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## **Chapter 6**

### **Children as Patients**

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#### **INTRODUCTION: BROAD AREA OF RESEARCH**

Research about health and illness extends very broadly across investigations of health and the spectrum of normality, to determine when illness and the need for treatment begin and to prevent unnecessary treatment. Research about children as patients includes studying the causes, prevention, and treatment of physical and psychological disorders. There have been great gains for child health and survival, and in preventing and treating children's illnesses, injuries and impairments. Social research about child patients' own views and experiences has helped to make medical treatment more humane and ethical, as reviewed later. Childhood is taken in this chapter to begin from birth, except for one example of the foetus as patient.

The more I reflected on the title I was asked to write about, 'children as patients', the more complicated the title appeared to be. This chapter therefore begins by reviewing eight contested meanings of how children are and identify themselves as patients. The borderlines between health and illness tend to be drawn differently in the minority richer world (less than one fifth of the world's total population of over 7 billion) and the majority poorer world. Later sections will review traditional types of research about children as patients, based on developmental medical and psychological models, illustrated by the example of cognitive behaviour therapy. Traditional methodologies are contrasted with more recent innovative ones, with their expanding concepts of childhood as a social construction, children's rights, their participation, competence, consent, and research ethics. The chapter concludes by reviewing how research with children as patients offers unique insights into children's capacities, their status and value to their society. The conclusion also discusses enablers and barriers to future research, which is intended to promote the effective, benign and respectful care of children as patients.

Until around 1990, research mainly concentrated on adults' views about children and was seriously limited in excluding children's own views. Since then, there has been a valuable increase in attention to children's views and experiences. However, research now risks falling into the opposite serious limitation: to attend only to topics and areas that children are assumed to be able to understand and discuss, and to exclude vital 'adult' concerns such as politics and economics. There is a danger of infantilizing child research, and of treating children as if they live in an artificial world of childhood sealed off from the 'real grown-up world'. This inadequate and misleading approach prevents thorough analysis of the social structures and pressures that shape child health and illness and treatments, and also influence how children and adults experience, perceive and describe health and illness. Childhood research is like emancipatory feminist research in

challenging patriarchal restrictions. Yet this does not mean simply separating children from adults (or women from men). It involves analysing many ways in which children's lives are restricted and oppressed, as well as nurtured and cherished by adults, and not simply at personal levels but at political levels too. For this reason, the chapter begins by reviewing the politics of child health, which show under-researched areas.

## **EIGHT CONTESTED MEANINGS OF 'CHILDREN AS PATIENTS'**

### ***The sick role***

Talcott Parsons (1951) identified disease as biological dysfunction. In contrast, being a patient is a social role. Parsons considered that the patient or sick role is governed by four expectations: exemption from normal role responsibilities; legitimization often by a doctor; wanting to get better; and seeking and cooperating with technically competent help. This section reviews eight examples of how, each year, millions of possibly healthy children are identified as patients and millions of sick and dying children are excluded from that role.

### ***Brief illness***

The first group is sick children in the minority-world who are briefly ill, although formerly many of them would have stayed in bed for weeks. Today, the average stay in paediatric wards in the United Kingdom (UK) lasts less than two days. Improved medication to control symptoms and aid rapid recovery has increased uncertainties about the difference between health and minor illness, and about when a child qualifies as a patient. Children who briefly feel unwell, and might hope to become patients, exempted from normal school and housework duties, are now often sent to school or nursery as usual, but with their antibiotics.

### ***Serious chronic conditions***

The second group is minority-world children living with serious long-term and potentially fatal conditions, cystic fibrosis or type I diabetes for example. Generally they maintain high standards of health and well-being. They attend routine healthcare appointments, but few see themselves as patients. They put great efforts into being 'normal', fitting medical routines of diet, physiotherapy or insulin injections as unobtrusively as possible into their everyday lives and saying 'I want to be like my friends,' 'I just want to get on with life' (Alderson, Sutcliffe and Curtis, 2006). Hundreds of research papers have been written on these young people's 'non-compliance' with medical regimes, mainly by clinical psychologists who aim to identify the problems and help young people to overcome them (DH and MRC, 2002; and see the Cochrane Collaboration of systematic reviews, which typically begin with thousands of papers and reduce these down to very few examples which meet the criteria of effective convincing research). Young people's resistance could be linked to a reluctance to fit the sick role (although they cannot 'get better' except in terms of managing symptoms more efficiently). Little research attention is paid to the many children who share in effectively managing their condition.

However, I suggest that 'non-compliance' involves differences between ordinary people's broad concepts of social health and healthcare practitioners'

narrower concepts of physical health, when they prescribe higher standards of healthy living than the average person would accept. Few adults stick rigidly to advice about diet and exercise, smoking or alcohol. They balance their ideas of 'social health', of 'having fun', being like their friends, and 'living life to the full' with their physical health needs. Children and young people with long-term conditions face similar conflicts when their prescribed very healthy living standards could undermine their social and emotional health by excluding them from friendships, fun, parties, carefree spontaneity, and, most of all, being accepted and included as a normal person. Their physical and social health and survival depend on balancing the demands of being a compliant patient with the vital and very complex challenges of also being 'an ordinary person'. Simply to classify them as patients misses how they have to manage these contradictions at the centre of their daily life and identity.

