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Human rights education in patient care

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Human Rights Education in Patient Care: A literature review

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Abstract:	The identification of human rights issues has become more prominent in statements from national and international nursing organisations such as the American Nursing Association and the United Kingdom's Royal College of Nursing with the International Council of Nursing (ICN) asserting that human rights are fundamental to and inherent in nursing and that nurses have an obligation to promote people's health rights at all times in all places. However, concern has been expressed about this development. Human rights may be seen as the imposition of legal considerations for nurses and other healthcare workers to bear in mind, as yet more responsibilities with the consequent fear of litigation. Although a more hopeful scenario, is that consideration of human rights is something that is supportive of good practice. If this more hopeful scenario is to be realised the role of education will be crucial. As with human rights generally, human rights education (HRE) is a global phenomenon, a practice-orientated expression of the Universal Declaration of Human Rights (UDHR), and the goal of HRE is to build a culture of respect and action for human rights for all. However, the nature of human rights has long been contested. A 'mapping exercise' of the academic literature on human rights identified 'four schools' or 'ideal types' that have shaped thinking about human rights. This sets out the conceptual context in which human rights problems are defined and solutions proposed which is particularly important for HRE. But it also complicates the picture. The different approaches taken by the four 'types' would likely lead to different outcomes in terms of HRE. It is timely to discuss the nature of HRE and examine its potential for impact on patient care. This will involve identifying the challenges and potential benefits of this approach and analysing the implications for professional practice.

Human Rights Education in Patient Care: A literature review

Introduction and Background

The identification of human rights issues has become more prominent in statements from national and international nursing organisations such as the American Nursing Association[1], and the United Kingdom's Royal College of Nursing [2] with the International Council of Nursing (ICN) [3] asserting that human rights are fundamental to and inherent in nursing and that nurses have an obligation to promote people's health rights at all times in all places. These assertions are based on the claim that nursing, in common with other healthcare professions, has a statutory framework of self-regulation founded on an ethical code that constitutes a 'social contract' with the public so is "…in harmony with the defence and promotion of human rights" (p. 7).[4] If this 'contract' is to be maintained the changing demands that developments in human rights make on practice need to be considered.

However, concern has been expressed about this development:

> There is a danger that rights may be seen as another bureaucratic imposition and yet another legal consideration for nurses [healthcare workers] to bear in mind, as yet more responsibilities with the consequent fear of litigation. A more hopeful scenario, however, is that consideration of rights is something that is supportive of good practice and will form part of critical reflective nursing [healthcare] practice, with nurses [healthcare workers]working in partnership with patients and colleagues to maximize the efficacy and quality of health care p. 232.[5]

If this more hopeful scenario is to be realised the role of education will be crucial. As with human rights generally, human rights education (HRE) is a global phenomenon, a practice-orientated expression of the Universal Declaration of Human Rights (UDHR), and the goal of HRE is to build a culture of respect and action for human rights for all.[6] However there is a plethora of terminology in this area which can present a challenge with regard to analysis. For the purposes of this review HRE

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is understood as being *about, for,* and *in* human rights. 'About' is human rights teaching to increase knowledge , 'for' is education for advocacy for human rights, and 'in' is the relationship between healthcare professionals, non-professionals and patients or service users (the term patient will be used to refer to both), shaped by human rights.[6] In sum HRE refers to what is known as 'Human rights in patient care'[7] or human rights applied for the benefit of patients. In the context of the review the term HRE will also encompass Human Rights Based Approaches (HRBA) when such approaches involve education about human rights applied to patient care. It will also encompass 'human rights principles' such as fairness, respect, equality, dignity and autonomy (FREDA) and participation, accountability, non-discrimination and equality, empowerment and legality (PANEL), some of which are explicitly moral principles used widely in practice.

However, the nature of human rights has long been contested. [8][9][10][11] A recent 'mapping exercise' of the academic literature on human rights identified 'four schools' or 'ideal types' that have shaped thinking about human rights. They are natural scholars, deliberative scholars, protest scholars and discourse scholars, and provides a summary of the positions taken.[12] This is helpful as it sets out the conceptual context in which human rights problems are defined and solutions proposed. This is particularly important for HRE which aims to embed human rights norms in core social institutions, such as healthcare services.[7] However it also complicates the picture somewhat in that different approaches taken to issues as informed by the four 'types' would likely lead to different outcomes in terms of HRE[12] for healthcare institutions, nurses, other health care staff, and patients.

It is timely to discuss the nature of HRE and examine its potential for impact on patient care. This will involve identifying the challenges and potential benefits of this approach and analysing the implications for professional practice. The paper is divided into two sections. First findings from a literature review of relevant studies and evaluations of HRE in patient care is presented.[6] This is followed by a critical discussion of the implications of the findings. The overall contribution of the

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paper is to subject the burgeoning trend towards HRE in patient care to critical scrutiny and identify

the potential for impact on professional practice.

The literature review

The aim of this literature review was to examine critically a range of literature on HRE in patient care

in order to evaluate why and how it was used and where possible to determine its effect on patient

care and its implications for professional practice.

Ethical considerations

No ethical approval was required for this literature review.

