

WHERE IS THE CARE IN CARING: A POLEMIC ON THE MEDICALISATION OF HEALTH CARE AND HUMANITARIANISM

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Abstract

Currently in the caring professions, the human condition of facing uncertainty and danger is often overlooked in the quest for measurable outcomes that prove efficiency, taking agency out of the hands of the individuals being cared for. Traits that make an 'ideal' practitioner include compassion, advocacy skills, and the ability to engage with people in vulnerable situations, and to establish trusting, respectful relationships. Within a system of models, quotas, and specialties, these traits are easily hindered within health care and humanitarianism. The critical examination in this article in no way rejects the valuable elements in the fields of humanitarianism and health care. Rather, it discusses how care can be re-introduced. Uncertainty and danger are part of the human experience, and caring interventions need to take that into account. This article highlights the benefits of a collaborative relationship between the person in crisis and the practitioner, instead of a paternalistic relationship in which the practitioner is viewed as the 'expert.' With a caring perspective, the individual who is experiencing the crisis will retain ownership of and responsibility for their life, and not rely solely on external sources of wellbeing and comfort.

Keywords: Medicalisation, Human Condition, Care, Collaboration, Compassion.

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INTRODUCTION

In order to trace the foundation of our arguments, it was thought to start back at its roots with the authors: Jordan Lindekens and Janaka Jayawickrama. As part of Jordan's internship with Janaka at the Department of Health Sciences, University of York, the authors established a dialogue about health and humanitarianism from June 4th to July 20th. This dialogue was based on the philosophical tradition of discourse derived from ancient Asian teaching styles (Izutsu, 1977).

Janaka Jayawickrama grew up in disaster- and conflict-affected Sri Lanka, but also worked in Asia, Africa, and the Middle East in disaster and conflict situations. He came to academia as a practitioner of disaster management and humanitarian aid delivery. He was initially trained in an individual model of psychological care, but soon realised that many communities value the collective rather than the individual (Martin-Baro, 1990; Summerfield & Hume, 1993). As a researcher he was concerned that, at best, the medicalised nature of humanitarian interventions was based in terms of 'do no harm' when, in reality, many interventions were inappropriate and/or culturally insensitive. To him, the delivery of care based on medicalisation was far from the care that crisis-affected communities required (Jayawickrama, 2010). He continues to build new models and ethical standards for humanitarian and development interventions.

Jordan Lindekens came to health care with an interest in science and in helping and connecting with others, and chose to train as a nurse instead of as a medical doctor. Jordan is passionate about the nurse's perspective and use of the biopsychosocial model instead of the biomedical model. Based on her practical experiences growing up, studying, and working in the US, she has developed a critical analysis of the existing model of health care. She values efficiency and productivity from a health-care management point of view, but is concerned about the diminishing space for compassion, humility, and care.

Not surprisingly, given these varied yet converging backgrounds, our shared view of care in health and humanitarian systems is somewhat radical. It emerges from an understanding of interpersonal relationships as a tradition of the political economy of nature. Through various experiences, both authors have seen the medicalisation of the human condition within health care and within disaster, conflict, and development contexts; this trend has been found to be ineffective and, more importantly, takes away agency from individuals and communities (Summerfield, 2018; Kleinman, 2006). The medical model of care has some use, but is not the only way to care. Tangible evidence supporting these findings have been identified and will be outlined throughout this article.

THEORETICAL FOUNDATIONS: FROM ANCIENT TO MODERN THEORY

What is Medicalisation?

Medicalisation is the application of medical knowledge to human experiences and behaviours that are not self-evidently biological or medical conditions, yet are treated as abnormal (Clark, 2014; Kleinman, 2006; White, 2002). Scholars such as Clark (2014), Jayawickrama (2010), and Summerfield (2005) argue that, for approximately the past 25 years, global interventions to deal with crises have become medicalised in nature. As a consequence, humanitarian responses have become more top-down, with foreign ‘experts’ diagnosing the affected populations with various conditions such as vulnerable, or suffering.

