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Bureaucratic violence: Professionals' views of the financial experiences of terminally ill migrants

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ABSTRACT

Background: Having a terminal illness is associated with an increased risk of living in poverty and destitution at end of life. This is more pronounced for migrants who may not have the same social and cultural capital, or local family support, that established citizens have. This paper explores the financial challenges for migrants with a terminal illness.

Methodology: Qualitative interviews were conducted with healthcare staff, and legal and migration specialists supporting migrants with a terminal illness in the UK. A total of 22 people were interviewed, comprising 14 working within health/palliative care settings, four in legal/policy settings, and four in migrant support.

Findings: Thematic analysis identified that having a terminal illness as a migrant accompanies severe financial and material challenge. Migrants continued to work while receiving chemotherapy and used unregulated money lenders to stave off poverty. The expense of visa applications, insecure visa terms, and exclusion from statutory and healthcare support combined to produce enormous financial, emotional and physical strain on terminally ill migrants. Interviewees situated these challenges as both impediments to their work supporting migrants, and as constituting a form of bureaucratic violence.

Conclusion: Financial precarity for migrants with terminal illness was exacerbated by bureaucratic systems and processes (e.g., immigration policy and welfare exclusion). There is urgent need for systemic reform to ensure that good quality of living and dying is not a privilege of the financially secure. However, this is predicated on a political will and interest to improve the lives and deaths of migrants with terminal illness.

1. Introduction

Dying is an expensive business (Gardiner et al., 2014). Financial hardship can occur due to loss of paid employment for the person with terminal illness and/or family caregivers, expenses associated with adapting the home to accommodate disability, costs of travelling to receive treatment, and in some countries the cost of healthcare itself (Dumont et al., 2009). Terminal illness can therefore have a detrimental impact on financial stability, increasing the risk of poverty and destitution (Aoun et al., 2005; Bowers et al., 2022; Emanuel et al., 2010; Jacobs et al., 2011; Lewis et al., 2011; Marie Curie, 2022; Quinn et al., 2023; Richards et al., 2024).

Studies in Poland, Czechia, Germany, India and Australia show that financial hardship is an internationally recognised phenomenon for people with a terminal illness (Aoun et al., 2005; Emanuel et al., 2010; Forbat, 2023). In the UK, an estimated 90,000 people die each year in poverty (Marie Curie, 2022) with the impact of terminal illness posing substantial financial risks to individuals and families (Quinn et al., 2023; Rowley et al., 2021b). Lower socio-economic status is a determinant of worse care provision at end of life with higher hospital use and hospital deaths (Davies et al., 2019) which is a proxy for poorer quality of death, (Wright et al., 2010), lower levels of hospice at home services (Buck et al., 2020), and reduced quality of life in the final months (Liao et al., 1999). The evidence about financial precarity has led to a call for more critical engagement in poverty research within palliative care to address the social context of death and dying (Richards, 2022; Stajduhar, 2020). While studies noted above are from high income countries, studies from the global south also indicate substantial financial hardship for families affected by terminal illness (Agom et al., 2021; Perez Murcia, 2023; Risat, 2023).

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Financial support for families of people at the end of life varies internationally, yet evidence suggests suboptimal provision across a range of countries including Australia, Canada, Ireland, New Zealand, the United Kingdom and the United States (Gardiner et al., 2019). Understanding and accessing support can represent an additional layer of labour for families already managing the demands of terminal illness. Charitable operations such as soup kitchens and foodbanks supplement support which is provided through state mechanisms (Gardiner et al., 2019). Poverty has been suggested as a component of *total pain* (Malhotra et al., 2020) which was initially proposed to include physical, psychosocial, and spiritual distress (Rowley et al., 2021a).

Many UK migrants originate from EU countries and/or are white (Migration Observatory, 2024). Those arriving with employment visas, often have substantial assets and can be in the top 1 % of earners (Advani et al., 2025). However, the risk of financial hardship is particularly prevalent for people from Black and minoritized ethnic groups (Stone & Hirsch, 2022). Two fifths of working age people from minority ethnic backgrounds, not just migrants, die below the poverty line (Marie Curie, 2022; Richards et al., 2024; Rowley et al., 2021a; Walker-Pow et al., 2024). Similar to the UK population as a whole, around one fifth of migrant households in the UK are living in poverty (Joseph Rowntree Foundation, 2020; Leon & Broadhead, 2024). Indeed, since 2019, there has been an increase of 136 % in destitute migrants in the UK (Fitzpatrick et al., 2023). Compatible patterns areobserved across Europe (Kesler, 2015).

Migrants on UK visas are commonly subject to 'no recourse to public funds' (NRPF), which limit access to state-provided services and financial support available to permanent residents and citizens. NRPF prevents fiscal costs from non-nationals accessing welfare or benefits. Hence NRPF can be understood as a deterrent against health tourism. The UK's explicit 'hostile environment' (Essex et al., 2022) for migration has led to tightening of NRPF conditions and increases in charges to migrants including the Immigration Health Surcharge (IHS), which allows use of NHS services (Alexander et al., 2025; Gower & McKinney, 2023). Having NRPF is strongly associated with financial insecurity and destitution, especially among groups such as minoritized women, or families with mixed immigration status (Dickson & Rosen, 2021; Jolly et al., 2022). The rights and entitlements linked to the NRPF are complicated and quite often misunderstood, which can lead to a lack of support from service providers, and reluctance for migrants to engage with public services (Farmer, 2017; Jolly et al., 2022; Lacey & Moran, 2023). A survey of social work professionals identified common barriers to supporting migrants subject to NRPF, which included insufficient resources, knowledge, skills, training, and support, as well as negative attitudes towards migrants (Lacey & Moran, 2023). Nonetheless, some professionals constructively sought workarounds despite these constraints.

