

Being and becoming: Pragmatics and children living with illness

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Introduction

Childhood can be seen as both a time of being a child, and as a preparation for adulthood¹. As a time of *being* and of *becoming*. Societies across the world invest heavily in this period of the life span, facilitating children to play, grow and develop, in part because of the established links between childhood and health, wellbeing and economic productivity in adulthood^{2,3}. In many cultures it is understood that children will perpetuate, develop or destroy the culture, and are therefore essential cultural players⁴.

Perhaps because of this cultural role, childhood is also highly romanticised as a natural process¹. Children can be seen as innocents; who's development is a "natural" process. Linked to this ideal of the naturally developing child is the conception of childhood as a time of health and wellbeing, as opposed to the cultural meme of old age as a time of disease and disability. It can be argued that "romantic naturalism" has also prevailed in the nursing of children. This lens would suggest that all women have maternal instincts and are therefore "naturally" able and willing to look after children. Further, that children's nurses do not need a theoretical understanding of children's nursing, because as women they just get on with caring for children. In the main the theories of nursing have been designed, developed and applied to adults, both physical health and mental health, but not designed for children or their childhoods. That is until the publication of Pragmatic Children's Nursing a new theory of children's nursing designed for children and their childhoods⁵.

Pragmatics as a philosophy⁶ can help us to unpack the "naturalistic romantic" view of childhood. As James said "We have to live today by what truth we can get and be ready tomorrow to call it falsehood"⁶. Or in other words this idealised view of childhoods might have served people in the past, but we have to consider the evidence available to us today and whether such an idealised view of children and their childhoods serves children living with illness, and or children's carers including us as children's nurses.

A decade of study of the sociology of childhood suggests that while childhood is socially constructed this construction is influenced by children themselves as social actors^{4,7}. We also know that there is an increasing population of children living with disease and disability facilitated by technology⁸, there is an increase in the number of children living with mental health issues⁹ and children living with life threatening/limiting conditions¹⁰ (Fraser et al 2011). As for children's nursing there is now a substantial literature which suggests that children's nurses do not practice the espoused philosophy of family centred care^{11,12}. In the modern era of family breakdown and reformation such a view of a unified "family" needs seem unrealistic⁵.

Using Pragmatics as an underpinning philosophy for children's nursing allows us to consider childhood in the times in which we are living. It also allows us to consider different childhoods and different ways to do children's nursing, as Pragmatics embraces contextual difference, rather than attempting to find a universal applicable formula for children's nursing. Pragmatist recognises that for different communities' different ways to nurse children may be useful and good for discernible but different reasons⁵.

Living with illness

The stated aim of Pragmatic Children's Nursing is that children's nursing is...

“about facilitating children who *live with illness* to live a childhood which as far as possible is similar to that of their peers in their communities.”

(Randall 2016 pp 40, emphasis added⁵)

Here we are using illness, rather than disease, disability or long term condition, because illness is the experience of disease (and, or arguably disability). The focus is on the lived experience, albeit that the theory also includes a consideration of the internal environment and external environment⁵. These pre stages to considering the negotiation of care between the triad of child, carer and nurse in a social context are framed in relation to how children live a childhood. Nurses should attempt to restore, stabilise and promote internal and external environments in order that children can access their childhoods. In Pragmatic Children’s Nursing we are acknowledging a physicality to the world albeit one which is interpreted by humans in a social context¹³. Children live childhoods in bodies which are developing and functioning in environments, increasingly we are understanding how children’s genetics interacts with their anatomy and physiology as they grow, and interact with environments, as well as social and cultural influences^{14, 15} our shifting belief and understanding will mean more complex nursing interventions which account for the epigenetic, social and cultural interactions.

In the case study and discussion below I wanted to unpack some of these aspects of what we mean by “living with illness” in childhood

Case study

Jamie is 3 he has severe developmental delay and dystonia, he lives with his mother Jenny and his father Eric as well as his older sibling Elsa. His mother Jenny has Multiple Sclerosis and has recently started to use a wheel chair.

The effects of Jamie’s developmental delay and dystonia on his experience of childhood are perhaps the most obvious here. His ability to interact with peers, and build relationships with his parents and siblings will be challenging. Repeated admissions to hospital and hospice will mean he is away from his peer group, and may mean he misses important life events such as birthday parties, or family holidays. His dystonia will often cause him pain which will affect his concentration and muscle contractures will affect his ability to build preschool play skills. However, his care needs will require more interaction between himself and his older sibling, his parents and other family carers which could lead to for filling relationships.

