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Résumé de l'article

Le vieillissement et le handicap sont souvent confondus en théorie et en pratique lorsque la vieillesse est considérée comme synonyme de déclin physique et cognitif. Mais des politiques, des cadres de plaidoyer et des mouvements distincts ont également conduit à l'exclusion et à la discrimination des personnes âgées handicapées, alors que les personnes âgées se voient offrir des services moins nombreux et de moindre qualité. Dans les deux cas, les stéréotypes persistants sur les capacités des personnes âgées conduisent à la conclusion qu'il n'y a pas grand-chose à faire pour aider les personnes âgées et les intégrer dans la vie de leurs communautés. Le droit international reflète également les préjugés liés à l'âge car il est au moins en partie basé sur un modèle médical qui accepte les handicaps de la vieillesse comme naturelles et inévitables quand ils surviennent pendant la vieillesse. Cet article plaide en faveur d'une approche du vieillissement fondée sur les droits et soutient que l'intersection entre la vieillesse et le handicap mérite d'être davantage prise en compte par le droit et la pratique internationale des droits de l'homme.

Old age and disability: Same or different for the purposes of human rights law?

Vieillesse et handicap : identiques ou différents aux fins du cadre international relatif aux droits de l'homme ?

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Abstract: Ageing and disability are often conflated in theory and practice when old age is seen as synonym to physical and cognitive decline. But distinct policies, advocacy frames and movements have also led to the exclusion and discrimination of older people with disabilities, when older people are offered fewer and poorer services. In both cases, persistent stereotypes about older people's abilities lead to the conclusion that there is not much that can be done to assist older people and to integrate them in the life of their communities. International human rights law also reflects age biases as it is at least partly based on a medical model that accepts old age impairments as natural and inevitable. This paper makes the case for a rights-based approach to ageing and argues that the intersection between old age and disability merits further consideration by international human rights law and practice.

Keywords: Human rights; Ageism; Ageing; Equality; Disability; UNCRPD

Résumé : Le vieillissement et le handicap sont souvent confondus en théorie et en pratique lorsque la vieillesse est considérée comme synonyme de déclin physique et cognitif. Mais des politiques, des cadres de plaidoyer et des mouvements distincts ont également conduit à l'exclusion et à la discrimination des personnes âgées handicapées, alors que les personnes âgées se voient offrir des services moins nombreux et de moindre qualité. Dans les deux cas, les stéréotypes persistants sur les capacités des personnes âgées conduisent à la conclusion qu'il n'y a pas grand-chose à faire pour aider les personnes âgées et les intégrer dans la vie de leurs communautés. Le droit international reflète également les préjugés liés à l'âge car il est au moins en partie basé sur un modèle médical qui accepte les handicaps de la vieillesse comme naturelles et inévitables quand ils surviennent pendant la vieillesse. Cet article plaide en faveur d'une approche du vieillissement fondée sur les droits et soutient que l'intersection entre la vieillesse et le handicap mérite d'être davantage prise en compte par le droit et la pratique internationaux des droits de l'homme.

Mots-clés : Droits de l'homme ; âgisme ; vieillissement ; égalité ; handicap ; CNUDPH

Introduction

Whereas disability is widely seen as a human rights issue, only recently did a human rights approach start to emerge within old age advocacy. Nevertheless, old age and disability are factors that, separated or combined, can make a person vulnerable to a range of human rights violations (United Nations, 2012a). Both groups may experience disadvantage as a result of their impairment and they share human rights concerns, such as independent living, accessibility and access to health (Schulmann et al., 2017). They are also subject to the same stereotypes of being economically unproductive, a burden on the welfare state, dependent and objects of pity and care, rather than active agents or citizens with equal rights (Zarb & Oliver, 1993; Priestley, 2000; Boyle, 2008; Flynn, 2016). Both older persons and people with disabilities have been excluded, silenced and isolated (Bickenbach, 2017). But whereas the UN Convention on the Rights of Persons with Disabilities (CRPD) has been developed in order to protect persons with disabilities from human rights breaches, demographic ageing has human rights implications that have not yet been adequately addressed by existing instruments (United Nations, 2022). This paper showcases that ageism poses specific barriers for people with disabilities and argues that the intersection between old age and disability merits further consideration by international human rights law and practice.

