

FATHER KNOWS BEST? CUBA'S PROACTIVE APPROACH TO HEALTHCARE DELIVERS RESULTS BUT PATERNALISM BRINGS SOME COMPROMISES

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Cuba's health outcomes, despite its developing world status and myriad internal and external problems, are unusually positive. These outcomes are partly owed to the proactive role of the Cuban public authorities in setting and overseeing public health policy. Particularly important has been the attention paid to monitoring and preventing health risks. This includes ensuring universal registration and medical coverage of the population, developing a comprehensive system of epidemiological surveillance, and intervening wherever possible to avert preventable causes of morbidity and mortality.

This paper goes on to argue, however, that this interventionist approach has also contributed to paternalistic tendencies in the way healthcare is delivered. This paternalism has adverse effects at the local level that partly undermine the benefits of positive aggregate health outcomes. Patient autonomy in decision-making and choice is sometimes neglected by the overarching pressure of state demands. This has led some patients to become complacent about their own role in healthcare, while others circumvent the official system by seeking unofficial ways to deal with health problems. These consequences are problematic in terms of the long-term sustainability of Cuba's health outcomes. A lack of patient participation could also be construed as detracting from the improved wellbeing brought by aggregate health im-

provements. It is arguable therefore that "state capacity" has not been satisfactorily consolidated in Cuba. For political principles and public policy competencies to be entrusted or embedded, citizenship entitlements need to be whole-heartedly endorsed by the populace, not merely imposed. The persistence of some resentments and obvious instances of non-participation seriously compromises the outcomes experienced by people generally.

METHOD

The primary research for this paper was conducted mainly during a period of seven months (March-October 2004) in Havana, and aimed to explore the factors contributing to Cuba's positive health outcomes, particularly in the area of maternal-infant health. The research was largely qualitative, including semi-structured, face-to-face interviews in Spanish with 24 respondents.¹ The interviews were not intended to achieve a random population sample, but to collect advice and opinions from experts within Cuba. Interviewees included: researchers specialising in public health at Havana University, the National School of Health, the National Centre for Sexual Education (CENESEX), the Centre for Sociological and Psychological Research (CIPS), and Havana's Higher Institute of Medical Sciences; family doctors; medical specialists; social workers; functionaries from the Cuban Ministry for Public Health (MINSAP), the Na-

1. As a measure to protect the identities of those interviewed, all the names of respondents cited in this article have been changed.

tional Commission for Prevention and Social Attention, the Federation of Cuban Women (FMC). Of those interviewed, 10 were men and 14 were women. Where relevant, the paper also draws upon a small number of subsequent interviews with expatriate Cubans living in Australia, interviewed in the period 2005–2006.

There were some limiting factors that should be acknowledged. Firstly, the time and budget available for this project meant field research was limited to Havana and therefore did not include perspectives from other provinces, where different responses may have been encountered. However, Havana was the ideal base for research as it allowed access to institutions at the national level and, since the programs within the health system are centrally administered, sources at the national level were also able to provide information about other provinces. While the selection of interviewees was largely dependent on whom I was able to access, I made a point of including medical staff from hospitals in different socio-economic zones. Vedado, for example, is one of the city's more affluent zones, while Marianao (a satellite municipality of Havana) and Arroyo Naranjo are among the city's poorer districts.

Secondly, as with any academic work in Cuba, especially by foreigners, research was also somewhat restricted by the political and intellectual climate within the country ensuing from its particular circumstances, both internal and external, that meant some interviewees may have felt limited in what they could express on tape. One of the means I used to balance and verify official interview material, however, was to record many personal observations and informal interviews in a fieldwork summary.²

CUBA'S PUBLIC HEALTH SYSTEM

Against the backdrop of its controversial global position and troubled relationship with the USA, Cuba has managed to build an unusually positive reputation in the field of health. The country's accomplishments in the area of health have been widely recog-

nized, even by World Bank officials. In 2001, World Bank President James Wolfensohn publicly congratulated the island on having done "a great job" in health and education (Climan 2001). The Bank's Vice President Jo Ritzen applauded the country's infant mortality and under-five mortality rates, encouraging other poor countries to study its social welfare policies.

It is worth noting nevertheless that a number of scholars have questioned the validity of Cuba's health outcomes. Nick Eberstadt (1988) and Carmelo Mesa-Lago (1969), for example, have drawn attention to statistical inconsistencies in the country's official outcomes and have suggested the Cuban government may deliberately misrepresent statistics as a means to promote a favourable image of the country's socialist project. Other researchers, including Feinsilver (1993), Santana (1988), and Waitzkin et al. (1997), have affirmed the accuracy and reliability of the outcomes. Others, such as McGuire and Frankel (2005), agree that the country's statistics are complete and reliable but have been critical of the commonly-held belief that the major improvements in Cuba's health statistics occurred after 1959. It is worth noting also that the controversial and isolated global position Cuba occupies has some influence on the nature of analysts approach to the case. On the one hand, some would argue this is a clear motive for the Cuban government to misrepresent its health outcomes as a means for defending the country's image. On the other hand, bearing in mind that no country's health statistics are completely reliable, any inconsistency in Cuba's statistics may be more harshly scrutinized and negatively construed than other less-controversial cases. Ultimately, as both critics and supporters of Cuba's health system have acknowledged, no definitive conclusions can be reached by foreign researchers given the restrictions they face when conducting research in Cuba.

