Segues and synergies – feminist economist and occupational scientists meet human rights

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How do the international rules of 'work' and 'economic activity' treat 'occupation'? What 'work' is constantly absent from the database for determining public resource allocations and investments? What occupies those whose work is unpaid? Is this work visible in Occupational Science research? What are the implications for 'over-occupation' in a human rights context? Are there opportunities for political economists and occupational scientists to work together on these issues?

KEYWORDS occupation and human rights; over-occupation; family carers

Introducing political economy and occupation

Thank you for the honour of the invitation to address you today. My discipline background is in political economy and public policy, my research is feminist, and for the last forty years, it has had a human rights focus. For occupational therapists, this address begins with a segue, a short introduction to a major feature of economics: its treatment of 'occupation'. I move to a discussion of synergies between my work and yours, in the environment of human rights, with a case study on the caregivers of those with HIV and AIDS using a capability framework. I describe my own experience of managing the care of a terminally ill family member, and what I learned from this. I conclude with the exploitation of women's unpaid care work.

My work in economics (Waring, 1988, 1999) has focused on the United Nations System of National Accounts (UNSNA). You will be familiar with the term GDP, and these growth figures are derived from the National Income Accounts. These are assembled in every country according to the rules of the UNSNA (1953, 1968, 1993, 2009).

The UNSNA was instigated in 1953 with the aim of enabling comparisons to be made between national economies, and serving as a guide to countries developing their accounting systems. In the UNSNA, national economies are defined in terms of market transactions to measure growth. A market transaction doesn't have to be legal to count as being good for

growth. Illegal trade in armaments, drugs, and people, as refugees or sex slaves, are all good for growth and counted in the GDP. Another important mechanism to understand is that these accounts don't have a debit side. When there's a major disaster, we don't deduct anything from the accounts. The Christchurch earthquake has been very good for New Zealand's GDP, for example, because building new structures requires a significant rise in market transactions.

Specific services and production do not count as 'work' in assessing our GDP. When these are produced by household members for consumption within the same household, they are specifically listed as outside the production boundary. These exclusions are:

- a. The cleaning, decoration, and maintenance of the dwelling occupied by the household, including small repairs of a kind usually carried out by tenants as well as owners.
- b. The cleaning, servicing, and repair of household durables or other goods, including vehicles used for household purposes.
- c. The preparation and serving of meals.
- d. The care, training, and instruction of children.
- e. The care of sick, infirm or old people.
- f. The transportation of members of the household or their goods. (UNSNA, 2009, p. 98)

This work does count in the GDP when it is supplied by government or voluntary agencies, and when there is payment for these activities. Then the workers are described as 'economically active'. But for the majority of women on the planet who perform this work without pay, the unpaid 'uncounted' tasks are unproductive. None of this work has an economic value; those who perform these tasks are 'at leisure' and 'unoccupied'. This work forms the largest single sector regarding hours worked in most nation's economies (see, for example, Budlender, 2010) but this work is not counted in the UNSNA. The lack of visibility of women's contribution to the economy results in policies which perpetuate economic, social and political inequality between women and men. There is a very simple equation operating here: if you are invisible as a producer in a nation's economy, you are invisible in the distribution of benefits.

Women present major challenges to the simplistic male systems. While primary production is a major productive sector, breastfeeding doesn't count. When a woman breastfeeds her four-month-old child, she is described as unproductive, unoccupied, and economically inactive, because her 'primary production' is consumed by a member of the household. Yet what is happening is more 'valuable' to the life of the child than any alternative. But there is no accurate way of economically ascribing value to this activity. There is no market

price for breast milk, so there is no replacement equivalent. Infant formula, whatever price is ascribed to it, cannot compete with the quality of breast milk, and its use can impact the future health and education of the child.

Do those who are 'unoccupied' have human rights?

Women's stories taught me to ask questions about unpaid work in the context of human rights, in a parallel to the investigation of human rights from the point of view of occupational science. We know that paid workers have rights. They have rights to healthy and safe working conditions, rights to paid holidays, and to some sick leave on an annual basis. They have the right to belong to an organised labour group such as a union, and much more, set out in national laws and international covenants and conventions.