In a way Elsa, although healthy herself, is also living with illness that of her brother’s long term, disabling and life threatening condition. She is also living with the illness of her mother. She may be expected to take on caring responsibilities for both her brother and her mother, to be a young carer to both. These caring responsibilities will alter Elsa’s relationship to both her mother and her brother. The social and educational consequences of being a young carer have been well described in recent years^{16, 17} and include being excluded from peer group activities and educational opportunities. However, young carers have also pointed to the sense of achievement and self-worth they gain from caring¹⁶.

Of course Eric and Jenny are also living with illness, in both childhood (Jamie) and Jenny’s own adult illness. As children’s nurses our focus here is on how living with this illness affects the parents’ abilities to parent, as the relationships between children and their main carers (parents) is vital to children’s experience of childhood⁷. Other nursing interventions may be required to support Eric and Jenny’s mental health and to assist in Jenny’s physical care. However, children’s nurses should

recognise these needs and make appropriate referrals to adult and mental health nurses allowing, children's nurses to focus on the children and their needs. While the challenges of caring for a disabled and life threatened child should not be underestimated, there also accounts from parents of the close caring relationship fostered between parents and disabled child¹⁸.

Discussion

The brief exploration of the case study above allows us to see the complexity of this case and of children's nursing. Charles Peirce, one of the founding fathers of pragmatism, stated that our all our beliefs and actions define a phenomenon⁵. Thus all of our beliefs' and actions about children's nursing need to be included in a Pragmatic Children's Nursing Theory⁵. The inclusion of the concept of "living with Illness" in the aim of Pragmatic Children's Nursing allow us to include aspects which relate, not just to the most obvious aspects, that of Jamie's disability and nursing needs, but also to consider his sister's needs as a young carer and sister of a child living with illness. In addition, we can account for parent and child relationships and wider social stigma of illness and disability in childhood. This focus on illness also helps to distinguish the work of children's nurses from that of public health nurses who work to maintain and promote health in populations, while Pragmatic Children's Nursing Theory clearly identifies the work of children's nurses as being with those who experience illness. This does not exclude health promotion and education, but frames this work as being the promotion of health and wellbeing for children with a disease, condition or disability, rather than with healthy populations. The separation of this work should allow nurses to press for both to be resourced, developed and evaluated.

Using Pragmatics and focusing on living a childhood also raises some challenges for nurses. As indicated above living with illness and the effects on parenting (and sibling relationships) affects the relationships between the child and their main carers. There is a risk that if nurses disrupt this relationship by negotiating to take on physical care and extending their role to social care, then the relationship between, say a mother and her child could be detrimentally affected. In effect the nurse denies the mother the opportunity to care for her sick child, the very occasions which might strengthen the mother's confidence in parenting and strengthen the relationship between child and mother¹⁸. This is a potentially increasing risk with increasing possibility of technically demanding care. Currently we do not have valid or reliable ways of assessing the relationships between parents (carers) and children, nor of detecting harmful parental reactions to illness in childhood. As these relationships and behaviours seem instrumental in children's experience of childhood, and often in adult mental wellbeing, we need to develop such tools to aid children's nurses in recognition of when and how to intervene to promote positive experiences.

We have discussed illness here, elsewhere I have discussed the problem that disease and illness (as an experience of disease) as concepts pose for nurses^{5, 19}. In summary the challenge is that nursing literature and theories almost exclusively discuss the restoration of function and health and wellbeing. However, nurses are also present when children do not recover health and wellbeing. Disability, death and dying are also part of children's nursing. For many disabled children, their internal health status may be relative, their disability means they live with poor function, which may improve or worsen, which in turn means their abilities to participate in childhood activities such as play, education and social activities are fluctuating. This might affect who nurses consider as Jamie's peers. Are we aiming to give him an experience of childhood similar to non-disabled children of his community, or of similarly disabled peers? We might find an answer from another pragmatist Richard Rorty²⁰ who argues that the use of ideas by communities should be seen as a political choice, and debated in political terms. In this case the issue of whether to aim for an experience of a disabled childhood, or as I would urge to aim for equality, is not a weakness of the theoretical

approach, but a political and social issue of disabled children's rights. In either case the stated aim is not to provide the same experience of childhood, but to attempt to provide as far as possible a similar experience. Disease, disability and death may frustrate our efforts as nurses, but we can strive with hope and aim for children, irrespective of the illness they live with, to be children who live their childhood.

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