To summarize the country's key achievements in terms of health outcomes, it records comparatively

2. To ensure the protection of source confidentiality and general security of information, this summary was mostly written on return to Australia.

low expenditure per capita on health,³ and health indicators that are uncharacteristically positive for a poor country, often comparing closely with developed world outcomes. For example, while it spends only US\$193 per capita on health as opposed to Brazil's \$631, Mexico's \$477, and the USA's \$4,499, Cuba's infant and under-five mortality rates are almost identical to those of the USA⁴ and more than three times lower than its Latin American counterparts. Almost all of the population (95–100 percent) has access to affordable essential drugs and immunization, and its doctor/patient ratio of 590 doctors per 100,000 people⁵ far exceeds the USA's 276, Australia's 260, and even Sweden's 311. Skilled health personnel attend almost 100 percent of births and the maternal mortality ratio is considerably lower than in other developing countries (UNDP 2000, 2003). In addition, Cuba has developed many vaccines and pharmaceuticals from scratch, including the world's only anti-meningococcal B vaccine, and has eliminated numerous diseases that were previously widespread (Carr 1999; Aitsiselmi 2001). These outcomes are unusual for any context of underdevelopment. In Cuba's case they are especially so considering conditions of material shortage typical to developing countries have been exacerbated by an ongoing US embargo on the island.

Cuba's health outcomes are even more surprising considering the myriad internal problems the country faces, including within the public health sector. Despite its survival of the "special period,"⁶ the Cuban economy is still in serious trouble. The country's

foreign debt has risen and foreign direct investment fallen since 2001 and tourism, while continuing to grow, has been affected by the current international political environment and does not produce enough jobs (Habel 2004).

An increasing inconsistency between salaries and living costs resulting from the country's double currency,⁷ combined with restrictions on individuals' accumulation of capital, has increased corruption levels and black-marketeering, as many state-employed Cubans seek an "alternative income" to make ends meet (see also Mesa-Lago 2002: 5; Pérez-López 1997: 19). A report in the weekly Cuban publication *Bohemia* gives some idea of the extent of this problem when it states that "between January and October 2003, the police found 181 illegal workshops, 525 clandestine factories and 315 spaces being used as warehouses" (Habel 2004).

Cuban doctors are not immune to the economic difficulties most state-employed Cubans face, as the following interview with a Cuban doctor suggests. Doctors are among those still paid in the domestic currency, along with the majority of the workforce.

No Cuban health professional in the present day, or from any of the generations born after the triumph of the revolution, graduates or decides to pursue a career in medicine for reasons of personal material gain because you know this is not what you will get. I, for example, have fifteen years of experience since I graduated, I work and teach in medicine and I have international experience. When I have been in other countries and told people that I earn twenty dollars a

3. In its *World Development Report 2004*, the World Bank argues that Cuba's health system is expensive. "Cuba spends substantially more of its gross domestic product on health than other Latin American Countries: 6.6 percent in 2002," the report points out. Indeed Cuba's expenditure as a percentage of GDP (*not* as an absolute amount) is greater than most other Latin countries for *public* health. When adding *private* health expenditure to the equation, however, most countries spend a greater proportion of GDP on health overall than Cuba does.

4. Cuba's infant mortality rates are now lower than US rates.

5. According to a public relations representative at Cuba's Ministry of Public Health (MINSAP), this figure includes doctors away on aid missions in Latin America and other parts of the world. Considering the extensiveness of Cuba's foreign medical aid, the actual doctor/patient ratio *in Cuba* would be somewhat lower.

6. A period of extreme economic crisis in the early 1990s, following the collapse of the Soviet Union. Having lost a majority of its markets almost overnight, Cuba was forced to restructure its economy in order to survive.

7. The restructuring of the early 1990s included allowing the circulation of the US dollar; the US dollar has now been fully replaced by the convertible peso.

month they can't believe it, they simply laugh at me (Herrera, interviewed September, 2004).

Clearly these salaries, which do not even come close to those of doctors in any other part of the world, account partly for the country's comparatively low expenditure per capita on health, especially considering that its doctor/patient ratio is one of the world's highest.

With the dramatic increase in living costs in Cuba since the introduction of the US dollar, even accounting for rations, free education and other state-provided services, Cuban doctors struggle to make ends meet on their peso salary. As is the case with a large proportion of state employees, stories of hospital staff "moonlighting as taxi drivers" (*The Economist* 1999b) or inventing some other unofficial source of income are not uncommon. Despite their lack of remuneration, though, Cuban doctors are generally reputed to be competent and committed, deriving motivation and satisfaction from their work. Non-medical workers in hospitals, such as cleaning and administrative staff, on the other hand, appear to be more dispirited by the low salaries and to have a greater tendency to demonstrate this through absence from and lack of efficiency in their jobs.

