If psychosis were cancer: a speculative comparison

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ABSTRACT

Recently, health policy in the UK has begun to engage with the concept of ‘parity of esteem’ between physical and mental healthcare. This has led one recent initiative to improve service provision for first episode psychosis, which aims to bring it into line with some of the principles underpinning good practice in cancer care. In this paper, we consider some of the metaphorical consequences of likening psychosis to cancer. While we find the comparison unhelpful for clinical purposes, we argue that it can be a helpful lens through which to examine service provision for psychosis in young people. Through this lens, specialist community-based services would appear to compare reasonably well. Inpatient care for young people with psychosis, on the other hand, suffers very badly by comparison with inpatient facilities for teenage cancer care. We note some of the many positive features of inpatient cancer care for young adults, and—drawing upon previous research on inpatient psychiatric care—observe that many of these are usually absent from mental health facilities. We conclude that this metaphor may be a helpful rhetorical device for communicating the lack of ‘parity of esteem’ between mental and physical healthcare. This inequity must be made visible in health policy, in commissioning, and in service provision.

INTRODUCTION

In this paper, we will explore the meanings and practices surrounding the understanding and response to both cancer and psychosis in young people. Our primary focus is on psychosis, and on the general lack of ‘parity of esteem’ which characterises cultural resources for making sense of mental health problems (particularly in relation to research, development and treatment), when compared with physical illnesses.

In the UK, ‘NHS England’ reports to the government, via the Department of Health, and is responsible for the delivery of the National Health Service in England. A recent mandate from the government to NHS England requires the health service to ‘put mental health on a par with physical health, and close the health gap between people with mental health problems and the population as a whole’.1

Although the general comparison between mental health and physical health provision is now being made directly, by policy-makers, we make our specific comparison speculative, and for rhetorical purposes, because we believe the parallels to be complex. One could argue that the comparison can be drawn because psychosis (and particularly schizophrenia) is often characterised in popular discourse as the ‘cancer-equivalent’ among psychiatric diagnoses, but this has stigmatising consequences. When this comparison is made in popular culture, it usually only extends to the severe implications of a diagnosis.4 Thus, psychosis acquires cancer’s negative qualities of threat to life expectancy, blighted quality of life and poor prognosis for recovery. This is not a helpful comparison: underscoring a narrative about psychosis with reference to a strong biological disease model is out of step with the direction of travel in much contemporary research, which may also compound the stigma that is already attached to a diagnosis of schizophrenia.5 We recognise these problems; for therapeutic and psychoeducation purposes, the comparison is unhelpful, but as a testbed for the issue of parity of esteem, the comparison may have utility, and in this paper we focus upon that aspect. Some aspects of the comparison which may be helpful, for example, include the importance of reducing delays to treatment after first onset, the considerable psychosocial consequences of both conditions and their significance in terms of mortality and morbidity.

WHY A METAPHORICAL COMPARISON?

Using the linguistic concept of metaphorical entailments, we will explore what occurs if the comparison is temporarily accepted and then further extended. Metaphors are commonly understood in terms of the conceptual link between a source domain (in our case, cancer) and a target domain (in our case, psychosis). The properties of the target are understood according to the concepts that we already use to understand the properties of the source.3 According to Kövecses,4 entailments are the consequences of this metaphorical comparison. Entailments can be explored whenever the source domain is enacted as a social–physical reality (eg, people with psychosis may receive treatments from medical professionals, just as people with cancer would do, and this would be an entailment of seeing psychosis as if it were cancer).

Thus, we can imagine and explore a hypothetical world in which psychosis and cancer are

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1We use ‘psychosis’ as an umbrella term for a range of distressing and anomalous experiences, including delusional beliefs and auditory hallucinations. This terminology is now common in the field of mental health. It is particularly salient in the context of Early Intervention services for young adults, which tend to work with ‘diagnostic uncertainty’, and to defer formal diagnosis of disorders such as ‘schizophrenia’.


