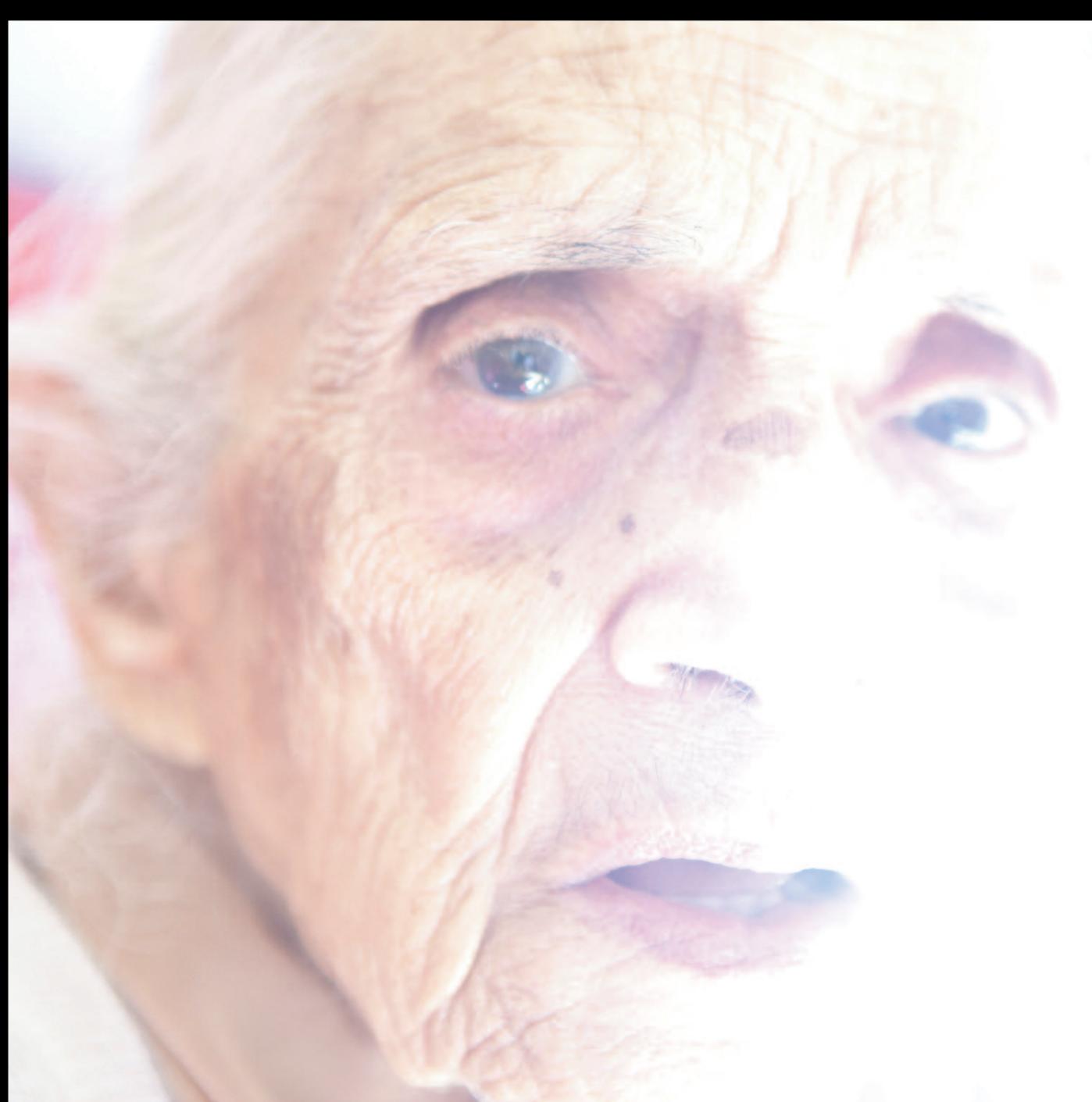




BACK COVER
© Sangita Mistry
Mrs Joshi, 2010
Care home in
Leicester for Gujarati
and Hindu people.

FRONT COVER
© Sonal Kantaria
c. 2012
Resident was 82
years of age. She
has tears in her
eyes when she
talked about her
family.



