A New-Materialist Reading of Disability, Senescence, and the Life-Course

Susan Flynn*
School of Social Work and Social Policy, Trinity College Dublin, University of Dublin, Dublin, Ireland
Email: Flynnsusan437@gmail.com
Orcid: 0000-0002-2807-0866
*corresponding author

Michael Feely
School of Social Work and Social Policy, Trinity College Dublin, University of Dublin, Dublin, Ireland
Orcid: 0000-0001-9256-613X

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ABSTRACT

The purpose of this article is to provide a new-materialist theoretical commentary on disability, senescence, and the life-course. A critical literature review with deductive thematic analysis was undertaken using an electronic database search strategy. For analysis, theoretical conventions of new-materialism were deductively applied to literature. New-materialism offers an approach taken by disability studies scholars within critical disability studies and elsewhere. A hallmark of the approach is attempting to return to the focus traditionally given in disability theory to physical and material aspects of disability. This would include complex issues such as exploring the corporeality of impairment and what embodied selfhood means. The central argument is that new-materialism and critical disability studies can effectively illuminate the relationship between disability, senescence and the life-course. To substantiate this claim, we apply new-materialist theory to discuss various dimensions of disability, such as impairment and social justice, relevant to the end phase of the life-course.

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Introduction
The purpose of this article is to offer a new-materialist theoretical commentary on disability, senescence, and the end phase of the life-course. As social injustices like exclusion and disadvantage continue to compromise the quality of disabled people’s lives, ableist and disabling attitudes must be challenged, and in this context, disability theory can be compelling, socially just, and disruptive (Thomas, 2007). From the outset, the intention is to be instructive rather than exhaustive, through extending scholarly debates, without claiming a basis in conclusive statements of fact. Theoretical commentary is therefore intended as a provocateur of conversation and debate. As such, the article offers a targeted intervention into varied fields of disability studies and critical disability theory as the core focus, as well as gerontology and geriatrics, critical dementia studies, and death studies, among others.

The above person-first terminology – “disabled person” – will be taken up in recognition of the barriers to equality and inclusion in society faced by disabled people, and as a reflection of our social justice perspective (Barnes, 2012). In the periphery of contemporary scholarship, addressed by our discussion, are groundbreaking works that have laid its foundation, such as Carol Thomas’ conception of impairment effects which dismantles a simple dichotomised approach to disability (2007), and Rosemarie Garland-Thomson’s (2011) concept of “misfits” which elaborates upon embodiment in interaction with the environment, in the broadest terms possible.

Further refiguring the boundaries of disability studies, and contextualising debates in this article around embodied selfhood, have been Margrit Shildrick’s work on self and other (2015), Jackie Leach Scully’s (2013) reading of disability and vulnerability, Susan Wendall’s (1989) attention to the embodied experience of disability/illness, and Ann Leahy’s (2021) seminal critique of disability and ageing. With specific respect to our sampling of literature, and mindful of the rise in citation inequality and monopolisation of scholarship by choice researchers (Nielsen and Andersen, 2021), core conventions of a critical literature review method (see Jesson and Lacey, 2006) were taken up as the substantive basis of our commentary. The intention was to draw in sources based on an a priori protocol and electronic database search strategy, to build on the scholarly state-of-the-art of predecessor literature, without swaying citation practice based solely on impressions of whose work ought to be considered most influential.

The central argument of our theoretically guided commentary is that new-materialism and critical disability studies can effectively illuminate the relationship between disability, senescence, and the life-course. The context of this article lies in
concern for both the physical and non-physical worlds where disablement unfolds (Garland-Thomson, 2011; Thomas, 2007). For good reason, many of the common corporeal concerns related to disability such as medical treatment of impairments, and bio-medicalised language associated with this, such as “disorder” and “diseased” have been shunned in disability studies, toward a reconceived disability epistemology. This was helpful because viewing disabled people from a solely medical lens received criticism for its failure to address the social aetiology of disability such as discriminatory laws, policies, and attitudes in society (Shakespeare, 2014). Disability studies scholars therefore re-envisaged disability as a socio-political artefact, where disablement is understood as being the product of exclusion and oppression of disabled people in society (for example, the British social model) (Barnes, 2012; Oliver, 1983, 1990, 2013; Shakespeare, 2014).

The cold shoulder toward biomedical and bioscientific views on disability and impairment has been vindicated on several counts. Early 20th century eugenics movement practices ushered in by Darwinism and a perspective known as biological essentialism, contributed to the misguided defence of forced sterilisation and euthanasia of disabled people. This underpinned the importance of the development of the Nuremberg Code of Medical Ethics. The aftermath of World War II and Nazi human experimentation also demanded no less (Herzog, 2018). Suffice to say, biomedical approaches to disability, where attempts to address people’s impairment were largely medical, scientific, curative, and uncontextualised have been deemed negligent across many strands of contemporary disability scholarship (Goodley, 2016; Shakespeare, 2014). Indeed, in support of social justice, an outright rejection of sustaining philosophies for eugenics and biological essentialism underpins and directs our theory.

Yet, it would be too simple to declare that these biomedical approaches, which inadequately accounted for non-biological bases of disability such as politics, society, and culture, are completely separate from approaches that do account for these factors. Specifically, biomedical approaches often located within the traditional medical model of disability, sometimes overlap with, and fail to contradict, non-medical approaches such as the Nordic relational model (Tøssebro, 2002, 2004) or the affirmative non-tragedy model (French and Swain, 2008; Swain and French, 2000).

