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Universalism, diversity and norms: gratitude, healthcare and welfare chauvinism

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ABSTRACT

Access to universal healthcare is a normative expectation of citizens in European welfare states. As part of a comparative study of healthcare in diverse European neighbourhoods, we met women who described failures of the public healthcare system, together with gratitude for that system. Challenges to European welfare states of ageing populations, the retraction of resources available for healthcare, and globalised migration streams have been linked to xenophobic 'welfarist' attempts to restrict access to services for new arrivals and those seen as failing to contribute sufficiently. Stories of healthcare systems' failure to treat symptoms, pain, and suffering in a timely and caring fashion came from eight women of non-European migrant backgrounds as part of a wider interview study in four European cities (Birmingham, Uppsala, Lisbon, Bremen). These accounts suggest that a normative aspect of welfare provision has been reproduced – that is, the expression of gratitude – despite inadequate services. Where welfarist attitudes to migration meet normative aspects of healthcare, suffering may be compounded by an expectation of gratitude. The regrettable unmet healthcare need of the eight women whose cases are presented suggests that other marginalised healthcare users may also be under-served in apparently universal healthcare systems.

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Healthcare; migration; access; Europe; women

Introduction

This paper examines women's expressions of gratitude in the face of inadequate or inappropriate healthcare. This gratitude was expressed spontaneously in interviews about how healthcare was accessed and assessment of the adequacy of that healthcare, but no explicit questions were posed around gratitude and therefore these expressions were striking. All the women who expressed gratitude had a migrant background. We seek an explanation of this gratitude in terms of the politics of welfare chauvinism that was in evidence at the time of the interviews. The ideal of universal access to socialised healthcare is interrogated for people who express gratitude for health services that fail to address their healthcare needs. The meanings of such expressions of gratitude in terms of both welfare norms and migration politics are explored.

An expectation of statutory healthcare provision is politically and symbolically important in European social democracies. The obligation of democratically elected governments to provide universal basic care was part of re-building citizens' trust in the state after the devastation of World War II and manifest in the establishment of the welfare state. The ideal of a welfare state as a

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means of re-creating a 'collective, organic, and egalitarian society ... where trust thrives and tolerance can be constructed' (Crepaz & Damron, 2009, p. 457) has persisted into the twenty-first century. Such trust and tolerance seemed to be threatened by a shift towards welfare chauvinism, defined as the belief that foreigners unsettle the fundamental principles of the welfare state by misusing public services for which they are not eligible and have not appropriately contributed (Crepaz & Damron, 2009, p. 249).

Do majority attitudes to migration-driven diversity represent a threat to a collective commitment to the European welfare state (Crepaz & Lijphart, 2008, p. 243) and the ideal of universalism? The extent to which accommodation to diversity (Häikiö & Hvinden, 2012) is in conflict with egalitarian ideals (Anttonen, Häikiö, & Stefánsson, 2012) has been interrogated, with the measurement of public attitudes towards welfare policies suggesting that a universal welfare state retains popular support (Gelissen, 2000, p. 299). While these findings pre-date the so-called 'migration crisis' of 2015–2016, the most recent polls of the Eurobarometer¹ of the EU Parliament suggest ongoing support. The polls indicate that 58% of Europeans believe that EU actions in issues of migrations are inadequate, with 73% considering that more actions should be taken. In the field of health and social security, 49% of EU citizens agree that actions are inadequate and 70% that more actions are needed.

The ideal of making basic services available across the population has remained central even as the practical challenges of provision have developed with respect to ageing populations, the shift in the burden of disease from acute to chronic, globalised migration streams, and the imposition of resource restrictions. The availability of accessible healthcare for those in need remains a powerful ideal, but this ideal has been more researched in general populations than in minority groups who may be subject to welfare chauvinism (although see van der Zwan, Bles, & Lubbers, 2017).

Background

Foucault showed how the emergence of the modern European state involved biopower – the development of techniques to subjugate bodies and control populations (Foucault, 1980). Biopower legitimated the nation state as a normative form of governance (Redfield, 2016, p. 160), such that proper and effective rule encompasses not only the law, but also hygiene and public health. Through its welfare provision, the nation state is responsible for citizens' well-being, with this provision, which we can term biopolitical, having a strongly normative aspect (Redfield, 2012, p. 157). In populations subject to globalised migration, citizenship is itself contested, raising uncertainty around eligibility and coverage for statutory healthcare. In Europe the rights of various categories of migrants to claim access to healthcare have been officially contested; for instance, the Swedish government failed to provide healthcare for undocumented child migrants (Biswas, Toebes, Hjern, Ascher, & Norredam, 2013), the UK government was shown to be illegitimately denying care for the 'Windrush generation' of migrants from the Caribbean (Gentleman, 2018), and in Portugal, undocumented migrants have been excluded from accessing health services (Padilla, Rodrigues, Lopes, & Ortiz, 2018).

