

# Neurological services in Darfur: a deprived rural community in a tropical zone affected by ongoing armed conflict

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**ABSTRACT** This report, compiled after a short visit to Darfur sponsored by the Association of British Neurologists, describes the status of healthcare in Nyala, the capital of southern Darfur. Four hospitals and 19 consultants supervise the care of over three million people. The most common neurological diseases in Darfur are infections of the central nervous system, characterised by meningitis during the dry seasons and cerebral malaria following the short rainy autumn. Trauma-related neurological disorders are common. Epilepsy, mostly symptomatic, is largely caused by untreated or poorly treated CNS infection, head injury and neonatal/childhood diseases. Epilepsy management is greatly hindered by the fact that the disease is considered to be a social stigma. Uncontrolled hypertension is the leading vascular risk factor, and stroke is frequently seen in younger patients who are not fully investigated. During his visit, the first author saw 46 patients in whom the most common neurological problem was infection and trauma-related epilepsy. The spectrum and presentation of neurological diseases was very different from the usual disease pattern seen by neurologists in the UK. Most components of a multidisciplinary team for neurological patients are lacking; no physical, occupational or speech and language therapy. The medical and neurology services in Nyala desperately need CT scanning to complement a reasonably equipped laboratory service. In addition, there is a need for local clinical guidelines to govern the practice of more junior staff and those working in disadvantaged health units.

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**LIST OF ABBREVIATIONS** Association of British Neurologists (ABN), African Neurology Interest Group (ANIG), central nervous system (CNS), computerized tomography (CT), cerebral vascular accident (CVA), general practitioner (GP), medical assistants (MA), magnetic resonance imaging (MRI), medically unexplained symptoms (MUS), outpatient department (OPD), transient ischaemic attack (TIA), World Health Organisation (WHO)

**DECLARATION OF INTERESTS** The first author received a travel bursary from UCB Pharma to travel to Darfur.

## DARFUR

Darfur, on the remote western border of Sudan, is a region the size of France with an estimated population of around 7 million people (Figure 1). Sudan is the largest African country in size, with a land area of more than one million square miles<sup>1</sup> and a total population of around 33.6 million. The population is predominantly young; 16.4% are estimated to be under five years old, 42% under 15 and, at the other end of the spectrum, 3.9% are 65 years or over.<sup>2</sup> These figures are explained in part by the health status of the nation, which has a life expectancy at birth of 47.2 for males and 49.9 for females. The adult mortality rate (per 1,000 population) is 357 for males and 268 for females (the adult mortality rates in Western Europe, including the UK, are 78–101 for males and 50–65 for females), and the percentage life expectancy lost due to poor health is 14.1 for males and 15.9 for females.<sup>1</sup>

Such figures reflect the low public health standards experienced in all parts of Sudan and will be worse in the poor and remote regions.

Geographically, Darfur extends southwards from the Sahara desert and is almost a thousand miles away from the country's main water lifeline, the River Nile. It is extremely dry and suffers from major and long-standing lack of water resources. There have been water shortages in most areas of the Darfur region over several decades – this not only affects individual and public health standards but also leads to poverty and widespread illiteracy, culminating in very low living standards. The most recent armed conflict has proved to be 'the straw which broke the camel's back'. As a result, the population in southern Darfur has recently doubled to approximately 3.5 million due to massive human displacement, with refugees fleeing their homes in search for water, food and security.<sup>1</sup> This



**FIGURE 1** Map of Sudan: Note the remote geographical location of Darfur in relation to the country's capital, Khartoum, and main water source, the River Nile. (Courtesy of www.dev.org)

worsening of security and the resultant humanitarian crises have further reduced the standards of the under-resourced hospitals. The whole public health service has been reduced to desperately low levels near to the breaking point of an already overstretched health system.

