Editorial/Van die Redaksie

Gemeenskappe se prioriteite in gesondheidsdiens

Met demokratisering in die lug, en veral soos dit graag omskryf word, 'deelnemende demokrasie', is dit belangrik om die oë oop te hou vir die wyse waarop dit die tradisionele paternalisme van geneeskundige praktyk raak, veral as die behoeftes onderling grootliks verskil, en die prioriteite streeksverskille dra.

Wie neem tans besluite oor die prioriteite van bepaalde gemeenskappe se unieke behoeftes? Is die besluite wat op nasionale vlak geneem word eties regverdigbaar en ekonomies verantwoordbaar aan elke gemeenskap? Hoe bereik die plaaslike prioriteit die nasionale besluitnemers?

In Julie 1988 het die Hastings Center Report berig oor die ontstaan, vanaf ongeveer 1980, van 'besluitnemingsorganisasies in die gemeenskappe', in verskeie state in die VSA. Onlangs het Bruce Jennings[1] oor die vordering in vier state verslag gedoen. Die evolusie van ons plaaslike besture na instrumente van deelnemende demokrasie kan baat by die idee.

Die inisiële stap ('Taking Steps'-program) het gepoog om individue aan te moedig om hul behandelingsvoorkeure bekend te maak in 'n toenemend komplekse, tegnologies georiënteerde gesondheidsorgsisteem. Spesiaal opgeleide besprekingsgroepleiers het 170 vergaderings gelei wat 3 500 mense in Vermont, VSA, bereik het. Die besprekingsleiers is uit verskeie geografiese streke gewerf en het 'n twee-dag opleidingsessie ondergaan. Elke groepleier het 'n pakket met professionele artikels, informasie oor die gesondheidsorgstelsel en riglyne oor die lei van besprekingsgroepe ontvang. 'n Videoband-besprekingsinset is deur 'n professionele groep gemaak, en vraelyste het 'n meningsopname oor 'n reeks sake wat betrekking het op bv. hulpbrontoedelings uitgestuur. 'n Brosjure is gesirkuleer en 'n perskonferensie is gehou ter bekendstelling. Die vrae wat die beplanners aangespreek het, was onder meer: Wat is die etiese probleme van 'n gesondheidsorgbeleid? Hoe ontwerp mens 'n bespreking deur 'n gemeenskap waar min mense enige in-diepte begrip van die organisering en finansiering van gesondheidsorg het? Hoe vermy mens die persepsie dat 'n bepaalde politieke agenda of 'oplossing' in die spel is? Hoe voorkom 'n mens dat daar uitsluitlik op die heersende 'warm debat' in gesondheidsorg gefokus word, of dat die blaam vir die jongste gesondheidsorg-debakel die besprekings kaap? Ten slotte, hoe voer 'n mens die gesprek ten einde menings oor fundamentele, blywende en langtermyn sake in te win?

Die prioriteite het baie van streek tot streek verskil. Nogtans het dit 'n oorkoepelende indruk gelaat oor die waardesisteem van die bepaalde streek. In Oregon is *voorkoming* prominent gesteun, en ewe sterk staan *gehalte van lewe*. Die komponente, soos die Oregonners dit sien, sluit (vir die pasiënte) in verbeterde produktiwiteit, sosiale funksionering, emosionele welsyn, herstel van lewenskrag, vermindering van pyn of lyding en 'n vermoë tot selfstandige lewensonderhoud. Daar is nie 'n hoë waarde geheg aan lewensduur as 'n alleenstaande deug nie; 'n duidelik identifiseerbare element van lewens-*gehalte* is altyd as kwalifiserende aanduiding daaraan geheg. Aangesien 70% van Oregonners tersiêre opleiding geniet het en 'n derde van die huisgesinne 'n inkomste van $50 000 of meer gehad het, die helfte tussen 21 en 50 jaar oud was en 93% blankes was, het hulle probeer vasstel wat hulle gemeenskap as die *gemeenskaplik wenslike* van gesondheidsdienste beskou. Dit het uitgeloop op wetgewing in dié staat wat die toeganklikheid tot mediese dienste verbeter het deur plaaslike vereistes vir lidmaatskap van Medicaid te wysig.