In feminist political economy, the key impediment to recognition of rights has been the restriction of the words 'work' and 'worker' in international human rights texts, to those who are in paid work. The definition of the "economically active population" is "all persons of either sex who furnish the supply of labour for the production of goods and services" (International Labour Organisation, n.d., para. 1). What do I think it encompasses? Well, it's obvious to me that unpaid work 'furnishes the supply of labour for the production of goods and services'. But those doing the defining mean that there is only economic activity if there is a market transaction.

If a woman or man is relieving an institution of the full-time responsibility of the care and attention of somebody, is she or he an enterprise or not? They are an enterprise when the person in their care is not a family or household member, but not an enterprise when the person being cared for is a family or household member. If the full-time caregiver wasn't 'working', the service would have to be performed in an enterprise. There is no other place for it to be done.

So we have patriarchs making the rules, and patriarchs making policy. Activities that are outside the production boundary are left out of policy considerations altogether. It is very difficult to make policy about invisible people doing invisible things. Cooking, according to the UNSNA, is 'active labour' when food is cooked and sold, and economically inactive labour when it is cooked and consumed at home. Housework is productive when performed by a paid domestic servant and non-productive when no payment is involved. Those who care for children in a centre are occupied; parents who care for the children at home are unoccupied. That's what economics says.

Applying human rights in field work research

My first rights explorations were into the International Convention of Civil and Political Rights (ICCPR) which applies only to individuals, and it is the only Convention where the guarantee of rights is 'immediately enforceable'. However, both sections 3 and 26 of this Convention and the Optional Protocol, have been used by women who have exhausted their domestic legal remedies, to communicate with the UN Human Rights Committee, and to gain an outcome that applied to a class of women also subject to the same discrimination (Waring, 1997, p. 117).

Looking for tools for analysis and research in my early work, I noticed the Optional Protocol and the Convention on the Elimination of all Forms of Discrimination Against Women (CEDAW) were different from the ICCPR and United Nations Convention on Economic, Social and Cultural Rights (UNESCR) in two ways that seemed to me to offer some traction: the first was that CEDAW appeared to offer a class action possibility; and the second was that the CEDAW Committee had made a General Comment on substantive equality.

I first heard of substantive equality in the case of *Andrews v. Law Society of British Columbia* (1989) which contested section 15 of the Canadian Charter of Rights, which reads: "Every Individual is equal before and under the law and has the right to the equal protection and equal benefit of the law." In addition to the meaning of equality, the court examined what was meant by non-discrimination.

First, the court established that, if a barrier is affecting certain groups in a disproportionally negative way, it is a signal that the practices which lead to the adverse impact may be discriminatory. Second, the court defined discrimination as:

a distinction whether intentional or not, but based on grounds relating to personal characteristics of an individual or group not imposed on others or which withholds or limits access to opportunities, benefits, and advantages available to other members of society. (*Andrews v. Law Society of British Columbia*, 1989)

The Canadian Women's Legal Education and Action Fund (LEAF) made submissions to the Court in *Andrews*. LEAF argued that under Section 15 equality should be understood as a matter of socially created, systematic, historical and cumulative advantage and disadvantage (Waring, 1997, p. 138). In this concept, equality is 'ameliorative' looking to the reality of people's lives and what discrimination does to them. It does not matter whether it is the result of innocently motivated practices or systems. The outcome, not the intention, is the point.

CEDAW, the United Nations Convention on the Rights of Persons with Disabilities (ICPD), and the International Covenant on Economic, Social and Cultural Rights (ICESCR) all now have General Comments which mention substantive equality, and more recent Optional Protocols (ICESCR, ICPD) have allowed class actions. For example, *General Comment No. 20* from the United Nations Committee on ESCR reads:

In order for States parties to 'guarantee' that the Covenant rights will be exercised without discrimination of any kind, discrimination must be eliminated both formally and substantively: ...