### LOCAL HEALTHCARE SYSTEMS

A unique healthcare system, dictated by circumstance, exists in Nyala, the capital town of southern Darfur. Four district general hospitals (in addition to eight satellite medical centres) serve different sectors of the local population: the Military Hospital deals with war casualties, the Police Hospital with the police and their dependants, the Specialist Hospital performs specialist procedures such as endoscopy, and the Nyala Teaching Hospital employs the majority of medical and nursing personnel in the town. These hospitals display good inter-hospital cooperation: a surgeon from the Teaching Hospital operates regularly on patients admitted to the Military Hospital, while the only ophthalmologist (the second author of this paper), employed by the Military Hospital, provides eye treatment and clinic services to all four hospitals. The medical and nursing staff of the four hospitals operate as one team willing to work for the benefit of the whole town.

As part of the healthcare team, MAs work alongside the medical staff. Medical Assistants are groups of well-trained specialist paramedics and nursing consultants who serve various specialties, intermingle with the medical staff and teach at the Nursing College based at Nyala Teaching Hospital. The specialties include an anaesthetic service for all major surgical procedures. Most healthcare personnel are local, from Nyala or the neighbouring villages, and have their posts long-term. They empathise with the local population and are willing to serve their people, usually in challenging circumstances (Figure 2).



**FIGURE 2** A donkey-propelled water supply unit, making an important and possibly rare appearance at Nyala Teaching Hospital. When water shortage looms, such a vital visit is desperately awaited by patients and carers: even inpatients might need to pay for their daily water supply.

Lack of proper epidemiological studies has resulted in an absence of accurate reports on incidence, prevalence and presentation of the most common diseases. The best available evidence is from WHO reports and health bulletins and the expert knowledge of respected long-serving local physicians. Healthcare personnel deal with a range of local health problems that are mainly the consequence of being in the tropics, deprivation and the prevalence of infection. The most common infections are clinically diagnosed malaria (30% of all hospital admissions and 3 million cases reported in 2003), acute respiratory tract infections, bloody diarrhoea and unexplained fever.<sup>1</sup> Tuberculosis has increased in prevalence, partly because of widespread malnutrition (among children, acute malnutrition is estimated at 22%). It is not known for certain whether poor housing and overcrowding are to blame for the increased number of infections. Although there are no reliable figures, HIV might be linked to the increased burden of infectious diseases affecting the areas inhabited by displaced populations from untraceable original habitats or subsequent movements.

Diabetes is not a common health problem, but systemic hypertension constitutes a major and growing health hazard and underlies most strokes and cardiovascular diseases.<sup>3</sup> This is partly due to a lack of medicines and proper follow-up, but also because hypertension is very prevalent in this part of Africa, tends to be severe and presents late due to lack of appropriate health awareness. The pattern of disease seen in this region is typical of a population in early epidemiological transition, where we see infectious diseases and diseases of poverty, with the emergence of hypertension as the first major vascular and indeed non-communicable illness.<sup>4,5</sup> Various injuries and post-traumatic disorders soared following the recent and ongoing armed conflict.



**FIGURE 3** A hemiplegic patient, with no physiotherapy input, who has developed fixed flexion deformities of the right wrist and elbow joints.



**FIGURE 4** A paraplegic patient using a locally manufactured hand-propelled bicycle. The exercise involved helps maintain cardiovascular fitness.

### NEUROLOGY SERVICES IN NYALA

There are currently no neurologists serving Nyala or Darfur as a whole. Indeed, the neurology service provision throughout the rest of Sudan is poor.<sup>6</sup> Similarly there are no CT scan or MRI facilities within Darfur, adding to the other burdens of the local physicians caring for patients with suspected neurological diseases. The neurology care is provided by fewer than six consultant physicians, who also look after all the other medical subspecialties. They tend to refer those patients whom they feel require brain/spinal imaging or a fuller neurological opinion to Khartoum.