Definitions and scope of the paper

The term *older people with disabilities* refers to adults who are faced with impairments and functional limitations for the first time when they reach old age. On the other hand, *ageing people with disabilities* (Garabagiu, 2009) are individuals who age with a disability they acquired at a younger age and who may face significant and similar challenges when they attain the old age threshold. This paper focuses on the former group, as it is written based on experiential knowledge gained through working for AGE Platform Europe, an EU-wide network representing older persons. The paper is primarily interested in capturing the realities and challenges of those individuals that face the risk of been labelled merely as ‘old’ or ‘elderly’ (and not disabled) and therefore are less likely to be the target of disability policies and related legal measures. In addition, older persons with support needs or functional limitations are also less likely to identify themselves as people with disabilities and therefore not seek protection under the CRPD. This group – as mentioned by the UN Special Rapporteur on the rights of persons with disabilities – frequently falls through the cracks (United Nations, 2019).



The conflation of ageing and disability in theory and practice

The experiences of older people with disabilities are often overlooked in theory and practice because disability is seen as intrinsic to the process of ageing (Boyle, 2008). Older age is often constructed as being equal to chronic illness, impairment and limited legal capacity (Law Commission of Ontario, 2011; Harpur, 2015). As a result, disability and ageing can be conflated for law and policy purposes. It has for instance been argued that *'deteriorating biological and psychosocial function therefore render older people particularly vulnerable to the loss of independence, dignity and privacy that may see them struggle to maintain their home, family relations, self-worth and identity later in life'* (Love & Lynch, 2018). Chinsung Chung, who was mandated by the UN Human Rights Council to draft a report on old age rights limited older people's vulnerability in armed conflict to aspects of physical mobility (Chung, 2010). Even in discussions around a new convention for older people, it has been argued that the mere application of disability rights may provide sufficient protection for older people (European Union, 2011). But such views that reduce old age inequalities to those associated with the physiological process of loss of functional abilities are theoretically and pragmatically unsatisfying.

First, '[a]ge alone cannot be used as a proxy for illness, risk or dependency' (United Nations, 2012b). Older people are a heterogeneous group. As Lloyd Sherlock notes *'some older people have high levels of vulnerability and dependence, others may be making more social and economic contributions than at any previous time in their lives and the great majority are both dependent and depended upon'* (Sherlock, 2013). Although the prevalence of disability increases with age, most older people do not have disabilities (Grammenos, 2013; United Nations, 2017). An increasing portion of the older population is living in good health, is not requiring financial assistance, and is even supporting younger generations (United Nations, 1995). A distinction must therefore be made between third age, which includes people who are physically and mentally fit to remain socially engaged and independent, and fourth age, which includes the very old, demented and frail (Laslett, 1996; Phillipson, 2013; Kesby, 2017). Although, sometimes all older persons beyond retirement are portrayed as dependent or frail¹, it is mainly in the construction of the fourth age that human rights issues surrounding disability and older age are more likely to overlap. Moreover, looking into old age only through the lens of impairment might be perceived as sustaining a medical model of ageing.

Second, even though we cannot ignore the biological process of ageing, which includes an increased likelihood of disability, inequality in older age is not the mere result of ill health and impairment (Harpur, 2011; Fredvang & Biggs, 2012; Kesby, 2017; Fundamental Rights Agency, 2018). Age categories are largely used by society as proxies for incapacity and a way to determine access to opportunities, rights, benefits and responsibilities.

¹ See for example 'dependency ratios' that take into account merely chronological factors to distinguish between active and inactive population.

Those who are perceived to be old are marginalized and lose power, they are subjected to violence (such as elder abuse) and to exploitation and cultural imperialism. They suffer inequalities in distributions of authority, status, and money, and these inequalities are seen to be natural, and thus beyond dispute (Calasanti et al., 2006).

Whereas disability was constructed as an exception to the idealised independent adulthood life course, for older people, dependency is predictable and thus part of the norm. Old age disabilities are therefore not seen as the result of social constructs, but as 'natural' or 'inevitable'. Older people are therefore disadvantaged not just because they are more likely to be disabled, but because stereotypes of older people as a burden, dependent, unproductive, inevitably senile, undeserving or helpless, structure society and undermine their dignity (Zbyszewska, 2015). This is what gerontologists call structured dependency, meaning that dependency in older age is not natural or inevitable but the result of social, cultural and economic structures (Townsend, 2006; Kesby, 2017).

