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What really matters in cancer? ☆

Putting people back into the heart of cancer policy

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Abstract Twenty-first century cancer is framed by the biomedical revolution. The cancer patient today enters a world dominated by the success and failures of biomedical science from gene to statistic. By any measure, bibliometric, financial, media profile or simply the lingua franca of everyday discourse about cancer, biomedicine occupies the majority of the cultural discourse around cancer. Yet the reality is that patients are people who are diagnosed, treated, survive and die with cancer in a world bounded by their personal and social experiences. Others they have known with the disease shape their values and concepts. The social determinants of cancer are of far greater importance in terms of prevention, treatment and care than is acknowledged in policy terms. In light of the demographic trend of a rapidly ageing population, increasing costs of healthcare and the urgent need to be able to deliver affordable cancer care set against the population's almost insatiable ability to absorb all types of healthcare, there is an urgent need to redress policy balance in terms of both understanding the social determinants of cancer and bringing new insights into evidence-based national cancer planning and delivery of services.

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1. Introduction

21st century cancer is framed by the biomedical revolution. The cancer patient today enters a world dominated by the success and failures of biomedical science from gene to statistic. By any measure, bibliometric, financial, media profile or simply the *lingua franca* of everyday discourse about cancer, biomedicine occupies the majority of the cultural discourse around cancer. Yet the reality is that patients are people who are diagnosed, treated, survive and die with cancer in a world bounded by their personal and social experiences. Others they have known with the disease shape their values and concepts. The social determinants of cancer are of far greater importance in terms of prevention, treatment and care than is acknowledged in policy terms. In light of the demographic trend of a rapidly ageing population, increasing costs of healthcare and the urgent need to be able to deliver affordable cancer care set against the population's almost insatiable ability to absorb all types of healthcare, there is an urgent need to redress policy balance in terms of both understanding the social determinants of cancer and bringing new insights into evidence-based national cancer planning and delivery of services.

2. The *biomedicalisation* of cancer care

The rise of modern cancer care from the words uttered by James Watson and Francis Crick, '*We wish to suggest a structure for the salt of deoxyribose nucleic acid* (*D.N.A.*)'[1] has seen an avalanche of new discoveries across the scientific spectrum. There is no part of cancer management, from early detection through to imaging, pathology, surgery, radiotherapy and systemic therapy, which has not radically changed in the last 50 years. Whilst the emergence of translational cancer medicine has been a relatively recent phenomenon,[2] it is now the dominant paradigm, absorbing over 80% of R&D funding and accounting for nearly 82% of all research publications.[3] This paradigm also dominates the public-policy-media nexus with biomedical technology, particularly cancer therapeutics dominating. Whilst this biomedical endeavour has produced great benefits to cancer patients, what is invariably lost are the awareness and policy implications that human social organisation is still the primary determinant of how the incidence of cancer is distributed in society, how patients are treated and the outcomes they experience. The price to be paid for this biomedical cancer revolution has been significant; our interventions are becoming less and less cost-effective, social determinants of cancer have become a policy backwater and medicine is increasingly disconnected from patients and their families and increasingly we focus on treating the disease rather than the person. A cancer patient will now at diagnosis 'hear' a bewildering kaleidoscope of biomolecules, gene therapies and stratified medicine. What is heard is science rather than care.[4]

The techno-centric nature of biomedicine coupled with the personalised medicine culture of cancer based on genes, molecules, targets and drugs has led to many unintended and detrimental consequences. Almost a quarter of overall lifetime spending on cancer occurs in the last year of an individual's life and yet paradoxically, whilst on the one hand older patients suffer discrimination in terms of both diagnosis and treatment,[5] on the other, we promote excessive treatments towards end-of-life that result in minimal, poor quality prolongation of already frail lives.[6] In some cases, treatments have become more complex and expensive with relatively modest effects on life expectancy and/or quality of life. In high income countries, cancer treatments are considered like 'luxury goods', in the sense that the wealthier the person or country, the more willing they are to pay a larger share of their income or healthcare budget on these modest survival prospects.[7] There is a tacit assumption drawn from a global ideology that technology[8] will ultimately control and cure cancer. However, this is wide of the mark both in terms of macro-policy (ageing demographics, affordability) and at the patient level where we overlook the importance of relational aspects of care,[9] and quality as well as quantity of life.

3. Missing the point: the social nature of cancer

The social determinants of cancer are rooted in human ecology, which in itself emerged from biological ecology through sociology.[10] The holistic nature of this tradition of understanding health and disease provides the ideal template for re-framing cancer policy in terms of value sets that can resonate with patients, carers and all cancer healthcare professionals irrespective of their hierarchy, state of knowledge, power or discipline. Whilst patients suffer and are treated as individuals the reality is that cancer is a community disease, in both its origins and (modifiable) risk factors, and that within care pathways, communities of health professionals, as well as individuals treat patients (Table 1).