The restriction of welfare access has been interpreted as an intentional feature of the migration policy framework. Mayblin et al. (2020) describe how such constraints shape the lived experience of asylum seekers in the UK, producing forms of slow cumulative harm that limit autonomy and participation in social and economic life – effects that have been theorised as necropolitical. Consumed with survival, this prevents any acts of resistance as people seeking asylum become passive, existing but not living, and in close proximity to 'economic, social and cultural death at the hands of governments' (Mayblin et al., 2020, p. 108).

Less understood are the challenges and financial implications that lie at the intersections of being both a *migrant* and having a *terminal illness* (Begum et al., 2022), especially if subject to NRPF and its complexities (St Christopher's Hospice, 2025). Although most migrants are healthier than the general population of both the adopted country and the country of origin (Kennedy et al., 2015), for some, serious illness will be part of their experience. Obstacles to accessing public funds due to NRPF, IHS costs and the financial consequences of being unable to work while ill are considerable. For migrants whose life in the UK is dependent upon visas, changing work/study practices or reducing work/study hours due to illness may violate visa requirements; an entire families' immigration status may depend on the activities of the person affected by illness. Therefore, those affected face the dilemma of continuing to work/study while unwell, having to cease work, or their relatives undertaking undocumented work. Migrants may also lack an intergenerational financial safety net and social capital of extended family members and/or parents in the same country (Ryan et al., 2015). Working migrants may also feel additional pressures related to providing financial support to family overseas.

Many migrants will be of working-age, a life stage associated with elevated risk for experiencing financial hardship with a terminal illness (Stone, 2024). People in their thirties and forties are particularly vulnerable to a substantial reduction in income due to inability to work (Timmons et al., 2013). Combining this with lack of access to State benefits (Moffatt & Mackintosh, 2009), alongside recognised deficits in culturally appropriate care (Schuster-Wallace et al., 2022), the multiple layers of risk and disadvantage become clear. A recent systematic review identified financial precarity as a recurring theme for terminally ill first-generation migrants (Sedgley et al., 2025).

Yet little is known about the experience of migrants, despite the layers of disadvantage they face, with limited social/cultural and economic capital and local family support. The focus of the research we present here is on professionals supporting terminally ill migrants, whose experiences can be hidden behind multiple layers of inequity.

2. Methodology

This was an inductive embedded multiple methods study. This paper reports one dataset, focused on qualitative interviews. The research questions guiding this part of the study were: (i) What are the experiences of financial precarity for terminally ill migrants? (ii) What strategies are used to manage financial precarity?

2.1. Sample

This study aimed to recruit to three cohorts.

1. Lived experience: people aged 18+ in the UK with lived experience of terminal illness and migration (and family members).
2. Professional supports: people supporting migrants and their family members affected by terminal illness.
3. Policy/Law: Current or former employees of the Home Office or local/national governments and legal practitioners.

2.2. Recruitment

Recruitment was conducted UK-wide via a wide range of organisations including (but not limited to), organisations supporting migrants/carers/patients, those providing financial advice and guidance, solicitors and immigration lawyers, hospices and palliative care providers, faith-based organisations, and local authorities (including No Recourse to Public Funds and Human Rights' departments). In total, approximately 300 organisations were contacted directly, although the reach was likely to be far higher with organisations forwarding adverts and recruitment materials to their own networks.

Patient/public involvement team members (people with lived experience of migration and terminal illness) and Steering Group members also shared recruitment materials with their networks.

Snowballing and social media (e.g. Twitter/X, LinkedIn, Facebook) were used, to expand the number and geographic spread of participants. Despite extensive efforts, it was not possible to recruit terminally ill migrants to participate in the study. The methods and findings below therefore reflect interviews with professional supports and policy/legal personnel.

2.3. Data collection

Separate interview topic guides were developed for each of the participant groups. Questions focused on, for example, key concerns, functional and maladaptive service responses, how people navigate treatment, work, and visa requirements, how terminally ill migrants manage financially, enablers and barriers to navigating healthcare, and immigration law.

Data were collected by two female post-doctoral qualitative researchers [JA and LF] with more than 10 and 25 years of experience respectively. There was no relationship between researchers and participants prior to data collection.

One-to-one interviews and a focus group were conducted, with all data collection occurring online, at the request of participants. Most interviews were one-off, though one participant requested a follow-up interview. All interviews were recorded, with consent, anonymised and transcribed. Interviews ranged from 38 to 84 min, with an average of 61 min per interview; one participant engaged in a 25-min follow-up interview. Transcripts were not returned to respondents.

2.4. Analysis

Thematic analysis (Braun & Clarke, 2006, 2022) was used to generate key themes across the dataset and to ensure that analysis moved beyond description to offer a cogent and theoretically rich contribution. Analysis was inductive, but data interpretation also drew on broader theories, for example, from feminist and critical race theory. Intersectional analysis was also applied (Bürkner, 2012) acknowledging people's multiple social identities and the way these inform social location.

Intersectionality (Collins et al., 2021) was understood both as a theoretical framework and as a methodological orientation, guiding attention to how (e.g.) race, ethnicity, gender, income, locality, and health status intersected within systems of power and inequality. During coding and theme development, we used analytic memos to capture reflections on how these dimensions interacted in participants' accounts, and to identify patterns of privilege and disadvantage across the dataset. Rather than treating social categories as discrete or additive, we examined how particular combinations of positionality produced distinct experiences of financial strain and care access. Team-based reflexive discussions were used to interrogate our own assumptions and positionalities, ensuring that interpretations remained grounded in participants' lived experiences and attuned to structural contexts influencing end-of-life financial hardship.

Three members of the research team [JA, LF, TS] were involved in analysis and contributed to coding transcripts and creating the coding framework using Nvivo. Analysis was an iterative process, and the researchers independently coded transcripts, reviewed each other's coding, and met regularly to discuss and unpick analytic decision-making. Theoretical sufficiency was reached.