Methodology

The design was a literature review. Electronic searches were conducted using Ovid MEDLINE,

ProQuest, Embase, PubMed and CINAHL databases. The search terms were a combination of

"Human Rights Education" OR "Human Rights Based Approach" AND "Patient Care" OR

"Healthcare". The Google Scholar advanced search facility was used because it can identify 'grey'

literature. Hand searching of the specialist journals *Human Rights Education Review* and *Journal of*

Human Rights Practice was carried out to ensure no key papers were overlooked. The database

searches, abstract and full text screening were undertaken between July and August 2019 with no

date restriction. The inclusion and exclusion criteria for the search are included in table 2.

Eligibility: inclusion and exclusion criteria

Table 2

Data evaluation

The study design and/or the approaches taken in each of the papers are summarised in Table 1. No

papers were excluded on the basis of quality because of the limited number of relevant papers

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found and there was no date restriction set in order to maximise the likelihood of finding relevant studies. All papers were reviewed independently by two reviewers for relevance and quality.

Of the 11 papers 3 were reviews.[13 14 15] Of the 8 remaining papers 1 reported a randomised controlled trial[16], 2 were evaluations[17 18], 2 were non-randomised uncontrolled pre and post-test service evaluation studies[19 20], 1 was mix review case study and interview based evaluation[21], 2 were case studies conducted as service evaluations.[22 23] Only the systematic review and randomised controlled trial described the methodologies used in detail. Of the papers included only one was a primary research study and research ethics approval was reported as a registered trial.[16] The remaining papers were reviews or service evaluations which did not report research ethics approval.

The randomised controlled trial was of very good quality when examined using the Critical Appraisal Skills Programme (CASP) RCT[24] check list. The systematic review was also deemed to be good quality based on the CASP systematic review[25] check list. The lack of randomisation and control in the pre and post-tests weakened their rigour as did the low level of post-test completion. The reviews were carried out independently of the organisations that delivered the HRE programmes.

Data analysis and synthesis

The analysis involved a critical review synthesising the findings presented in the papers. A thematic approach was used. Data from all the papers was extracted, coded and iteratively compared for similarity of topic, interpreted and grouped together under more general themes and relationships between the themes identified. Finally, conclusions were drawn to produce an integrated picture of human rights education in healthcare.

Results

From a total of 854 potential papers identified by electronic searches 489 were selected based on their title, 200 on the abstracts, and 10 following review of the full text versions. The Google Scholar

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advanced search tool identified 4 studies. Hand searching of *Human Rights Education Review* and

Journal of Human Rights Practice produced no further papers. A total of 11 articles were identified

for inclusion in the review. The PRISMA flow chart[26] framework was used to report the search and

retrieval element of the review (see Figure 1.) Table 1 includes a summary of the type of papers and

studies including the geographic location of the work reported. Studies were conducted in a variety

of areas and settings ranging from homes in rural villages, public mental health hospitals, public and

private acute hospitals, to charities, and NGOs (see Table 1.)

Four themes were found: embedding a human rights culture; developing the decision-making skills

of staff; developing assertiveness of patients to improve services; and barriers to implementing a

HRE approach to patient care. These are discussed below.

Embedding a human rights culture

Two papers referred to the moral nature of human rights thought necessary for human rights to be

embedded in healthcare practice and that this was a reason for recourse to HRE.[14][15] One study

claimed that the moral nature of human rights in practice was important even if it resulted in no

change in outcomes because "human rights are fundamental pillars of justice and civilisation"

(p.263).[14] An example of the moral importance of HRE was where human rights were linked to the

idea of a 'public service ethos' which for health care workers could plausibly be understood as a

moral ethos defined in the paper concerned as [the]: " Ethos of caring in social work, the Hippocratic

Oath for medical professionals and ethical standards in local government" (p. 62). [15] Similarly HRE

can "…reconnect staff with their original motivation for taking up their profession" (p. viii). [15] A

participant in the study, presumably a social worker, stated:

[R]ather than seeing human rights as yet another regulatory burden social workers on the ground are enormously excited once they start to see what it could mean. It very much resonates with the care professionals' idea of what their job is all about (p. 63). [15]

There were frequent reports of human rights being embedded in patient care as a result of HRE empowering front line staff to use the language of rights as a means of doing this. [14 17 18 21 23]

It was argued that to embed a human rights culture in health care organisations, human rights need to be made contextually meaningful to practitioners and patients.[17 21 22 25] In several of the studies included in this review participants, (both professionals and patients), commented that the examples used in HRE were relevant and beneficial, enabling them to make connections between what was taught and their own experiences.[14 17 19 20] In some cases it was the moral principles of FREDA (fairness, respect, equality, dignity and autonomy) or PANEL (participation, accountability, non-discrimination and equality, empowerment and legality) that participants found particularly relevant to practice and reported using them rather than the articles of human rights law.[13 15 22]

To embed a culture of human rights using HRE in patient care organisations, high level management support was required [15 18 21 22 23] even if healthcare professionals took the lead and managed implementation.[23] For example, in Armenia the Ministry of Health developed national standards for palliative care. Without such support, or where support is intermittent, efforts to embed human rights education are likely to fail.[18 22 23]

In the UK, reviews of studies conducted before 2015[22] suggest that despite HRE human rights had not been embedded in public authorities (public authorities defined here as those with statutory powers, such as the NHS or the Police, in contrast to 'hybrid' arrangements-where private and charitable organisations provide a public service). Two reasons for this are offered. First, in the decade following ratification of the UK Human Rights Act in 1998, there was a lack of leadership from Government and so an opportunity was missed to use the Human Rights Act as a tool to improve delivery of public services (p. iii).[22] Second, although there were some government led

