

At the Fringes of Pride Politics

Experiences of Bisexual and Chronically Ill
LGBTQ+ People in Portugal

ABSTRACT

This paper draws attention to the tensions generated within LGBTQ+ movements in Portugal. Although recent legal developments have put Portugal on the map as a European country welcoming LGBTQ+ people, on a local scale, movements have been less ready to expand their notions of inclusion within the LGBTQ+ spectrum.

Drawing on two studies carried out through twenty qualitative interviews between 2017 and 2020, the authors focus on the tensions that emerge in the narratives of two groups of people: bisexual activists and chronically ill people who also identify as LGBTQ+. Both studies explore to what extent practices of exclusion are at play in Pride politics in Portugal and what forms of (in)visibility are privileged over others. The analysis uses the concepts of middle ground (Hemmings 2002) and boundary work (Egner 2017) to show how Pride politics are often oriented towards a normative definition of able-bodied, white gay and lesbian people. They also tend to exclude from public space some intersectional subjectivities, through active opposition or indirect discrimination. The paper offers a relevant perspective to reflect on the tensions generated by public action within LGBTQ+ communities, compromises between care and belonging, and the future advancements that will need to be made.

Keywords: bisexuality, illness, disability, Portugal, activism

THIS ARTICLE INTERROGATES the forms of visibility and the dynamics of inclusion within LGBTQ+ movements in Portugal, with a specific focus on the cases of bisexual people and people with chronic illness who identify as LGBTQ+.

The history of Portugal in the twentieth century is characterised by political foundations on a colonial and fascist matrix: the longest dictatorship in Europe (1936–1974) caused decades of political and social repression (Vale de Almeida 2010). However, in recent years, Portugal has positioned itself as one of the most progressive countries when it comes to legal and legislative issues regarding LGBTQ+ rights: in particular, rights that foster equality and non-discrimination principles have been granted through legislative advances on partnering, parenting, and gender identity recognition (Santos 2018; ILGA Europe 2020). Such achievements have been made possible through a combination of national and international factors.

The LGBTQ+ movements' ability to establish alliances with other socio-political struggle movements, such as women's right to abortion, and the international pressure exerted on Portugal as the country joined the European Union and its political project, created a fertile terrain for Portugal to affirm universal recognition of sexual and reproductive rights (Santos 2013). The demands of the LGBTQ+ movements have been met favourably by subsequent governments that have implemented effective measures, such as the recent National Strategy for Equality and Non-Discrimination (2018–2030) and the action plan Portugal +Iguar (*Portugal More Equal*).

Despite legal and socio-cultural changes, however, recent studies show that the values, attitudes and behaviours of Portuguese society towards sexual diversity continue to reproduce cisheteronormativity, and there have been continued reports of violence and discrimination based on sexual orientation, gender identity and expression (ILGA Portugal 2019; OECD 2019; Rede exaequo 2020). In 2020, the European LGBT Survey (FRA 2020) showed that LGBTQ+ people are still victims of violence in public spaces (26 percent of respondents), at school/university (26 percent) and in the workplace (22 percent). More than

half of the surveyed (54 percent) reported having been teased, insulted or threatened because of their LGBTQ+ identity.

Since the emergence of the first political organisations after the Democratic revolution (1974), the LGBTQ+ movements in Portugal have followed, sometimes anticipated, the changes in the political sphere. The very first LGBTQ+ Pride Party (*Arraial Pride*) took place in 1997 and the first Pride march was organized in Lisbon the year after. In the decade that followed, several informal groups and organisations emerged, both on local and national level, reflecting increased dialogue between social movements and political forces devoted to stimulating legislative change rather than creating ruptures in society. This configuration, called “syncretic activism” by Santos (2013), provided a long period of stability within LGBTQ+ movements and created the basis for a proliferation of smaller organisations, in particular in peripheral towns and the interior regions. In the last few years, Pride marches and LGBTQ+ events have been organised in the principal cities as well as in interior towns and the islands of Madeira and Azores.

Nowadays, the LGBTQ+ movements in Portugal are facing changes that challenge the practices of activism and point to new directions that need to be taken into account (Santos 2023). The illusory state of comfort created by the significant legislative changes may have encouraged the emergence of homonormative tendencies within the movements which render experiences that deviate from that of the white, able-bodied, binary subject invisible (Oliveira et al. 2013). The intersectional push that reflects a global turn in LGBTQ+ movements is also creating a growing demand for incorporation of new instances into the LGBTQ+ struggle: asexuality, non-binarism, the voices of migrant and racialised subjects.