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understood by the public, by researchers or by health professionals, in comparable ways. In this case, services for young people with psychosis are conceived, funded, delivered and evaluated according to similar values and criteria applied to cancer services. It is clear that the UK Department of Health’s recent ‘Access and Waiting Time Standards’ for Early Intervention in Psychosis are intended to move us closer to this kind of world. These standards require service users and families to wait no more than 2 weeks before receiving a National Institute of Health and Care Excellence (NICE)-compliant (ie, evidence-based) service. These principles are drawn from good practice standards in cancer care. Thus, the metaphor is already in use, guiding policy, and some further examination of its consequences and limits is merited in order to illuminate some of the cultural values and moral assumptions which underpin the provision of mental healthcare, particularly for young people.

WHY THIS COMPARISON?

A historical perspective may be helpful here. Cultural resources for making sense of cancer have evolved rapidly. In 1978, the American writer Susan Sontag argued that—such was the stigma, fear and mystery surrounding cancer—simply saying the word carried the connotation of hastening or summoning the disease. Perhaps, the reverse is true in contemporary society: saying ‘cancer’ out loud seems to have hastened the cure, rather than the disease—the mobilisation of funding for cancer, the increase in support for those with cancers and their loved ones, and the provision of services for cancer treatment have all been brought about, or at least hastened, by our ability to speak of ‘cancer’ without taboo or mystery. There is now a cultural discourse around cancer that is less fearful, and not shameful or stigmatised. We would no longer shun someone with cancer for fear of somehow ‘catching it’, as Sontag described. Sontag argued that cancer was kept mysterious, and thus feared, through the use of metaphor. She discussed how physicians were encouraged to avoid naming the disease and ‘further afflicting’ their patients; she argued that this only served to mystify the illness, increase secrecy and medical paternalism: ‘The solution is hardly to stop telling cancer patients the truth, but to rectify the conception of the disease, to de-mythicize it’.

In introducing the comparison between cancer and psychosis, we want to consider Sontag’s arguments regarding the role of metaphor and myth, before making a more detailed comparison of the two. Today, we could argue that it is ‘mental illness’, not cancer, that remains relatively mysterious, stigmatised and feared, despite much work to change this. Of all mental health issues, the experiences of hearing voices or holding unusual beliefs tend to be particularly frightening for those experiencing them for the first time, and for the people around them. Whereas Sontag noted that one ‘mystification’ in the 1970s was the belief that ‘cancer=death’, we could observe that today ‘schizophrenia=intractable disability’ (a ‘severe and enduring mental health problem). In everyday discourse, this is a common trope, though it is not one that we (or many in mental health services) would endorse. Sontag argues that this type of myth has distressing impacts for those who are unwel; in particular, it can delay people seeking treatment and support. It is worth noting that such delays can be reversed, if easily accessible assessment services are combined with good information provision about when and why to seek help.

Concerns about the stigmatising effect of labels (eg, ‘schizophrenia’) are commonplace. The benefits of normative physical illness comparisons are questionable. To begin with, there is the complex nature of mental health problems. Mental illness is not physical illness—it does not generally involve pathogens or cell mutations. With many problems and syndromes, it is contested as to whether any observable abnormalities in brain structures, chemistry or genetics provide necessary and sufficient causal explanations. Often, life events, developmental experiences and the impact of the emotional environment are implicated. Yet, the language of disease and illness is used by many, and the medical model has predominated. In effect, recent moves to introduce parity of esteem are attempts to capitalise on this, rather than to change it, but the analogy between mental and physical health is not without difficulties. Focusing only on psychosis as an example, we can identify a number of challenges. Starting a campaign to bring about transparency is immediately mired in the contested language (and aetiology, prognosis, treatment, etc.) of the experience. Labels are complex in this context, because the appropriate conceptualisation of the phenomenon is disputed. Schizophrenia is a contentious diagnosis, and its status as a category is not secure. As a result, many organisations now use ‘psychosis’ to describe a range of different symptoms and experiences, but the term still carries significant negative and stigmatising connotations in everyday discourse. Despite attempts to move beyond the medical ‘mental illness’ approach, which many have found stigmatising and antithetical to recovery, we have not acquired an agreed-upon language with which to speak about these human experiences. In Sontag’s terms, we have silenced ourselves through fear of offence. Without an agreed-upon common language, we struggle to say anything that can be heard and understood by the majority, and thus we stifle the conversation before it has begun.