Table 1
Participant characteristics.

Role
Solicitor
Immigration Lawyer
Resettlement Policy Officer
Local Authority Service Lead
Immigration Advisor
Family Support Social Worker
Clinical Nurse Specialist
Palliative Care Social Worker
Refugee Support Case Worker
Family Support Social Worker
Social Work Student (hospice-based)
Refugee Support Worker
Welfare Rights Case Worker
Refugee Support Worker
Palliative Care Team Focus Group (n = 9)
• Palliative Care Consultant x 1
• Healthcare Assistant x 2
• Nurse x 2
• Clinical Nurse Specialist (CNS) x 4

2.5. Participants

Fourteen interviews and one focus group were conducted, resulting in data collection with a total of 22 people (see Table 1).

Six further people contacted the research team expressing an interest in participating, but did not proceed to interview, either declining due to not meeting inclusion criteria, or not responding to further contact.

Some professionals had a wealth of experience working directly with the intersections of terminal illness and migration. For instance, a solicitor routinely worked with clients meeting our study inclusion criteria and regularly dealt with elements of immigration and asylum. They worked with people fearing persecution; people wishing to bring partners from overseas; students from abroad; people wishing to set up a business or to work in the UK; people that have a terminal illness and cannot return home.

2.6. Ethics

Approval was granted by the University of Stirling ethics panel (reference: 15282) on October 31, 2023.

Participants decided on the mode of data collection (e.g. telephone, in person, MS Teams), and had sight of interview questions in advance. Participants were advised that disclosures of visa violations would not be passed to law enforcement.

2.7. Research team reflexivity

The team comprised individuals who currently or have previously lived as migrants [TS, LF, LLP], and where all team members identify as politically left leaning. The team are ideologically focused on equalities for marginalised people and motivated to address the financial impact of terminal illness on migrants in the UK.

3. Findings

We analysed data from 22 participants (14 individual interviews and one focus group). The coding tree is provided in Fig. 1, and in this paper we report five superordinate themes.

i) Terminal illness as an economic shock
ii) Survival through solidarity
iii) NRPF as institutional invisibility
iv) The financialisation of legal status
v) Work, immigration and the cost of staying alive

3.1. Terminal illness as an economic shock: the collapse of household income

Interviewees witnessed significant financial insecurity among families at the intersections of migration and terminal illness. Families lacked regular income, many were suddenly unable to work, and their visas included the No Recourse to Public Funds (NRPF) condition, which constrained access to State benefits and support. The dramatic effect on people's lives and finances were clear in all interviews, citing risk of eviction, fuel and food poverty:

Often in our setting, it is the patient who has been the person who's been the money provider in the home […] all the family become quite

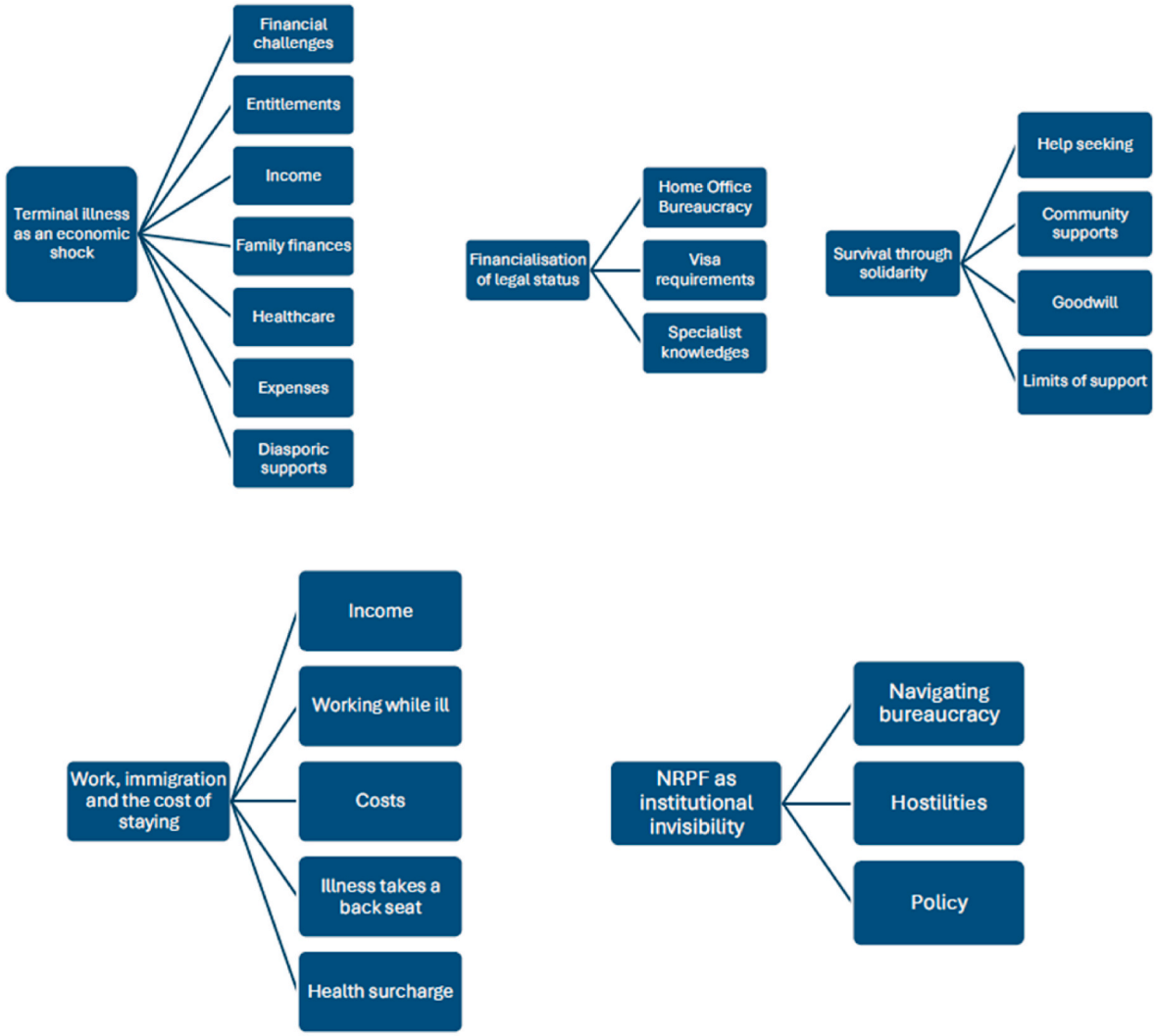

Fig. 1. Coding tree.

