

Productive Pathologies: Poverty, Biovalue and Commodification of Disease in Urban Egypt

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June 2005: It is the annual end of year examination period in Al-Qasr Al-Aini Medical School in Cairo when some students in their clinical years have to carry out their practical examinations next to the bedside. Outside of the medical school and on campus there is an unusual presence of patients wandering around. Some are wearing their *gallabiyas*, the traditional costume in Egypt, which simultaneously indicates a rural background, and covering their heads with white scarfs. Many of them have skeletal bodies and pale faces, a sign that ailments have taken control of their bodies and immediate medical intervention to restore their ailing health is needed.

This scene is not of 'ordinary' patients who resort to the hospital to seek the medical services of this prestigious institution that was established in 1827 by the French professor Antoine Barthelemy Clot to mark the first medical school of its kind in the history of modern Egypt and the whole region [1] (Sonbol 1990; Kuhnke 1992; Inhorn 1994). These are what I call 'professional patients' who orbit around the hospital of the medical school especially when clinical exams are administered to assess the knowledge of the students next to the bedside. However, these patients do not resort to the hospital in order to seek medical services. Rather they aim to secure a place in one of the wards in order to avail their bodies and their diseases to medical scrutiny and to participate in the assessment of the students' medical knowledge. Their encounters with students provide them with opportunities to extract financial resources in exchange of the knowledge and the diseases they offer them (Abdalla 2015).

During my fieldwork in al-Qasr al-Aini Medical School in 2004-2005 and the following years, I could observe these patients and their participation in students' assessments. They also offer their 'disease services' in the informal parallel system of private tutoring centers in the proximity of the medical school, which have mushroomed to make up for the deteriorating teaching conditions in the formal settings. For this purpose, professors of medicine are hired from the neighboring school of medicine to teach classes in their medical specialty and gain valuable funds to supplement their low salaries. Professional patients interested me already during this earlier research on medical education in Egypt (Abdalla 2010) because they presented a unique phenomenon of utilizing one's body and disease condition for economic survival. However, I could come in contact with them only in later years given the sensitivity of the topic and the services they provide. The accounts of some of these patients constitute the topic of this article, which tells the story of bioavailable diseased bodies that are caught between neoliberal state policies that left many people unable to take up social responsibilities and their roles as breadwinners and providers for their families.

In this article I argue that, in contrast to previous theorizations of sickness and the sick-role in which patients become dependent on others, have to seek medical assistance and are exempted from their social responsibilities (cf. Parsons 1951, 1952), the onset of disease can

be a source of agency to certain citizens who suffer from poverty, social marginalization and disempowerment. In these circumstances, patients find a biovalue in their diseased bodies and utilize them to extract economic benefits for daily survival. Furthermore, caught in poverty, marginalization and social impotence connected to their unmet social roles as providers, the meaning of health and well-being may shift among certain groups to embody notions of social well-being through providing for the family and taking up economic and social responsibilities. I finally turn to the medical setting and argue that the mere presence of professional patients in medical schools challenges the basic moral values of medicine, which are ideally geared towards cure and healing.

Borrowing from Catherine Waldby (2000), I use the term biovalue to refer to how disease conditions are taken advantage of in order to assume certain responsibilities and make social and economic gains. Such gains are geared toward the social and the economic well-being of family members and the diseased body itself. The ailing person, in this context, sacrifices him- or herself for the welfare of the needy healthy ones.

