

Time to Change the Narrative: An Anthropology Inspired Policy Response to Cancer Inequalities in the North East of England.

The North East (NE) of England has some of the highest areas of national deprivation in the country, which translates into many forms of health inequalities (HI). This gap in HI is widening compared to more affluent areas of the country. Which manifests as shorter life expectancy, with lives lived more likely to be in poor health and increased likelihood of premature death from preventable diseases (Corris et al, 2020). The NE has the highest national rate of cancer incidence (Office for National Statistics, 2019). This regional HI equates to the likelihood of avoidable deaths and shorter survival periods. South Tyneside Council (2019) estimate ‘There would be around 15,300 fewer cases and 19,200 fewer deaths per year across all cancers combined if socio-economically deprived groups had the same incidence rates as the least deprived’.

The National Health Service (NHS) is a health system that is free for UK residents and citizens, with open access. It has national cancer strategies, prevention and treatment programmes to give better health outcomes to all. Despite this, there is no evidence that these strategies have been effective. There continues to be a disparity in cancer outcomes in patients from the most deprived areas, with England lagging comparable European countries (Exarchakou et al, 2018). The recommendations for policy makers by Exarchakou et al study (2018) was to change the focus away from individual factors to healthcare system factors, with further research needed to increase effectiveness of future initiatives.

To change that focus, I will look at cancer inequality in the NE through the lens of anthropology. This will help unpack the cultural, political, and social issues that play a somewhat concealed and unconsidered component in the issue. I will consider the: social determinants of health as defined by the ‘status syndrome’; unpick the role of the state, biomedicine, and Public Health (PH); and recognise the lived structural violence experienced in deindustrialised communities. Using ethnographic examples to navigate this, I will then attempt to design my own anthropology-inspired policies.

At present the medical establishment, biomedicine, constructs disease as a physical concept, whether through treatment, diagnosis or research. Disease is regarded as separate and distinct to the social groups and contexts in which it is found (Singer & Baer, 2011). Biomedicine is an integral and ingrained part of our health system and culture and has improved and extended the lives of millions. It is accepted by the majority to be apolitical (Wendland, 2010). Medical anthropology looks at health through the lens of cultural construction and lived narratives of people. This bio sociocultural approach enables health to be viewed as a characteristic of the human condition. Critical medical anthropologists recognise health in relation to control and access over the rudimentary material and non-material resources that are needed to maintain and support life’s fulfilment (Singer & Baer, 2011).

Marmot (2004) highlights how health is directly linked to social determinants, naming this the ‘Status Syndrome’. The status syndrome reveals how the social determinants of health follow an explicit gradient that connects wealth, job prestige, degree of education, social standing, autonomy, community, family, connectedness and environment. He argues that irrespective of genetics and lifestyle risk factor behaviours, the higher one is on the social gradient will have a direct correlation to health outcome. Consequently, people below the top of the gradient have a greater chance of poor health:

The health of the population is not just a matter of how well the health service is funded and functions, important as that is: health is closely linked to the conditions in which people are born, grow, live, work and age and inequities in power, money and resources – the social determinants of health. (Marmot et al, 2020, p 6)

In 2010 the Marmot review ‘Fair Society, Healthy Lives’ was published. It was an evidence-based strategy designed to address these social determinants of health. The 2020 Marmot report ‘Ten Years On’ is scathing of the government and Public Health England (PHE) in its lack of acknowledgement and response to the issue. Stating the nation is plummeting further into time spent in ill health with a decrease in life expectancy for those living in the most deprived areas, especially the North. This was reinforced by the shocking United Nations (UN) (2019) report into extreme poverty in the UK. It found due to the drastic cuts to the local authorities budgets the social safety net had been badly damaged:

The bottom line is that much of the glue that has held British society together since the Second World War has been deliberately removed and replaced with a harsh and uncaring ethos. A booming economy, high employment and a budget surplus have not reversed austerity, a policy pursued more as an ideological than an economic agenda. (UN, 2019, p 1)

The factors that Marmot (2004) cites that have a direct effect on the social gradient effecting the lives lived in poor health and shorter lives are supported by regional statistics.