When we look at how cancer and mental health are communicated to the public, we can see a distinction. Adverts from cancer charities talk about humankind pulling together to beat the disease—if we support each other, or if we collaborate to raise money for research and treatment, for example. The recent breast cancer campaign, ‘We’re stronger together’, illustrates this trope. By contrast, campaigns from mental health charities focus on encouraging the individual with the mental health difficulties to talk about their experiences (such as in the ‘Time to Talk’ campaign). The emphasis seems to be less on ‘cure’ and more on individual responsibility. Whereas Sontag describes cancer discourse having once mimicked historic perceptions of tuberculosis, and thus entailing a ‘diminution of the self’ based around ‘fictions of responsibility’, now this seems an apt analysis of the impact of mental health difficulties. In cancer, the idea that a person has a moral responsibility for ‘fighting’ the illness is now subject to sustained critique. The writer Jenny Diski’s reflections on her own terminal illness are particularly powerful: ‘Under no circumstances is anyone to say that I lost a battle with cancer … I reject all metaphors of attack or enmity in the midst’. Some critics of the way that the ‘recovety’ concept has been appropriated from the survivor movement by mental health services have also pointed out that recovery has provided a vehicle for ‘personal responsibility’ to make a problematic return to mental health discourse—see Beresford et al. More than one mental health organisation has run social media campaigns this year on how to succeed at ‘fighting your demons’, for example. It is easy to see how the

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For example, a recent campaign by Macmillan Cancer Support emphasises the shared experience of cancer: https://www.macmillan.org.uk/about-us/what-we-do/our-ambition/not-alone-campaign.html
line can become blurred between sharing insights about ‘what works’ and marginalising those who do not feel they are winning the ‘battle’. If we are to demystify and reframe ‘mental ill health’, we must of course do it in a way which empowers service users, changes public attitudes, enhances the funding possibilities for research, treatment and support. We must do it in a way which does not simultaneously blame or exclude service users. Can this happen in the way that it has for cancer? We think that the focus of cancer-care educators on shared responsibility and ‘supporting each other’ (via many forms) is a helpful lesson which can be applied to mental health.

EARLY ADULTHOOD
Psychosis typically first occurs in late teens and early adulthood; so, perhaps the most salient comparison can be made between early psychosis and teenagers experiencing cancer, rather than cancer as a whole. We are thus concerned here with the provision of care to young people in late adolescence and early adulthood. ‘Emerging adulthood’ is a distinct and important developmental stage of life.12 13 Young adults at this time are defining their views, developing their identities, experimenting with risk, consolidating their education and forming important new relationships. Thus, Morgan et al14 have argued that adolescents and young adults are a distinct group with specific needs. Education, social service and criminal justice systems all view this group as distinct and treat them differently to younger children or adults. In many health settings, this is also the case.

EARLY INTERVENTION SERVICES: A POSITIVE PARALLEL?
A description of service provision is helpful here. Services are the enactment of our historical, cultural and political understandings of ‘problems’. They tell us something about how the problem is construed, how important it is and whose responsibility it is. We begin by exploring the one dimension—the provision of specialist outreach community care—on which early psychosis compares reasonably well with cancer care for young people. Specialist early detection and intervention services have been developed internationally over the last 25 years.15 They deliver evidence-based, multidisciplinary interventions during the ‘critical period’ following first onset of psychosis, when such interventions can make the most difference to young people’s long-term health and functioning.