Based on a biopolitical approach, contemporary welfare regimes have a logic of care that 'treats individuals as members of a population' (Stevenson, 2014, p. 17) in which individual feelings and values (or subjectivity) become irrelevant. This form of healthcare, focused on the national population (Stevenson, 2014, p. 20) is 'anonymous care' and holds the prospect of being egalitarian, by offering every patient similar care, based on an expert assessment of patients' symptoms and expressions of need. However, expert assessment may not attend to the patient's own experience and this inattention can itself constitute a form of injury (Stevenson, 2014, p. 19).

The demands on universal welfare systems as a result of ageing and diversification of populations, the rise of chronic disease combined with restrictions on healthcare resources through the politics of austerity, have made failures of care more visible. The withdrawal of public health services has opened up space for a 'new patterning of social welfare mechanisms with techniques

of commercialization and calculative choice' (Collier, 2011, p. 26). Tax-funded models of welfare are no longer trusted to provide for national populations and discussion of alternative models has garnered attention (Piketty & Goldhammer, 2014).

The withdrawal of the public health system allows populist anti-migration politics to question the rights of those seen as non-citizens and/or non-contributors to receive scarce services. Taxpayers and citizens in democratic welfare states who have seen their services cut can query newcomers' rights to those services by questioning their entitlement. Those made vulnerable by welfare retraction have been re-labelled as undeserving of support (Bambra & Smith, 2010). Newcomers, immigrants, visible minorities, with disabilities and mental health problems become labelled as failing to contribute and therefore deemed undeserving. New arrivals who have not paid taxes and yet demonstrate 'excessive need' due to disability or chronic illness, and who need interpretation or cultural mediation support, are vulnerable to being seen as undeserving. Women migrants who do not appear to have integrated properly are blamed and perceived as problematic (Casey, 2016) given their role as mothers (Loneragan, 2018). The cases presented in this paper are all women of migrant background.

Despite a lack of evidence that welfare is a motivation for migration (Mladovsky, Rechel, Ingleby, & McKee, 2012), migrants' arrival is taken as evidence of the desirability of European welfare. Making migrants the scapegoat for the failure of public services was a disputed aspect of Europe's response to the refugee crisis of 2015-2016 and of the UK Brexit referendum of 2016. Contesting vulnerable migrants' eligibility to receive healthcare affects individuals' willingness to engage with providers (Bradby, Liabo, Ingold, & Roberts, 2017). In order to understand the expression of gratitude for inadequate health services by women of migrant background, the undermining of undeserving migrants' eligibility to claim healthcare needs to be taken into account. Our focus here is to understand the meaning of grateful utterances made to community-based researchers (Hamed, Klingberg, Mahmud, & Bradby, 2018) and what they can tell us about the failures of universal healthcare for diverse populations (Anttonen et al., 2012) – those marginalised in terms of origin, age, language, gender, and mental health. By de-centring the professional perspective to include a wide range of subjective responses to healthcare, we sought to re-imagine what accessible and transformative care for diversifying populations might look like in European welfare states.

Research context

This paper draws on a project examining healthcare from the bottom up, by talking with residents in diverse neighbourhoods about what actions they took in accessing services to address particular health concerns. By focusing on what people did to respond to particular symptoms, pain, or troubles, we did not differentiate between health services accessed through the public health system and other types of service accessed privately, via the internet, friends and relatives, locally and trans-globally.

We sampled adult residents of diverse neighbourhoods in four European countries with different type of welfare state regimes – Portugal, Sweden, Germany, and the UK (Phillimore et al., 2015). In each city (Lisbon, Uppsala, Bremen, and Birmingham), we chose two neighbourhoods to include significant proportions of new and old migrants (see Supplemental data Appendix 1). Each neighbourhood was street mapped, which involved gathering evidence by walking the streets, noting resources available in shops, libraries, churches, community centres, etc., chatting to locals, and taking photographs as appropriate. Later, we interviewed residents of the neighbourhoods as healthcare users. Considering the ways residents used both formal and informal services allowed us to render visible the range of health work that is hidden when the focus is delimited to the public health system and when professionals' accounts of the availability of services are prioritised (Phillimore et al., *forthcoming*).

