Title: Human Rights in Nursing Practice (Accepted version)

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Abstract

This article explores the tension between appeals to human rights and how to care for people within the NHS which provides universal access, free at the point of entry, and trying to do the greatest good for the greatest number. It explains where rights come from and what they do. Recent legal challenges concerning human rights and demands for continued treatment are discussed and the relationship between nursing and human rights explored. We explain that if nurses focus upon moral rights, such as dignity, and enhancing solidarity with fellow human beings it is highly likely that they will be complying with human rights law.

Key Words: Nurses; nursing; human rights; Human Rights Act 1998;

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Background

Every patient wants to be seen and valued as a unique individual (Authors et al). Central to compassionate care is the ability to see who the person before them really is, to be present with them, and not to abandon them. However, not every person has been so valued or received compassionate care. Connection to others across the whole social spectrum and recognition of how ill-health and misfortune were not linked to moral worth, led to the inception of the welfare state. The state’s recognition of its obligation towards its citizens regarding their health and well-being is expressed through the UK National Health Service (NHS). This aims to improve individual and community health regardless of moral character, social status, ability to pay, or willingness to adopt healthy lifestyles. The NHS treats people “…irrespective of gender, race, disability, age, sexual orientation, religion, belief, gender reassignment, pregnancy and maternity or marital or civil partnership status. It has a duty to each and every individual that it serves and must respect their human rights” (Department of Health (DH), 2019). To help monitor and enforce this, the Care Quality Commission (CQC) (2019) introduced a human rights approach to regulating health and social care services in February 2019. This article explains what rights are and how they are relevant to nursing.

Human Rights and the NHS

The NHS Constitution (DH, 2019) contains seven key principles (Box 1). Under Principle 1, the state “has a duty to each and every individual that it serves and must respect their human rights. At the same time, it has a wider social duty to promote equality through the services it provides and to pay particular attention to groups or sections of society where improvements in health and life expectancy are not keeping pace with the rest of the population” (DH 2019, p14). This means that individual people’s rights are not absolute as the wider aim of the NHS is to improve the overall health and well-being of the nation. For example, people can be quarantined against their wishes to protect the public (The Health Protection (Coronavirus) Regulations 2020). Also, resources are finite and the NHS faces individuals, or their families, making demands that exceed what is clinically necessary.

Time Out 1

Read the NHS Constitution and reflect on what this says in relation to the seven key principles listed in Box 1.

Human rights are neither just needs nor wants, rather they are expressions of fundamental concerns for what it is to be human. There can be needs and wants that simply do not meet the threshold for human rights. Human rights impose mandatory obligations on the state so campaigners sometimes try to attach human rights claims to their demands. Separating needs, wants and rights (see table 1), has continued to be difficult for decades (BMA 2001). Put simply, a "need" is what an individual "ought" to have, whereas "want" is what an individual "would like" to have (Line 1974 p.87).

Even where the focus is on well-established human rights, there are practical concerns within healthcare about appropriate actions. Some of the most challenging decisions relate to life, suffering and death (McAuley 2016). Disputes over the provision of medical treatment have increasingly ended up in the courts with families, and sometimes nurses, claiming that a patient’s human rights are being infringed or violated. Some families have conducted media campaigns and used social media to mobilise support for their case. In one example, a child (Alfie Evans) with such profound degeneration of his brain that no discernible white matter could be seen on scans, there were eight separate court cases, alleging the breach of various articles of the Human Rights Act (HRA) 1998 including Articles 5, 8, 14 (See Box 2). There was even an attempt to suggest that doctors were conspiring to commit murder. This article explains what rights are and suggests that the maintenance of a moral and professional focus towards all patients, as something nursing has always professed, should mean that they practice within human rights law and importantly go beyond it. In other words, nursing and human rights practices share common ground even though disputes may occur.

Where do human rights come from?

