Funding preventive or curative care? The Assiut Burns Project

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This case-study examines the achievements of a small Egyptian NGO, the Assiut Burns Project, and the problems it faces in becoming financially sustainable. Burns injuries, despite their prevalence in developing countries, are given low priority by governments and aid agencies alike, as medical care is expensive and the poor are unable to pay for treatment. Yet neglected burns produce crippling disfigurement and deformity which may leave men unemployed and women and children as social outcasts. Current development policy favours primary preventive health care, according curative care low priority even where this involves wider development issues. Assiut deals with issues central to development management, including:

- the right of the poor to basic health care;
- women's rights and access to health care;
- the integration of medical, preventive and social care;
- social and economic rehabilitation of the disabled;
- local capacity-building through:
  - appropriate research and training;
  - building links with other key providers, including the state.

This innovative programme faces problems in raising funds because the work rests on medical care which is unattractive to many donors who prefer low-cost preventive work, and refuse core costs, especially salaries, in the name of sustainability.

The Assiut Burns Project: a victim of funding policy?

Poverty and accidents

Throughout Upper Egypt, the poor are at high risk from burns and scalds. Domestic accidents are the major cause of injury for women and children. Women squat to cook, using badly designed Kerosene stoves placed on uneven dirt floors amid free-ranging goats, chickens, and children. Scalding is common when children or animals overturn large, unstable cooking pots, and ill-fitting wicks can cause the stove's fuel-tank to explode. Women and girls also wear long, inflammable dresses of synthetic fabric, cotton now being too expensive. Butagaz is gradually becoming affordable, and leaking cylinders cause dramatic accidents often injuring a whole family. Men are injured both in the home and at work in conditions which pay scant regard to health and safety. Finally, punishment and suicide by burning is prevalent throughout Egypt, with young women being the main victims.

Access to treatment

State medical care is theoretically free, but in practice patients must pay towards their treatment. Even so, chronic under-funding results in low standards of care. Doctors and, in particular, nurses receive nominal salaries which they supplement through 'tips' from patients. There are few drugs and little equipment, even basic items such as dressings, rubber gloves, sheets, and waterproof mattresses being in short supply.

The position is even worse for burns patients, who need scrupulous care. Most public hospitals offer only palliative care in grossly unhygienic conditions where infection is the norm. Difficult cases may be refused admission, or patients may be discharged early with suppurating wounds and left to die or survive as best they may. Despite the high burns injury rate, (over four cases per thousand per year), the Assiut University and District Hospitals are the only ones in Upper Egypt with specialised burns units; and they have just 46 beds to serve a population of over 15 million. The University Hospital, which has the best facilities, limits in-patient admissions to two days per week and takes only burns less than 24-hours old, to reduce infection rates.

Even these service standards are declining as government funding fails to keep pace with inflation and World Bank structural adjustment policy

moves resources to the already large free-market sector. Given the poor facilities and the cost of treatment, it is hardly surprising that, although the immediate treatment of burns is vital, the poor commonly resort to folk remedies, or the pharmacist, going to hospital as a last resort. This combination of delay and poor quality care means the poor have a high risk of suffering permanent scarring and disability.

Disfigurement and disability

Neglected, infected burns fail to heal or accept grafts, which results in permanent disfigurement and painful scarring. Malnourishment increases the risk of infection. Only the specialist hospitals offer compressive dressings or grafting or any physiotherapy, yet without this muscles and skin contract resulting in major disability, including:

- necks sealed to the chest wall, so that the head cannot be raised;
- fingers sealed together and the hand contracted to a useless claw;
- arms sealed to the chest wall;
- lower leg contracture, making walking impossible.

Disability and disfigurement carry harsh consequences. Women, especially, may end up as social outcasts; divorced and denied custody of their children, or unable to marry in a society where this carries a heavy stigma. Those who die, and many do, may suffer a protracted and agonisingly painful death. It must be stressed that the disfigurement and deformity that result from poor treatment are avoidable and rare in most developed countries.

Good medical care is not simply curative, it *prevents* deformity. Furthermore, provided old injuries are caught within about ten years, then operations, grafting, proper dressings, and physiotherapy can restore some mobility to the disabled. Much of the Assiut's work involves the treatment of such neglected burns.

The Assiut Burns Project

The Assiut Burns Project (ABP), a small independent NGO, was set up in 1990 by two remarkable men as a direct humanitarian response to this unnecessary suffering. Phillipe Macchi, a Swiss national, regularly encountered burns victims while working as an administrator with a trachoma project in Upper Egypt. Unable to ignore their plight, he began taking individual children to the private clinic of Dr Mahmoud el Oteifi,

a skilled plastic surgeon and burns specialist at Assiut University Hospital. The children were treated free or at nominal cost and funds were raised on an *ad hoc* basis, often from friends.

