LGBTQ+ HEALTHY AGEING

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How Queer History Impacts Healthy Ageing

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This book is dedicated to biological and chosen friends and families close at hand and further afield. They are a vital part of our stories, not as a chapter, but as a theme – a golden thread running through our lives.

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INTRODUCTION – THE ROAD TO UNDERSTANDING: THE JOURNEY FROM CLINICAL CARE TO RESEARCH

I don't expect to touch the sky with my own two hands.
—Sappho (c. 610 BCE – c. 570 BCE)

Some time in the late 1990s, when I was in my early twenties, a much older, and now sadly departed, friend said to me, 'You're going to be a nurse one day'. I remember pooh-poohing the idea. I couldn't stand the sight of bodily fluids, and the long hours didn't appeal to me at all. Many years later, what I thought at the time to be a gross misjudgement of my character was actually an insightful prediction.

Years later, I returned from a spell in Hong Kong teaching children English as a Foreign Language (TEFL). The experience taught me many things, but most of all, I realised that I wanted the security of a career path. Arriving back in the UK and needing money, I applied for a job as a care assistant at a private care home. Intended only as a stop-gap, it was the first step on an incredible journey. The hours were long and gruelling, and the pay was chicken feed, but gradually, I realised that I had – at last – found my niche in life.

For the first time, my own family apart, I realised that other people needed me, not only as a shoulder to cry on, but to be the responsible adult in the room. My squeamishness at bodily fluids was soon forgotten as the need to ensure the dignity and comfort of the service users took over. I became intimately involved with their lives on a personal level, getting to know their likes and dislikes, their loves and regrets, their routines, and their families.

Previously, I had thought of older people as being one homogeneous mass, their lives dominated by ill health. However, the evidence of my eyes and ears told me this was not true, even for those with advanced dementia and other debilitating conditions. Instead, my work became all about maintaining their quality of life and happiness. Gradually, I realised that there was a schism

between the societal ageist portrayal of older age being one of misery, and the reality of diversity and complexity in ageing.

A pivotal moment came when my mentor asked me to play a key role in the palliative care of one of the residents. This particular resident and I had bonded over a number of months, striking up a good friendship. It was a relationship which made both of our lives a lot brighter. I would dress him and give him breakfast every morning, include him in the daily activities, made sure he was happy during the day, then help him to bed on a night. We trusted one another, and it was a continuity and depth of care which made his final few months all the more special.

Palliative care was a revelation, and the co-ordination between the senior staff at the care home and the district nurses and the local general practitioner (GP)s made sense to me. The resident was the focus of all our efforts, from medication changes as his health declined, to the construction and installation of a profile bed, to learning how to change bedsheets without the patient having to get out of bed at all. Palliative care is the constructive coordination of dignity and respect in one's final days. It is epitomised by compassion with a clarity of focus.

Yet, palliative care goes far beyond the organisational needs of an imminent demise. It also lies in the extra efforts of those around the dying person. I remember that our team kept vigil round the clock. I pulled up a chair to his bed, and he instinctively reached out. I held his hand in the stillness of the dull afternoon, the simple gesture of touch letting him know he wasn't alone. I remember sitting there thinking of how the care home environment was like a jigsaw. There were many pieces to the jigsaw, and yet only the right components could interlock. When completed, the result was a picture of good care, of dignity, and of respect. More than anything, though, it was clear to me that holding the hand of the dying was a privilege. I realised that I would probably never do anything quite as immediately important as that ever again. They were quiet moments, but profound in their gravitas.

I began to look ahead to my own older age, wondering what that might look like. Involving the families of the residents was key to the applied care in the home, as grown-up children and grandchildren regularly visited their relatives. I knew that my older age would look different. I am a single gay man, and I will never have children. Would my niece and nephew come to visit their old uncle? Would there be wider support there? Would I end up in a care home at all? The care home in which I worked was excellent, but to my eyes, ageing relied on the security of heteronormative families, a duty of care being passed down from generation to generation. In that sense, I felt as though I had broken the vertical chain of care. It was a thought which I would return to much later, and in greater depth.