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initiatives to embed human rights in public services in England and Wales, which led to small but

important changes, overall there is a lack of evidence of the effectiveness of human rights based

approaches, including HRE, in health services (p.120).[14 19 22] Similarly, where there seems to be some

evidence of effectiveness it is acknowledged that it can only be an indication that HRE may be

successful because of its limited nature.[14 19 22] In one paper human rights were not explicitly

mentioned even though they seem to have been used via other terminology and laws.[13]

Although embedding human rights is the focus of this theme it is difficult to consider it without

discussing the impact of HRE. Embedding human rights through HRE involves continuing change if

long-term effectiveness, in terms of placing human rights at the centre of healthcare, is to be

achieved. All the studies claimed that HRE increased healthcare professionals' or carers' knowledge

of human rights values or/and (for UK studies) the Human Rights Act. However, this did not

necessarily influence staff attitudes or behaviour. One study found no significant statistical change in

attitudes and/or relationship between a change in attitude and knowledge of human rights following

HRE.[19] (The pre-test score for attitudes was high and the training focussed on cognitive rather than

emotional change which may explain the limited change). A randomised controlled trial involving

439 participants found no difference in patient care resulting from a HRE programme, which

questions the efficacy of HRE in bringing about cultural change, even when there is a positive

change in attitudes and an increase in knowledge (p.vi).[16] In contrast, a qualitative synthesis of

mental health care indicated there was both a positive change in staff attitudes and improved

outcomes including increased patient satisfaction and a reduction in the use of seclusion following a

HRE programme, although it was noted there was a need for more rigorous research to investigate

the impact of HRE on these outcomes.[18] A review which examined the effect on health outcomes of

human rights interventions in maternal health, found that four studies reported local improvements

in care (3 in rural India and 1 in Uganda) but not all the findings were statistically significant.[13] Also,

there was no significant impact on the health system in the form of changes in legislation, policies,

protocols or guidelines (p.13).[13]

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Developing the decision-making skills of clinical in staff

All the studies reported an increase in knowledge of human rights amongst participants. Some also reported that the healthcare professionals and patients involved developed more confidence to use them in practice, with some participants reporting feeling able to communicate with colleagues about how human rights can improve the delivery of care. [14] [16] [17] [20] However, some respondents in one study reported a reluctance to challenge colleagues' views because they lacked confidence in their knowledge of human rights.[20] HRE interventions, particularly those focussed on human rights values, can increase care workers' confidence to balance risk in decision making. For example, 86% of 82 post-test respondents in one study reported they felt a human rights approach could help them resolve disputes between the needs of different service users (p. 5).[21] Similarly, a pilot study designed to empower frontline mental health/capacity practitioners to deliver 'rights respecting care' found the respondents believed: "A human rights-based approach [HRE] has given us a process by which to make decisions in messy and difficult situations. Teams are just doing this naturally now" (p. 7). [17]

Although, this was not the case in all settings. An RCT found that staff in the intervention group, who had received HRE, resorted to hierarchical decision making and referred issues to senior staff only slightly less often than those in the control group.[16] This indicates that despite claims staff made about their decision-making being more person-centred, there were no changes in their actual behaviour that supported such claims. In addition, the intervention group rated hierarchical decision making second in the frequency of decision-making strategies used, behind team-working/talking to other staff. The authors recommend the findings be treated with caution as there may have been some conflation of hierarchical decision-making and teamwork, also it was found that HRE had a limited impact on practice.[16]

Finally, the studies in this review contain little detail about *how* participants' decision-making skills

improved, even though examples from case studies showing changes in practice were included. [14] [17]

[18] [20] [21]

Developing the assertiveness of patients to improve services and care

A stated aim of several HRE projects reviewed, particularly those focussed on mental health[14] [17] [19] [21],

older people[19], palliative care[17] [23], and gender inequality and women's rights[13], was to foster the

development of assertiveness on the part of patients. This was intended to enable them to improve

services by identifying when their rights were not recognised or upheld. As with the reports of HRE

involving healthcare professionals and care workers, one study found service users reported they

had learned something new about human rights and how they related to care (p. 53).[21] Although the

participants had not used their learning for a specific purpose, they had discussed their experience

with family, friends and community networks.[21] This study also found that the HRE developed an

understanding of proportionality (p. 54) among advocacy workers who intended to use their new

knowledge to improve their skills in helping patients express their needs, though no evaluation of

the actual impact of this intention was undertaken.

In one review (of the experience of women in rural India and Uganda) a lack of reported conflict or

challenge was surprising because empowerment of individuals through HRE is meant to foster

challenge of power relations and change the status quo (p.13).[13]

Some organisations ensured patients and family members were given HRE and payment to enable

them to work with managers and staff at all levels and at all stages of the programme (p. 117).[22] This

may have had the effect of minimising conflict by reducing power differentials. In a postal survey of

236 patients and family carers, 94% stated that being involved in decision making made a positive

difference to them as a person and 61% reported they were more involved in decisions about their

care and treatment than they had been in the three years prior to the programme.[22] Positive

benefits in terms of the mental health were also reported (78% patients ;79% family carers) (P. 117).