There is good evidence that these services are efficacious and cost-effective,16–18 and highly acceptable to young people and their families.19 However, in the UK, such services are now under considerable pressure as the changing economic climate affects healthcare.20 21 A number of them have been closed or subsumed into larger, less specialist mental health teams, with concern growing about the impact upon service users and families. A recent government set of ‘access standards’ for NHS England now requires that ‘more than 50 per cent of people experiencing first episode psychosis will begin an evidence-based package of care within two weeks of referral’.22

In the UK, government guidance22 also recommends that young people with cancer must be cared for in age-appropriate facilities and those under 19 should have ‘unhindered access’ to age-appropriate facilities and support. Cancer treatment is largely hospital-based, but it can involve a blend of inpatient and outpatient treatment. Recent guidance for young people with cancer recommends a reduced number of outpatient appointments, follow-up services which are close to home, access to education and information, seamless transition to adult services23 and for care to be coordinated across the health system.22 The parallels with the ethos of Early Intervention (EI) for Psychosis should be clear here. EI is obviously more community-based (and one of its claims to cost effectiveness is reduced days spent in inpatient care), but its ethos is age-appropriate and family-focused, and the new access standards are emphasising that—like cancer care—it must provide evidence-based intervention (including psychological therapy, medication, family support and psychoeducation) in a timely fashion.

NICE guidance also emphasises the role of cancer networks in ensuring that the needs of children and young people with cancer are met, noting that each young person with cancer should have a key worker and a multidisciplinary team. One way that care is being provided to young people with cancer is through ‘network-focused nursing’24 where nurses work to sustain relationships between the young person and their family, friends and wider social circles. This includes holding ‘network meetings’, where people from the young person’s social network are invited to discuss illness, treatment and impact on the young person and their relationships. It also makes provision for the young person’s burgeoning independence by arranging ‘parent-free time’ for the young person to consult nursing staff privately, and encourages family and friends to spend time with the young person.

In psychosis, the Early Intervention approach includes a similar role: young people are allocated a care coordinator, with a relatively small case load of patients (in comparison with other professionals working in generic mental health teams). This allows them to spend a significant amount of time visiting the young person and their family within the community, in places where the person feels safe (usually their home). The Early Interventions Team will usually include a psychiatrist, clinical psychologist, social worker, support worker, occupational therapist and community mental health nurse. The interventions offered might include medication, social and vocational activities, individual support with activities, psychological and family therapies.

INPATIENT CARE: A LESS FLATTERING COMPARISON
Although the aim of Early Intervention Services is to keep young people with psychosis out of hospital wherever possible, it is nevertheless the case that in times of acute crisis, hospital stays may be necessary to manage risk and contain overwhelming distress. It has been argued that such stays away from home would be better managed in bespoke respite environments, rather than hospitals per se. Whatever the site, it is important that inpatient services are as well resourced and age-appropriate as outreach services. However, the comparison with cancer services is here much less favourable. In our experience of researching inpatient care for young people with psychosis,25–27 we have observed a number of striking differences in: the relative comfort and accessibility of the physical environment, the acceptability of the care practised within it, the psychological environment on acute wards, their permeability to family and friends, and their adequacy in promoting recovery and well-being. Over recent years, psychiatric inpatient care has increasingly been described as ‘in crisis’.28 Young adults are typically cared for in general acute wards and, in the absence of specialist care, the problems which affect these services in general are also experienced by young people. A report produced by Rethink29 describes this crisis in some detail, outlining problems related to

https://www.england.nhs.uk/2015/02/mh-standards/
a controlling and bleak environment, overcrowding, understaffing and lack of activities. For some, the shock of this stark environment, when combined with compulsory detention, may even be traumatising. This is critical, because for many young people experiencing psychosis, a period of inpatient care after a crisis can be the entry point to mental health services. Future relationships and engagement are shaped by these experiences. While hospital treatment in cancer care would usually be voluntary, there is an important parallel in terms of establishing the basis for future engagement in treatment, which is likely to be important for the best outcomes.

The entailments of our comparison between cancer and psychosis can be explored further by reviewing the public face of the cancer unit for young people at our local hospital. The hospital is justifiably proud of this resource: a virtual tour is available on the organisation’s website, with frequently asked questions, information for families who wish to visit or stay over, and a large number of photographs, showing brightly coloured soft furnishings, televisions and videogames, common rooms and bedrooms (figures 1 and 2).