"I would not necessarily say an older person had a disability if they have got age related hearing loss. I would say well that's something that happens with age. It is like your hair going grey" (Priestley & Rabiee, 2001).

Different standards and treatment for old age and disability

The result of viewing old age disability as distinct to disability in adulthood, is the fragmentation of policies for people with disabilities of working age and older people². Under this spectrum older people may appear as less deserving of support to live independently or remain included in the community. At an institutional level in many countries, old age and disability are treated by completely separate administrations, without any coordination between the two³. In some cases, it is the law that establishes differential treatment for older people, for example imposing age limits in access to disability benefits, mobility allowances or personal assistance. Limited resources compound the situation and may be used as an excuse not to extend the same level of protection to older people with disabilities (Jönson & Larsson, 2009). Moreover, older people with disabilities are faced with lower quality or fewer options of services,

² For example, several policy reports or initiatives deal separately with long-term care in old age, see for example: European Commission, Directorate-General for Employment, Social Affairs and Inclusion. (2014). Adequate social protection for long-term care needs in an ageing society & European Commission. (2013). A Good Life in Old Age?: Monitoring and Improving Quality in Long-term Care.

³ See Salvador-Carulla L. et al. (2009). *The Barcelona declaration on bridging knowledge in long-term care and support* stating that: 'bridges across the fields of disabilities and ageing have been limited, and they coexist with significant barriers to communication and information sharing'. This may also explain the limited attention to older people in state reporting. On this see also the above-mentioned report of the United Nations. (2019). Report of the Special Rapporteur on the rights of persons with disabilities, General Assembly.



different levels of support and abusive practices, such as delayed, refused, inadequate or undignified treatment (Equality and Human Rights Commission, 2011; World Health Organization, 2011; United Nations, 2012b)⁴. Many older persons with disabilities lack access to preventive healthcare and affordable rehabilitation services, which take into account their specific needs. This is often linked to the fact that disability policies focus on preventing disabilities in working life⁵. In addition, senior workers may lack a right to reasonable accommodation and be required to retire on the basis of assumptions of their ability to work beyond retirement age⁶.

The former UN Special Rapporteur on the rights of persons with disabilities stressed that the 'intersection between older age and disability results in both aggravated forms of discrimination and specific human rights violations against older persons with disabilities' (United Nations, 2019). She has also identified several human rights challenges affecting older persons with disabilities, including stigma and stereotypes; direct and indirect discrimination; denial of autonomy and legal capacity; institutionalization and lack of community support; violence and abuse; and lack of adequate social protection.

A concrete example of the application of different standards on older persons with disabilities is the fact that under human rights law, older people's right to receive support and live in the community is not guaranteed on an equal basis with others, but only for 'as long as possible' (United Nations, 1991; Council of Europe, 1996, 2014; United Nations, 1995, 2002). This framing looks at individual vulnerabilities, instead of the vulnerabilities of our systems, that make unequal treatment in old age permissible or even the norm. Persistent stereotypes about older people's abilities may lead to the conclusion that there is not much that can be done to assist older people and to integrate them in the life of their communities. Instead, we need to look at the circumstances that no longer make it possible to live at home, such as the range or quality of services, to identify societal barriers and perceptions that create limitations, because we can all contribute and prosper in an enabling environment and with adequate support. Unless we change once and for all the way we frame our responses to ageing, violations will continue.

⁴ Also, European Network of National Human Rights Institutions. (2017). Human Rights of Older Persons and Long-Term Care Project: The Application of International Human Rights Standards to Older Persons in Long-Term Care, arguing that there is no automatic right to receive long-term care services, nor to choose the provider or care setting. Recipients of long-term care are not automatically entitled to immediate treatment or healthcare if they require it - they only have the right to the same equal access to available services, which may mean being placed on a waiting list.