8 (b) **Substantive discrimination**: Merely addressing formal discrimination will not ensure substantive equality as envisaged and defined by Article 2, paragraph 2. The effective enjoyment of Covenant rights is often influenced by whether a person is a member of a group characterised by the prohibited grounds of discrimination. Eliminating discrimination in practice requires paying sufficient attention to groups of individuals which suffer historical or persistent prejudice instead of merely comparing the formal treatment of individuals in similar situations. States parties must therefore immediately adopt the necessary measures to prevent, diminish and eliminate the conditions and attitudes which cause or perpetuate substantive or defacto discrimination. (United Nations Economic and Social Council, 2009)

Substantive equality is a very important concept to be understood and distinguished in Occupational Science. If I think about the Introduction to Gail E. Whiteford and Clare Hocking's *Occupational Science: Society, Inclusion, Participation* (2012) and the references to

- The increasing burden of caregiving in communities at one end of the spectrum affected by population diseases such as HIV/AIDS, and at the other end because of increased life expectancy;
- The continued occupational deprivation experienced by populations affected by natural disasters and conflicts;
- The mobilization of oppressed and marginalized groups into civic action as a response to the exclusions and occupational injustices they have experienced. (Whiteford, 2012, 4)

then both class actions and a focus on outcomes need to be the human rights approach. This requires a lot of sophisticated understanding of the human rights' regimes, to focus on "Occupational injustices that prevent inclusion and participation" (2012, p. 4).

In my work in political economy, I began to look at the concept of capability. I have noticed recent work in occupational science which also uses a capabilities perspective (Hammell, 2015). What is important in the capability model is what people can or cannot be, and what they can or cannot do, given the opportunities or the freedoms. Capabilities are a means to an end. They reflect access and the time to participate, the time and access to make informed choices, or in other words, the freedoms to function effectively. In 2008 I had the opportunity to join Anit Mukherjee, Robert Carr and Meena Shivdas in research where we could operationalise a capability analysis in fieldwork.

The researchers met at a Commonwealth Ministers meeting in Kampala, Uganda and began discussions on the human rights of the 24/7 caregivers of those with HIV/AIDS. The Commonwealth Secretariat decided to work on the issue of women's role in HIV care and support, with a specific focus on women's unpaid work.

The public health sector is a major expenditure item for any government, whether it is being met from redistributing national revenues, or from development assistance programmes. In more advanced economies, the economic imperative of the last twenty years has been for health institutions to develop more 'efficiencies' and 'effectiveness'. One of the chief manifestations of this approach has been to discharge patients earlier from public care facilities. In many countries where HIV/AIDS is of epidemic proportions and hospitals cannot cope, they have just sent all patients 'home'. In making this policy choice, there is a presumption that there is a reserve army of unpaid labour available in the family or community to immediately resume responsibility for the discharged patient. Just who is it that the policy makers are presuming will do this caring role?

Insufficient or inadequate care at the onset of illness can exacerbate its severity, with costs incurred across sectors. This occurs from the loss of labour from the market sector; the loss or diminution of unpaid service, productive and reproductive activities, either when the woman of the house is ill, or when she has to forego other daily household tasks to carry out the caring work; or when a child is removed from school to assist in caring roles. We know that the known outcomes of longer term illness increase the possibilities of poverty, poor nutrition or hunger, and a range of other vulnerabilities.

It is also important to remember that household work includes the daily maintenance of well-being, which tends to be even more invisible than caring for the sick. Household access

to water, hygienic practices, and a clean environment are all daily household routines that enable a healthy paid, informal or subsistence labour force to remain productive. This work is of significant economic importance. The work is very complex and difficult, and the list of things to do is very long.

The study design consisted of three main phases: a literature review; qualitative research with caregivers with women from households impacted by HIV as well as with those involved in caring for family members living with HIV or with a clinical diagnosis of AIDS; and, finally, an economic rights-based analysis of our primary data (Waring, Carr, Mukherjee, & Shivdas, 2011).

The literature review made it obvious that the research focus in the field would be most usefully situated within a rights-based framework, and in particular focussed on the dignity of the caregiver, in a capability approach analysis. It highlighted different impacts on carers by age, cultural expectations, religion, sexual orientation and gender, and most of this overlaid with stigma.