Rights and especially human rights have a contested nature. There are different views as to whether human rights are moral rights, legal rights that can be claimed in a court of law against the state or an institution, or political rights. Moral rights are ‘pre-legal’ or, broader, ‘pre-institutional’ and often are used to claim what the legal rights *should* be. Human Rights belong to all people not just individuals within a certain country or legal jurisdiction. This is based on morality. All people have equal moral status; all equally matter morally so moral rights belong to all people. The Kantian notion of the dignity and inviolability of every individual who has rights in virtue of their humanity, chimes well with the Universal Declaration of Human Rights (Formosa and MacKenzie 2014). Moral rights can be used to criticise the law but the existence of a moral right does not always mean a legal right exists. Only those moral rules that become law (legal rules) are ones that can be *enforced* as ‘substantive rights’ in the courts. The Handbook to the NHS Constitution explains “A right is a legal entitlement protected by law…These rights are not necessarily for individuals to take action in the courts; they may depend for enforcement on action being taken by other health organisations” (DH 2019 p.5).

Historically, not every individual has been seen as having moral or legal rights. In the 1980s, Hudson (1988) showed how some people were valued less than others both in terms of rejection of their *claims* to have rights and, especially for people with intellectual disability, even their moral status was denied or at best devalued. They were sometimes seen as less than human. Such attitudes underpinned healthcare practices such as sterilisation of women with learning disabilities (Hudson 1988). Likewise, prisoners and people with mental illness or dementia were often seen as having less worth than other citizens and received inferior care. Nowadays, UK law, through the HRA 1998 and other legislation such as the Care Act 2014, provides better recognition of moral rights and claims to legal rights for *every* individual by placing obligations on institutions and practitioners to support human rights. Nurses’ practice should demonstrate respect for human rights. The British Institute for Human Rights website (nd) provides practical examples of rights being supported through advocacy rather than recourse to the courts.

Human rights are enshrined in international conventions that countries sign up to with the intention that signatory nations will incorporate the principles within their own national laws. These may be used as justifications for sanctions, including physical intervention, against countries that are abusing human rights. There are social political rights such as freedoms of conscience, freedom of expression and freedom of religion. Political rights are those that entitle citizens to vote and exercise political activities. And there are also economic and social rights such as the right to health, freedom from poverty and from culturally imposed acts such as female genital mutilation. In the 2019 Reith Lectures, Lord Sumption explained “…in a democracy there are only two kinds of right that are truly fundamental…There are rights to a basic measure of security for life, liberty and property, without which life is reduced to a crude contest in the exercise of force. And there are rights such as freedom of expression, assembly and association, without which a community cannot function as a democracy at all.”

The earliest recorded declaration of rights in the UK was made in the Magna Carta (the Great Charter of Liberties) 15th June 1215 which included a right not to be unjustly imprisoned. This right is now incorporated into Article 5 of the European Convention on Human Rights and Fundamental Freedoms (ECHR) 1950 (European Court of Human Rights Council of Europe, 1950). The ECHR followed the United Nations’ (1948) Universal Declaration of Human Rights. A later statement of rights appeared in Article 12 of the 1966 International Covenant on Economic, Social and Cultural Rights (ICESCR): “...*the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.*” Governments have an obligation to respect, protect and fulfil human rights such as Article 25 *“everyone has the right to a standard of living adequate for the health and well-being of himself and his family.*”

The HRA 1998, which came fully into force on 2 October 2000, incorporates into UK law the bulk of the substantive rights set out in the ECHR. Publicly-funded hospitals, nursing homes and private or charitable organisations providing care paid for by the NHS or local authorities are ‘emanations of the state’ so a nurse’s actions or inactions fall under human rights law. And the government has an obligation to protect its citizens even within privately funded healthcare organisations. It is uncertain whether after ‘Brexit’ UK citizens will still be able to appeal to the European Court of Human Rights or whether the highest court of appeal will be the UK Supreme Court. Finally, some rights are ‘procedural’ rather than ‘substantive’. In other words, the right relates to whether the proper process was followed when a decision was made rather than relating to the decision itself.