vulnerable at the point that they have that terminal diagnosis. (Focus Group - Palliative Care Consultant)

This quote highlights how terminal illness underpins an abrupt and destabilising economic shock when the principal earner has a terminal illness. Such financial trauma was intensified by the uncertainty faced by families when employment and immigration status are placed in jeopardy. In this context, the medical diagnosis became the catalyst for financial precarity.

Some terminally ill migrants got into debt and relied on family for financial assistance. Migrants frequently had dual obligations in supporting family members overseas whilst having to take care of themselves in their host country. In such cases, the global cascading effect of terminal illness is illuminated by a transnational stream of scaffolding currency. Consequently, wider care and responsibility networks are affected, with the economic cost of terminal illness not solely limited to a single-family household.

Some people borrowed money from unregulated and illegal money lenders. This form of predatory lending has extortionate interest rates that are ultimately often unpayable:

I've seen some cases where people end up being pushed to loan sharks. Not payday loans but like loan sharks within the community […] Many have sent funds overseas, sometimes they're in such a situation where they have to ask for money. (P8 – Resettlement Officer)

This implies a risky type of coping strategy, where people are forced to access exploitative networks because of structural exclusion from conventional social and financial support systems.

The support provided by professionals often exceeded the remit of their roles. While palliative care embraces a biopsychosocial approach, the following quotation shows the dominance of housing and heating issues when supporting one terminally ill migrant:

I seem to be dealing with housing issues, to do with rent, and worries. At my first contact visit, this person was sitting with no heating […] It's emotional, because every time I go to see her, she doesn't ask me about pain relief, she doesn't ask me about things that are related to what's meant to … like, my job. She asks me things like she's worrying who's paying her rent. She keeps getting messages from her landlord to pay for the rent. So when she's asking questions, it's 'how am I going to pay this, will they put me out of the house, what will happen to the children' … I just find it all really frustrating because she looks to me to try and help her as much as I can, but it's obviously [outside of] my role. But then I bring it into my role because I want to help her. (P5 - Hospice Nurse)

The speaker's experience illustrates the ethical and moral distress experienced by healthcare practitioners navigating care within systems where basic needs are unmet. Perspectives on care in practice are redefined, as the terminally ill migrant's fear of the consequence of financial insecurity usurps their need for symptom management. Practitioners become case managers by default in a system where joined-up

care is lacking, their emotional labour underscoring a shift in relational care; where clinical care is unavoidably enmeshed with complex bureaucratic social advocacy within an indifferent or hostile system. The quote conveys the pervading concern that obtaining the basic financial and material necessities requires persistence and continual effort and time. The hospice nurse tries to work holistically to fill the gaps in support, but this means they are working outside of their remit.

The data indicated that financial pressures are worsened when terminally ill migrants are responsible for medical bills:

We have some adults who have quite high-level care needs who are being denied healthcare that they require, because they can't pay the charges. Or they get the healthcare because it's urgent or immediately necessarily. But then they are sent a bill for thousands and thousands of pounds that they're never going to be able to pay. (P11 - Local Authority Service Lead)

This exposed the intersection between healthcare as a right and healthcare as a commodity. Palliative care was transfigured into a process of accumulating debt, as access to care was dependent on ability to pay. Consequently, dying migrants were forced to face the stress and anxiety of economic shock and collapse created by the government's requirement for reimbursement.

Some participants noted that financial challenges led people to return to their country of origin rather than face additional post-death costs in the UK. The speaker said after a death in the UK:

The [financial] burden will now fall on their dependants. […] it's cheaper to buy a £1,000 ticket and go home than to go to funeral costs of over £4,000. […] some of them just realise they will never get the help they deserve at that end-of stage, so they realise it might be better to go home, to return back home where there's a community to support. (P10 - Hospice Social Work Student)

The quotation above shows how professionals view terminally ill migrants as having to make end-of-life decisions based on financial consideration, rather than emotional and/or clinical need or preference. Terminally ill migrants must assess the sentimental and symbolic worth of dying in their home country, versus the economic implications of dying in the country to which they have migrated. The idea of 'realising' and 'deserving' are set in contrast to the notion of hope and pervasive financial blockages and constrained community help, which would enable them to die in the UK.

3.2. Survival through solidarity: providing supports that statutory systems don't

Without formal support systems, community networks and informal solidarity become lifelines. The data showed churches, schools, individual professionals, and food banks perform roles far outside their mandates:

[I went] outside of my professional role, I took her to the movies a couple of times just to check in with her because she was struggling so much, and she lives locally, but I was obviously always very careful to stay professional. But she just needed something that wasn't sadness for a little while. (P1 – Immigration lawyer)

Being built on human empathy, as opposed to institutional obligation, such acts illustrated a profoundly relational form of care. Consequently, rather than being universal entitlements, such supports were reliant on the material capacity and moral compass of citizens within the community. The data underscore how sustainability is precarious when the social safety net relies on goodwill rather than policy.

