

Treatment

Report of the Treatment Expert
Working Group to the New Zealand
Cancer Control Steering Group

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Citation: Ministry of Health. 2003. *Treatment: Report of the Treatment Expert Working Group to the New Zealand Cancer Control Steering Group*. Wellington: Ministry of Health.

Published in September 2003 by the Ministry of Health
PO Box 5013, Wellington, New Zealand

ISBN 0-478-25681-7 (Website)
HP 3672

This document is available on the Ministry of Health's website at
<http://www.moh.govt.nz/cancercontrol> and on the New Zealand Cancer Control
Trust website at <http://www.cancercontrol.org.nz>



MANATŪ HAUORA

Members of the Treatment Expert Working Group

Assoc Prof John Collins (Chair), Surgeon, Middlemore Hospital, Auckland

Jane Lyon (Co-ordinator), Senior Analyst, Clinical Services, Ministry of Health

Dr John Childs, Oncologist, Auckland Hospital, Auckland District Health Board

Dr Robin Corbett, Paediatric Oncologist, Christchurch Hospital

Assoc Prof Vernon Harvey, Medical Oncologist, Auckland Hospital, Auckland District Health Board

Prof Brett Delahunt, Head, Department of Pathology, Wellington School of Medicine

Natalie James, Clinical Nurse Specialist, Wellington Cancer Centre, Wellington Hospital

Colleen Winera, Director Māori Health, Capital and Coast District Health Board, Wellington

John Booth, Consumer Advisor, Auckland

Dr Juliet Walker, Auckland

Dr Hilary Blacklock, Haematologist, Middlemore Hospital

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Introduction

The Treatment Expert Working Group commenced its task at a full-day face-to-face meeting where a wide range of issues relevant to the treatment of cancer were discussed. The Group was familiar with the content of the recent report *Improving Non-surgical Cancer Treatment Services in New Zealand* and aware that the Health Funding Authority had already reviewed paediatric oncology.

The Ministry of Health had also announced its intention to review Surgical Cancer Services with the Royal Australasian College of Surgeons (RACS). The possibility of overlap was carefully considered but the Group believed it was important to re-state some priority actions such as workforce issues and adolescent cancer as well as exploring some of those (ie, multidisciplinary clinics and specialised treatment units) which will be considered in depth by the RACS. Potential Candidate Priority Actions were identified and members undertook responsibility for researching these further as well as developing draft reports. These drafts were further discussed by teleconference on three occasions. Ten Candidate Priority Actions were finally agreed upon and form the basis of this report.

Candidate Priority Actions

1. To improve the efficiency of cancer reporting in New Zealand.
2. To focus research across the spectrum of cancer control.
3. To develop a co-ordinated National Cancer Care Workforce Strategy.
4. Cancer patients should have access to the best available treatment technologies, surgery and drugs.
5. All treatment providers should follow defined standards of integrated care for the management of cancer patients.
6. To improve the quality of care delivered to adolescents diagnosed with cancer and their families/whānau.
7. The integration of conventional and complementary care for cancer patients.
8. The empowering of patients through:
 - a) promoting a patient-centred approach to care
 - b) ensuring that all cancer treatment providers follow principles of patient-centred and co-ordinated care.
9. The improvement of cancer treatment for Māori.
10. The development of treatment guidelines.

This report is the outcome of a significant amount of work by the Treatment Expert Working Group and their time and commitment is sincerely acknowledged.

Candidate Priority Action 1: To improve the efficiency of cancer reporting in New Zealand

Introduction

This proposal advocates improving the efficiency of cancer reporting in New Zealand by ensuring that the resources available to the New Zealand Cancer Registry are sufficient to meet the reporting requirements of the New Zealand Cancer Control Strategy. It would require the collection and provision of timely information regarding temporal, ethnic and geographic variations in the incidence of specific forms of malignancy. Such improvements would facilitate timely identification of variations of cancer incidence within the population and provide evidence to account for these trends.

Background

The Cancer Registry was established in 1948 and since 1974 has been population based. The Registry forms part of the Health Information Service within the Ministry of Health. According to the requirements of the Cancer Registry Act 1993 all diagnoses of cancer (excluding common skin malignancies) are to be reported to the Registry by the laboratory responsible for the diagnosis. Survival information is abstracted by Registry staff who review death certificates and autopsy reports. Registry staff are also responsible for the interpretation of clinical information and although they are well trained within their professional areas, there is only limited input from qualified medical staff consultants on an honorary basis.

The current practice is for the hard copy laboratory report to be forwarded to the Registry and for staff to abstract relevant information that is entered on the Registry database. This is a time-consuming and inefficient process and plans are in hand to establish a computer link to source laboratories. The data transfer process is further complicated by the incompleteness of data contained in the laboratory report that often does not include sufficient details to allow accurate tumour staging.

Private laboratories provide histology reports to the Registry, however patient information obtained from the majority of private hospitals is frequently limited to that provided in the discharge summary and may contain insufficient clinical diagnostic or staging details. It is estimated that in excess of 95 percent of cancers are reported to the Registry and no formal audit of cancer registrations has been undertaken. Therefore the true cancer accrual rate is uncertain.

