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Ethics in AI

Human rights in care homes for older people:

From rhetoric to reality

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Every care home resident has their own story how they came to live in a care home. Moving into a care home is a big transition in life, which is made easier with care professionals and families who understand this and who support residents to have a good life in this new phase. A major human rights consideration is therefore the culture of a care home, in which staff and visitors are also open to listening to residents and learning – human rights really are about respectful and positive relationships inside care homes. (Nightingale Hammerson Care Home residents, submission to the Joint Committee of Human Rights Inquiry into human rights protection in care settings, 2022)

About my work

'Interdisciplinary human rights research' – Law, sociology, gerontology

- **Pre-PhD (2014-2016):** Research with German care home staff on what does 'human rights' mean to them in relation to defining quality of care
- **PhD (2016-2020):** Human rights in care homes for older people from multiple perspectives
- **Post-PhD (2020-ongoing):** Defining human rights research priorities with care home residents, relatives and staff; Right to a care supporter study; Notices to quit and their impact on relatives of care home residents; Human Rights and Social Care Forum; work with the UN Open Ended Working Group on Ageing and wider human rights of older people movement

This talk

- Seeks to highlight some *challenges/limitations of the concept of human rights to support high quality care and relationships in English care homes, based on empirical research*

Which are?

- *Negative connotation of ‘human rights’*
- *Unclarity and confusion around practical applicability*
- *Conceptual shortcomings*

- **it does not primarily** tackle the quality of government policy/the wider economic or political context of social care or human rights obligations of governments
- I am assuming a basic level of knowledge on ‘human rights’

What empirical research?

- National and international policy/legal and regulatory analysis
- Engagement work with care home residents, staff and visitors on scoping human rights research priorities (in England/Scotland)
- Altogether around 150 qualitative interviews
- Across 4 qualitative studies
 - Perspectives on the role of human rights in care homes
 - The 'right to a care supporter' study
 - Notices to quit and their impact on people in care homes

1: Introduction

- a. Who lives, works in and visits English care homes
- b. The care home as 'intimately relational space'
- c. Defining 'human rights' in care homes for older people

2: Challenges and limitations

- a. The negative connotation of 'human rights' language
- b. Unclarities around the practical application of human rights in care homes
- c. Wider conceptual challenges

3: The way forward (in discussion with you)

- a. Challenging the current human rights culture
- b. Training

1a: Who lives, works in and visits English care homes?

Residents:

- 372,035 (England/Feb 2023) (ONS, 2023)
- 49% classified as self-funders (ONS, 2023)
- 39% residents aged between 85-94 (ONS, 2023)
- Majority female with roughly 2.8 women for each man in 2011 (ONS, 2014)
- Estimated 70% of residents living with dementia (Alzheimer's society, 2014)

- *'UK care home residents are invisible in national datasets'* (Burton et al. 2020)
 - No system for standardized data capture for residents in care homes, despite data-richness – DACHA study addressing this (Burton et al. 2022)

Who works in care homes?

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- 14,859 registered care homes
- (10,617 residential/ 4,235 with nursing)
- 380,000 people working in care homes
- Over 80% female
- Average age: 44 years
- Majority white ethnic background and British nationality (Skills for Care, 2023)
- Training: 36% nursing homes, 41% residential homes hold a Care Certificate (agreed set of standards that define knowledge, skills and behaviour)

Who visits care homes?

- Families (but many residents do not get any family visiting) (studies on roles of families include Purveen et al., 2018)

“For many of our residents we have not seen any relatives in months...we become their family” (a care home manager)

“My daughter hasn’t been here for 6 weeks, she will get a right telling off when she comes next” (A care home resident)

“I come here every day, I don’t trust them with my mother’s care at all” (a relative of a care home resident)

“My only daughter died of cancer a few years back, as did my wife. I am now all alone” (A care home resident)

- Friends (again, many do not have friends)
- Volunteers
- Healthcare professionals including first aiders
- Funeral directors *“Death stares me in the face”* (A care home resident)
- Researchers
- Service providers
- Children (e.g. when nursery on site)
- Police/coroners
- Regulators

1b: Conceptualising 'care homes'

- **Practical definition:** Building-based spaces of care in which residents live permanently and receive nursing/social care.
- **Influential conceptualization of care homes in England and more widely:** Institutions, drawing parallels to prisons i.e. with a punitive character ('carceral care' - *Lucy Series, Deprivation of Liberty in the Shadows of the Total Institution*, 2022; Erving Goffman, 1961; Peter Townsend, 1962...)