Moreover, the idea of a futile medical model that has entirely failed to consider environmental and societal issues would be ludicrous to propose. Nor are transdisciplinary spaces like critical disability studies or cultural disability studies that heavily consider immaterial dimensions of disability, entirely unwilling to infuse themselves with exclusively biomedical concepts. Shildrick (2015; Shildrick, 2019; Shildrick et al., 2018), for example, offers elegant and transformative work from a post-conventional slant that rethinks human organ transplantation, neither denying the physical body nor overindulging it. Other works similar to this exist where disability as a biological medical issue is combined with the understanding that disability also arises from discrimination in society. Yet what is arguably evident, despite
such convergence of perspectives, is a gulf between classic biomedical perspectives on disability, and contemporary disability studies scholarship. And whilst this gulf is not completely unpopulated, it does offer few analyses that cross-fertilise these otherwise often unacquainted areas of scholarship (Shildrick, 2019).

In this context, the present analysis includes the perspective of new-materialism which is an approach that reclaims the value of the material body and material world as a focus for disability studies scholarship. We underpin our application of new-materialism with a social justice agenda concerned with disability equality and non-discrimination. The analysis seeks to extend the reach of the new-materialist tradition into biosciences traditionally associated with the medical model. This allows us to disruptively reimagine the ontological meaning of disability within the end phase of the life-course. Here new-materialism is a valuable theoretical lens as it is equipped to deal with the corporeality of impairment and the embodiment of self, as well as surrounding material worlds within which disabled people are located (Feely, 2016). New-materialism is also valuable as according to Coole and Frost (2010), as its core focus includes biopolitics and bioethics as applied to corporeal bodies and material biotechnologies, like those that prolong life.

Coole and Frost (2010) further conclude that a core strand of new-materialism is concerned with ontology, the status of life and of the human. Such issues are central to the intersection of disability, senescence and the life-course when viewed from a social justice perspective. In particular, strands of new-materialism related to biopolitics, bioethics and the status of life will be taken up most strongly within the specific approach to new-materialism in this paper. Arguably these strands cohere effortlessly with critical disability studies due to the focus in the latter on social, relational, political, and discursive forces of disablement enacted on people with impairments (Goodley, 2013). The only caveat is that a departure from theorising corporeal bodies and material worlds has been evident in critical disability studies to date (Flynn, 2017; Shakespeare, 2014). Thus, bringing new-materialism into the theoretical fold is enriching and required, as it provides well-rehearsed tools to re-engage social theory, such as critical disability studies, with physicality. In this article, to augment discussion of biomedical conditions from a new-materialist slant, there will also be uptake of concepts from the transformative theoretical field of critical disability studies (Goodley, 2013, 2016).

Finally, in seeking to achieve its central aim, the article takes the following structure. First, we outline how conventions of a critical literature review method of literature retrieval were combined with deductive theoretical analysis. This is followed by an explanation of new-materialism, and the evolving theoretical agenda of critical disability studies (Goodley et al., 2021). Next, discussion around the capacity of disability to act as somewhat of a destabiliser of the common understanding of senescence is presented. Here the purpose is to begin to outline the value of new-materialist thinking for shedding light on key aspects of disability, senescence and the life-course. Following this, the concept of life-span longevity is considered as well
as the meaning and consequence of a life worth living. This leads to an exploration of social interdependency within the life-course.

The intention is to substantiate the central argument of the article, namely, that new-materialism and critical disability studies can effectively illuminate the relationship between disability, senescence and the life-course. Discussion of various concepts relevant to this claim such as life-span longevity and social interdependency illuminate the value of new-materialist thought in a social justice context. This pushes the theoretical boat out within a space already populated with the intellectual acuity of critical disability studies (Goodley et al., 2021). In concluding, the paper returns to an explicit consideration of the implications of insights for new-materialist theory. Here, a reimagining of the ontological meaning of life, and of matter and abstraction, is possible and unfolds through the new-materialist approach (Barad, 2007; Jamieson, 2016; Kirby, 1997, 2008, 2011; Wilson, 1999, 2004, 2008).

Methods
We take up a critical literature review method, which, according to Jesson and Lacey (2006, 14), offers an “effective, analytical, original assessment of previously published information”. It is an open, exploratory qualitative method capable of accommodating a wide variety of competing views on a given topic (Grant and Booth, 2009). The method requires researchers to critically consider literature with respect to its purpose, context, audience, authenticity, quality, and merit using critical analytical skills (Bowen, 2009). A perceived limitation, however, is that texts are viewed through the researcher’s biased worldview (Grant and Booth, 2009). As such, the specific theoretical lens of new-materialism and critical disability studies has been declared and applied for transparency.

An electronic database search and grey literature search strategy were undertaken using an a priori review protocol. The protocol was based on three sources which were the Joanna Briggs Methods Manual for Scoping Reviews (Peters et al., 2020), the authoritative Arksey and O’Malley (2005) scoping review approach and guidance obtained from a subject librarian to inform the electronic search strategy developed based on the PRESS Checklist (McGowan et al., 2016). The relevant central research question was: how do concepts of new-materialism, disability, death, ageing, senescence, and the life-course present in the literature with reference to one another?

Based on this central question, conceptual categories were identified, and within these, specific search terms and search strings were developed, and combined with database tools like truncation and Boolean operators. Inclusion and exclusion criteria were predefined. A grey literature search was also undertaken to mitigate against publication bias (Rothstein, Sutton, and Borenstein, 2005). Manual hand-searching of journals was excluded. See Table 1 for details of concepts and search strings:
Table 1  Concepts and search strings

<table>
<thead>
<tr>
<th>Concept,</th>
<th>Search strings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disability</td>
<td>disability* OR condition* OR disorder* OR defect* OR impairment* OR illness* OR handicap* OR “learning difficulty” OR “learning disability” OR “intellectual disability” OR “special needs” OR disablement* OR “differently able” OR “special educational needs” OR “mental health problems” OR “mental health concerns” OR disabled* AND</td>
</tr>
<tr>
<td>Life-course</td>
<td>“Life-span” OR “life-course” OR life OR “life cycle” OR “life stage” OR lifetime OR “course of life” AND</td>
</tr>
<tr>
<td>Ageing</td>
<td>Age* OR senescence* AND</td>
</tr>
<tr>
<td>Death</td>
<td>Death OR die* OR mortality OR expiry* AND</td>
</tr>
<tr>
<td>New-materialism</td>
<td>“New materialism” OR “new material” OR “new-materialism” OR “new-material” OR critical disability studies OR material* OR materialism</td>
</tr>
</tbody>
</table>

