The word nobody used

Sociologist Alexandra Lopes on what long-term care systems reveal about inequality, and what they manage to keep out of sight

Lets-Care project

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Author: REVES Aisbl

You can see it from the corridor.

In the Portuguese rehabilitation units where the LeTs-Care researchers carried out one of their ethnographies, the workforce is colour-coded and uniforms mark professional groups. At the bottom are the blue ones: the cleaners, the ones who bathe residents, change the beds, do the heavy work.

"All ladies," says Alexandra Lopes, who coordinates the University of Porto team within the project. "Most of them black ladies, often from Portugal's former colonies."

Above them, white garments: nurses, physiotherapists, speech therapists. Still mostly women, but this time nationals, white. Above them, the doctors. Men.

"No collar, no colour," Lopes says. "Those can wear their own outfits. They just keep the stethoscope around their neck. It's there. That's the symbol."

The observation costs nothing to make. No survey, no dataset, no ethics protocol. "You don't even need to ask, you don't need to collect data. It's there. You just walk in the corridors and it's there."

Which raises an obvious question. If inequality is that visible, why is it so hard to talk about?

Lopes led the LeTs-Care work on the meanings of inequality in long-term care as they show in policy debates and stakeholders' narratives across the project's seven countries, namely Austria, Denmark, Italy, Lithuania, the Netherlands, Portugal and Spain.

One of her findings has to do with something that goes much deeper than care systems: language.

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In the interviews with stakeholders all across the seven countries, "we noticed that the word 'inequality' was avoided a lot. It was absent. So, it's one of those classic cases where silence speaks a lot."

They had other words. Differences. Heterogeneity. Disparities. Variation.

"When you say there is inequality, in a way you are recognising that there is something unfair that needs to be corrected. When you talk about differences, when you talk about variation, it's a bit more neutral. It doesn't carry that moral obligation to do something about it."

The scientific literature has no such difficulty though. Horizontal inequality, vertical inequality, equity, the vocabulary is settled and shared. It is the people who run, fund and regulate care systems who reach for the softer term.

There is another layer to that silence. Inequality, as a statistical topic in its own terms, is not included in any national statistics on long-term care in any of the seven countries, with the partial yet very relevant exception of Spain. More about it later.

There is plenty of data about long-term care. There is no data organised around the question of who is being treated unfairly and how. What exists is administrative data, collected for other purposes, which "sometimes, incidentally, reveals gaps."

And if something is statistically invisible, Lopes says, it remains invisible as a political problem.

So where does inequality actually live?

The project found it in several places at once, and in different places depending on the country.

Two systems, two problems

The first divide is between kinds of system, and it determines what the word "inequality" is even asking about.

Denmark, the Netherlands and, to a degree, Austria run long-term care built on a universal right, with the principle written into law. Lopes calls them egalitarian by design. Someone who needs care has a right to care, and the system allocates the resources to honour it. The classic sources of inequality are handled by default, which is why her interviewees there found the topic slightly odd. At worst, they treated it as a side effect of a system underperforming. Not a feature of how it was built.

Portugal, Spain, Italy and Lithuania sit elsewhere.

Latecomers to formal provision, they heavily rely on informal care, with coverage gaps and territorial imbalances to match. And while eligibility does rest on assessed need, there is not enough provision to meet it. And where the public system runs out, what you can afford determines what happens next: a live-in carer, a commercial home-help service, a bed in a private nursing home. Access, in Lopes's words, is constrained, "or you can even say rationed by what people can afford."

"In these countries you could say that inequality is not a vague thing, it's not an abstraction. It's something very real. It's the daily reality of who gets cared for and who doesn't."

The same word therefore describes two different problems.

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Where coverage is short, the question is quantity - access or no access. Where coverage is universal, it shifts to quality and choice: more hours of assistance, additional devices for complex needs, a better room. "If you have a bigger pocket, you can have a slightly better quality of care."

That second problem is real, and Lopes does not dismiss it. But it is a problem you can only have once the first one has been solved. Reading the two through a single European lens produces nonsense in both directions: it makes Danish concerns look trivial and Portuguese ones look like a service-quality gap that better management would close. "I would say that in both settings, though, inequality as a political problem remains very shy."

Gender: the one thing everybody names

Gender is the exception to the silence. Lopes calls it the usual suspect, the topic that gathered the widest consensus across all seven countries, and the one most clearly present in national debates. Put inequality on the table and this is what stakeholders reach for first.

