

SETTING UP CHRONIC DISEASE PROGRAMS: PERSPECTIVES FROM ABORIGINAL AUSTRALIA

Objective: To share some perspectives on setting up programs to improve management of hypertension, renal disease, and diabetes in high-risk populations, derived from experience in remote Australian Aboriginal settings.

Principles: Regular integrated checks for chronic disease and their risk factors and appropriate treatment are essential elements of regular adult health care. Programs should be run by local health workers, following algorithms for testing and treatment, with back up from nurses. Constant evaluation is essential.

Components: These include testing, treatment, education for individuals and communities, skills and career development for staff, ongoing evaluation, program modification, and advocacy. Target groups, elements, and frequency of testing, as well as the reagents and treatment modalities must be designed for local circumstances, which include disease burden and impact, competing priorities, and available resources. Pilot surveys or record reviews can define target groups and conditions. Opportunistic testing will suffice if people are seen with some regularity for other conditions; otherwise, systematic screening is needed, preferably embedded in primary care streams. The chief goal of treatment is to lower blood pressure, and if the patient is diabetic, to control hyperglycemia. Many people will need multiple drugs for many years.

Challenges: Challenges include lack of resources, competing demands of acute care, the burden of treatment when disease rates are high, problems with information systems, and in our setting, health worker absenteeism.

Funding: Businesses, altruistic organizations, and pharmaceutical and biotechnology companies might fund feasibility studies. Where governments or insurance companies already support health services, they must ultimately commit to chronic disease services over the long term. Effective advocacy requires the presentation of an integrated view of chronic disease and a single cross-disciplinary program for its containment. Arguments based on preserving the economic base of societies by preventing or delaying premature death will carry most weight, as will the costs of dialysis avoided in countries that already support open-access programs. (*Ethn Dis.* 2006;16 [suppl 2]:S2-73-S2-78)

Key Words: Australian Aborigines, Chronic Diseases, Renal Disease, Hypertension, Diabetes, Cardiovascular Disease, Detection and Prevention Programs

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BACKGROUND

Control of emerging chronic diseases is important for many minority populations and developing countries and is critical for those also facing excess illness and death from other causes.¹⁻⁴ The Western world has much to learn as such programs are developed.

An epidemic of hypertension, diabetes, renal disease, and cardiovascular disease appeared among Aboriginal people in Australia in the early 1980s. Those living in remote areas are most severely afflicted. Nationwide, age-standardized death rates are 2 to 3 times those of non-Aboriginal Australians, and entry into renal replacement programs is elevated ≈ 10 times, but in some remote regions deaths are increased six-fold, and the annual incidence of treated end stage renal disease varies from 1500 to >3000 per million.⁵⁻⁹ Renal disease, hypertension, diabetes, and cardiovascular disease are intimately related in this environment.¹⁰⁻¹⁴ Among the evolving mix of factors contributing to this epidemic are changing lifestyle under conditions of serious socioeconomic disadvantage,¹⁵ improved survival of low birthweight infants in the last 40 years,^{16,17} and

reduced competing deaths from other causes.¹⁸

In Australia, tertiary care for Aboriginal people (hospital care, complex procedures, renal replacement therapy) is of a reasonable standard. However primary healthcare services, which rely on a complex and sometimes inscrutable mix of federal, state, and territory funding and with a wide range of operational models, have been underfunded, chaotic, and woefully insufficient. Deficiencies in chronic disease management have been particularly severe because of belated recognition of the problem, a failure of the medical community to articulate solutions, lack of national leadership, and for the one third of Aboriginal people who live in very remote areas, the tyranny of distance. Distance imposes extra costs and delays, impairs access to services and information, weighs against professional and political advocacy, and causes high turnover of non-Aboriginal staff.