### PLANNING AND ETHICAL CONSIDERATION

The first author of this paper has roots in Sudan, where tropical medicine, communicable diseases, vaccination, malnutrition and deficiencies constitute major areas of public health interest and are given considerable weight; great emphasis is placed on the clinical courses and practical skills taught in the local medical schools. This background enabled the author to make useful links, such as registration with the local Medical Council. In addition to substantial overseas clinical experience, the author was fluent in the local languages and had knowledge of the traditions and customs governing these remote communities where resources and technology are in short supply. The author had the added advantage of years of exposure to the practice of medicine in the UK and links to the ANIG of the ABN, promoting the knowledge and practice of neurology in Africa.

### NEUROLOGY TEACHING VISIT

As the visit was only for one week, we designed an intensive five-day programme. Each day started with an early morning clinic, followed by the main lecture and small group discussion (tutorial for MAs and medical

staff), and concluded with seeing patients (OPD and ward referrals). Main lectures covered neurological emergencies, stroke, CNS infections, epilepsy, neurological investigations, coma, brain death and medico-legal and ethical aspects of neurology. Audiovisual illustrations were used, and printed leaflets were handed out to healthcare personnel, carers and patients to promote awareness of epilepsy and meningitis. Tutorials were targeted at junior medical staff and the MAs. The programme was attended by a large number of matrons, nurses, paramedics, MAs and physicians from all four hospitals, and was covered by local radio and television. The aim was to raise public awareness of neurological problems needing urgent attention while acknowledging the need for long-term measures designed to engage local groups and solve health problems.

The most common neurological diseases in Darfur are infections of the central nervous system characterised by meningitis during the dry seasons and cerebral malaria following the short rainy autumn. The WHO reported *Neisseria Meningitidis* serogroup W135 to be the causal agent in 55% of 71 meningitis cases, with five fatalities in one small geographical area in Darfur.<sup>1</sup> Trauma-related neurological disorders (post-traumatic epilepsy, headache and nerve palsies) are common. Epilepsy, mostly symptomatic, is largely caused by untreated or poorly treated CNS infection, head injury and neonatal/childhood diseases, whether infectious or congenital (due to high levels of consanguineous marriage). Epilepsy management is greatly hindered by the fact that the disease is considered to carry a social stigma. This problem is made worse and propagated by illiteracy rates of more than 50% and many social and tribal taboos. Patients are sometimes kept hidden at home and not brought to medical attention until in a coma or *status epilepticus*, resulting in variable degrees of permanent brain damage.

**TABLE 1** This shows a breakdown for the 46 patients seen in five clinics over four days (first column), and the percentages of the most common neurological diseases encountered (third column) – based on clinical diagnosis of largely OPD and few inter-hospital referral patients but excluding acute admissions (these patients are not normally seen by a neurologist).

\* Meningitis: no patients with acute presentations were seen, but more than half of the 28.3% of patients in the infection/post-infection category gave a clear-cut history of an initial acute meningoencephalitis-like illness, preceding the neurological presentation. Therefore, the percentage of patients who might have presented with an acute/chronic CNS infection, among other illnesses, is estimated to be more than 14.3%.

Total patients seen (n = 46)	Comments	Common neurological diseases (according to the examined sample)
Epilepsy 16	7 are post-infection, possibly symptomatic 6 are post-trauma (likely symptomatic) 3 are idiopathic/familial	Epilepsy – 34.8% (16 patients)
Post-infection neurological illness 6		Infection/post-infection – 28.3%* (+ 7 patients with epilepsy = 13)
Stroke (brain + 1 spinal cord infarction) 4		CVA – 8.7%. (1 patient: ? spinal cord infarction)
Paraplegia/paraparesis (of various causes) 4		
Lumbosacral/cervical spondylosis 4		
Trauma/post-traumatic illness 4		Trauma/post-trauma – 21.7% (+ 6 patients with epilepsy = 10)
Headache 2		Headache – 4.3% (2 patients)
Hereditary 2		Hereditary – 4.3% (2 patients)
Movement disorder 1		Movement disorders – 2.2% (1 patient)
Miscellaneous/undiagnosed 3		Functional – 2.2% (1 patient)
Cognitive/dementia – none		
Multiple sclerosis – none		