The reason is partly that the evidence is overwhelming and partly that the ground was prepared elsewhere. Decades of policy argument about gender equality and work-family balance have made this a legible category; care was always going to be where it landed.

Care work, formal and informal, has been done overwhelmingly by women, on the assumption that it comes naturally to them, which is precisely why it pays badly and carries so little recognition. Hard work, low salaries, difficult hours. The effects then compound outwards: interrupted careers, lower lifetime earnings, documented damage to physical and mental health, and a direct line into old-age poverty among women.

The majority of informal carers in every one of the seven countries are women.

Territory: the paradox

Territorial inequality is where the project's method earns its keep, because the finding is one that no single-country study could have produced.

Almost every LeTs-Care country decentralises long-term care to some degree. And almost everywhere, stakeholders name decentralisation itself as a source of inequality. Even in Denmark - the most egalitarian system of the seven, organised at municipal level, decentralised down to a very micro level of governance - interviewees pointed out that different municipalities may apply different eligibility criteria and different quality standards. Your postal code should not determine the care you receive; in practice it does.

Then there is Portugal: the one heavily centralised system in the project. The complaint there is identical in shape and exactly opposite in content. Because the system is so centralised, the argument goes, it has no flexibility to adapt to the specificities of each territory, to what each place actually needs. So, you end up with inequalities across the country because of centralisation.

Same grievance. Opposite diagnosis. And both, from inside their own systems, entirely coherent.

This is not a curiosity. It has direct consequences for how European institutions write about care, because EU and OECD documents tend to treat decentralisation as self-evidently good. Never stated

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outright, Lopes says - you read it between the lines, as "a kind of call for countries that are more centralised to become more decentralised." Subsidiarity, local responsiveness, proximity to need: the merits are assumed rather than argued.

Put that recommendation in front of the seven countries and it doesn't hold.

A Portuguese stakeholder would welcome the pressure, because in Portugal decentralisation means the possibility of a service shaped to the place it serves. A Spanish stakeholder would be far more sceptical, because in Spain decentralisation is not a proposal but a lived arrangement: care is a competence of the autonomous communities, and the gap between what a wealthy region can fund and what a poorer one can is impossible to ignore. Meanwhile Denmark, already as decentralised as it gets, is building a national framework of shared standards, moving in the direction the recommendation would steer countries away from, and for exactly the reason the recommendation overlooks.

The word "decentralisation" simply doesn't mean the same thing across these countries.

"We are pressing towards a shared direction as if we are all coming from the same place, when we are not."

This is the core LeTs-Care claim, arriving through a policy debate rather than a theoretical one. Not that harmonisation is wrong, but that harmonised vocabulary can conceal how differently the same term functions in each system. When a European framework says needs, or sustainability, or decentralisation, seven sets of stakeholders hear seven things, and a recommendation calibrated for one of them may be inert or actively harmful in another.

Where the data exists

There is one place where the numbers are there, and it shows what changes when they are.

For a decade IMSERSO, the Spanish national body overseeing long-term care, has been collecting and publishing at a level no other country in the project approaches. Waiting lists. Types of care received. Broken down by gender, by age bracket, by region, by socioeconomic status, by education level. "And the data is publicly available, which is great," says Lopes.

None of it is organised around the concept of inequality, that category still doesn't exist in national statistics anywhere. What Spain has is a rich administrative record, built to run the system rather than to interrogate it, in which the inequalities become impossible to miss. "They are collecting data, and the data makes it visible that there are inequalities."

The consequence shows up in Spanish politics. Territorial inequality is a hard, live argument there and largely a non-topic elsewhere, not because Spanish regions differ more than Italian or Portuguese ones, but because in Spain the difference has been counted. The gap between what a wealthy autonomous community can fund and what a poorer one can is not a suspicion or an anecdote. It is a published table.

"If the data is there, sitting in front of you, you can't ignore it."

Lopes is careful not to overclaim the direction of travel. Better data may push a problem onto the agenda; a problem already on the agenda may be what produces the data. She points out that Spain's

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long-term care debate has been running for twenty years or more, the data may be the consequence of the argument as much as its cause. "They seem to go hand in hand. They seem to travel together."

Either way, the asymmetry stands. Six countries where regional variation in care is common knowledge and doesn't carry much political weight. One where it is a hot topic in political debates.