Characteristics:

- Enclosed and isolated settings, 'closed institutions', separated from the community (Series, 2022, Chapter 3)
- People held against their will/deprived of their liberty;
- Subject to powerful actors who dictate residents' days and choices;
- Subjected to human rights violations, like abuse and neglect, loss of privacy, autonomy and control.

Care as transaction – being done to - with inherent power imbalances

“The Special Rapporteur (Anand Grover, right to health, 2008-2014) stresses the impact of institutionalisation on the autonomy of older persons and its often harmful effect on their dignity... Loss of full independence and, restricted freedom of movement and lack of access to basic functions would cause feelings of deep frustration and humiliation to any individuals ...As with other vulnerable and marginalized groups, special attention is needed to protect older persons from abuse and to ensure their rights in settings where they might be especially prone to violations” (UN General Assembly, 2011 p. 13)

An alternative approach

Care homes as ‘intimately relational spaces’ (e.g Nolan et al., 2004)

Communal spaces of life and living, with complex relationships between people marked by previous ‘lives lived’, emotions and pressures that shape the experience of care home life.

Characteristics:

- People need to negotiate relationships with people they did not choose to live/work with;
- Complex relationships, including with ‘visitors/non visitors’;
- Subject to range of emotions like envy/jealousy; fear; grief; anger; shame; sadness; overwhelm; love; hope; empathy, etc.
- Facing various pressures like declining health and impairment, intersectional disadvantage/inequality (e.g. Westwood, 2016) prejudices, hyper-regulation, resource constraints etc.

Compassionate relational care: “[Caring is] the meetings of needs of another, in a way that respects them as a person, which involves acknowledging the responsibilities that come with caring and which must be understood in the context of a mutual relationship”. (Herring, 2017)

1c: Defining the role of human rights in care homes

- The institutional approach to care homes has been widely influential on human rights framework in England (Series, 2022), as has been the liberal ideal of the entitled, autonomous rightsholder – **translated into law and regulation – law of institutions.**
 - Putting in place regulatory and monitoring mechanisms to ensure that staff are treating residents (and other staff) in line with human rights;
 - Coming out of litigation and journalistic scandals;
 - Highlighting the human rights issues in care homes and addressing them with human rights mechanisms e.g. Mental Capacity Act 2004 (Deprivation of Liberty), s73 of the Care Act (care providers are exercising a function of public nature under the Human Rights Act 1998 when caring for someone whose care has been arranged or funded by public authority)
- **Relational approach:** Recognising the inherent equality and shared humanity of people living in care homes, who work in them and visit them – multi-actor responsibility to protect them.
 - Next to other values like compassion, kindness, friendship, love, selflessness etc.;
 - Human rights structure relationships in a way that foster values (Nedelsky, 2008, Herring, 2013,2017);
 - Approach to care homes that sees them as partners rather than as perpetrators of human rights violations

1) Why do we need a human rights approach?

Applying CQC's values:
Excellence: we consider human rights as vital for good care
Caring: about human rights
Integrity: protecting, respecting, and fulfilling human rights
Teamwork: in promoting rights

To CQC's purpose:

We make sure health and social care services provide people with safe, effective, compassionate, high-quality care, and we encourage services to improve

2) What do we mean by human rights?

Applying our human rights principles:

- Fairness
- Respect
- Equality
- Dignity
- Autonomy
- Right to life
- Rights of staff

To our five key questions:

- Are health and social care services:
- Safe
 - Effective
 - Caring
 - Responsive
 - Well-led

Leads to our **human rights topics**

Leads to our human rights topics

3) Building human rights topics into assessment frameworks

- Regulations (led by the Department of Health and Social Care)
- Guidance on how we regulate services
- Key issues to look for



4) Developing our human rights approach for each type of regulatory activity

- Risk to human rights: measures and monitoring data
- Inspecting for human rights: methods, tools, information
- Building confidence in human rights: learning and development for CQC staff and empowering staff to act to improve human rights
- Embedding human rights in registration and enforcement



5) Supports principles for applying human rights approach

- Putting people who use services at the heart of our work
- Embedding human rights into our regulatory approach
- Delivering in a culture of fairness, equality and inclusion for staff
- Everyone involved in regulation can use it with tailored advice and support from human rights specialists in CQC
- Promoting human rights in a single shared view of quality