The need for critical interrogation of forms of invisibilisation within the LGBTQ+ spectrum and of practices of exclusion in activism is the point of departure in this article, which explores the narratives of bisexual and chronically ill people in LGBTQ+ activism in Portugal. Based on two empirical studies conducted in Portugal between 2017 and 2020, this article aims to reflect on the tensions and mechanisms of exclu-

sion within Pride politics; in particular, it focuses on how dominant discourses within LGBTQ+ activism privilege some forms of visibility and marginalise others. The first study exposes some of the challenges that bisexual activists face inside the LGBTQ+ movement in regard to recognition and safe spaces, interrogating how these challenges are interlinked with bisexual citizenship. The second study aims to understand how the experience of illness is intertwined with LGBTQ+ identification in regard to networks of care, time and intimacy. We also explore the narratives emerging from the bisexual communities, highlighting the difficulties of gaining recognition of bisexual identities and the tensions that arise in the creation of actual safe spaces. In the section that follows, focus is shifted to the experiences of LGBTQ+ people with chronic illnesses, and the difficulties – such as lack of accessibility, demand of performativity, and invisibility of illness as a political issue – they face when engaging in Pride politics. In the conclusion, we reflect on the boundary work generated within LGBTQ+ communities in Portugal and the generative impact the collected narratives may have in activism.

Conceptual framework

The reasons for bringing together the experiences of two such seemingly different communities as the bisexual and the LGBTQ+ chronically ill touch on two main keystones: the concept of middle ground, and the boundary work in social movements.

In her work, Hemmings (2002) states that “bisexuality is always the middle ground between sexes, genders and sexualities, rather than being a sexuality, or indeed a gender or sex, in itself. Unlike the proverbial no man’s land, however, the bisexual middle ground of contemporary feminist and queer theory is anything but neutral” (2002, 2). The concept of middle ground is crucial for locating the present reflection and bringing together the experiences of bisexual and chronically ill LGBTQ+ people in our analysis because the experiences of both groups have the potential to be everywhere while belonging nowhere, calling into question the rigidity of borders. In the bisexual epistemologies,

bisexuality configures as a form of disruptive presence within the binary categories of sex and gender, thus representing a destabilizing positioning in different domains, such as academia, media representation, and even LGBTQ+ movements. As will be further elaborated, the confusing characterisation of bisexuality is a key element in understanding its conflictual, sometimes even contradictory, relationship to the LGBTQ+ movement in Portugal and bisexual citizenship.

From the perspective of crip studies (McRuer 2006; Kafer 2013), chronic illness is also configured as a middle ground between able-bodiedness and disability. While it impacts the body-mind balance and forces adjustment of ability and performativity, it is also invisibilised and seldom recognised as an experience of disability. The ambiguity of chronic illness in the dichotomy of able-bodiedness/disability is one reason for the historically scarce relationships between disabled people's movements and those of people with chronic illnesses (Samuels 2003).

Considering bisexuality and chronic illness as expressions of middle ground (between sexes, genders, sexualities, able-bodiedness, disability) is our starting point for investigating to what extent this ambivalence influences the politics of inclusion and exclusion within LGBTQ+ communities in Portugal.

Throughout the article, we employ an understanding of visibility and invisibility as parts of a spectrum (Pieri 2019; Esteves 2023), which gives us an important key to understanding how bisexuality and chronic illness complicate the notion of "middle ground" when applied to LGBTQ+ movements. If bisexuality has the potential to be conceptualised as the ultimate position of sexual transgression, it can, in a lesbian and gay framework, be conceptualised as a reproduction of the binary gender model. This view denotes the replication of a social imaginary in which bisexuality is placed within a normative sexual geography, ignoring the diversity of bisexual experiences.

Our second important point of departure is in what is considered a crucial element in social movements: boundary work. As Ward (2008) and Egner (2017) advance, communities that mobilise around specific claims activate strategies to define the boundaries of their identity: they

trace the lines of who is in and who is out of the group and based on this produce forms of inclusion and exclusion. These strategies are vital for the reproduction and survival of the communities, to the extent that they contribute to forming a sense of social belonging. However, they also produce contradictory consequences, especially in communities that have an inclusionary vocation, such as the LGBTQ+ community.

Whereas bisexuality is by default included in the LGBTQ+ acronym, it is often the case that the letter “B” disappears under the symbolic weight of other claims (McLean 2018; Yoshino 2000). As Maliepaard and Baumgartner (2020) underline, the importance of recognising bisexuality as a valid identity is often underestimated and its political implication dismissed. The boundary work operated within LGBTQ+ groups can exacerbate such dismissal or obstacle the creation of a sense of belonging for bisexual people (Esteves 2023). Boundary work also includes symbolic and discursive tools that reinforce a certain way to be in the community and sanction differences: in this sense, it can be understood as an important instrument of homonormativity (Duggan 2002) and mono-normativity within LGBTQ+ groups.

Boundary work and homonormativity have been used in queer movements to denounce assimilationist practices regarding ideas, values, lifestyles, and imaginaries that impose normative models of identity and behaviour. In particular, homonormativity reinforces normativity and able-bodiedness through discursive practices and representations that frame it as the only possible model. Subjectivities that deviate from it are marginalised which creates hierarchies of inclusion, in which dissident practices are pushed to the margins and suffer new forms of violence from within the community. According to Lisa Duggan (2002), homonormativity is a system that does not challenge structural and institutional normativity: on the contrary, it maintains it, and encourages the existence of a de-politicised, privatised, gay subjectivity, centred on consumerism and the private sphere. The alignment with neoliberal currents is tight, to the extent that homonormativity conceives “a way of being reasonable and of promoting universally desirable forms of economic expansion and democratic government globally” (2002, 177).