Much of our investigation is based on the philosophical foundations of Hinduism, Buddhism, Daoism, and Christianity. Each of these philosophies acknowledges that suffering through uncertainty and danger of life is defined as part of the human experience. The epic of Mahābhārata in Hinduism (Ganguli, 2002), explanations of the impermanent nature of being in Buddhism (Radhakrishnan, 1950), theories of the nature of reality in Daoism (Blakney, 1955), and the Book of Job in the Bible point toward this. In the same line, scholars such as Kleinman (2006, 1980), Jayawickrama (2018, 2010), Korn (1997), Martin-Baro (1990) and Sen (1985) have extensively argued for the need for care at different levels to deal with the challenges of life, including disasters, conflicts, and uneven development. Scholars

such as Summerfield and Hume (1993), Summerfield (2005), Wignaraja (2005), and Jayawickrama (2013, 2009) have critically examined the failure of Western approaches to challenges in life.

In both health-care and humanitarian approaches today, Western philosophical foundations are dominating the rest of the world in the guise of scientific methodology (Bracken, Giller, & Summerfield, 1995; Wignaraja, 2005). Eisler's (2015) cultural transformation theory focusing on the partnership/continuum model emphasizes the balanced perspective between the partnership and domination systems that provide our cultural development as humans with various beliefs, institutions, and relationships. Cultural transformation theory challenges mainstream, dominant approaches, and examines dichotomies such as traditional and modern, eastern and western, and urban and rural, as well as attitudes, values, and beliefs. Eisler (2015) argues strongly that care, spirituality, compassion, humility, and community play an important role in creating equal, transparent, and accountable collaborations, which are often lacking in both the health-care and humanitarian sectors.

MEDICALISATION OF HEALTH AND HUMANITARIAN APPROACHES

Early humanitarian assistance was purely health-centered: nutrition, mother and child care, and preventing and responding to infectious diseases (Davey, Borton, & Foley, 2013). Health-care workers and humanitarian workers both tend to have specific traits that define an 'ideal worker' in both fields, providing this discourse with some common ground. These traits include compassion; adaptability; skills in facilitation, advocacy, and empowerment of the people they are working with; and the ability to engage with people in vulnerable situations and to establish relationships of trust and mutual respect. Expression of these traits is hindered by the medicalisation of both systems (Table 1).

Table 1: Medicalisation of health-care and humanitarian approaches

Health Care	Humanitarianism	Attribute	Ideal
Resource-heavy and top-down	Multi-billion-dollar industry and top-down	Formal	Collaborative
Specialisation approach	Cluster approach	Efficiency	Relevance and effective
Driven by doctors	Driven by external or foreign 'experts'	Didactic	Experiential and equal partnerships
Learning through formal education	Learning through higher education	Positivist	Subjective
Individual centred	Individual category centred	Reductionist	Holistic
Model-based treatment	Policy and framework-based interventions	Universal	Contextual
Objective	Neutral and impartial	Scientific	Combining science with spiritual, social and cultural mechanisms
Treat the symptoms	Short-term interventions	Analytical	Integrated
Dominated by the industry	Dominated by the global marketplace	Cost-effectiveness	Wellbeing of the people
Influenced by European and North American powers	Controlled by the global political and economic powers	Knowledge superiority	Humility and Do Good (opposed to Do No Harm)

Source: Authors

Table 1 is not a rejection of the attributes of health care and humanitarian systems altogether. Rather, it shows that the current power structures in both sectors allow the attributes to control the relationships, suppressing the views and expertise of patients and crisis-affected communities. This creates unequal relationships and partnerships. With this power dynamic comes underperformance related to under-utilised skills, knowledge, and tools of local expertise from lived experiences. If there is a space for patients and affected populations to collaborate with medical and humanitarian experts to mature and work to evolve the power dynamics, then the single voice emerges into a two-sided conversation where all skills, knowledge, and tools can be employed.