Mendenhall (2019) has done ethnographic research applying the theory of syndemics, which reflects on Marmot’s work. Through her ethnographic work from the narratives of Mexican American women from areas of high socioeconomic deprivation with diabetes, she demonstrates that aside from lifestyle factors, social suffering may be embodied in diabetes. Syndemics is the interaction of social and health conditions and how they journey and interact via populations through biological, social, or psychological routes being driven by political and social influences. Syndemics can be applied to all disease. Mendenhall (2019) describes them as being situated among ‘fault lines’ of social suffering, appearing in clusters of disadvantaged and vulnerable communities.

Kleinman (1995) argues the state is heavily influenced by the two powerful masters of biomedicine, professional autonomy and bureaucratisation. This results in families and patients having little control and influence over their care. He argues that in industrialised societies biomedicine is the major institution in control of social reality. The outcome is that instead of addressing the underlying social determinates of health is instead to reinforce a blame culture of stigmatising through the self-regulation of those in society afflicted with diseases such as smoking, obesity, alcoholism, mental health, and drug abuse. He goes on to reason that in postmodern Western societies, biomedicine has become so powerful it has “out-stripped its own professional autonomy and become inseparable from the state” (Kleinman, 1995. p39p).

This can be seen in the narrative for new PH, which is viewed through the lens of modern epidemics, obesity, smoking and alcohol. The focus of disease prevention is on self-control, lifestyle and individual responsibility. This results in chronic disease being perceived as individual failure. The danger in this approach is the way it shapes the perceptions of health care professionals who influence and commission care. The narrative is then reinforced by PH campaigns and the media and becomes part of public consciousness. This was demonstrated by an in-depth qualitative methods study to explore how to engage high-risk individuals from socioeconomically deprived areas in early lung cancer diagnosis. This found

people felt they were not entitled to health care services and not worthy of seeking help due to their smoking habits, (McCutchan et al, 2019).

The danger of HI being addressed through a rhetoric of individual choice and bad behaviour, is it obscures the disparity of the most powerless and stigmatised socio-economic groups (Bell et al, 2011). Marmot (2020) asserts the conditions in which people live are closely related to health behaviours. It is much harder for people to change unhealthy behaviours when dealing with other life stresses such as poor housing conditions, financial hardship and safety. Poverty limits choice and options in life with healthy choices often being unobtainable or unconsidered due to the energy consumed in living. Marmot (2010) argues that the easy option has been taken by Public Health England (PHE), the Government, and other organisations through the pursuit of addressing the proximal causes, such as actions to change behaviour instead of addressing the complex social inequalities that shape the behaviour. He concludes that unless the fundamental cause of inequality is addressed even if lifestyle factors were levelled HI would likely continue between socioeconomic groups.

The post-industrial landscape of the NE has resulted in the breakdown of once strong and vibrant communities. This has been exacerbated by government and the PH approach. This directly effects the many lives and communities at the heart of the NE. This sees those living in poorer areas affected the most, with the NE fairing worst. To understand how this works from a social determinants of health approach as opposed to a PH and state narrative it is important to understand some of the NE history and the effects it has had on its communities. The once industrial landscapes of the North East were sustained by coal, steel, and ship building. These communities were strong and powerful in their leadership and identity. The Centre for Social Justice (CSJ), (2018) describe a psychological scar that has divided the North and South of England since the first industrial revolution. This economic and social gap has been growing since the onset of deindustrialisation seeing the NE with twenty two percent of low waged jobs. Deindustrialisation has and continues to socially and economically devastate the communities of the NE that had previously relied on a small number of dominant employers. This plays out in the shocking statistics voiced in the Marmot (2020) report that states the gap has grown and continues to grow between lowest life expectancy (LE) in the NE and highest in London. For women LE has declined since 2010 with an increase in life spent in ill health.

Warren (2018) has some rich insights in his case study of the communities of Teesside and the socio-economic change. His conversations, interviews and observations give some first-hand accounts of the sense of jobs for life, with employers that cared for their staff. One of his interviewees remember:

ICI looked after its people, at least it did when I first worked there, things changed over the years. I remember there used to be an ICI logo and it said on it 'our greatest asset is our people' then at some point, I think it was in the 1980's it was changed to 'our greatest asset is our customers'. That sort of summed up how things went after that (Warren, 2018, p161).