The context of caring is set up to be welcoming, permeable, safe and comfortable. This seems to chime with the reality: in an evaluation of Teenage Cancer Trust specialist units, The Futures Company consultancy describes benefits for patients and families in terms of improved control, comfort, stimulation, personalisation and connectedness. For example, they found that young people were given control over when and what to eat, when to go to bed and get up, and over small but important things, such as adjusting the colour and intensity of lighting around the bed. A sense of control is particularly important, given that young adults are just beginning to gain independence at this time. Families are also able to visit whenever they want and to stay overnight, to cook and eat together, or to play computer games or pool together. The evaluation also noted that free internet access was the norm, and that equipment such as laptops, pool tables, juke boxes and games machines were provided to combat boredom. Wall graphics, large windows and access to outside spaces helped young people to stay connected with the outside world. Young people could bring bedding from home, and had the use of some shelf space, white boards, picture frames and cupboards for personal items. The bright, welcoming environments in these units mean that siblings and friends feel more comfortable and are more likely to visit. While it is true that young people’s presence on a mental health unit may be involuntary, in our view this only makes it more important that the environment should feel safe and comfortable, be amenable to visits by family and friends, provide access to appropriate technologies and activities, and provide assessments and interventions which can be maintained and developed further in community care. An ethnographic study of a teenage cancer ward by Kelly et al describes such features: safety and psychological security, peer support and youth-oriented activities. By contrast, Cleary’s ethnography of an inpatient psychiatric ward describes growing pressures upon staff, with more complex care needs in direct conflict with organisational pressures to limit occupancies to ever shorter periods of stay.

The context of psychiatric care is often established with rather different implicit assumptions to those shaping cancer care. To begin with, most psychiatric services do not typically provide specific inpatient units for young adults—though there are exceptions, such as our own local hospital in the West Midlands, or the unit in Lambeth, London. The former was true of the organisation where we conducted our research. Neither this hospital, nor the services which we studied in our research, have a website which provides anything more than the most basic information about the facilities (eg, address and contact details). Again, this is typical: readers may wish to run an internet search for their own local inpatient psychiatric wards. These will generally provide little or no information about these services (in terms of pictures, what to expect, what to bring, what activities and therapies are offered, when to visit, etc). However, such searches do tend to turn up a number of negative reviews from service users, with complaints about both experiences and facilities. Finally, such services are typically

Figure 1 Example of an interior designed for young people with cancer. From the Teenage Cancer Trust website: https://www.teenagecancertrust.org/get-help/how-we-can-help/our-units/queen-elizabeth-hospital-young-persons-unit.

Figure 2 Further example of a bed space designed for young people with cancer. From the Teenage Cancer Trust website: https://www.teenagecancertrust.org/get-help/how-we-can-help/our-units/queen-elizabeth-hospital-young-persons-unit.
designed with the assumption that the mental health issue is a problem for an individual, rather than for a person with a family and a network of others who are involved in their life and well-being. Even those organisations which do provide more thoughtfully designed spaces and more accessible information still tend to reflect very medical, institutional environments (figure 3).

Families and young people with psychosis often report not knowing what to expect about hospitalisation,25 26 or else they describe expectations which were often not met during the short stays which typify acute care.34 35 Sadly, rather than describe wards as ‘welcoming, permeable, safe and comfortable’, the young people, nursing staff and parents in our studies instead use terms such as ‘frightening’, ‘shocking’, ‘horrible’ and ‘terrible’ (Thompson J, Boden ZV, Fenton K, et al. The experiential impact of hospitalisation: Psychiatric nurses accounts of caring for young people with early psychosis. Unpublished manuscript).25 26 These are not atypical evaluations of inpatient psychiatric care.29 35 Very few of the features described in the evaluation of teenage cancer wards, above, would be found in an inpatient psychiatric ward. It is worth underlining a point made earlier: both services mark the beginning of a treatment journey and are likely to play an important role in setting up the service users’ relationship to the service for future engagement.