Within the humanitarian sector, the crisis-affected population is commonly labelled as vulnerable (Jayawickrama, 2010; Summerfield, 1999). For example, whenever there is a crisis, humanitarian agencies rush to 'save lives', on the assumption that the affected populations are incapable of doing so. In health care, once the patient arrives at the hospital, the priority is to diagnose (Wade & Halligan, 2004); consultation among different yet overlapping specialties is common due to

comorbidities and complications that require special attention (Cassel & Reuben, 2011). A patient with cancer who has dermatitis from radiation will see an oncologist and a dermatologist, among other professionals. A woman who has experienced sexual and gender-based violence (SGBV) in a refugee camp works with a SGBV specialist, and goes to the Health Cluster Service Provider to address any health concerns. In some cases, the person can receive multiple services from the same provider, though this is considered rare.

Models for Providing Services

A model is a conceptual framework in which care can be delivered; of the many models within the health-care system, the biomedical model is the most widely used (Borrell-Carrió, Suchman, & Epstein, 2004). In the humanitarian sector, responses are commonly driven by the top-down project-management model; however, the delivery of responses have countless policies developed by the United Nations and other humanitarian agencies (Krause, 2014). Models provide a structured way of analysing each condition to plan outcomes (Borton, 2009). Outcomes are based on indicators, and are evaluated on their efficiency and impact, concepts derived from a business approach that has greatly influenced service delivery in both sectors (Borton, 2009; Wade & Halligan, 2004). When driven by efficiency and impact, one could see how treating the symptom is considered most effective in order to prove that the intervention is adequate. Care outside of this framework, however, seeks to treat beyond the symptoms.

Individuals and communities can positively manage uncertainties and dangers in life without help from an 'expert' (Das, 2002). Whether a tsunami or heart disease, people draw resources from their culture and values in order to cope. According to Kleinman (2006) and Jayawickrama (2010), crises such as job loss, illness, road accidents, and natural hazards are part of the human experience and associated uncertainties are a part of the human condition. While individuals are addressing their imminent crises, 'experts' are documenting and diagnosing vulnerabilities instead of developing a deeper understanding of how people 'make sense' of uncertainty. This depends on the nature of events that take place and the ways they

are experienced by the individuals or communities. The onset of crises is sometimes sudden: a young and active father diagnosed with lung cancer who dies shortly thereafter. Some crises take the form of a continuous reign of suffering: Palestinian refugees in Lebanon over the last 50 years. Even when suffering is not present in such striking forms, there can be slow deterioration of family and community, such as through the development of chronic alcoholism of an ex-serviceman who served four tours in Iraq and Afghanistan. Suffering takes many forms, especially in non-medical settings.

The dominant influence on the health and humanitarian sectors comes from Europe and North America even though there are many advanced health and humanitarian approaches developed in Asia, Africa, and the Middle East (Dabashi & Mignolo, 2015; Jayawickrama, 2018). Interventions in both sectors aim at achieving a tangible solution, measured by statistics that prove their impact, which is frequently a short-term fix (Wade & Halligan, 2004; Summerfield, 1999). However, the challenge is that crises in health and humanitarian situations are often caused by a combination of multi-layered factors, including social, political, cultural, economic, and environmental influences. Therefore, symptom-based and short-term interventions may provide instant gratification but do not facilitate a long-lasting solution that goes deeper than what can be measured.

Current Challenges of Medicalisation

The World Health Organisation defines health as “a state of complete physical, mental and social wellbeing” (WHO, 1948). In 1948, this definition was groundbreaking because of the ambition it represented (WHO, 1948). Due to the constantly evolving nature of disease patterns and contexts at socio-political, economic, and cultural levels, this definition may no longer hold the same significance it once had (Rutter, Tizard, & Whitmore, 1970). This definition claims that an individual is healthy when they have complete wellbeing among their social, mental, and physical parameters. In this sense, utter wellbeing and the concept of health are equal; however, this definition is not achievable because it does not consider contributors to total health such as income and lifestyle (Rutter et al., 1970).