My memory has gone and so have my eyes

**PUBLISHED BY
AUTOGRAPH ABP**

Text commissioned by
Autograph ABP
Text © Yasmin Gunaratnam
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**AUTOGRAPH
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CARES...**

design: engin@tyrographics.co.uk print: Colchester Press Ltd



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Bhaji and tomato ketchup The care home provides Indian food to its elderly residents as a way of familiarising and a reminder of home. ©Sonal Kantaria, c. 2012



**Go away, she cries in a slumber
I ask who she is talking to but she is unable to respond
She tells me she has gone mad. Everything has gone,
she refers to her mind** Resident suffers from dementia, believing the doll was one of her children. ©Sonal Kantaria, c. 2012

WHO CARES...

Traditionally in Indian culture mothers and grandmothers are the central figures in the household. They raise and nurture their children and in turn when they grow old the children must look after them. It is still very common in the UK for three generations of the extended family to be living in one household, a tradition that has been maintained for decades.

When the time comes it is the duty of the son or daughter to look after their mother until she passes away.

More recently, a growing trend in the UK has been the rise of care homes for Indian elderly people. The household and extended family unit has been replaced by these homes as a growing elderly population emerges and busy lifestyles take over traditional values.

This project explores the role of the elderly matriarchal figures within Indian culture and the shift of traditional values in a growing British Indian society.

My engagement with an Indian elderly care home in Leicester spanned over a period of two years. I would travel to Leicester from London and often spend a number of days at the home speaking to and interacting with the residents, all of whom wanted some company.

During this period my own nan passed away and the project became ever more pertinent. Respect to the women featured in the project who have now passed away.

All images photographed between 2010–2012 at Diwali Nivas in Leicester.

Sonal Kantaria



The residents pass their days in this room Resident sits in the living room in a line of red armchairs.
© Sonal Kantaria, c. 2012



The living room in the elderly care home Entertainment consists of TV programmes on Indian channels and bhajans (Indian religious song). © Sonal Kantaria, c. 2012

WHO CARES...

WHO CARES...

IN EXTREMIS

In the photographic work, *In the House of My Father*, a papery house held together by pins, rests in the palm of a hand. The house is made of human skin; a remnant from one of many operations that the artist, Donald Rodney, underwent as a result of sickle cell anaemia. If Rodney’s fragile fabrication reminds us that skin is our last dwelling place, it also brings us to the playful and painful accommodations of the racialised debilitated body. Another twist to Fanon’s pathology-inspired idea of race-making as **‘epidermalisation’**¹. In the history of the visual archive and post-colonial critique, it is disabled, ageing and infirm bodies that remain marginal.

For nearly twenty years now, **haunted**² by unacknowledged realities, I have been researching the worlds of dying **migrants**³. The foreigner in need of care is a figure that reappears throughout the Abrahamic religions and continental **philosophy**⁴ as the test of the moral worth and making of a community. More recently, writers such as **John Berger**⁵ and **Hanif Kureshi**⁶, have parodied capitalism’s repression of the migrant worker’s vulnerability and finitude: “they do not age: they do not get tired: they do not die”, Berger writes. For Kureshi, the migrant “is impossible to kill or finally eliminate... because there are waves of other similar immigrants just over the border coming right at you”.

AND WHAT OF THE REAL? THE AGED OR INCAPACITATED MIGRANT WHEELED INTO A CHURCH OR TEMPLE, LUMBERING WITH HER WALKING FRAME INTO A DOCTOR’S SURGERY, BEING LED BY THE HAND AROUND THE SUPERMARKET, WATCHING THE WORLD GO BY FROM A PARK BENCH OR FILLING THE HOSPITAL WARD WITH TOO MANY VISITORS AND HER CARE HOME UNIT WITH TOO MUCH STUFF?

In the UK, we are at a point of historical transition. As new waves of migrants “come at us”, those who migrated from Ireland, Eastern Europe and the Commonwealth in the 1950s and 60s, are ageing and dying. At times of diasporic debility, different scales, times and frontiers of life intermingle. There is the **perverse subsidy**⁷ of migrant labour that underpins our care systems, resulting in devastating care deficits in low and middle-income countries. There are the uneven circuits of big Pharma – **90% of the world’s morphine is consumed by 10% of us**⁸. And there is the diasporic body itself.

