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Utopian visions/dystopian realities: Exploring practice and taking action to enable human rights and occupational justice in a hospital context

Danika Galvin,¹ Clare Wilding¹ and Gail Whiteford²

¹School of Community Health, Charles Sturt University, Albury, NSW, Australia, and ²Pro-Vice-Chancellor - Social Inclusion, Macquarie University, Sydney, NSW, Australia

Aim: This article reports some preliminary findings of an Australian action research project that aimed to investigate, and affect, occupational therapists' understanding of human rights theory and occupational justice philosophy in everyday occupational therapy practice.

Method: Over the course of one year, nine therapists from a range of practice areas in a major metropolitan hospital participated in monthly discussion groups. Narrative data was collected through audio-recording and transcribing the discussions. Data was qualitatively analysed using line-by-line coding and theme-building.

Results: Two preliminary themes are discussed herein: the invisibility of human rights issues in an Australian occupational therapy setting and the dissonance between the ideal and the reality of human rights practice in occupational therapy.

Conclusion: The authors suggest that through discussion, and with the support of a community of practice dedicated to exploring human rights and occupational justice issues, occupational therapists can increase their awareness of human rights challenges. And, therapists can increase their actions to better enable occupational justice in their practice.

KEY WORDS *action research, continuing professional development, critical reflexivity, enablement, occupation.*

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Introduction and literature review

Human rights are a set of entitlements that are universal and belong equally to all people as a condition of being human (Winston, 1989). Lien, who consulted to the United Nations Economic and Social Council on the philosophy of human rights, viewed human rights as the quality of 'complete freedom to develop to their fullest possible extent every potential capacity and talent of the individual for his [sic] most effective self-management, security and satisfaction' (Lien, 1949, p. 24).

An important element of the idea of human rights is the notion of having a 'claim' to them (Winston, 1989). It is in having a claim to human rights, or in thinking of oneself as a holder of human rights, that people experience a sense of self-respect, which in turn gives rise to the notion of human dignity (Winston). Human rights are rights of the individual, and yet they also engender a civilised and moral society by imbuing a responsibility for the individual to act with humanity towards fellow human beings (Lien, 1949). An injustice is created when a claim to a fundamental human right is not respected, protected or fulfilled by one's fellow human beings, institutions or levels of governance (Winston).

Given the research described in this article occurs in an Australian setting, it is important to briefly consider the governance of human rights in Australia. Despite overriding support in the National Human Rights Consultation (2009) for a national Human Rights Act, the Australian government committed only to enhanced education and legislative review and to the deferral of a Human Rights Act (Australian Human Rights Commission, 2010). This decision was criticised as likely to perpetuate inconsistencies and gaps across Australian federal, state and territory laws and to limit citizen access to remedies for human rights breaches (Australian Human Rights Commission, 2010). Thus, unlike other nations across Europe and the United Kingdom and in South Africa, Canada and New Zealand, Australia remains the only liberal democracy that does not provide constitutional guarantee for human rights (Grover, 2009).

Danika Galvin BHSc (OT); PhD Candidate. Clare Wilding PhD, MAppSc (OT), BAppSc (OT); Lecturer. Gail Whiteford PhD, MHSc, BAppSc; Professor.

Correspondence: Danika Galvin, School of Community Health, Charles Sturt University, Elizabeth Mitchell Drive, PO Box 789, Albury, NSW 2640, Australia. Email: dgalvin@ csu.edu.au

Occupational therapy and human rights: An occupational perspective of human rights

A growing discourse within occupational therapy has raised concerns for how power can privilege or marginalise persons in relation to their right to engage in human occupation (Whiteford, Townsend & Hocking, 2000). Leaders of the profession have called for occupational therapy to therefore broaden its professional objectives towards meeting wider community needs (Pollard, Sakellariou & Kronenberg, 2009), and to espouse a global citizenship that is responsive to socio-political context (Watson, 2005) and the human and environmental consequences of professional decisions (Thibeault, 2006).