⁵ For example, according to the EU Disability Strategy the EU aims to support policies that reduce the risk of developing disabilities during working life -to date- it has paid limited attention to preventing and tackling disability in old age. Moreover, according to the thematic study of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health (United Nations, 2011a), older people are faced with '*several specific concerns, including the lack of adequate prevention and management of chronic illnesses and disability among older persons. Overall, age-based discrimination is cited as a significant barrier to accessing health care that compromises meaningful communication between patients and medical personnel, with consequences for the accuracy of diagnosis and quality of treatment*'.

⁶ The EU Employment Framework Directive gives a right to reasonable accommodation only on the basis of disability.

Separate movements and advocacy frames

Another issue which compounds the equal application of disability rights in old age is the fact that organisations of older people represent people with varying abilities and do not necessarily identify themselves as Disabled People's Organisations (DPOs) (United Nations, 2019). Moreover, historically and strategically some organisations may wish to distinguish old age from illness, frailty and disability. This approach may relate to national discourse about maintaining positive old age identities, but also to the division of power between disability and ageing policies and administration. For others, disability in old age may be seen as the norm, which on a positive note is associated with less stigmatisation, but on the negative side, may lead to collective inaction to address challenges related to disability. Either way, it can be argued that for older people's groups old age disability is not a distinct identity, which poses barriers in advocating on the sole basis of disability discrimination. As a result, organisations of older people have limited understanding of the opportunities to use the CRPD as an advocacy frame and are rarely consulted in the development and implementation of disability policies (Priestley, 2001; Garabagiu, 2009).

Moreover, organisations of people with disabilities rarely include in their membership older people who acquire disability late in their lives and therefore are not well placed to address their specific barriers in their advocacy (Priestley, 2003). Whereas some isolated cases bringing the two movements together can be noted, further action is needed to raise awareness among old age advocates about the usefulness of the CRPD and among disability organisations about the need to involve older people's groups. In addition, Member States need to be encouraged to include older people's organisations in consultations and national monitoring mechanisms, as well as to address older people in their reports.

The limits of the CRPD in addressing old age inequalities

The CRPD has helped shed a light on disability discrimination and ableism; but as already explained above, later life inequalities are not exclusively related to the existence or perception of declining abilities. Ageism, meaning prejudice, stereotypes, and discrimination on the basis of age, cuts across and reinforces other forms of oppressions, but there is little acknowledgement of how it interacts with disability (Zarb & Oliver, 1993).

The CRPD has enshrined protection for two forms of intersectional discrimination affecting women and children with disabilities. Although the link between older persons and persons with disabilities has been underlined by the CRPD Committee (United Nations, 2013), the OHCHR (United Nations, 2012a, 2012b), the UN Special Rapporteur on the Rights of Persons with Disabilities (United Nations, 2019), the Independent Expert on the Enjoyment of all Human Rights by Older Persons (United Nations, 2015), and the UN



Secretary General (United Nations, 2011b) among others, no substantive provision acknowledges the situation of older people with disabilities as a type of intersectional discrimination. It thus remains unclear from a legal, policy and advocacy perspective whether old age is just an additional characteristic that compounds the disadvantages linked with disability, or whether there are specific challenges due to the combination of old age and disability, constituting thus a unique vulnerable situation that needs to be recognised as a distinct barrier to the realisation of rights.

Moreover, older people's discrimination takes various forms that is not necessarily related to disability. They are subject to mandatory retirement because their disengagement from society is seen as natural or inevitable and regardless of their abilities or wish to continue working (Sargeant, 2004; Fredvang & Biggs, 2012). Precisely because they are approaching retirement age, they are less likely to benefit from initiatives aiming to harness their potential, such as training (AGE Platform Europe, 2016). Because ill health is seen as a symptom of older age instead of as a medical condition that merits treatment, older people are excluded from preventive screening, from surgical treatment and organ transplantation (Thompson, 2005; AGE Platform Europe et al., 2017). Ageism also leads to the wide use of restrictive and abusive practices in care settings (Phelan, 2008). In some cultures, the discounting of older people may even lead to direct killing and other death hastening practices (Chung, 2010; HelpAge Kenya & HelpAge International, 2009; NHS Greater Glasgow and Clyde, n.d.).