Methods

The project used multiple methods, including neighbourhood mapping, interviews with residents and providers, mini-ethnographies, and a residents' survey, sequentially and in parallel across diverse

neighbourhoods in Portugal, Germany, the UK, and Sweden (see Supplemental data Appendix 1). Full details of neighbourhoods and methods are available elsewhere (Phillimore et al., 2015). The project received ethical approval from the ethics committees of the Universities of Bremen and Birmingham, the University Institute of Lisbon, and the regional ethics committee, Uppsala.

The interviews with adult healthcare users constituted a maximum diversity sample in that each interviewee was recruited to have different characteristics from those who had already been interviewed in terms of age, country of birth, length of residency, citizenship, migration status, languages spoken, profession or occupation, state of health, etc. To achieve this type of diversity sample, representing a range of languages and cultures, multi-lingual and socially active residents of the neighbourhood were trained in qualitative interview techniques to work as community researchers, recruiting, interviewing, and interpreting in collaboration with academic research staff. Community researchers' involvement in convening and sometimes conducting interviews facilitated interviewees choosing the language and location of the interview as these were negotiated with a familiar face, in a familiar language.

The aims and objectives of the project and the interview procedure were described, and written informed consent (available in a range of locally appropriate languages) was signed. See Supplemental data Appendix 2 for the interview schedule in English.

Interviews were audio-recorded and transcribed and each transcript was double-checked by a second interviewer or researcher. Interviews conducted neither in the local national language nor in English were translated into English or the respective national language. To enable comparison of findings across the four countries, at least a fifth of all interviews conducted in Bremen, Lisbon, and Uppsala were translated into English and structured summaries were available of all interviews.

A common codebook was developed cooperatively across the four countries and throughout the coding process. It was tested on at least two interviews in each country with amendments subsequently incorporated. The coding was done using the software package MAX QDA.

Sample

Residents

A total of 160 interviews were undertaken with health service users across the four countries, ranging in age from 18 to 80+ years with overall slightly more women than men. There was wide variation in migration status, citizenship, length of residence, language, marital status, religious affiliation, and socio-economic status, as shown in Supplemental data Appendix 3. Since our focus was on diversity rather than on specific minorities, we included the national ethnic majority in our sampling. Across the whole sample, 20% of respondents were citizens by birth and 12% were naturalised, with the majority having been born overseas. Only 3% of the sample were undocumented migrants and 4% were refugees or asylum seekers, with 24% having permanent residency rights (plus 23% missing data).

Service providers

We also interviewed 76 service providers across the four countries and this material is detailed elsewhere (Phillimore et al., [forthcoming](#)). For current purposes, we note that across the four countries, public healthcare providers work in complex partnerships across non-governmental and third sector organisations, the commercial sector, and parallel charitable healthcare providers. Partnerships across a range of sectors were particularly evident in Portugal, where cuts imposed by the triumvirate of the European Commission, the European Central Bank, and the International Monetary Fund, known as the Troika, lasted until 2014 and bit hard into public service funding (Legido-Quigley et al., 2016), and the UK, where austerity politics have been ongoing since 2008. By looking across sectors, it was clear that healthcare providers were undertaking work to meet

service users' needs by adapting their provision, connecting with other agencies to work in new ways that we have described as bricolage (Phillimore et al., [forthcoming](#)). They were engaged with 'remarkable resilience, creativity, and sheer magnitude of the work represented in the ongoing maintenance and reproduction of established order' (Jackson, [2014](#), p. 222).

Despite the efforts of service providers to meet the healthcare needs in their neighbourhood, they acknowledged that sometimes they failed for various reasons. The focus of this paper is not mapping cases of unmet need *per se* but rather making sense of the apparent contradiction of unmet need combined with expressions of gratitude. The meanings of these expressions are considered for what they can tell us about the ideal of universal access to healthcare in contemporary liberal democracies.