[22] However, although several putative benefits were reported, all the studies highlighted challenges

involved in delivering HRE in patient care.

Barriers to implementing HRE in patient care

Even with high level policy support for embedding human rights in patient care through HRE from,

for example, the Scottish Human Rights Commission, the Department of Health, NHS England, and

the Armenian Ministry of Health, there were significant organisational, cultural and systemic barriers

which hampered progress.[18 20 22 23] One review [15] identified three types of barriers in specific

organisations and four barriers in the public sector as a whole. In specific organisations the first

barrier was identified as contrasting professional and organisational cultures, the second- lack of

trust and autonomy of staff, and the third was initiative overload leading to inertia (p.92). The first

and second barriers reflect the conflict between a professional *ethos* of public service for the good

of the patient and organisational imperatives driven by a market culture and an emphasis on

financial efficiency (discussed below). The third is about the slow rate of organisational change

where organisations adopt a wait and see approach in the form of 'passive non implementation' (p.

99).[15] One example from a local authority organisation was

> …the avoidance of adverse publicity which might come from 'actively promoting policies on
>
> behalf of unpopular cause' (in this case, Travelling people) (p.99). [15]

In addition surveys of public opinion including public service staff found they expressed hostility to

HRE based on the Human Rights Act believing it to be a "charter for people who want to 'cheat the

system' " even though a majority of people in Britain support human rights legislation.(P. 162)[15]

A more general lack of interest and engagement in a human rights approach [HRE] amongst the elected members of the organisation had an adverse effect on support for front line staff. In addition, and related to the first two barriers, was the implementation of specific improvement schemes within organisations resulting in 'initiative overload' and competing demands (p. 100).[15]

In the public sector more widely the four barriers were: lack of information about legal and non-legal remedies for perceived human rights concerns and inadequate independent advocacy; 'silos of state' which inhibit governmental cross department working exacerbating initiative overload; the commissioning process which prioritised cost-reduction over human rights considerations; and lack of integration of human rights principles into professional training curricula and codes of practice. These systemic barriers are more difficult for individual organisations to address alone.[15]

Finally, a further barrier to implementing HRE in patient care is the need for evaluation of impact to demonstrate a cause and effect relationship or at least being able to show that changes were driven by HRE.[16 20 22] This is claimed to be "…an essential prerequisite for any profound changes in the relationship between human rights and healthcare" (p. 120).[22] Commissioners of health services may only be persuaded to support HRE in patient care if it can be 'proven' they make a difference and improve the quality of services and that they are "equally if not more cost effective than other interventions" (p. 121).[22] Demonstrating a linear 'cause and effect' relationship in such a complex area of practice is inherently problematic and is explored further below.

Discussion

HRE in patient care is intended to prevent human rights abuses and inform better and person-centred care[13 14 17 20 21 22] and this review suggests the evidence to support such assertions is mixed. The discussion is organised into three main sections: the ethical norms of healthcare professionals, decision making, and leadership and management.

The ethical norms of human rights and the ethos of healthcare professionals

Two studies in this review emphasised the importance of the moral nature of human rights[14] [15]

irrespective of outcomes[14] and as a public service ethos understood in moral terms such as caring

and the Hippocratic Oath for medical professionals (p 62), reconnecting staff with their original

motivation for taking up their profession (p viii).[15] So rather than HRE being new, it provides a

renewed moral emphasis on a global perspective which transcends national nursing cultures. This is

consistent with the broader HRE literature which asserts it can "…*reconnect* staff with their original

motivation for taking up their profession" (p. viii, emphasis added) or help with a "*re-moralisation* of

healthcare" (p. 7, emphasis added).[7] This assumes healthcare professionals have lost or become

disconnected from their ethos. Yet the professional ethos can itself be a barrier [7] [22] [27] to HRE. When

HRE focuses on human rights principles (FREDA and PANEL for example) rather than being

recognised as enabling re-connection with professional motivation, it may be regarded as

unnecessary because practice is already guided by legislation and standards set by regulatory bodies

consistent with these principles. Furthermore the 'protest' school of human rights[12] may contend a

need to breech such standards and question legislation, and such 'activism' would question

healthcare professionals' roles, particularly in countries where serious breaches of human rights are

uncommon.

Decision making

A related but more specific concern about what HRE adds to the normative concerns of healthcare

professionals such as nurses is that of moral decision making and that some moral decisions

generally and in patient care in particular can be difficult. This review has found that healthcare

professionals and care workers frequently claim that HRE, with its emphasis on law, has improved

their decision-making skills in clinical practice. [14] [17] [20] [21] [27] Some studies go so far as to suggest that

human rights are helpful in making concrete decisions and/or objective and proportionate decisions,

unlike moral decision making.[17] However it is important to note that healthcare professionals who

have experience of the 'general' law do not always apply it in particular cases despite the claims

about the legal process providing clear answers in such circumstances.[27] This is sometimes

contrasted with moral decision making as being subjective with regard to what is morally right or

wrong and characterising moral decisions as the expression of 'mere' personal opinion. As one

participant put it

> It [Human rights education] gives us a shared language and an objective, values-based
>
> framework and gets away from people's personal opinion about what is right and wrong
>
> (p.7).[17]

There are two, closely related, concerns here. The first is the claim that an emphasis on law and legal

process can help improve decision making skills in practice and the second that moral process and

decision making are subjective and of little or no help to practitioners. These concerns are closely

related in that they are both examples of practical reasoning. Even though the law has a hierarchical

source for decision making, something that moral decision does not have, both judges and nurses do

not have algorithms that give a specific answer in all cases; both need judgement.[28] So whether the

principles are moral or legal precedence they need interpreting and applying in context.