Professional Patients in Contexts of Marginalization and Shifting State Policies

Over the past few decades, the Egyptian government adopted major restructuring of its economy by embracing an open-door economic policy in the 1970s, followed by aggressive neoliberal economic plans during the 1980s and 1990s (Koaryem 1997). These policies have resulted in rising living costs, high rates of unemployment, external migration to seek better jobs in the oil-rich Gulf States and resorting to various informal survival strategies. Practically, the new policies deprived many people of the promised services and failed to provide the population with plausible solutions to their problems. As a result, large segments of the Egyptian populace, especially the marginal and the poor, similar to other countries (cf. Silberschmidt 2001; Dilger 2011) have tremendously suffered from the violence of the economic modifications and the loss of state support. Therefore, the introduced changes have challenged people in the most intimate notions of their daily life namely their social roles, masculinity and femininity, sexuality and health (Choucri 1977; Rugh 1988; Brink 1991; Russel 1992; Hoodfar 1999; Ayubi 2001; Ali 2002; Abdalla 2007). To resolve their daily economic problems, some found solutions in medicine by selling organs and blood. For others, the answer was found in their diseases, which they commodified and marketed in relation to the production of knowledge in the medical school settings.

The analysis provided in this article is based on observations that I made in Al-Qasr Al-Aini Medical School and around some of the private tutoring centers scattered in its proximity in 2004-05. This fieldwork-stay was followed by several research visits as part of my ongoing research on this phenomenon until today, which allowed me to have informal conversations with some professional patients. The larger research project focused on medical students and their daily interactions with one another, with their professors and with patients. It also examined the students' changing perceptions of medicine after going through the hurdles of learning. The larger research revealed that the experiences of the students is entangled in corruption, feelings of marginalization and estrangement as a result of state policies and the quality of education offered to them.

While the larger project benefited from various research methods including participant observation, open-ended interviews, and the analysis of media representations and websites created and maintained by students, the analysis I provide in this article is based mainly on preliminary research that I conducted among professional patients for which I carried out informal conversations and observations of the activities of the patients. For the purpose of the preliminary stage, I opted for a low-profile research where I intended to establish contacts, and maintain others, with medical personnel and patients in order to prepare for the larger project and to establish a rapport with the interlocutors. My intention to do so was the sensitivity of the research topic, and to some extent, the illegality of the activities of the professional patients. Furthermore, despite the fact that there are female professional patients, my focus at this stage was on male professional patients since it was easier for me, as a male researcher, to access the lifeworlds of male patients. The larger forthcoming project, however, pays close attention to gender issues and the participation of women and their roles in the activities of the professional patient group.

For the purpose of this article, I focus on the stories of two patients, Saad [2], a man in his early 60s who suffers from chronic liver complications as a result of his infection with hepatitis C. Emad, a man in his late 40s, to the contrary, suffers from a hernia that requires a simple and affordable medical intervention that could be easily carried out in any hospital. However, both Saad and Emad seem to take advantage of their disease conditions by commodifying their ailments to be able to generate incomes produced through the sale of knowledge about their diseases among medical students both in the medical school and the different informal tutoring private centers.

Poverty, Marginalization and the Production of Disease Identities

Scene One: Saad

Saad lives with his wife and five children in the low-income district of Shubra al-Khaima in northern Cairo. Previously, he worked as a seasonal street vendor. Owning a donkey-cart, he sold different fruits and vegetables: "I sold what the season offered: sometimes oranges, bananas, strawberries and at other times cactus figs or apricots." [3], he said. The funds generated from his business, however, did not afford him an income high enough to take over financial responsibilities for the family. Saad stated:

"Everything has changed... you need a lot of money for everything, food, rent, school, clothes, private classes, healthcare for the children, and this all costs beyond what I earned, that I could not manage anymore, I just could not provide for my family."

On the wake of discovering that he suffers from hepatitis C, Saad explained that he was 'talked over by some people' to take advantage of his condition and market it in medical schools and private centers. After learning the needed knowledge about his disease in medical terminology, Saad turned his disease into a commodity or an 'economically productive pathology' as I want

to call it, that generates income for his and his family's survival:

"... even if I opted for treatment, it is so complicated and unaffordable... The solution is to keep going and to learn how to live with the disease."