### *Sad, bad, mad or ill?*

Until recently, the third group was regarded as within the normal range, or as sad, odd, difficult or naughty, but not sick. Now they compose the largest and expanding group of minority-world child patients. Their experiences and behaviours are redefined as forms of sickness requiring medical interventions: obesity, shyness, insomnia, hyperactivity (APA, 2013). China Mills (2012: 444-445) reports a marked rise in the UK of NHS prescriptions of the medication Ritalin, for attention deficit hyperactivity disorder (ADHD), from 3,500 in 1993 to 250,000 in 2006, while private prescriptions and other treatments for ADHD considerably increased this total, which has continued to rise steeply over the past decade, and in the USA doctors write 2 million prescriptions a month. Neurologists, Baughman and Covey (2006), estimate that each year in the United States (US) between five and eight million children are treated for ADHD. It is claimed that 80 per cent of young children with ADHD also have early-onset bipolar disorder and extensive medication needs (Papoloses and Papoloses, 2007). These include Zoloft for depression, Ablify for bipolar disorder, Guanfacine for twitchy eyes, and medication for anxiety and depression. A graphic example of children's enforced patient-hood is when they are unwillingly but 'voluntarily' admitted to mental hospital by their parents' agreement, although not their own. Then they are denied the rights held by patients whose admission is enforced by the state. A survey of child health and well-being in 21 rich countries (UNICEF, 2007b) and in 29 countries (UNICEF, 2013) took six main measures: material well-being; health and safety; educational well-being; family and peer relations (trust, 'just talking with parents', 'kind and helpful peers'); health and risk behaviours (smoking, drinking); violence; and subjective well-being (feeling healthy, liking school, personal satisfaction). Two of the wealthiest countries, the United Kingdom and the United States, had the worst results in 2007. By 2013, the UK had risen to sixteenth out of the 29 richest countries, but was still behind the rest of Europe (UNICEF 2013). The World Health Organization (WHO, 2008) also reported high mortality and morbidity in the United States and the United Kingdom, attributing these results to extreme inequality between groups living in wealth or poverty. The general picture is confirmed by extensive international research (Wilkinson and Pickett, 2009).

General paediatricians now treat broadly social rather than medical problems: emotional and behavioural difficulties, obesity, school and other social

exclusions, violence and child abuse, dysfunctional families, self-harm and attempted suicide, drug misuse, and teenage pregnancy. These conditions seldom fit the medical model of identifying clinical conditions and their causes, in order to prevent, alleviate and cure disease. To call all the children in this third group 'patients' can imply and even assume that they are ill and need medical care, but these are questions which will be considered later.

#### *Majority-world children*

Fourth and conversely, millions of majority-world children who are severely ill and in urgent need of medical treatment have no hope of becoming patients in terms of receiving diagnoses and formal healthcare. UNICEF (2007a, 2009) estimates that each year over 50 million newborn children are not registered by the state and are therefore not entitled to any state services or protections. An estimated 0.37 billion have no access to professional healthcare. Many families cannot afford to pay for healthcare, and even in the US after the 2010 legal reforms, around 23 million people including children still do not have health insurance. Some progress has been made. UNICEF et al. (2012) reported that although an estimated 12 million children aged under 5 years died in 1990, by 2011 the number had fallen to 6.9 million. Yet that is still almost 19,000 everyday. On violence, 53,000 children are victims of homicide; up to a third of children are severely beaten at home with implements; 150 million girls and 73 million boys are raped or violently sexually abused (UN, 2006). Hazardous child labour, lifelong bonded labour and trafficking jeopardize child health. Migration of healthcare staff away from poorer countries further reduces the chances of this fourth group of children being treated as patients. 'There are, for example, more nurses from Malawi in Manchester than in Malawi and more doctors from Ethiopia in Chicago than in Ethiopia' (Khor, 2006: para. 6).

Basic services and standards are crucially relevant to 'children as patients' as they prevent them from becoming ill. Yet one in six people in the world does not have clean safe water; one in three has inadequate sanitation. Malnutrition results in the illness, disability and death of countless children: almost half a billion children suffer severe hunger and 100 million young children have vitamin A deficiency, a major cause of blindness, illness and death (UNICEF, 2007a). High maternal mortality rates increase infant morbidity and mortality.

Armed conflicts, which tend to occur in urban areas with high child populations and to begin by damaging local sanitation, water and health services, along with floods, droughts, hurricanes and enforced migration, increase each year the numbers of children who have serious physical and psychological illness and injury. Numbers of refugees, with numerous health problems, are rising. Over 45.2 million people were displaced in 2012. Of the 15.4 million refugees who fled abroad, an estimated 46% were children aged under 18. Of the almost one million asylum seekers, a record 21,300 applications were by unaccompanied children (UNHCR 2013). Climate change and pollution from burning fossil fuels is reported to be killing millions of people each year (Levy 2012), while floods and droughts are forcing up food prices and hunger, especially in the poorest countries with the youngest populations and highest proportion of children (Carty, 2012). Tropical diseases are spreading into the southern US and Europe. The local anxieties

of paediatricians about how to prevent and treat social problems for children in group three escalate to a global scale for children in group four, challenging governments and international aid agencies.

Pharmaceutical research relating to children as patients reinforces these inequalities by investing mainly in medication to treat minority-world children, and investing far less in treatments for the diseases that kill and disable most children – tuberculosis, malaria, which infects 500 million people each year, and other tropical infections.

