

Do children become patients by medical diagnosis or economic status?

Priscilla Alderson (2008) *Children's issues*, 12, 1:7-11.

Abstract

The article identifies eight groups of either mainly healthy children who become child patients, or else mainly ill children who are denied health care. The article questions whether children become patients through medical diagnosis or economic influences, and seeks to explain seemingly illogical international patterns in child health and illness.

Introduction

This article reviews eight contested meanings of 'children as patients' in how children are identified and identify themselves as patients. The borderlines between health and illness tend to be drawn differently in the minority richer world (about 17% of the world's total population of 6.5 billion) and the majority poorer world. Parsons (1951) identified disease as bodily dysfunction, whereas being a patient is a social role. The patient or sick role is governed by four expectations: exemption from normal role responsibilities; legitimation often by a doctor; wanting to get better; and seeking and cooperating with technically competent help. Each year, millions of possibly healthy children are identified as patients, and millions of sick and dying children are excluded from that role, as the following examples illustrate. The eight groups of children each raise questions about why they are or are not identified as patients.

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, followed by convalescence and quarantine, to prevent infection spreading to other children. Today, the average stay in many paediatric wards lasts less than two days. Improved medication to control symptoms and aid rapid recovery has reduced fears about cross infection. It has also 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, with antibiotics.

Is it in the children's interests to be treated as 'normally healthy' when they have infections and feel unwell and tired? Should they have extra care and rest, for their own sake, and to prevent frequent cross infection, especially among younger children at centres where colds and tummy bugs regularly circulate?

Long term serious illness

The second group is children living with serious long term and potentially fatal conditions, cystic fibrosis or type 1 diabetes, for example. They live in the minority world; few survive in the majority world for lack of affordable services. Generally they maintain high standards of health and well-being. They attend routine healthcare appointments, but seldom 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 (DH and MRC, 2002), basically their 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 set their ideas of 'social health', of 'having fun', being like their friends, 'living life to the full', before their physical health. 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.

How can these children best be enabled to promote their physical and their social and emotional wellbeing?

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 (Coppock, 2005). Their experiences and behaviours are redefined as forms of sickness requiring medical interventions: obesity, shyness, insomnia. Between a quarter and one half of ordinary children at United States (US) summer camps 'jostle for their morning medications: Zoloft for depression, Ablify for bipolar disorder, Guanfacine for twitchy eyes and a host of medications for attention deficit disorder', some have a cocktail of drugs to treat hyperactivity, anxiety and depression (Gross, 2006). Only in the US and New Zealand can these drug be advertised directly to parents. 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 lack even the rights held by patients whose admission is enforced by the state. During a conference in 2007, US and UK paediatricians, all mainly dealing with general problems, not hospital specialists, discussed how they now encounter 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, teenage pregnancy. A survey of child health and well-being in 21 rich countries (UNICEF, 2007b) 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 UK and the US, had the worst results. The paediatricians described feeling uncertain and helpless about how to adapt social problems into the medical model of identifying clinical conditions and their causes, in order to prevent, alleviate and cure disease. 'General paediatrics has lost its way' commented one doctor. To call all the children in this third group 'patients', who are implicitly best served by healthcare practitioners and treatments, can confirm questionable medicalising assumptions. Research with children being treated for mental distress finds that they do not want to be pathologised, they want services that respect and listen and respond to children's own views and definitions of mental distress and need, with fewer drug treatments and more peer support (Laws, 1998).

Are medical treatments and medication effective and appropriate treatments for many of these social conditions? Or are they palliation to suppress symptoms? Do they divert attention away from social and economic problems, their causes and prevention, in ways that harm rather than benefit children?

Severe and fatal illness in the majority world

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 (2002, 2007a) estimates that each year 40 to 50 million newborn children are not registered by the state and are therefore not entitled to any state services. An estimated .37 billion have no access to professional health care. Many families cannot afford to pay for healthcare and, even in the US, 40 to 50 million people including children do not have health insurance. Globally, each year up to ten million children aged under 5 years die; 53,000 children die from 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 and slavery jeopardise child health. It is estimated that there are almost 5,000 child 'sex slaves' trafficked into the UK (Craig et al., 2007). Migration of health care staff away from poorer countries means that this fourth group of children are still less likely to be treated as patients. 'There

are more nurses from Malawi in Manchester than in Malawi and more doctors from Ethiopia in Chicago than in Ethiopia' (Khor, 2006).