Searches were conducted over a three-day period using the following databases: Academic Search Complete (ASC), PsycInfo, Applied Social Science Index and Abstracts (ASSIA), Social Science Premium Collection (SSPC), Google Scholar, Pub Med, and Scopus. Ancestral searches were included. Titles and abstracts were scan read, in line with the approach of Jesson, Matheson, and Lacey (2011), which designates that this initial quick reading is a sufficient basis to identify what literature should be kept or discarded. The quality of research-based papers was screened using guidance from Caldwell, Henshaw, and Taylor’s (2011) Research Critique Framework. This entailed checking, where relevant, if papers satisfied several quality indicators such as quantitative studies reporting the sample population, and qualitative studies explaining study design (Caldwell, Henshaw, and Taylor, 2011). A flow chart of the results retrieved is provided in Table 2.

Interobserver agreement or trustworthiness testing was not deemed applicable in the method of this article given that analysis is based on new-materialist theory and is inherently subjective and therefore not amenable to replication. As new-materialism theory is actively enacted and develops in the writing process of the paper, a smaller sample of sources were also drawn in at the write-up stage where required. Overall, a deductive thematic approach was taken to the application of theory (Tjora, 2018). This means that themes based on theoretical conventions were first identified and then applied to the sample of literature (see Figure 1 below).

New-materialist theory unfolds within the rest of this article in line with the existing tradition of new-materialist scholarship, whereby theory is implicit and subtle.
(such as Garland-Thompson, 2011), rather than explicitly structured in such a way as to contradict poststructuralist influences on new-materialism. With the approach of the literature retrieval and analysis now delineated, what remains to be considered, is the theoretical perspective of new-materialism itself, as well as the theoretical field that we have situated around this, known as critical disability studies.

**Theoretical Perspective**

New-materialism, which we locate for our purposes within the wider approach of critical disability studies, constitutes the theoretical perspective of this article. New-materialism, similar to critical disability theory, is often enacted toward arriving at a new understanding of old phenomena (Jamieson, 2016; Minich, 2016; Schalk, 2017). The term “new-materialism” or “neo-materialism” can be traced to pioneering thinkers Rosie Bradiotti (2000) and Manual DeLanda (1996) around the late 1990s (Van der Tuin and Dolphijn, 2012). It arose from theoretical precedents set by intellectuals such as Donna Haraway whose cyborg manifesto built
Table 2  Themes within the analysis process

<table>
<thead>
<tr>
<th>Step 1: Theoretical themes across new materialism and critical disability studies are identified.</th>
<th>Step 2: These themes are deductively applied to the literature with reference to the research question: “how do concepts of new-materialism, disability, death, aging, senescence and the life course present in the literature with reference to one another?” Key segments of text are extracted and recorded under the relevant theme.</th>
<th>Step 3: Themes, under which key text segments or extracts have now been gathered, are combined based on similarity to form overarching themes for write up.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Themes:</strong></td>
<td><strong>Themes:</strong></td>
<td><strong>Themes:</strong></td>
</tr>
<tr>
<td>Global disability perspective (Goodley 2013)</td>
<td>Bodies and matter (Goodley 2013)</td>
<td>Materialism (Goodley 2013)</td>
</tr>
<tr>
<td>Biopolitics and bioethics (Coole &amp; Frost 2010)</td>
<td>Critical disability studies as methodology (Schaik 2017)</td>
<td>Inter- and trans-sectionality (Goodley 2013)</td>
</tr>
<tr>
<td>Natural and human sciences (Coole &amp; Frost 2010)</td>
<td>Critical theory and materialism (Coole &amp; Frost 2010)</td>
<td>Self and other (Goodley 2013)</td>
</tr>
<tr>
<td>Critical view on disability (Shildrick 2012)</td>
<td>Matter as productive and agentic (Coole &amp; Frost 2010)</td>
<td>Influences of post-structuralism, post-conventionalism, and postmodernism (Shildrick 2012)</td>
</tr>
</tbody>
</table>

- **Example of literature under a theme:**
  - Theme 1 – global disability perspective: Senescence related death overwhelmingly constitutes the most common basis of departure from life for populations of the global north and developed countries (Bongaarts 2009)
  - Theme 1 –bodies and matter: Critical disability studies forces new understanding of embodied selfhood (Liddiard et al. 2019)
  - Theme 2 –self and other: Selfhood of people with disabilities tends to be envisioned with direct reference to abled others (Goodley 2016)

- **Overarching Theme 1:** Disability and Senescence
- **Overarching Theme 2:** Beyond Longevity: Theorising Quality of Life
- **Overarching Theme 3:** Social Interdependency and Self

powerful conceptual bridges for ensuing theorists to cross (Haraway, 1991). Vicki Kirby’s (1997, 2008, 2011) work was exemplary of the new-materialist propensity to question the relationship between matter and life. This propensity segues smoothly into a defining strand of new-materialism, and indeed of this paper, namely new-materialist readings of biopolitics and bioethics. The concern here is with how life comes to be evaluated within changing political and ethical parameters (Coole and Frost, 2010).