Scene two: Emad

Emad lives in the Cairo's rural district of Dar El Salam. He provides for his wife, four children and his elderly parents. Emad worked as a construction worker: "It is a heavy labor that requires carrying heavy materials and carrying out tough duties." After a long day of hard work, Emad had some abdomen pain and was discovered to suffer from a hernia. Having a friend who earns his income as a professional patient, Emad did not hesitate to explore the possibility to market his disease condition in medical schools. He explained:

"The problem is that with my job, I did not have any security. I worked very hard and made little money. Sometimes, I was hired to work for a day, but for ten days or more I would not get anything. In the end of the day I have to feed seven persons and myself and if I miss a single day of work, then I am in trouble... Everything is very expensive and I have to pay for food, doctors' fees, transportation, children's education, rent etc. How can I manage all of that?"

Emad's professional patient friend introduced him to the business of 'selling sickness.' Now he successfully markets his disease in medical schools and in private centers:

"Well, this hernia causes me some discomfort sometimes, but one learns how to live with it. The discomfort of poverty is far more disturbing than the pain of the hernia and as long as it is not a life threatening problem, then why not take advantage of it?"

Living on the Margins of Disease

In Egypt, the adoption of patient-centered teaching by Clot Bey in the early 19th century created a need for patients in the teaching and assessment settings. Similar to other parts of the world, during the early years of the medical school, the newly established army provided the needed patients for this purpose (Sonbol 1990; Kuhnke 1992; Fahmy 2004). In recent years however, the increasing need for cooperative patients in the medical settings has led some patients to take advantage of their ailing bodies to generate quick income. By providing their disease services, the professional patients are able to extract monetary funds from students by providing them with access to needed medical knowledge to pass their exams (Abdalla 2015).

Saad and Emad represent two extreme cases of social suffering and disease. On one side of the spectrum stands Saad with a chronic disease. On the other side, we find Emad with an acute but less life-threatening disease. However, the commonality found in both cases is the

biovalue they find in their disease conditions, which they commodified to exchange for monetary value in order to secure their economic survival. In the two cases presented here, ailing bodies have become the prerequisite for economic gains that provided them with agency and opportunities to assume social roles. Disease, in this case, has provided them with a certain level of economic leverage and social respect by providing them with the opportunity to restore their breadwinner status. In Egyptian society, taking over social responsibilities and being the breadwinner operates as an important asset of acquiring the masculine identity. However, this image has been destabilized and challenged after the introduction of the harsh neoliberal state policies, which left citizens unable to meet daily needs. In this regard, poverty and marginalization coupled with difficult national and global economies have contributed to the reshaping of people's daily experiences and their perceptions of their bodies, health and disease.

Given the harsh experiences of poverty and marginalization, patients like Saad and Emad start to view their health and their ailments in different terms. While diseases may become their perceived salvation from poverty and social degradation, health loses its valuable meaning to be observed in other terms connected to social status, productivity and materiality. Saad commented:

“... What is the point of being healthy and hungry or unable to provide for the family? I know that I will die sooner or later, my liver is ailing and I do not know how long I can make it, but what is better?: to be able to support my family now and leave them some money when I die or to die and leave them only debts and misery?”

While sickness in Egyptian society is a social affair that requires support, cooperation and the mobilization of resources to assist in restoring the health of the afflicted (El-Mehairy 1984; Kamal 2004; Sholkamy 2004), disease in the case of Saad has acquired a new meaning. It is transformed into an embodied source of value. A biovalue that empowers, provides status, and becomes focused on harvesting quick and short-term economic profitability that is translated into capital value for daily survival.

For this purpose, the pathology and the knowledge connected to it are transformed into cash remittances to contribute to the well-being of other persons, children and other members of the family, who are perceived to have more value. Therefore, the biovalue of disease stems from its transformation into a productive pathology, which is geared toward the comfort of the people involved. Well-being here, however, does not refer to physical health. In this context the patient's own physical health is ignored and even sacrificed in order to enable other persons that are deemed to be more valuable to enjoy physical, but also social and economic well-being.