#### *All in the mind?*

Fifth is the small but challenging group of children who feel very ill, with nausea, severe pain, exhaustion and incapacity, but whose doctors refuse to recognize them as ill because they have no identifiable medical sign: for example, no abnormal hormone, blood count, anatomy and x-ray or scan profile, or gene. Conditions such as myalgic encephalopathy (ME) raise debates about whether these are real or imagined illness, and they illustrate further complications of the sick role. To become a patient, it is not enough to suffer extreme and prolonged symptoms. Doctors look for an accepted sign to legitimate illness. Also, the sick role obligation to cooperate with technically competent help (Parsons, 1951) requires effective help with which to cooperate, but so far treatments for ME are mainly ineffective or highly controversial. Children in this fifth group highlight a paradox when doctors refuse to accept them as patients, whereas doctors do accept countless children from group three, who also tend to have no clinical signs and in addition often lack symptoms of pain, nausea and inertia.

#### *Screening and the worried well*

The sixth group is mainly healthy general populations who undergo medical screening. Most screening is an initial broad sweep to find the few who may be potential patients, who will have further tests. Usually, screening is for older age groups, to help practitioners to give them informed advice on healthy lifestyles, or to offer treatment for cancer and other ailments. In contrast, the other routine screening/scanning is prenatal, when the main 'treatment' offered is not lifestyle options but termination of pregnancy if the foetus is impaired or, in some societies, female. Pre-conception screening aims to identify prospective parents who carry genetic conditions; and in vitro fertilization (IVF) may involve checking and selecting embryos before they are implanted into a uterus. Prenatally, 'children as patients' extends to include the foetus and even the IVF embryo because of emphases in prenatal services associated with modern childhood that potentially influence child–parent relationships well before birth: risk, anxiety about imperfection and failure to fulfil potential, costly reliance on medical information and technology (Ehrich, et al. , 2008).

An unusual example of screening, which brings direct benefit, is when all newborn babies are checked for phenylketonuria, and treatment begins immediately to prevent severe learning difficulties from developing. However, another neonatal screening, for cystic fibrosis when earlier detection and treatment before symptoms develop might improve health and survival rates, raises the usual but so far unresolved controversies associated with almost all screening. Are screening costs recouped by outcomes in terms of healthier

lives and disabled lives prevented? Are scarce practitioners better employed in screening or in treatment services? Does earlier detection and treatment, even for serious but rare conditions, produce better outcomes? How does screening itself arouse unnecessary anxiety in the healthy majority, who may become the 'worried well', and when parents may perceive their child as a vulnerable potential patient? Why do so many people ignore advice based on screening results? This is being shown in current screening of school children for obesity.

Genetic screening raises further ethical questions (Clarke and Ticehurst, 2006; Evans et al. 2011). Should children be tested or informed, when no prevention or cure can be offered, and when the condition (Huntington's chorea, breast cancer) might not develop until decades later? If children are found to be carriers of genetic conditions, when they will not have cystic fibrosis, for example, but might pass it on to their children, when should parents and children be informed?

### *Children who are disabled*

Group seven is children who are disabled, when medical services cannot cure or alleviate their physical, sensory or learning difficulties. While valuing medical services to treat illness, disabled academics have questioned medical 'management' of disability. They contrast the medical with the social model of disability (Oliver, 1990). They criticize the misuse of medical services and time, and the risks of arousing false hopes of a cure. They argue that instead of reducing disability, the medical model can increase its worst aspects, stigma and exclusion: by identifying and trying to treat the problem within the individual child; by keeping the child and family dependent on healthcare practitioners and on separate services, such as special schools; by constantly comparing the child's failings against 'normal' standards; and by generally expecting disabled children to play the sick role but without hope of recovery.

There are medical debates about whether repeated operations for children who have spina bifida or cerebral palsy increase their infections, pain and immobility and do more harm than good. One girl in my study of consent to surgery had had over 40 operations (Alderson, 1993). Yet it is hard to research children's private views, because they are so loyal to the adults who care for them (Bluebond-Langner, 1978). Linda aged eight, facing repeated surgery, wanted to know the surgery details and asked, 'What if it goes wrong?' Although, she said: 'My doctor and my mummy decided about my operation. They knew what I wanted. After all she is my mum and I do trust her' (Alderson, 1993; 30). However, although she was cheerful while her mother was present, after her mother and aunt left she said: 'When I get back [from the operation] tomorrow, they'll be in tears for me' (1993: 128). Trying to research private views can be very damaging if researchers raise doubts in children's minds, or try to break through their stoic coping. It is also hard to contact those children and parents who opt out from surgery services.

In contrast, the social model identifies disabling factors not in the child's impairments but in the barriers and negative attitudes of an uncaring society. Special services are replaced in these ways: by inclusive mainstream ones where disabled and non-disabled children live and learn together (Richards and Armstrong, 2010); by assuring access to public buildings and transport; by overcoming negative discriminating attitudes; by respecting and

valuing children for themselves, rather than for their performance or 'normality'. Most crucially, the child is regarded as a person, not a patient, and disabilities are not seen as personal medical problems but as political and economic challenges, which disabled and non-disabled children and adults work together to change.

### *Children in medical research*

Finally, group eight is children taking part in medical research, which can draw strange boundaries between supposed 'patients' and 'non-patients'. For example, many children with asthma use inhalers for daily prophylaxis (to prevent rather than treat asthma attacks). If they stop using inhalers, they are likely to react for days or weeks by having more attacks. If the children take part in randomized controlled trials, they may be 'patients' in a treatment arm, or they may be in the arm which has inhalers containing placebo (dummy or non-treatment). In effect they stop being patients when they no longer have treatment, although for all they know they may be reacting to the new drug rather than to having a non-drug. Logic, ethics, and concern for the children's safety would suggest that the best trials compare a new treatment against a known treatment, unless there is not yet an accepted treatment – but there are effective treatments for asthma. It also seems obviously unscientific to compare the effectiveness of a drug against non-treatment of a group of children who are having severe withdrawal reactions after their usual medication is suddenly withheld. Surely that would give an unfair misleading advantage to the new drug. However, the Food and Drug Administration (FDA), the US agency responsible for medical research, prefers placebo trials (Ross, 2006).