However, both men were acutely aware that this barely touched the sea of need. They developed a proposal for a Burns treatment centre for the poor, particularly women and children. Initial support came from Oxfam UK/I (now Oxfam GB), Médicins pour Tous les Hommes (MPTH), and a Swiss support group, Fondation en Faveur des Enfants Brulés, (FEB), founded by Phillipe's friends. MPTH and FEB continue to support the work.

The Project's formal charter stresses human rights:

> Access to medical treatment of a certain standard, and efficient rehabilitation, is the right of every human being. This right takes into account the whole person; not just physical needs, but also psychological, social and economic needs.

The programme operates from a cramped seven-bed unit in a converted flat in Assiut, a major provincial capital in Upper Egypt. The surrounding rural areas are some of the most impoverished in the country. They now treat over 800 patients a year in their own centre, and improve treatment for hundreds more through their collaborative work with Assiut University and District Hospitals, and charitable dispensaries run by Christian nuns in neighbouring rural areas. Sectarian strife is a fact of life in Upper Egypt, yet ABP employs both Christian and Muslim staff, and treats patients irrespective of religion. They operate with about 50 core staff, and need a budget of over £100,000 a year to cover general running costs.

More than a medical programme

The ABP has pioneered treatment which integrates medical, social, and community work. It has also developed innovative training courses and a successful programme of health education and accident prevention which is markedly reducing the incidence and severity of burns in the villages in which it is being piloted. The key elements of the ABP, which are almost unique in Egypt, are:

- high-quality surgery and nursing care plus compressive dressings, and physiotherapy to prevent scarring and contractures;
- protein supplements and protein-rich food for in-patients to ensure survival and good response to treatment;
- financial support through subsidised fees;

- social work support to help patients maintain lengthy and painful treatment programmes;
- rehabilitation work to help families and individuals cope with the consequences of burns injuries and, where possible, find jobs;
- social support groups and income-generating projects for the poorest and those rejected by their families;
- health education, both intensive in selected local villages, and mass through school programmes, stressing, 'Pour water on burns, and get treatment quickly';
- prevention programmes in selected villages to test out ways of reducing burns accidents ;
- collection of statistics from local hospitals and pharmacies on numbers of burns, causes, and mode of treatment (basic research);
- provision of basic and upgrading training for doctors, nurses, physiotherapists, dressers, social workers, health educators, and village outreach workers. Training is also offered to collaborating centres, including local hospitals and dispensaries;
- outreach work, providing training, personnel, and essential supplies (including dressings and food supplements) to support and upgrade the work of other centres, including government hospitals and charitable dispensaries.

It is difficult to encapsulate the achievements of this complex programme, which has broken new ground in almost every respect. The integration of social and medical work, and the support given to women, illustrate its quality.

Social support

The doctors were not initially convinced of the value of dealing with social and economic problems, but now recognise the importance of this work in helping patients regain the will to live and endure the long treatment. Social workers keep surgeons informed of the progress of patients which in turn motivates the surgical team. This holistic approach is at the heart of true Primary Health Care (PHC).

Social workers, who are trained by the centre, assess the family situation and ability to pay, and provide care, counselling, and practical

support, from the patient's first contact with the programme. Two key elements of their work are:

- Counselling: Burns cause great physical and psychological trauma. Social support can re-kindle the will to live, without which treatment is ineffective. Reconciliation work with families is particularly valued, as it is virtually impossible to live a normal social life outside the family setting.
- Out-patient support: successful treatment is dependent on completion of out-patient programmes, which may involve over a year of painful dressings and physiotherapy. Many people are tempted to give up, depressed and frustrated at the slow progress. The social workers give practical support, for example through transport subsidies, and moral support through their sheer stubborn refusal to forget the patients and allow them to give up.

Helping women

Given the abject poverty in the region, the family acts as an economic unit; children work from an early age and women's work is essential. A disabled, disfigured woman is, in many cases, an unwanted burden, being of no economic use and unmarriageable. Men take the key decisions in the family and women are bound by strict traditions which limit their freedom of travel and association and right to work outside the home. Apart from giving them priority in admission, the ABP takes account of women's special needs many ways. For instance:

- attempted suicides, who are mostly young females, do not pay any fees;
- if, after persuasion, a family refuses to pay for a woman's treatment, the case is treated free;
- families may bring young girls or elderly women as 'willing' skin donors. In such cases, the centre refuses and tries to persuade healthy adult males to give skin;
- facial disfigurement, although not technically disabling, is regarded as such for females and given high priority;
- families may object to females travelling for follow-up treatment. The centre helps with costs and 'safe' arrangements, and may treat in the home if persuasion fails;

- the centre provides a temporary refuge for women who are rejected by their families, and counselling to promote re-conciliation, or to face the future outside the family if necessary;
- legal advice to help rejected women claim their rights to economic support and child custody;
- help with finding work and income-generation schemes, which also involve rebuilding social confidence;
- disfigured children, especially girls, find it hard to face their peers and continue at school. Priority is given to counselling these children and their families.