Supports from non-statutory services tended to be short-term and delivered piecemeal:

Usually how [the food bank works], they would give maybe two to three packages for a family and then say, 'you know what, I got you through this short period of time, another solution will have to be found'. In this particular case, the food bank supported this family for weeks, months on end because there was just no other solution. We were really pushing any immediate one-off support to just continue because there was nothing. (P12 – Refugee Support Worker)

The quotation above demonstrates the capacity of individuals within under-resourced services to meet varying moral dilemmas. Short-term crisis-oriented interventions are being extended indefinitely because of inherent structural limitations within the formal system.

Reliance upon these important supports was precarious and unreliable. Interviewees described times when in the absence of statutory levers to assist, they had personally provided support:

In [some] cases I've had to buy food for some people in their situation. I've had managers who were very kind and they say, you know what, let's do this unofficially, let me give you money out of my pocket and do this. (P6 – Palliative Care Social Worker)

There were many examples within the data of professionals moving beyond the remit of their roles to provide support and care for terminally ill migrants. This appeared to be motivated by ensuring people, especially those with NRPF and without any employment or State income, have their most basic needs met. The discretionary nature of this support also introduced inconsistencies based on what resources were locally available and the practitioner's willingness/ability to work outside of their scope of practice.

Such community solidarity, driven by compassion, lead to the provision of items - foodbank access, clothes, housing, etc. Material aid in the form of donated goods may meet subsistence needs but fails to restore autonomy. The absence of financial support means people cannot choose what they eat, wear, or how they live, which are essential markers of personhood and cultural identity. This turns recipients into passive consumers of others' decisions, reinforcing paternalistic models of care where gratitude is implicitly expected and choice is constrained.

Migrants with terminal illness are linguistically framed as passive recipients, they receive rather than participate and are not positioned as active agentic people.

[The church] connected in with the school, and again they went above and beyond, and it was teachers bringing in food, bringing in duvet covers, bringing in clothes […] they had no responsibility to do that, that wasn't their remit, *it wasn't part of their role. But again, just that human-ness, they all wanted to do that, and wanted to provide these things. […] it made sure that she got the things that she needed. (P4 - Social worker)*

Presenting terminally ill migrants passively carries the risk of reinforcing narratives of dependency. Such representations, even when unintended, may shape how needs are assessed and how support is offered, potentially limiting space for agency or co-produced care.

3.3. NRPF as institutionalised invisibility and bureaucratic obstruction

When someone is too unwell to work and earn money, and cannot access State funds, there are considerable repercussions. Interviewees frequently referred to NRPF, as a condition linked to certain visas which limits access to statutory support.

Lack of knowledge about NRPF meant professionals were ill-informed about what services people could access:

My conversations with Adult Social Care in relation to this Chinese gentleman, was, I'd ring them and I'd say, 'he needs help with housing, like, he has no accommodation'. And they'd say, 'we're Adult Social Care, we don't do that'. And I'd say, 'yeah, alright, I've spoken to Housing Options and because he's got No Recourse to Public Funds, they won't help either, and he has care needs because he's currently having chemotherapy, he's super-super-super vulnerable'. And then I'd say, 'he's NRPF' and they'd be like, 'I don't know what that is'. (P7 – Refugee Support Case Worker)

This interviewee illustrated deficits in legal literacy among frontline personnel, resulting in a systemic failure to recognise and address legal conditions that significantly impact service accessibility. The quote captures how NRPF is a hyper-powerful tool for gatekeeping access to resources whilst simultaneously being poorly understood, which leads to confusion, avoidance, and inaction.

One interviewee indicated that the hostile immigration narrative was having specific consequences for dying migrants when combined with misinformation about NRPF:

Councils are biting back at migrants as well. We're getting phone calls saying, 'oh this person's turned up, saying their homeless, sorry but they've got no visa, why would we help them' and you have to then start to look at housing legislations and whatnot and again, going back to that question of domiciling and saying, well you kind of have an obligation. (P2 – Immigration Lawyer)

This reflected the entrenchment of 'the hostile environment' in local practice. NRPF becomes part of a broader narrative of suspicion which contributes to a culture where care is withheld or denied based on immigration status, disregarding the person's vulnerability and genuine need for medical care. Thus, suffering was reframed as a bureaucratic liability versus being a shared human condition.

The NRPF designation functions not only as a legal barrier but as a bureaucratic dead-end - a label that signals non-eligibility across institutional domains. Participants describe professionals and agencies recoiling at the term, using it as a disqualifying shortcut that halts further discussion. This recoil can be understood as a form of moral disengagement and reflects the prevailing neoliberal governance approach, which places a premium on budgetary control, arguably at the cost of providing appropriate care or taking moral responsibility. The small numbers of people affected alongside lack of clarity and ownership, and risk aversion, creates a form of systemic non-responsiveness that effectively renders terminally ill migrants invisible within care and welfare infrastructures.

Other parts of the system were more knowledgeable about NRPF, but this acted as a barrier to help rather than a way of signalling need.

I sit with a colleague who is in a different team, a very good colleague, and the moment she hears 'No Recourse to Public Funds', she is shouting already, 'no, no, no, no, no, we can't provide care'. I'm like, 'keep it down, let's look at it a bit more', [mimics colleague]. 'No, no, no, no, we're not touching it!'. (…) they just see that as a problem, problem, problem, red flag, red flag, red flag, red flag. (P6 – Palliative Care Social Worker)

The quote demonstrates that the negative connotations of NRPF are so fundamental, that the mere mention may provoke strong reactions in professionals and trigger an immediate rejection of support. Consequently, individuals and families may inadvertently be declined support they are entitled to.