There were, however, service users in the care home who did not conform to the heteronormative model of ageing. One woman with dementia was regularly visited by her wife. None of the other residents batted an eyelid, and there was no deficit in care from the staff closest to her. I wondered if the same indifference would be applied to married men since, at this point, same-sex marriage had only been legal for a very short while. Another woman, having very few biological family members left, had a chosen family of young friends who cared for her as though she was their grandmother. It was gratifying to see, and I noticed that the staff adapted their approaches to these residents to accommodate their way of leading their lives. For instance, the notion of who could be the next of kin was discussed between the resident and the care home and was formally expanded. Thus, same-sex spouses and the most responsible of chosen families became the resident's next of kin.

The standards in the care home were excellent, hence the scope for adaptation of approach, but I became well aware through scandals in the media that not all care homes were as good as the one in which I worked. Furthermore, I knew that many older people wished to stay in their own homes rather than go into a care home. Thinking about all of these variables, I wondered what the lives of older LGBTQ+ people looked like in other environments, and what options were available to them.

From there, my interest in how immediate environments helped or hindered the care of older people grew, especially with regards to diversity in ageing. It was like looking at the world with new eyes. Suddenly, I was aware of every grab rail, of the positioning of furniture, and of every step and slope. I became aware of generational experiences and attitudes among the residents and the staff, particularly regarding minority populations. I wanted to deeply analyse how all of these jigsaw pieces fitted together – if they did at all.

It was to this end that I decided to go back to university to take an undergraduate degree in occupational therapy. For those unfamiliar with this field, occupational therapy is the evidence-based practice of adapting environments and objects to enable human productivity, and to achieve a good quality of life (Royal College of Occupational Therapists, 2024). Occupational therapists are the practitioners to whom patients are referred after an operation, for example, to aid their mobility and safety in their own home. OTs are the suppliers of mobility aids, and the go-to advisers on how to pace oneself to conserve energy, and the prescribers of activity, such as gardening and exercise, to aid in one's mental well-being. Occupational therapists are the *nuts and bolts* people for *doing things*.

One of the seminal theories of occupational therapy is the *Person, Environment, Occupation Model* (Law et al., 1996). The *PEO Model* proposes that

there is an intrinsic and symbiotic relationship between a person, their occupation (the function or activity they are performing), and the environment which they inhabit. If there is a deficit in one of these overlapping domains, it has a knock-on effect on the other elements. For instance, if a care home environment is not adapted to the needs of a resident, it negatively impacts their ability to perform activities of daily living (ADLs) such as washing and dressing, and consequently, their physical and mental health.

This theory certainly chimed with me as the undergraduate practice placements took me out of the environment of the care home into hospital and domiciliary settings. I assisted with the evidence-based assessments and allocation of grab rails in the homes of patients released from hospital after joint replacements, and for those whose overall mobility was becoming restricted as a result of their co-morbidities. The placements also involved me engaging with acute mental health patients in meaningful activities such as the sequencing involved in shopping for food and cooking in preparation for fending for themselves on discharge. I helped people with learning difficulties pace themselves in the workplace, and children in care to learn about themselves through art in Child and Adolescent Mental Health Services (CAMHS).

In the hospital neurology department, I took part in activities at the bedside of post-stroke patients, and in the practice kitchens. The aim of these activities was to critically assess how the patient would cope on their own at home performing ADLs, such as washing and dressing, making a cup of tea, or going to the toilet. From these assessments, the necessary evidence-based interventions could be designed and targeted through clinical reasoning (Schell and Schell, 2008) to enable the promotion of effective function.

Outside of the profession, occupational therapists are often derogatorily referred to as *basket-weavers*, but within the profession, the running joke is the ubiquity of making cups of tea. There is a very good reason for this. Having a brew is culturally important in Britain, as much as queueing and talking about the weather, and culture is central to occupation. Beyond this, making a cup of tea is a highly complex procedure. It involves walking to the kitchen, holding, and filling up a kettle which gradually becomes heavier the more it is filled. These two first steps alone involve good tone in the limbs, and the ability to perambulate effectively, not to mention the ability to navigate, to sequence, and to move one's limbs with varying degrees of range. Then there is the ability to pour boiling water from the kettle into the cups without burning oneself, and to perhaps bend down to get the milk from the fridge.

If a patient has had a stroke, for instance, the act of making a cup of tea, and therefore, keeping oneself hydrated, becomes a lot more difficult. The negative effects of a stroke can be numerous. Cognition might become

affected, reducing the ability to sequence through the steps of an activity (Grieve and Gnanasekaran, 2008). Eyesight might be impaired. Hemianopia is the condition of becoming blind in one half of both eyes (Manchester University/Manchester Royal Eye Hospital, 2020). What happens if you're no longer aware of anything on your left or right? Then there are the physical debilitations. Spasticity can develop in the arms, for instance (Monaghan et al., 2017). How does a person feed or water themselves then?