Crucially relevant to 'children as patients' are basic services and standards to help to 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 mainly occur in urban areas and begin by damaging local sanitation and health services. Along with enforced migration, floods, droughts and hurricanes, conflicts increase each year the numbers of children with severe physical and psychological illness and injury. In January 2008, half a million people are expected to be made homeless by huge floods in Southern Africa. Tropical diseases are spreading into the southern Europe and into southern US where they affect many Black and Hispanic children who cannot access health services. The local anxieties of paediatricians about children in group three escalate to a global scale for children in group four, challenging governments and international aid agencies (UNICEF, 2007a; Monbiot, 2007). 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.

Why do healthcare services and research attend so much more to the broadly healthy minority world children, and so much less to majority world children in greatest need?

Symptoms without signs

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 recognise 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 chronic fatigue syndrome and 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 duty of 'cooperating 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.

Why do doctors insist on finding a clinical sign before they diagnose certain illnesses with severe symptoms, but readily diagnose other 'illnesses' that have neither signs nor symptoms of physical illness?

Screening and scanning

The sixth group is the mainly healthy general majority world populations who undergo medical screening. 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 and scanning is prenatal, when the main 'treatment' offered is not lifestyle options but termination of pregnancy if the fetus is impaired or, in some societies, female. Preconception screening aims to identify prospective parents who carry genetic conditions, and in vitro fertilisation (IVF) may involve checking and selecting embryos before they are implanted into a uterus. Prenatally, 'children as patients' extends to include the fetus 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, reliance on medical information and technology (Alderson, 2002). Parents' decisions may depend on whether they relate to the fetus as a person, a patient, 'nobody', or a commodity (Williams, Alderson and Farsides, 2001).

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 ethical questions, along with other genetic screening (Clarke and Ticehurst, 2007). 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?

So-far unresolved controversies are 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? In Britain there are serious shortages of midwives in labour wards but growing use of midwives in prenatal screening. Does earlier detection and treatment, even for some cancers, produce better outcomes? Is the unnecessary anxiety aroused in the healthy majority, who may become the 'worried well', justified? Why do so many people ignore life-style advice based on screening results? In January 2008, vast plans to increase screening in the hope of reducing illness were announced by government in London. Childhood obesity is just one example. However, screening can be counterproductive. Advice on diet, exercise and other healthy habits is similar for preventing many health problems so that it is often not necessary to screen in order to identify a particular potential problem. Yet if one is detected, people may feel that there is little they can do and that they might as well enjoy a shorter merry and unhealthy life. Alternatively, if they are told that there have no potential problems, they may see no reason to stop unhealthy habits. Anxiety when feeling that they should change tends to induce fat people to have another doughnut, and smokers to light another cigarette.

Why is so much being invested in costly screening services for mainly healthy populations, which does not benefit most children, can harm many

(female feticide), and takes funding and staff away from under-resourced treatment services?

Disabled children

Group seven is disabled children, 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), although Shakespeare (2007) has modified this distinction. They criticise 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 'special' services; 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, for example, about whether repeated operations for children who have spina bifida or cerebral palsy might increase their infections, pain and immobility and do more harm than good. 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 by inclusive mainstream ones where disabled and non-disabled children live and learn together (Alderson and Goodey, 1998); 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.

In many countries, despite far more inclusive and accessible amenities for disabled people to share with everyone else, and despite years of research about the social and medical models, why are so much staffing, funding and resources still devoted to medical model services for disabled children?

Children in research

Finally, medical research can draw strange boundaries between supposed child '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 randomised 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 many 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, 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 research and practice scandals continue to be reported (Kennedy, 2001; Redfern, 2001), the exploitation of children in psycho-pharmaceutical research (Sharav, 2003; Coppock, 2005; Baughman, 2006) and the use of dangerous experimental drugs on African children (Save the Children, 2007). There are regular debates in medical journals about commercial interests, which distort research funding and agendas, bioethics committee judgements and peer reviewing for journals.

