Framing Dementia as a Disability and as a Human Rights Concern

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Overview

Changes in our understanding of dementia over time from ‘normality’ to ‘organic brain disease’ to ‘personhood’ to ‘disability and human rights’.

Relevance of the UN Convention on the Rights of Persons with Disabilities (CRPD, 2006) to PLwD, their family members and advocacy organizations

Examples of human rights often denied of people who have dementia

How might practitioners contribute to a person’s excess disability?

What can be done to support a person with dementia exercise their human rights?

What is needed in applying a human rights based approach to practice?

Recent developments and future directions
The way we conceptualize dementia shapes what we see as legitimate needs and as possibilities for intervention and has strong repercussions for how we understand and consider the QoL of these people (Munro, Small & Froggatt, 2006)
What is dementia?

For most of last century dementia was seen as a normal part of ageing ...’doting’, ‘senility’, only ‘old age’. AD was then regarded as a pre-senile form of dementia.

Only since late 60’s early 70’s has the disease model for dementia emerged – dementia began to be seen as brain disease ..... characterized by plaques, tangles, loss of neurons, atrophy and the personal tragedy theory of dementia has also come to the fore!

Since the 90’s dementia is increasingly being framed as a disability (Kitwood, 1993, 1997, Sabat, 1994, Bartlett, 2000, Dorenlot, 2005) and more recently as a disability rights issue.
Dementia as a disability

The range of diseases causing dementia result in significant disability or inabilities - examples include inability to remember, plan ahead, problem solve, negotiate one’s way in a three dimensional world, apply rational thinking, communicate effectively and so on.

Society can also further disable people living with dementia through negative attitudes, unhelpful environments and discriminatory policies: this leads to ‘excess disability’

As a disability dementia is covered nationally under disability legislation nationally and internationally under the UN Convention on the Rights of Persons with Disabilities (CRPD) where it considers disability as:
Dementia as a Human Rights Concern

Injustice: Respect for dignity and autonomy can be overlooked

Discrimination: May be denied access to diagnostic and post diagnostic services

Inequalities: May be treated very differently to others

Social exclusion: People living with dementia are often socially marooned
Emerging Dementia Rights Movement

A Charter of Rights for People with Dementia

Participation
People with dementia have the right to be provided with accurate information, and necessary supports to enable them to exercise their rights to participate in decisions and policies that affect them.

Peopke with dementia have the right to live as independently as possible with access to recreational, leisure and cultural life in their community.

People with dementia have the right to fully participate in all needs assessment, planning, decision-making and emerging plans.

Accountability
Public, and private bodies, voluntary organisations and individuals responsible for the care and treatment of people with dementia should be held accountable for the respect, protection and fulfillment of their rights.

Non-discrimination and equality
People with dementia should be free from discrimination based on any ground such as age, disability, gender, ethnicity, sexual orientation, religious beliefs, or membership of a marginalised community, and family status.

Empowerment
People with dementia have the right to access appropriate levels of care providing protection, rehabilitation and support.

People with dementia have the right to help to attain and maintain maximum independence, physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.

People with dementia have the right to access opportunities for community education and lifelong learning.

People with dementia have the right to health and social care services provided by professionals and staff who have had appropriate training on dementia and human rights to ensure the highest quality of service.

Loyalty
People with dementia have the right to be treated with dignity, respect and as equal rights to everyone else. Where duress or significant capacity to take specific action or decision due to their cognitive condition, please acting for them we must have regard for acutal decision making capacity of individual in context.

In these rights are not observed, the right to seek remedy through effective complaint and appeal procedures.
WHO GAP on Dementia is strongly embedded in rights based principles

Policies, plans, legislation, programmes, interventions and actions should be sensitive to the needs, expectations and human rights of people with dementia, consistent with the UN Convention (CRPD) and other international and regional human rights instruments (WHO, 2016)
So if dementia is a disability and a human rights concern, can human rights agreements/legislation be used to interrogate policy and practice?

One approach is using UN Convention (CRPD, 2006) [http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx](http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx)
Widening the debate and applying a human rights lens to interrogate dementia policy and practice (Cahill, 2018)
UN Convention (CRPD, 2006) is:

An agreement (treaty) which brings together a range of human rights and through a set of principles explains how they can be made real in the context of disability.

A developmental tool – requiring governments to implement approaches to ensure that PwD can enjoy full and equal participation in society.