What do human rights do?

Rights are powerful. If needs, grievances or wants can be translated into rights-based claims framed as moral or legal rights they can become recognised as demands or entitlements that ought to be met and possibly enforced through the courts. Human rights are empowering for communities built on shared beliefs, such as those adhering to certain religious beliefs claiming a right to practice their religion freely. Solidarity of such groups often stems from individuals who have been, or consider themselves to be, discriminated against. However, the law exists to protect its citizens and its collective values so individual ‘rights’ based on the collective values of a group might be over-ruled. For example, the Prohibition of Female Circumcision Act 1985 makes cutting a crime despite any cultural or religious beliefs (Author, 2013). Human rights protect people in public hospitals and care homes (and private ones providing care for the NHS) from physical abuse and care that compromises their dignity and adversely affects their health. Generally, human rights are powerful protections of individuals’ ability to be and live a human life free of undue or wrongful intervention by the state. For example, Article 5 (right to liberty) has protected people with autism from wrongful detention in psychiatric hospitals (the Bournewood case which led to the introduction of the Mental Capacity Act 2005: HL v UK [2004]). Article 5 underpins the Deprivation of Liberty Safeguards (DOLS) which will be replaced by Liberty Protection Safeguards (LPS) from 1st October 2020. The new LPS framework will apply to private homes, domestic settings, and supported living as well as hospitals and care homes and apply to people over the age of 16 years.

Few rights are ‘absolute’ meaning that, although the state must act to protect rights, almost all rights can be infringed if proportionate to do so. The right to life (Article 2), for example is conditional so that countries can legally execute people if their law allows. Even in the UK, the military and police can, in some circumstances, legitimately use lethal force, for example to prevent an act of terrorism (Roth 2004). Rights claims, however, can sometimes lead to a clash of one right against another. For example, an unborn child’s ‘right to life’ is countered by a woman’s right to bodily integrity; a child’s right to life is countered by the right to be free from inhuman and degrading treatment.

Confusingly, practical guides about human rights frequently make speculative claims of a very tentative nature making it seem that a breach of human rights is more likely than it really is. For example, soiled sheets *might* be a breach of human rights (Age UK nd). Nurses need to be aware that in addition to imprecise information, there is also inaccurate information published on the internet. For example, the Scottish Human Rights Commission website (nd) states “Some rights are **absolute**, in particular the right to life” which is inaccurate. If it were accurate, the NHS would run out of money because it would have to make every attempt to save life regardless of cost or clinical effectiveness.

Time Out 2

The ward is short-staffed, and nurses have been told to only ‘top and tail’ patients rather than give them a full wash. Does this breach patients’ human rights under Article 3 (see Box 2)?

Tensions can be experienced between those providing healthcare and their understanding of rights of a particular patient or service user and the understanding of the individual patient, family or others. Rights claims must be based on facts and often the facts in patient care are ‘evaluative-facts’. That is, even if a nurse and a patient agreed on the biological facts, how they evaluate those facts in relation to any rights claims regarding what they ought morally and legally to do, can be quite different. As medicine becomes more complex, moral worth and rights can seem to overlap. Discontinuing futile treatment from a patient does not imply that person has no worth. Although the language of human rights can be invoked by all parties, it is the law that will decide on legal human rights disagreements. Any infringement of someone’s rights needs to be proportionate. In a recent case that invoked Articles 2 and 8, the court ordered that intubation should continue in the case of a minimally-conscious patient (Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust v TG & OG [2019]). The judge recognised that this would put a “huge burden” on the treating team as it was contrary to their evaluation that it was clinically inappropriate. The very nature of healthcare involving issues around quality of life, and death, means that such disagreement can be very emotive and difficult. Even after the courts have decided, beliefs about moral rights may remain making relationships difficult.