Results

Resident interviews

The residents that were interviewed expressed opinions on the healthcare that was available to them, ranging from great satisfaction to utter dissatisfaction, which was to be expected from a diversity sample. Most stories represented elements of satisfaction and of dissatisfaction at various stages of the complex process of addressing health issues. Here, we focus on the small minority of residents, all migrant women, who explicitly expressed their gratitude for the public health service received at the same time as giving an account of poor quality of service or compromised access to services together with significant levels of unmet need. The number of individuals who represent this combination of gratitude and unmet need was small – only eight – from the Swedish, British, and Portuguese neighbourhoods. Despite looking for equivalent accounts from the German neighbourhoods, we did not find them. The interviews quoted from here took place in women's own homes where the interviewer(s) were usually offered hospitality in the form of tea, biscuits, nuts, etc., making it a sociable encounter at which conversation – and sometimes tears – flowed.

In focusing on these accounts of gratitude in the face of poor service and unmet need, we make no claims of representativeness. Rather, we are interested in what gratitude means in the context of the ideal of accessible universal health services at a time of migration-driven diversity, in which some groups' right to access health services is contested. Those vulnerable to being seen as not deserving of healthcare through their 'excessive' need and failure to contribute include recent migrants with disabilities or chronic illness, who have not been employed or paid taxes and are perceived as not having integrated appropriately, a group in which women are over-represented.

Forms of gratitude

Episodes of everyday life where someone seeks and obtains a good service or support from another may attract an expression of gratitude in English and other Western European languages. However, comparing across eight languages from five continents, linguists suggest that in general 'social reciprocity in everyday life relies on tacit understandings of rights and duties surrounding mutual assistance and collaboration' (Floyd et al., [2018](#)). But explicit expressions of gratitude to healthcare providers, both written (Herbland, Goldberg, Garric, & Lesieur, [2017](#); Miron-Shatz, Becker, Zaromb, Mertens, & Tsafir, [2017](#)) and spoken (Heyn, Ellington, & Eide, [2017](#); West, [2006](#)), have been studied to understand patterns of patient–professional interaction, with women more likely than men to express gratitude (Kashdan, Mishra, Breen, & Froh, [2009](#)).

The expressions of gratitude, communicated to researchers, some of whom came from the same neighbourhoods and spoke the same first language as the interviewee, can be described as falling into three groups. The first type of gratitude we term 'situational gratitude' – and it was expressed by women who had a bad experience but managed to find a better solution and are still grateful for the services despite the poor service. The second type of gratitude we term 'generalised

gratitude' referring to those who had a bad experience but maintain their gratitude by rationalising or justifying the poor service with reference to general welfare problems, including austerity, a lack of personnel or time, depending on the form of the welfare state and national regime. The third type is 'positional gratitude' and refers to those who are grateful despite bad services because of an awareness of their own marginalised position. In what follows, we work through these three types, illustrating them with the women's own words.

Three women in their early thirties, expressed 'situational gratitude'. They described short-comings that they had experienced, but having subsequently realised alternative routes to access healthcare, were nonetheless grateful.

UK: Sila² had grown up in France where she had citizenship, and was of mixed, including Turkish, ancestry. She had lived in Birmingham for six years and was highly critical of the National Health Service (NHS). Sila found the lack of continuity between doctor and patient bewildering when she had consulted for symptoms of numbness and the sudden appearance of subcutaneous lumps. She described how doctors 'do not have the time' so there was a 'lack of connection, lack of time, lack of relationship' with a doctor such that when 'you are coming with the symptoms' there is 'no context, not your background: there is not a holistic approach'. Sila described how getting healthcare, especially for 'less dramatic types of illness', involved

multi-actors that we have to go through and timing, the scheduling of the appointment, the way the whole process ... it is too long. Waiting, all of the different points of contact that you have to do to address the problem. It is a journey that is way too long. It is too administrative, too much mail and text messages.

She referred to 'the anonymous way of treating a patient, and just treating the symptoms' which meant that 'I have no trust'. In this respect, Sila identified all the disadvantages of the anonymous logic of care that Stevenson (2014) associates with biopolitics. At the close of the interview, when asked if she wanted to add anything, Sila said 'Thank you the NHS!'

Sila's words reflect the idea of 'anonymous care' as failing to understand the patient's own experience, understood as part of her context and background. Despite her sense that she had not received appropriate care, her expression of general thanks to the NHS as an organisation supported the principle of social healthcare. Sila's numbness and lumps remained unexplained, but she felt able to seek alternative sources of therapy and support, including the internet.