What the data cannot see

Existing statistics usually permit one comparison at a time. Poor and well-off. Men and women. Rural and urban. Migrant and national. What they do not permit is the cross-tabulation.

Go back to the blue uniforms.

What is visible there is not gender inequality, or racial inequality, or class inequality, or the position of migrants in a national labour market. It is all four, in the same person. A woman. Black. Migrant, or the daughter of migrants from a former Portuguese colony. Low formal education, low pay, and the heaviest physical work in the building. Move one floor up the hierarchy and one of those variables drops away – the nurses and therapists are still overwhelmingly women, but nationals, and white. Reach the doctors and two more fall: men, and no uniform to mark them at all.

Each of those categories exists separately in the statistics. Nobody counts the woman who is all of them.

And Lopes is careful that this is not simply a striking image.

"This is not just an observation," she says. It shapes how the organisation actually runs, the daily operations, the way teams work, the distribution of power inside the building. The people at the bottom of the food chain are also the people with the least capacity to change anything about it.

An intersectional perspective is missing from the discussion because it is missing from the data.

Some of the stakeholders LeTs-Care interviewed run services in remote rural regions, and their difficulty is not funding a post but filling it. Nursing home residents are older than they used to be and arrive with several conditions at once, needing health assistance. So the home needs a nurse on site. In some areas there are simply no nurses to hire. They are not there.

What happens instead is that the home contracts a nurse who lives a hundred kilometres away, on a service-provision basis rather than a proper employment contract. She comes when she is needed, three times a week, or thereabouts. The home pays by the hour, and pays for the travel.

"The financial pressure this puts on these organisations – most of them non-profits with limited funding that are always operating on very scarce resources - is absolutely crazy. That contrasts, for example, with operations in urban centres, where there is still a shortage of labour, but not at this level."

Just another example pointing at the need of an intersectional approach.

"We can discuss, based on data, socioeconomic inequalities, gender inequalities, territorial inequalities and so on. But when you think about someone who has complex needs, lives in a rural region, is poor, a female, all these layers of disadvantage seem to cluster, come together."

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When assumptions fail

There is one more source of inequality, and it is the one that follows most directly from how the southern European and Baltic systems are built. If a care system quietly assumes that families will do the work, then not having a family becomes a structural disadvantage, and nobody has designed it that way, which is precisely why nobody counts it.

In a rehabilitation unit in Portugal, Lopes's team was looking at discharge dynamics. People are admitted after a fall, a fracture, a stroke, something that leaves them needing rehabilitation, with the aim of getting them home rather than straight into institutional care. They stay a set period and then they leave.

“I remember we interviewed a lady, it was amazing. She was actually the one who approached us, because she was curious about who we were and what we were doing. This was right at the beginning. She was clearly a bit bored, and struggling to walk, and she shared with us that she had taken a fall, broke her leg, had surgery, and was there to recover from the surgery. But it was hard, she was 96 years old. Ninety-six. We couldn't believe our eyes. So we talked with her a bit, and then we left.”

“Some six weeks later, we met her again. She was coming out of the physiotherapy room, so we greeted her, and we realised she was walking much better now, the rehabilitation was working. We asked her how things were going, and she was very sad, because she was feeling very good, she wanted to go back to her place, she was feeling ready to go, but she told us they were having a hard time finding a home-help service for her. She was clearly stressed with the situation. We asked her about family. She did not have any family. She was a widow, she had no children, no extended family. So she was basically stuck there, seeing other people being discharged, maybe people who are not as well health-wise, but still they can find some sort of alternative to be discharged.”

Luckily that story ends well: a solution was eventually found and she went home with the home-help service she needed. But the mechanism does not end well at all.

The same logic runs through the dementia cases in those units, which are not equipped for dementia care and where patients often end up isolated, many of them bed-ridden.

Those with families received visitors, something as simple as regular company, and the stimulation that comes with it. Those without were alone. Nobody is to blame for not having a family. But outcomes diverge according to resources a person can or cannot activate, and a system built on the assumption that those resources exist has made their absence into a penalty.

When the researchers cross the border

The consortium's own meetings turned out to be a small experiment. Each host country organises field visits to care facilities, so partners can see what the others are describing.

After the Netherlands, Lopes asked her Dutch colleagues, half seriously, for a fast route to citizenship: "This is where I want to age!”