Several interviewees (e.g., Palliative Care Social Worker, Immigration Advisor, Refugee Support Case Worker) talked of applying to the Home Office for a Change of Conditions on behalf of their clients. Where successful, this lifts the NRPF condition and enables access to State funding, which in turn can alleviate financial pressures:

We've had record successes, I would say a hundred percent of getting their status changed, we've done that a lot. So, that's a luxury of time we have with working with these patients in a charity or third sector agency. We don't have that in local authority, they wouldn't have allowed me to write a letter to the Home Office, the local authority would say, signpost them to a lawyer, who would then charge them thousands of pounds. So, we've saved grieving patients and their family members thousands of pounds for just picking up our pen. (P6 - Palliative Care Social Worker)

Yet, the approach this social worker talks about is reactive and applied on a case-by-case basis. It is also time-consuming, taking weeks or months, which is time that people with a terminal diagnosis do not necessarily have. This illuminates how third-sector services navigate complex systems in ways that statutory bodies may not.

Professionals supporting terminally ill migrants tried various tactics to circumnavigate obstructions:

There were a few different things that we tried, which we were told no because NRPF status. But there were other things that you could do - but it would be a one-off. (P15 – Refugee Support Worker)

An economic analysis was offered by one interviewee based on their experience of cost allocations. People requiring support who are NRPF are funded through local councils, whereas when people do have recourse to public funds, funding is provided centrally through (e.g.) the Department for Work and Pensions. The idea of 'regularised' visas in the quote below means that it gives the person a form of settled status and hence lifts the NRPF condition:

[Hiring a migration lawyer is] seen as a lot more cost effective by local authorities for them than to have somebody permanently in NRPF and paying for housing, social work. It's … the advice that is given is normally if you regularise the situation so that they can … they're entitled to PIP or Universal Credit, you know, all the different social protection mechanisms, it's a lot more cost effective from a local authority perspective to do that than to have somebody on the books for years and years as NRPF. And especially if they're terminally ill, that's a lot of complications. (P8 – Resettlement Policy Officer)

Moving costs from local council to central government funding meant, especially for complex situations where family members are involved, there was a financial incentive to remove NRPF. One interviewee summarised the pivotal role that NRPF plays in migrants' financial experiences when facing a terminal illness:

This is all down to the imposition of the NRPF condition, and so if we didn't have that then that wouldn't be an issue, and access to benefits would be determined through income and need as it is for everybody else. So, that's the big thing, if you took that away then some of these challenges wouldn't … well, they wouldn't be challenges. (P11 – Service Lead)

Thus, access to welfare is positioned by interviewees as a human right, not as being about bureaucratic justifications and privilege. Yet, it is the bureaucratic mechanisms which dictate terminally ill migrants' access to State services.

3.4. The financial cost of legal status

Migrants faced additional fees to extend, or change, visas. This came at a very high cost alongside the visa health surcharge (mandated for most study/work migrants) and dwindling ability to engage in paid work:

If you've got someone (with a terminal illness) who needs to renew their visa they are still facing the challenge of acquiring a massive fee to get that done in the first place. If they don't have the fee, they might be able to apply for a fee waiver, but there's now a massive backlog in fee waivers. […] The impact of hiking up the immigration health surcharge has probably led to more people not being able to afford their 'leave to remain' applications, and then also needing to apply for the fee waiver, so that probably has an impact [on Home Office backlog]. (P11 – Service Lead)

One consequence of visas expiring was placing people in a very vulnerable legal and migration situation. Visa costs run to tens of thousands of pounds for families and cannot be paid in instalments. For some, claiming asylum was the most cost-effective solution and produced immigration security while their application was processed:

Respondent: … to claim asylum is free.

Interviewer: So effectively, people could be claiming asylum because they don't have enough money, but another kind of immigration status would actually be more appropriate?

Respondent: I think so, yes. (P7 – Refugee Support Case Worker)

Interviewees spoke of families where each member had a different visa status and hence different levels of immigration security:

What we hear of happening sometimes is that families can't afford to pay for [visas for] everybody in the household to secure 'leave to remain' at the same time. So, you might have the parent getting it and not the children or it might be that they can't all regularise together. (P11 – Service Lead)

Although visa waivers can be applied for, this must be done before the visa expires and requires extensive evidence regarding the person's lack of ability to pay. If the visa expires, then this can severely delay another member of the family's ability to apply for settled status, but importantly also mean the individual/s have overstayed their visas:

If that [visa waiver] application is refused, what the Home Office policy says is, that well, you've now got ten days to pay and make the application, otherwise, you're an overstayer. (P2 – Immigration Lawyer)

Overstaying could lead to fewer rights, higher charges and removal/deportation. Substantial delays at the Home Office can therefore have severe consequences for migrants and particularly so for those navigating treatment and the emotional and financial repercussions of a terminal illness.

Visa fees, the Immigration Health Surcharge, and application charges function as blocks to legality and entitlements. When individuals are unable to pay, they risk becoming 'overstayers,' a label that further entrenches exclusion. In this way, in the UK immigration system asylum may not solely be a last resort from persecution, but a last resort from poverty for some.

3.5. Work, immigration and the cost of staying alive

Immigration status is directly tethered to work/study for many migrants. This dynamic forces people with terminal illness to continue working through debilitating treatments, even taking on additional hours to maintain an income for as long as they could. This work delayed the inevitability of joblessness and breached visa conditions.

Accounts of migrants taking on additional hours included those working up to 12 h per day, often in physically demanding work to compensate for anticipated loss of income:

I've had clients working on building sites whilst having their chemotherapy (P14 – Welfare Rights Case Worker)

There is little room for vulnerability within this system; illness becomes a liability, triggering visa insecurity, deportation/removal risk, or destitution. The inability to easily access alternate employment further entrenches precarity, making terminal illness not only a health crisis but a legal and economic emergency.

