Members' Newsletter

BHMA
British Holistic Medical Association

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Too much diagnosis?

- the creeping normalcy of healthcare

The second major international conference on preventing overdiagnosis happens in Oxford this month, marking another challenge to the medicalisation of illness. This article looks at some of the intriguing hidden issues.

When a major change happens suddenly we all notice it. But when it happens very slowly we fail to perceive a change until for some reason we are confronted with the reality of what is happening. Sometimes this is already too late to take effective action. Tolstoy described this phenomenon thus:

> "*There are no conditions to which a man cannot become used, especially if he sees that all around him are living in the same way."(1)*

This was termed 'creeping normalcy' by Jared Diamond in his book, *Collapse*, in which he gives this as the second of four reasons for the collapse of societies, even whole civilisations (2). It is a widespread phenomenon in human cultures. We have seen it recently in relation to child sexual abuse amongst Roman Catholic priests and by celebrities (notably Jimmy Savile), and also the neglect of frail older people in NHS hospitals.

"But disease theory says nothing about sick persons."

In all these cases courageous attempts by victims and whistleblowers to speak out were suppressed or ignored. I suggest that this creeping normalcy is also part of the problem with overdiagnosis. The medical model of treatment is crucially dependent on diagnosis which in turn relies on the overriding concept of disease as an explanation of illness. This now dominates to such an extent that other understandings of sick persons have become invisible. The consequences of this blindness are far-reaching and serious.

The heritage of diagnosis is 'knowing the disease', encouraging us to see the disease as an entity in its own right, a natural phenomenon that 'invades' and is localized to different parts of the body. This very familiar picture of illness depends on disease theory – 'the concept that when people are sick, a disease can always be discovered whose constant characteristics provide a rational basis for the illness and for the action of doctors' (3). Disease theory originated in France in the early 1800s. For the first time, a classification of diseases, looking rather like a classification of species, transformed the physician's task into one of identifying the disease by defining its features with ever more accuracy, just as a botanist identifies a plant. But disease theory says nothing about sick persons. The sick person becomes the often difficult terrain where the rare plant grows. The terrain must be overcome to reach the real prize: the abstract concept that is 'disease'.

PREVENTING OVERDIAGNOSIS
Winding back the harms of too much medicine

This abstraction has made possible the explosion of science in medicine: the study of the parts and their processes leading to the application of technology and the transformation of healthcare. The spectacular success of this international venture is a tribute to man's ingenuity. It has enabled us sometimes to prevent disease, or cure it, or at least control or delay the disease

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Two boys
Ashyer and Ashur

Here are two stories about two five year old boys. The first, Ashyer, is from Southern England and will be familiar to many of you because he has recently been in the newspapers and on the TV. The second boy, Ashur, you do not know because he comes from Syria and because he is imagined.

Ashyer's story

This story starts with Ashyer recovering in Southampton General Hospital from major surgery to remove a brain tumour. His parents, Naghemeh and Brett, are Jehovah's Witnesses. They wanted Ashyer to have post-operative proton beam therapy (PBT). This is not available in the UK and the hospital medical team did not recommend it. On 28th August Ashyer's parents removed him from the hospital against the doctors' advice and travelled with his six siblings to Spain. In the next two days, Ashyer was made a Ward of Court which takes responsibility for his care away from his parents. Then following police appeals on TV & social media, and an Interpol missing person alert, a European arrest warrant through the Crown Prosecution Service (CPS) was issued and his parents were arrested at a guesthouse in Spain. The next day the parents appeared in court in Malaga and the day after in the Madrid High Court. They are held in separate jails. On 4th September, the CPS withdrew the criminal charges and the parents were released from jail in Spain though Ashyer remains a ward of court. On 6th September the High Court in UK gave permission for the parents to take Ashyer to Prague where they flew by private jet on 8th September.