As previously pointed out, uncontrolled hypertension is the leading vascular risk factor. Stroke is frequently seen in younger patients who are not fully investigated, and the underlying cause is rarely identified. Alcohol- and drug abuse-related neurological disorders appear to be uncommon because such practices are illegal and socially unacceptable as well as unaffordable. Multiple sclerosis is an almost unheard-of condition.

The spectrum and presentation of neurological diseases is very different from the usual disease pattern seen by neurologists in the UK. For instance, late presentation of known neurological disorders, which tend to be seen and managed much earlier in the UK, exposes local and visiting physicians to unusual rare clinical entities and complications. The causes are multifactorial: lack of the appropriate health education necessary to drive patients to seek medical advice early, cost implications, patients' distance from medical help and safety concerns about travel to the hospital.<sup>1</sup>

Most components of a much-needed multidisciplinary team for neurological patients are lacking.<sup>6</sup> Medical staff and MAs do their best, but a wide gap remains between what is required and what is possible, given the absence of so many of the important medical sub-specialities. For instance, there is no physical, occupational or speech and language therapy. The concept of neurorehabilitation is very remote in the minds of the practising physicians, MAs and nurses. It is a real challenge for patients who need rehabilitation support, such as physiotherapy to stay mobile, occupational therapy to remain fully or partially independent, and speech and language therapy to continue communication and feeding (see Figures 3 and 4).

During this visit, 46 patients were seen from OPD clinics and inpatient neurological referrals requested by general physicians. Tables 1 and 2 highlight some important observations made on this group of patients, and a comparison with typical neurology referrals and OPD patients seen in the UK. Although it is difficult to draw

**TABLE 2** Attempts at illustrating the actual and potential differences between the available local resources in Nyala (southern Darfur) and the established neurological services in the UK (and Western Europe and the USA), by comparing the provision of neurology services, access to CT scanning and the profile of the most common neurological diseases in the two communities.

	Neurology services in the UK (and Western Europe and the USA)	Local resources in Nyala, Darfur (According to 46 patients seen)
Neurologists per population	1 for 164,000 <sup>6</sup> 1 for 177,000 <sup>7</sup>	1 for 5,009,908 for Sudan None for ~ 4,000,000 in Darfur
% of neurology patients seen by neurologists	32.6% (mostly acute admissions) <sup>8</sup>	0%
Most common neurological problems (hospitals)	CVA: 22.7–34.3% <sup>8–12</sup> Seizure/epilepsy: 10.2–26.5% <sup>8–12</sup> Headache: 4.8–17.7% <sup>8, 9, 10, 12</sup>	Epilepsy: 34.8% Infection/post-infection: 28.3% Trauma/post-trauma: 21.7% CVA: 8.7% Headache: 4.3%
Other neurological problems seen in hospitals	Cognitive/dementia: 5.3–11.7% <sup>13, 11</sup> Movement disorders: 7.1% <sup>8</sup> Functional symptoms: 4.5% <sup>10</sup> Multiple sclerosis: 2.76% <sup>8</sup> Meningitis: 2.7% (ID 39.78%) <sup>8</sup> Cognitive/dementia: 0%	Movement disorders: 2.2% Functional symptoms: 2.2% Multiple sclerosis: 0% (Estimated to be at 14.3%)
% of neurology referrals scanned	9.1% <sup>8</sup>	0%
CT scans obtained within 48 hours	62.4% (mostly stroke or TIA patients) <sup>8</sup>	Not applicable
% of functional or medically unexplained symptoms (MUS) seen in OPD	55.1–65.8% – Total functional/MUS <sup>14</sup> 47% – Anxiety and depression <sup>15</sup> 34.9% – Somatoform disorders (according to the ICD-10 and DSM-IV criteria) <sup>16</sup> 8.67% – serious suicidal ideations <sup>17</sup> Total functional: 2.2%	Anxiety and depression: 0% Somatoform disorder: 0% Serious suicidal ideation: 0%
% of patients with functional or MUS diagnosed by neurologists	50% pick-up rate (most were referred to the appropriate specialists/departments) <sup>14</sup>	Not applicable