Further, despite its aid to Latin American neighbors⁸ in the provision of scholarships and medical assistance, many of the problems at home resulting from an extreme lack of hard cash are not resolved. Cuban hospitals struggle to afford even the most basic health provisions. While positive outcomes have been achieved despite this, the difficulties related to resource shortages are still felt. As Marquis (2000) points out, Cuban hospitals suffer extreme shortages in medical supplies from antibiotics and asthma medication to clean water. Medical staff make do with broken and outdated equipment and patients are often required to bring their own soap and sheets when admitted for surgery.

These shortages are further exacerbated by what is generally seen as inefficiency and corruption. General maintenance of hospital facilities obviously suffers due to inefficiency or absence of maintenance workers and cleaners, as visitors to Cuban hospitals can observe. Further, low salaries and other systemic factors have also generated corruption amongst many state employees. As similarly occurs in many other Cuban workplaces, for example, hospital culinary employees have been known to steal meat and other foodstuffs the state provides for patients and take these home to eat or sell (Fieldnotes, report of an expatriate experience in a Cuban hospital, 2004). The following recorded passage from an interview gives a similar account of shadow economic activity in the health system.

The people who work there [in the hospitals] have their own problems at home. Here [in Cuba] in any given workplace where they deal with anything saleable, any product, the employees always try to take something home for themselves because here wage earners don't earn anything. So everybody tries to steal something. If you are a mechanic, you steal a spanner; if you work with food of course you steal some rice. So, what happens? People keep taking and taking. Normally small things don't get noticed much but slowly greed makes you steal more and more. If earlier you stole a bit of rice, one day you want to take a chicken to eat for yourself because in your house there is no chicken, and soon you are stealing one that you need to eat and another one to sell. So you keep going like that until one day people go and report you to the boss (Diaz, interviewed October, 2004).

In the context of these problematic internal and external circumstances, how was it possible for Cuba to perform so well in some areas of health (see Table 1)?

SURVEILLANCE AND PREVENTION

Cuba's Public Health Law, adopted in 1983, specifies that the state has a fundamental and permanent obligation to protect and improve the health of the

8. Cuba provides considerable medical aid to other developing countries and even to developed countries. It frequently sends teams of doctors on medical assistance programs to African countries and its Latin American neighbors and provides medical scholarships to thousands of foreign students each year, including 250 medical scholarships per year to US students from underprivileged backgrounds (Aidi 2001).

Table 1. Comparative Health Indicators

	Cuba	Brazil	Mexico	Haiti	China	U.S.A.	Australia	Sweden
Infant Mortality (per 1000 live births) 2001	7	31	24	79	31	7	6	3
Under-five mortality rate (per 1,000 live births) 2001	9	36	29	123	39	8	6	3
Maternal mortality ratio reported (per 100,000 live births) 1985–2001	33	160	55	520	55	8	..	5
One year olds fully immunized (Measles/ Tuberculosis, %) 2001	99/99	99/99	97/99	53/71	79/77	91/..	93/..	94/..
Births attended by skilled health personnel (%) 1995–2001	100	88	86	24	89	99	100	..

Source: UNDP 2003 (Table 6) UNDP 2000 (Table 10).

Cuban population. Furthermore, the law stipulates that institutions forming part of the national health system should give high priority to preventive actions and measures (Evenson 2005). Superficial indicators show that Cuba's preventive approach to healthcare has contributed to its positive health outcomes. The country's rate of vaccination, close to 100% of target populations, gives some indication of the attention paid to preventive measures. As a result of this (following from mass vaccination programs that were some of the country's first preventive health measures after 1959), the prevalence of infectious diseases preventable by vaccines has been reduced to a level below all other nations at similar levels of economic development (Waitzkin et al. 1997).

In a broader sense, Cuba's proactive focus on prevention shapes the way healthcare is delivered and the overall structure of the health system. At all levels, the system is geared towards foreseeing and averting health risks before they become major problems leading to morbidity and mortality, an approach that has clearly made a profound contribution to the country's surprisingly low morbidity and mortality rates. This includes a comprehensive system of registration, surveillance and monitoring of the population,⁹ beginning at the community level with the Family Doctor Program (a unique model of family medicine involving a team of a doctor and nurse living and working in each community).

As part of their role, the family doctor and nurse are required to see each person at least twice a year and to keep comprehensive and updated health records

for all of their population (Waitzkin et al. 1997). A focus on foreseeing and averting *potential* rather than *actual* health problems entails a level of involvement in patients' lives virtually unheard of in other global contexts. As one interviewee observed, Cuba was the only country he had seen where it was normal for a family doctor "to knock on the door, to make sure the children are bathed and check that your bathroom and sanitary service are in a reasonable condition" (Herrera 2004). In Western liberal contexts, by contrast, the expectation that doctors will actively contact or pursue patients rarely extends beyond sending an occasional letter of reminder for appointments or checkups. It is conceivable for patients to live periods of months or even years without seeing a doctor. Even in countries where national universal schemes exist, health services are rarely delivered automatically but depend on the initiative of individual patients to solicit them.