Wilcock (2006) was one of the first authors to make explicit the relationship of human rights to the profession of occupational therapy. She considered that the Universal Declaration of Human Rights was inherently occupational in nature, given its emphasis on the human right for all people to participate in work, cultural life, leisure, education and so on (Wilcock). The World Federation of Occupational Therapists (WFOT) (2006) made a significant advance towards human rights practice for the profession when it released a Position Statement on Human Rights. This position statement articulated the human right to participate in and make choices about occupation, and critically, the right to be supported in this participation. It outlined a role and responsibility for occupational therapists in identifying and seeking to address, situations of occupational injustice affecting clients.

The WFOT Position Statement on Human Rights has contributed to human rights receiving increasing attention in occupational therapy practice. In South Africa, from where a significant share of occupational therapy literature with an explicit focus on human rights has emanated, a range of themes have been profiled relating to the human right to rehabilitation (Lorenzo, 2010). These themes include, exploration of the principles of autonomy (van der Reyden, 2008a, 2008b), participation in work for persons with mental illness (van Niekerk, 2008), access to wheelchairs (McIntyre, 2010) and human dignity (van der Merwe, 2010).

It is through the concepts of enabling occupation and occupational justice that occupational therapy has distinguished the unique contribution that the profession can make in supporting human rights. Occupational justice differs from social justice and distributive justice through its emphasis on the unique capabilities and needs of individuals and groups. It recognises the aspirational dimension of occupational participation (Whiteford & Townsend, 2011). The intention of the concept is to foster public awareness of the *injustices* that impact individually and collectively when participation in occupations is deprived, imbalanced, alienated, marginalised or otherwise restricted (Townsend & Wilcock, 2004).

Political engagement with the issues that limit opportunities and capabilities for occupational participation is requisite if occupational therapists are to enhance human wellbeing and human rights (Hammell, 2008). In addition, Wilding and Whiteford (2009) argued that occupational therapists have a moral and ethical obligation to ensure that occupational therapy practice is occupation focussed. However, there has only been a small amount of research conducted into the extent to which understandings of human rights and occupational justice inform and guide everyday practice in medical settings. One such article, Riegel and Eglseder (2009), reported that engaging occupational therapists in critical reflexivity around the concept of occupational justice could, through alignment of quality improvement activities, lead to more inclusive occupational therapy practices.

Research into the *experience* of occupational injustice, such as for young persons in residential care (Magasi & Hammel, 2009) or persons with disability seeking employment (Jakobsen, 2009) have not yet evolved into research about how occupational therapists *respond* to injustice. To this end, Whiteford and Townsend (2011) revised and re-released the Participatory Occupational Justice Framework 2010 as a conceptual tool for *doing* justice. This framework has been intended for use by occupational therapists practicing with individuals, families, groups, communities, organisations or populations; however, as it is still an emergent concept there is as yet little known about its clinical utility.

As is evident then, a gap exists between occupational therapists' understandings and practice of human rights. As opposed to seeing human rights as a static pronouncement, as for example in the Universal Declaration of Human Rights, Ife (2008) argued that human rights could be shaped by different people in different contexts talking about what human rights mean to *them*. Ife proposed that use of a discursive approach could broaden the dialogue about the practice of human rights beyond a legal voice and human rights law, and include the voices of health professionals. For this reason, it is important to create dialogic spaces in which occupational therapists can engage more actively with, and be informed by, human rights discourses.

It is the authors' contention that occupational therapists can enact human rights and contribute to the building of just and inclusive society through enabling occupation and occupational justice. However, given the limited amount of research about human rights enablement in health care, this statement has not been fully tested. Therefore, the first author decided to discursively explore if and how some Australian occupational therapists could consider human rights issues in their daily practice. Three central research questions were: (i) How do occupational therapists understand and enact occupational and human rights issues affecting everyday practice? (ii) What conditions constrain or support occupational therapists in enabling occupation and occupational justice? (iii) What action can occupational therapists take to practice ethically and wisely?