Portugal: Norma had lived in Portugal for 11 years, having grown up in Brazil. Portuguese was her first language and she was familiar with the National Health Service (NHS) and other available health resources. Her main health concern was an episode when her baby daughter, who was generally healthy, was ill and the difficulties of getting care continued to trouble Norma. Norma had, as usual, called the telephone line 'Health 24' for advice. As the baby's fever had worsened, Norma had then called the emergency service at the NHS Children's Hospital to let them know she was bringing her baby in. On arrival, the baby was put under observation for a while and then given a nebulisation treatment and sent home. Once home, Norma realised that her baby was getting worse, so she took her to another NHS hospital, where her baby was admitted for four days, having been diagnosed with Bronchiolitis. Norma felt her baby's symptoms and her own legitimate concerns were dismissed by the Children's Hospital and as a result of the delay in treatment her baby had both breathing difficulties and an ear infection such that a course of antibiotics was required.

Norma expressed great dissatisfaction with the services offered by the Children's Hospital, due to their failure to diagnose her baby's condition and to listen properly to her, as a mother, but favoured the second NHS Hospital that took care of her baby, saying 'I am extremely grateful to the health professionals of (Name) Hospital. Next time my baby gets sick, I will go there'. Like Sila in Birmingham, Norma experienced an anonymous form of care, where her subjective experience was ignored in the healthcare providers' interpretation of her baby's symptoms. Finding the Children's Hospital's response to her baby's symptoms profoundly misguided, she was able to get access to an alternative provider to whom she directed her gratitude. Norma's gratitude was conditional on

the service that she received for her baby, and it was withheld from the healthcare professionals who failed to offer adequate diagnosis and treatment.

Portugal: Manu, 30 years old and a University graduate, had arrived from India, in 2016 to join her husband. While speaking English (among other languages) she did not speak Portuguese. During her first pregnancy, Manu was refused healthcare by two different local health centres and only achieved access through the intervention of a non-governmental organisation (NGO). She was refused timely care at delivery as well and her baby was born with serious health problems due to this delay and, after being referred to another hospital, died. Manu filed an official complaint, with the support of the NGO, but the outcome stated that her inability to speak Portuguese was the main problem. The NGO supported Manu throughout her second pregnancy and she felt thankful to have met 'a good doctor' and her second baby was safely delivered.

Norma and Sila had alternative means of getting healthcare when they did not get the service they felt was appropriate initially. Sila explored alternative treatments for her symptoms and Manu, with the support of a NGO, gained access to healthcare, despite initial refusals and received good care for her second pregnancy. Their negative experiences did not negate their gratitude for the healthcare system in general, at least after they had solved their health concerns.

Next, we describe four women whose experience of healthcare was negative, and who were unable to identify alternative forms of care or alternative means to access care, but who nonetheless expressed gratitude. This was generalised gratitude that did not refer to their own experiences.

UK: Marie, a widow aged 81 years, born in the Caribbean, had lived in the UK for 60 years. She had had high blood pressure for a long time and also experienced seasonal affective disorder. She said 'I suffer from SAD ... but knowing I lack vitamin D, as informed by my Doctors who wrote to me about it', meant she knew she should sit in her garden whenever possible.

Despite Marie's generally high opinion of the health service, she was very reluctant to make use of health services: she would only consult her own General Practitioner and even then, never discussed her mental health. Marie did not offer a reason for her reluctance to get help for her mental health troubles, but she did describe difficulty using the telephone ring-back system:

Yes, I find some difficulty with that and again the doctor has to call you back, if it requires a doctor to call you back. Sometimes you miss the call because I don't use my mobile as effectively as I should and if I do not have it on me, I could miss the call for the day. And they may ring when somebody may be on the phone or when it's not convenient. That is the only thing, but I go with the flow.

The difficulties of making contact with a healthcare professional may have under-pinned Marie's reluctance to discuss mental illness with her GP, but it was not presented as a cause for complaint.

UK: Agathe, 43 years old, Rwandan born, divorced, and employed as a part-time support worker, like Marie, did not complain. She repeated more than once 'I trust the GP' and cited the diagnosis of her diabetes as a reason for being positive about and grateful for services. A couple of years earlier Agathe had had a 'personal situation that caused to have high level of depression' so she had visited her GP who referred her to the counsellor, and when, after a three month wait, the counsellor got in touch, she learned that she was only to be offered monthly contact. She explained:

Yes, it was long time to wait. I was seen after three months. Then we could meet every month. It might not have been enough but she had many people to deal with. What she was saying was that she didn't see any need for us to meet so often because she thought that I took all the steps that I was supposed to take. So, I didn't see any need of meet again, because I didn't want to go through it again and again.