British ethical guidance (RCPCH [The Royal College of Paediatrics and Child Health], 1992/2000) insists that children should be involved in medical research only if the research cannot equally well be done on adults, and if the findings are intended to benefit children. US guidance does not have this standard, so that children are recruited simply to increase numbers of subjects in trials, but with no guarantee that they will be studied as a separate group in order to benefit future child patients (Ross, 2006). Despite bioethics safeguards, harmful and fraudulent medical research and practices continue to be reported (Sharav, 2003; ; Baughman and Covey, 2006; Slesser and Qureshi, 2009; Kolch et al. 2010; Sercombe 2010; Mills 2012), such as the use of dangerous experimental drugs on African children (Save the Children, 2007; Boseley 2010).

Why does dangerous and unscientific medical research continue to be conducted on children despite decades of critical reports and guidelines? And what is the dominant influence in all the above eight examples? The concluding section will address these questions, after the following sections have considered research methodologies. The chapter title, 'children as patients', raises many complications as well as showing how illness and health pervade many aspects of life.

## **METHODOLOGIES**

### ***The broad range***

Research about childhood illness covers most research data collection methods: biochemical and genetic laboratory research; clinical experiments,

comparisons and trials; systematic and thematic literature reviews; research on the aetiology, epidemiology, prevention and treatment of disease; questionnaire surveys for statistical, international and longitudinal studies; action research; economic evaluations; ethnography and case studies; examining children's essays, diaries, images and formal records; increasing use of data on the internet; and a range of interactive methods using interviews, focus groups, play, cameras and drama.

Complex topics, such as childhood cancer, are like a mountain surrounded by many academic or practical disciplines. Each one can see only a limited view of the topic that reveals some aspects and conceals others, ranging from biochemistry to social experiences of living with cancer. This range of kinds of knowledge also applies to insights about childhood itself. At the intersection between the biological and the social, understanding of child illness is particularly well served by multi-disciplinary and multi-method research.

### ***Traditional developmental research***

'Traditional' methods stretch back for over a century. Although they have been complemented and often replaced by newer approaches, which will be described later, they still strongly influence the mainstream research journals and the funders. Indeed, new requirements in many universities to demonstrate the 'impact' of research is leading to new emphases on large, quantitative, positivist health-related projects. Methodologies combine research methods with theories about epistemology (the study of knowing and belief, and how we know and can validate what we know) and ontology (the study of reality, being and existing things and people, relationships and structures). Most research on children has been dominated by psycho-medical research models and methods, in which powerful beliefs (epistemology) about the slowly developing child can confuse and distort data about the being/ontology of real children (Alderson, 2013). When adults are perceived positively as fully developed human beings, children are seen partly negatively, in the sense of not yet developed, still deficient, lacking full competencies and therefore dependent and requiring firm adult control as well as protection and care.

The medical model of research is very useful when it searches for pathology, in order to identify and treat it. However, this approach can become a negative over-emphasis on failings and problems in some psychological and social research. The research tends to overlook children's strengths and achievements, and not to value babyhood and childhood as fulfilling times in their own right. Anxiety about problems experienced by children may go to the extremes of perceiving childhood itself as 'toxic' (Palmer, 2007). The medical metaphor that 'the child's remedy is to grow up' (O'Neill, 1988: 463) is another typical example of an ontology that identifies childhood with the sick role and its four expectations (Parsons, 1951) reviewed earlier. Children are exempted or excluded from normal (adult) role responsibilities. Legitimization of the sick role of childhood by paediatricians has a long history from seventeenth-century Dr Locke to twentieth-century Dr Spock (Hardyment, 1984). Wanting to 'get better' can mean wanting to become more adult.



### ***Traditional and mainly quantitative methods***

Predominant older child development research approaches include:

1. observations, case studies, tests and experiments about child behaviour in laboratories, intended to produce generalizations;
2. questionnaire surveys, usually of adults' assessments, which measure children's health and behaviour against prescribed norms;
3. higher scores for childhood problems and morbidity, whereas 'normal' or very good behaviours tend to have negative zero scores;
4. collection of standardized data for statistical and economic analysis;
5. assumptions that all kinds of data on diverse experiences should be quantified, measured and compared;
6. standardized 'objective' detached relationships between child research subjects and teams of researchers to avoid bias;
7. efforts to produce self-evident data and facts to support evidence-based solutions and policies.

### ***Limitations of traditional methods***

These 'hard science' methodologies have brought great gains for child health in clinical research, but are limited in social research about children's views and experiences. The approaches tend to be conservative rather than innovative. Previously used and validated questionnaires are favoured. Britain's longitudinal studies of birth cohorts from 1958, 1970 and 2000 repeat themes and questions from the earlier surveys in order to compare across generations (Dex and Joshi, 2007), despite numerous changes in childhoods and child health across the decades. Systematic reviews examine previously published research sometimes conducted decades ago, often influenced by cautious policy and funding agencies, and with omissions that the reviews can only replicate, for example, the absence of children's own views.

Larger studies, privileged as statistically and epistemologically more convincing, may filter further conservative emphases into reviews because, like oil tankers, they tend to take longer to design and complete or change. When managed by large hierarchical teams, they can be less flexible in their design and processes, and are very costly, which deters risky innovations and prefers tried and tested methods. These can all be ways to silence child patients' voices, although this can limit the relevance, validity and effectiveness of research evidence and conclusions. Further limitations will be reviewed, numbered to pair with the above numbered research approaches.