Methods

This research was undertaken in partial fulfilment of the first author's Doctor of Philosophy studies. Collaborative action research (CAR) is a form of qualitative inquiry, which was selected as the method for the study. CAR is an adaptation of participatory action research (Wilding, 2008). This form of inquiry aptly suits the research questions as the method allows researchers to simultaneously reflect upon and act upon their practice. And as such, the research is an ethical form of study that is well suited to improving professional practice and exploring how practice ought to be undertaken. A collaborative approach to inquiry also enables development of individual practice knowledge and research capacity, and builds a supportive network of collaborative relationships that can help to maintain research activity over time (Stringer, 2007).

Participant recruitment

An invitation to participate in the research was extended to all members of an occupational therapy department at a major metropolitan hospital in Australia. Eight people initially agreed to participate in the research. During the course of the research, two of the therapists withdrew from the study due to their resignation from the organisation, and one additional person joined the group. Thus, a total of nine occupational therapists participated in the study.

There were three male participants and six female participants. Participants came from a range of practice contexts within the hospital, which provides acute and community services, including a focus on physical and mental health. The participants had a mix of experience, with three being new graduates, four having 3–10 years experience and two with more than 10 years experience in occupational therapy. Ethical approval was obtained from the human research ethics committees of the hospital in which the study was undertaken and the university at which the first author was a student.

Data collection

Over the course of one year, the participating therapists engaged in cycles of planning, acting and observing and reflecting, as part of the action research spiral that is described by Kemmis and McTaggart (1998). Each participant participated in a monthly group discussion that explored how the therapists worked for occupational and human rights issues in their everyday practices. In the groups, the participants also planned improvements to their human rights practice. The text, *Enabling Occupation II: Advancing an occupational therapy vision for health, wellbeing, and justice through occupation* (Townsend & Polatajko, 2008), was used as a stimulus and guide to the group discussions. It was selected for its emphasis on ethical and just occupational therapy practice. The group discussions were audio-recorded and later transcribed by the first author. These transcriptions formed the major dataset used for the analysis of the study.

Analysis

The transcripts of narrative data were analysed through the use of coding, category development and thematic construction as is described by Liamputtong and Ezzy (2005). The first author completed line-by-line coding of narrative passages; codes were produced by reflecting on the meaning of each line/paragraph and creating a short phrase that best 'made sense' of the passage. These codes were then sorted and organised into categories of meaning. Finally, the categories were further differentiated and classified as they were built into themes.

Findings

Occupational injustices perceived as lacking visibility in the course of everyday practice

In the initial stages of the study, the participants experienced difficulty in seeing how human rights issues were relevant to the clients they worked with on a daily basis. Prior to the study, when thinking about human rights abuses, the participants tended to think of people who were living in situations of war and poverty, which they perceived as not being the usual condition for an Australian citizen:

Liz: I think it is more difficult in Western societies because you haven't got such glaring diversities

Matthew: Not in your face, as it is in Sudan or wherever else

Liz: Yeah, the injustices that are there [Sudan], they need something doing about it, and there are great structural things that need to change. If you did come across somebody who didn't have an indoor toilet [in Australia] or you saw that there was something that needed something doing, you would address that on an individual basis I think rather than saying 'What other people haven't got them? What is the sanitation like here? What is the drinking water like? What other things can you do?'

However, despite perceptions that in general many Australians (including the clients who accessed the health services that they worked for) had their survival needs met and were afforded basic choices for participation in occupation, the participants were able to identify isolated cases of clear injustice. For example they were very mindful of the injustices that affect some groups of Australians, such as Indigenous Australians and homeless persons. Joshua could clearly see injustices that applied to the people he worked with, who had mental illnesses: For me in psychiatry it is very obvious; the disparateness compared to the general population, in terms of health outcomes. And in terms of one of my bugbears, vocational status, a very high percentage are unemployed but of that group most of them want to work, but there are very few opportunities for them to work in ways that are meaningful. When you go to the sheltered workshop ... where they get \$5 a day, to then have to compete in open employment, and there is very few things in between.