Boundary work is also mobilised through policies around access: physical inaccessibility and obstacles to presence are important elements of the construction of boundaries. The literature on LGBTQ+ disabled people has often stressed how queer spaces are constructed around an ideal able-bodiedness that erases the notion of disabled subjectivities as sexualised (Raffo & Brownsworth 1999; McRuer, 2006). Chronically ill people share accessibility issues with disabled people but also encounter additional difficulties through the invisibilisation of their symptoms and the misrecognition of their conditions (Pieri 2023).

In light of these elements, bisexuals and chronically ill people can be considered particularly fragile to the normalizing pressures operating within LGBTQ+ movements and thus more vulnerable to the epistemic erasure that defines the rules of belonging in the community.

Methodology

This article draws on two empirical studies conducted through qualitative interviews in Portugal focused on the experiences and personal accounts of participants. The first study was conducted by Mafalda Esteves during 2018 and involved participants between the ages of 20 and 56 who self-identified within the bisexuality spectrum and where involved in bisexual activism. In order to ensure a heterogeneity of experiences, the participant selection procedure included diversity criteria on gender identity, age and relational status. The sample was composed of six people identifying as cis women; two as cis men; one as trans male; and one as non-binary. All participants were or had been involved in LGBTQ+ informal groups, organisations or events in different cities of the country.

The semi-structured interviews (Adams 2015) were conducted within the context of a broader study² aimed at understanding the intersections between bisexuality, intimate citizenship and psychosocial well-being in Portuguese society from a critical social psychology perspective. One particular goal of the study was to discern and understand the main narratives and discourses around bisexual citizenship from a bisexual activism point of view in relation to four main themes: bisexual activism,

biphobia and related forms of violence, communities and social networks of support and the role of the state.

The second study³ was conducted by Mara Pieri between 2017 and 2020 and involved young adults aged 25 to 40 who self-identified within the LGBTQ+ spectrum and had a chronic illness. The main scope of the study was to understand how the experience of illness intertwined with LGBTQ+ identification, in particular with regard to networks of care, time and intimacy (Pieri 2023). This article focuses on the twelve narrative interviews (Atkinson 1998) conducted in Portugal. Seven of the participants identified as cis women; two as non-binary; and three as cisgender men. As to sexual orientation, three identified as gay; four as lesbian; two as bisexual; and three as pansexual. All had one or more chronic illnesses characterised by chronic pain and difficulties taking part in everyday activities. Although being involved in the LGBTQ+ movement was not a requirement for participation in the study, most participants were members of LGBTQ+ community organisations or groups or took part in their events.

Participants took part in the studies on a voluntary basis and in both studies all interviews were fully transcribed (verbatim) and all sensitive data anonymised.

In both studies ethical issues were considered at all stages. Although the research did not present any risks to the participants, a list of associations and entities that offer free psychosocial support to LGBTQ+ people was shared. All participants read and signed an informed consent form before the interview. The anonymisation of raw data, their storage and access procedures followed institutional guidelines.

The twenty overall narratives⁴ considered in the article were analysed through thematic analysis (Braun & Clark 2006), an approach that allows for collective experiences to emerge through the juncture of individual stories. This method of analysis allowed us to identify, analyse, and report themes within the data in each of the studies and then identify common patterns between them.

The narratives provide a dense and deeply meaningful insight into the ways participants make sense of social meanings and shared experienc-

es, merging political and individual aspects. While unpacking the two studies, we found numerous connections that linked them, in particular with regard to the multiple tensions that participation in LGBTQ+ events was reported to give rise to and the difficulties participants had feeling part of the local formal and informal LGBTQ+ groups. Invisibility and exclusionary practices were noteworthy aspects in both studies. In the analysis that follows, we analyse to what extent the narratives contribute to challenging the limits of participation in LGBTQ+ politics as well as introducing different layers in the debate on Pride politics.

The bisexual paradox: is there a home for bisexuals in LGBTQ+ spaces?

The first forms of organisation of bisexual activism in Portugal appeared in 2010, with the birth of two informal groups: Ponto Bi and Associação B visibilidades. Although their existence was fleeting, they represent the first moment of public visibility of bisexual people. Later, in 2013, Actibistas – a collective aimed at creating bisexual visibility and exclusively addressing issues affecting people who identify as bisexual – was created. In recent years, the collective has gained significant traction both online and at Pride events and marches. Other groups, of various levels of institutionalisation, have also emerged throughout the national territory, along with individual bisexual activists integrated within other informal groups, highlighting the intersectionality of bisexuality. The visibility of bisexual identification seems to be growing, despite the bisexual movement being fragmented and unorganised.

The recognition of the bisexual existence

From the analysis of the interviews, the relationship between LGBTQ+ communities and bisexual communities appears to be marked by tensions concerning, on the one hand, how bi+ activism is perceived within LGBTQ+ communities and on the other, how inclusive LGBTQ+ spaces, communities, and events are for bi+ people.

