



“The perspectives of the patient and her carer” for the upcoming series “Diagnosis and Treatment on Primary Breast Cancer in Older Women”

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This article is the only one in the series ‘Diagnosis and Treatment of Primary Breast Cancer in Older Women’ that has been written from a patient-carer perspective. As a narrative, it is more journalistic in style than is usual in scientific publications and capitalisation has been used to transparently provide pseudonyms. Written by a patient advocate, this is a case report that has been overseen by the National Audit of Breast Cancer in Older Patients (NABCOP) and is intended to complement the other articles in the series.

Let’s be clear here: I am no ‘carer’ to my mother-in-law. I am the subordinate to a Matriarch. This isn’t something you’d guess as she’s half my size in every dimension and has a quiet concentrated stillness that I put down to her struggle with the Hartlepool accent when she first landed there as a 20-year-old Parisian to marry Jimmy. The Matriarch never goes to the GP (unlike my generation of asthmatics, coeliacs, diabetics, etc.) but wouldn’t boast about this because having zero comorbidities and a sporty and sociable lifestyle is her ‘normal’. Whether under the neon lights of a hospital clinic her quiet and unassuming demeanour is considered ‘undemanding’ or whether her thick French accent suggests ‘questionable understanding’ or whether the slight frame of a golfing fanatic who loves lobster is re-envisioned as ‘average pensioner’ we will never know. Something though drove a difference between her cancer treatment and mine.

Unlike myself and every other 40–50-year-old triple-negative breast cancer (TNBC) patient that I have mentored through Breast Cancer Now’s (BCN) ‘Someone Like Me’ scheme (1) over the last 6 years (upwards of 80 women from NHS Trusts ranging from Dumfries to the Isle of Wight),

my mother-in-law wasn’t considered for neoadjuvant chemotherapy (NAC) and wasn’t offered an appointment with an oncologist ahead of her mastectomy. She’s also the only person I’ve ever known to be told that TNBC is good news [every breast cancer (BC) rookie knows that TNBC is the bad one] (2); was this ignorance on the part of the BC nurse or a white lie told to ‘oldies’ who are unlikely to double-check on the internet? She is also the only person I know to whom it was told that it would be indefensible to offer chemo, a point demonstrated by the oncologist saying that she ‘wouldn’t ‘do it’ to her own parents’. And critically, she is the only person I have known to be discharged with positive margins (as a BCN mentor I know that some Trusts provide belt and braces capecitabine to my age group even if there’s just 5mm of residual TNBC in the lumpectomy after NAC). Before the official discharge letter arrived in the Matriarch’s letterbox she’d returned to the hospital with brain, liver and peritoneal metastases and had been offered palliative care. This was the turning point: the Matriarch finally conceded to the subordinate that there’d been age bias and, with fear overriding embarrassment, agreed to change Trusts. The New Oncologist acknowledged the Matriarch’s reason for changing Trusts (that she’d been discharged without clear margins and without further treatment) with the smallest raise of the eyebrows; was he caught between the conundrum of collegiate solidarity and improving practice?

Forgive my speculation, but isn’t tailoring cancer care all about speculation? From the 2020 NABCOP (3) 40% of the World Health Organisation (WHO) performance status data points were missing for those aged 70–79. So

when a case arrives at the multidisciplinary team meeting (MDT), unless the 2 professionals who met the patient (Registrar and BC nurse in the Matriarch's case) are present and sufficiently informed to speak up and vouch for the patient's ability to withstand treatment and desire to survive, the key data points that define the initial treatment pathway are limited to molecular biology, tumour size and date of birth (with genetics and further imaging being requested by the oncologist later in the pathway). This means that, if it were not for speculation, me and the Matriarch would have had the same treatment: at a data level the only difference between my diagnosis and hers is the date of birth—and treatment guidelines do not differentiate by age.

High Court judges believe that it is for the claimant to prove their case, not for the defendant to prove they didn't. But in geriatric oncology which patient lives long enough to prove age bias? My mother-in-law and I went hand-in-hand through her treatment. We, the TNBC patient and ex-TNBC-patient-carer, are able to prove an age bias that eludes the Professionals. Identifying barriers to treatment (and poorer survival) in those over 70 years was an inquiry of the All-Party Parliamentary Group on Breast Cancer (APPGBC) in 2013 with the report 'Age is just a Number' and has been the mission of NABCOP since 2016. However, proving age bias amidst the incomplete data points and plethora of confounders is almost impossible. Instead, discussions in these boards and working groups explain away the variation in care of older patients with interpretations such as: we're the obese man of Europe, patient choice, co-morbidities, poor fitness, demographics, risk of over-treatment, and the need for 'tailoring'. Proving age bias can only be done in the context of the individual; the whistleblowing on age bias would have to come from the patient directly, and which patient of this generation is sufficiently informed, sufficiently outspoken, and survives long enough to do the job?

The 'indefensible' chemo has been happening for 6 months. The Matriarch's disease is stable and her life is full. She pencils in her eyebrows, plays golf, cares for her grandchildren and Jimmy, uses her exercise bike daily and sends photo-postcards to her 93-year-old sister Nicole in Paris to illustrate that 'Ma pauvre' isn't so 'pauvre'—because that generation expect horrors when it comes to cancer care.

As to me, my foray into geriatric oncology didn't start as an over-zealous patient-carer with an axe to grind. It started with an invite to the NABCOP project board in

2016 for which my background in epidemiology, real-world data and TNBC patient advocacy were a good fit. At NABCOP I sit amongst the professional community who saved my life and, with them, hope to evidence the need for a change in practice that will give the Matriarch and her cohort the same treatment opportunities that were given to me.

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Footnote

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