The Cuban health system is characterized by health workers' proactive intervention into patients' lives on a frequent and ongoing basis. The Cuban family doctor, upon arriving in a new community, begins a process of actively surveying and classifying the population with the goal of detecting early signs or risks of preventable health problems. In the case of the Maternal Infant Program, for example, this includes scheduling consultations and keeping comprehensive sexual health records for all women in the catchment area from when they reach reproductive age. Hence, by the stage of the woman's first pregnancy, the local doctor already has substantial knowledge of her health status. Family doctors serve one area usually

9. In its *World Development Report 2004*, the World Bank revisits the question of how Cuba performed so well in health despite its low levels of growth. It concedes that one of the key factors contributing to Cuba's positive health outcomes, in particular its low infant mortality rates, is its close monitoring of the health system (World Bank 2004b).

for a minimum of five years, which allows enough time to develop a comprehensive knowledge of the population (Castilla 2004).

If I arrive as a new family doctor to a community, and just say it has 1500 people, the first thing I have to do is characterize that population. Here we characterize into four groups; healthy patients, patients at risk, group three is sick patients and group four is patients with disabilities. I start visiting the patients or they come to the *consultorio* and as I do this I am also classifying.... Looking at the family all together in the home environment allows us to decide whether that family is at risk.... Doctors here have to walk a lot to visit all the families [which is important] because this allows us to observe and modify their lifestyles.... Just suppose there is a family in my community that has a man and a woman and they have a daughter and the daughter has reached reproductive age; just say she is 22 years old. The girl gets married, wants to have a child and falls pregnant. At this point I already know this girl because I visited her family's house while she was growing up so I already know if this is likely to be a pregnancy with risks or a normal pregnancy. ... It is much easier this way than if a [pregnant woman] arrives who I don't know (Castilla, interviewed September, 2004).

As Feinsilver observes, Cuba's approach to healthcare is an integral one that "combines prevention with cure and treats the individual as a bio-psycho-social being, living and working or studying in a given environment" (1993, 29). Doctors and patients interact with one another in a range of situations and contexts; in the *consultorio* (doctor's office), in the patient's household, and around the neighborhood where both live. Aside from improving doctors' ability to anticipate patients' health risks, the close and ongoing doctor-patient relationship improves trust between the two parties (Almeida, interviewed August, 2004). This leads patients to be more forthcoming in seeking help and providing doctors with information. Doctors' close contact with patients usually continues when patients are referred to other health institutions. When a patient is hospitalized, for example, family doctors normally travel to the hospital to keep records and coordinate specialist care. Similarly, after a new infant is born, doctors keep a close watch on the infant's progress. They

schedule regular appointments and visit the infant's household to administer vaccinations, monitor hygiene conditions, identify risk factors, and educate parents on how to care for the child.

Supervision of health services in Cuba is centrally coordinated and based on a hierarchy. The records family doctors keep are monitored by and answerable to a "Basic Work Group" (GBT) pertaining to the local polyclinic. Polyclinics control other resources than family doctors offices and each one services around twelve family doctor communities. A GBT pertaining to a polyclinic is made up of the twelve doctor/nurse teams (known as a "Basic Health Team") along with three specialists who worked from the polyclinic—a gynecologist/obstetrician, a clinician, and a specialist in internal medicine (Castilla 2004). Polyclinics report to health organizations at the municipal level. These report to the provincial level, which in turn reports to the national Ministry of Public Health (MINSAP). This top-down organizational structure works as a way to ensure a coordinated effort at all levels of the system to implement the goals set at the national level. At the local level, polyclinic supervisors place considerable pressure on family doctors to sustain routine observation of their local communities. When any preventable health problems emerge in their community, family doctors are held accountable, and the same follows suit through to the national level (Herrera 2004; Valdés 2004; Castilla 2004). Information regarding chronic and acute illnesses is transferred sequentially through this ladder via a computerized surveillance system that enables nation-wide health surveillance of factors such as changing patterns in the spread and distribution of diseases, as well as the emergence of any new epidemics (Waitzkin et al. 1997).

The proactive, central role of the Cuban state in setting and implementing health goals has clearly been a success in terms of improving aggregate health outcomes. On the one hand, the pressure exercised at the national level over all other health institutions appears to have been technically effective in delivering results. As the following section explores, on the other hand, this top-down approach can sometimes ob-

secure local-level issues that are important to the quality and sustainability of these results. In particular, patients' role in healthcare decision-making, a factor influencing sustainability as well as experiences and perceptions of the system, can be compromised by state demands for health workers and patients to comply with its overarching agenda.

DECIDING WHAT IS GOOD FOR THE POPULATION: BENEFICENCE AND LIMITATIONS TO PATIENT AUTONOMY

After centuries of medical paternalism, contemporary medical practice has shifted away from the previously overruling authority of physicians to an emphasis on patient autonomy and participation (see Chin 2002). The clear consensus in medical ethics literature is now that healthcare service delivery should involve patients' informed consent and that decision-making on health issues is a role that doctors and patients should share (Sugarman 2003). Numerous studies have demonstrated that increased autonomy (participation by informed, competent patients) and shared decision-making in medical service delivery improves overall health outcomes, including patients' satisfaction with outcomes (Kravitz and Melnikow 2001; Kee 1996; Kaplan, Greenfield and Ware 1989).