1. Observations of child patients based on laboratory animal study models tend to examine children's behaviour, but not their reasoning which can often justify seemingly irrational behaviour. When children feel nervous in strange settings, they may not show their real competence.
2. Normative questionnaires, which concentrate on adults' assessments and include the pre-designed questions and answers, are also liable to miss children's actual experiences and understandings, as well as new and challenging insights.
3. A century of medical and psychological research has emphasized child morbidity and failings over their strengths and contributions.

4. Standardizing data for statistical analysis involves representative samples, hypothetical questions, vignettes, and analysis of separate variables. In contrast, child patients' experiences tend to be diverse, individual, richly personal narratives, unexpected, and unique interacting combinations of many factors, and these experiences slip elusively through traditional research data collection. Economic research on cost–benefits and what works well is useful, but can be limited and reductionist when benefits vary among different patients, and are hard to define and measure precisely.
5. Assumptions that research equals measuring tend to dismiss valuable data about children's own views and experiences, which may not easily be measured.
6. Attempts at standardized 'objective' detached relationships between child research subjects and researchers to avoid bias can deter and intimidate children. Talk is likely to remain at a superficial 'public' formal level, whereas skilled researchers move beyond this level by encouraging rapport and intimate, frank 'private' talk.
7. Efforts to produce 'self-evident' data to support 'evidence-based' services conceal powerful unexamined theories and assumptions.

### ***Cognitive behaviour therapies (CBTs)***

The example of research about CBTs, linked to the high rates of child mental health problems reviewed earlier, illustrates some of the above limitations. An economist has proposed that happiness can be measured and promoted by cost-effective evidence-based CBTs (Layard, 2007). So the UK Government planned to spend £170 million during 2007–2010 on the therapies. However, critics make the following points (Leader and Corfield, 2007) linked to the above seven limitations as indicated by the numbers in brackets.

Happiness and unhappiness are too complex, personal and diverse to be measured or managed wholly in standardized ways (pp.4–5). Proper therapy, Leader and Corfield consider, involves exploring each person's unpredictable problems and deeper reasoning, through the non-judgemental relationship between client and therapist (pp.1–4, 6). In contrast, CBT remains at the superficial level of behaviour (p.1). Claims that CBT has been evaluated by trials comparing groups with the same profile and problem and receiving standardized therapy are invalid for these reasons. People's profiles all differ. They each have several and not only one identifiable problem. The problems cannot be wholly predicted or classified in advance. Effective therapy has to be partly spontaneous and responsive. By definition, it cannot be standardized; ironically, therefore, it cannot be evaluated in formal trials (pp. 2, 4–7).

The CBT trial is an example of efforts to research health problems and treatment through formal methods that differ from real clinical practice, so that the findings are of limited practical use. How did the CBTs appear to be effective? The trial was mainly designed by CBT therapists with only short-term follow-up, when CBT can seem to be effective before the symptoms reappear (7). Research about cost–benefit and what works well can be more thorough when it is independent. For example, independent research by Roberts, et al. (2004) found that the UK Government's favoured mentoring of

'anti-social' young people can harm their mental health when mentoring becomes yet another stressful failed relationship for them.

The CBT research and policy emphasize the medical model of individual treatment evaluated with cost-effective economic measures. However, the social model of critical policy, outlined earlier in relation to disabled children, also applies to the whole concept of childhood itself, as the next section considers. Much healthcare research is criticized as being the 'handmaiden' of medical research, collecting social data about health and illness by using conservative research models, which work well in pharmacology but less so in unpredictable social matters. Scambler (2002) criticizes social researchers for spending too much time on collecting and reporting surface appearances and associations (such as poor health indices and behaviours) and too little time on searching for deeper realities and explanations, as considered later. Concepts of childhood and children's rights are among these deeper issues.

### ***The United Nations Convention on the Rights of the Child (UNCRC, 1989) and children's competence***

The UNCRC combines economic welfare rights with liberal civil rights. The UNCRC enshrines children's rights to the best attainable healthcare and an adequate standard of living. Children's civil or participation rights, modified versions of adult autonomy, involve children in expressing their views on all matters that affect them, and adults giving the views 'due weight in accordance with the age and maturity of the child' (UN, 1989, UNCRC Article 12). Potentially, the UNCRC expands the rights of millions of children to higher standards of healthcare and participation. English and Commonwealth law in over 50 countries goes beyond the UNCRC, in respecting the legally valid consent of minors, provided they are competent in having sufficient understanding and discretion to make a wise choice in their best interests (*Gillick v. Wisbech & W Norfolk AHA*).

My research on the age when children are competent to consent to major surgery, in the view of the adults caring for them, studied 120 children aged from 8 to 15 years having elective, mainly orthopaedic, surgery (Alderson, 1993). They were interviewed in hospital the day before their operation and a week later, and I spent months making observations and, with a colleague, interviewing parents and staff. Many of the children had two or more serious long-term illnesses or disabilities, and had already had on average four or five operations, so they deeply understood from experience the nature and purpose, risks and hoped-for benefits, attendant pain and immobility, of the planned surgery. Most children showed impressive understanding and maturity (see also Bluebond-Langner, 1978), as if their hard experiences had increased their maturity and coping with complex and distressing events.

'I think they should tell you honestly. You are much less frightened when you know what's going to happen' (David, aged 10, in Alderson, 1993: 116).