Nursing and human rights

Nurses and doctors have a tradition of benevolence and altruism. They frequently go beyond the call of duty to provide the best care possible even in the face of threats and abuse which may occur when severe disagreement about rights arise in patient care. A group claiming to be supporting a particular patient’s rights, invaded a paediatric intensive care unit, blocked hospital staff from getting to work, and left staff, other patients and family members “frightened” (Evans v Alder Hey Children’s NHS Foundation Trust, [2018a]). The court in Alder Hey Children’s NHS Trust v Evans [2018a] praised the staff at Alder Hey for their “extraordinary patience, and generosity… professionalism and compassion”.

In another case involving the same child, Re E (a child) [2018] the “warm and compassionate energy of the nurses” was noted. The professionalism of nurses exemplifies how their personal and nursing values, as exemplified in The Code (Nursing and Midwifery Council (NMC) 2018) may help mitigate challenging situations. They treated people with “kindness, respect and compassion”, worked “in partnership with people” to deliver effective care, and acted in the “best interests” of people at all times. NMC Standard 1 (“Prioritise People”) sets out the moral foundation for good nursing practice, reflecting the concept of moral rights (NMC 2018). Nursing, as a profession, reflects a group approach to human rights as moral rights and this is a helpful way of approaching human rights in patient care.

Whilst supporting individual rights obviously has a place in healthcare, it is important to maintain awareness that none of us is an island. We are connected. That connection is what underpins the NHS and its values as enshrined in the seven key principles. In providing a comprehensive service to all we express solidarity for each other. Solidarity is a difficult concept, but one that is growing within bioethics and one that has long been used in nursing though perhaps under the term ‘relationship’. Put simply, solidarity can be described as people’s identities and preferences being linked to the context and the relationships in which they are embedded.

The growth of social media has helped foster connections and the forming of campaigning groups. Such group solidarity can be positive, for example, in bringing about a government commitment to introduce ‘Natasha’s law’ in response to the death of a teenager from a sesame seed allergy (Department for the Environment, Food and Rural Affairs 2019). However, social media seems to foster emotional responses to difficult situations and such group solidarity can be much more contentious as exemplified in high profile media cases about particular patients and disagreement about rights. Patients or families may be at risk of exploitation by campaigning groups who may become a barrier to effective communication between parents, doctors and nurses. Lord Justice McFarlane noted the introduction of a “darker side” to the support for Alfie Evans and said “the representation of the parents may have been infiltrated or compromised by others who purport to act on their behalf” (Evans v Alder Hey Children’s NHS Foundation Trust [2018b]).

In two known cases, ‘medical experts’ undertook covert ‘examinations’ contrary to the law, without the knowledge of the clinical team, and almost certainly in contravention of their professional registration standards. On one occasion, a doctor from Poland failed to disclose her identity and the purpose of her visit to paediatric intensive care when challenged by nurses (Re E (a child) [2018]). Nurses need to be vigilant in protecting the Article 8 rights of their patients to privacy.

Time Out 3

The family of a child on your ward is filming that child on their mobile phone. Are any rights being breached?

Nurses help families handle the emotions associated with devastating news and terminal diagnoses. They often find themselves acting as intermediaries and peacemakers. In Alder Hey Children’s NHS Trust v Evans [2018b], Mr. Justice Hayden praised the fact that “a channel of communication, however fragile, has been maintained between the family and the hospital”. Nurses are central to supporting channels of communication. They demonstrate solidarity with both their profession and their patient even when arguments about rights are waging around them. If the nurse understands that some families make demands for ‘clinically inappropriate treatment’ because they want to do the morally right thing, they can help maintain relationships.

Sadly, some nurses act immorally and treat patients cruelly but this does not mean that the state has breached those patients’ human rights. Such violations will be addressed through an NMC Professional Conduct hearing. Nursing’s recent Code, though very limited on explicit use of the term ‘human rights’ does address many of them in spirit. Lenuta Botezatu was struck off by the NMC in February 2019 for misconduct including threatening and physically assaulting a patient with dementia by giving a ‘Chinese burn’ to and twisting his nose. She was in breach of domains 1, 2, 3, 17 and 20 of The Code. Clearly, she treated the patient in a way that was inhuman and degrading but the hospital was not at fault as it had a clear policy for de-escalating situations and managing violent patients (NMC 2019).