I found that one of the biggest challenges on these practice placements was learning not to intervene. In the care home, we had been trained to help with everything, from dressing to toileting, to eating. I remember a practitioner, quite rightly, putting her arm in front of me, barring me from helping a man who had had a stroke simulating how he would shave using a handheld mirror. I found watching him struggle with an audience challenging. However, the difference was that occupational therapy helps people to help themselves, and I began to wonder if even the best care homes created occupational impoverishment through carers doing absolutely everything for their residents out of a misplaced belief that they were helping.

I saw a lot of service users during my practice placements, but only one of them, as far as I can recall, belonged to older LGBTQ+ populations. They were conspicuous by their absence – so where were they all? They had to exist somewhere. LGBTQ+ people don't just disappear in a puff of smoke once they hit a certain age. Consequently, I considered the locales where I had been trained in the field. Rural North Yorkshire is not a place of diversity. Most people are White and present as being heterosexual. Perhaps, had I been based in a more urban environment, I might have encountered more older LGBTQ+ people?

It was with this in mind that I began to scour the academic databases for evidence, yet here too, older LGBTQ+ people seemed to be largely absent. It was through these unstructured searches in my free time that I began to understand the academic landscape of sexual and gender minority studies. However, a large proportion of the studies seemed to relate to HIV/AIDS, which I found to be understandable, given the high profile of the epidemic which began in the 1980s (France, 2016). In a past phase of my life, I worked in a London gay bar for several years and experienced first-hand the public health messages and interventions prevalent on the gay scene, including free condoms and regular fundraisers. The charity who delivered the condoms packs used to deliver them when the bar was shut, so they would sling the bulky parcels over the garden fence for us to pick up later as though it had been raining condoms.

A lot of the studies seemed to focus on LGBTQ+ youth. This was no surprise either. I knew first-hand that cultural ageism was rife on the gay scene,

particularly with regards to gay men (Simpson, 2014). Anecdotally, youth was venerated, and once that life phase was deemed to be over, gay men became invisible and undesirable from a relatively early age when compared with their heterosexual counterparts.

Aside from LGBTQ+ culture, it was at this point that being taught research methods enabled me to see something else which was equally as crucial. In the small print of study methodologies, particularly in quantitative studies, LGBTQ+ populations, who I knew from personal experience to be diverse, were actively homogenised. The acronym LGBTQ+ created to be an umbrella of a heterogeneity of identities was, instead, used to homogenise whole populations under the term of *other*, or they were not mentioned at all. Furthermore, the historically pathological term *homosexual,* long since phased out on the gay scene in favour of the modern term *gay* to mean same-sex attraction (GLAAD, 2020), was still being used frequently in article titles and academic discourse.

Expecting to find a plethora of studies on older LGBTQ+ people in urban environments, instead, I found a big black hole where the populations in question had disappeared over the event horizon, never to be seen again. Thus, the dots began to connect. Occupational therapy is an evidence-based practice (RCOT, 2024). The evidence is question is accumulated through studies. If certain populations are in the blind-spot of research methodologies, then it follows that the data on them cannot be collected, and the services which rely on this data cannot reach them. Sometimes, services and practitioners are not even aware they exist at all.

Years later, I was giving a lecture to postgraduate public health students on hidden populations. One bright spark piped up, 'Hidden populations… hidden from whom?' Indeed, it was a pertinent question. Back in the London gay bar, the older members of the LGBTQ+ clientele would regale me with stories about what it was like when being gay was illegal, and therefore, *had to be* hidden. They would speak Polari (a language derived from traveller communities) when in public so they could discuss illegal matters openly and often narrowly escaped being arrested for having sex in public toilets (Houlbrook, 2006). Even then, I realised that remembering these stories was important so that they could be passed down as cultural history in the (then) more enlightened times of the 1990s and early 2000s.

In a way, I was an amateur insider researcher engaging in ethnography, unscientifically collecting qualitative data from people with whom I shared mutual characteristics (Saidin and Yaacob, 2016). The point is that through my position as a bartender in a gay bar, ageing LGBTQ+ populations were not hidden at all, rather, they were right in front of me and willing to impart their lived experiences.