What do these tragic stories, so similar and yet so different, tell us? Of course, Syria and UK are at very different moments in their histories. The vicious Syrian civil war is now in its fourth year with conflict spreading through Iraq, and the death toll approaching 200,000 with no end in sight. The institutions of state that provide the infrastructure that is fundamental to human dignity and survival is non-functional, severely damaged or destroyed in many areas. Much of the population has fled to neighbouring countries. The UK's problems in 2014 are of a different order, but more insidious, less visible and I suggest deceptively serious.

> **"From what we can observe, Naghemeh and Brett have been good consumers."**

Ashyer's story shows a mutual loss of trust between his parents and the institutions upon which they were depending. This led to a grossly inappropriate series of events. In their desperation the family may have been seduced by the marketing hype of the Prague Proton Therapy Centre's front organisation, 'Medical Travel', and seemed to be pinning all their hopes on PBT. We don't know why relationships broke down with the medical staff in Southampton, but whatever individual culpability there may have been, I suggest this is really part of a general trend within UK society as we grapple with universal free healthcare in a corporatized world. From what we can observe, Naghemeh and Brett have been good consumers. They have done exactly what our consumer society encourages them to do: to shop around for what they want. But instead of being fêted as model citizens, they were disqualified as inadequate parents and imprisoned.

> **"Western nations have too much top-down institutionalization ..."**

This points to a deep hypocrisy within consumerism as applied to a complex universal good such as healthcare. The essence of consumerism is to create this 'wanting' population, but there will never be enough healthcare to meet everyone's wants. In the words of writer, Jeremy Rifkin, this is 'the stark picture of an anonymous marketplace where an invisible hand mechanically rewards selfish behaviour in a zero sum game.' (1). Ashyer will get his proton beam therapy whether it will help him or not.

Nature knows no justice, nor entitlement. The distribution of the prerequisites for human survival and dignity depend on human values

two tragedies

same planet, different worlds

Ashur's story

Ashur's home is in Syria; he is a Sunni Muslim. On 20th August, following a bombing raid, his home was destroyed and he was separated from his parents and siblings. He was found by his uncle wandering amongst the rubble of his home. His uncle took him and his own 10-year old daughter in his truck on the risky journey to the border with South East Turkey. Here they were told the refugee camps were all full. After their truck broke down just over the border they got a lift to the city of Gaziantep. For three nights they slept rough. On 23rd August they met a group of older children and young adults who let them share an empty basement. The uncle carried Ashur to the address. Ashur and his cousin joined the older children begging. They were sometimes attacked by local people who did not want Syrians begging on their streets. On 5th September Ashur became ill with fever and severe diarrhea. His uncle went for clean water and dehydration salts but the local shops would not serve him. In desperation he stole one packet of salts and a bottle of water but was caught and arrested by police. He spent the night in a police cell worrying for Ashur and his daughter. The next morning a UNHCR worker arrived at the police's request. She went with him to the basement squat where they found Ashur very weak. She arranged his admission to hospital for rehydration and found places for the three of them in a newly opened refugee accommodation on the ground floor of a high rise block. On 8th September, Ashur was discharged from hospital to join his uncle and cousin.

and human actions. This is the 'Tragedy of the Commons', the title of Garrett Hardin's famous but gloomy 1968 essay about the impossibility of fair distribution of universal goods, short of forced birth control to reduce population (2). Now I believe we know better.

The story of Ashyer shows the problem, and the story of Ashur points to an answer. It took me a long time to understand why I wanted to invent this brief drama, but I knew instinctively it would show the way. In the awful circumstances of a war-torn

nation, the infrastructure we rely on is stripped away and we see what is left. In their journey from the ruins in Syria to the relative safety of Southern Turkey, our little group of survivors show resilience and ingenuity. They make friends who help them, including the police and ultimately the volunteer with United Nations High Commissioner for Refugees. Here is a mixture of realism, co-operation and sympathetic institutional support, which was manifestly otherwise in Ashyer's story. The irony is that contemporary Western nations have too much top-down institutionalization in which corporations have excessive power. In our modern fragmented communities mutual-reliance is replaced by dependence on services, trust by fear, co-operation by envious competition, sharing by owning, improvisation by regulation, friendship by suspicion, reciprocity by narcissism, being by having. Rifkin makes the visionary case for the re-invention of the collaborative commons as our dominant social arrangement (3). This grass roots change is already happening all over the place, so every one of us can begin to help in building a better world.