The second phase of the research involved key informant interviews with women, men and girls from households impacted by HIV, caring for family members or partners living with HIV or with a clinical diagnosis of AIDS. Subjects for the interviews and focus groups were chosen directly by the researchers or through researcher's networks or brokered by civil society organisations providing support to women and girls in households affected by HIV. The primary research was interviewing with women, men, and children involved in the HIV care economy.

In our purposive sample list, the respondents were to be from the following countries, and caring for individuals in the following categories:

Bangladesh: an intravenous drug user in an Islamic household

Botswana: a nuclear family in receipt of food aid

Canada: a woman prisoner or street woman or child with HIV

Guyana: a woman-headed household/violence

India: a sex worker

Jamaica: a gay man/violence, or stigma and baby mother

Namibia: a grandmother in the caring role

New Zealand: transgender

Nigeria: a Muslim woman in the compound caring for relatives

Papua New Guinea: subsistence/rural

Uganda: a child carer in one of the Christian CC schemes

The interview schedule collected background information first:

What is the relationship between you (the carer) and the HIV patient?

How long have you lived in the same household?

How long have you been providing care?

How many of you live here regularly – or from time to time (i.e., who else sometimes lives here)?

Can you describe a typical day in **your** life before X became so sick?

Our capability focus came in the next section. We went through the ICCPR, ICESCR, CEDAW, and UNCRC and developed questions directly from Covenants' human rights articles. Examples of the questions included the following:

Did you feel you had any choice about becoming the primary caregiver?

What are the nearest public health services?

Does anyone come to visit to provide help?

Does anyone ever come to give you some rest?

Have you had any advice or training to help you with this work?

How is your health?

Can you describe the hardest physical tasks you have as a carer?

Are you able to get any free exercise time?

Can you describe the toughest emotional tasks you have as a carer?

Have you felt depressed or stressed?

Can you describe the meals you prepare in a day?

Are you able to do any work outside the home? E.g. gardening, cooking, petty marketing, paid employment, fetching firewood/water?

What has happened to your finances or savings since you have been a full-time carer?

Can you go to any community meetings or political meetings?

Did you ever do any of that – or want to do that?

Have you ever had a holiday? When was that? What did you do?

For example, the question 'Did you choose to be the carer?' was a response to Article 6 of the UNCESCR, which "includes the right of everyone to the opportunity to gain his (sic) living by work which he (sic) freely chooses and accepts". In the capability analysis, the presence or absence of choice is fundamental. Carers were daughters, grandmothers, sisters, best friends and gay partners. While the universally accepted definition of work does not encompass these carers, they cannot be seen to be at leisure.

I had no choice because there was no other person close to my mother to assist her when she fell sick or to look after my younger brother and sister. (Uganda)

After the death of my own mother, my aunt took care of us. No-one else can do this. My grandmother is old now, so I'm the primary caregiver to my aunt. (India)

I didn't have any choice about becoming a caregiver. It wasn't a choice. I would do anything for my brother. (New Zealand)

Another question was, 'Does anyone come to help you?' If the carer had no choice about what they were to do, we needed to know if they got any assistance or help or relief from their work, 24 hours a day and seven days a week. How did the carers manage their endless responsibilities? Is Article 7 of the International Covenant on Civil and Political Rights which recognises the right of everyone to the "enjoyment of just and favourable conditions of work" relevant here?

Nobody comes to provide me with help. Last year some people from the church came, and they took some information from me but still no-one has come. (Namibia)

Sometimes once in a while the home-based care people come. I don't want to involve anybody else in the household to give me rest. I do not want to involve my sister. I do not want her to get frustrated and to disturb her studies. (Botswana)

We didn't get any help from anyone. No-one here helped us. During the time of caring no-one came to give me or the family a helping hand. We had no support. (Papua New Guinea)

We asked, what is the work like? Article 7 of the ICESCR recognises "the right of everyone" to "just and favourable conditions of work which ensure safe and healthy working conditions." This is mirrored in CEDAW Article 11(1f). In this context, we asked carers to describe their work.