In addition to some groups of people who were clearly identified as suffering injustice, it appeared that in some pockets of practice, such as those in hospital emergency departments, human rights problems were more evident. There it was possible to observe clients' needs and vulnerabilities, for instance, how limited access to financial or social support could preclude participation in occupation.

However, in other specific practice areas, such as in medical hospital wards, injustices were rendered less visible. In these instances, the depersonalisation of the clinical environment had a homogenising effect that made it difficult for therapists to see the individual needs and injustices of each person. The hospital wards were stark and cleared of most of the client's belongings and usual means of expressing occupational identity, interests and needs. Clients in their hospital gowns shared the same characteristics and seemed to be unseen and anonymous, which one participant described as being like 'a white person in a white bed'; the lack of contrast between client and background made it difficult to see either person or context clearly.

Hayley: It does very much depend on the population you are working with. I think from my ED [Emergency Department] days where you see a lot more people on the fringe. Whereas the kind of people we are getting on the wards, and I suppose if they suffer that sort of injustice, deprivation or whatever, it is it may not be as obvious to us on the wards because we do not necessarily see where they are at home.

Joshua: It is almost like if you look at suppose Maslow's hierarchy of needs isn't it, the bottom needs of food, shelter, they are the really obvious ones. But the more existential ones, the lack of balance, with a bit of tinkering here and there you will be more satisfied with your life, a bit of actualised, appear less in Western society perhaps overall.

The invisibility of human rights issues was heightened because, even though the concept of human rights is that no one human right is more important than another, participants viewed needs, injustices and rights on a hierarchy of importance. It seemed that participants considered that the violations of civil and political human rights happening elsewhere in the world (and to a lesser extent in Australia) were more damaging and urgent than the right of people in Australia to realise their health and full human potential. This is certainly a problematic issue, and not surprising given many Western nations, such as Australia, have traditionally conceptualised human rights along civil and political lines rather than as social, economic and cultural issues.

Such a view, of some rights as more important or more visible than others, serves to diminish the significance of the everyday occupational problems that many clients experience due to their illnesses, disabilities or difficult life circumstances. While participants were cognisant of some of the injustices experienced by clients, the group's dialogue did not consider the full range of societal injustices, such as poverty, legislative injustices, racial prejudices and discrimination, social discrimination, etcetera.

The participants' apparent 'blindness' to human rights seems problematic insofar as the net impact of such an inactive, or inert stance is the potential for an overly instrumental focus in practice, that is, a focus on self care tasks and impairment reduction. Thus, occupational therapists might work to ensure that a client is safe to get on and off the toilet, rather than encompassing interventions that could enhance clients' quality of life, such as enabling clients to care for their pets or participate in recreational pursuits.

The participants' lack of awareness of injustices and their rating of human rights issues in Australia as less important than those in war-torn countries might have existed because, particularly at the beginning of the research, there was a lack of opportunity for occupational therapists to engage in dialogue about human rights and occupational justice. Indeed, Hayley suggested that the idea of human rights had not yet been contextualised locally by the profession or at an individual practitioner level:

WFOT have done it and obviously put out the challenge to OTs and OT associations to make it more relevant at a local level. I am not yet convinced that has perhaps happened. I have never seen an OT Australia Association response to it. I don't know if it exists?

Such experiences indicate the need for the profession to pay further attention to human right issues and to introduce dialogue about occupational justice.

As they participated in the research and discussed how human rights related to their daily practice, the participants began to see more clearly how issues of justice and injustice were a part of their everyday practice. This issue is illustrated well by Hayley's experience when drafting a submission for the Australian Human Rights Consultation about the significance of a human rights charter. Her occupational perspective differed to others' emphasis on civil and political human rights, however, Hayley found it difficult to find the words to convey this.