For others work ceased only when they were hospitalised:

We had that young man who was adamant he was going back to work because he had to or his visa was no longer valid. Even though he went to surgery and had his hip repaired, he then started oncology cancer treatment, and despite all of that and him feeling absolutely wretched he was absolutely adamant that he was going back to work because that was the only thing that was keeping him in the country. (P13 - Clinical Nurse Specialist)

However, most engagement with work was due to fear of financial repercussions or negative changes to their visa status. For example, international students in the UK can only take only 60 days away from their studies due to illness before visa sponsorship is withdrawn. Migrants in the UK on employment visas must apply for an ill-health exemption to be granted more than four weeks of medical leave. Their status in the UK is dependent upon a specific employer's sponsorship, and the rigidity of the visa system meant employers effectively required people to be at work. Tenuous visa status meant that sick pay was not available and if they were unable to work, their employer did not wish to keep them on:

There was one [client who felt obliged to continue working while ill] but he is challenging [the employers] now because they had to force him to leave because he was very unwell, he could not continue. But I think what it is, some of the work visas, you are tied to that employer, you can't switch employment and your renewal of your visa is dependent on them. So, they've got that power over you and I have had meetings with patients who said, we can't continue this employment unfortunately and they can't get sick pay as well, even statutory sick pay. (P6 – Palliative Care Social Worker)

Families with mixed migration status were not necessarily in a stronger position. For example, where a British citizen was terminally ill and had a partner on a visa, the impact was felt across the whole family system. As one interviewee summarised:

The family […] are struggling financially, obviously because the British partner can't work, but the applicant also can't work because they're caring, or anyway, even if they could work, can't work enough for everything that everyone needs. That applicant, can't then apply for public funds because of their immigration status, so can't apply even for non-means tested benefits. It affects entitlement, the carer's allowance, for example. And so they have to choose between financial difficulty or caring for their partner (P3 – Immigration Advisor)

As these quotes illustrate, it was not only the lack of income people are concerned about, but that giving up work meant breaching visa conditions and consequently had ramifications for immigration status. The fundamental human experience of dying, or accompanying a partner through that process, was constrained by bureaucracy and legalities that prioritised work and productivity over providing care:

It's almost like they don't have the privilege to just go through the distress of someone dying. (focus group – Clinical Nurse Specialist)

Both living and dying were borne as financial costs which terminally ill migrants struggle to pay. Interviewees emphasised the dominance of financial worries above their physical health for this group. The speed of resolving issues (like visa/finances) was slow, hence they remained dominant for a long time, resulting in a prolonged focus on psychosocial matters.

4. Discussion

Migrants with terminal illness occupy a very precarious position. Being too unwell to engage in work or study puts them at risk of non-compliance with visa regulations, and risks destitution through reduced income. The use of loan sharks is a clear warning of the level of financial precarity that terminally ill migrants face. With interest rates as high as four million percent, and passports being taken as collateral, the risks are substantial (Saunders, 2019). The implications of financial burden mean more pressure on family members/informal carers (Choi & Seo, 2019), worsening quality of life (Belcher et al., 2023), and unaffordability of private healthcare as an alternative to publicly funded care.

The hostile immigration context of the UK is writ large in the difficulties people have in securing healthcare, financial support, and living well until the end of life. Immigration can be understood as a social determinant of health, reflecting the influence of migration policy and wider social structures on individuals' access to care and financial security (Castañeda et al., 2015). The data suggest that staff were deeply affected by the financial hardships experienced by terminally ill migrants, illustrating how structural and policy-level inequities can

become internalised and expressed at the individual level as moral distress or moral injury (Corradi-Perini et al., 2021). This shift—from societal and systemic injustices to personal emotional and ethical strain—highlights the entanglement of the social and the psychological in end-of-life care contexts.

The bureaucratic obstructions and sluggishness of visa changes or access to supports can be understood as forms of structural (Galtung & Höivik, 1971), bureaucratic (Norberg, 2022) and legal violence (Jimenez, 2021). Mayblin et al. (2020) suggest that immigration status, NRPF, and policy inaction produce suffering not through direct violence but through institutional neglect and exclusion, creating an intentional form of slow violence that challenges mere survival. Economic precarity and the fragility of visa status create additional levels of pain over and above that endured through terminal illness which strips people of the right to a dignified death.

Ideology is embedded in policy (Alexander et al., 2025; Norberg, 2022). The inability to access healthcare, housing, or benefits is not random, it is structurally imposed, and is experienced most frequently and acutely by those in poverty (Farmer, 1996). Embodied suffering is at the heart of terminally ill migrants' struggles, and while dying migrants may lack agency in determining where their food or clothes come from, there is certainly agency within bureaucratic government departments determining visa status and NRPF conditions. Yet a key feature of bureaucratic violence is the erosion of discretion (Norberg, 2022) which was evident in the way that NRPF blocked access to support needed to meet even basic needs.

Theories of citizenship are also of importance. Citizenship is not just a legal status, but a moral and political boundary used to determine who is 'deserving' of care and supports (Anderson et al., 2011). NRPF operates as a sorting mechanism, separating the 'deserving' (legal, productive, native) from the 'undeserving' (precarious visas, ill, or economically dependent). This is stark in discussions about migrants being denied housing, benefits, or healthcare because they are not perceived to belong. Ideas of deservingness operate through racialised, classed and moralised lenses in both UK policy and frontline practice. Intersections of race, income and illness lead to compounded vulnerability (Crenshaw, 1991). Thus when citizenship, conveyed through rights instated as a consequence of visa compliance, is at risk, then a binary of citizen/migrant and legitimate/illegitimate is reified (Anderson, 2024). Risk of deportation or removal underpin the severity of consequence in being the wrong side of this binary if work or study becomes an impossibility due to severe ill-health (Nicholas, 2002).