Mum kept the information to herself, and she said in the clinic, 'Judy, go out.' I said, 'No.' [The doctor agreed.] Mum changed after that. She realized

it's better for me to be informed, and she started explaining things. (Judy, aged 12, in Alderson, 1993: 116)

If I didn't want the operation, my parents wouldn't make me have it. If I was going to die they'd make me. It would be the only sensible thing to do, but I'd agree. (Gemma aged 11, in Alderson, 1993: 43)

I would like to see the age limits [on consent] completely scrapped, and maturity brought in. As you grow up, your age has a stereotype. I'm trying to escape from that stereotype. (Robin aged 13, in Alderson, 1993: 43)

The group was unusually experienced, but instead of being exceptional children, might they be ordinary children in exceptional circumstances? Minority-world children are so highly protected from risks that major surgery is a rare time of serious danger. Do most children have latent capacities, which may be demonstrated during serious crises, and which more fortunate children do not have the need or the opportunity to reveal? The evidence from research with disadvantaged majority-world children suggests that very many of them do indeed have great reserves of courage and competence. For example, Invernizzi and Williams (2008: 133) observed parents in Peru encouraging their 'children to have small businesses in the street at a very early age as a means of boosting income as well as learning about people, environment and business'. Although it might seem healthier for children to be in school, early independence for very disadvantaged children can help to improve the family's living conditions and diet, and the child's chances of survival, especially if the parents become ill or die.

However, it seems to be hard for adults to recognize these early capacities, which counter dominant developmental theories about childhood deficits unless:

1. they have direct contact with competent children;
2. they then feel forced to reconsider their beliefs and make the paradigm shift of understanding how beliefs about slowly developing childhood/adolescence are social constructs and not simply biological facts; and
3. they work with children to transform their relationships with them, to trust and respect them, and through shared risk-taking to find (sometimes stressfully) how greatly the trust is validated and moves on to new, and arguably increasingly healthy stages of mutual respect.

Each person's own changing experiences and values structure their perceptions of childhood, meaning beliefs about what children and their relations with adults are and should be like. Many adults who research, work with and care for children socially reconstruct the dyads of: the providing adult and helpless needy child; the rescuing protective adult and victim child; the corrective adult and deficient delinquent child; or confident resourceful child-adult partnerships. Childhood research shows how children's views and relationships are worthy of study in their own right, and how children actively co-construct their lives, relationships and contexts, while international comparisons how childhoods vary widely and are not fixed facts. Researchers

construct different childhoods through their research design, theories, questions, methods, findings and conclusions.

### **SHARING INFORMATION AND DECISION MAKING WITH CHILDREN**

When can children begin to be involved in serious complex decisions? When do, or should, adults begin to involve them, for example, in the contentious examples when children are born with ambiguous genitalia? In such cases, surgery is very rarely needed to improve function and is usually cosmetic, primarily in order to reassure parents. Many affected adults now regret that they had surgery as children, and many feel they were assigned to the wrong gender (Preeves, 2003). Parens (2006) and colleagues agreed that, in most cases, surgery should be postponed until the child is old enough to begin to request it, or at least to indicate a clear gender preference that guides surgery decisions.

When can children begin to form and express views that can influence their healthcare? Children who live with a long-term condition can gain profound understanding through social experience, well in advance of their supposed biological developmental stage. For example, they begin to share in managing their diabetes injections and diet early on (Alderson et al., 2006). We interviewed 24 children aged 3 to 12 years about their type I diabetes. From four years, some understood that 'insulin is the key that turns sugar into energy', and shared in doing their daily blood tests and injections, although others wanted to wait until they were older. Parents knew that informing, involving and respecting children were all vital so that they could avoid rows, force and coercion, and be able to trust their children to be careful about their diet at all times. Ruby (aged 5) could work out from doing her blood test how much cake she could eat at birthday parties. Jessie (6) explained how she did blood tests and Simba (7) explained why he needed insulin (2006: 30–31).

Some of the children had become very ill before they were diagnosed, and so they had intense experience of the life-threatening nature of their condition. Moogum (7) diagnosed when she was aged five years, said, 'My sister was at home in bed and she was crying because she thought I was dead' (2006: 31).

Observations of premature babies have discovered the babies' eloquent body 'language', which adults can 'read' (Als, 2012). The babies' healthcare needs for quiet, for dim lighting, for resting in individually preferred positions, and also their agency in their own self-healthcare, are ignored in many neonatal units. However, a few 'baby-led' units continually learn from the babies' expressed 'views' and adjust the care accordingly.

How can mental health research interviews with very disturbed young children about parental abuse discover the children's needs and views without distressing them still further? During research interviews, each child aged four to seven years had a small box to decorate with craft materials, creating images of the child on the outside, and of the child's wishes and feelings within (Winter, 2012). Children were able to control the pace, timing and topics during the interview, such as by saying 'pass the glue' to deflect or pause before answering a hard question. Concentrating on their work also avoided problems of potentially intimidating sustained eye contact. The method created spaces in which children seemed to feel confidence, trust and some control, so that they were willing to talk rationally in detail in their own

time. The family courts usually ignore the views of these children, believing they are too young to form sensible views. Yet the interviews showed that if decisions about residence are made without consulting or explaining to the children, this can undermine their mental health and increase their distress, anxiety and sense of guilt. Children who are not engaged in the process are at very high risk of needing long-term adolescent and adult mental healthcare. Effective interviews depend on adult interviewers' skill, tact, patience and psychological stamina to cope with sharing the children's pain.