If psychosis were cancer, then we might expect that specialist inpatient services for young adults would be commonplace. These services would be staffed by nurses and doctors with special expertise in working with young people with psychosis, and they would be complemented by psychologists, applied health professionals and youth workers, all of them providing evidence-based interventions. These services would provide more than ‘containment’ and risk management, even if an acute crisis was the trigger for an inpatient stay, because it would be recognised that the groundwork for good community was being established. The environments to which young people and their families turned for help in times of acute distress would be open to receiving them, and would be permeable and welcoming to visits by friends and family members, thus providing peer and/or family support, and helping the young person to maintain important relationships. Partners and family members would be able to stay overnight, as in the cancer ward, in order to help their loved one feel calmer and safer, at a time of acute distress. Young people would be seen in relatively small and homely units, which would feel (and be) safe. These age-appropriate environments would include access to simple, freely available amenities; resources such as kitchens, books, games, activities, and routes to safe and pleasant outside spaces; equipment such as televisions, videogames and exercise kit. The equipment would work.

**DISCUSSION**

Our exploration of the ‘psychosis-as-cancer’ metaphor has been provided, not for clinical purposes, but in order to highlight inequities in service planning, commissioning and delivery for young people with psychosis; but what it really communicates is the inherent cultural attitude which leads to a disparity of esteem. Although prevalence rates are hard to compare, both cancer and psychosis are serious, potentially life-threatening and sufficiently common that they require a well-organised systemic response. Both conditions carry a significant increased risk of suicide.36 37 Both carry significant economic costs to the state. If we see psychosis as the responsibility of healthcare services, then it is reasonable to make the comparison that we have made here, and to consider the parallels and disparities.

Sontag argued that ‘the metaphorical trappings that deform the experience of having cancer have very real consequences’. Currently, it may be true that the mystery and stigma surrounding psychosis, and mental ill-health more generally, are having the same very real consequences; however, there really is plenty of confusion, controversy and disagreement surrounding psychosis, its aetiology and treatment. Despite this, there should be no confusion about how young people and their families are supported when they are at their most vulnerable, whether from cancer or psychosis. Those very real consequences include similarities and differences when we compare current understandings of cancer and psychosis. Similarities between the two include a commitment to multidisciplinary, age-appropriate, network-focused community services, although it is a concern that such important specialist services for psychosis are under growing pressure. The differences are stark, however, when we consider the provision of age-appropriate inpatient care, the wider cultural representation of the ‘problem’ and the environment in which such care is provided. Further unfavourable comparisons could no doubt be drawn in other domains (physical healthcare, for example), but the scope of our paper has been to focus on underlining the general lack of parity. The different elements of the social, political and clinical system organised around each of these problems (cancer, psychosis) are configured in different ways. The political landscape is different. The orientation of hospitals towards young service users and their parents is different. The patterns of commissioning and funding are different. Even the landscape for charitable fundraising and contributions are different.
Yet, similar services are needed to care for both groups (a combination of age-appropriate, multidisciplinary inpatient and outreach). Acceptability of services is important for both groups. In both cases, there are important stakeholder groups (families and a range of professionals) who should be considered. The social and political agenda in each case ought to be very similar—but clearly it is not. Currently, we appear a long way from the ‘parity of esteem’ being called for. If psychosis were cancer, we would see evidence of an unequivocal and universal public response to supporting the recovery journey of young people with psychosis, and we would see this reflected in social media and cultural narratives. We could see it enacted in health policy, commissioning and service provision. We would know if it were happening, because psychosis services and hospitals would be as transparent and welcoming to young adults as cancer services are.

We recognise that there are in fact some serious problems with the wholesale application of the medical illness model to the experience and symptoms of psychosis. In some respects, the metaphor is not speculative at all: young people with psychosis are already likely to be subjected to a medicalised approach, just as many people who experience other forms of psychological distress are. A strong critique suggests that this may not be the most appropriate approach for understanding and responding to the needs of people with psychosis.48 Alternative approaches, such as the open dialogue approach,49 are gaining ground. Nevertheless, at a more fine-grained level, the entitlements which we discuss in this paper ought to prompt some serious reflection on our faulty cultural assumptions about the meaning and context of psychosis. If we accept that psychosis is a healthcare problem, then the standards and resources which are dedicated to the support and treatment of people with psychosis ought to be comparable with those which are applied to serious physical health problems, such as cancer, and we should see a similar coherent view underpinning the entire care pathway.

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