For Harshini’s mother, it was dementia that unearthed a **“distributed perception”**⁹ not tied to a single time or place. Telling her family “I am going to the fields”, she would wander off from her house in Leicestershire believing that she is ambling in the rural village in India that she left many years ago. “Even today, although she is not aware of what she is doing with her hands, without a mala... her fingers are

still working as if she is praying”, says Harshini. With language and self-consciousness lost, Harshini’s mother, now in a care home, is living on the edges of her life. She is not quite in the here and now, not quite a Hindu, not quite the mother Harshini knew. It is only the phantom mala beads and the ‘foot anarchism’ of the new **‘desire paths’**¹⁰ that she carves out as convenient shortcuts between England and India, that flicker with the rythmns of a past life.

These are stealthy migrations, underneath the skin. The body stays in place and summons distant places, people and times to it. As thinking and perception are rearranged, difference does its work from inside the body. In this sense, diasporic debility is queer in the way that Gayatri Gopinath describes it, as being marked by **“the failure of generation, and the losses and desires associated with normative genealogies of belonging”**¹¹. New questions emerge. Not so much, ‘Who are you?’, and in the case of migrant bodies, ‘Where are you from?’, but *“When are you?”*

WHEN ARE YOU?

In England and Wales, those racialised as being black and ethnic minority amount to about 707,300 residents aged 65 in 2009, with numbers estimated to rise to over 13 million by 2026¹². These populations are ageing and dying in successive waves, mirroring patterns of migration and settlement. According to estimates by the All Party Parliamentary Group on Dementia, in 2013 there were nearly 25,000 people with dementia from black and minority ethnic communities in England and Wales. **The number is expected to increase by nearly seven times to over 172,000 people by 2051**¹³.

Under the sway of institutional multiculturalism, the care needs of these elders have been translated into such matters as diet, religious observation and ethnic customs. A lifeline to some, this mapping of need by culturalist categories is always already missing a beat. As Stuart Hall has reminded us **“since the colonized subject is positioned in relation to cultural narrtives which have been profoundly expropriated, he she is always somewhere else”**¹⁴.

SHE IS ALWAYS SOMEWHERE ELSE

At the end of a life, changing biochemistry, neurology and hormones thicken this “somewhere else”, with bodily symptoms showing the intimacy between cultural and biological life. Neuroscience research on **“social pain”**¹⁵ – the pain of marginalisation – is providing evidence of the theoretical claims made by feminist and postcolonial scholars about how social **inequalities and injustice hurt**¹⁶ and how unspoken trauma can be passed on from **one generation to another**¹⁷.

With disease or impairment – changes of sight, hearing, taste, muscle memory, face and motion – can bleed into and tinker with cultural emblems and unzip cultural hybridities. **Second languages are lost with dementia**. For others, the spiciness or colours of once familiar food on a plate might trigger nausea. Voice synthesizers flatten accents or impose vocal ethnic and gender transitions. The usual culturalist indexes slip and slide. There is more room for play and misrecognition.

The protagonist in Andrea Levy’s semi-autobiographical novel, *“Every Light In The House Burnin’”*, is Mr Jacob, who sailed to England in 1948 on the Empire Windrush. The novel follows Mr Jacob and his family over 20 years, chronicling his demise from cancer and his desultory journey through the National Health Service. It is a rabbi who administers to Mr Jacob on his deathbed in a hospital ward. His surname, together with his repeated calling out to ‘Lazarus’ in bouts of terminal delirium, gave the impression that he was Jewish. **“They got you a rabbi, Dad Levy writes, God knows where you’ll be now”**¹⁸.

Mr Ali’s turn to Judaism came when he was admitted into a hospice. In an interview, his wife tells me that he ate the Kosher options on the menu. In matters of the gut, Kosher food seemed closest to the spirit of Islamic prescriptions and without the inflammatory spices of the halal dishes. Pakistani-born Fatima relished the opportunity to try out British vegetarian food, **whilst English patients chose the halal options when they craved a curry**¹⁹. Such deathbed conversions produce hundreds of inventive and opportunistic mixes. People step out of and across cultural nationalism and life-long habits, sometimes becoming foreigners to themselves and their loved ones.