The claim in this review that human rights law, unlike morality, has helped decision making may be a

conflation of a criterion of right or good or law with actual decision making.[28 29 30] The criterion of

morality is contested and so is the law.[28] But an important point is that the *practical* use made of

HRE in patient care is often difficult. As one study emphasises

> The provisions of international human rights treaties… are written in open and broad
>
> language, and mere knowledge of them rarely if ever provides clear-cut answers to the real
>
> conflicts health providers face in practice. Human rights, like all law, require interpretation
>
> (p.6).[27]

A related issue in decision making and HRE in patient care is the difficulty determining when a

concern in healthcare practice becomes a human rights infringement, and when a human rights

infringement becomes human rights violation.[31] For example, it can be difficult to determine when in

a particular situation poor or negligent care meets the threshold for transgression of human rights

law. The need for proportionality in decision making is but another form of practical judgement.

Even though the results reported in several of the papers included in this review and the wider

theoretical literature suggest recipients of human rights education felt able and confident to make

concrete decisions [14 17 20 21 27] no explanation is given of the basis for such assertions. Even when it

was reported a decision was made, there was no information included to indicate if the individual

concerned acted on the decision. There was a 'gap' in the literature regarding what health service

professionals and care workers perceived or claimed about improved clinical decision making and

the reporting of actual outcomes. For example, a theoretical discussion of HRE in patient care claims

it complements bioethics because "[It is] a method for arriving at concrete decisions…and a set of

procedures for *enforcing those decisions*" [7] (p. 16 emphasis added). However, claims of participants

in an RCT about improved decision-making ability were not reflected in their subsequent behaviour

and demonstrates that training in HRE did not enable staff to practice in a more person-centred

way.[16] This suggests that HRE alone is unlikely to result in change. As noted in this review staff as

well as patients need to feel empowered to make individualised decisions which focus on the human

rights of clients.

HRE in patient care founded on the 'protest' perspective of human rights[12] and developed as a

'transformational' form of HRE [32] has the potential to change the way oppressed or people lacking

justice think by empowerment through knowledge. For example, to be treated with respect is not

something they should have to hope others will provide but something they can morally and legally

demand. Advocates of this approach suggest it could transform the professional patient/service

user relationship from one of 'beggar', being reliant on professionals' promise, charity, or mercy, to

one of 'chooser' based on an entitlement to care.[33] Such approaches may blur professional and

personal boundaries depending on the level of 'protest' or 'activism' involved.

Although healthcare professionals, might recognise human rights abuse in practice, they sometimes

do nothing to help prevent it despite knowing it is wrong.[34] An explanation of such inaction can be

found in the literature on the 'dual loyalty' of healthcare professionals. This is a feeling of

conflicting obligations to their employing organisation and to their patients.[14 35] In extreme cases,

dual loyalty, or perhaps fear more than dual loyalty, can place healthcare professionals in situations

where they witness torture or other abuse. Even where they believe they would not and should not

carry out such actions themselves , they sometimes refrain from acting to prevent such torture or

abuse.[27 34] However when such risk to themselves or others would be high, for example when

torture is state sanctioned, involving healthcare professionals or otherwise, and where intervening

to prevent it carried a high probability of death or torture to themselves, then even moral reasoning

generally (so not always) holds one is not obliged to help at such cost.

HRE is also implicit in professionals' decision making. The findings from this review indicate that

embedding a human rights culture is often supported by existing legislation, for example in the UK

by the introduction of legislation such as the Mental Health Act 2007 and the Care Act 2014.[17] In this

way the legislation enhances the advancement of human rights by enshrining their principles, with

which professionals should comply.[17] In this way adhering to such legislation is consistent with

upholding patients' human rights. [22 27]

 The foregoing discussion may be taken to suggest the current focus on human rights is misguided.

However an incident reported in one paper indicates it remains an issue of concern.[17] A patient

detained under the UK Mental Health Act who had no access to a bathroom and was given a bucket

to use for toileting and was expected to clean it. A patient advocate raised it as a human rights

concern with clinical staff who agreed and resolved the situation immediately. The good thing is of

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course that this practice was stopped. However, it does raise questions about the clinical staff

involved and the culture of professional working and institutional practices in the setting. The clinical

staff surely knew that from a moral perspective (professional morality or otherwise) what they were

doing was wrong and it only requires minimal moral acumen to recognise this, so why was it

necessary to invoke human rights to stop this practice? Even if threats of legal sanctions alter the

professional patient/service user relationship it is puzzling indeed why national laws that are

designed to protect patient and human agency, such as laws of consent or negligence or laws related

to mental health, are not sufficient to warrant the prevention of such practice and why the use of

human rights law should make the difference.