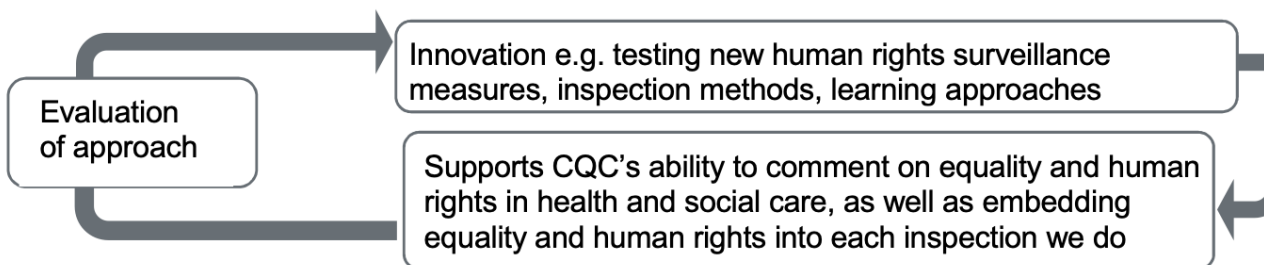


6) Continuous improvement as inspection model develops

Evaluation of approach

Innovation e.g. testing new human rights surveillance measures, inspection methods, learning approaches

Supports CQC's ability to comment on equality and human rights in health and social care, as well as embedding equality and human rights into each inspection we do



The Care Inspectorate is a scrutiny body which supports improvement. That means we look at the quality of care in Scotland to ensure it meets high standards. Where we find that improvement is needed, we support services to make positive changes.

Health and Social Care Standards: my support, my life

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Part of: [Health and social care](#)
ISBN: 9781788510158

Standards setting out what people should expect when using health, social care or social work services in Scotland.



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[Principles](#)

[1: I experience high quality care and support that is right for me](#)

[2: I am fully involved in all decisions about my care and support](#)

Introduction

These Health and Social Care Standards (the Standards) set out what we should expect when using health, social care or social work services in Scotland. They seek to provide better outcomes for everyone; to ensure that individuals are treated with respect and dignity, and that the basic human rights we are all entitled to are upheld.

The objectives of the Standards are to drive improvement, promote flexibility and encourage innovation in how people are cared for and supported. All services and support organisations, whether registered or not, should use the Standards as a guideline for how to achieve high quality care.

Principles

Dignity and respect

- My human rights are respected and promoted.
- I am respected and treated with dignity as an individual.
- I am treated fairly and do not experience discrimination.
- My privacy is respected.

Compassion

- I experience warm, compassionate and nurturing care and support.
- My care is provided by people who understand and are sensitive to my needs and my wishes.

Be included

- I receive the right information, at the right time and in a way that I can understand.
- I am supported to make informed choices, so that I can control my care and support.
- I am included in wider decisions about the way the service is provided, and my suggestions, feedback and concerns are considered.
- I am supported to participate fully and actively in my community.

Responsive care and support

- My health and social care needs are assessed and reviewed to ensure I receive the right support and care at the right time.
- My care and support adapts when my needs, choices and decisions change.

2. Challenges and limitations - a. The negative connotation of human rights language in care homes

"You have people here by and large against their will. They don't want to be here, so it is a form of being incarcerated. It is a humanitarian incarceration... It's a jail for their own interest. (a relative)"

"Interviewer: What does it mean to you, human rights?"

Participant: I don't think we've got any human rights

Interviewer: What makes you say that?"

Participant: I don't know. Because they always get their way in the end, anyway. Interviewer: Who's they?"

Participant: Government.

Interviewer: Do you feel human rights is something that's important to you here [in the care home]?"

Participant: No. I think we're safe in here. (a resident)"

"When a care home really is in a state...that's when you have to have these things... I have had a few care homes that have everybody on soft diets because it is easier and have everybody on pads because it is easier. We can't have that. So that's when these rules have to come into place. (a staff member)"