Just as impairment can cut into and sever cultural and national allegiances, there are other external forces at work, heaping pressure on diasporic identifications. **“Living the Dream”**²⁰, a poem by Ash Sharma donated to my **Case Stories archive on social pain**²¹, transports us to a final journey from the Midlands to India and the scattering of a father’s ashes into the mighty Ganges. It is an ancient ritual, now shamelessly profane and commercialized. Any seductive fantasy of homecoming dissolves into angry flotsam, muddying what psychoanalysts see as the fluid borders between **grief and grievance**²². Our people are no less exploitative of vulnerability than others, “Is this all he’s worth?/ Holy men with calculators/ Standing guard on the river’s edge, soiled with foreign currencies./ Ashes escaping in the torrent/ Holding back the rage and sorrow.”

IS THIS ALL HE’S WORTH?

Despite initiatives to document and archive these far-flung coordinates of diaspora, a sort of dementia impedes our efforts. As Arjun Appadurai observes, **“Migration tends to be accompanied by a confusion about what exactly has been lost, and thus what needs to be recovered or remembered”**²³. With the rise of the online archive, Appadurai sees memories as being actively made through diverse connections that are not reliant on kinship, nation or face-to-face relationships. This is the archive as *“intervention”*, returning to its “more general status as a deliberate site for the production of anticipated memories by intentional communities.”

How do we want to intervene in the remembering of our elders and our dead? What communalities do we wish to foster? If queer postcolonial writers, such as **Jabir Puar**²⁴, are correct in suggesting that we have given far too much attention to capacity, language, linear time and disabled exceptionalism in our critical engagements, taking postcolonial concerns to the everyday life of the luncheon club, the care home and the hospital is long overdue. Here, in the sideboards bulging with whatnot, in music, in the sociality of the communal meal, in the ornate rhythms of a syringe driver pumping morphine, are many other facets to Donald Rodney’s **epidermal home making that both help and hurt**

Yasmin Gunaratnam 2014

Notes

- Frantz Fanon, *Black Skin, White Masks*. 2nd ed. (London: Pluto Press, 1986).
- Yasmin Gunaratnam, *Death and the Migrant: Bodies, Borders, Care*, (London: Bloomsbury Academic, 2013).
- For the sociologist Avery Gordon, haunting is a social rather than supernatural phenomenon. It signifies the spectral presence of “fugitive knowledge from below and outside the institutions of official knowledge production”. Avery Gordon, *Ghostly Matters: Haunting and the Sociological Imagination*, 2nd ed, (Minneapolis, MN: University of Minnesota Press, 2008). xviii. Writing with regard to the Korean diaspora, Grace Cho sees haunting as a trope for how “unspeakable and uncertain” diasporic histories can be dispersed across place, time and generation. Grace Cho, *Haunting the Korean Diaspora: Shame, Secrecy, and the Forgotten War*, (Minneapolis, MN: University of Minnesota Press, 2008), 40.
- See Alphonso Lingis, *The Community of Those Who Have Nothing in Common*, (Bloomington: Indiana University Press, 1994), 12.
- John Berger and Jean Mohr, *A Seventh Man*, 2nd ed., (London and New York: Verso, 2010), 68.
- Hanif Kureshi, *The migrant has no face, status or story*, (The Guardian, 30 May 2014). Available online: http://www.theguardian.com/books/2014/may/30/hanif-kureishi-migrant-immigration-1
- Maureen Mackintosh, Parvati Raghuram and Leroi Henry, A Perverse Subsidy: African Trained Nurses and Doctors in the NHS, *Soundings* 34,(2006):103–113.
- Pain and Policy Group, *Opioid consumption data* (2010). Available online: http://www.painpolicy.wisc.edu/opioid-consumption-data
- Gilles Deleuze and Felix Guattari, *Anti Oedipus: Capitalism and Schizophrenia*, (Minneapolis: Minneapolis University Press, 1983).
- Nicholas Crane, *Two Degrees West: An English Journey*, (London: Viking, 1999).
- Gopinath, Archive, Affect, and the Everyday: Queer Diasporic Re-Visions. In Janet Staiger, Ann Cvetkovich, and Ann Reynolds, eds, *Political Emotions: New Agendas in Communication*, (New York, NY: Routledge, 2010), 165-192, 167.
- Natalia Calanzani, Jonathan Koffman and Irene J Higginson, *Palliative and end of life care for Black, Asian and Ethnic Minority groups in the UK: demographic profile and the current state of palliative and end of life care provision* (2013). Available online: http://www.scie-socialcareonline.org.uk/palliative-and-end-of-life-care-for-black-asian-and-ethnic-minority-groups-in-the-uk-demographic-profile-and-the-current-state-of-palliative-and-end-of-life-care-provision/r/a11G000001893YIAQ
- House of Commons, All Party Parliamentary Group on dementia, *Dementia Does Not Discriminate: Experiences of Black Asian and Minority Ethnic Communities in the UK* (2013). Available online: http://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=1186
- Stuart Hall, *Minimal Selves*. In Homi K Bhabha, ed. *Identity—the Real Me* (ICA Documents 6), (London: Institute of Contemporary Arts, 1988), 44–46, 44.
- Neuroscience research suggests that there is structural correspondence between physical and social pain in their sharing of the same somatosensory substrates. Naomi Eisenberger, Broken Hearts and Broken Bones: A Neural Perspective on the Similarities Between Social and Physical Pain. *Current Directions in Psychological Science*, 21 (2012): 42–47.
- For examples, see Yasmin Gunaratnam, Morbid Mixtures: Hybridity, pain and transnational dying, *Subjectivity*, 7(2014): 74-91.
- Brian Dias and Kerry Ressler, Parental olfactory experience influences behavior and neural structure in subsequent generations, *Nature Neuroscience*, 17 (2014): 89–96.
- Andrea Levy, *Every Light in the House Burnin’*, (London: Headline, 1994).
- Yasmin Gunaratnam, Eating into multiculturalism: hospice staff and service users talk food, ‘race’, ethnicity, culture and identity, *Critical Social Policy*, 21 (2001):287-310.
- Ash Sharma, *Living the Dream* (2013). Available online: http://www.case-stories.org/ash-sharma
- The Case Stories project was the basis of a British Academy (Mid-Career) Fellowship (MD120033). See: http://www.case-stories.org
- See Lita Crociani-Windlanda and Paul Hoggett, Politics and Affect, *Subjectivity*, 5 (2012): 161–179.
- Arjun Appadurai, Archive and Aspiration. In Joke Brouwer and Arjen Mulder, eds, *Information is Alive: Art and Theory of Archiving and Retrieving Data*, (Rotterdam: Naj Publishers, 2003): 14-25, 17.
- Jasbir K. Puar, *Coda: The Cost of Getting Better*. Suicide, Sensation, Switchpoints. GLO, 18(2011): 149–158.