A useful tool for reframing dementia as a human rights issue and for providing a language and framework to highlight the injustices and discrimination some people with dementia and their family members can experience.
Examples of human rights from the UN Convention relevant to people living with dementia and their family members
## Articles or Principles

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But in promoting human rights some key dilemmas exist for practitioners

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Actions of practitioners which may breach rights

**DESKILLING**: Placing the individual in a wheelchair as its easier safer and quicker

**DISCRIMINATING**: Cherry picking residents in care homes and neglecting to match activities to individual biographies/life stories.

**DEGRADING**: Physically restraining residents or applying technologies without obtaining consent or without first trialing other approaches

**DISEMPOWERING**: Preventing a resident from using their retained abilities

**OBJECTIFYING**: Treating the person as an object or as socially dead

**INFANTILIZING**: Relating to a resident like a child “you are not allowed...”
How actions can contribute to ‘excess disability’

{The } ‘discrepancy that exists when a person’s functional incapacity is greater than that warranted by the actual impairment’ (Sabat, 1994, p 158)

Much more difficult to regain an ability than to retain it in the first place

Antipsychotic medication can contribute to excess disability leading also to excess mortality, stroke and gait disturbance (Banerjee, 2009; Coon et al, 2014, Kales, 2015)
Excess disability, consider the following:

“At 5pm precisely I have to give her medication: warfarin and [an antipsychotic]. Within half an hour the change in her is drastic. On one occasion she has slumped sideways and fainted. She cannot move or talk properly and we virtually have to carry her into the car to take her back. I only found out yesterday just exactly what these [antipsychotics] are for. They had been described previously as ‘to take the edge off the Alzheimer’s’. To be frank I am now worried to death at the consequence of them, considering that [before] she started taking them she never had any trouble with her chest whatsoever.” (Carer of a person with dementia living in a care home in Banerjee, 2009, p 16)
“My father liked the small dining room at the ward, but he had to leave it quite quickly. He summoned the personnel too much. He cared much for the other residents and called for the personnel when they dropped things, {on the floor} and then he was not allowed to sit there anymore and was moved to the kitchen where those who are most sick are placed. He became so anxious about that, looking at them sitting in their wheelchairs. He became worse after that. There should be an alternative- one of the personnel could be nearby and help them while they are eating” (daughter of resident with dementia, Naden et al, 2013, p 754).
Minimising excess disability and supporting people with dementia using a Human Rights based Framework
Practice within a Human Rights Framework

An approach to practice underpinned by the social model (rather than biomedical model) perspective & builds on a person-centred care philosophy (VIPS, Brooker, 2004) and on most health service professionals’ code of ethics.

It highlights the barriers people experience to the realization of their rights and the changes required to remove such barriers (Garcia Iriarte, 2016). Gives people voice and changes the balance of power

Promotes practice underpinned by values of respect, dignity and autonomy, fairness and empowerment. In the context of dementia it includes positive risk benefit assessment, ‘doing with rather than doing for’ and adopting a more relational nuanced view of autonomy
Using a HR framework requires training to:

Bring about a major shift in thinking as it demands accountability, dignity, fairness, and social/political action.

A rights based approach challenges power relations, changes negative discourse, requires us to change our language.

It builds on person-centered principles (VIPS, Brooker, 2004) and brings the person living with dementia to the centre stage.
Requires training which:

• Targets both attitudes and knowledge (Redman et al, 2012) but does not require significant new learning

• Complements core views on fairness and equity (Kinderman and Butler, 2006) and can build on person-centred principles and philosophy (Cahill, 2018)

• Everyone needs training not just front line staff and a rights based culture needs to be embedded in entire organization (Audit Commission, 2003)
Recent developments including reports pertinent to human rights with significant consequences for PIWD

Implementation of Assisted Decision Making Capacity Act

Global Action Plan on Dementia (WHO, 2016)

Alzheimer Europe 2 recent reports on Dementia

New report on ‘Developing and Implementing Dementia Policy in Ireland (O’Shea et al, 2017)
New Irish Report on Dementia

DEVELOPING AND IMPLEMENTING DEMENTIA POLICY IN IRELAND

EDITED BY EAMON O’SHEA, SUZANNE CAHILL AND MARIA PIERCE
Conclusions

Lots of different ways to frame dementia think & talk about it
Must move away from the doom and gloom language of sufferers, victims, plaques, tangles, drugs, atrophy and locked wards and think about the person, growth, love, creativity, their humanity and their fundamental rights
The CRPD (UN, 2006) is one powerful tool which can be used to further promote quality of life
Public policy on dementia is becoming increasingly rights based
A rights based approach does not necessarily require any significant new learning and can build on and extend on elements of person-centred care
Thank You

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