If this is accepted then cancer policy takes on a very different hue, one that should be seen through the prism of social capital – physical and human.[11] The challenge to the contemporary wisdom of cancer treatment is that it has become indifferent to 'mode of life', what we eat, what we do, what air we breathe. Institutional forces frame the promising possibilities of patient choice and action whether they are in medical research or as part of their clinical care.[12] We consistently forget that interpersonal trust is also a critical part of the social fabric of cancer. For the cancer patient, this is where patient self-help and support groups, meeting in person or virtually play a vital role. They create the bond where they can

Table 1
Ecology of cancer: how to frame policy issues in light of the social determinants of health.

Equity and **Justice** in social relations	The widening cancer survival gap reflects a serious societal issue with equity. Social inequity and inequality need to be core policy issues for the cancer community
Access to development and resources	Differential access to cost effective high quality care pathways drive a fundamental sense of unfairness
Respect and caring for peoples worth and dignity	Leadership which demonstrates respect is fundamental to setting the tone of care delivery
Work as a means to fulfilment of existence and survival	Labour policy is as critical to overall good health as it is to cancer. Support and anti-discrimination policies are essential for both cancer patients and their careers
Aesthetic values of beauty and environment	Greater emphasis needs to be placed on the environment in which care is delivered
Well being for all	Policies need to address a more holistic offering and a recognition well being is a core aspect of cancer care

meet people who are going through similar experiences. With so much of the focus on secondary and tertiary care there is no longer the sense of accountability or responsibility for the broader aspects of cancer public health. There is a strong sense that in becoming careless about the social detriments of cancer we have created a moral hazard. The consequences are clear: the erosion of affordable cancer care,[13] a failure to tackle the compression of morbidity problem, i.e. increasing life expectancy but no compression of years spent in disability,[14] and a very mixed success in terms of implementing effective population health programmes, e.g. the Scottish Diet Action Plan.

The ageing population and changing patient profile have also been ignored from the policy debate. Frailer older people, with sometimes the added burden of poorer mental health associated with ageing e.g. dementia, an increasing number of cancer survivors with additional healthcare needs after diagnosis and shortly before death (now almost 2 million in the United Kingdom (UK), or 3.2% of the population),[15] and the escalating problems with social exclusion, all have an effect on the patients we care for and their eventual outcomes.[5] Unequal societies have a huge impact on cancer outcomes and patients' perceptions of fairness and justice.[16] Despite this knowledge, we are seeing ever-increasing gaps open up between affluent and deprived cancer patients.[17] None of this can be fixed with further investment in biomedicine. It can only be solved when policies are directed at the social determinants of cancer.

4. Compassionate cancer care: what should this look like?

This discussion of cancer would be incomplete if it ignored patients' experience of treatment and care. Cancer has a special status in the public mind. For most people, a diagnosis of cancer is devastating, and too many patients are told their diagnosis in settings where they have no support and little privacy. For a great many patients, after the initial shock, the experience becomes closer to that of other patients with long-term conditions, where continuity of information, communication and care coordination are far greater concerns.

The experience of cancer patients is determined by the same relational and transactional issues that determine the experience of patients generally: respect for the patient's dignity and autonomy; how the patient is treated as a person; whether staff respond sympathetically to pain, anxiety and distress; how they treat the patient's family and friends; whether they solicit information about the patient's preferences; whether care is fragmented or continuous and how it is co-ordinated.[18]

Caring for the person in the patient presents sociological rather than technological problems. The complexity of cancer treatment and sheer number of health professionals involved in caring for the same patient requires agreement about effective clinical leadership, common aims, skills in multi-disciplinary teamwork and team processes and education and training that equips staff to deal with relational and interpersonal aspects of care-giving.

5. Conclusion

Whilst the biomedical revolution has delivered extraordinary advances, cancer medicine is still social, from issues of prevention, uptake and access to services all the way through to the core end-of-life determinants. In the rush to embrace the molecularisation of cancer research, funders, professional organisations and governments have relegated social cancer medicine to the sidelines. Funding for research has been scaled back and addressing social issues in cancer policy discourse has been modest. Macmillan's *Discrimination at Work* initiative is a prime example of the sort of actions that are needed. Furthermore, research into the social aspects of cancer is as valid as any study in molecular biology. Patient-centred care requires a balance between both.

Conflict of interest statement

None declared.

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