Repeated nurse research studies about managing children's pain conclude that even young children should be involved in explaining and deciding their needs for pain relief (for example, Kortelainen, et al. , 2008). Hospitals give children pain relief pumps after surgery, so that within given limits they can administer their own analgesia and, knowing this, they tend to use less pain relief. More generally, hospitals have changed over the decades from bleak frightening places into attractive colourful family-centred spaces, in response to children's views, from films of distressed lonely young children in the 1950s (Robertson and Robertson, 1989) to today's routine consultations with young people about planning and providing services. For example, they have recommended that reception desks should be low enough for children to see over them.

## **INNOVATIVE RESEARCH METHODOLOGIES, ETHICS AND FINDINGS**

This section considers closely related aspects of current research: methodologies adapted to respect children's rights and competence and high standards of research ethics. The challenge to the medical model by the social model, described earlier with disabled children, applies equally to childhood. Is childhood a condition of personal disability/deficit? Or are childhood 'deficits' partly or mainly socially and politically ascribed and imposed, much as women used to be seen as inevitably inferior to men? Women's health improved immeasurably when they came to be respected (more or less) as equal to men (Doyal, 1995). We have to research how much of children's physical and mental morbidity stems from their economic and social inequality with adults (far beyond biological differences). The ontology of the child as a real person now, not only a human becoming or future adult, introduces an epistemology of trust in children's own views and experiences as valid sources of knowledge, beyond relying on adult controlled 'facts' about children's observed behaviours.

The UNCRC (1989) has promoted research that consults and respects children's views to form and express their own views in all matters affecting them. All nation states except the USA and Somalia have ratified the UNCRC and thereby agreed to report regularly to the UN review committee, and some involve children in compiling their reports. Governments, service providers including healthcare services and funding agencies now routinely commission research about children's own views. There are the dangers of token consultation, poor methods of enquiry, and false claims about what children 'want' and 'choose'. Children and their advocates are disappointed that, despite all the funding and effort invested in consulting children, in the UK at least, few of their ideas and requests are implemented (Percy-Smith and Thomas, 2010).

Most consultation is with groups of children. However, consulting with individual child patients before major treatment is an exception that leads the way in several respects. The child is consulted about a practical decision, which will almost definitely be made and implemented, and not referred on to some other agency and probably forgotten. As a patient, the child shares with adult patients the benefits of a long medico-legal history of respect for voluntary consent (Nuremberg Code, 1947) and informed consent (WMA, 1964/2008). The adults concentrate on one child's views and, uniquely, the child patient's views about his or her own body matter most, whereas in other family and group decisions the child's views and interests will be balanced with other people's, and may be discounted. So although parents may be the main deciders, within the constraints of available healthcare, they should set the child patient's interests first. If the child disagrees with the decision (in the UK) efforts are usually made to inform and involve the child, sort out fears and misunderstandings, negotiate as much as possible, and avoid imposing a decision on a fearful resisting child. The UK sets high ethical standards (for example, RCPCH, 1992/2000) although these have been undermined by European law on medical research with children (Biggs, 2010).

### ***Participation in topic, aims and methods***

Participative research with children involves newer methods which, to be effective, engage with the topic and aims of participation. In contrast to the numbered conservative methods listed earlier, innovative childhood study methods involve:

1. observing children in the context of their everyday lives where they are the experts; even very young children and those with speech and learning difficulties can communicate beyond words through their body language and everyday activities and relationships;
2. creating with children questionnaires, which are child-friendly in their design and content, instead of relying solely on adults' replies, and also researchers avoiding normative judgements, and instead assuring children that there are no right or wrong answers but that their views matter, while trying to understand children's own standpoints and reasoning (Mayall, 2002);
3. concentrating on competent, positive aspects of child patients' lives, as well as their problems, and considering possible causes of problems beyond children's own failings, besides learning from historical and international examples how different childhoods are reconstructed;
4. attending to children's complex diverse experiences through their narratives and play, by using open questions, semi-structured narrative interviews and ethnographic observations as well as statistical analysis (questions about economic research are reviewed later);
5. working on qualitative and quantitative data analysis, on theoretical and critical explanations;
6. encouraging rapport and trust between researchers and child participants with high standards of ethical respect for informed consent and confidentiality;
7. having a cautious critical awareness of the differing limitations of every research method, of the tenuous links between data, analysis, findings,

recommendations, and possible future policies and practice, while being aware of the risk that research tends to serve the interests of powerful groups over those of children.

Although further developed since 1989 (Christensen and James, 2008), these methodologies have a long history. In the 1950s, several moving films showed young children's lonely anxiety in institutions without their parents (Robertson and Robertson, 1989). The paediatrician who allowed the film *Laura* to be made in his children's ward, which he considered to be very happy, was horrified to see Laura's severe sadness and at first rejected the message of the film. But he became convinced and was a leading advocate of 'mother care in hospital' (MacCarthy, 1979). Maureen Oswin's (1971) powerful ethnographic accounts of her work as a care assistant in children's sub-normality hospitals led to radical policy changes. She graphically explained not only the inadequate mass 'care', but also the children's complex emotions at a time when they were dismissed as 'idiots' and 'vegetables'. After describing a child in tears after her parents' rare visit, Oswin commented 'cabbages don't cry'. Her channelling of children's experiences led to a government inquiry and the fairly rapid transfer of children out of the vast hospitals and into small family units, as well as much more support for parents caring for their children at home as persons and not patients.