Echoing what has been pointed out in the literature (Weiss 2003; LeBeaus & Jellison 2009), the accounts of the participants of the study

suggest that LGBTQ+ communities in Portugal are defined by political agendas mostly oriented towards lesbian and gay people, although not always and not necessarily in a visible or declared way (Esteves 2023). Despite the proliferation of LGBTQ+ initiatives in the last decade, the experiences of lesbian and gay people (and, more recently, of transgender people) seem to retain a centrality that limits the space offered to people that identify differently within the LGBTQ+ spectrum, such as bisexuals.

Indeed, the first element of tension in the narratives of bisexual activists relates to the recognition of bisexuality – an aspect that has been at the centre of theoretical debates in critical bisexuality studies (Maliepaard & Baumgartner 2020). For all the people interviewed, the recognition of bisexuality as a valid non-heterosexual identity that a significant group of people identify with was a relevant issue that should be brought to the debate in LGBTQ+ communities because of its political implications. This issue has been present throughout the history of bisexual activism, especially since the 1990s, when bisexuals began to make known their experiences within and outside the LGBTQ+ movement (Highleyman 1995). The difficulties LGBTQ+ communities have in recognising bisexual identities create obstacles for bi+ people and have serious effects, as indicated by most of the people interviewed. On the one hand, the fragmentation of bisexual politics is perceived to hinder the affirmation of a firm and effective identity project with political implications (Tucker 1995; Burrill 2001). On the other hand, the difficulties extend to the psychosocial level (Jorm et al. 2002; Albelda et al. 2009; Haus 2021). Moreover, as is highlighted in the literature, the lack of recognition of bisexuality also has epistemic implications, since it reiterates the supremacy of heteronormativity and compulsory monosexuality (Caldwell 2010; Roseneil et al. 2020) and makes bisexuality unintelligible (Yoshino 2000). These political, psychosocial, and epistemic implications preclude the right to live bisexual intimacies freely and complicate both the state's and civil society's recognition of bisexuality, seriously compromising bisexual (intimate) citizenship (Evans 1993; Roseneil 2001; Plummer 2003).

Interviewees report several episodes of (direct and indirect) prejudice and discrimination against bi+ people within LGBTQ+ communities. Such experiences point to a phenomenon of double discrimination (Ochs 1996) that concerns bisexuals as members of LGBTQ+ communities and in broader society – considered heteronormative *per se*. According to interviewees, prejudice against bisexuality is consistently present in LGBTQ+ communities, especially among lesbian and gay people. All of the people interviewed report a certain instrumentalisation of bisexuality in the LGBTQ+ movement's struggle to achieve a broader political agenda and in the view of bisexuality as a secondary issue within the movement. For example, an interviewee from the Blergh Collective emphasises:

Within LGBT activism, bi issues are rarely mentioned or discussed, and when they are... sometimes, I see resistance, even when people are not actively biphobic, they often have the attitude of... kind of putting things in a corner, like it's not that important. (Xoni, 30–34y)

In addition to the invisible resistance and disregard for bisexual claims, jokes and irony are often used to reject the demands or requests for attention within the LGBTQ+ communities. This depreciation of bisexual claims is in line with what several authors have pointed out (Maliepaard 2017; Van Lisdonk & Keuzenkamp 2017).

However, the interviews also convey instances of mobilisation around bisexual visibility and recognition within LGBTQ+ communities, as in the example of the LGBTQ+ Pride marches. Several interviewees explained how the Lisbon Pride march's organising committee is composed of members from various informal LGBTQ+ groups and organisations. Together, they decide on the central theme of the year and negotiate the order in which informal groups, LGBTQ+ associations and even sponsor enterprises will parade on the day of the march. Several interviewees identified one particularly tense episode that illustrates the devaluation of bisexuality during the preparations for the march. Moira, from the *Actibistas* collective, recalls:

Suddenly, in a preparatory meeting for the 2018 march, which neither I nor [name of another bisexual activist] managed to attend, the last meeting, it was decided that the order of the march, previously discussed and approved – the order of collectives, associations and companies – should be completely changed ... and the bisexual block placed in a, let's say, much less prominent space. [...] It was decided by people who said they had issues with our visibility. The truth is that none of the other people present, who are supposedly part of a community, thought that that was the least bit weird. (Maira, 30–34y)

From a symbolic perspective, the location within the march turns into a field of dispute at the centre of tensions, especially if we consider that the Lisbon march, being the oldest in the country, is also the one with the greatest media impact. As such, the depreciation of bi+ issues easily finds resonance at media level, namely with the media channels that disseminate LGBTQ+ content for an LGBTQ+ audience aimed at the LGBTQ+ movement. Jo, from the Blergh Collective, explains her experience about the participation in the same Lisbon Pride march:

The only mention I heard of the first bisexual block the march had in its 19 years of existence, was in Dezanove [*LGBTQ+ newspaper*]: it was one paragraph. In all the other media outlets there was nothing, in all the photos of collectives and people who participated in the march, nothing: you didn't see a single word. So even when we exist, we are ignored, even if we are there with megaphones screaming, people ignore us. So, it's complicated. (Jo, 30–34y)

The resistance to engaging with bisexual lives and the lack of representation of bisexual experiences is a crucial issue in bisexual activism (Maliepaard 2020): these elements act to maintain a sexual and gender normative project that symbolically renders bi+ people invisible, in a state of non-existence (Yoshino 2000).