In this context, Jane Bennett’s (2010) work and Karan Barad’s (2003) contributions have radically recuperated ontological questions about materiality and human agency that progressed new-materialist work around theories of matter. Bennett (2010) and counterparts were among new-materialist thinkers to refine a further strand of new-materialist theory regarding acknowledgement of key theories of
politics. Therein, democracy and citizenship alongside the positioning of corporeal and
carnal bodies in political environments have been transformative for new-materialism
(Coole and Frost, 2010). Meanwhile, critical materialism developed as an integral
dimension of new-materialist thought, which entails a resurgence of critical theory
from ground-breaking sociological and phenomenological theorists, including
Weber, Bourdieu, de Beauvoir, Foucault, Lefebvre, de Certeau, and Merleau-Ponty.
Here, with productive force, critical theory was thrust upon issues of ordinary matter
and everyday corporeal life (Coole and Frost, 2010; Van der Tuin and Dolphjn, 2012).
Finally, multimodal new-materialism offers another example of the heterogeneity of
new-materialism. It ushered in a preoccupation with different modes of activity and
of explanation. This compels theory to be more holistic and accessible, supporting a
social justice imperative (Marshall and Conana, 2021), which arguably ought to be
extensively embedded in disability theory anyway (Beckett and Lawson, 2021).

Another example of ground-breaking new-materialist work is Elizabeth Grosz’s
theorisation (2010, 2021) which helped to progress the notion of dynamic material-
ity in the sense that new-materialists saw matter as dynamic, resilient, changing,
agentic, and productive. Here new-materialists commonly viewed materialisation as
an active process encompassing human relations rather than the eternal passive
recycling of inert, dead matter. This defining feature of new-materialist thought cen-
tred on the directedness, productive, and self-processing resilience of matter (Coole
and Frost, 2010). New-materialists that occupy the critical disability studies space,
are then empowered to bring such perspectives to bear on matters of social justice,
for the disability community and humanity at large (Feely, 2016; Flynn, 2017).
Overall, it is clear that new-materialism is not entirely uncontested. Yet it is a school
of thought that operates within some set parameters that most can agree upon.
Within this, the rejection of arbitrary binaries such as between nature and culture
(Kirby, 1997, 2008, 2011) is one hallmark of the new-materialist position (Jamieson,
2016). Other academic behaviours within the material turn, according to Jamieson
(2016, 110) are “critiquing anthropocentrism, reconsidering the agency or vitality of
the non-human, and addressing knowledge in ontological terms”. In this context,
“the problematization of politics as a distinctly human domain and invention” is also
indicative of, and influential upon, new-materialism (2016, 110).

Finally, there is the matter of diffraction to address. As we provide a new-
materialist reading of literature, we are challenged to go beyond reflexivity and
hierarchal oppositional ordering of ideas and literature, toward diffractive
reading (Barad, 2014). Diffraction did not affect literature selection, but dif-
fractive reading was undertaken by dialogically reading texts through one
another in such a way as to attune to waves of difference across disciplines,
ideas, and corpus of literature, so as to create a difference from our own diffrac-
tive reading (Barad, 2014; Geerts and van der Tuin, 2021; Murris and Bozalek,
2019). Within these processes, diffraction also allows us to view new-materialism
through critical disability studies and vice versa, within their application to the
topic. At the heart of this has been a commitment to read in a different attentive
way and remain critically conscious of difference across literature and also created beyond it (Geert and van der Tuin, 2021), as well as mindful of social justice.

Critical disability studies, alternatively, whilst not the same as new-materialism, is often enacted alongside new-materialism according to Goodley et al. (2019), by scholars such as Flynn (2017) and Feely (2016). It is a transdisciplinary area of scholarship, which often builds strategic allegiances with other schools of thought like postcolonialism and feminism (Flynn, 2017; Goodley, 2013). Whilst its title entails the word “disability”, it does not dwell on disablement alone. Rather it is just as concerned with ableness, as well as ableism which is a form of discrimination that benefits abled people, in addition to considering the meaning of humanity for all human bodies and minds (Campbell, 2008, 2009; Goodley, 2013, 2016). The manner in which disabled people are often compared against abled people is also deemed significant within this, as are the spaces between oneself as a disabled person, and others in the social environment (Goodley, 2013; Shildrick, 2012). Moreover, much of critical disability studies aligns with postmodernist and poststructuralist thinking and allied to this is some rejection of biologically essentialist and hyper-medical ways of understanding disability (Flynn, 2021a; Goodley, 2013, 2016). Finally, encouraging global awareness and re-engaging with the importance of the physical body feature among the imperatives of critical disability studies scholars (Flynn, 2021a; Goodley, 2013, 2016; Shildrick, 2012).

Overall, the theoretical impetus of new-materialism, within critical disability theory, will be used in this paper as a lens to view concepts from the biosciences and elsewhere, toward generating a new understanding of disability, senescence and the end phase of the life-course. It is therefore toward this subject matter, that a theoretically guided rather than an entirely nomadic reading of literature, will now unfold.

Disability and Senescence
It is useful to begin by considering disability and senescence. The starting point is a concern that the way disability is understood alongside physical deterioration with age (also known as senescence), ought to be broadened. As such, the intent is to throw into question bodily orthodoxy, and rather than presenting a definite and confident new understanding of disability and deterioration with age, pursue a more unfettered one. Coole and Frost (2010) designate that new-materialists contest the definitive break between sentient and non-sentient beings, and question the very definition of the human in relation to the non-human. Here new-materialism is critically receptive to the wisdom of natural and human sciences (Barad, 2003; Coole and Frost, 2010).

Bringing this focus into our analysis, within the life sciences the notion of cellular or replicative senescence describes a loss of the cell’s capacity for division and growth (Crews, 2003; McHugh and Gill, 2018; Stinson, Bogin, and O’Rourke, 2012). Alongside other physiological mechanisms such as telomere shortening within human
chromosomes, it is associated with physiological ageing (McHugh and Gill, 2018; Zhiwei and Inuzuka, 2013). As a quality of life, it eventually will cause death in the instance of avoiding fatality by other means such as by having an accident, through predation linked to death arising from predatory attack, homicide, terminal injury, or environmental hazards (Crews, 2003; Zhiwei and Inuzuka, 2013). Physical ageing is complex, however. Many in the anti-ageing field are currently lobbying for ageing to be explicitly classified as a disease to enable the drugs we suspect to delay the process to be re-marketed. This is partly a continuation of a process of profit through pathologisation, but nonetheless presents helpful opportunities (Sinclair and LaPlante, 2019).