Vermont weer, het op die prioriteite van gesondheidsbronnetoedeling in hulle staat gefokus, en is besig met 'n ondersoek na die prioriteite hiervoor. Hulle vertrou dat dit ook op regeringsvlak weerklank sal vind. Hulle soek in hulle streek na 'n waarde-oordeel op vrae soos die prioriteit van gesondheid teenoor ander sosiale dienste, of gesondheidsversekering alle dienste moet dek of net 'n basiese pakket, en probeer 'n rangorde van gesondheidsnorme en doelwitte opstel.

In New Jersey, verteenwoordigend van die VSA in die kleine, soos blyk uit die etnisiteit, sosiale en ekonomiese stratifikasie van die streek, blyk dit dat daar 'n sentrale tema deur al hul aktiwiteite heen loop: 'n behoefte om aan besluitneming deel te neem (waar bv. 'n koma dit sou verhoed, verkies hulle dat familie namens hulle moet besluit). 'n Middeweggroep tussen ideologiese ekstremiste skyn die dominante groep te wees, en hulle het 'n pragmatiese benadering. Persoonlike beheer, waar daar keusemoontlikhede is, geniet hoogste voorkeur. Hulle het vertroue dat die meerderheidsopinie nie 'n slagveld hoef te wees as dit om gesondheidsprioriteite gaan nie, maar wel 'n ontmoetingsveld kan wees omdat daar baie waardes in gemeen is.

Na 3 jaar het Kalifornië nou konsensus dat toegang tot basiese gesondheidsdienste, ongeag die vermoë om te betaal, die wenslike ding is. Hulle hoop om in 1991 by 'n definisie van 'basiese' of 'voldoende' gesondheidsorg uit te kom.

Ralph Crawshaw het 'n 'visie' op 'n nasionale gesondheidsbesluite-beweging vir die gemeenskap wat sal toeneem in geloofwaardigheid, diepte en mag, in die geloof dat gemeenskappe deur rede, respek, betrokkenheid en liefde bepaalde norme aanvaar. Hy hoop dat dit in alle state sal posvat. Hieruit put hy hoop dat die verwarring van 'n gesondheidsdiens (wat mense tegnies gesproke beter maak, maar slegter laat voel) opgelos sal word deur 'n funksionele, demokratiese, nasionale gesondheidsbeleid. Bruce Jennings vat dié bydraes saam: of die hervormings, wat volgens minister Sullivan wel kan plaasvind, inderdaad stuk-stuk toegepas sal word, is onseker. Maar dit is reeds aan die verander, en dit gaan eintlik oor basiese norme. Hy is oortuig dat die besluite deur die gemeenskap toon dat 'n omskakeling van die private na die openbare mening nie alleen makliker is as wat gedink word nie, maar dat dit ook (en meer dringend) deur die Amerikaanse publiek verlang word.

Die geredelike wyse waarop ons in Suid-Afrika die dikwels oppervlakkige onsinnighede van Amerikaanse kultuur aanvaar, laat 'n mens hoop dat hierdie sinvolle idees minstens ernstig oorweeg sal word nou dat plaaslike owerhede by ons tot hulle reg begin kom.

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There are other human retroviruses too — a note on myelopathy associated with HTLV-I

The retroviruses — so called because of the enzyme reverse transcriptase, which allows the transcription of viral RNA to proviral DNA — have long been known to cause disease in animals.[1] Tthe advent of the 1980s saw the isolation of the first human retrovirus — human t-cell lymphotropic virus type I (HTLV-I) — from a patient with adult T-cell leukaemia (ATL).[2] There followed the discovery of the other human retroviruses, viz. HTLV-II, which has been linked to hairy-cell leukaemia, and HIV, the cause of acquired immunodeficiency syndrome (AIDS).

The next milestone was the serendipitous finding of antibodies to HTLV-I in the serum of two patients with tropical spastic paraparesis (TSP),[3] a disorder that has been an enigma to neurologists working in several parts of the world, including Natal, South Africa.[4] The association of TSP with antibodies to HTLV-I was soon confirmed by workers in the Caribbean,[5] South America,[6] the Seychelles[7] and Africa.[8] Sporadic cases have been reported from the USA, Europe, Canada and Chile.

In 1987 Osame *et al.*[9] described a similar association among the Japanese, and called it HTLV-I-associated myelopathy (HAM). The condition is now generally referred to as HAM/TSP. Osame and his colleagues[10] also showed that the viruses found in ATL and HAM/TSP are identical.