There have, however, been attempts to break the silence and isolation experienced within the LGBTQ+ movement. One initiative of

particular importance was taken at the 2018 Pride marches in the cities of Lisbon and Porto. In an action coordinated by various informal bisexual groups, groups and individuals who identified as bisexual gathered together in the same section of the marches under the banner of a 6.5-meter-wide bisexuality flag, for the first time forming a “BI Block” in Portugal’s Pride marches. The action meant occupying a physical space in the marches and aggregating people who, both individually and collectively, identified as bisexuals. It also, in both a literal and figurative sense, meant occupying a public space, “inviting” people to acknowledge the existence of bisexuality and accept the right of bisexuals to participate in the Pride marches. In evaluating the action, activists were very positive about its social impact on identification and recognition of bisexuality:

A girl I didn’t know from anywhere came up to me and asked if she could take my picture with the flag. And at that moment I realised that you need identification, you need representation! Just the fact that I was there with a flag and had a complete stranger, who was so happy to see “her” letter [the B in the LGBTQ+ label] represented, come up to me and ask to take a picture, either because she didn’t have one, or because it was the only point in the march where she felt identification, made me realise that this is important. (Zara, 30–34 γ)

(Un)safe spaces for bi+ people

A central theme in the experiences shared by the interviewed activists concerns the devaluation of their voices. As pointed out in other studies (Nutter-Pridgen 2015), such depreciation, at both the individual and collective level, causes a feeling of detachment from LGBTQ+ events and of non-belonging in LGBTQ+ spaces and communities among bisexuals. The recurrent episodes of biphobia, the incessant jokes, and the constant questioning of the legitimacy of bisexuals’ participation evident in the interviews point to a need of problematising the idea of LGBTQ+ communities as safe spaces, also identified by other authors (Israel & Mohr 2004; Barker 2015). Indeed, the discomfort many report experiencing in these spaces may be reason to create alternative spaces

and informal groups that can serve as “spaces of resistance”. Such groups, where bisexual people can share common experiences, may offer a form of “care bubble”, counteracting the isolation and devaluation experienced within the more organised movements and encouraging communal discussion about the social and political demands of bi+ people. Rather than being an organised movement with a clear political agenda, such spaces are made up of *ad hoc* groups (Hemmings 1997; Toft & Yip 2017; Maliepaard 2017). Iris, a member of the Blergh Collective, recounts the reasons why she distanced herself from parts of the LGBTQ+ movement:

The jokes were so incessant that I stopped feeling comfortable there. [...] That’s what led me to move away from those people, but in one respect that’s good, because I didn’t feel, I couldn’t be fulfilled around those people, you know? The feeling that I could only say things up to a certain point, that if I talked about the other spectrum [bisexuality], nobody valued it, that was an unpleasant feeling in my group of friends. (Iris, 25–30)

On one hand, this tension shows how the exclusion of bisexual people from LGBTQ+ spaces and communities helps maintain the position of bisexuality as a subaltern political identity (Maliepaard & Baumgartner 2020). On the other hand, it removes bisexual experiences from daily life and the political arena and, therefore, reinforces the invisibility or non-existence of bisexuals (Gonzalez, Ramirez & Galupo 2017).

Fear of facing the hostile climate and the actual or potential stigma associated with bisexuality is a recurrent theme in the narratives. Because of it, some bi+ people choose to remain in a regime of invisibility and not come out in LGBTQ+ spaces, instead adopting a strategy of “passing” (Maliepaard 2017), i.e., pretending to be lesbian or gay. Vanda, for example, says:

You’re never comfortable. You’re never comfortable – not in an LG environment, not in a lesbian environment, not in a straight environment – you’re always trying ... Sometimes, sometimes you end up unintention-

ally trying to hide, you're in a lesbian environment and you're trying to hide that you like men too, and you're participating in the dialogue trying to appear to be a lesbian or trying not to have them find out that you like men. (Vanda, 34-40y)

These strategies of “passing” function not only as a protective measure for bisexual people, involving negotiation and permanent management of the individual dimension of bisexuality (McLean 2008), but also have repercussions at the collective level and implications for the consolidation of bisexual activism. Indeed, they reinforce the idea that bisexual people “do not wear certain things, do not say certain things, and do not present material clues that make them assume themselves as members of an organised bisexual community or any other bisexual community” (Maliepaard 2017, 328).

As the interviews show, bisexual activism struggles to have its demands met within Portuguese LGBTQ+ communities today. Despite cases of resistance and visibility, the majority of bisexual activists do not feel welcome or supported in LGBTQ+ communities.

Unapproachable activism: the case of chronically ill LGBTQ+ people

The invisibility and exclusion bisexual interviewees report experiencing is reflected in the narratives of chronically ill people that identify within the LGBTQ+ spectrum. Although the impacts of chronic illnesses on the body-mind may vary greatly, they frequently involve chronic pain and low energy levels and difficulties performing routine activities (such as cooking, working, walking) and accessing public spaces. However, symptoms are often invisible to the observer and chronically ill people need to manage information about their illness, choosing between coming out and remaining invisible (Samuels 2003). The management of multiple levels of visibility and invisibility and the stigma attached to both illness and LGBTQ+ identification make the experiences of LGBTQ+ people with chronic illnesses particularly complex.