Recommendations

- Reorganise the Cancer Registry as a unit under the direct control of the body responsible for the implementation of the cancer control strategy in New Zealand.
- Ensure that the Registry is provided with adequate resources to appoint epidemiological and clinical health professionals who are able to co-ordinate data collection and analysis.
- Promote the development of synoptic reporting by pathology laboratories in order to streamline data transfer.
- Develop facilities to permit electronic transfer of data from source pathology laboratories to the Registry.
- Establish regional centres to permit abstraction of accurate and complete data from hospital records and undertake detailed audit of entries.
- Establish electronic reporting of standardised management and outcome data from oncology and haematology treatment centres. Online reporting could also be set up to permit oncology staff access to relevant collated data.
- Modify the current minimum data set recorded by the Registry to permit collection of additional relevant data. This should include data on stage of the disease at diagnosis; maximum primary tumour diameter; date of treatment; treatment modality, target, intent, dosages and duration; patient status at end of treatment; recurrence interval.
- Establish facilities and resources to permit electronic reporting of full clinical/pathological data from private hospitals.

Conclusion

At present there is incomplete accession of clinical data relevant to cancer control. A minimum data set is collected for all patients while an enhanced set is recorded for malignancies identified as having particular significance to the community. Detailed reporting of all malignancies with the addition of staging information, treatment modality and treatment outcome fields would enhance detection of changes in tumour demographics. It would also facilitate studies on prognosis assessment and optimal management of malignancies.

The transfer of management of the Registry from the Ministry of Health to a newly established cancer control organisation would require specific legislation. Additional resources for the Registry should be the responsibility of the Ministry of Health while the establishment of regional reporting/audit units should be funded at District Health Board level.

Candidate Priority Action 2: To focus research across the spectrum of cancer control

Introduction

Research can contribute to cancer control in any situation where detailed knowledge is lacking. The dramatic differences from Australia in the incidence and mortality for lung and breast cancer in females and in colorectal cancer in both sexes (Skegg and McCredie 2002) identify a priority for research into the reasons why over 600 more females and over 200 more males die per year in New Zealand than in Australia. The saving of life would be very substantial indeed if the factors responsible for these survival differences were identified and their elimination became priority actions in the strategy. This demonstrates the potential for research-based cancer control initiatives.

Similarly, comparative epidemiological studies of breast cancer show widely different incidence rates in different countries and cultures, but precisely what factors are responsible for these differences remains unknown. Further epidemiological research is needed into the causes of breast cancer. By contrast, it has been known for 50 years that cigarette smoking is a dominant cause of lung cancer. Behavioural research is needed into strategies able to more effectively alter lifestyle patterns.

A commitment to build and sustain a strong foundation for research is vital for effective cancer control. Furthermore, a strong research culture is required to permit any cancer control strategy to respond to new knowledge and technology. Research is thus essential for the national strategy to evolve and continuously improve (Canadian Strategy for Cancer Control).

The requirement for clinical research

Cancer health professionals have expressed concern that there is insufficient clinically relevant research related to cancer in New Zealand (Clinical Oncology Group, letter dated 30 April 2002).

Cancer Society review of research

The Cancer Society of New Zealand periodically reviews the current state of cancer research in New Zealand and the most recent review was undertaken in 2000 (Coates et al 2000). The group viewed basic research, treatment and prevention of cancer as incremental and interdependent processes. They recommended that support of the existing national strength in molecular biology should remain at the core of the Society's portfolio of project grants but, to combat cancer, the Society must nurture the continuum of research from molecular and cellular investigations, to clinical and psychosocial aspects of cancer, and to public health interventions for cancer prevention and control. The Society was encouraged to strive, over the course of the following two or three years, to broaden its portfolio of project grants to include research which falls broadly across the entire spectrum of cancer control.

Research objectives in overseas strategies

Canada

The research working party for the Canadian Cancer Control Strategy recommended:

1. increasing research funding to position Canada as a leader in cancer control
2. aggressively addressing the human resource crisis in cancer research to improve career structures and recruitment and retention of staff
3. fostering funding mechanisms to promote primary breakthroughs and interdisciplinary research
4. championing national priorities for cancer control research
5. establishing a national information resource for data collection related to patients and populations
6. establishing a national voice for research in cancer control.

Canada has as one of its five priority areas in cancer control, 'Define research priorities and create a plan for strategic investment in priority areas'.

England

Includes the objective, 'To build for the future through investment in the cancer workforce, through strong research, and through preparation for the genetics revolution so that the NHS never falls behind in cancer care again'.

France

Includes as an objective, 'Co-ordinate research programmes' as a strategy for cancer control.

Ireland

Includes as an objective, 'Facilitating greater co-ordination of cancer research'.

Norway

Includes as priority actions, 'Experimental treatments should be the responsibility of the health service and the opportunity to take part in clinical trials must be a real possibility' and 'Knowledge production. A strategy for clinical cancer research in Norway is to be developed'.