The post-industrial jobs that have filled these communities are mostly low paid, with poor working conditions and lack of contracts. CSJ (2018) link the combination of type of work, unemployment, and increased dependence on the welfare state to social atomisation and a sense of loss. Ortner, (2016) talks about this in terms of the post-modern condition of neoliberalism where the lack of permanent contractual employment supersedes the perpetual institution of emotional, cultural, professional, sexual and international and political spheres.

She argues that a more effective war has been waged on the poor beyond deindustrialisation which is evidenced through ethnographic examples.

Through the breakdown of communities emerges the concept of social capital, a term used by Marmot (2004). It can be measured in the trust and safety one feels in their community and can be directly linked to poor health outcomes. Marmot (2004) argues that a deficiency in social connectedness causes a lowering of an immunity which increases the risk of disease, a range of illness and death. This access to social connections becomes less the further down the hierarchy one is. A three-year participatory action study in a former coalmining village in the NE examined the managed decline and removal of social housing. It found that chronic urban trauma through place-based effects of slow violence had become hardwired into the community (Pain, 2019).

The breast cancer paradox is something that has been considered by epidemiologists and anthropologists alike. The BC paradox occurs in women from more socio-economical deprived areas, where the incidence of BC is lower, but deaths are higher. This is replicated globally where there are populations of contrasting scales of wealth and deprivation, (Smith et al, 2019). Death from BC is most common in females who live in the most deprived areas of England, (Cancer Research UK, 2020). The NE has a significantly lower BC survival rate compared to the national average, (Martin et al, 2018).

A systematic review in 2019 of BC and the association between area-level deprivation and breast cancer screening uptake in Europe found that despite universal health systems, such as the NHS, women who live in the most deprived areas are less likely to attend BC screening than women living in areas of least deprivation (Smith et al, 2019). Qualitative evidence from this review suggests a limited knowledge of BC screening, misconceptions concerning cancer and mammography, embarrassment, fear, transport costs, and family commitments could all be barriers for women living in areas of high deprivation (Smith et al, 2019).

Absent from this study are the insights and recommendations in an ethnographic study by Hubbell et al (1995) into the BC paradox in California. Here Latina (Hispanic) women had a lower incidence of BC compared to Anglo women (white non-Hispanic) but had a higher grading of tumour at the time of diagnosis. Focusing on the cultural understandings of the groups instead of the biomedical knowledge, they were able to establish that the two groups had very different understandings, knowledge, and beliefs about BC. Further ethnographic study by Chavez et al (1999) saw the merger of the two models, the biomedical model that the Anglo women shared and the Latina model that emerged from the different communities of beliefs held by the different Latina groups. By the women being able to openly express their beliefs, ethnographers were able to obtain a better understanding of the cancer related knowledge, behaviours and attitudes, which in return empowered the women. These cultural beliefs were incorporated into cancer education for the women which was found to increase the use of cancer prevention and screening procedures (Chavez et al 1999).

Inhorn (2006) in her consolidation of copious ethnographic studies found that women rarely classify their health issues in the same way as biomedicine does. Instead, they define their health through the many stresses that have impacted on them throughout life. These include, poor pay, poor housing, community violence, lack of access to healthy foods, disrespectful interactions in clinical settings, lack of social support from partners, and numerous stresses on their pregnancies. These ethnographic studies have also found that all too often the women affected and defined by the prevailing biomedical model and PH have little influence over the boundaries that define them and their health problems (Inhorn, 2006). Concluding that for

interventions and research to be effective in health promotion, there must be a recognition of the bigger picture that shapes the social conditions of women's lives. By using an anthropological approach, through ethnographic evidence from the people at the core of the question, may be part of the solution. This slight change of focus and approach may be a key to increasing prevention and early diagnosis of cancers, adding a sense of autonomy and control for the people it is addressing.