Why does dangerous and unscientific medical research continue to be conducted on children despite decades of critical reports and guidelines?

Discussion

Doctors appropriately diagnose and effectively treat many children. However, instead of a clear straight line between health and illness, wildly shifting boundaries place 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, in seemingly arbitrary and illogical ways. Scambler (2002) criticises 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, the spider that is spinning the web. Visible health data are like countless falling objects; research about them means little unless they are connected to the invisible forces and influences that explain the falling, for example, gravity.

The driving force and common explanation about child health and illness appears to be economics. Douthwaite (1999), Stiglitz (2002), Scambler (2002), with many others, analyse how current economic theories massively increase poverty and ill health when prosperity and productivity are the priorities. These are assumed to flourish in regimes of low taxes, and low income and benefits (for workers and young families), with deregulation, high profits for industry, and immense wealth for business leaders, which is supposed to 'trickle down' to benefit all, but fails to do so. Instead, growing inequalities between the wealthy few and the many poor are major indices of increasing child poverty and ill health (Pickett and Wilkinson, 2007). During the 1990s and despite increasing global prosperity, 100 million more people were reduced to living in poverty (Stiglitz, 2002:5). For the poorer 50 per cent of British people, their share of the national wealth fell from 10 per cent in 1986 to 5 per cent by 2002. Over half the children in inner London live in relative poverty, and nearly 90,000 are homeless or in temporary accommodation. They have up to 25 per cent higher risk of severe ill-health and disability and are up to four times more likely to suffer mental health problems than other children (Mitchell 2006). Governments' main aims include increasing their Gross National Product (GNP). But along with the 'goods', such as healthcare and housing, costly 'bads' also increase the GNP: 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).

Economists' replies to the above eight questions would include the following.

1. Better medication reduces childhood illness and infection, enabling slightly ill children to attend to school and parents to go to work and increase the GNP instead of staying at home nursing children.
2. With cystic fibrosis and diabetes, it is more cost-effective to maintain current health and education systems than to attempt to retrain all practitioners in new emancipatory ways of working with children to promote their physical, social and emotional well being.
3. It is quickest, cheapest, easiest and most profitable for industry and therefore the GNP, to treat so called 'social problems', the failings of inadequate people, with medication, economists would reply. Doctors are reluctant to become 'political' and to admit that they are attempting to treat social and not medical problems. However a critical economics analysis would indicate that political remedies are needed: redistributing wealth, alleviating poverty and reducing inequalities (Scambler, 2002; Pickett and Wilkinson 2007).
4. The industries running healthcare services and research attend so much more to the broadly much healthier minority world children, and so much less to majority world children, because profits are made in the minority world, and losses in the majority world.
5. Doctors insist on finding a clinical sign before they diagnose certain illnesses with severe symptoms, if there are no available effective drugs. They readily diagnose and even construct other 'illnesses' without signs or symptoms when profitable drugs can be prescribed.
6. Similarly, screening and scanning services, that may offer little benefit, may harm children, and may withdraw resources from treatment services, are installed when the providers can profit and persuade governments to buy or hire the equipment and services.
7. The second reply also applied to disabled children.

8. Dangerous and unscientific medical research continues to be funded, to be approved by ethics committees and peer-reviewers, to be published and implemented because all these processes and systems, including the FDA, are so heavily funded by the pharmaceutical companies, supported by governments whose main concern is to back profitable industry. The current privatising of former state hospitals and health services (Pollock, 2004), with its immense threat to child health, is too large a topic for this article.

In conclusion, children become patients when adults (parents, governments, insurers) are willing and able to pay for their treatment, and when it is profitable for companies to sell treatments. Sick children are denied their rights (Alderson, 2008) and the status of patient for economic rather than medical reasons. Children's lives, so precious to their family and community, may not count, in global policy terms, as worth even the cheapest healthcare.