Sushruta Samhita, the Ayurvedic textbook of medicine and surgery (6th Century BC) has one of the oldest definitions of health in the world: quality rest, an adequate ratio of food intake to stool output, and a harmonious relationship with society and the environment (Lad, 2002). With this definition, each individual can determine their own health status by taking responsibility and identifying what they can do to adjust within their personal terms (Johnson, Ford, & Abraham, 2010). Through medicalisation and the loss of traditional approaches, the measurement of health has greatly shifted since the 6th Century BC due to historical and global elements (Dabashi & Mignolo, 2015). In a global post-Cold War society, the result of various historical socio-political interactions is a single capitalist marketplace that has consequently affected the way people are cared for (Collyer & White, 2011). In this product-oriented system, efficiency and impact have turned health care and humanitarianism into commodities (Borton, 2009; Collyer & White, 2011).

The Reality of Caring

In this globalised marketplace, it is difficult to maintain the vision of caring for someone simply as a lifestyle. In ancient and traditional cultures, the services of healing or helping were spiritual rather than driven by financial benefits. Healing brought people a sense of satisfaction that did not require a trade or a level of professionalisation. Currently, medicalisation incentivises health-care workers to be efficient and meet quotas. Similarly, this pushes humanitarian workers to be more concerned about proposals and reports of their efficiency and impact. A few years ago, insurance companies stopped covering costs associated with hospital-acquired urinary tract infections (UTIs), which put the burden of these costs onto the hospitals (Peasah, McKay, Harman, Al-Amin, & Cook, 2013). Consequently, catheters were used as little as possible, leading to a decrease in the rates of UTIs. In this case, a positive improvement in health care was the result of a cost-containment decision, exemplifying how the establishment of the 'medical industry' has shifted care from human-centred to monetarily driven.

With the prioritisation of efficiency came the division of labour and the development of pathways for each problem, under the assumption that one set of interventions is

transferable to every individual case with the same primary diagnosis. For the humanitarian sector, what works in Liberia in the West African context cannot be transferred to Yemen in the Middle Eastern context. The 'one size fits all' approach may be efficient, but leaves little space for human emotions and actions; assuming this is equivalent to caring can be misleading.

There are no pathways for the Ayurvedic practitioner, because they use their expertise to combine the roles of various specialists into one human connection taking into account physical, psychosocial, and spiritual health as well as the environment during the process of healing (Lad, 2002). The relationship between practitioner and patient is not one of 'expert' and 'vulnerable', but instead a collaborative facilitation of healing (Johnson et al., 2010). In medicalised approaches, a person refers to different experts to receive different services. A simple cough might take multiple consultations in search of a complex answer, when it might just require a lifestyle adjustment. The basics can be easily forgotten among the minute details of each specialty.

A health problem could be overcome by a meaningful relationship with a primary care or public health provider who sees their patient as a whole. Though these providers may want to get to know patients and establish relationships, they are spread thin with extreme time limits and a large volume of patients. Issues like these within the system can lead to lack of trust in providers. In the humanitarian sector, donor-driven, short-term interventions limit non-local humanitarian workers from establishing long-term relationships with affected populations. For example, the current Syria humanitarian response in Turkey has one of the highest staff turnovers within the system. This is due to the two-year project management cycle that the donors demand from the implementing agencies. This timeline does not allow adequate time for contact with the affected populations, and it is difficult to even maintain continuity of the response.

In any helping profession - teacher, doctor, nurse, humanitarian worker, social worker - trust is vital to a meaningful relationship with people. Trust does not come with the profession; it has to be earned with each person by developing and

practicing trust-building skills. Clusters, pathways, and specialties do not facilitate relationship-building because the marketplace and numbers dominate care and relationships. The numbers of people who were treated or fed matters more than how it happened. One of the identified key challenges in the humanitarian sector is coordination among agencies, because each agency is attempting to provide their own response and claim that they are doing better than the rest. As a result, practices such as visibility, reporting, and developing the next project are far more important than long-term relationships with affected populations. Even though the job is done and necessary quotas met, it was out of the desire to prove who had the best outcome, not who really cared.