Moreover, in line with Braidotti’s work (2013), and new-materialism more broadly, rather than anthropocentrically omitting other non-human organisms from this discussion, it is of interest to note that human life-span restrictions by senescence are not reflected by all other lifeforms (Stinson, Bogin, and O’Rourke, 2012). Indeed new-materialist writing engages strongly with cultural norms, including those that embrace human exceptionalism which places humans above other species, and supports post-anthropocentrism which challenges the idea of human supremacism (Van der Tuin and Dolphijn, 2012). Turning to consider other species, therefore, makes sense across new-materialist lines. Finch’s work (2009) on negligible senescence in turtles and naked mole-rat, for example, was a mark of the possibility that some organisms can live greatly enduring lives, where maturity is not so insistent on mortality. The giant turtle, for instance, is thought to be capable of living beyond 200 years by defying age-related illness. Notwithstanding this, towards a reconceived understanding of senescence, critical disability studies highlight the potential for disability to be particularly germane to how humanity overall is understood in this context (Ellis et al., 2019; Flynn, 2021b; Goodley, 2013, 2016). Where disability most strongly unsettles the idea of senescence, is perhaps through denaturalising it and then politicising it, within a broader politics of life. Here death caused by senescence, rather than being only of biomedical importance, is perhaps also a pressing matter of equality and opportunity.

Nirmala Ervelles (2011) among other scholars, for example, has progressed critical disability studies’ desire to pursue global consciousness and global representation in its scholarship (Goodley, 2013). In the spirit of moving past the self-referentiality of global north disability scholarship, it is of interest to note that death by senescent mortality is not so much a unifying concern for all humankind, then it is a concern of prosperous nations where inhabitants have the opportunity to grow old. Figures indicate, for example, that senescence-related death overwhelmingly constitutes the most common basis of departure from life for populations of the Global North and developed countries (Bongaarts, 2009). Meanwhile, in the Global South, where most disability occurs, among the most common causes of death are non-senescent mortality through infectious or communicable disease, environmental and material conditions, and terminal injury (World Health Organisation, 2019).

Moreover, disabled people living in the UK and Ireland do not appear to have equality of opportunity or outcome with respect to biological ageing and senescent
mortality in the same way as majority population peers. Here the irony of new-materialism is as soon as we begin to consider matter, then we are distanced from it, and instead immersed in the immaterial world of thought (Coole and Frost, 2010). Yet, the very reasons for global inequality in senescent mortality are oftentimes matters of matter. Access to physical medications and risks to life based on physical objects like firearms, ammunition and bombs are examples of material realities that etch away the life-span of disabled people. The behaviour of such matter, nonetheless, remains governed by power-laden factors including geopolitics, policies, biopolitics, and cultural and historical norms. As such, social justice must remain a central consideration.

Alongside this, premature death, poorer standards of health and shorter lives overall in comparison to non-disabled peers, lead to mandatory foreclosures on what should otherwise be lengthy lives for global north disabled people (McCarron, Haigh, and McCallion, 2017; National Health Service, 2020). Moreover, this occurs even though exposure to environmental hazards like large-scale militarised violence or infectious diseases are not a significant problem in these jurisdictions. It would seem, that whilst senescent mortality in the bioscientific literature is considered a condition of life that applies to all people (Crews, 2003; McHugh and Gill, 2018), senescence-related death is somewhat of a privilege for an exclusive few. Worth accenting here, is the nature of senescence-related death as a marker of social inequality. As the purpose of this paper lies in presenting a new-materialist reading of disability, senescence and the end phase of the life-course, it would be remiss to omit the key issue of quality of life. It is towards discussion of this that we will now turn, with a view to further substantiating the sustaining proposition of the paper, that new-materialism and critical disability studies effectively illuminate the relationship between disability, senescence, and the life-course.

**Beyond Longevity: Theorising Quality of Life**

Clearly, it is hard to fathom the value of longevity and life-span extension, without anticipating the need for a meaningful quality of life (Lang and Rupprecht, 2019). Yet, difficult balances must be struck in understanding quality of life as an aspect of the lifestyles of disabled people. Poorer reported health, elevated social exclusion and discrimination, and susceptibility to poverty and socio-economic disadvantage cannot always be watered down (World Health Organisation, 2011), in favour of an affirmative perspective (Swain and French, 2000). Yet whilst this is the case, the misappropriation of disability by automatically conflating it with negativity and misfortune has been highlighted by disability scholars from the academy, arts movements, and activism work, as being unhelpful and at times offensive (French and Swain, 2008; Swain and French, 2000).

In this context, ableism is a form of discriminatory favouritism of abled people and the ideals and practices that privilege abled people (Campbell, 2008, 2009, 2014, 2018; Goodley, 2014). In Maria R. Palacios’ (2017) compelling account entitled “Naming ableism”, one excerpt captures the kind of patronising sympathy that
disabled people can experience which stems from ableist rationality. More specifically, Palacios’ (2017, no page) says, “Ableism is when ‘whole’ is a word reserved for the able-bodied, or when you say that I’m beautiful despite my differences and fail to recognize that I’m beautiful because of them”. The implication is arguably clear. Namely, in determining what quality of life means for the lives of disabled people, an anti-ableist perspective must be taken, within which assumptions about disability are abandoned. Here hardships and loss associated with disability and impairment are not ignored, nor are they assumed to be uncelebrated by disabled people. Concurrently, the joyful, productive and affirmative parts of leading disabled lifestyles, which contribute to quality of life, must also be afforded due attention (French and Swain, 2008; Swain and French, 2000).