References:
1. Rifkin J, The Zero Marginal Cost Society, New York, Palgrave Macmillan, 2014, p63.
2. Hardin G, The Tragedy of the Commons: http://www.bhma.org/ and follow links to "Sustainability" on home page.
3. Rifkin ibid, chapt 1.

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Comments on any of the articles very welcome
http://j.mp/bhma-nl

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progression. But such a clever spectacle beguiles us, and when it promises to save our lives, it becomes irresistible. This is well known to TV broadcasters, politicians and, of course, corporations. With so many vested interests, the central place of diagnosis and hence the medical model is assured. But what of the sick person? Therein lies the shadow. We call for compassion, for kindness, for patient-centred care, but the spectacle of conquering disease with science and technology leaves little room for this.

"...to be uninteresting is perhaps the most crushing epithet any person can apply to another."

In the new medicalised 'normal' the person, sick or not sick, has little power or importance beyond being the terrain that harbours disease or when none is found, perhaps harbingers of disease. Without even these, the *person* is often considered to be uninteresting, perhaps the most crushing epithet any person can apply to another.

The September 2014 Oxford UK conference is the second of its kind and marks the culmination of more than 10 years of campaign-building. So perhaps we are beginning to move beyond the creeping normalcy of overdiagnosis towards addressing the remaining two of Jared Diamond's reasons for the collapse of societies: failure to attempt to tackle a problem once perceived and failure to take appropriate action even when there is a will to do so. The main reason for the former is blocking by powerful vested interests – very familiar in healthcare. For the latter, it is dogged adherence to practices and priorities that are no longer relevant. A healthcare example is the reliance on outdated and largely irrelevant research priorities and methods that perpetuate the medicalisation of life. Let's hope that this year's conference can help to redress the balance towards other ways of knowing and understanding sick persons.

References:

1. Tolstoy L, *Anna Karenina*, 1878, Oxford, OUP (2008) Part 7, chapt13
2. Diamond J, *Collapse - how societies choose to fail or survive,* London, Penuin, Chapt 14; book review at: http://www.bhma.org and follow links to 'Sustainability' on home page.
3. Cassell E, The Nature of Suffering and the Goals of Medicine, 1991, Oxford, OUP, p5.

Comments on any of the articles very welcome

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Going Forward

by Fiona Hamilton

Naturally we were transported
by the thrilling momentum
of the first cog turning on a slick of oil,
an invisibly pressurised piston
promising speed and relief.

Our hearts and minds rejoiced
at ineffable prizes
borne of familiar toil,
the sweat of hands and arms,
skill, ingenuity, tenacity.

Impossible to count how many tears dried
or were shed,
how a swift new route through earth and rock
eased fresh wounds.
Easier simply to appreciate lovers reunited
on a station platform
and give thanks.

Don't think we were too dazzled
to clock subtle shifts
like how soon our feet couldn't keep up
and how difficult it was, at first, to grow wings.
But we soldiered on.

You will surely agree
we are to be congratulated
for our ingenuity and adaptability
in reconfiguring existing protocols.

Hand on heart
we have succeeded, virtually,
in making the tangible
immaterial.

We have every confidence
a readily-available solution
is available.
Please bear with us.

All frequently asked questions have answers
and current indications suggest.
Please keep up.

You are held in a queue
due to circumstances
beyond your control.

Thank you.

Your patience

is appreciated.