I could not buy her foods because I did not have any money. Our ways of getting food was difficult. My sons were little boys when I took them out of school to help me. You have to fish, go to the market and sell the fish, buy whatever you can. If no fish, no food and we stayed hungry. They were only young, but they were trying to do the job of a man. During this time I was hungry all the time. If we had food I would spoon feed her. (Papua New Guinea)

I wake up early in the morning, wash clothes, prepare food and boil water for everyone. I do everything, breakfast, lunch, dinner, and other work. Wherever my aunt goes, I make sure she should have everything with her: water, medicine. The hardest physical task I had was fetching water from outside and storing it in the house. (India)

The hardest physical task for me was lifting. Near the end, D was just a dead weight, and it was very heavy to lift him. I had to build up momentum just to get him off the bed, change his bedsheets, things like that. Getting him up and down the stairs and into the car. I'm a pretty strong man, but you know, sometimes I just thought wow, heavy. (New Zealand)

Did you get any rest or a holiday? We asked our participants. Article 7(d) of the ICESCR recognises the right of everyone working to "rest, leisure and reasonable limitations of working hours and periodic holidays." Our answers were not surprising. "No-one comes to give me rest. I don't rest. I'm always thinking of what is going to happen to my young siblings when my mother passes away" (Uganda). "A poor person like me knows nothing about holidays" (Botswana).

All participant carers had been in formal or informal work or education before they had no choice but to become carers.

Before my sister became so sick I used to go into the bush and fetch firewood for selling. I had to stop this. I used to buy melon seed and break it and sell it. (Nigeria)

Before my aunt started to get too sick I worked in one of the teachers' quarters as a maid. (Botswana)

I loved going to school, and I wanted to complete it so I could look for a simple job and sustain my siblings. (Uganda)

Looking back on this work as I prepared for this symposium, it seems that what we have here is over-occupation – in what Ann Wilcock (if I understand her appropriately – and outside my disciplines) – referred to as:

- Occupational alienation sense of isolation, powerlessness, frustration, loss of control, engagement from society or self as a result of engagement in occupation which does not satisfy inner needs.
- Occupational deprivation deprivation of occupational choice and diversity because of circumstances beyond the control of individuals or communities.
- Occupational imbalance lack of balance or disproportion of occupation resulting in decreased wellbeing.
- Occupational justice equitable opportunities which enable people to meet their potential and experience wellbeing. (Wilcock, 2006, pp. 164–172)

We also found some warnings about cultural presumption. Clare Hocking has rightly drawn our attention (Whiteford & Hocking, 2012, p. 58) to the western epistemological presumption of individualism and the concern for culture. But many cultures are riddled with stigma. To have HIV, to be gay, breaks the presumption. You are alone. Our participants told us stories of stigma and discrimination, of domestic violence, poverty, despair, hunger, poor health, social exclusion, losing income, withdrawal from education. Many were abandoned by traditional networks of the church or extended family. The sole 'good story' was a child carer who lived in a Prostitute's Collective, and these women made sure she went to school and had some respite to be with her friends.

Participant observation of over-occupation

Being a researcher and author writing about unpaid caregiving is one story. The impact of having to do this yourself, even in wealthy western situations, is quite another. For 14 months in 2013–2014, I was the care manager and a primary caregiver to my 88-year-old terminally ill father, with terminal cancer where melanoma roots slowly and methodically invaded the twelve cranial nerve tunnels on their way to the brain stem, and for my mother of 87. I took a 12-month sabbatical, gave up any consultancies and travel and only had time for reading drafts from my 20+ postgraduate research degree students.

Folbre defined direct care services as "paid or unpaid efforts to meet the needs of dependents, including direct care work that involves personal connection and emotional attachment to caring recipients" (Folbre, 2009, p. 112). She further noted that caring work occurs within the paid economy but that it is typically segregated, in that the paid roles in child care, teaching, food services, elder care work, nursing, cleaning and other domestic service work, is overwhelmingly performed by women (and/or migrants) and at lower rates of pay than workers in other sectors. This mirrors the lack of value of the work taking place unpaid in households.