With this established, it is useful to turn our attention back towards the sustaining agenda of this article. More specifically, the aim has been to demonstrate the value of new-materialist thinking for understanding disability, senescence and the end of the life-course when the transformative nature of critical disability theory comes into the fray (Shildrick, 2012). Starting with the concept of declarative or explicit memory, it is now well established in fields like medicine, behavioural neuroscience and psychobiology, that memory is not a single mental faculty but rather involves a plurality of memory types, such as implicit (nondeclarative behavioural and habitual memory) and long-term memory (Squire and Dede, 2015). Moreover, several disabilities associated with senescent mortality and ageing also entail memory loss, for example, Alzheimer’s Disease within which working memory and long-term declarative memory are jeopardised early on (Holger, 2013).

For critical disability studies scholars, adults and children with life-limiting conditions can be understood as “theoretical provocateurs” in so much as they can challenge “us to reconsider the meaning of life, death and disability” (Liddiard et al., 2019, 1473). In the case of Alzheimer’s Disease, for instance, dementia is the condition that refers to symptoms such as memory loss associated with the illness. Moreover, dementia is now the leading cause of impairment for older persons (Oliver, 1990, 2013; World Health Organization, 2012). It would appear from a critical disability studies lens, that experiences of dementia may indeed be “theoretically provocative” on a number of accounts, through prompting difficult questions, and forcing new understanding of embodied selfhood, as follows (Liddiard et al., 2019, 1473).

First and foremost, critical disability studies scholar Margit Shildrick has used organ transplantation and heart transplantation to rethink the boundaries of self, and question what a hybridity in one’s self entails (Shildrick, 2015). One premise for this work, is the reported discomfort of organ transplant recipients, with regard to the sense of “otherness” of their received organ, leading to their constitution as a hybrid amalgam of themselves and parts of another. This emotional awareness of the other in their body, is mirrored on a cellular level whereby immunosuppressant drugs must often be prescribed to stop their body’s immune system from attacking the organ which is deemed to be alien
and other (Shildrick, 2015, 2018). In the same way that a critical disability studies lens on organ transplantation troubles otherwise assumed boundaries between self and other, arguably, so can it render problematic the speculative boundaries of self in cases of dementia.

Of particular interest are the questions so often raised by new-materialists, namely where does self end? and where does it begin? (Coole and Frost, 2010). Toward a provisional response, meta-synthesis of qualitative research on the lived experience of dementia highlights the significance of a sense of continuity whilst also living with change. Here, residuals of awareness and memory function are evidently most impactful on people’s experiences (Górska, Forsyth, and Maciver, 2018). Moreover, within this, the imperative of grasping onto and retaining one’s memory as an emblem of self-continuity, is perhaps linked to a drive to hold onto oneself. In this tradition, memories are equated with some constitution of who one is (Conway, 2005). Such a conceptualisation of “self” is a bounded one, in which the self is located within oneself, as a fragile ontological artefact, in some ways constituted by memory that maintains behavioural patterns and habits, and permits reminiscence over former experience (Conway, 2005; Rowlands, 2017).

Along this line of reasoning, once the material body is expended, the self vanishes too. However, the existence of fringe and controversial phenomena like consciousness during cardiac arrest, terminal lucidity and paradoxical lucidity in dementia (see the work of Dr Sam Parnia and the AWARE studies), raises the possibility of a much more complex picture of the end of life. Of interest to question here also are the narratives that emerge within and from surrounding networks of drugs, defibrillators, life support machines, professionals, grieving relations, religious beliefs, and scientific taboos. Also, critical here is the new-materialist question of how biotechnologies interact with biopolitics and bioethics to privilege some lives above others (Coole and Frost, 2010). Medical technologies have developed to support the life function of the body, and therefore self becomes contingent upon the presence of matter in technological form. Biopolitics, and societal and cultural norms then govern who can access these technologies. From a radical new-materialist perspective, therefore, the very notion of self can be interrogated, by demonstrating how it simply cannot be separated from spaces, physical objects (medical technology, clothes, homewares) as well as societal and cultural norms, as self becomes discursively, socially and practically dependent on their presence.

Disability, overall, can provoke alternative possibilities, in which the self is constituted through complex social support infrastructures and social interdependencies. To begin to trace this alternative understanding, however, first we will need to consider the concept of social interdependency, and which is most helpfully undertaken, through a new-materialist frame. In particular, here the purpose of discussing social interdependency and self, is to progress the case being made for new-materialist thinking as offering pathways to learn about disability, senescence and the end phase of the life-course.
Social Interdependency and Self
Disability demands no less than a recognition of the social interdependency upon which all human life is sustained (Caldwell, 2014; Goodley, 2014). In this way, it reshapes interdependency within social exchanges such as personal hygiene support and mobility assistance, as well as forging new cyborg co-dependencies with assistive technology that can transcend the traditionally fettered capacity of the human body (Goodley, 2016; Haraway, 1991). In this reimagined space, selfhood within the memories of a person with dementia, albeit under assault from degenerative illness (Holger, 2013), still endures, partly revived through the memories of others. From here, memories may be recounted in words, envisioned in one’s mind or co-constructed through conversations. Memories may also be re-inscribed into artefacts for use in life story work, music therapy or reminiscence boxes for supporting people with dementia (Kaiser and Elly, 2016).

Moreover, the notion of an “outsourced self” where one’s sense of self is built with the help of others such as through therapies for people with dementia, has implications for the loss of a person through death, or indeed for the sense of an ebbing away of a person’s selfhood from dementia-like degenerative conditions or acquired brain injuries (Górska, Forsyth, and Maciver, 2018; Kaiser and Elly, 2016). Within transformative fields like narratology, for instance, self and identity are believed to be developed through narrating a plot from otherwise disordered and meaningless lived experience, in which the character of the self as a focal protagonist in the life story develops (Bamberg, 2011; Riessman, 1993, 2008). More specifically, it is believed that we tell stories about ourselves and our lives, and these stories create a coherent sense of who we are, from what would otherwise be random, unconnected events in our past experience (Riessman, 1993, 2008).