Moral requirements such as not to make patients use and clean buckets for toilets can be demanded

just as legal requirements can be demanded. The latter, if a breach of human rights, however, may

trigger large financial and possibly criminal sanctions. The relationship between for example, the

nurses and the patient is however altered when it takes such sanctions to change behaviour, as

described in detail in the work of Edmund Pellegrino and David Thomasma[36][37] and is reflected in the

concern about HRE and nursing stated in the introduction and remains relevant to much healthcare

practice. That we want healthcare professionals to intrinsically care about our good and not do so

because of external imposition and threats of sanction; we want healthcare professionals to care for

us well even when 'no one else is looking'.

Leadership and management

Most of the papers in this review suggested there was a need for good leadership if a culture of

human rights was to be embedded in practice.[14][15][18][22][23] This involves leaders publicly promoting and

displaying the core institutional values of the public service concerned. However, managers and

leaders in public sector organisations are under pressure in an era of global market forces to act in

ways that may not be consistent with these values. Where the manager or leader is also a healthcare

professional tension is also created between roles reflected in the concept of dual loyalty.[36] However

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professional bodies and/or professionals, often in partnership with NGOs such as Human Rights

Watch including Physicians for Human Rights, can role model advocacy of medical care[7][27] and

provide support for cases of dual loyalty.

Limitations

Of the relatively small number of studies found which examined HRE in health care, most were

carried out in Great Britain and   drew on a limited number of the same empirical studies. The

evaluation reports included in this review, were for the most part conducted independently by

evaluators who were not involved in the provision of the HRE programme concerned.

Conclusion

It is likely that HRE in patient care meets neither of the concerns of healthcare professionals about

applying human rights in practice. HRE need not be seen as being based upon litigious threats. The

content of much HRE is embedded in existing statute and case law, national policies and guidelines

and moral and professional norms which begs the question do we need HRE? Despite the evident

enthusiasm for and purported benefits of HRE in patient care the distinctiveness of HRE

interventions needs to be made more explicit in order to better identify their impact. It is part of

critical reflective nursing[7] to examine this because HRE has become such a prevalent global force

and the claims that it can improve the provision of patient or person-centred care need to be

rigorously examined before its wider adoption.

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Table 1 Data Abstraction

	Citation	Title	Aim	Study Population & Location	Design	Key Findings
1[16]	George, A. Branchini, C. Portela, A.2015; PloSONE 10(10): e0138116. Doi:10.1371/journal.pone.0138116	Do interventions that promote awareness of human rights increase use of maternity care services? A systematic review	Assessment of interventions that promote awareness of rights of women to go through pregnancy and childbirth safely to increase use of maternity services	No figure given. Sample taken from 77, 495 households and 50, 374 people in 25 communities and 12 villages. Pregnant women or women in labour Rural India Rural Uganda Villages Mainly ante natal care at home	Systematic review Cluster RCT Participatory action research Pre and post test Promotion of human rights at community meetings	Of 707 documents 4 documented effects of rights on outcomes. Outcomes measured were increased antenatal care and facility births. Improvements in human rights outcomes such as availability, acceptability, accessibility, quality of care, capacity of rights holders and duty bearers reported to varying extents. Very little information on costs and almost no information on harms or risks described.
2[17]	Mann S Bradley V Sahakian B Human Rights and Healthcare Journal 2016; 18(1) 263-275	Human Rights Based Approaches to Mental Health	To review instances of HRBA to mental health care, intellectual disability and dementia care, carried out by service providers	10 studies included. Range: single case study to nationwide initiatives. 3 national human rights commissions 1 national health department 4 reports on work of state hospitals 1 case study 1 service user advocacy group Scotland, India, England Northern Ireland, South Africa New York High security forensic hospital Prison, General mental health institutions, Case studies of individuals with intellectual disability and mental health issues. Mental health clinic. Bereaved family's public initiative Day care facilities	Narrative Review. (Unspecified) Human rights based approach	Ten studies reported benefits of HRBA Subjective reports of improved work environment. Provision of previously unavailable services. Negative reports less frequent mainly about communication or inclusion. Three studies reported impact (on patient access to treatment, well-being or MH outcomes) using quantitative data. Half the studies used self-assessment. Two of the external evaluations carried out by National Human Rights organisations. HRBA can be introduced successfully and beneficially in MH settings.