All these policy people who were going to write some document and I thought 'what am I doing here'? ... Anyway, one of the girls said to me 'what do you think human rights are?' and I was sort of thinking about social needs, human needs, whereas they are thinking freedom of speech, at a political level. I think housing though, food, shelter...but I was trying to be all 'occupational' and trying to convince them that that should be a human right. They couldn't quite see where I was coming from, but I was trying!

After the group read and discussed the WFOT Position Paper, Hayley found a resonance between the position statement and the occupational view of human rights that she had tried, though with difficulty, to advocate for at the meeting. Hayley could see the potential of this position statement as offering a framework and language to what it is that occupational therapists do.

I wish I had of seen this [position statement] when I did what I was talking about last time about the Human Rights thing. This is what I was probably trying to say to them but couldn't quite get those words out. No not quite like that!

Aspirations for human rights practice are not always pragmatic

When contemplating how the WFOT Position Statement on Human Rights related to their practice, the participants considered that it was an important vision for occupational therapy practice and a worthwhile goal to aspire to. However, they had difficulty reconciling the utopian visions of the statement with the practice realities of everyday occupational therapy. For example, Matthew doubted that there was the possibility that an actual place where human rights ideals are fully respected, protected and realised, as described in the WFOT Position Statement on Human Rights, could ever exist:

I just read it [the WFOT Position Statement on Human Rights] and thought: could you take me to a place in the world where you can tick off all these boxes, and we are all happy and dandy? Because I just couldn't imagine a place where you can literally tick off every one of these things.

The tension between enabling rights and fulfilling duty of care obligations was evident when clients' decisionmaking capacities were impaired. Eloise shared the story of a client, a war veteran, who resided in a nursing home due to cognitive and physical disability. While completing an assessment of the client's ability to use a scooter in the community, Eloise experienced pressure from nursing home staff to make an assessment of the client that demonstrated that the client lacked the capacity to use a scooter.

The issues at the heart of the situation were brought into sharp focus, when on Anzac Day (an important national Australian day of remembrance of those who have served in the Armed Forces) the client made his way to be with his friends at a public bar without making his whereabouts known to the nursing home staff. To the chagrin of the client, the staff filed a missing person's incident with police. Eloise recognised the complexities of this situation:

When he returned on his own, their big issues was "we have a duty of care to you to know where you are" and his big thing was "what about my rights as a person, [when] you have to know where I am at all times"

Eloise could see that the nursing home staff's concerns for client safety could lead to oppression of the client's human right to freedom of movement, participation in community life and the right to experience enjoyment through occupation; there is considerable challenge in balancing duty of care with a dignity of risk. This practice story illustrates some of the complexities of the practice of human rights within occupational therapy, and provides an instance in which the ideals of the WFOT Position Statement on Human Rights are not easy to apply.

Some participants encouraged one another to appreciate the position statement for its aspirational quality; however, others were of the view that its ideals were too far removed from the realities of occupational therapy practice.

Harry: But this is a stamp; this is their statement... [It] makes them not look connected to what is actually happening. It therefore takes a bit of respect away from them because it's almost they are setting all these gold high standards and you are working as an OT here and thinking "that bar is nowhere near where I am getting to".

Although the position statement may aim to inspire, Harry's response shows that it is possible for occupational therapists to read the statement and be discouraged about the dissonance between human rights principles and everyday occupational therapy practice.

As they participated in the research, participants developed an appreciation for how the aspirational nature of the WFOT Position Statement could help them to align their practices with a vision of occupation and justice. Thus, rather than seeing a dissonance between '[the ideals of] uni [university] therapists versus the [practices of] hospital occupational therapists', Harry reconciled that the position statement could stimulate his thinking about the possibilities for enablement of occupational justice. I thought back to that WFOT proposal of the human rights, and how that is the goal to achieve and that might be difficult, but at least it is something to aim for. If the academic side are setting out fairly high goals or high bars then at least it is something to aim for.

An opportunity to participate in a dialogic space centred upon human rights and occupational justice, exposed participants to new and different ways of thinking about occupational therapy practice, which they had otherwise rendered to an academic domain.