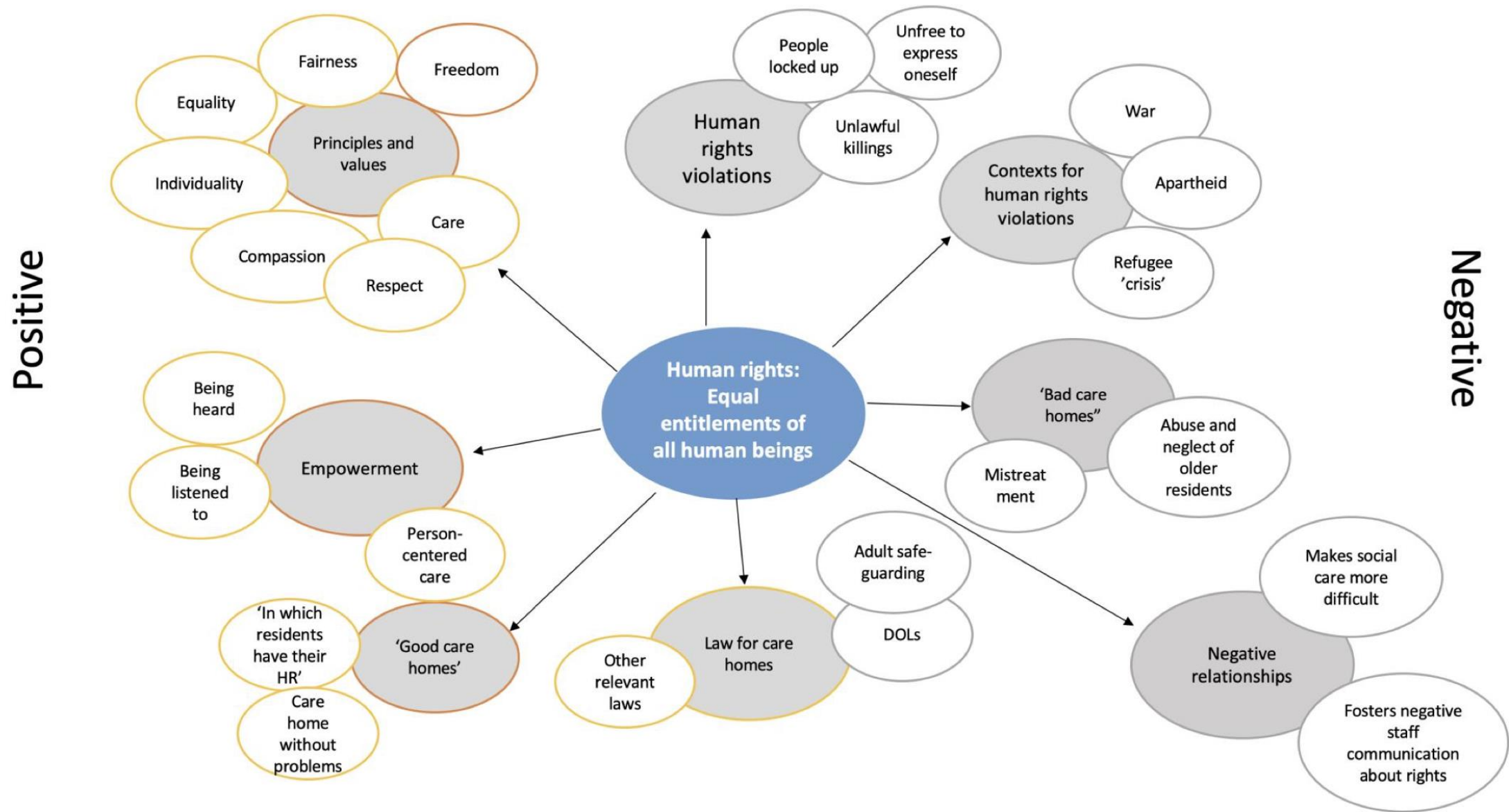
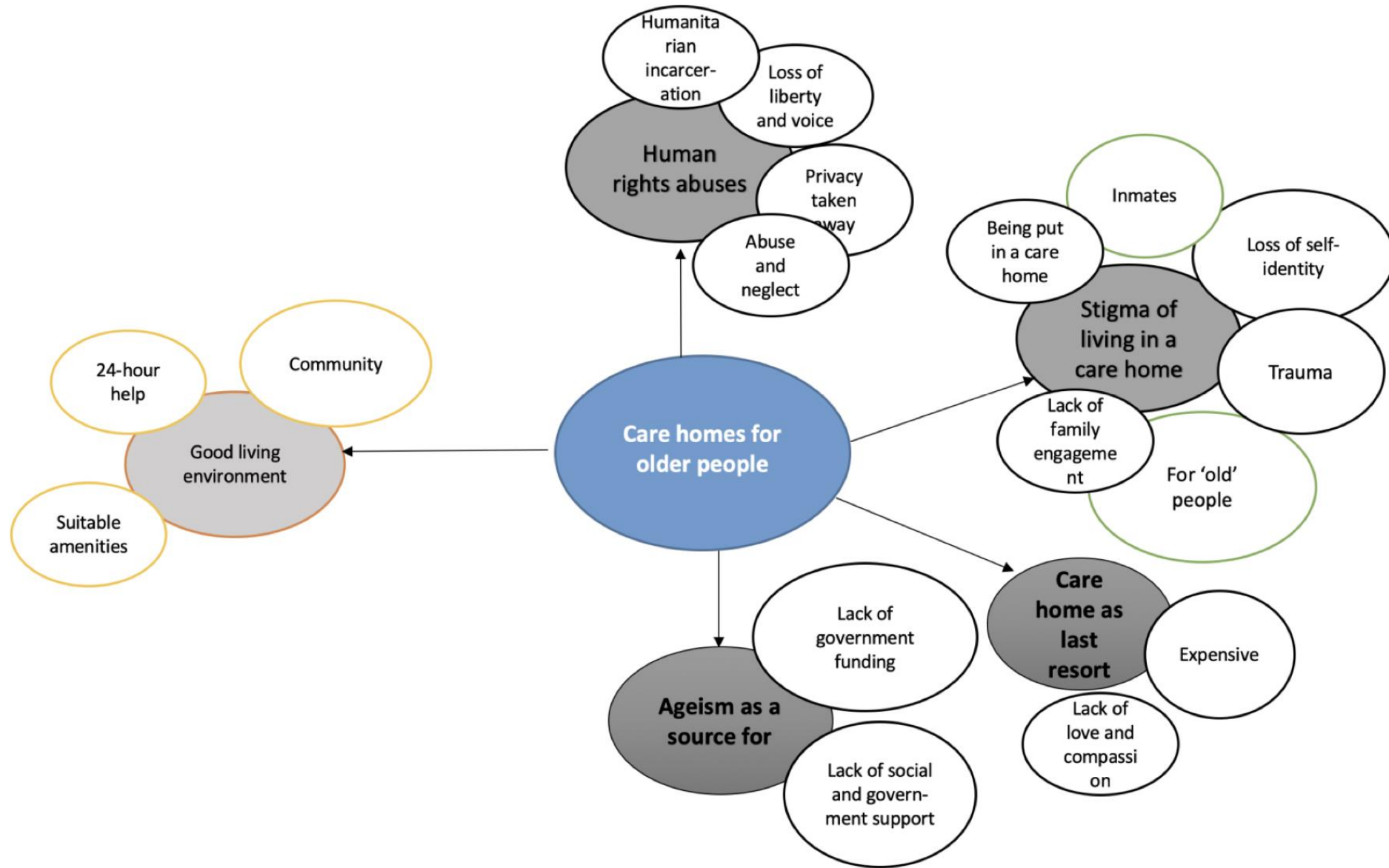