3[18]	Donald, A. Watson, J McClean, N. Leach, P. Eschment, J. Equality and Human Rights Commission 2009.	Human Rights in Britain since the Human Rights Act 1998: a critical review	To review the available evidence of the understanding of human rights and the implementation of the HRA in Britain since the Act came into force in most of the UK in 2000	70 people involved in human rights based education in some way. Great Britain High security forensic hospital, Mental health and Learning disabilities Hospital	Analytical review of available literature from past decade. 30 semi structured interviews. 4 roundtable discussions with senior figures. Human rights education	Culture of respect for HR largely failed to take root among public authorities in the way anticipated. Lack of leadership at Govt level. Absence until recently of a commission to promote HR. HR often been used by ministers as scapegoat for unpopular decisions. HR too often seen as tick box exercise Public authorities need to see them as an aspiration not something to comply with Leadership is essential No template for embedding HR in an organisation. Process is creative rather than prescriptive, not widely understood in public services. Evidence for three types of benefit: 1 Engaging service users to improve services 2 Organisational renewal public service ethos 3 Business case for HR as tool for managing risk, transparency, balanced, objective proportionate solutions to complex problems.
4[20]	Equality and Human Rights Commission 2009	The impact of a human rights culture on public service organisations (in England and Wales): lessons from practice	Findings from the second research project of which 3 was the first	5 case studies including Mersey Care. England, Wales, Welsh Assembly Government, National Policing Improving Agency, Southwark Council, Mental Health and Learning Disabilities Hospital, Age Concern Charity	Evaluation of 5 case studies Human Rights Act FREDA principles	Focus on FREDA principles rather than Human Rights Approach More focus on a Human Rights Approach needed. Robust monitoring of outcome needed to determine difference Human Rights Approach makes over longer term. Too early to say what a human rights culture looks like or might operate.
5[22]	Graves J. Shields, T. Belchamber, C. European Journal of Palliative Care 2018; 25(1) 9-14	Human rights in end-of life-care: implementation and early evaluation of a Sue Ryder training programme	Evaluation of first six months of a human rights approach to end of life care.	256 participants in the training programme Sue Ryder staff and external practitioners independent hospices, NHS trusts, Marie Curie, Macmillan Cancer Support Great Britain	Pre post intervention survey. 4 hour training for non-registered staff. 1 day workshop for registered staff and students. 2	Workshop increases knowledge of human rights. Majority of attendees rated their confidence higher post training. Barriers to introduction identified: Lack of knowledge of other staff Professionals' paternalistic views Conflicts among patients' families

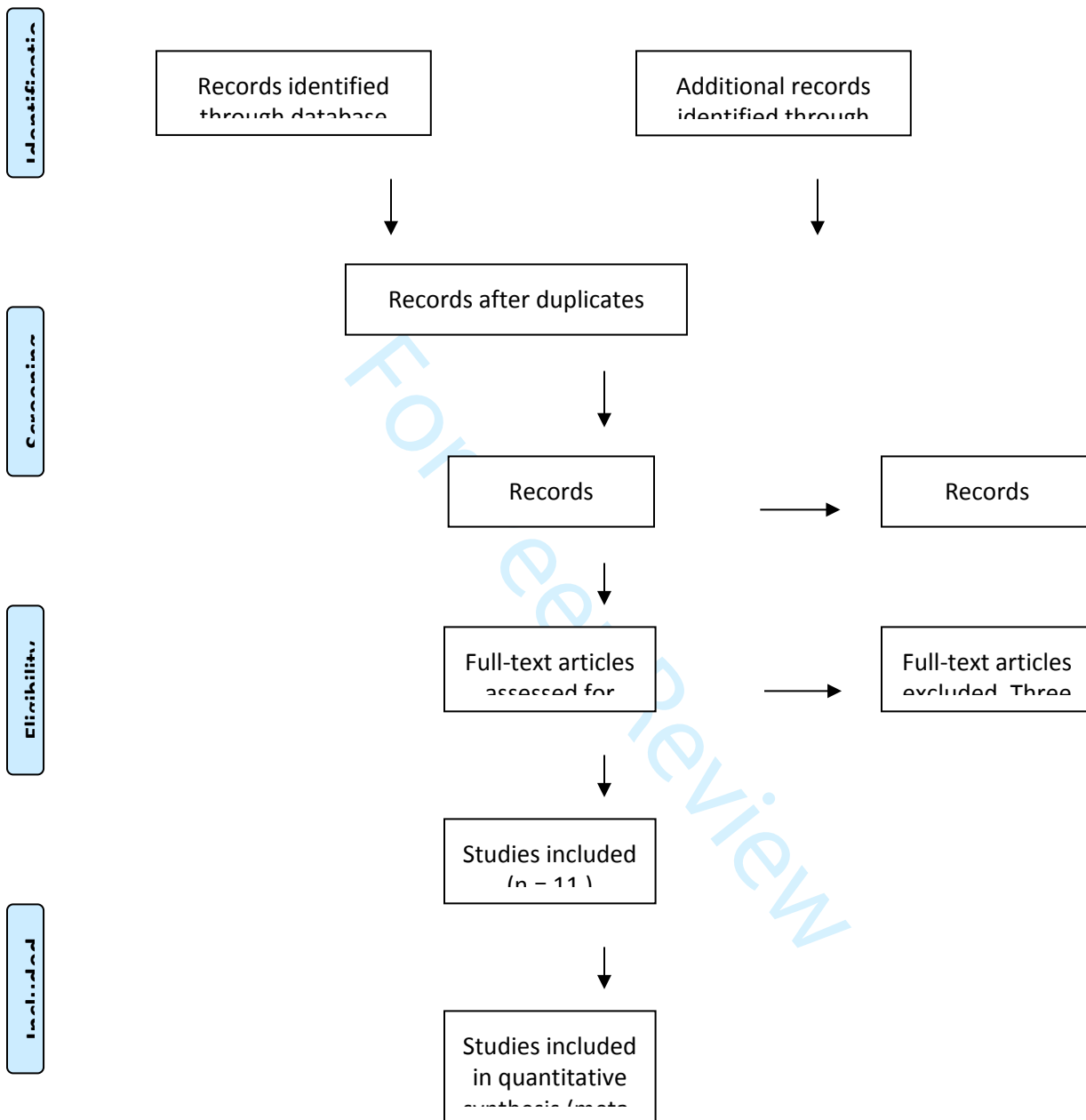|					Charity with hospices	day train the trainer workshop	
6[15]	Kinderman, P. Butchard, S. Bruen, A. Wall, A. Goulden, N. Hoare, Z. Jones, C. Edwards, R. *Health Service Delivery Research* 2018; 6(13) 1-164.	Randomised controlled trial to evaluate impact of a human rights based approach to dementia care in inpatient ward and care home settings	To evaluate the impact on the quality of care delivered and the well-being of the person with dementia.	People with dementia residing on dementia inpatient wards or care homes, and staff working at these sites. 439 people with dementia. England Dementia in patient wards in care homes	A cluster randomised trial design comparing impact of implementing a human rights based approach intervention (training in the 'Getting It Right' assessment tool; receiving booster sessions) at 10 intervention sites with 10 control sites.	No significant differences in the reported quality of life of residents between control and intervention groups after the intervention [F(1,16.51)=3.63; p=0.074]. This led to questions about efficacy of training in bringing about cultural change and improving care practices
7[21]	Redman, M. Taylor, E. Furlong, R. Carney, G. Greenhill, B. *Tizard Learning Disability Review* 2012; 17(2)80-87	Human rights training: impact on attitudes and knowledge	To examine factors contributing to effective human rights training for staff.	23 support staff in NHS Learning Disability settings. England. Mental Health and Learning Disabilities Hospital	Pre and post intervention knowledge and attitude tests. Human rights knowledge and attitudes test.	HRAT had a significant effect on human rights knowledge scores. Training had no significant effect on attitudes to human rights and relationship between staff attitude and human rights knowledge.
8[23]	Ekosgen, The University of Bedfordshire and Queen Margaret University 2011	Evaluation of Care About Rights; report to the Scottish Human Rights Commission	To evaluate Care About Rights- training and awareness programme which aims to embed a human rights based approach in delivery of care for older people. (Report of Phase 2)	Strategic stakeholders including Scottish Care, Scottish Social Services Council, SCSWIS Age Scotland and COSLA. 20 older people who participated in the outreach programme. 400 care workers Scotland Older people at home and their care workers Private and public sector; mainly private.	Literature & Policy Review. Consultation with strategic stakeholders. Consultation with 20 older people. Base-line and post intervention survey of care providers. Case studies with a sample of organisations demonstrating	Increased understanding and applicability of human rights. Increased confidence to communicate with colleagues about human rights. Potential to use a human rights approach to balance risk in decision making and resolve conflict Aided effective delivery of person centered care. Unlikely to achieve cultural change