Agathe did not complain about the delayed and restricted access to a limited service at her moment of crisis, but rather justified the situation explaining that a widespread lack of funding led to a shortage of resources for all service users. Neither Marie nor Agathe sought out alternatives to the anonymous service that did not meet their needs, and nor did they find alternative routes to access the care that they lacked. Their gratitude was aimed at the health service in general and was not affected by their own experience. Their acceptance of the anonymous care that did not meet their own needs was explained by the general shortage of funding and personnel which affected everyone.

Sweden: Laila and Aisha were close friends and neighbours. In their 50s, they had migrated from East Africa twenty years earlier, worked full time, and spoke Swedish fluently, although the interview was conducted in their mother tongue. While these women did not express gratitude explicitly, they were reluctant to criticise the health system despite having experienced severe failures of care. Without describing the details that would make her identifiable, Laila had lost a baby at term and Aisha's daughter had had a near miss when giving birth. Laila's loss was not an isolated case, with city-level data showing elevated peri-natal mortality rates for women of sub-Saharan African origin when compared with native Swedes (Essén, Hanson, Ostergren, Lindquist, & Gudmundsson, 2000). Despite failures of care which they described as avoidable, and despite feeling that their foreign-accented Swedish meant being deprioritised for care when booking appointments through the telephone system, Aisha and Laila would not criticise the healthcare system.

Laila and Aisha expressed generalised gratitude for the public healthcare system and made no link to their own negative experiences where anonymous care failed them. The universal system of healthcare offers equal access to all those with Swedish residency rights and these women could not or would not mobilise their own experience as evidence that this founding principle had failed. This is striking given that they felt they were consistently deprioritised due to their foreign accents.

Finally, we describe two women, whose 'positional gratitude' was expressed in the face of limited or negligent provision of healthcare because of obligations felt to apply to immigrants in particular.

Sweden: Wangui, aged 52 and originally from Kenya, had been in Sweden for twenty years, had learned Swedish, and worked as an auxiliary nurse. She said that in Sweden there is 'help everywhere' and that it is easy to get help. However, speaking and understanding the language is 'very important' in order to be able to get the help needed.³

Despite her positive assessment of the Swedish healthcare system, Wangui had had a recent allergic reaction to pollen and the medication she had been issued through the primary care centre and the pharmacy had given her a further adverse reaction which necessitated cortisone treatment. Neither the doctor nor the pharmacist had informed her of possible side-effects, but Wangui was adamant that she could not hold these professionals accountable for the difficulty that she had faced, given the stress under which they work. As a response to having suffered an adverse reaction, Wangui emphasised that she would avoid consulting the health services again in the future.

Wangui felt that rather than complaining about services, people should be thankful, and with reference to immigrants, they should always think about what they have left behind in their country of origin, which should induce gratitude for what was available in Sweden.

Sweden: Sara, a 60-year-old woman of Palestinian origin, had been in Sweden for more than a decade. She spoke and read very little Swedish and was largely illiterate in Arabic. Her uncertainty about reading meant that she mostly stayed at home unless chaperoned by her husband or children. Sometimes she went to a local Arabic-speaking playgroup for social contact even though she had no young children.

Sara worried about her family back home, disliked the long dark winters, and had a painful knee arising from a traffic accident for which she said she was unable to get appropriate treatment. Sara was receiving support for mental health problems, but was reluctant to discuss this. She reported a lack of interpretation services at healthcare encounters and that her doctor at a specialist centre said an operation was not appropriate for her knee problem, recommending that Sara exercise instead. Sara implied (but did not state) that exercise was not an appropriate treatment for her injured knee. The interviewer asked Sara whether her experience of healthcare was *mabsoota* مابسوطة, which translates as something between 'happy' and 'satisfied'. Sara replied that she was happy/satisfied with her healthcare.

Rather than talk about healthcare, Sara described her domestic circumstances, which were the cause of distress and sadness: she was living in temporary accommodation because her house and contents had burned down. With tears in her eyes, Sara expressed her relief that nothing happened to her children during the fire and said:

I really love this country and the people here. I love the doctors, the nurses, they are all very nice and helpful. If you would go to any Arab country, no one would look at you, no one would care ... it is true that there is a better social life there but there is a system here and there is everything and they help so they are all very kind.