Research ethics initially developed within medical research, which incurs the highest risks. The central principles are respect, justice and avoiding harm when possible, with utilitarian balancing of harms and risks with hoped-for benefits, the basis of medical ethics guidelines, which tended to emerge from publicity about medical scandals involving harm to children. The guidelines help to protect medical research and researchers as well as research subjects. The Nuremberg Code (1947) emerged from the trials about Nazi experiments. Helsinki (WMA, 1964/2008) followed the episode when pregnant women took Thalidomide and their babies were born with deformed limbs. Work by Beecher (1966) and Pappworth (1967) about harmful research on children led to the rise of medico-legal and philosophical bioethics, and to many publications, for example, USNC (1977), Beauchamp and Childress (1983/2001), Melton, et al.(1983), Nicholson (1986).

During the 1990s, review by research ethics committees (UK) and institution research boards (US) gradually became a routine part of designing healthcare research. During the 2000s this informs and has spread routinely into much social research in the ethics questions that arise at every stage of research from first plans to final dissemination (Alderson and Morrow, 2010).

## **CONCLUSIONS**

The above review of many aspects of research relating to children as patients raises perplexing contradictions, which are considered in this final section. Are there any general answers or rules, themes or underlying realities to explain the following puzzles?

Instead of a clear straight line dividing child patients from healthy children, the eight initial examples showed wildly shifting boundaries placing many extremely sick children in the 'non-patient' zones, and many children who are healthy, or who perceive themselves as healthy, in the patient zones. The medical model, intended to promote health, can paradoxically increase



the numbers of 'children as patients' who experience disabling stigma, social exclusion, blame and guilt about their 'abnormalities'. The model tends to overlook children's own views about their distress and needs, and also their strengths and competencies. The pharmaceutical company websites show that research for minority-world children is far more highly funded than research about the vastly greater needs of majority-world children, although many of their illnesses can be prevented and treated, per child, at extremely low cost.

In research and practice, medical models of individual children's illness and failings differ markedly from emancipatory social models. The medical model is appropriate for treatable illness or injury. Yet by searching for problems within individuals, it can reduce social and political problems into 'dysfunctional' children, youth and families. General paediatricians observe many problems in the unhealthy behaviours and relationships, diet and housing, families and communities that damage children, but they often feel uncertain how to explain, prevent or cure children's suffering. The strength of the medical model, to identify/diagnose the main disease or cause of illness, and administer effective treatment instead of simply trying to alleviate its symptoms or effects, is often missing in public child health policies.

In research about children as patients it is necessary to examine the powerful influence of economics. Pharmaceutical companies publicize the problem of 'therapeutic orphans' (illnesses that have no accepted treatment), mainly in the minority world to justify involving more children as research subjects. Yet the companies say less about their very slight changes to marketed drugs and 'orphan drugs' (drugs in search of illnesses), which increase company profits, or about their relative neglect of research for loss-making drugs for majority-world children dying from TB and tropical diseases. Meanwhile, governments promote national and international policies to increase prosperity but which also increase inequalities, thereby damaging child health. Despite governments' aims to 'end poverty', economic inequalities are growing, and are the greatest source of physical and mental ill health (Wilkinson and Pickett, 2009).

Setting the health of future generations in peril, governments' growth and productivity priorities damage the finite planet. Governments increase their Gross National Product (GNP) not only with 'goods', such as healthcare, housing and business profits, but also with costly 'bads' linked to illness: dealing with accidents, illness, pollution and disasters. Above certain poverty levels, paradoxically, a rising GNP involves steady increases in the 'bads' of infant mortality, child abuse and poverty, teenage suicides, drug use and mental illness (Douthwaite, 1999). Economic wealth does not necessarily increase child health, social well-being, justice or equity, once the national average income has passed a certain basic level (not met yet by many sub-Saharan African countries). Instead it tends to increase wealth inequalities, which are clearly linked to worse child health. The first recommended way to promote child health is therefore to reduce inter- and intra-country economic inequalities (Wilkinson and Pickett, 2009; WHO, 2008). Many analysts conclude that the key adverse influence on health is neo-liberal economics (Stiglitz, 2010; Wacquant, 2009) in the growing divisions between wealthy (generally older) and poor (generally younger) generations, resulting in the growth in child poverty, war and the destruction of natural environments,

which all increase child illness. Neo-liberalism involves disorganized deregulated global capitalism, the withdrawal of practical material support for citizens by the welfare state, but also the invasion of state and economic power and control into adults' and children's public and private life. People are then treated less as active determining citizens (agents), than as passive clients (patients) of state services, and as dependent consumers guided by the mass media and drawn into debt.

Economics is the key factor in the initial eight examples. Children become patients when adults are willing and able to pay for their treatment, and when it is profitable for companies to sell treatments. Sick children are denied the status of patient for economic rather than medical reasons and children who are so precious to their family and community may not count, in global policy terms, as worth even the cheapest healthcare. From this perspective, future research to benefit children as patients would promote multi-disciplinary multi-method research, which works: to overcome qualitative/quantitative, factual/constructionist, 'hard/soft', adult-centred/child-centred divisions; to see how contrasting approaches can inform and enrich one another; to combine 'micro' research with individual patients with 'macro' critical political and economic analyses; to attend more critically to connections among data, interpretations, policy recommendations and practical implementation; to investigate children's many views and experiences seeing how they exercise their rights to be involved in all matters, processes and decisions that affect their healthcare; to learn about their capacities from child patients' exposure to exceptional risks; to examine the principled and the cost-effective benefits of humane respect when adults work with child patients as partners.

Barriers to these aims, in Britain at least, include the increasingly commercial nature of research, controlled by funders' agendas, and treated by universities as income generation. However, ways to enable research that is intended to promote the effective, benign and respectful care of children as patients include the enthusiastic cooperation of many children and parents, of agencies working for children's rights, and of many researchers and practitioners across the world.

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