HTLV-I is transmitted through sexual intercourse, blood transfusion and intravenous drug abuse and from mother to child. However, transmission is not as efficient as that of HIV. Males spread the virus more effectively than females, and hence both seropositivity and disease are more common in women. Mother-to-child transmission is thought to be through breast-milk. This has serious implications in Third-World countries when control measures are considered.

The clinical features of HAM/TSP consist of gradual onset of spasticity and weakness of the legs, frequent sphincter dysfunction and mild or insignificant sensory disturbance. Upper limb tendon reflexes are brisk in about half the patients. The mental state and cranial nerves are usually spared. Antibodies to HTLV-I are detected in the cerebrospinal fluid (CSF) of most patients. The virus has been isolated from both the peripheral blood and the CSF of HAM/TSP patients.

Although the association between the virus and the myelopathy has been firmly established, two major problems remain unresolved. Firstly, only a small proportion (1 in 2000 - 3000) of seropositive individuals develop the disease.[11] This must be viewed against the background of carrier rates as high as 30% in some areas.[12] Secondly, the pathogenesis of spinal cord damage is unknown.

Both host and viral factors probably play a role in the development of disease, but how they do so is unclear. Usuku *et al.*[13] found HLA haplotypes that were specific for their HAM/TSP patients and absent in their patients with ATL. Our data failed to demonstrate such a convincing association of HLA predisposition (Bhigjee *et al.* — unpublished), and Kawai *et al.*[14] showed that HAM/TSP-associated haplotypes did not prevent the development of ATL. Other host genetic factors may yet be important. For example, viral replication is increased in HAM/TSP patients when compared with asymptomatic HTLV-I carriers.[15,16] There is experimental evidence that a host nuclear factor may be important in the regulation of HTLV-I gene expression.[17] HAM/TSP patients also show higher antibody levels[11] and greater lymphocyte proliferation[13] than healthy carriers or ATL patients.

Virological aspects to consider in the development of disease after exposure include viral strain, neurotropism, viral load and mode of transmission. As already mentioned, strains isolated from HAM/TSP and ATL patients are identical on DNA blotting.[10] However, minor differences have been noted in the restriction maps[18] and effects on T-cell function[19] when HAM/TSP isolates are compared with the HTLV-I prototype. The relevance of these observations awaits elucidation. The latency from infection to disease is shorter and the disease more aggressive when transmission is by blood transfusion.[11] This probably reflects the higher viral load as well as the immunosuppressive effect of blood transfusion.[20] Although not proven, transfusion, as opposed to the other modes of transmission, may serve as an enhanced risk factor in the development of myelopathy.

The pathogenesis of neurological injury is undefined. Evidence of damage to other parts of the nervous system can be found clinically, pathologically or by imaging, but the brunt is borne by the spinal cord. The peculiar susceptibility of the cord is unexplained but has been noted in other non-human retroviral infections such as visna-maedi in sheep.[21]

The evidence for direct viral-induced injury is limited. Liberski *et al.*[22] reported the presence of virus-like particles in the spinal cord of a TSP patient, but preservation was suboptimal. There is some *in vitro* evidence that HTLV-I can infect glial cells, although the number of cells that became infected following exposure was small.[23] Wayne Moore *et al.*[24] demonstrated the presence of HTLV-I p19 core protein in mononuclear and glial cells in a TSP spinal cord using immunocytochemical methods, but cross-reaction with control tissue has also been observed.

We have not demonstrated either viral proteins using a panel of monoclonal antibodies, or viral nucleic acids using *in situ* hybridisation. However, we have detected proviral DNA in the spinal cord using gene amplification techniques (Bhigjee *et al.* — unpublished data). Also the persistence of IgM anti-HTLV-I antibodies in the CSF of some patients for several years after the onset of disease suggests ongoing viral replication and the presence of new viral antigens.[25]

In contrast, there is accumulating evidence that much of the injury is immune-mediated. The histological findings have been compared to those seen in acute disseminated encephalomyelitis.[26] The presence of activated T cells,[27] antigen-specific oligoclonal bands in the CSF,[28] increased expression of interleukin-2 receptor molecules[25] and response to steroids[11] provide support for an immune-based pathogenesis. The presence of predominant CD8+ T cells within the spinal cord[24] and the demonstration of high levels of circulating CD8+, HTLV-I-specific, cytotoxic T lymphocytes in HAM/TSP patients[29] suggest a role for cell-mediated neurological damage.