Age discrimination is not explicitly prohibited under international law and is generally subject to several exceptions and justifications (United Nations, 1995, 2009; Human Rights Committee, 1997, 1998, 1999a, 1999b). The absence of clarity as to what is a justified limitation to age equality, renders treaty bodies responsible to rule which situations should be prohibited and which can be allowed. Unfortunately, the CRPD Committee has not yet dealt with cases of combined discrimination on the basis of age and disability and therefore has not provided guidance as to how the rights of older people with disabilities can be applied and claimed in practice. Furthermore, lacking an old age perspective in the CRPD implementation, results in the parallel existence of competing paradigms, such as those of dependency and institutionalisation, which – as mentioned earlier - are widespread in policy and human rights documents on ageing (United Nations, 2012a; United Nations, 2015).

Challenges in equally addressing ageism in human rights practice

There are two factors that makes it relatively difficult to accept old age as an equally valid and severe form of oppression. First, unlike women and people with disabilities, historically older people were not oppressed but rather valued by societies. It is indeed the welfare state that shifted societal attitudes to stigmatising old age (Phillipson, 2013). Older people are therefore sometimes seen as relatively privileged, wealthy individuals that accumulate power and have increased opportunities for growth and self-fulfilment (Vincent, 2003; Mégret, 2011; Kesby, 2017). Many older people are active contributors to their



society and with adequate support they are able to remain independent, productive and achieve personal growth. More than half of the global population over 60 are still economically active (Petrušić et al., 2015). Besides, a large number of older people contribute in the informal sector, in particular, as volunteers and caregivers (Ehlers et al., 2011). In addition, in some societies ageing is associated with increased social status (Vincent, 2003; Law Commission of Ontario, 2011). So, there is a tension in law, policy and scholarship between seeing older people as active and autonomous on the one hand and as frail and vulnerable on the other (Mégret, 2011; Fineman, 2012; Kesby, 2017). Both these models are deficient since they do not celebrate older people as truly equals and as subjects of rights. They perpetuate the separation between aged and non-aged individuals and view ageing as a problem (Fredvang & Biggs, 2012; Mikołajczyk, 2015, NHS Greater Glasgow and Clyde, n.d.).

This tension is exemplified in EU policy and discourse. On the one hand, the EU has gradually shifted its approach and has recognized the opportunities of an ageing population and the importance of intergenerational solidarity and of active and healthy ageing. But they have not done so unambiguously or in a consistent way. In practice, the competing paradigm of ageing as a problem is still prevailing. During the pandemic older people have been stigmatized as homogeneously vulnerable and in need of protection. But also, the recent Green Paper on Ageing has as its departure point the idea that an ageing population is a challenge for economies and for future generations (European Commission, 2021). This framing is highly problematic and stands in stark contrast with the recent Council Conclusions, which called for a rights-based approach to ageing (Council of the European Union, 2020, 2021).

Second, ageism operates at an unconscious level and rarely reflects an intention to harm (Mikołajczyk, 2015; Ayalon & Tesch-Römer, 2018). It is also deeply rooted in popular thinking, policies, laws, institutions, attitudes and beliefs. As a result, age-based differentiations are not only used widely, but also considered necessary and unproblematic. Consequently, abuses against older people are not always adequately monitored nor categorised as human rights violations.

The pandemic has rendered more visible that our society often treats older people as second-class citizens, or as 'expendable'. Whereas we would consider discriminatory to impose confinement on the basis of race, or to deny people necessary health treatment because of their gender, such practices, largely applied during the pandemic, are still considered acceptable and not against the law. Ageism does not only drive such practices; it also obscures our collective ability to perceive such measures as unjust and as a violation of human rights. The biggest inequality suffered by older people is therefore the fact that their unequal suffering is not seen as a form of discrimination for the purposes of law, policy and public opinion.

Additionally, since older people internalise ageist stereotypes, they are also less likely to seek protection and redress in case of abuse. The denial of the human rights dimension of disadvantages faced by the older population



exhibits why there is a need to pay close attention to older age as an oppression that intersects with other forms of inequalities, including disability.

Conclusions and recommendations

This paper has exposed some of the unique challenges faced by older people with disabilities in the equal enjoyment of their human rights. The analysis has also provided evidence that – despite the growing attention of the human rights community to older age - international human rights law is at least partly based on a medical model that accepts old age impairments as natural and inevitable (United Nations, 2019). This approach legitimises the use of older age as a criterion to deny or restrict rights. Insofar as this happens, human rights protection will merely aim to compensate for the inevitable decline. If on the other hand, it recognizes the structural barriers that are the root cause of inequality, it will be geared towards eliminating those.