Historically, the LGBTQ+ movement in Portugal has made no significant efforts to establish connections with the disability movement or patient advocacy organisations (Martins & Fontes 2016). The reciprocal distance reflects, on the one side, the cultural stigma around sexuality in relation to disability and illness and, on the other, the structural ableism that still permeates Portuguese society, including the LGBTQ+ movement. The only significant exception is the creation of “Sim, fodemos” (literally, “Yes, we fuck”), an organisation advocating disabled people’s rights to sexuality and sexual diversity (Santos & Santos 2017).

The LGBTQ+ people interviewed in the study analysed here all reported difficulties performing everyday activities; some also had mobility issues and were dependent on the constant support of a care network. Such difficulties also have political implications when it comes to participating in LGBTQ+ community life. The narratives collected recurrently touch on three main issues: accessibility, performativity, and invisibility.

The lack of accessibility in LGBTQ+ spaces

As a political issue, accessibility is largely absent in the manifestos of most LGBTQ+ organisations and seldom mentioned as a priority in relation to Pride marches (Pieri 2021). The demands for attention around the issue that have been made in recent years have mostly come from individuals within the organisations frustrated by the inaccessibility of LGBTQ+ events. The first Pride march that was explicitly made accessible to persons with reduced mobility was organised in Lisbon in 2018, 19 years after the first Pride march. Some other accessible events have followed, but accessibility still seems to be viewed as a matter of adjustment to individual needs and demands rather than as an issue that directly engages with the practices of LGBTQ+ movements and the LGBTQ+ struggle against multiple discrimination.

The most common accessibility issue concerns the absence of structural aids for people with mobility issues. In the context of Pride marches, such structural aids can mean ramps and plain routes, but also benches where participants can stop to rest, available and accessible restrooms,

and safe areas where a certain distance between participants can be guaranteed. Some interviewees also mention the importance of knowing the route in advance, so that participation can be accurately planned, others recognisable organisation representatives whom you can ask for help, since absence of such representatives results in feelings of isolation and abandonment. Momo, a participant with mobility issues caused by multiple sclerosis, states:

I'd have loved to take part in the Pride march on May 17: last year I was very upset about not being able to go. But the streets of my town are no help, and the route of the march is bad. The only stretch that would have been ok is when we cross the bridge; that's safe and doable. But the rest is just horrible. (Momo, 32y)

Crowded spaces are another challenging element of inaccessibility in the marches: physical contact with other people, especially when dancing or moving around, can provoke pain or trigger sensory overload; the lack of signalled exit routes can spark anxiety and panic attacks; loud music, often used on floats, and unexpected sounds, can be a problem for people with some conditions; and stroboscopic lights, often used near the end of the Pride marches, are a danger to people who suffer from migraines and epilepsy. Moreover, most events do not provide sign language interpretation for deaf and hearing-impaired participants, nor do they offer other forms of support for blind and visually impaired participants.

More than the possibility of facing these triggers, it is the lack of alternatives that often discourages people from participating. Lisa, for example, says:

Unlike the march, the fair⁵ is stationary, so it should be more accessible ... but there are no spaces where we can rest. There are loads of tables, but they're always full of people eating ... if there was a space with sofas or benches – you know, many of us have leg pains ... and that would help. (Lisa, 27y)

It is important to note that for several interviewees, the Pride march is one of few opportunities in the year – if not the only opportunity – they get to be part of an LGBTQ+ event. In bigger cities – such as Porto, Lisbon, and Coimbra – there is a variety of LGBTQ+ events throughout the year, but in smaller towns, especially those in the interior parts of the country and the islands of Madeira and Azores, the Pride march is the only LGBTQ+ event. Hence, for many LGBTQ+ people with chronic illnesses, the choice to participate is loaded with expectations and when they are unable to access events they often experience deception. And the obstacles they encounter in accessing the event are lived as a major deception.

The growing number of participants in Pride marches in recent years, even in small towns and peripheral areas of the country, has not corresponded with any growing interest in the accessibility politics of LGBTQ+ events. This mismatch can be attributed to two main factors. The first is the limited amount of human and economic resources in LGBTQ+ activism in Portugal: many groups consist of fewer than ten members and cannot count on any significant financial support in organising marches. The efforts to ensure accessibility at events can thus prove too onerous for the organisations. The second factor is the cultural ableism which still permeates LGBTQ+ movements. Despite the increased focus on intersectionality politics in some organisations (Santos 2018), the struggle against ableism and the efforts to make LGBTQ+ people with disabilities and chronic illnesses more visible have not fully entered into the political debate and are still considered of marginal importance. Accessibility is still regarded as an individual need rather than as a collective issue of fundamental importance to practices of inclusion and exclusion within LGBTQ+ movements (Egner 2019). In other words, LGBTQ+ movements do not seem aware of the ableism they reproduce and show no signs of being keen on an internal debate about the issues or on re-imagining their practices of activism in order to be more inclusive of people with disabilities and chronic illnesses. The evidence collected in the study reinforces that:

as sites of celebration and/or protest, Pride events are nevertheless still sites of potential oppression, whether from within or without. These different experiences of Pride demonstrate that such events do not universally engender a sense of community or feeling of belonging. (Formby 2017, 166)