To summarise, the current evidence suggests that in susceptible individuals, the virus triggers an immune response directed against neural tissue. This is a rather simplistic assessment, and much further work is necessary before the pathogenesis of HAM/TSP is fully understood.

At a broader level, the association of HTLV-I with TSP represents an exciting chapter in neurological research and could form a springboard for the elucidation of other unexplained neurological disorders. While HIV correctly occupies centre stage in many minds, it must be remembered that there are other human retroviruses too . . .

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Is there a need for surgical oncologists in South Africa?

In the early history of cancer care the surgeon dominated the field. Some surgeons even made significant contributions in the early development of chemotherapeutic and hormonal management of patients with cancer, while some even were involved in administering radiation therapy.

With the increase in knowledge about cellular biology and radiophysics and the availability of more effective sophisticated high-voltage equipment and, coincidentally, more complex regimens using multi-agent chemotherapy, both radiation oncologists and medical oncologists established their own training programmes and specialties.

In 1990 the South African Medical and Dental Council recognised medical oncology as a subspecialty within the specialty of internal medicine.

The role of the surgeon as the leader in the care of the cancer patient has thus steadily diminished since the early 1960s. Surgeons began to concentrate their efforts in other areas when it became clear that more radical operations were not resulting in higher cure rates. The newly trained general surgeon often was not fully informed as to the current approach to the care of the cancer patient.

Concerns over these trends are leading world-wide to concerted efforts to train surgeons with a specific philosophy and expertise in the methods of cancer care. Training programmes tailored specifically for general surgeons are being established in several of the major cancer centres. The trainee surgeon rotates through pathology, medical oncology and radiotherapy services. In this way a close rapport develops with these specialists in addition to an understanding of alternative methods of therapy. The surgeon gains an intimate knowledge of the biological behaviour and natural history of tumours and is exposed to new developments in cancer detection, diagnosis, treatment and rehabilitation. This experience enables surgeons to become important members of the multidisciplinary team at tumour clinics and pretreatment conferences.

It is very difficult to define a surgical oncologist. A good general definition describes the surgical oncologist as a well-qualified general surgeon who has had additional training and experience in the multidisciplinary approach for the prevention, diagnosis and treatment of cancer and rehabilitation of the patient, and then devotes a major portion of his professional work to this activity.

There are those who argue that it is not possible for a so-called surgical oncologist to perform all cancer surgery and that members of the surgical subspecialties trained in the fundamentals of cancer surgery in their specific field of activity are far more competent to perform the standard excisional procedures pertaining to their subspecialties. While immediately accepting this premise, I would like to emphasise that the surgical oncologist has a broader role. The academic surgical oncologist should not only have clinical expertise but also the exposure and the training to plan and implement innovative and meaningful clinical and laboratory research and to join multidisciplinary teams with the aim of improving patient care.

The Society of Surgical Oncology in the USA, previously known as the James Ewing Society, has instituted 2-year surgical oncology training programmes.[1] The surgical oncology fellowship encompasses a minimum of 2 years' continuous training following completion of training in general surgery. At least 18 months are devoted to clinical training. The 2 years can include a period of rotation on non-surgical oncology services and might include time devoted to clinical or laboratory research.

During the course of surgical oncology training there should be adequate opportunity for interaction with companion surgical specialties in the overall management of cancer patients. This will best be accomplished by formal rotation on the services, participation in structured multidisciplinary conferences, and joint attendance in specialty tumour clinics. Outpatient management and follow-up of cancer patients is crucial to the training experience. The ultimate objective is to qualify the surgical oncology trainee to participate appropriately in multidisciplinary and interdepartmental tumour programmes.

It is not envisaged that training in surgical oncology should conflict in any way with the regular training programmes in general surgery. Neither is it intended to compete against general surgeons or surgeons of the subspecialties who will continue to manage the majority of cancer cases. Surgical oncology training is aimed at developing a focus of excellence in the treatment of complicated cancer cases and participation in multidisciplinary cancer management teams.

Multidisciplinary management of difficult cancer problems by properly trained and thoroughly informed medical, surgical and radiotherapeutic members of a team can only be for the good of the patient.

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