Yet whilst stories are a resource to us, memory lapses and memory loss in dementia or cognitive impairment toward the end of one’s life entails the loss of capacity to recount experience. It is helpful therefore that narratologists believe that selfhood is something that we co-narrate with others, by co-constructing with others a story of who we are (Bamberg, 2011; Reissman, 2008). Selfhood is therefore both an internal and external condition of the human being. A common concept, however, addressed in critical disability studies is the concept of “self and other”. This concept entails the recognition that there is a tendency for the selfhood of disabled people to be envisioned with direct reference to abled others (Flynn, 2017; Goodley, 2013, 2016). In this way, disabled people are often understood in comparison to abled people, such as by focusing on differences in abilities between both and using this to define what it means to be disabled (Campbell, 2008). Accordingly, it is perhaps important not to fall foul of this tendency and to remain mindful of what is common to all people. Namely, that the answer to the question of who we are, is an answer we do not arrive at alone, but rather with reference to our complex interactions with others.

In this context, controversies such as the Terri Schiavo case, provoke the possibility that our selfhood is both a corporeal artefact (such as being based on our physiological capacity to retrieve memories and express our personality), and socially
outsourced (such as being about how others see us and recognise us). Terri was placed in an irreversible persistent vegetative state following cardiac arrest, which led to years of battling in which her right to die was contested. In the end, Terri’s feeding tube was removed leading to an official pronouncement of death (Caplan, McCarthy, and Sisti 2006; Goodman, 2010). At the crux of the controversy was the contention of some of her loved ones that life-prolonging measures were sustaining Terri’s biological body, whilst the essence of Terri’s selfhood such as her personality and her lifeforce, were deemed to have been dearly departed (Schiavo, 2006). For these loved ones, it was believed that Terri was already gone and that machines were simply keeping her physical body alive. Others saw Terri as a vulnerable individual at serious risk due to other’s attempts to end her life. Such attempts were allegedly couched in the language of ethics whilst denying that “Terri was nothing less than the victim of judicial murder” (Schindler et al., 2006, x). Alternatively, concern that Terri was trapped in endless purgatory bound by liminality between life and death, may have been based on good intentions of compassion and care towards her (Goodman, 2010).

Whatever the case may be, such instances of controversy destabilise the possibility of arriving at a clear, simple explanation of what the self is, including where it begins and ends, as well as the difference between life and death. In the biosciences, death might predominately be considered to be a clear-cut continuous cessation of biological functioning, but a new-materialist perspective would suggest it is not so simple. Indeed, legalities and medical complications around the subjective pronouncement of death has been a longstanding practical problem, with advances in resuscitation permitting the revival of those traditionally diagnosed as “dead” through cardiac arrest, apnoea or enduring loss of consciousness and cognitive function. Most spectacular in this respect, are hundreds of cases, scattered across history, of bodies misdiagnosed as dead thereafter returning to life (Klarsfeld and Revah, 2004; Youngner, Arnold, and Schapiro, 1999).

Overall, new-materialist disability theory helps us to understand more complex meanings of selfhood, life and death. Within this, new-materialism seeks a return to matter within the material turn in disability theory (Tuin, 2011, 271). In keeping with this return, however, is a commitment to not forget the cultural, social, lingual and discursive lines through which disability also occurs (Jamieson, 2016). In this article, the purpose has been to offer new-materialist theoretical commentary on disability, senescence and the end phase of the life-course. It is arguably clear by now that this purpose has been fulfilled, with new-materialism effectively illuminating the various dimensions of this subject matter.

Critical commentary in this article has sought to reflect the diversity of issues represented in the literature under the banner of the research question, “How do concepts of new-materialism, disability, death, ageing, senescence and the life-course present in the literature with reference to one another?” Within this, the varied ways of understanding life-span limitation through disability scholarship in this article, have not been in their own constitution new-materialist, but rather read in a new-materialist
way. Moreover, this way of understanding alludes to complex debates animating the biopolitics of life (Cohen, 2009). Some socio-political activists, for example, criticise the importance placed on biological referents of life-span longevity, by reasserting the history of exclusion and discrimination whereby disabled people have been denied their life-course positioning (such as not being allowed to live independently or have intimate relationships despite reaching adulthood) (Oliver, 1983, 1990, 2013). Alternatively, post-conventional critical disability studies theory renders problematic the traditional lines of demarcation between one person and another, and the end of life from the beginning of death (Shildrick, 2015, 2019). Underpinning much of these debates, thankfully, is the important social justice recognition that human beings, be they identifying as disabled or not, are deserving of dignity and respect.

Finally, scholars within a posthuman disability studies tradition, claim that disabled people have been denied at times their very membership in humanity, and in this context, a priori assumptions and rhetoric about a valuable life for people with life-limiting impairments need to be dismantled and re-addressed. In particular, assumptions that a better life is one that is longer and of more quality (Goodley et al., 2019, 1474), or indeed in the case of dementia scholarship, a life that is remembered (Górska, Forsyth, and Maciver, 2018), are not universally shared by those facing significant life-limitation. In its essence, this speaks to the possibility of another way of understanding senescence and the end of the life-course.

Overall, whilst applying new-materialism has been helpful thus far, a shift in the approach of the paper will now occur in drawing to a close. More specifically, a more explicit new-materialist orientation will help us to consolidate learning thus far, through rejection of simple binaries that have troubled scholarship of the body for some time now (Barad, 2007).

**Discussion: Implications for New-Materialism**

In this article, the manner that disability forces us to reconsider common understanding of senescence and the end of the life-course has been the focus. This was achieved through applying new-materialist thinking, placed within critical disability studies, to understand disability, senescence and the end of the life-course. This approach tells us that simple binaries such as between oneself and others, and between a good life and a bad one, can be as much undermined by the physical biology of the body, as by abstract conceptualisations of it (Shildrick, 2015, 2019). Therefore, toward a new understanding of senescence, disability, and the life-course, biomedical aspects of conditions like dementia have been unapologetically taken up, and moreover, discussed with reference to theoretical perspectives that go against the significant medicalisation of disability (Goodley, 2013, 2016).