The performativity of activism

The second important element of tension that emerges in the narratives analysed concerns an aspect of physical accessibility tied to the performative side of activism. Although LGBTQ+ activism has increasingly moved over to digital platforms in recent years, due to the Covid-19 pandemic and the growing centrality of social media, some parts of it still require physical participation (Hedva 2018; Wendell 2001). The investment of time and physical presence needed to organise and take part in events, rallies, and marches is often not affordable for people with the limited energy resources chronic illness entails:

Activism requires a permanent public *persona* and I get exhausted just thinking about it. You have to be constantly performative – a relationship, motivation and performance making machine. I don't have the energy for all that, I don't. (Marcelo, 35y)

Some of us also have mental health issues [...] and keeping everything together and doing things quickly ends up being complicated. When it comes to one-time things, like interviews or seminars, it's easier to say "I'm in". But continuous work, in a fixed setting, that's very hard. (Safo, 24y)

Being involved in activist work also requires keeping up with rhythms that are often incompatible with the unpredictability of illness: the expectations of being there, doing things and being available can seem impossible to live up to. As Wendell states, "activism still assumes a consistently energetic, high-functioning body and mind, and certainly not a body and mind that are impaired by illness" (2001, 24). Such expectations are a reflection of the system of compulsory able-bodied-

ness (McRuer 2006) which crosses all social settings, reproducing the implicit view of able-bodiedness and health as normalcy and constructing disability and illness as uncommon deviations. This same system sets expectations about timing and rhythms which are incompatible with “crip time” (Kafer 2013; Apelmo & Nordgren 2021) – the rhythm disabled, ill and impaired people must adopt. In activism, it is not only taken for granted that all activists are healthy and able-bodied, but also expected that they will perform as such without adjustments. However, as authors from critical disability studies highlight (Kafer 2013; McRuer 2018), able-bodiedness is an unstable, fleeting state of privilege that can change at any moment.

The story of Maria, one of the participants in the study, is particularly illustrative. For years, she was a prominent LGBTQ+ rights activist with high media exposure and a large network of connections. Some years ago, she was diagnosed with a chronic illness that puts strong restraints on her mobility and drastically reduces her energy levels. At first, she did not publicly disclose her condition and simply turned down her involvement in LGBTQ+ events. That elicited rumours about her absence: some people speculated she had turned her back to the movement and others suggested a conflict with her organisation:

I feel I need to explain to people why I am not there, why I cannot make it, because people think I don't care. I felt this pressure. And at a certain point, I felt I had to write [...] on Facebook [...] I didn't say exactly what I had, it wasn't worth it, but I said I had an illness that caused fatigue and sometimes limited me, so that people would know that if I was not there, if I didn't show up, it wasn't because I didn't care, it was because I couldn't make it. (Maria, 35y)

In Maria's words, the expectation of able-bodiedness in activism was a burden to such an extent that it forced her to unwillingly come out about her condition. The episode is significant, particularly if located in a political context that celebrates coming out as a conscious choice and visibility as an act of freedom (Samuels 2003).

The invisibility of chronic illness as a political issue

In addition to accessibility and performativity, a third recurrent theme can be traced in the narratives of chronically ill LGBTQ+ people: the invisibilisation of chronic illness within the movement. As previously discussed, the lack of collective mobilisation around issues concerning chronic illness, the absence of specific connections between the disability rights movement and the LGBTQ+ movement, and the historically rooted idea of illness as an individual matter constitute the main factors explaining why disability and chronic illness are not considered part of the politics of mobilisation by LGBTQ+ people. As a consequence, chronic illness is invisible in everyday life and remains a non-issue around which no collective reflection takes place in spaces of LGBTQ+ activism. Some of the interviewees end up feeling detached from activism, even deceived, because of this double invisibilisation and the indifference to issues of illness within the movement:

I didn't divorce activism, but I did divorce Pride marches and involvement in live activities. It's just too hard to participate. I'm focused on the disability issue as well and it's not possible to find space for both. (Momo, 32y)

During the Pride march, I had a crisis, because of the heat and the emotions – it was raining so I was all covered up and sweating. Afterwards I saw the pictures, and in every picture – every single picture – you can see the rash on my face. I hate it. Nobody noticed, my comrades did not notice. Maybe other people looked at me and thought I was weird. But my comrades, no, they didn't notice. (Lourdes, 27y)

The epistemic ignorance (Fox & Ore 2010) around chronic illness and its implications for the lives that LGBTQ+ people are able to live creates tensions in encounters with activism. The boundary work at play is embedded in a profound and often unacknowledged ableism within LGBTQ+ movements. Some, like Momo, choose to silently distance themselves from the movement after having concluded that an expansion of the political debate towards disability issues is not possible. Others, like Lourdes,

invest in their participation even though feeling sad and deceived when they realise their condition is not taken into account. In other cases, the choice of passing oneself off as healthy and able-bodied (Pieri 2019) seems to be the safest strategy in LGBTQ+ spaces: interviewees engage in events and marches without disclosing their illness or accessibility needs because they do not feel their coming out would be well-received. As in the cases illustrated in the previous section, the strategy of passing is an active strategy of invisibility that creates a sense of safety and reduces the risk of discrimination within the group to which you want to belong, also for people with chronic illnesses (Brune & Wilson 2013).