In her book *Being Alive Well*, Naomi Adelson (2000) shows how members of the Cree population in Canada perceive health as strongly connected to the well-being of the land. In this context, Adelson shows how health 'is never a simply biological category,' rather 'experiences and understandings of health and well-being are always historically and culturally mediated' (2000: 3). This strongly applies to the case in hand since, as Saad earlier mentioned, being physically healthy did not make up for all the worries and social impotence professional patients

may experience in the absence of disease. Similarly, Adelson argues that health is ‘interpreted, idealized and enacted in various ways’ (p.3). Among the professional patients in Egypt, similar to the Cree population in Canada, health and well-being are thus strongly tied to gaining agency and taking up responsibilities for the family, social relations and (re-)acquiring the breadwinner status.

In the case of professional patients in Egypt, poverty challenged their identities as male providers. Furthermore, neoliberal policies and the state’s abdication from responsibilities towards its citizens have contributed to putting their male identity into jeopardy. Only with the onset of disease these patients have started to restore their position in society by assuming social responsibilities supported by remittances that their diseases yield for them. Among the interlocutors of my research, well-being was strongly connected to being a provider for oneself and others. Being unable to provide can be daunting, stigmatizing and disempowering. In these circumstances, the emergence of disease is what makes life, or what is left of it, worth living and gives meaning to the meaningless. In the face of the neoliberal economy, the meanings of health and disease change and experiences that are considered otherwise undesired start, against all odds, to convey positive connotations to people like Saad and Emad. In this regard, Emad explained:

“I used to have long sleepless nights worrying about how to buy medications for my parents or taking a sick child to see a doctor. Today, I earn enough and I am thankful for what I have.”

Deliberate Deviations: The Deployment of Disease and its Ethical Ramifications

Deviation from societal and familial expectations, either by not seeking medical assistance or by deliberately inflicting disability by deforming the body to qualify for the sick-role is a practice that can be observed among certain segments of the poor in Egyptian society. Adopting disease and enacting a disease identity, as extreme as it may seem, is only one strategy to survive poverty. For instance, an increasingly observable phenomenon is the attempt to take advantage of ailments and deformities to collect alms in the streets and in coffee shops. This phenomenon has been depicted in novels by famous Egyptian writers, such as Naguib Mahfouz in his novel *Zuqaq el-Midaq* (n.d.) (The Midaq Alley), first published in 1947, and Youssef el-Sebaei’s novel *Ard el-Nifaq* (1952) (The Land of Hypocrisy), first published in 1949. Ahmed Al-Sab‘awi’s film *Al-Mutasawil* (The Beggar), produced in 1983 and starred by Adel Imam, highlights the dynamics of becoming a beggar in Egyptian society. This literary and artistic work shows to what extent some people might utilize their bodies, e.g., blinding or crippling themselves, in order to qualify to being disabled bodies in order to receive the empathy of the public and collect alms for themselves and their families’ well-being.

The professional patients’ phenomenon is part and parcel of this wider phenomenon in which ailing, deformed, disabled or diseased bodies are used for daily survival. What is novel, however, is how disease in the context of biomedicine itself, a modern science supposedly

geared towards the well-being of the population, has been turned into a generative force that provides agency, new subjective experiences and different meaning to disease itself. In the cases of Saad and Emad, the maintenance and taking advantage of pathology, in medical settings, have provided them with opportunities to experience their masculinity differently, to take over responsibilities, provide for their families and consequently enjoy a position in society that was not possible for them as 'healthy' citizens.

Hence, poverty, economic and social challenges have led the professional patients to develop different perceptions of their bodies and their well-being in a medical context, namely the medical school, which may not match the societal and the medical expectations of patients and what is held as a mainstream path to restore health (Freidson 1960).

What is remarkable – and particularly disturbing – in the evolving relationship between professional patients and the medical school in today's Egypt is that the medical institution and its professionals tolerate the presence of professional patients, cooperate with them and accommodate to their needs (Abdalla 2015). However, the presence of professional patients in medical schools and their contribution to the learning and assessment activities of medical students, nevertheless, pose a challenge to the medical institution and raise ethical questions and concerns. What is at stake here is that this encounter involves suffering, portrayal of lived experiences of disease and the selling of knowledge connected to them. This is simply because the actors involved are 'real' patients and not simulated patients who are provided with a script of a particular disease, like in the case of some economically affluent countries, to portray suffering in a performative manner to medical students (Taylor 2011).