I used the categories of the 2009–2010 New Zealand Time Use Survey (Statistics New Zealand, 2009) to list the work description of my activities in my parent's home as a caregiver (see Table 1). These were: accompanying an adult, available for care of adults, mail organisation, financial budgeting, household administration, providing accounting or advisory services, attending a meeting for unpaid work, managerial and executive work, administration secretarial or clerical work, home maintenance or improvement, purchasing health services, waiting for health services, delivery and driving services, purchasing durable and non-durable goods, food and drink preparation and cleaning, purchasing repair services, arranging, organising and running events or activities, packing away goods. My mother undertook all indoor cleaning, laundry, ironing and other clothes care, tending plants and harvesting edible produce.

Think of all the different job descriptions in all those processes. These activities embrace the extent of the unpaid work that must be done to 'care' in a household. Problematically, front line 'caring' is too frequently seen as bounded by the job descriptions and demarcations of professionals – paid workers – so that the range and extent of the activities necessary for one person to undertake unpaid are lost. This loss of specificity is not strategically or politically useful. Alternatively, the role is seen principally as one of cooking, cleaning and shopping. These were the easy parts. Management and logistics were the cause of my monthslong vice-like headache in caring for my parents

There are important insights here. First, if the work would have to be done in institutions caring for dependent residents, then it has to be done in microcosm in the household for a dependent, with no possibilities of economies of scale. Second, I am a well-educated assertive, resourced person with telephone and internet access, and a knowledge of the forms and functions of different government and other providers. I struggled. How would I manage as the mother of a teenage girl with multiple, complex, severe health issues, that a friend was writing about at the same time? Over two years, this mother had to deal with 22 personnel from 18 different agencies. For this mother and myself, occupational therapists were just one of the numerous health-care specialists that we needed for assistance.

I found some research by occupational therapists about the need to work with carers, and to assist in preventing burnout, but not a lot. An early reference was Jenny Ching-Ching Chung's focus on family care-givers for individuals with dementia and the implications for occupational therapy practice. She found that negative caring experiences outweighed positive ones. She recommended occupational therapists should include therapy for family carers as part of treating individuals with dementia, as well as collaborative work with family carers. She found that although family carers play a significant role in the caring process for a person with dementia, occupational therapists seldom addressed their needs to enhance their caring duties.

In 1995, Gitlin, Corcoran and Leinmiller-Eckhardt commented that occupational therapists lacked a framework to develop services that were geared towards the needs of family carers. Participants used up almost all their time by performing both caring duties and household chores. Negative experiences of caregiving expressed by exhausted participants far outweighed positive experiences.

In 2009, Ben J. Atchison wrote that the belief in the value of home-based care was well established in many rehabilitation professions. It was critical that rehabilitation programme plans were both client and family centred. Atchison recognised the 'over-occupation' issue of potential caregiver burnout which needed to be a standard element of the team plan of care. Opacich (1997) quoted in Atchison, called for occupational therapists to be cautious about placing excessive burdens on family members and suggested that realistic expectations, plans, and supports be provided for patients and caregivers. Atchison's participants had little private time. When they were asked about their happy experiences during the caring process, a brief period of silence was noticed in both groups.

Conclusion

While many of the challenges for Occupational Therapists are about creating occupation, attention must be paid to over-occupation – a lack of any time to spend in pursuing a therapeutic occupation, to fulfil human rights activities, to have leisure and play time, to have opportunities to enhance the quality of life. Social inclusion includes the rights of citizenship in everyday life for everyone.

Occupational therapy client-centred practice, with an emphasis on client's goals, means 'educating the family in order to increase participation in and performance of daily activities for the client', is just another chore for the caregiver to fit in somewhere. Family members, and especially the primary caregiver, must be given choice and voice. Many of their human rights are being transgressed, and health practitioners can assist in and maintain this outcome, or take it into consideration in their professional practice.

It seems to me there are some very interesting synergies, and research opportunities, between economics, human rights and over-occupation. Occupational therapists and feminist economists could have a lot more to say to each other.

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