References

- Alderson, P. (2008). *Young children's rights, revised second edition*. London: Jessica Kingsley/Save the Children.
- Alderson, P. (2002). Utopia or dystopia? The new genetics as an environment for childhood. In M. Gollop & J. McCormack (Eds.), *Children and Young People's Environments (1-18)*. Dunedin: Children's Issues Centre.
- Alderson, P. & Goodey, C. (1998). *Enabling education*. London: Tufnell Press.
- Alderson, P., Sutcliffe, K. & Curtis, K. (2006). Children as partners with adults in their medical care. *Archives of Disease in Childhood*, 91,3000-3.
- Baughman, F. (2007). *The ADHD fraud: how psychiatrists make patients of normal children*. Victoria BC: Trafford.
- Clarke, A. & Ticehurst, F. (2006). *Living with the genome: ethical and social aspects of human genetics*. Basingstoke: Palgrave Macmillan.
- Coppock, V. (2005). 'Meeting the challenge? Voicing children and young people in mental health research', in J. Goddard, et al. (Eds.), *The politics of childhood*. Basingstoke: Palgrave Macmillan.
- Craig, G., Gaus, A., Wilkinson, M., Skrivankova, K. & McQuade, A. (2007). *Contemporary slavery in the UK*. York: Joseph Rowntree Foundation.

DH & MRC, Department of Health & Medical Research Council (2002). *Current and future research on diabetes*. London; Department of Health.

Douthwaite, R. (1999). The need to end economic growth', in M. Scott Cato & M. Kennett (Eds.), *Green Economics (27-35)*. Aberystwyth: Green Audit Books.

Gross, J. (2006). Breakfast buffet at camp echo. *New York Times*, 16 July.

Kennedy, I. (2001). *Learning from Bristol. Report of the public inquiry into children's heart surgery*. London: Stationery Office.

Khor, M. (2006). Medical brain drain hits poor nations. *Third World Network*. 10th April.

Laws, S. (1998). *Hear me! Consulting with young people on mental health services*. London: Mental Health Foundation.

Mitchell, F. (2006). *Chance of a lifetime: The impact of bad housing on children's lives*. London: Shelter.

Monbiot, G. (2007). *Heat: how we can stop the planet burning*. London: Penguin.

Oliver, M. (1990). *The politics of disablement*. Basingstoke: Macmillan.

Parsons, T. (1951). *The social system*. Glencoe Ill: Free Press.

Pickett, K. & Wilkinson, R. (2007). Child well being and income inequality in rich societies. *British Medical Journal*, 335,1080-89.

Pollock, A. (2004). *NHS PLC: The privatisation of our health care*. London: Verso.

RCPCH – Royal College of Paediatrics and Child Health. (2000). Guidelines on the ethical conduct of medical research involving children. *Archives of Disease in Childhood*, 82,177-182.

Redfern M (2001). *The Royal Liverpool Children's Hospital Inquiry Report*. London: The Stationery Office.

Ross, L. F. (2006). *Children in medical research: access versus protection*. New York: Oxford University Press.

Save the Children (2007). *Why social corporate responsibility is failing children*. London: SCF.

Scambler, G. (Ed.), (2001). *Habermas, critical theory and health*. London: Routledge.

Shakespeare, T. (2007). *Disability rights and wrongs*. London: Routledge.

- Sharav, V. (2003). Children in clinical research: a conflict of moral values. *American Journal of Bioethics*, 3 (1)1-99.
- Stiglitz, J. (2002). *Globalization and its discontents*. New York: W W Norton.
- UN – United Nations. (2006). *The United Nations Secretary General's study on violence against children*. New York: UN.
- UNICEF. (2002). *State of the world's children*. New York: UNICEF.
- UNICEF. (2007a). *State of the world's children*. New York: UNICEF
- UNICEF (2007b). *An overview of child well-being in rich countries*. New York: UNICEF.
- Williams, C., Alderson, P. & Farsides, B. (2001). Conflicting perceptions of the fetus: person, patient, 'nobody', commodity? *New Genetics & Society*, 20, 225-238.