Interviewer: so, you are getting the help and support that you need here?

Sara: yes, yes, they are very good, we respect them and all my children respect them. When we came here, they opened their borders and we were able to stay and live and educate our children and raise them.

Discussion

The cases described here are a minority of those interviewed for a wider study of how healthcare works in diverse neighbourhoods. In the wider sample, there were cases of isolated, elderly, or illiterate people who had good access to appropriate services and other people who reported serious problems with health services and were anything but grateful. These eight cases were unusual because gratitude was explicitly expressed, despite the receipt of poor or negligent services. We are neither claiming wholesale failure of national health services, nor a universal aspect of gratitude. Rather, we are interested in how expressions of gratitude in the face of poor healthcare can be understood in the context of anonymous care aimed at national populations. The retraction of services on the grounds of austerity or the unwillingness to make universal services more accessible and approachable to diverse populations is linked to a politics of welfare chauvinism and we link this to women's expression of gratitude.

The cases under discussion here are all women who had a migrant background and who expressed gratitude for the healthcare system, despite the experience of poor, inadequate, or negligent service. The women who we described as showing situational gratitude criticised the healthcare they had received, but had means of seeking alternative therapies (Sila), alternative access to public healthcare (Norma), or NGO-supported access (Manu). Despite criticism of specific care providers, their situational gratitude was expressed for the health service in general. Two UK women expressed a generalised gratitude for the healthcare system and did not have alternatives to the compromised and limited healthcare which failed to meet their own needs. Agathe and Marie had mental health problems and they did not identify alternative forms of healthcare or alternative access to the public system. These two women justified the failure of care that they experienced as being a result of austerity cuts. Laila and Aisha, from Sweden, also expressed generalised gratitude for the universal system, despite negligent care and their own needs being deprioritised and dismissed. Finally, positional gratitude was expressed by Wangui and Sara, who, despite highly negative experiences, said that immigrants ought to be grateful, even where services are inadequate.

This paper suggests that when the norms of anonymous care ignore subjectivity in healthcare settings, this inattention can be itself injurious (Stevenson, 2014, p. 19). Sila protested against a system that only treats symptoms, while Marie, Agathe, and Sara had mental health problems that they could not or would not discuss with healthcare providers. Wangui, Sila, and Norma (who did not report mental health difficulties) described avoiding public healthcare providers where possible, while Manu was only prepared to consult the doctor she identified as 'good'.

Women's tendency to express gratitude and support of the system, even while shouldering a disproportionate burden of inequality (Williams & Labonte, 2007), suggests that the normative ideal of anonymous care is widely understood and accepted. Why such expressions of gratitude persist when the actual service does not respond to urgent needs, requires further attention. Our suggestion is that the politics of welfare chauvinism is an important context in which to develop such understanding, while bearing in mind the specific ways that this played out in different countries.

These expressions of gratitude were from women of non-European immigrant background, who, with the exception of Sila (born in France), had been born outside Europe. The interviews were conducted between September 2015 and April 2017, coinciding with the arrival of

unprecedented numbers of asylum seekers to Europe and a rise in public expressions of populist xenophobia, linked to efforts to restrict welfare, labelling some groups as undeserving. These women were visible migrants to varying degrees, as a result of their appearance, dress, spoken language, or accent. Only Sara and Manu did not speak the local language, but others (Aisha and Laila) felt their accent marked them out as foreign-born. Skin colour and wearing a head-scarf made others feel themselves to be part of a visible minority. Migrants describe their own sense of being vulnerably visible, which is particularly painful when their entitlement to access health services is contested (Bradby et al., 2017; Padilla et al., 2018). Women, and particularly those with children, are often seen as a burden on the public system by failing to speak the local national language or to follow normative dress codes or dietary habits (Gedalof, 2009; Yuval-Davis, Anthias, & Campling, 1989). A repeated reiteration of gratitude can be seen as an effort to acknowledge anonymous care as a legitimate system of distributing healthcare and avoid being identified as excessively needy, undeserving newcomers.