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Hands Care home in Leicester for Hindu-Punjabi people.
© Sangita Mistry, 2010

Mr Latif Residential housing for all members of the community
in Rochdale, Greater Manchester. © Sangita Mistry, 2010

The Office for National Statistics (ONS) states that in 1983, there were just over 600,000 people in the UK aged 85 and over. Since then the numbers have more than doubled reaching 1.3 million in 2008. By 2033 the number of people aged 85 and over is projected to more than double again to reach 3.2 million – accounting for 5 percent of the total British population.

As the ageing population is on the increase the aim of the project is to highlight the different care needs of the elderly, more specifically from different ethnic communities. I have researched the importance of culture-specific care homes and residential housing. The findings clearly show that there are many

commonalities as well as differences in needs and in the way that we care for our elderly. The vernacular space within each image is reminiscent of one's culture, religion, community and identity, values that they hope to have passed on to the next generation.

Find within each image an individual, a story, a past, a memory; the future.

No matter how big their differences, every human cultural ethos is upon analysis subject to similar definitions, and this should help us to understand why the differences are of fundamental importance, and how those that care for our elderly can relate to those differences.

Within our own culture we are all steeped in the shared meaning of symbols and the language we think in and speak, and we have our share of an individual and collective experience – we are our history and tradition. We have our core values, beliefs, expectations and goals, and our social interactions and behaviour pattern are guided by conventions, rules and practices, as well as rewards and punishment.

Members of the same culture share sets of concepts, images, ideas and values which enable them to relate to the world around them. Importantly, it's not language alone that produces meaning, but also behaviours and practices.

Sangita Mistry



Waiting for lunch Care home in Leicester for Gujerati and Hindu people.
©Sangita Mistry, 2010

WHO CARES...



Chairs Care home in Manchester for Polish people.
©Sangita Mistry, 2010

WHO CARES...