Discussion

The research described in this article raises important questions about whether occupational therapists may be not addressing human rights and occupational justice issues. Occupational therapists may neglect occupational injustices because they tend not to see them in the first place, due to an overemphasis on civil and political rights and an under-emphasis on occupational needs and rights within the societal and practice context. In addition, the way that health service spaces and practices are configured might obscure understanding of clients' needs (i.e. needs other than their medical needs). A third way that human rights might be neglected is due to the lack of dialogue about these rights; it is difficult to address needs that are not routinely discussed. However, even if occupational justice issues are recognised, it may still be difficult to address them as it is unclear how the ideals of human rights practice can be incorporated in the messy world of everyday health practice.

As has been briefly mentioned, a way that the participants were able to better recognise the human rights needs of their clients was to begin a dialogue with each other and with a researcher who encouraged them to think critically about their practice. Other occupational therapists are also recognising this need for dialogue about human rights. For example, at the 15th Congress of the World Federation of Occupational Therapists, in Santiago, Chile, Townsend *et al.* (2010) conducted a workshop that explored how the ideals of the WFOT Position Statement on Human Rights might be implemented in occupational therapy; and a subsequent WFOT Bulletin was dedicated to opening up dialogue for how occupational therapists across a range of practice contexts think about, and practice, human rights (Bryant, 2010).

(The authors consider that the research described in this article illustrates the potential for how occupational therapy practice can be renewed and extended. There are two reasons that research of this type is transformative: (i) through discourse with like-minded, supportive colleagues, it is easier to consider new ideas and work through how they can be applied to the realities of practice; and (ii) academic and practice collaborations aimed at creation of dialogic spaces and opportunities can revolutionise occupational therapy practice. When working as part of a community of practice that discusses real, case-based application of theoretical ideas, occupational therapists can slowly but surely change their practice (Wilding, 2008; Wilding & Whiteford, 2007). Ife (2008, 2010) has previously proposed that both academic and practice perspectives are necessary to foster the creation of society in which human rights are protected and enabled. And Wilding (2011) has advocated for the importance of critical reflection upon occupational therapy practice, as occurs during action research, as necessary to ensure that occupational therapy practice remains centred on its core domain of enabling occupation (and occupational justice). The rationale behind these assertions is that a purely academic emphasis fails to attend to practice realities, and in doing so will not lead to human rights uptake in practice. On the contrary, it is important for practitioners not to be too immersed in the world of practice and to be overly reliant on perpetuating practice as it has always been undertaken; such hegemonic practice fails to benefit from the advances in knowledge and understandings produced by those in academia and collaborative research.

It appears that currently, there may be few opportunities for occupational therapists to talk about clients' occupational injustices, in their own practice settings, and thus occupational therapists may remain ignorant of human rights concerns and abuses of the people they work with. In Australia, where many occupational therapists work in medical practice contexts, or are influenced by a dominant medical model, it may be even more important, and even more challenging for discussions about enabling occupation and occupational justice to occur. The research described herein, illustrates that such discussions, with and under the leadership of occupational therapy managers and professional associations, are requisite for aligning occupational therapy practice towards the profession's mandate of enabling occupation and justice; and for benefiting clients of occupational therapy services with the opportunities and capabilities to participate through occupation.

Conclusion

Human rights are not only universal, but also contextual in nature. If occupational therapists are to really enable occupation and occupational justice they may need to become more aware of the full range of human rights challenges and concerns that face people; each person's situation may be different and thus there is much to be discussed about the variety of different ways in which human rights can be enabled and denied.

The authors encourage occupational therapists to engage in greater discussion about human rights issues, and both academic and practice perspectives are considered essential for this discussion to be useful. A human rights framework may have great potential for helping occupational therapists to better see and address issues of enabling occupation and justice, not only at a population level, but also as part of their work with individual clients. To facilitate the translation of utopian ideals into practice reality, localised, contextualised discussions may prove to be most effective.

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