Figure 10.1 Study participants' associations with human rights

Positive



Negative

Figure 10.2 Study participants' associations with care homes



Figure 10.3 Study participants' associations with older people and older care home residents

2.b Unclarity regarding practical application

- **Competing interests**

e.g. 'Duty of care' versus autonomy rights

" When I find someone in a pool of blood I have breached my duty of care, when I don't let someone walk by themselves in the garden I have violated their human rights... We can't win, it's an impossible situation"
(A care home manager)

- **Understanding of human rights in practice:**

"I think that human rights is always one of those things that is exploited for the wrong reasons... It complicates things... I had a resident in the old home I worked for and he was very aggressive... He had cellulitis on his legs... he would never wash, he would urinate everywhere, he actually got gangrene and died through septic shock... But is it against his human rights, could you actually maybe got him, put him in a shower, showered him and he would have lived, do you know what I mean?" (a staff member)

- **How to 'claim' human rights:** *"You come in here, you talk to us about human rights and then you leave and nothing changes for us"* (a care home resident)

2.c Wider conceptual challenges

1: The 'pick and choose' phenomenon:

- 'Human rights that are particularly salient in care homes'/human rights principles – what about the rest of the human rights catalogue?
- Inventing new rights e.g. right to a care supporter

2: Claimability/abstraction (Onora O'Neill)

Who is the duty-bearer? What does the human right mean in the care home context?

"What about people who don't have anyone who can be their care supporter?" (member of the community)

3: Public/private divide

Applicability of s73 Care Act only to self-funded individuals

3. What is the way forward?

1: Human rights language is powerful, but it is time to challenge the human rights culture we have created

2: Training

3: Address the cracks and limitations courageously