When the consortium came to Portugal, she took them to a nursing home run by an associated partner, by Portuguese standards a good one, a top one. The Danish partners were visibly puzzled. The reason was shared bedrooms and shared bathrooms. In Denmark, a private room is a question of

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fundamental rights. In Portugal, with a chronic shortage of places, sharing optimises space, reduces cost, and means more people get in at all.

“If sharing is a question of choice, fine; the problem is that you don't have that choice. And this was very shocking for our Nordic partners. Or, for example, given that here most of these facilities are run by non-profits that have a religious imprint - Catholic imprint - it's very common in these places to have religious symbols everywhere. So you walk in the corridor and you have the cross, the saints, the chapel. It's part of the local culture, and for them this was shocking, because these are supposed to be secular places: what about people who are not Catholic?”

It's in those kinds of details that some of the differences across countries lie.

And that's where LeTs-Care is bringing a meaningful contribution.

“We start from acknowledging precisely this: that in some aspects we are really coming from different planets. This tendency to try to harmonise everything, to assume that we all interpret things the same way, that when we talk about needs we are all talking about the same thing, when we talk about sustainability we are all talking about the same thing, our work has been demonstrating that we are not. And this, in a way, is what the chapter on inequalities is about. That's why inequalities, in a way, cut across all the other themes, all the other chapters.”

Lopes believes this is a much more nuanced field than sometimes international and even national debates seem to suggest.

“And again it comes to the very core of what LeTs-Care is all about: meanings, context-sensitivity. Not all differences should automatically be read as inequalities, but the difficulty sometimes in acknowledging that there are inequalities also should not be taken as evidence that there are no inequalities. So it goes both ways.”

The case for visibility

Inequality involves this idea that something is unfair, and that’s what makes it a dark subject.

Which is precisely why Lopes argues it has to be made visible and put high on the priorities list of international forums.

Despite her criticism about how the EU or OECD often address inequality with that one-size-fits-all approach that may not be the best approach, she acknowledges they have merit in continuing this effort.

The report Lopes led draws a parallel with two topics that took the same route in earlier decades, poverty and disability.

Both are areas of soft policy, where the EU has no power to compel, as with long-term care, the mandate sits with national governments, and there is not much Brussels can impose. What it can do is put the topic at the front of the debate and let comparison do the work. Naming and shaming, in Lopes's phrase, and the EU has used it successfully before.

The poverty precedent is worth spelling out, because the mechanism is not obvious. Following the Nice agreements, Member States agreed on a common set of social indicators – income, material deprivation – to be published annually for every country. Nothing about that compelled anyone to do

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anything. But once the numbers existed, the EU could publish reports comparing Member States on poverty risk and social exclusion, and the comparison itself became the pressure.

"Sometimes I talk about this using the metaphor of the family photo," Lopes says. "You gather the family and take the photo, and everybody goes and puts on their best dress, because no one wants to look bad in the photo."

Some Member States looked very bad indeed in those first photographs. That created an incentive that no directive had created. Convergence, she argues, often comes from exactly this, not from law, but from the discomfort of appearing badly in a comparison you cannot opt out of. Indicators nobody thought twice about at the time are now so embedded in European social policy that it takes an effort to remember they had to be invented.

Long-term care is now at the beginning of the same process. The European Care Strategy of 2022 led to a common framework of indicators for monitoring care systems across Member States, which has since been published. Lopes calls it an embryo, a first version of what could become a far more sophisticated system of data collection. Once reports start appearing on coverage, on care poverty, on unmet needs - topics the scientific literature has been discussing for decades without them reaching the policy arena - the same incentive starts to operate.

None of that reaches everyone equally, though.

Making a problem visible at European level depends on someone being able to describe it.

“The people who are typically most affected, who bear all the impacts of these multiple layers of inequalities, are typically the ones in a weaker position to voice their needs, their situations, their problems.”

Looking at the ecosystems studied by LeTs-Care, the ones who can still somehow voice their agenda are those who have some sort of formal mechanism of organisation and representation, care workers, for instance.

“But when you look at those who receive care, what is the voice of those who are poor, who have very complex care needs, no social support networks? What are the chances of this being heard? Because these are the most vulnerable within the vulnerable, and these are the ones that are typically silenced.”

Lopes believes LeTs-Care is about giving voice to this inner layer that remains a bit invisible. “At least that's the motto that drove us all when we decided to do research in this field.”

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