In the last 10-12 years, however, information has been accruing. Regional patterns of hospitalizations, renal failure, and deaths have been defined.⁶ Dialysis is now, overwhelmingly, the single most common hospital procedure for Aboriginal people, and the costs of maintaining individuals on this treatment have been assessed.¹⁹ Surveys of chronic disease have been performed in several regions,^{10,11,13,20-26} and various guidelines have been formulated for its containment.^{10,27-30} The sensitivity of blood pressure to good treatment is clear.^{10,31} Better diabetes care has reduced hospitalizations of people in the Torres Strait.³² Renal and non-renal deaths fell in one community with a systematic screening and treatment

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approach,³¹ with dramatic savings in dialysis avoided,³³ and renal deaths rapidly resurged after the intensity of the intervention program decreased.³⁴

We conducted a chronic disease program in four remote communities in the Northern Territory. Their populations ranged from 480 to ≈1800 people, and 67% to almost 100% of adults (≥18 years of age) participated ($N=2009$). Only two of these communities had a resident doctor at any stage during this work. Experiences in this program have been described elsewhere.^{10,11,14} In summary, we found that chronic disease rates were excessive in all areas but differed by community. People were interested in chronic disease issues and keen to participate and learn. Health workers grasped principles and procedures quickly. Plenty of new diagnoses were made by testing. Many people required institution or increase in medicines, and sensitivity of blood pressure to treatment was confirmed.

PRINCIPLES

Testing for all locally important and treatable chronic diseases should be offered to high-risk people at intervals throughout life, and treatment of people who need it should follow. Local health workers or trained community liaisons can conduct the work, following protocols for testing and treatment. Programs should include education for staff, participants, and community and give input into modalities of primary prevention. Ongoing evaluation of processes, outcomes, and costs is essential. Programs must be modified as information accrues, seeking better approaches and responding to an environment of changing risk factors. Accrued information should inform arguments for advocacy and needs-based health services planning.¹⁰

Target groups, tests, and medicines will vary with local conditions and can become more expansive as time and

resources allow and preliminary results accrue. Details of programs in developing countries will necessarily differ from those in Westernized countries.

TESTING

Considerations

The setting of chronic disease activities, target groups, elements of testing, reagents, frequency of testing, and the nature and intensity of treatment all have serious implications for staffing and costs. They must be designed for local realities, which include disease burden and impact, competing priorities, and available resources.

Hospital records and mortality data can help establish regional disease priorities. Estimates of community-based disease burdens can be based on impressions of healthcare providers and reviews of existing medical records and through pilot screening programs.

Setting

Chronic disease activities should be embedded in primary health care. Most Aboriginal health services now incorporate these activities in standard care plans. Where no primary healthcare streams exist, chronic disease activity could be the nucleus around which the people develop.

Chronic disease checks can also occur opportunistically, if most adults have a healthcare encounter at least once every few years. This often undersamples males, especially young males. Testing of adults when their children receive healthcare services is one possibility. Without additional staff, opportunistic testing will not occur consistently in services that are already stretched or are overwhelmed with acute care. The physical setting can be flexible and include clinic buildings, women's centers, community halls, work sites, homes, a mobile unit, or a more rudimentary car, truck, or van.

Target Groups

Current programs in remote Aboriginal communities involve testing of all consenting adults. This is based on the high rates of renal and cardiovascular deaths; the lack of knowledge of individual community profiles, aside from those cited; and the fact that proteinuria, in some groups at least, is not restricted to people with hypertension, overweight, diabetes, or infections. Testing could ultimately become more focused, as we analyze more community profiles and can identify high-risk people through the predictive value of factors like age, sex, past history, family history, and current weight.

In other settings, if most illnesses are largely segregated in middle-aged or elderly people or in overweight or obese people, chronic disease surveillance can be focused on these groups. If chronic renal disease occurs mostly in the context of hypertension, or diabetes, then urine protein testing might be reserved for those people. Similarly, if diabetes occurs mostly in the context of overweight, then testing of blood glucose might be reserved for overweight or obese people.