Another ethical concern this phenomenon raises is the inequalities it produces between the students. The mere fact that the patient-student encounter is based on monetary transaction for exchange of knowledge to pass exams is a prerequisite for inequalities and marginalization of those who lack the economic means to pay the fees of the patients. In such circumstances, the chances of students to be exposed to fair assessment situations are not guaranteed and accordingly their performance, the knowledge they procure from the patients and the grades they achieve are all conditioned to the patients' cooperative attitudes, the fees they receive and their willingness to interact with the students.

Finally, the increasing need for patients in the patient-centered teaching setting in medical schools and the reliance on professional patients in teaching and evaluation settings have created a dependency on professional patients given their conditional compliance to the medical school and their pricey cooperation with the students. Nevertheless, the more serious challenge, posed by these patients, is that their paid encounters with medical students contribute to the production of incompetent medical expertise.

Conclusion

Disease may challenge social roles. It stigmatizes, excludes, disempowers and in some cases leads to social and economic impotence. However, in extreme cases as the ones presented

above, disease produces new subjectivities by shaping new identities and providing agency to those who lack it. Disease in this case has gained a social and an appropriated biomedical value that can be traded for economic resources that guarantee respect and elevated status for the patients in their families and in communities where they live.

The now professional patients experienced feelings of disempowerment, insecurity, fear and feelings of emasculation as healthy citizens. In conditions of poverty, exclusion and structural inequalities, the emergence of disease produced opportunities to extract valuable cash resources that seemed to be a solution for the powerless and the poor. In these conditions, disease is being transformed into an asset for economic and social survival.

These practices, however, pose challenges to the medical regime and the future physicians. As practicing physicians, the students who were dictated answers and provided with the needed medical knowledge by professional patients to pass their exams will be confronted with medical realities in which patients will talk about what discomforts them; they will only tell their symptoms and not the diagnosis of their afflictions. In such encounters, the lives and well-being of these patients, when seeking the medical service, will largely depend on the competence of the medical professionals and what they have learned in medical schools.

Furthermore, the acceptance of the professional patients in the medical school setting, as real and disturbing as it may sound, turns human bodies and their diseases into objects that have their value only because of their pathological condition. Similar to what Taylor (2011) highlights in relation to the standardized patients, professional patients become mere 'professional guinea pigs', who willingly participate in this encounter only for the economic benefits they extract from it. Therefore, their commitment is not for the training of students, nor for providing them with opportunities to learn and improve human health conditions. Rather, their commitment stems from economic advantages that contribute to the well-being of their families and themselves. However, here I refer to well-being not in the physical, but rather in the social and economic sense. Yet, these practices raise ethical concerns since harvested material profits and elevated social status of professional patients are achieved at the expense of their suffering and the ailing health conditions. More troubling is that the suffering and the commodification of disease take place in the context of medical institutions, which challenges the moral and ethical values of medicine today.

The case of the professional patients, as presented in this article, could be read from different angles. One way of reading it could be the manner in which patients are abused and taken advantage of by the medical school and the students alike. It could be further read as a violation of human rights. These readings are valid and might be true. However, this article is written from the professional patients' perspective. It shows how, in the middle of uncertainties and the messiness of people's experiences, new subjectivities and strategies for survival are produced. It further highlights how these professional patients, given the lack of legal channels to survive poverty and social suffering, are forced to find value in their diseased condition leading them to view their experiences of changing social roles from healthy to diseased citizens and the transformation this shift entails in positive terms: gaining agency, restoring social responsibilities and achieving a certain level of respect for providing for the family and contributing to its well-being.

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Footnotes

[1] When established, the medical school was located in Abu Za‘bal in the North of Cairo, but was relocated in 1836 to its current location on the Rawda Island near the city center.

[2] No real names are used in this article.

[3] Interviews were conducted in Arabic. My translation.

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