conclusions from such a small sample of patients, the most common neurological problems are clearly epilepsy, infection and trauma related. A working diagnosis and management plan was formulated in most cases, and patients were asked to revisit treating physicians for the initiation of treatment and and follow-up.

Explanation was the only treatment required in many cases where the diagnosis had already been made by local physicians but not fully communicated to patients. This might be related to the acknowledgement by local physicians and MAs of a culture that is uncomfortable with breaking bad news to patients. It worked both ways, by giving patients hope and courage to fight disease, but also left patients with incurable neurological diseases (e.g. a patient seen with long-standing paraplegia) in complete denial waiting for a miraculous cure. A number of children and adolescents were brought to the clinic by anxious parents. Following their neurological assessment they were

given review appointments with the local paediatrician to formally decide on diagnosis and further management.

Forty-five (97%) of the 46 patients appeared to be suffering genuine neurological complaints. Only one patient, a young woman with background history and symptoms suggestive of a psychogenic illness presenting as tension headaches, was thought to have medically unexplained or functional complaints in the absence of any form of neuroimaging. It is worthy of note that these neurology consultations were free of charge, unlike the local referred clinics that charge patients relatively high fees. In 30 (70%) patients, brain or spinal imaging (CT or MRI) was indicated. This was perceived by most patients and their relatives as bad news because they could not afford to pay for the cost of obtaining these tests, which are only available in the capital, Khartoum. The costs include a 1.5-hour plane journey, accommodation and subsistence for a few days and amount to between

£380–450 per patient (double, should a relative accompany a very ill patient).<sup>8</sup> Twenty-seven percent of the patients who were referred stated that they would not be having the scans because of financial or social problems and the inconvenience of the journey.<sup>7</sup>

The financial burden on patients, their carers and families is huge because they pay for any form of treatment received from the local healthcare units. The cost of treatment, irrespective of the quality of care provided, is disproportionately high in comparison with the average income, partly because it is delivered in a hospital setting. Patients approach the hospital for almost every illness, because the primary health centres staffed by MAs (the equivalent to the UK's GP surgeries) do not cover all areas, operate for limited number of hours and are understaffed and extremely under-equipped.

### HEALTHCARE REFORMS

The future for neurological services in Darfur seems to be very grim and the way forward is rather uneven in spite of local efforts.<sup>2</sup> The only light at the end of the tunnel comes from statistics showing that some infections are on the retreat and others have been fully eradicated.<sup>1</sup> Healthcare systems are underfunded and overstretched with lack of effective statistical feedback.<sup>6</sup>

Neurology services in Nyala, Darfur and Sudan lack personnel, equipment and adequate information technology. In addition, there is no evidence-based vision, planning or inspiration to set in motion a national plan of reforms. For the neurology service in Nyala, there is a desperate need for CT scanning to complement a reasonably equipped laboratory service in helping local physicians deal with challenging health problems and addressing the neurological needs of four million people in the Darfur region. There is also a need for drawing up local clinical guidelines to govern the practice of more junior staff and those working in disadvantaged health units. The importance of the input from bodies such as the ABN and ANIG in promoting clinical neurology in rural hospitals cannot be overemphasised. However, unless local governments empower their people and their health institutions, all these bodies' efforts might possibly go unnoticed.