Division of Care: Forgetting the Empowerment

In a meaningful relationship with their primary care provider, the patient is an active participant in their care and takes ownership of their health (Franks, Clancy, & Nutting, 1992). Empowering the individual was a challenge in the humanitarian sector because it took more than 50 years to accept that the affected populations are the first responders to any crisis (O’Keefe, O’Brien, & Jayawickrama, 2015). In a market controlled by donor mechanisms and cluster systems, each actor has their own investment that they want to see through, instead of collaborating with interest in the preferences of the affected populations (O’Keefe et al., 2015). The role of the local communities gets lost in the chaos of trying to find a measurable solution that meets the needs of each stakeholder. Conversely, with the integration of care, a streamlined model would allow a client or community to do what they know and need for their wellbeing.

The global marketplace is constantly establishing more and more divisions within the systems of health and humanitarian sectors, which in turn, create gaps in knowledge and level of understanding between each party (Cassel & Reuben, 2011). The individual in the vulnerable situation is constantly the one with the knowledge deficit. When there is no expert, there is no imbalance in power. According to the biomedical model, the patient is told by the doctor (expert) what to do and what medicine to take, and gets discharged based on the doctor’s orders. This removes

the say they have in their own life and their self-empowerment. Through her clinical experiences, Jordan has come across patients who lack awareness of their diagnosis and medications. They were not active participants in their recovery process, but rather passive individuals, made vulnerable. A refugee who has to provide written evidence of torture to seek relocation in a safer country is at a loss, because after making their case, they have no involvement in the asylum process. Further, there is a mismatch between their power and the expectations of the system.

Re-introducing Care into Caring

The current market-oriented economy has taken control over the original intentions of the health-care and humanitarian systems. The ‘ideal’ health-care or humanitarian worker identified in this discourse would not be satisfied in providing their services if there is no human connection. There has to be a balance between the economics and the providing of care. Increased pressures to ‘marketise’ these sectors by meeting quotas and efficiency levels leave little space for health-care and humanitarian workers to care for their patients or for crisis-affected populations. One cannot forget that both health and humanitarianism are human-centred practices. The current medicalised model values diagnoses and treatments that are tangibly measured; however, by re-introducing care into both of these sectors, the commitment extends beyond the immediate and measurable outcomes. The relationship goes deeper than any procedure, humanitarian intervention, or medication.

As previously mentioned, the traditional medical practitioner is not necessarily a ‘professional’ who cares for people as a trade, seeking a return. In general, a traditional medical practitioner from India or China facilitates healing processes because they have a responsibility and duty toward humanity and nature. Their lifestyle is balanced through their intimate connection between themselves and the environment, including what may not be tangible. Therefore, their idea of professionalism was a set of morals and a sense of duty to their society. There is a disconnect between the value of the practitioner in healthcare in the biomedical model and the traditional systems. The practitioner serves a clearly defined purpose within the biomedical model. But, in the traditional sense, they were a trusted part

of their society. Their society knew that they would be accountable in a time of need, regardless of whether that need was humanitarian or health-related.

There is a need for a fundamental shift in the delivery of health care and humanitarian responses away from ‘quick fixes’ and toward prevention. This involves facilitating skills among communities and patients to prevent crises and effectively deal with unavoidable circumstances (Jayawickrama, 2010; Kleinman, 2006). As caretakers accept these challenges as a natural part of human existence, they start facilitating people to handle these challenges and maintain a quality of life on their own terms. This can be in prevention or support while the problem is occurring or has occurred, but it does not involve completely rejecting the problem or the mindset that the problem should not be a part of being human (Kleinman, 2006). Once outcome-oriented interventions shift toward long-term collaborations, trust will be reinstated within the system, motivating patients and crisis-affected populations to become active participants in their recovery (Eisler, 2015).

