenting and Pragmatic Children's Nursing



Adapted from Randall 2016

## Childhoods, living with illness

In *Pragmatic Children's Nursing* I talk about children living with illness (Randall 2016). I have also expanded on the term in a paper for the *Journal of German Paediatric Nursing* (Randall 2017b). To summarise this work; children who have a disease or condition live with illness, but so do their siblings. In addition, we might consider children who are carers for adults with a disease, condition or disability also live with illness (Becker 2007). The child's access to and experience of childhood is affected by a close family member having a disease, condition or disability (Bluebond Langner 1996).

However, what I have not explored in any detail is the sense in which these children living with illness experience that childhood through their carers' reaction to the illness and their understanding about children and childhoods. We know that adults have a variety of attitudes to children, childhoods as well as to illness both in general and in childhood (James et al 1998, Burley Moore and Beckwitt 2004, Azar et al 2008, Corsaro 2012). What is perhaps less clear from the literature is how these various attitudes and conceptions of illness in childhood and the parenting role are conceived of together and enacted. For example, we know that disability in childhood may be seen as a tragedy (Gordon 2009) but that some parents see their role as parents as being to deal with whatever occurs to their children (a fatalistic approach) but how do these conceptions conflict or coalesce?

The lack of clear research evidence is perhaps in part due to some obvious challenges to gathering empirical research data on how parents, parent a child living with illness. Ethical concerns about burdening carers with research participation who are already coping with difficult circumstances, and the more prosaic concerns about engaging children and parents where the child may deteriorate, or have episodes of intensive care. Where it may be difficult and ethically inappropriate to follow up data collection at certain times. Albeit other issues such as children's intensive care experiences and palliative and end of life care have been investigated and the challenges addressed (Bellali et al 2007, Moules 2009, Grinyer 2012). However, in addition there are perhaps challenges of the social judgements that research into parenting might evoke. A fear of social judgements on parenting in extremis might deter recruitment (Shields et al 2003). There is also the challenge of outcome measures. What these should be is unclear. However, many outcome measures in childhood tend to be longitudinal (such as school performance, social engagement) and longitudinal research is known to be expensive, resources intensive and difficult to pursue over extended time periods (Eskenazi et al 2003, Goodenough et al 2003). Quality of life measures in childhood have been established (Seid et al 2005, Varni and Limbers 2009) and would provide some indicator perhaps to parenting functioning, but such measures would need to be used with extreme caution. It is not established that quality of life can be influenced by parenting styles in illness, nor how parenting interacts with illness, disease and disability aspects of quality of life. Such that a parent may provide supportive care as best they can, but the natural progression of the condition degrades quality of life (one might think of a condition such as Duchene's Muscular Dystrophy). We might assume that a constructive positive parenting style (what can be described as high warmth, low criticism) might help children to cope with illness, but without evidence we cannot be certain.

To return to *Pragmatic Children's Nursing* this theoretical framing of the nursing of children living with illness has I think some advantages. Firstly, as set out above the parenting of the next generation is a highly complex area which is contextual and relative. Pragmatics embraces such diverse, complex contextual situations, thus it provides a way rather than attempting to simplify and codify a right way to parent children living with illness, it allows for many different approaches which may be "good" for children in a certain time and space. It should be remembered that Peirce advocated that in pragmatics we see things as being "good" for "definite assignable reasons". (Murphy 1990, p.57). To which Charles James added that these benefits should be "expedient in the long run and on the whole of course" (Murphy 1990, p. 55). From this we might infer that pragmatics is not only concerned with what might seem good at this moment, but in how such actions play out over time, and that this must be justifiable.

This helps nurses to address not just what might seem expedient on this shift, for the next few hours, but also the effect on the child and importantly on the child's relationships with their carers over longer periods of time, and phases of the illness experience. A classic example might be parents wanting to slip off the ward and not tell their children when they are leaving and when they might return. In the moment this might avoid the parents having to see their child upset, but such practices undermine the child's sense of trust in their carers/parent. A negotiation of leaving and returning involving the child, the carer (parents) and the nurse is good for assignable reasons- it builds trust that the carer may leave, but will return, and in the meantime the nurse is there to care for them. It also speaks to a longer term negotiation of how care is to be managed, that a carer may need to leave to look after other siblings, but that this can be borne if the child understands their carer will return.

## Conclusion

Children, like most humans do not live in isolation; they live, as most of us do, in a nexus of relationships, influenced by the time and spaces they inhabit (Corssaro 2012). The relationships which affect how children experience and access their childhood, with their peers in their communities are complex, culturally, socially and politically bound. If we add to this complexity a layer of illness then the contextual, relational complexity is increased. Pragmatic Children's Nursing opens new vistas, new horizons for nurses, children and their carers to explore. It is in the nature of Pragmatics as a North American pioneer philosophy (Rorty 1996b) that it opens up such views. For children's nurses these new vistas include how parents (and other carers of children) and nurses work in partnership to help children in a new age, in changing times, to live with illness. This task for this generation of nurses and parents will be different to the same task for the next generation as childhood changes, as societies conceptions of children, childhoods and of parenting change. Pragmatic Children's Nursing is then an ever evolving theory and set of practices in which parents, children and nurses are bound together attempting to find solutions that work for children and their childhoods.

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