### CONCLUSIONS

The clinical knowledge and attitude of UK-based physicians (neurologists) benefit from visits that explore how deprived communities cope with different yet great health challenges and, in a sense, the whole question of existence. Physicians are presented with examples of tropical health problems they do not normally deal with, although these are considered regular medical challenges overseas. The skills of the visiting, as well as the local, physicians are enhanced by such unique encounters, in addition to the ethical, moral and personal lessons gained. Many of these lessons are of interest to a wider audience in the medical profession, and this is one of the purposes of this humble writing experience.

Darfur, currently suffering armed conflict on top of long-standing deprivation, is indeed an extreme and chilling example, even for the troubled tropics and deprived sub-Saharan Africa. Darfurians are living in a chronic situation of conflict, survival and fear. The raging war and deprived socioeconomic situation do not allow a health system to flourish. The hope is that, in the near future, improved security and social and economical stability will stop the decline in the population's health and enable an improvement in a sustainable health service for the ordinary people of Darfur.

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First of all, we would like to thank the people of Nyala for the hospitality, cooperation and admirable resilience they display in the face of many challenges they tackle every day. We also thank the ABN for guidance and sponsorship, the ANIG initiative for inspiring this and similar teaching as well as small research projects aimed at promoting clinical neurology in African hospitals, and UCB Pharma for funding the travel of the first author to Darfur. We sincerely thank the hosting healthcare personnel and the local authorities for approving this teaching project. This visit would not have been possible without the encouragement, enthusiasm and dedication of medical and nursing colleagues in Nyala, who displayed the utmost levels of care and organisational effort throughout the visit.

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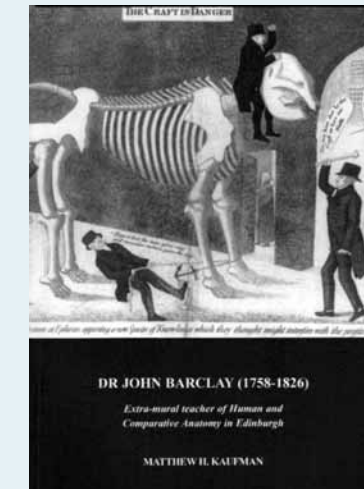
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## DR JOHN BARCLAY (1758–1826)

By Matthew H Kaufman (*The Royal College of Surgeons of Edinburgh*, 175 pp, £25)

This scholarly and authoritative account of the life and times of a great Edinburgh anatomist further enhances Professor Matthew Kaufman's reputation as a medical historian and complements his magisterial study of medical teaching in Edinburgh in the eighteenth and nineteenth centuries.

From 1797 to 1825, Dr John Barclay had his own extramural medical school in Edinburgh, at which he taught anatomy, comparative anatomy, physiology and surgery. The school was located first in High School Yards and later at 10 Surgeon's Square. Barclay was an inspiring lecturer who, through the quality of his teaching, made an important contribution to the international fame of the Edinburgh Medical School.



Professor Kaufman has produced an impressive chronicle of Barclay's career and achievements. This is more than a conventional biography, however, since it includes material of wider significance, such as the reasons for the pre-eminence of the Edinburgh Medical School in Barclay's time, the provenance of cadavers for dissection before 1832 and the evolution of rational anatomical nomenclature.

The various scientific and academic controversies in which Barclay was

involved are fully described, as are his relationships with his illustrious Edinburgh medical contemporaries and the development of his famous museum of comparative anatomy, which he bequeathed to the Royal College of Surgeons of Edinburgh.

Barclay's publications are critically assessed, in particular his magnum opus, *Life and Organisation*, in which the philosophical basis of his concept of the vital principle is expounded.

Professor Kaufman's book is not lavishly illustrated and there are no pictures in colour, but all illustrations are well chosen and reproduced.

This brief review can only convey a faint flavour of the fascinating material presented, in what has clearly been a labour of love. It is enthusiastically recommended to medical historians, to anatomists, to all who value anatomy as an intellectual discipline and to all who deplore the current status of anatomy in the undergraduate medical curriculum.

IF MacLaren