Contemporary health-care and humanitarian systems are approximately 150 years old, yet humanity survived without them for the last 6,000 years by developing sophisticated yet pragmatic approaches to dealing with uncertainty and the dangers of life. There is currently a mistaken belief that wellbeing can be externally controlled instead of being controlled from within oneself (Munindo, 2005). Sustainability involves the practice of prevention and being able to deal with a crisis as it arises. This not only a goal to try to achieve, but a long-term and continuous effort to evolve, that requires creating solutions for present crises without leaving residual damage for the future to address (WCED, 1987). During the 2004 tsunami in Sri Lanka, international responses were focused on the immediate, ‘lifesaving’ needs but ignored waste from their interventions that damaged the environment (Telford & Cosgrave, 2007). To address water and sanitation issues, interventionists used plastic tubing for plumbing even though local communities already were using biodegradable clay. Investment in the future wellbeing of society is not currently aligned with the global marketplace.

In order to promote long-term healthy living, health-care workers have to establish a culture of health defined by social, mental, and physical wellbeing. Similarly, prevention and dealing with humanitarian crises needs to be developed and implemented by communities, not by external stakeholders. The culture of health is established by developing a life that increases human capability to maintain wellbeing. Facilitating communities to be equipped for future crises without the expert's support is the goal. Caretakers should operate as if, one day, they will not be needed, because the community is capable of dealing with their future crises themselves (Jayawickrama, 2010).

For example, the biological causes of obesity (though there are some genetic influences) are rooted in lifestyle choices. Without an active physical, mental, and spiritual environment, any treatment of obesity is ineffective. The 'modern' lifestyle can be sedentary, full of media and processed foods. Prevention is an intersection between cultural considerations, medicine, and social support. The only way to be rid of the obesity epidemic is to address the underlying cause, not the symptom.

In South Asia, flooding in countries such as Bangladesh and Sri Lanka is connected to rapid urbanisation, increased uneven development, and the widening gaps between economic classes (O'Keefe et al., 2015). There are no mechanisms to aid the natural runoff processes and the sewage systems and waste management that are not sufficient for the growing urban population. When the next flood occurs, agencies will respond to the immediate problem and disregard the need to improve urban infrastructure in South Asia. Long-term improvements and prevention are really the optimal cost-containing solutions.

There is a need to examine and employ new methods of inquiry within equal partnerships between health professionals and patients as well as between humanitarian workers and affected populations, to develop an all-inclusive representation that embraces the whole humanity (Eisler, 2015). This has to be done with an equal, transparent, and accountable discourse about the delivery of health and humanitarian responses, rooted in mutual respect, humility, and compassion. What this theory yields is that while the divisions, such as clusters and specialisation,

are useful in operationalising health and humanitarian responses, the aim of health and humanitarian workers has to be caring for the people who are in need. This can only be done when the health and humanitarian workers are facilitated to establish collaborative partnerships with people they serve. Partnership, as Eisler (2010) explained, is understanding the humanity within all. When this is facilitated through education, policies, and practices, creating equal, transparent, and accountable collaborations becomes possible. This will lead to developing new philosophical foundations that are relevant and effective in dealing with uncertainty and danger of life, including disasters, conflicts, and uneven development.

CONCLUSION

To connect back to the two definitions of health, the WHO definition (1948) and the biomedical model operate on the complete rejection of illness and disease. If there is anything wrong with the patient, it has to be labelled and treated. In ancient practices such as Ayurveda (Lad, 2002), caring for the individual considers how they want to address the issue. Today's generation has the necessary technology to reach a level of comfort higher than ever before, yet also suffer from epidemics such as obesity, depression, and opioid addiction. With higher comfort comes the expectation of increased happiness, even though the reliance on external factors for happiness has proven problematic. If the health and humanitarian sectors ever desire to re-integrate the human condition into their current processes, they ought not forget or underestimate the voice of the affected individuals (Eisler, 2015). It is common to label crisis-affected communities as vulnerable, when they are actually just in a vulnerable situation. As humans, we are chasing immortality and putting a price tag on it, instead of measuring health based on the person's quality of life. In a globalised marketplace, something's worth is determined by efficiency and impact. How can these measures be applied universally? The 'ideal' health-care or humanitarian worker cannot. They simply hold certain values as a professional that naturally prioritises the dignity of the individual they are caring for.

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