Funding: 'selling the programme'

Assiut has built a programme of integrated care which offers lessons not just for other burns programmes but for health work in general. Despite this success, the ABP now faces problems in securing future funding. Although it has attracted funding from several major international NGOs, these donors tend to see themselves as catalysts, giving grants for an initial period after which they expect the project to become 'financially self- sustainable'. As it comes to the end of this 'honeymoon' period, ABP faces a major problem, common to many health projects: How do you finance good health care for the poor, when the clients cannot cover the cost and the state is unwilling or unable to do so?

Currently, the ABP raises about seven per cent of its budget from fees, which are index-linked to inflation. But it can never hope to recover more than a small minority of the costs given the poverty of the clients and the nature of the treatment. Assiut uses the simplest techniques and has no specialist laboratories or intensive-care unit, but the costs of burns care are high. Even dressings and physiotherapy are expensive when treatment lasts for months. Two examples:

High-cost case: 35 per cent burned area costing £1,800 for 100 days in hospital + four operations + dressings + 72 out-patient physiotherapy sessions

Low-cost case: 16 per cent burned area, an old burn costing £115 for one day in hospital + dressings + 25 out-patient physiotherapy sessions.

International donors are driven by their own logic and development rhetoric, which pose a number of problems for projects such as Assiut. Firstly, many donors are unwilling to fund core running costs preferring

to support capital costs which do not commit their future budgets. And secondly, there is a general focus upon PHC, which tends to exclude specialist medical care even when combined with social and educational objectives.

Selective funding

The ABP has a good record for obtaining funding for capital items which do not entail a long-term commitment. Covering core-costs, especially treatment costs and staff salaries, is much more difficult. Yet development depends on people, not just things, and Assiut's real achievement is to have built a team of skilled, committed, local staff. The Project has secured most of the costs of building and equipping a new centre, a formidable achievement for a small local group, but cannot go ahead without the ability to support staff salaries. For Phillipe this selective funding policy made no sense:

> I fought hard for percentage contributions instead of funds for special activities; we do not wish to sell little pieces of our work, but to find partners who will share with us in our care for the whole programme.

Primary Health Care (PHC)

Many NGOs give priority to PHC programmes, with the stress on low-cost, preventive care, health education, and outreach work, often using low-paid or volunteer labour. Only simple curative care is likely to be accepted as part of PHC. This means that many donors look at the Assiut project in simplistic terms, labelling the majority of its work as medical and curative simply because it deals with burns. They are happy to fund the village preventive work which is much cheaper and fits with their priorities. Phillipe wrote:

> since most of the organisations consider that prevention work is intelligent and curative stupid, I feared many times of having far too much for preventive work and no money at all for curative.

For Assiut, the integrated nature of the programme is crucial; springing from the right of the poor to proper care, not just health education. They believe that their preventive work is successful because it is part of a wider programme. Villagers accept the ABP community workers because they know and respect the project's work in providing the poor with good

medical treatment. One key element in PHC, and one which donors readily support, is the idea of the poor defining their own priorities. There is little doubt that good curative treatment is a priority for the poor, as for all of us. Prevention is better than cure, but Utopia belongs to the future, while disease and accidents are a reality today. It is this reality which fuels Assiut's commitment to an integrated programme.

If donors could cast away their simplistic view of curative care, they would see that Assiut, with its complex web of research, health education, practical prevention work, training, medical, paramedical, social and economic support, directed at the family, not just the patient, is the very essence of quality PHC.

Assiut has been called an 'island of excellence', and in the eyes of donors who seek to measure impact in numbers and readily replicable projects, this is damning with faint praise. But quality is important too, and Assiut shows what can be done using basic techniques and giving local people the skills, motivation, and opportunity to deliver good care to the poor, something which is not possible within the state system at present. In Egypt, radical reform is on the agenda but is unlikely to yield positive results within this decade. In this context, the ABP should be seen as a beacon of light, to be tended until other beacons can be lit. Unfortunately, the fuel for this beacon is money, and if neither the state nor major donors will fund humanitarian care for the poor, then the prospect is truly bleak.

Postscript

At my first evaluation meeting with Assiut, I was briefed to express 'my' donor's policy that money should be directed towards preventive care and treatment of medium to mild burns. Representatives of FEB were shocked that any aid agency could suggest this. The arguments raged furiously, and there was much puzzlement over what this concept of 'development' was if it excluded the seriously ill. Then Phillipe was called away. On his return he said he had admitted a woman burned from the chest down and almost gangrenous, having been 'treated' for several weeks in a small hospital which had then discharged her when her money ran out. They had heard there were honest people in Assiut, and travelled 250 kilometres to reach help. I was asked if I would have refused her. My answer was 'No'. The view from the ground looks different.