Despite rhetoric that migrants are a drain on welfare, international data challenges this prejudice (Cebolla-Boado & Miyar-Busto, 2020; Giulietti, 2014). Indeed, migrants add to the country's gross domestic product (e.g. in Sweden, Römer, 2023), use welfare systems less than natives (e.g. in the UK Saunders et al., 2021) or are healthier than the native population (Ichou & Wallace, 2019). Inequitable access to healthcare for migrants is visible in a range of jurisdictions e.g. Nordic countries (Greve, 2016), and Switzerland (Tzogiou et al., 2021), despite being a legal right. Reduced access may be a function of limited knowledge of access, or deployment of 'street level bureaucrats' whereby administrators who facilitate or block access to supports (Ratzmann, 2021). This intentional pattern reinforces the global relevance of this issue. Especially in countries with universal health systems, terminally ill migrants encounter obstacles grounded in nationalist and racialised discourses of entitlement. Global health inequities persist not because of a lack of frameworks or funding, but because of deeply embedded ideologies that shape who is counted worthy of care.

5. Limitations

A key limitation to this study was, despite extensive efforts, the lack of recruitment of people with lived experience of being a migrant with a terminal illness. This recruitment difficulty reflects the marginalised and risky status of terminally ill migrants. Our patient/public involvement and experience (PPIE) group (three individuals with lived experience of terminal illness as migrants who provided advice to the academic researchers) shared their view that people may be fearful of identifying themselves to organisations, and subsequently to the Home Office or law enforcement. Due to this feedback, recruitment materials made explicit reference to the confidentiality arrangements. This fear is also reflected in the PPIE members asking not to be named in this paper/the acknowledgements.

Recruitment was conducted UK-wide via a wide range of organisations including (but not limited to), organisations supporting migrants/carers/patients, those providing financial advice and guidance, solicitors and immigration lawyers, hospices and palliative care providers, faith-based organisations, and local authorities (including NRPF and Human Rights' departments, and Councillors). In total, the team contacted approximately 300 organisations directly, although the reach was likely to be far higher, with organisations forwarding on to their own networks, as we invited contacts to do. PPIE and Steering Group members facilitated recruitment, sharing recruitment materials and adverts with their existing networks. We used snowballing, and social media (Twitter/X, LinkedIn, Facebook and meet-up groups), to expand the number and geographic spread of participants. Initial posts on Twitter/X achieved 3327 views. We also posted adverts in the Marie Curie bimonthly newsletter, the Association of Palliative Care Social Workers, and the Immigration Law Practitioners' Association website.

We anticipate that recruiting terminally ill migrants to any future study would need a considerably longer lead-in with greater time to build trust and relationships with organisations and individuals.

However, insights from professionals closely supporting this vulnerable group still offer valuable practice-based perspectives that illuminate the ethical tensions surrounding their care and support, and the structural and institutional challenges they face.

Our study focused explicitly on individuals experiencing financial hardship, a group for whom private healthcare (or private medical insurance) is highly unlikely to feature meaningfully. No participants mentioned private healthcare or private insurance as part of their coping strategies or healthcare pathways. In the UK context the uptake of private medical insurance remains relatively low (around 11 % - most of whom state they use the NHS too (YouGov, 2025)), particularly among lower-income or financially vulnerable populations. Similar studies to ours in other countries may wish to specifically probe for accounts of balancing public and private healthcare options.

6. Conclusion

This analysis reveals how financial precarity for migrants with terminal illness is framed by immigration policy, welfare exclusion, and bureaucracy. The data illuminate the emotional weight carried by both terminally ill migrants and professionals as they navigate a system that sees care as conditional on the ability to contribute to its cost. Yet migrants have already paid via the IHS and National Insurance contributions, so it seems that the emphasis is on ability to pay, specifically through being "productive" and revenue producing members of the workforce.

In response, informal solidarity and professional empathy emerge as necessary counterbalances (Lacey & Moran, 2023), but they also point to the urgent need for systemic reform to ensure that dying in dignity is not a privilege of the financially secure.

While frontline workers often act with compassion and ingenuity, their efforts expose a broader experience: the experience of terminal illness in the UK is conditional and exclusionary when filtered through immigration policy.

Better understandings of NRPF and mechanisms to lift this would mean terminally ill migrants had swifter access to the housing, care and financial support they need. However, this is predicated on a political will and interest to improve the lives and deaths of migrants. The World Health Organisation posits palliative care provision as a fundamental

right. Yet this is far from commonplace, and certainly not guaranteed for migrants subject to visa conditions.

Terminally ill migrants may face simultaneous medical, legal, and existential crises: loss of income, risk of destitution, fear of removal/deportation, and isolation from family networks. This precarity highlights the intersection of neoliberal and postcolonial structures, which make care conditional on economic utility and legal status rather than shared humanity (Anderson, 2014). Through a postcolonial and ethics of care lens, this situation reflects a moral contradiction: The UK's healthcare system espouses universality and compassion, yet its immigration and welfare frameworks actively exclude those who are rendered non-productive by illness. Migrants' bodies thus become sites where neoliberal economies of value and colonial hierarchies of worth intersect: their labour is welcomed, but their suffering is beyond the remit of services. The consequence is not only individual hardship but also a systemic erosion of collective care ethics.

Enabling people to live and die well requires more than clinical provision; it demands an inclusive moral and policy framework that recognises the dignity and interdependence of all who contribute to society, irrespective of immigration status.

CRediT authorship contribution statement

Tim Sedgley: Writing – review & editing, Writing – original draft, Validation, Project administration, Formal analysis. **Joanne Alexander:** Writing – review & editing, Writing – original draft, Validation, Project administration, Formal analysis, Data curation. **Laurence Lessard-Phillips:** Writing – review & editing, Writing – original draft, Funding acquisition. **Aisha Macgregor:** Writing – review & editing, Validation. **Liz Forbat:** Writing – review & editing, Writing – original draft, Validation, Supervision, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization.

Data management and sharing

Anonymised data set is available on receipt of a written request, accompanied by approval for secondary analysis by a recognised research ethics board. Requests for data should be submitted to the corresponding author.

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Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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