					good practice in the roll out and embedding of Care About Rights	
9[24]	Dyer, L. *Health and Human Rights Journal* 2015; 1792 111-122	A review of the impact of the Human Rights in Healthcare programme in England and Wales	To analyse the Human Rights in Healthcare programme. Examine development of approaches to measuring outcomes and impacts of HRBAs.	Mersey Care organisation England Wales Mental health and Learning disabilities Hospital	Case study to examine Mersey Care's contribution to the programme	Because of the way programme was introduced it did not provide the level of evidence of impact required to effect in the relationship between human rights and health care.
10[19]	British Institute of Human Rights 2017	Using Human Rights: Independent evaluation of embedding a human rights approach	Report of an independent evaluation of 3 BIHR projects.	Delivering compassionate care: connecting human rights to the frontline Care and Support: human rights based approach to advocacy Supporting people with autism and or learning disability England Mental health Hospitals, City Council, Dementia wellbeing service, Mental health and Learning disabilities Hospital Hosing association, Child and adolescent mental health ward in a hospital	Evaluation	Increased patient empowerment. Human rights approach embedded in some organisations Increased knowledge and confidence of service users to advocate for their rights. Human rights have a crucial role in increasing the capacity of the voluntary sector to ensure people with mental health/capacity issues have increased control and autonomy over treatment decisions and are treated with dignity and respect.
11[25]	Luca, G. Zopinyan, V. Burke-Shyre, N. Papikyan, A, Amiryan, D. *Public Health Reviews* 2017; 38(18) 1-11.	Palliative care and human rights in patient care	Clarifies state obligations and addresses rights of patients and providers.	Multi stakeholders Armenia Physicians, health providers patients, families and NGO	Discussion and case study	Application of a human rights framework to patient care requires a range of measures; adequate laws, policies, documentation of abuses within healthcare service and legal remedies.

Inclusion Criteria	Exclusion Criteria
English Language	Other Languages
Focus on HRE that was applied to patient care and evaluated	HRE with no focus on actual practice: so pre and post-tests all in the class room not based on evaluating patient focused practice.
Patient care	Purely education Right to health or broader aspects of social and economic factors that impinge on health
'Rights talk' if it focused on HRE and patient care	
Focus on health care professionals including non-registered care workers and service users actual practice	Purely educational evaluations about cognitive change regarding human rights. The focus was on needs assessment for human rights education.

Table 2: Inclusion and Exclusion criteria

Figure 1. PRISMA Flowchart of the integrative literature review (Moher et al 2009).

Identificatio	Records identified through database	Additional records identified through
Screening	Records after duplicates	
	Records	Records
Eligibility	Full-text articles assessed for	Full-text articles excluded. Three
Included	Studies included (n = 11)	
	Studies included in quantitative synthesis (meta-	

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