Success depends on the willingness of people to participate and what they hear through community networks. They appreciate a collaborative, rather than an authoritative, approach, dignified encounters with a same-sex health worker, participation in testing (eg, recording their results), and flexibility in site of testing. We also use the occasion for education and personalization of health goals.

Elements of Testing

The minimal elements of testing will vary depending on local circumstances. Tests we perform in remote tropical Aboriginal Australia are shown in Table 1. The usual coexistence of illnesses^{10,11,12,14} dictates integrated screening, which we now suggest should include testing for hypertension, renal disease, diabetes, cardiovascular risk,

Table 1. Regular Check Up: Chronic Disease Outreach Program

Minimal elements

- Chart review: Existing diagnoses, parity, contraception, medicines, etc
1. History: smoking, drinking, drugs, existing diagnoses, menstruating?
 2. Weight, height (once), waist
 3. Blood pressure
 4. Skin exam for sores, scabies, fungus
 5. Urine dipstick for protein, blood, nitrites, leukocytes
 6. Capillary fingerstick for hemoglobin
 7. Capillary fingerstick for random glucose

Some common additional tests according to algorithms

- Repeat urine if apparently contaminated
- Urine culture is apparently infected
- Urine ACR if dipstick 1+; if diabetic, hypertensive, or history of proteinuria
- Fasting glucose if random glucose suspicious
- HbA1c if diabetic
- Full blood count if anemic
- Serum creatinine if overt albuminuria (ACR 34+)
- Electrolytes if considering ACEI, ARB
- Lipids sometimes

In addition

- Involve the participant
- Maximize on-site testing
- Immediate feedback and education
- Personalize health goals
- Start treatment on first visit if needed/possible

and chronic lung disease. Diabetes is the least common condition among the metabolic/vascular/renal conditions in this environment and occurs significantly later than hypertension and proteinuria, which underlines the weakness of a diabetes-centric screening approach.

Labor is the main budget item for primary healthcare activities in Western countries, but the cost of urine dipsticks, urine albumin-to-creatinine ratio (ACR) assays, blood glucose tests, and Hb A1C tests are major impediments in some developing countries. These tests need not be widely applied if people are prioritized according to likely risk or where more modest tests suffice (such as urine tests for protein by sulfosalicylic acid, or Benedict's urine tests for glucose). In Australia, this team does not recommend a urine ACR or a serum creatinine for people with normal blood pressures, without diabetes and without urine protein by dipstick. All universally applied tests can be done at the point of care (POC), with immediate feedback to participants who have normal results. This avoids specimen preparation, stor-

age, and transportation by air to distant laboratories, as well as later work and attendant costs in filing results and recalling participants. POC technology has also performed well in measurement of urine ACR and Hb A1C levels³⁵ and can be applied to assays of blood levels of creatinine and lipids. However, developing countries need not try to emulate these first-world luxuries, especially where much florid disease is undetected and untreated, and triage systems and simpler tests can be applied.

Other items that might be included in a chronic disease visit will depend on regional health profiles. In the remote Aboriginal setting they can include immunizations, antihelminthic treatment, cancer checks, and surveillance for sexually transmitted diseases and tuberculosis. The visit should also include advice about health behaviors, alcohol use, smoking, family planning, nutrition, and available social services.

Frequency of Testing

The increase in prevalence of illnesses with increasing age^{10,11,14,18} dic-

tates that chronic disease testing be repeated throughout life. The optimum frequency of such testing, which would avoid excessive use of resources but detect newly appearing illnesses reasonably early, has not yet been defined, but cross-sectional profiles and accruing incidence data from longitudinal studies might soon inform this issue. Testing of high-risk individuals every one or two years might be appropriate, while testing every five years might suffice for young adults with previously normal results and no interim untoward events.

TREATMENT

Whom to Treat

Target conditions will vary. In regions with large burdens of florid and untreated disease, programs might have higher threshold levels for treatment of blood pressure and will probably not test for, or treat, microalbuminuria in otherwise unaffected people. Where measurement of lipids is not routine, some qualifying people will not be recognized or treated.