The information I gained over the bar was of a depth and richness I was just not seeing on the academic databases years later. Where there were some very good examples, they were most often associated solely with HIV/AIDS, or LGBTQ+ youth, or both – but very rarely about older LGBTQ+ populations and their later lives. I became concerned that the quantitative requirement to fit people's identities into predefined boxes was automatically erasing populations whose lived experiences of existence were not black and white, but entirely a shade of grey.

I found that the existing knowledge about older LGBTQ+ populations fared better away from the renowned academic databases such as CINAHL and PubMed. The need for me to look further afield beyond the confines of what the university made available via their online portals, particularly regarding EBSCO, felt like a familiar experience. LGBTQ+ academic literature was very much an afterthought. It was a niche which was available, but I would have to work much harder to find it. However, even this felt like progress compared to my high school years during the days of Section 28 (HM Government, 1988) where discussion of LGBTQ+ matters in schools was prohibited altogether. Having to work a bit harder to gather LGBTQ+ data still feels like a luxury, even if it does conform to a very heteronormative establishment mindset. In the days of Section 28, the heteronormative milieu was institutional (HM Government, 1988). Nowadays, it is algorithmic, a point which will be discussed in greater depth later.

While the literature available in the university library was limited but promising, I found paying for books myself more intellectually lucrative. Some of the library books were up-to-date, but thrillingly, a copy of *The Naked Civil Servant* (Crisp, 1968) had been stamped exactly a year to the day before I was born – and I am now hurtling headlong towards being 50 myself. While these books were (slightly humorously) historical artefacts in their own right, it was clear that I would have to look elsewhere to sate my curiosity.

The first book I bought online on this subject – *Bodies of Evidence – The Practice of Queer Oral History* (Boyd and Ramirez, 2012) felt like an epiphany. It is a methodological manual on how to collect qualitative data of sexual and gender minority populations, using existing research as a case study per chapter. In this book, study participants relate their lived experiences about being LGBTQ+ in America and Cuba in days gone by. If the reader is starting out on a similar journey, this author highly recommends it.

For me, Boyd and Ramirez (2012) applied what I had been taught about research methods to the populations in which I was interested, and this gave me the desire to do it for myself. However, the studies *they* collected were all about other countries, and I wanted to apply these methods to the UK. By this

time, I was nearing the end of my undergraduate degree, but feeling like I had to pursue my passion further, I signed up for a master's degree in public health. I knew then that I wanted to conduct a study, and one way or another, I was going to get it done.

Public health was much more appealing to me than occupational therapy ever had been, principally because it focuses on population health rather than personal health. Public health asks the *really big* questions – why some populations carry a heavier burden of disease than others, for example. That is not to denigrate occupational therapy at all – far from it, as I found that some occupational therapy theories dovetailed neatly with those of public health (more of which, later) – but because I realised that my studies had pushed me into asking those larger, more profound questions.

Key to public health is the concept of social determinants (Dahlgren and Whitehead, 1991, 2021). These are the influential factors of health, some of which are present from birth so that populations have no control over, such as where they are born, natal sex, ethnicity, social class, education, and geographic area (Dahlgren and Whitehead, 1991, 2021). I began to wonder if having a sexual minority or gender minority status could be among these determinants too, and what implications these factors might have on population health outcomes. I found that these questions tallied with my professional queries about older LGBTQ+ populations which had come about through my clinical practice. Namely, what does LGBTQ+ ageing look like? And what support is there for older LGBTQ+ people in the UK?

It was then that I first met Dr Dorothy Hannis, who is a healthcare professional and a key member of staff on the Public Health master's and doctorate courses at Teesside University. She would go on to be an influential figure in my subsequent career. An anthropologist by training and a lecturer and author of nursing and midwifery journal articles as well, I knew immediately that if I was going to study for a doctorate in the future, I wanted her to be my supervisor. The reason was simple – in her seminars on International Public Health, Dorothy related the enabling and challenging factors of public health initiatives directly to public health practitioner understanding of population-specific cultures. This point chimed with me, as I came to realise that an understanding of LGBTQ+ cultures and lived experiences was instrumental to any studies on these populations. It was Dorothy's understanding of the importance of this emphasis which I correctly surmised would provide me with the experienced guidance I needed to continue my studies.

Before long, I turned my master's degree into the first year of a Doctor of Public Health qualification with Dr Dorothy Hannis as my academic supervisor. Finally, I had the freedom to pursue my area of interest through conducting