As mentioned by the UN Special Rapporteur on the rights of persons with disabilities in her landmark report on older persons with disabilities,

The effective application of a rights-based approach at the intersection between older age and disability needs to be accompanied by a paradigm shift with respect to society's perception of ageing and older persons. While impairment might be a normal aspect of ageing that should be embraced as part of human diversity, discrimination and social exclusion are not (United Nations, 2019).

To address these issues, there is a need to both take action to ensure an equal application of disability rights through the CRPD across the lifecourse and to fight ageist norms through improved legal and policy measures and public awareness.

Although drafted with a consciousness of demographic ageing - the implementation of the CRPD has not been contextualised within the context of old age. Instead, it has focused on issues affecting those of working age and below. Despite ongoing attempts to integrate a lifecourse approach in the disability framework⁷, the co-existence of ageing standards that sometimes are in sharp contrast with the CRPD (United Nations, 2019), renders difficult the application of norms at the intersection of ageing and disability. There is a need to recognize the systemic, multifaceted, structural discrimination faced by older people with disabilities, which is driven by the combination of ableism and a distinct form of oppression, that of ageism. But whereas prejudice on the basis of race, sex, gender and disability are subject to explicit human rights

⁷ For example, the CRPD Committee has clarified that older age is a potential ground for multiple and intersecting forms of discrimination and, in its general comment No. 6. (2018a) on equality and non-discrimination, further recommended that States adopt specific measures for older persons with disabilities.

obligations for States to take steps to eliminate them, this is not the case for ageism and needs to be rectified.

The CRPD is not well-equipped to address ageism. It lacks the specificity and ambition needed to inspire a new conception of the lifecourse, to fight assumptions about individual capacity based on chronological age and to trigger a new kind of ageing policies. There are steps that can be taken to raise awareness of the relevance of the CRPD among older people's advocates with a view to increasing their participation in monitoring its implementation as well as to provide legal clarity and policy guidance for duty bearers, human rights practitioners and self-advocates. But the CRPD was never intended to promote an anti-ageist agenda, so it is not surprising that it falls short in addressing old age-related oppression and disadvantage.

Mainstreaming the rights of older persons with disabilities in the CRPD⁸ (and in other human rights treaties) can only take place if there is clear positive obligation, including a duty to monitor violations against older persons and a duty to eradicate them. A new UN convention aiming to increase visibility of and eliminate all forms of ageism that drive human rights violations in old age will provide a much needed legal and moral compass to challenge all those practices that keep us from living fairly and freely as equals when we are older. On the basis of such a treaty, human rights bodies can also develop general comments as concrete guidance of how other human rights provisions can be interpreted from an ageing perspective. A UN convention on human rights in older age would then serve the threefold objective of increasing accountability on older persons' human rights; providing legally binding standards by expanding CRPD provisions from the experience of old age; and developing norms for the consistent implementation of disability rights across the lifecourse. A new instrument would include a clear prohibition of age discrimination in all aspects of life and in doing so it would drive legal change and incite public awareness that is necessary to combat ageism.

In parallel, the implementation of the CRPD can be improved in the following ways in order to incorporate the experience of acquiring disability in older age.

- Make sure that older people with disabilities and their representative organisations are regularly consulted in the development of disability law and policies at national, regional and international levels⁹,
- Collect comparable age-disaggregated data on the situation of older persons with disabilities across various spheres of life,
- Provide trainings about the relevance of the CRPD for older persons with disabilities both for civil society and government actors,
- Integrate in the CRPD reporting guidelines an obligation to consider older people/older age in order to improve monitoring,

⁸ The UN Special Rapporteur mentioned the following recommendation: 'Mainstream the rights of older persons with disabilities into all disability and ageing-related policies and programmes in order to ensure that the concerns and needs of older persons with disabilities are adequately addressed'.

⁹ The CRPD Committee recognized the obligation of States to consult with groups at risk of intersecting forms of discrimination, including older persons, in its general comment No. 7. (2018b).



- Include experts and/or self-advocates on the intersection of ageing and disability in the work of the CRPD Committee.



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