A complex conundrum arises when considering these theoretical developments in the context of Cuba, however. The basic principle/foundation of Cuba's approach to public health—the legal stipulation that the state has an obligation to protect and improve the health of the population, using preventive measures wherever possible—assumes to some extent a position of beneficence. In other words, the state is seen to have a duty to act in the best interests of the population. Moreover, the emphasis on preventive measures requires that the state carry out this duty in *proactive* manner. This is undoubtedly positive if it results in better health outcomes. However, a complexity arises when considering that the state's position on what are the appropriate actions for improving and protecting population health might not always be congruent with individual citizens' goals or interests. The following discussion of maternity homes in Cuba provides a practical example within the health system where this problem arises.

The Case of Maternity Homes

While family doctors usually monitor the pregnant women in their community successfully, they sometimes have trouble managing cases that fall into a high risk category but were not serious enough for hospitalization. Women who are severely underweight, those carrying twins, and those with what interviewees referred to as “social problems” are amongst those that family doctors, along with local Federation of Cuban Women (FMC) representatives, have the option of sending to an institution known as an *hogar materno* (maternity home) (Arango 2004; Castilla 2004; Díaz 2004; Espinoza 2004; Ramírez 2004).

Maternity homes in Cuba were first developed for women living in remote areas who did not have easy access to hospitals. The homes were situated close to maternity hospitals and pregnant women were sent to live there during the period directly leading up to the birth, to allow easy access to hospital once they went into labor (González 2004). Maternity homes used for this purpose were a way to deal with the dramatically increased risks associated with births where medical assistance was absent (according to Bergstrom, “women living far away from health facilities may suffer a maternal mortality four times as high as similar women living close by”). Maternity waiting homes or maternity villages of this sort have been used in various parts of the world to overcome problems of geographical isolation with varying success (Bergstrom 1994, 313).

In Cuba, this idea has been expanded to include women from major population centers, incorporating services as a preventive measure for a variety of other situations. The duration of time women stay in these homes ranges from short periods to entire pregnancies, depending on individual circumstances. Family doctors make decisions about the length of stays and usually continue to visit and monitor the woman throughout this period. While in these homes, women are provided with measured diets and close observation. Aside from the occasional excursion, they are required only to rest, eat and listen to educational talks from nurses on topics such as adolescent pregnancy and risks associated with smoking.

Women admitted to maternity homes are not free to come and go as they please but require official passes to leave the institution (González 2004). When questioned about the apparently compulsory nature of admission to the homes and how the system dealt with women who were reluctant to be admitted, a representative from the FMC gave the following explanation.

The first thing we have to do is talk with the woman to explain clearly to her the need for her to go [to the maternity home]. Since the women who go there don't have problems of hypertension or any life threatening disease, they don't feel like they are sick so they don't understand why it is important for them to be there. ... There is another situation, which is that often the woman, who as I mentioned, doesn't feel sick, leaves behind one, two, or even three children in her house when she goes to the maternity home. She worries a lot because she wants to be with [the children]. There is another small percentage that worries that while they are away their husbands might be having affairs. So they don't want to be there for fear of being away from their family. What used to happen with much more frequency is that women would escape from the maternity homes. In other words they would leave without authorization, without asking permission. ... [When this happens] the maternity home has to immediately inform the woman's family doctor, who goes along with the other community organizations to the woman's house to convince her again, to work with her and [make her understand] that it is important for her to be there (Arango, interviewed October, 2004).

The above passage provides an illustration of the tension that can exist between individual and state goals. In this example, what is seen as best for the pregnant women from the perspective of the public institutions involved, and whose primary interest was to achieve an optimally healthy pregnancy and childbirth, conflicts with what some individual women see as best for them based on a range of other factors (such as personal and family-related emotional considerations). To what extent, then, can the state be justified in acting to persuade or coerce individuals into complying with its public health agenda? To what extent should those administering health services comply with state demands to prioritize the im-

provement of aggregate outcomes, in cases where individual patients object to the measures required to do this?

Medical Paternalism

As Katherine Hirschfeld observes in *Health, Politics and Revolution in 20th Century Cuba*, most studies of the Cuban health system continue to focus only on health statistics with little attention to the measures by which the statistics were produced (2006). While there is little doubt that lower rates of mortality and morbidity bring fundamental improvements to population wellbeing, it is important to remember that wellbeing is a complex and multi-dimensional concept linked to a myriad of factors.

Statistical outcomes do not reveal, for example, patients' experience of the health system. In other words, it is conceivable to achieve a technically positive result in terms of physical health through means that isolate, humiliate, or otherwise negatively impact on the patients' emotional or psychological wellbeing. One of the doctors interviewed provided the following account as an example of the adverse consequences that can result when patients are not involved in medical decisions.