In day to day practice, nursing and human rights share common ground. Thinking of human rights as moral rights underpinning person-centred care helps nurses to practice within human rights law. This is the approach being taken by the CQC (2019) who explain that rather than using the Articles listed in the HRA 1998, they are focusing on human rights principles of “fairness, respect, equality, dignity, autonomy, right to life, rights of staff” when regulating health and social care services. Nurses can advocate for patients or press for changes in practice at the organisational level to support human rights.

Laws concerning negligence, consent and equality are perhaps better known and used by nurses than the HRA 1998. They help nurses to practice properly because they encompass the spirit of human rights by supporting people to live a truly human life characterised by autonomy and dignity. The greater value of human rights talk is that it supports the global reach of moral rights and develops a sense of solidarity over global issues, such as poverty, which can and do affect the ability to live a truly human life. Nursing has a voice in groups such as the International Council of Nurses (ICN) which endorses the Universal Declaration on Human Rights. Their Position Statement reminds nurses that they have “a duty to report and speak up when there are violations of human rights, particularly those related to access to essential health care, torture and inhumane, cruel and degrading treatment and/or patient safety” (ICN 2011). Nurses can also advocate for global change using Human Rights to good effect (RCN, ICN).

Time Out 4

Read the International Council for Nurses Position Statement on Human Rights. They state that “Nurses have an obligation to safeguard, respect and actively promote people’s health rights at all times and in all places.” What one change could you make to promote patient’s health rights?

Nurses have human rights too. The NMC was found to have breached two nurses’ Article 6 right to a prompt and fair hearing because their Professional Conduct hearing lasted nearly three years (R on the Application of Johnson v Nursing and Midwifery Council [2013]).

In conclusion

Nurses are central to supporting communication between patients, families, nurses and members of the multidisciplinary team. By demonstrating solidarity with the moral values of their profession they can help ensure high quality care is delivered even when arguments about rights are waging around them. If nurses focus upon moral rights, such as dignity, and enhancing solidarity with fellow human beings it is highly likely that they will be complying with human rights law. Actions that nurses can take include:

* acting on safeguarding concerns
* making person-centred decisions, with the person whenever possible and advocating for those who cannot speak for themselves
* upholding people’s dignity and rights to privacy
* respecting people’s private life and home
* treating people non-judgmentally with respect and compassion
* ensuring that people with mental health problems are not unlawfully detained
* working with patients and clients to keep them safe when they are at risk of self-inflicted harm
* challenge organizational practices that restrict human rights
* challenging poor practice in care and residential homes
* supporting families to visit those who are receiving treatment or care and speaking up if that care or treatment is being provided too far away for loved ones to visit

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Box 1: The seven key principles of the NHS

Principle 1: The NHS provides a comprehensive service available to all.

Principle 2: Access to NHS services is based on clinical need, not an individual’s ability to pay.

Principle 3: The NHS aspires to the highest standards of excellence and professionalism.

Principle 4: The patient will be at the heart of everything the NHS does.

Principle 5: The NHS works across organisational boundaries and in partnership with other organisations in the interest of patients, local communities and the wider population.

Principle 6: The NHS is committed to providing best value for taxpayers’ money and the most effective, fair and sustainable use of finite resources.

Principle 7: The NHS is accountable to the public, communities and patients that it serves.