This coheres with new-materialist thinkers such as Karen Barad, who appear antidualist and wholly welcoming of the cross-fertilisation of theory by natural and human sciences (Barad, 2003; Coole and Frost, 2010; Tikvah Kissmann and Joost van Loon, 2019). Indeed, the most eminent scholars to influence former materialist philosophy such as Marx, Lacan, Spinoza, Descartes, Freud, and Nietzsche, were
admittedly swayed, and at times outright schooled by natural sciences (Braidotti, 2006; Coole and Frost, 2010; Grosz, 2021). New-materialist pioneer Rosi Braidotti describes these thinkers as “continental” and oftentimes producing work that is productively refigured toward the later rethinking of matter (Braidotti, 2000). No doubt, many of these theorists were also productive in the setting up of their own rendition of a corporeal, carnal and bodily new-materialism (Braidotti, 2006), as were they instrumental for other new-materialists such as Elizabeth Grosz (Grosz, 2021), and toward the post-millennium development of new-materialism itself (Coole and Frost, 2010; Grosz, 2021).

The key point is that new-materialists have been engaged closely with the human sciences. Here biopolitics and biopower form core strands of new-materialism (Coole and Frost, 2010). Yet, there is an inherent problem when it comes to applying this to disability theory. Disability studies activists, theorists and allies have been generally clear, that a traditional medical model is outdated, and at times insulting. This has led to a lack of engagement with, and even dogmatic rejections of, literature and research from the human sciences (Shakespeare, 2014; Shildrick, 2019). This intellectual ambience is arguably unsophisticated and offers a destructive undertone to contemporary disability studies theory. New-materialists understand that the manner in which humans interact with matter and materialization, is contingent upon cultural norms (Coole and Frost, 2010). As such, the right culture must be fostered within disability studies so that a refocus on material objects can happen, to conceptualise material objects that have the most significant social justice implications, from life support machines, to assisted suicide drugs, to resuscitation equipment. This is necessary to engage with the kind of matter that matters most for social justice, including the very corporeal reality of impairment. Here a principled disengagement with medical research and literature will only serve to cut disability studies theory off from cutting-edge medical discoveries and advancements, that ought to be critically theorised.

In this context, the gravity of contesting binaries should not be underestimated. New-materialists and critical disability studies theorists hold a shared desire to deconstruct binaries and interrogate singular systems of understanding. We argue that ultimately this is necessary for social justice. Our concern follows Beckett and Lawson (2021, 5), in proposing that we ought to “maximise the potential of research to enhance social justice for disabled people”. For social justice, we must destroy the remaining residuals of outdated brute binaries such as between materialism and constructivism, medical and social views, and disability and impairment (Shildrick, 2019). This will create conditions of possibility for convergent space between approaches like new-materialism and critical disability studies, and with such newfound convergence, will come new social justice possibilities. This includes reimagining notions of self-directed support, independent living services, palliative care and assisted suicide mechanisms, infused by recognition of the significance of disability as a way to interrogate and debate such topics. We suggest therefore, that by breaking down binaries and singular systems of reasoning, space is opened up for
better cross-fertilisation of fields of scholarship such as critical disability studies and new-materialism. This then enables a more holistic and informed approach to the most complex and emotionally laden issues across human life.

Overall, this article has been concerned with disability, senescence and the life-course, and indeed it is arguably now conclusive that new-materialist rationality can illuminate the consequence of these for social justice, among other pressing agendas. Yet there remains more to new-materialism that could ever be engaged with here. New-materialists are concerned with biology and ecology, as well as medicine and technology. Within this, new-materialists question how physical bodies interact with digitally advancing worlds, including biotechnologies like resuscitation and life support machines, that have a stake in the choice of which lives longer than others (Coole and Frost, 2010). In this context, the thrust of theoretical discussion has been to stimulate conversation and debate, but never to exhaustively address the myriad of ideas, trends and topics that exist within the broad base of literature on disability, senescence and new-materialism.

There are many ways that disability productively disrupts common understandings of life (Liddiard et al., 2019). Perhaps what new-materialism adds to this, is the possibility of an entangled ontological whole encapsulating all of this and more. Here the potential for a singular system of understanding to be capable of explaining the ontology of life, in the context of the end of the life-course, is debatable. What is certainly clear, is that new-materialism and critical disability studies as pathways toward new understanding, continue to be disruptive, and immensely required.

Conclusion

The aim of this article was to provide a new-materialist theoretical commentary on disability, senescence, and the end phase of the life-course. Critical literature review, based on an a priori protocol and electronic database search strategy, as well as deductive theoretical analysis were the methods employed. Within theoretical commentary, the disruptive reimagination of the meaning of life has been furthered through a critical disability studies approach. Notwithstanding the value of this, some limitations remain with respect to our work. Despite our transparency around a rigorous approach to researching literature and our efforts to represent all key aspects of the topic, further detail on the topic was necessary to omit, as was a more in-depth application of theory. Therefore, we suggest that future directions for research might include a more comprehensive account of disability, senescence and the life-course.

Disability, for some time now, has begun to move away from a niche identity that is deemed to be of only marginal interest beyond a defined set of disabled people and their allies (Goodley, 2016; Shildrick, 2012). Rather, disability is a phenomenon that touches everybody’s lives and yields a new understanding of the contested nature of the human, albeit to varying extents (Davis, 2002; Goodley, 2016). In looking to the future, questions of the meaning of life continue to weigh heavy in the hearts and minds of people, regardless of their identification with disability or not.
Therefore, the stakes are high, and this is why analyses such as this must proceed, not just for the sake of provoking new reflection and stimulating debates, but also as a continued moral and ethical imperative.

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CONFLICTS OF INTEREST
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