We had at one stage a problem with a nineteen-year-old patient who had a slight mental delay but she was in secondary school ... [and she was] a patient with whom one could have a conversation. She fell pregnant with [a heart condition that prevented a normal pregnancy] meaning we had to order a termination. However, we knew the condition could then be corrected in an operation, after which the patient could fall pregnant again and have a child normally. So what happened? The patient came through the usual system in her local area but the social worker in her community made an additional report saying that the patient had schizophrenic tendencies, that she had family members with schizophrenia. The social worker was trying to influence the doctors into sterilizing the patient using arguments that really were not valid. ... Even if you are schizophrenic, when you are using medication and your condition is under control, there is no reason why you should be denied the right to have a child. If you can be a good mother, a dedicated mother, why should I deny you the ability to be a mother? Despite the fact that we recommended very

specifically that this patient should *not* be sterilized, the obstetrician responsible for carrying out the pregnancy termination on this young woman went ahead and sterilized her, without our consent, without the patient's consent and without the family's consent. How did I discover this? By pure coincidence. The family wanted to bring the girl in to have tests done to find out whether, after all, she would be able to have children. When I examined her I discovered the doctor had sterilized her. ... This example happened as a result of paternalism (Valdés, interviewed August, 2004).

Through fieldwork interviews and observations, it appeared that the approach of beneficence adopted at the state level filtered down through the system and affected the way healthcare was administered at subordinate levels. There seemed to be a tendency, in other words, for practitioners to make medical decisions based on what they thought was best for patients, often without thoroughly informing or involving the patient (Blanco 2004; Valdés 2004; Herrera 2004; Fernández 2004).

The doctors interviewed for this project were clearly aware of ethical developments relating to shared decision-making. “[Doctors] should work as a doctor-patient relationship” said one doctor. “In a consultation they should really give a diagnosis and discuss treatment options with the patient. ... That is the way I work but we know that not all doctors act in this way.” The respondent went on to argue, however, that working under strict demands from above limited doctors' autonomy, which in turn affected the way they dealt with patients (Valdés 2004, a point also raised by Herrera 2004). In other words, doctors in Cuba find there is little room for allowing patients a role in decision-making because ultimately the system holds doctors responsible for outcomes. Fearing the possible risks involved with giving patients choices, and the blame for any negative consequences, many doctors prefer to take what they see as a safer option of basing decisions on their own judgement rather than encouraging patient participation. While

it is not being suggested here that a strong role for the state in health policy *per se* leads to medical paternalism, in Cuba's case it would appear that the state's dominance over other societal groups—including doctors—contributes to the paternalistic nature of healthcare delivery. In other words, doctors have little room to allow patients to participate in decision-making because they themselves have limited autonomy.

Here in Cuba there is too much of a burden of accountability placed on the doctor. Even though in many cases the patient is the one to blame for a health problem, the doctor is always blamed. This is often what causes the Cuban doctor to be paternalistic. I know that they are going to measure my medical ability based on my results without considering that maybe I did everything correctly but the patient didn't, so the only way to protect myself is to be paternalistic with the patient. ... If [the patient] doesn't seem very disciplined I am going to impose this and that and make sure that she does everything possible so that things turn out ok because I know that if I don't, I am the one they are going to question. So the paternalism comes from a problem of the system questioning me if anything goes wrong and that to avoid this I am going to impose [and tell patients] “you have to do this and this and this and that's all there is to it” (Valdés, interviewed August, 2004).

If paternalism is the norm in Cuba, then judging by the country's health indices it could easily be argued that the approach has been effective. However, “good health outcomes” measured purely as statistics of low mortality and morbidity and increased life expectancy do not reveal all about the quality of a health system.

In an anonymous interview,¹⁰ one Cuban respondent discussed her experience visiting a dentist in Sweden. She described how surprised she was when the dentist began explaining the treatment procedure to her—“now I am going to give you the anaesthetic, then I will clear the canal of the tooth because you have a deep cavity” and so on. The respondent was

10. “Anonymous interview” here refers to an interviewee who did not want to be identified in any way, including by name, occupation, or place of work.

completely unaccustomed to this. She said that in Cuba, by contrast, patients often felt confused when they came out of a medical consultation.

Here doctors don't tell you what exactly they are doing and sometimes they give you a diagnosis in very medical terms from a medical text book and you come out of the consultation thinking: "So what is it that I have?" The other day a neighbor of mine arrived at my house and asked me if I had a medical book. I said I didn't have one and asked her what was wrong. [She told me:] "The doctor diagnosed me with *lupos eritematoso* and said I have to take vitamin E but I want to know what it actually is that I have" (García, interviewed October, 2004).

The respondent said she had spoken to others who were panicked after an HIV test because they had been told to come back and repeat the test in several months and they didn't know why. It had not been explained to them that there was nothing abnormal about their test results. It was simply standard procedure to test for HIV every six months because the virus had an incubation period before it could be detected.

It is not being suggested here that all experiences of the Cuban health system were unpleasant or isolating in this way. It is my argument, however, that some adverse effects on wellbeing at the local level resulted from the paternalistic nature of a system that unnecessarily limited patient participation in the decision-making process. Furthermore, these effects detract from the overall benefits to wellbeing resulting from improved health outcomes.