Conclusions

In the article, we bring together perspectives from two communities that locate themselves at the fringe of LGBTQ+ politics: bisexual people and chronically ill people. The analysis focuses on tensions and forms of exclusion rather than on examples of resistance, since the aim is to critically engage with the limits of Pride politics in LGBTQ+ movements in Portugal. As the narratives demonstrate, despite the differences that characterise the experiences of the two communities, they both represent examples of territories where the politics of inclusion and acceptance of differences within the LGBTQ+ spectrum seem to fail. For example, by entering LGBTQ+ spaces and movements, bisexuals challenge the rigid boundaries between gender and sexuality: as such, bisexuality is read as a dangerous sexuality. However, as bisexual epistemologies underline (Hemmings 2020), this nature of challenge holds a powerful potential. The shared space between these communities (i.e., of not fitting into the binary framework and the multiple forms of discrimination to which they are subjected) can bring together, give voice to, and empower those who identify with them. In addition, it can provide a platform for collective organisation and activism on a broader scale, beyond individual identities (Eisner 2013; Flanders 2017; Hayfield 2020).

Moreover, in the past two decades, LGBTQ+ activism in Portugal has grown considerably and made important advances in the legislative area through a strong politics of alliances and mainstreaming. However, this

propulsive force seems to have enhanced homonationalist and assimilationist positions and discouraged the emergence of peripheral experiences within the LGBTQ+ spectrum. The narratives provided by the bisexual communities point to a lack of space for struggles that deviate from the mononormative experience. The voices of bisexual and chronically ill people reflect the broader demands made by marginalised subjects within the LGBTQ+ movement for an LGBTQ+ activism that is truly intersectional and aware of multiple forms of discrimination (Chin 2017). Other examples that reflect this tendency in the Portuguese context are the emergence of informal black feminist groups and the emergence of asexual/aromantic activism (Alcaire 2020). The experiences of all these groups challenge the mainstream movements and push for a critical debate on the practices of activism. In this sense, the encounter between bisexual people, chronically ill people (and others) as a middle ground, can neutralise the tensions between various positionings within Pride politics.

If presence in public space is a fundamental aspect of intimate citizenship, the experiences of bisexual and chronically ill people are evidence that participation is limited and that boundary work (Egner 2019) is at play, limiting access within the LGBTQ+ spectrum. As evidenced in the article, the boundaries of exclusion/inclusion within LGBTQ+ movements hinder opportunities of creating safe spaces for all who identify within the LGBTQ+ spectrum. The practices of inaccessibility and the subtle but persistent exclusion of bisexual people from the debate clash with the preoccupation of creating safe spaces which has been at the centre of LGBTQ+ politics for decades (Bell et al. 2001). In a small and fragmented context such as Portugal, the loss of such opportunities means loss of engagement with many people who cannot count on having the resources to be part of LGBTQ+ activism and feel a sense of belonging. Through the lens offered by the concept of middle ground, we advance that the exclusion of subjectivities such as the bisexual and chronically ill is directly connected to the disruptive, destabilising and ambiguous character of these subjectivities.

In future research, it would be particularly interesting to explore the possibilities online spaces offer. In the aftermath of the Covid-19

pandemic and in light of the growing importance of social media platforms, virtual communities are changing not only the content of LGBTQ+ debates, but also their practices: on the one side, virtual communities may be more accessible for those who encounter obstacles to physical participation; on the other, they may offer a viable alternative when it comes to gathering the invisibilized experiences of bisexual, chronically ill and other people who feel marginalised in the traditional in-presence spaces. Digital platforms, such as TikTok, Twitter and Instagram, are increasingly becoming spaces where marginalised experiences find representation and an audience, changing the alliances, discourses and practices of activism (Ellis 2023).

Finally, the visibilisation of bisexual narratives and chronically ill LGBTQ+ people's experiences provides an important example of why LGBTQ+ movements need to rethink their mobilisations and move beyond binaries and fixed identities, embracing a multiplicity that is ever more central in individual lives and needs to be translated into political practices.

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NOTES

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2. This study draws on an ongoing PhD thesis titled *Invisible Sexualities: Intimate Citizenship and Psychosocial Well-Being in Bisexuality* at the Centre for Psychological Research and Social Intervention (CIS-ISCTE-IUL) (original name: *Sexualidades invisíveis: Cidadania íntima e bem-estar psicossocial na bissexualidade*).
3. The research was conducted for the PhD thesis *Chroniqueers: Time, Care and Visibility in Narratives From Queer People With Chronic Illness* at the Centre for Social Studies (University of Coimbra).
4. Eight interviews from the first study, twelve from the second.
5. The Lisbon Pride march is followed by a fair called Arraial, which lasts several days and where various cultural events are held and foodstands and bars are open.