The ways in which gratitude was expressed can be linked to the local politics of welfare as well as migration. In Lisbon, there has long been a parallel healthcare system – Santa Casa da Misericórdia – which means that searching out alternatives to the mainstream public health and social care might be more common than in the UK or Sweden. NGOs have developed over past decades to support new arrivals' access to healthcare, particularly those who are vulnerable, while the pressure on public healthcare from the Troika cuts has been shared across the population. In the UK, women mentioned the politics of austerity, where everyone is affected by restricted resources, as a key circumstance, and austerity is unavoidable as a central debate in healthcare. In Sweden, where the strong welfare system and universal healthcare are a matter of national pride, there was an unwillingness to make any general criticism. Integration has been the by-word in managing migration and any general criticism could be taken as a failure to integrate appropriately.

If welfare chauvinism is part of the circumstances for understanding gratitude in Sweden, the UK, and Portugal, where the politics of welfare and migration have been linked, why not Germany too? Why were no similar expressions of gratitude found in Bremen neighbourhoods?

The cases described here are rare in our overall sample and our diversity-sampling method may have simply not captured similar cases in the Bremen neighbourhoods. Another explanation may be that the universal models of public healthcare provision that characterise the Swedish, Portuguese, and British systems are more likely to reproduce normative aspects of anonymous care. The social insurance model of provision in Germany, whereby patients choose a service provider that their insurance agency subsequently reimburses, may be less likely to result in norm-driven-care. Healthcare in Germany is not provided as a one-size-fits-all universal system and patients are required to shop around various providers in order to find appropriate care. In this sense, the care provision does not amplify the logic of 'anonymous care' and norms that might be driven by biopolitics may be differently configured.

Conclusion

The welfare state is held up as a progressive means of imagining our shared humanity (Crepaz & Lijphart, 2008) and social healthcare is a key aspect of this ideal. By attending to failures, we can begin to imagine healthcare systems that avoid the negative normative aspects of anonymous care. In an era of neoliberal reform, where even public and universal services are increasingly provided by for-profit organisations, the metrics that monitor effectiveness and quality are crucial. Efforts to improve the quality of healthcare services through commercial models of 'client' feedback would not map the failures of care described in this paper. The experiences of these women would not be registered in customer satisfaction surveys and their pain and suffering would not trigger any quality improvement action: their disappointments would remain hidden from the metrics of quality assessment. At the very least, this analysis adds to the evidence that high levels of patient satisfaction can be combined with poor experience of services, suggesting 'experience'

rather than 'satisfaction' as a better measure of the quality of healthcare provision (Jenkinson, Coulter, & Bruster, 2002).

We have offered a general critique of universal healthcare systems that create harm by ignoring individual needs. To have one's suffering go unrecognised or diminished represents a potential injury of normative anonymous care and is restricted neither to migrants nor to women. To feel that gratitude should be expressed for that inadequate care, possibly to distance oneself from other immigrants who are seen as ineligible for services, compounds that harm. We only found these expressions of gratitude for poor service provision among women of migrant background.

The women whose cases we describe represent an extreme case in that their entitlement to claim healthcare may be called into question as immigrants who are seen as excessively 'needy' and/or insufficiently integrated in a context of welfare chauvinism. These marginalised women reveal the shortcomings and limitations of the provision of anonymous care – the harm that it produces and the costs for those trying to access care when their injuries are compounded. These women's accounts call into question the notion of universal care. The costs and injuries that their stories reveal may not only be accruing to marginalised women of migrant background, but also to others whose needs are less visible because their marginalisation is not so extreme or not so stigmatised. The ideal of the human right to health and the principle of healthcare available on the basis of need are not fulfilled in these cases. If universal healthcare systems are to be able to fulfil the promise of universal access for populations characterised by migration-driven diversity, then new ways of making healthcare not only accessible, but also approachable, equitable, and appropriate are called for, along with greater attention to subjective aspects of need.

The means of addressing unmet need, as described by these women of migrant background, have been well described already: good quality and accessible interpretation and cultural mediation services, together with sensitive out-reach for populations marginalised through old age, mental distress, and/or poverty. Unfortunately, these are exactly the services which tend to be cut first under conditions of austerity, although the claim to be providing a universal service is not dropped.

Notes

1. <https://ec.europa.eu/migrant-integration/librarydoc/integration-of-immigrants-in-the-european-union—special-eurobarometer-survey>
2. All names are pseudonyms and some details of the stories are withheld to avoid identifying the interviewees.
3. Wangui requested that the interview not be audio-recorded and therefore her words were noted down by the interviewer.

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