Some Responses to Paternalism: Over-Dependency and Self Medication

Interviews in Cuba, as well as personal observations during the fieldwork period, revealed some of the patient responses to this apparent exclusion from medical decision-making. Some patients developed a dependency on doctors to the extent of becoming complacent about their own role. One sociologist, specialising in the area of public health, said she thought Cuba had developed a culture of over-relying on doctors: "Cubans recognize the leadership of doctors and consult them for everything, sometimes in excess" (Blanco 2004). Another respondent, a psy-

chiatrist and social worker, agreed that Cuba had not managed "to achieve an outcome of people understanding their own responsibility in caring for their health" (Fernández 2004). She compared the experience of the Cuban system to "having a father who deals with all your problems," saying that a consequence of this was that Cubans didn't make much effort on their own part.

She said one example was the fact that Cubans were not conscientious about attending appointments for pap smears or other scheduled consultations. In most cases, she said, it was the doctor who continually knocked on patients' doors and convinced them to come to these consultations. She argued that Cuba needed to make patients more aware of their role in healthcare if Cuba's health outcomes were to be made sustainable (Fernández 2004). Indeed, it can be reasonably assumed that informed patients who participate in choosing treatment options are more likely to understand their responsibilities and follow through with treatment than those who are simply told what to do. Other respondents raised the issue of the poor contraceptive use in Cuba as an example that individual responsibility needed to be encouraged. According to the respondents, despite widespread availability of contraceptives and education programs, contraceptive use (a domain that relies on individual responsibility) was still extremely inefficient (Blanco 2004; Sánchez 2004; Valdés 2004).

Conversely, some patients responded to the limited decision-making powers in the official system by taking matters into their own hands. A lack of information from doctors and unreliable supplies of medicines at pharmacies caused confusion and frustration that undoubtedly contributed to what was a widespread phenomenon of self-diagnosis and self-medication. According to one sociologist at the University of Havana, *automedicación* (self-medication) was extremely common among Cubans. She said this was particularly the case for women, who frequently exchanged remedies and medical advice between friends. This ranged from giving advice on herbal home remedies to exchanging prescription pharmaceuticals (Blanco 2004). In her dissertation on Cuba's health system, Crabb¹¹ makes a similar observa-

tion. She describes a culture in Cuba whereby people often sought and gave medical attention or advice between friends. She relates an incident where a neighbor asked for help to sort through a large bag of random pharmaceuticals (most without dosage instructions) that had been sent from the neighbor's family in Miami.

None of them were medications I had ever heard of, and most of them appeared to be out of date. I tried to caution her against taking them without at least finding out what they were for, but my advice was immediately drowned out by other neighbourhood "experts," who began to offer their own analyses of what the medications (sic). One woman lifted a bottle out of the pile, "Look. This one says 'Gastrosin,'" she said. "It must be a stomach medicine." "Can I take some to my sister?" Another woman asked, pointing to the vial. "She's been having stomach problems." I tried to point out to her that the label actually read, "ganostin," but she felt the distinction was unimportant and took the medicine away and presumably gave it to her sister. When I expressed alarm about this unsupervised sharing of unknown pharmaceuticals to another neighbor later in the evening, she laughed sadly and said Cuba was the only country she had ever seen (she had lived abroad for many years) where people were so casual about informally exchanging medicines (Crabb 2001, 179).

As this example suggests, the consequences of relying on informal means to solve medical problems can be dangerous. While, on the one hand the official medical system in Cuba is highly accessible both economically and geographically, internal problems of paternalism that exclude patient decision-making, combined with problems of inefficiency and unavailable pharmaceuticals resulting from black-market activity, make it inaccessible in other ways.

The fact that medical services are incorporated in a single nationalized system facilitates organization, inter-sectoral cooperation, and epidemiological surveillance. However, it also means that patients who are unsatisfied with the official system have few safe and

regulated alternative options. In the case of prioritized and closely-monitored health programs, such as the maternal infant program, individuals have difficulty escaping the practical and social/moral pressures to comply with the regulations of the official system. In less politicized areas of health, it is common to take advice from laypersons or seek professional advice through unofficial channels such as networks of friends or *socios*. While no statistical evidence exists to show how prevalent these unofficial practices are, or what are their consequences, it seems logical to assume that they work against state efforts to register, track and prevent medical problems.

POPULAR PARTICIPATION IN HEALTH POLICY-MAKING

Just as patient autonomy has been recognized as important to the sustainability of health outcomes, so there has been a growing recognition that the sustainable development of health systems benefits from citizen participation in health policy-making (see PAHO 2006). Aside from issues of patient participation in decisions at the doctor's office, a discussion of participation in Cuba's health system should also include consideration of citizen participation in broader decisions relating to health policy.

Cuba is one of the few, if not the only, Pan American Health Organization (PAHO) country that has managed to establish a coordinated system of popular participation at the national level (Feinsilver 1993, 80). The establishment of Peoples' Power Assemblies at the municipal, provincial, and national levels in 1976 led to greater administrative decentralization and increased opportunities for non-health workers to participate in health policy-making. "The polyclinic became accountable to the Ministry of Public Health on issues of norms, policies, and methodology and to the municipal People's Power Executive Committee in administrative and operational matters" (1993, 81). Each level of people's power (including its local services) brings together representa-

11. Now Hirschfeld.

tives from the corresponding levels of the country's mass social and political organizations such as the Committee for the Defense of the Revolution (CDR) and the FMC (Ramírez 2004).