As Marmot (2020) and other organisations emphasise there is an urgent need for a government review that can incorporate and act on the policies suggested within it. There are no quick fix solutions, to really address social determinates of HI takes time and commitment. Other essential components to this process are community development, partnership and capacity building, continuing investment, and professional development. Macmillan Cancer Support (2019) does have policy suggestions and recognises the care and health system is one of the biggest elements of HI. Whilst it has some great policies the emphasis is for those mostly with a cancer diagnosis. These incorporate addressing the barriers and consequences poverty can bring when receiving treatment. What it does not address is the work needed to be done in deprived communities and throughout society as a pre cursor to cancer, to reduce the HI gap. Below are some of my own anthropology inspired policy suggestions, specifically for the NE.

Policy ideas to help decrease the NE cancer burden

It is Time to Change the Narrative. The biomedical way of thinking, with its neoliberal self-regulatory mantra is embedded into the consciousness of the nation. Academics may know and understand how important the biosocial approach is to health, but most people and health care professionals have no idea. The majority would be astounded that there is an obvious additional way of understanding and looking at health. This requires re-education to change the mindset and culture. The government, PH and the media need to lead a debate that all can access and participate in. Underprivileged communities faced with overwhelming structural disadvantages should be outraged by the way policies changes in recent years have impacted their health for the worse (UN, 2019). By empowering people with the truth, these communities can reconnect and rekindle their political ties of the past, seeing the regeneration of local democracy. This will give people a sense of autonomy and social capital.

This should be a bottom-up approach reigniting the widespread use of parish, district, and county council influence.

Ask the people: So many decisions are made for others by others, this supresses autonomy disempowering people. By allowing people to voice how they feel and what they need allows for empowerment, a sense of ownership, invested interest and social capital. Ethnographical evidence has emphasised that when given agency people are more likely to respond and engage in health prevention and screening iniatives as they have had their needs understood on an inherent level.

Aside from public consultation, research of an ethnographic or critical medical humanities approach is needed to gain insights into what may work in relation to health and early diagnosis and what can improve people's lives. This facilitates a bridge between two worlds, biomedicine and the people.

Community hubs run by the community for the community:

Every community needs an inclusive space where people can access a range of different support and social sustenance to meet their needs. Autonomy and social participation aid

human flourishing and health (Marmot, 2004). By creating these hubs people will become invested in their communities, creating social cohesion and capital.

It should be recognised that each community is different and will have different needs. This should be decided upon by each community but have access to the same recourses. There are already some amazing initiatives happening, but they are rare and not always known about. Health prevention can be part of this agenda once peoples needs are established, as opposed to being told what to do.

There should be emphasis and encouragement of cooperatives, social enterprise, and social franchises within these hubs. This will help re-empower communities and be suited to specific community needs and keep the money in the local economy. Everyone in their community should know, be included and have access to these hubs.

Presently there are some amazing third sector projects throughout socially deprived communities, these are often not known about as the information is not in one place. People need to know where and how to find these spaces. A directory of county wide community and support groups with contacts people can use needs to be available. An open and shared approach to ideas and networks between groups should be nurtured and encouraged.

So many GPs have joined into bigger amalgamations with the loss of a trusted family doctor or nurse relationship. The district nurses (DN) have become centralised and task based. When the DNs are based in with the GPs there is a greater familiarity and knowledge of the community, the care becomes less reactive. It fosters a relationship of trust and familiarity, which helps with prevention and education. If we are to take the social determinants of health seriously as health care professionals the community hubs would be a constructive place to have a presence along with other tailored support.

As a health care professional and citizen, the biomedical model is so entrenched in my thinking, it has taken the process of writing this to understand and change the way I have been looking at HI. Although my focus is on cancer, I have demonstrated through syndemics and status syndrome that the specific disease is almost irrelevant. Take the cancer out of the equation and it is replaced with one or more other core morbidities such as diabetes, heart disease or congestive obstructive pulmonary disease that leach the quality of life and life itself out of those most disadvantaged in society. The solution is profound and requires a whole societal change. A health campaign here and a screening there is barely a sticking plaster on a severed artery. This requires health revolution and the nation to awaken and see health from a biosocial perspective. My policies go a small way to addressing this. Until this happens the continued PH interventions and cancer plans will be futile.

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