Box 2: Articles enshrined in the Human Rights Act 1998

Article 2: Right to life

Article 3: Prohibition of torture, inhuman or degrading treatment or punishment

Article 4: Prohibition of slavery and forced labour

Article 5: Right to liberty and security

Article 6: Right to a fair trial

Article 7: No punishment without law

Article 8: Right to respect for private and family life

Article 9: Freedom of thought, conscience and religion

Article 10: Freedom of expression

Article 11: Freedom of assembly and association

Article 12: Right to marry

Article 14: Prohibition of discrimination

Article 16: Restrictions on political activity of aliens

Article 17: Prohibition of abuse of rights

Article 18: Limitation on use of restrictions on rights

Learning Points

* There are different views as to whether human rights are moral rights, legal rights or political rights.
* Human rights legislation focuses upon the state’s relationship with the individual.
* The UK Human Rights Act 1998 sets out legal rights derived from the European Convention on Human Rights and Fundamental Freedoms 1950.
* Publicly-funded hospitals and nursing homes are ‘emanations of the state’ so a nurse’s actions or inactions could be a breach of a patient or resident’s human rights.
* Few rights are ‘absolute’ and most, such as the right to life, have exceptions; inaccurate information about which are ‘absolute’ appears online and in publications from some organisations.
* The Care Quality Commission introduced a human rights approach to regulating health and social care services in February 2019.
* Proving breaches of human rights in the context of healthcare is very difficult and is decided in the courts.
* There may be agreement regarding the biological facts of a case yet disagreement on how to evaluate those facts resulting in conflicting appeals to different rights.
* Patients, families and others are increasingly using the Human Rights Act 1998 to disagree with healthcare decisions and demand medical treatment or other ‘rights’.
* If nurses focus upon moral rights, such as dignity, and enhancing solidarity with fellow human beings it is highly likely that they will be complying with human rights law.

Table 1: Distinguishing rights, needs and wants

|  |  |  |  |
| --- | --- | --- | --- |
|  | Human Rights | Healthcare Needs | Healthcare Wants |
| *Definition* | “rights inherent to all human beings, regardless of race, sex, nationality, ethnicity, language, religion, or any other status. Human rights include the right to life and liberty, freedom from slavery and torture, freedom of opinion and expression, the right to work and education, and many more.  Everyone is entitled to these rights, without discrimination.” (United Nations 1966) | “what is required for a person to optimise their potential for successful social interaction through minimising physical and mental disability” (Doyal 1995) coupled with “a capacity to benefit from treatment, which would be determined primarily in terms of clinical outcome and effect on quality of life” (British Medical Association 2001) | “the boundaries [of a healthcare want] are defined by individual choice…However… the individual will tend to want the best treatment available, but  may not have sufficient information to make rational choices” (British Medical Association 2001) |
| *Characteristics* | Basic human requirements that have been enshrined in law or through international treaties and conventions. There is agreement that the rights impose a collective obligation to protect and satisfy specific needs of individual human beings. Protected human rights are enforceable by individuals against the State. | An external authority, such as the government, an organisation or a health professional, decides what is a healthcare need. This external authority may restrict the level of treatment offered to individuals as they have to consider the needs of all those that they have responsibilities towards. | Wants are often personal, aspirational, and consumerist in origin. Wants are sometimes linked to people’s prejudices. A failure to satisfy a person’s wants may not directly affect that person’s survival or quality of life |
| *Examples* | Nurses have to be non-judgmental and not discriminate against people. | Nurses should ensure that a person with sepsis has their antibiotics on time. | Someone wants to only be cared by nurses of a certain ethnicity. |
| *Examples of Conflicts* | The Article 8 right to privacy means that people’s dignity and privacy should be protected. In the case of someone at serious risk of suicide, the nurse has to consider if it is proportionate to place them under continuous observation, even when in the bathroom. The right to life has to be balanced against the right to privacy. | Triage of patients in Accident and Emergency involves prioritising one patient’s needs over another. In another example, a patient might say they *need* a drink but if they are awaiting surgery, the nurse may refuse. The nurse has to consider the risk of vomiting and the risk of dehydration. | A patient *wants* the district nurse to visit at the specific time that the patient has chosen so as not to interrupt a favourite television programme. To manage her workload and meet the healthcare *needs* of her other patients, it is reasonable for the nurse to explain that she cannot always do this. |