While these structures play an important role in educating and mobilizing the population to participate in the implementation of health policies (a considerable achievement), some researchers have been critical of the degree to which they offer real participation in actual policy-making. Feinsilver argues that the extent to which People's Power Assemblies offer a means for popular participation is greater in theory than in practice: "[S]ince these services are under the normative and methodological control of the Ministry of Public Health, actual decision making and planning do not take place in the assemblies but rather in the ministry and at the local level of administration by ministry appointees" (1993, 81–82). Similarly, in a discussion of popular participation in Cuba, Hernández and Dilla argue that it is important to distinguish the difference between participation and real power: "To participate is not simply to have access to multiple areas of discussion but to contribute to decision making in these areas. Participation in discussion and execution is relatively high; in political decisions and their control it is considerably less" (Hernández and Dilla 1991, 53).

STATE CAPACITY

These empirical findings are relevant to a number of interesting and important theoretical considerations, particularly in light of recent literature on "state capacity." In recent decades, a revival of interest in state capacity has drawn attention to the positive developmental role of the state (see Weiss 1998; Mann 1986; Krieger 2001; Block 1987). In particular, this has generated criticism of mainstream economists' approach to development that has tended to view the state as ineffective and inefficient, and to advocate market-based economic growth as the solution to problems of poverty, including poor health outcomes. State capacity theorists have been more optimistic about the ability of societies (through state institutions) to collectively plan and achieve developmental outcomes. In other words, state capacity theorists have argued that deliberated political

decisions can achieve positive developmental outcomes (such as improved health indicators), that economic or other forces would not spontaneously produce. Generally speaking then, the case of Cuba, where positive health indicators were achieved through state efforts to proactively monitor, foresee, and prevent health problems, is a success story of state-led development.

However, in light of the findings discussed in this article, there are some factors that complicate this conclusion. Contemporary state capacity theorists have conceptualized the modern state not as a single actor that makes decisions independently of a society, but as a body of institutions that act as a mechanism for collective decision-making. In doing so they have differentiated between different types of regimes, based on how "embedded" states are in society (equivalent to the level of citizen participation in state-led decisions). In *The Sources of Social Power*, Michael Mann identifies two types of state power: despotic power (whereby the state can act arbitrarily, free from constitutional restraint) and infrastructural (the state's ability to embed itself in society). In modern polities, infrastructural power is more prevalent and important than despotic power (Mann 1993; see also Mann 1984). "State strength," the neo-statists argue, "increases with the effective embedding of autonomy, whereas state weakness ensues from despotic abrasion against society" (Weiss and Hobson 1995, 7). In other words, the more concentrated and arbitrary the state's power, the more it becomes isolated from social groups. However, when state power is integrated into society, its strength is increased by its capacity to generate and to focus economic and social energy (Krygier 1997, 115).

A factor in "state strength" is surely the state's ability to produce lasting outcomes endorsed by citizens that are not easily torn down by competing forces (market forces, competing political interests, and so on). It can be logically assumed that state decisions that are the product of a general democratic will face fewer competing forces and would therefore have a greater likelihood of sustainability and permanence, than coerced decisions.

Following from this, the issue of citizen participation in the process of health policy formation and implementation is important when considering long-term sustainability both of Cuba's health outcomes and of its public health system as a legitimate challenge to a privatized system. While health outcomes in Cuba are a state achievement, maintaining that achievement over the long term would depend on health policy being embedded in generalized community trust and accepted unambiguously by a majority of the population. Cuba has managed to build up some important participatory structures since the introduction of People's Power Assemblies. These are a positive development, even if they only to increase participation in implementation of state-led goals and not in actual policy-making as some authors have argued. However, even if these channels for popular participation in policy-making are adequate, patient autonomy in medical decision-making is also important.

The paternalistic tendencies in the way healthcare is delivered in Cuba, while perhaps effective in achieving outcomes quickly, could work to undermine the system's otherwise positive outcomes in the long term. If patients respond to this paternalism by becoming complacent in their own role or by evading the system, then the system has failed in some dimensions despite the overall statistical indicators of success. Citizen participation in healthcare decisions

at the local level (i.e., shared medical decision-making) would be likely to increase citizen confidence in and support for the health system that would increase its chances of long-term survival.

CONCLUSION

This research found that Cuba's positive aggregate health outcomes owe much to the Cuban state's proactive and preventive health policies. There are lessons to be learned from Cuba's success in reducing morbidity and mortality. In particular, it demonstrates some degree of "state capacity" in determining health outcomes.

This paper has also demonstrated, however, that statistical outcomes, while important, do not tell all about a health system's success. It is worthwhile for researchers and policy-makers interested in evaluating health system performance to also look beyond general population indicators to assess more local-level factors, such as the means by which healthcare policies are delivered. Considering factors such as the extent to which patients are involved in medical decision-making may tell something about the long-term sustainability of a health system's outcomes. Such considerations are also important to evaluating the way patients experience a system. This, too, is important since the goal of improving population health indicators is surely, after all, to improve peoples' lives and wellbeing.

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