Medicines

Choices for medicines to treat hypertension, renal disease, hyperglycemia, dyslipidemia, and cardiovascular risk depend on availability, affordability, side effect profile, efficacy, and ease of administration. We can only comment on Western medicines, but many herbal remedies, especially those for lowering blood pressure, might have important roles.³⁶ For renal and cardiovascular disease prevention, the primary objective is to control blood pressure. Target blood pressures give something to aim for,³⁷ but any blood pressure reduction reduces stroke, ischemic heart disease, and renal failure.³⁸ Control of blood glucose in diabetics adds benefit.

In Australia, we use renin-angiotensin system (RAS) blockade (angiotensin-converting enzyme inhibitors [ACEI] or

angiotensin-receptor blockers [ARB]) as first-line treatment for hypertension and renal disease. The antihypertensive, renoprotective, and cardiovascular-sparing effects, as well as their protective effects against diabetes and dyslipidemia^{39,40} make them ideal agents; their major drawbacks are contraindication in potentially fertile women and, for ACEI, the occasional irritating cough. Additional antihypertensive therapy, as well as hypoglycemic and lipid-lowering therapy, aspirin, and beta blockers, will be needed in many people.

Long acting, once-a-day medicines are preferred, where available. Health workers can start treatment immediately upon diagnosis, with swift upward titration of dose and prompt introduction of additional medicines and combined ACEI/ARB treatment for resistant blood pressure or heavy proteinuria.^{41,42} We recommend universal treatment of diabetics with ACEI/ARB in this setting,⁴³ as almost all qualify by Heart Outcomes Prevention Evaluation study criteria.^{44,45}

The young age at diagnosis in Aboriginal people anticipates many years of treatment. In the Northern Territory communities, screening data predicted >34 years of treatment for afflicted individuals to aspire to a life span of 75 years (still less than the non-Aboriginal Australian life expectancy). Most will be on multiple drugs by midlife, as >80% of people age ≥55 years have more than one illness. Health services must plan for this lifelong undertaking.

There is a pressing need for innovations in this area, which might include a range of "poly pills,"⁴⁶ containing therapeutic doses of several agents for people with established disorders, and development of transdermal drug delivery systems (creams, patches or possibly implants). Consideration might also be given to primary pharmacologic prophylaxis for people not yet affected.⁴⁷ Proper treatment imposes a large burden on health services in communi-

ties with high rates of disease, and they need to be resourced accordingly.^{10,11}

CHALLENGES

Challenges we have encountered included lack of resources, competing demands of urgent care, weary doctors, high turnover of non-Aboriginal staff, and overburdening of the program by treatment needs.^{10,11}

Lack of health workers and absenteeism were disabling elements for all clinic activities. Health workers are the crux of chronic disease programs in this setting: they have the community connections to encourage participation, are geographically stable, develop the best view of what works, and can quickly acquire organizational, clinical, and computer skills. Why are they underperforming? Historically they have been relegated to second-class roles, feel lectured and hectored, are often pulled into emergency coverage, can be blamed for poor outcomes, are sometimes not paid properly, and can be stressed by family and community responsibilities. Many are retiring now, and fewer trainees are graduating because, in part, literacy and numeracy are reduced since remote education was secularized. The situation might improve if health workers were accorded meaningful roles, responsibility, authority, and respect and given clear instructions, proper backup, equitable pay, and some flexibility in scheduling. Multistaffing is also essential so they do not have to violate skin group, relationship, or gender barriers in caring for participants and so that leave and other absences can be covered. Because so few health workers are available, chronic disease care has to become routine business for them all.

Other potential pitfalls include screening that is not followed by treatment, suboptimal treatment, excessive frequency of screening, screening not repeated throughout life, lack of tracking mechanisms, and program

attrition as enthusiastic advocates step aside and other priorities are declared or resources dwindle. These will always threaten until chronic disease management is as entrenched in adult health care as growth surveillance and immunizations are entrenched in child health care today.

Another potential pitfall is overmedicalization of the program. Even if enough resources or doctors or nurses were available to serve remote areas, asking them to routinely conduct chronic disease activities is inappropriate and wasteful. Their role should be to support health workers, deal with unusual cases or difficult decisions, articulate problems, propose solutions, evaluate trends and outcomes, design better approaches, and work on prevention and advocacy.

INFORMATION SYSTEMS

Programs must be tracked from every perspective. These include program implementation, participation, uptake, community attitudes, clinical indicators, tests ordered, medication used, individual and community health profiles, evolution of clinical parameters, costs, and outcomes like hospitalizations, renal failure, and death. Tracking is the only way to evaluate suitability of programs and the need for changes and to support arguments for advocacy. We used a web-based program that integrates clinical and laboratory findings and allows immediate interaction and decision-making from multiple geographic sites.⁴⁸

Mechanisms of tracking can change over time, moving from paper records to local software or public domain software. Funds for ongoing analysis should be incorporated into every program budget. In these early years, information on databases and analytic assistance could be sought through agencies such as the International Society for Nephrology's Commission for

the Global Advancement of Nephrology Research Committee, who have also formulated an approach to early diagnosis and prevention.^{4,48}

FINDING RESOURCES AND PERSUADING GOVERNMENTS

Find your funders and partners wherever you can to get programs launched. They might include employers, altruistic organizations, and pharmaceutical and biotechnology companies. However, where governments already support health services, they must ultimately commit to such programs. Members of government might be already sensitized by health events in their personal life, family, or professional circles but they will be most receptive to arguments based on supporting the economic base of their societies through reduction in deaths and disability of people in the prime of life. This will be critical in some places facing a "quadruple burden" of diseases causing premature death and disability: pretransitional diseases, emerging chronic diseases, injuries, and HIV/AIDS.³ Savings from reduced hospitalizations and disability can be emphasized,^{32,33} and the prospect of containing costs of renal replacement therapy should be attractive to governments that support open access for this service.^{10,14,33,49}

In approaches to government, be positive and propose solutions. Give an integrated view of chronic disease across disciplines (primary care, public health, diabetes, hypertension, cardiovascular, renal, chronic lung disease), and avoid separate advocacy by multiple groups for individual programs. Show how success can be measured, over one or two political cycles, as well as over the long term. Finally show how favorable exposure can be gained from the processes and outcomes.

Australia gets a mixed report for its achievements in the last decade. Chronic disease awareness, particularly in

indigenous people, has improved. Kidney Health Australia, the National Heart Foundation, the Stroke Foundation, and Diabetes Australia are collaborating to integrate policies under the Chronic Disease Alliance. Most standard care guidelines for indigenous adults now include chronic disease care,²⁷⁻³⁰ there is a push to improve information technology, and excellent sources of information are available.^{7,30} Access to medications has been facilitated, and new funding mechanisms are being evaluated. Resources, however, remain inadequate, are not indexed to need, and reimbursements are chiefly focused on services rendered by doctors, although many communities have no resident doctors. No standard approaches to policies and services exist across states, regions, and communities. Finally, Australia has no ultimate system of accountability for policies, processes, or outcomes in indigenous health.

ACKNOWLEDGMENTS

Our observations and perspectives were derived from projects approved by human research ethics committee of the Northern Territories Department of Health and Human Services and the Menzies School of Health Research and by the relevant local councils/health boards. Approvals were also received from the human research ethics committee of the University of Queensland where relevant. We thank the Colonial Foundation, Rio Tinto, Kidney Health Australia, Servier, Australia, Helen Hayes, and the Office of Aboriginal and Torres Strait Islander Health for their support. We are grateful to all the residents in these remote communities and their councils for their support and participation. We also thank the health workers, nursing staff, and the medical officers working in these communities.

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