Investigator-initiated research

The Cancer Society of New Zealand currently invests \$2 million annually in the investigator-initiated, contestably funded project grants for research into various aspects of cancer. Over the last three years 80.2 percent of the total budget has been allocated for biomedical research, with 17.0 percent for clinical research and 2.8 percent for epidemiological research.

The Health Research Council (HRC) funds investigator-initiated research in each of nine portfolios. Cancer research forms part of the ‘non-communicable diseases’ portfolio and accounts for about a third of that allocation. Another third, being \$4 million per year, funds cancer projects, while \$3 million is spent on basic biomedical research and \$300,000 each on occupational cancers, clinical cancer research and epidemiology.

Ministry of Health-related research

The Health Research Council is obliged to align its activities with the New Zealand Health Strategy and with the New Zealand Disability Strategy, and would be similarly obliged if research were a principal objective or priority action in the cancer control strategy.

The Health Research Council also works co-operatively with various elements of the Ministry of Health in joint ventures. As a joint venture partner, it project manages research contracts while funding for joint ventures comes mainly from the Ministry ‘topped up’ by the HRC.

Such joint-venture research (a joint research portfolio) commences with the formation of a steering group which includes representation from the partners (Ministry and HRC), from special interest and expert groups, and from Māori and Pacific groups. They define the new knowledge required. Individuals and organisations interested in research within the portfolio are invited to submit a three-page expression of interest.

Promising expressions of interest are identified and applicants invited to make a fully detailed proposal. The advantage of this type of managed research is that those funding the projects receive specific answers to questions that are of particular concern to them, unlike investigator-initiated research where the investigator determines what is to be investigated. This process is also much more rapid than the annual cycle of investigator-initiated project granting.

Objective

To rebalance the portfolio of cancer research so that it more evenly spans the spectrum of cancer control, and to develop a rapidly responsive mechanism for defined research of particular relevance to cancer control.

Rebalancing investigator-initiated research usually takes at least a generation to change the predominant culture in the cancer research community and to appropriately train the workforce. However, advocating such a change in strategy would encourage moves in this direction among young researchers and funding agencies.

Mechanisms already exist whereby the HRC can, through requesting proposals and joint-venture project management, rapidly commission well-defined research projects designed to determine evidence-based answers. Such information could be invaluable in defining the initial directions or in subsequent monitoring and modification of the priority actions of the cancer control strategy.

The joint venture partner with the HRC would be the body responsible for the monitoring and review of the strategy.

Goal

To provide mechanisms to promote research which will lead to increases in the effectiveness of the New Zealand Cancer Control Strategy.

Target

To increase the amount and proportion of research funding for projects related to cancer control in New Zealand.

This can be measured by the:

- funds allocated annually by the Ministry of Health and the Health Research Council through portfolios for research directly related to cancer control
- funds allocated to investigator-initiated research related to cancer control by the Health Research Council, the Cancer Society of New Zealand and other funding agencies that provide grants for research related to cancer
- proportions of research funding allocated to prevention, detection and early diagnosis, treatment, rehabilitation and support, and palliative care.

The body responsible for the implementation and monitoring of the cancer control strategy should collect and analyse these data annually.

The body responsible for periodically reviewing the cancer control strategy should comment on and make recommendations in relation to progress toward these targets.

When the Health Research Council reviews its non-communicable disease portfolio, it should be asked to more evenly distribute research funding across the spectrum of cancer control.

Recommendations

- No new legislation is required.
- The Ministry of Health should make annual budgetary provision for a joint research portfolio for research related to the cancer control strategy and undertaken jointly with the Health Research Council and other agencies.
- The body responsible for the implementation of the cancer control strategy should communicate with all agencies that fund research related to cancer, informing them

of the value of research across the entire spectrum of cancer control. This should be undertaken in the first year of operation. Organisations responsible for implementation of this aspect of the cancer control strategy are the Ministry of Health, the Health Research Council and the Cancer Society of New Zealand.

- The implementation of this strategy should provide a much improved evidence base, and thus cost-effectiveness, for the activities directed by both government and non-government agencies at reducing the incidence and impact of cancer.

References

Canadian Strategy for Cancer Control. Research Working Group Report and Recommendations. URL: <http://www.cancercontrol.org>.

Coates A, Gavin J, Sambrook J. 2000. *Research Review 2000: A review of the present state and future directions of research sponsored by the Cancer Society of New Zealand (Inc)*. Cancer Society of New Zealand (Inc) 1–53. Unpublished.

Skegg DCG, McCredie MRE. 2002. Comparison of cancer mortality and incidence in New Zealand and Australia. *New Zealand Medical Journal* 115: 205–8.

Candidate Priority Action 3: To develop a co-ordinated national cancer care workforce strategy

There needs to be national co-ordination for development and implementation of a human resource and workforce plan for cancer. There are significant gaps in the current cancer workforce. A plan is required to augment the preliminary work that has commenced on workforce planning. The planning and implementation for workforce has to take place with full co-operation between the Ministry of Health, District Health Boards and other provider groups.

Shortages of specialist professional staff in many areas of cancer care are affecting our ability to provide appropriate treatment and support for people with cancer and their families and whānau.

Some of the workforce gaps have been well identified, for example in radiation oncology services the work capacity has been marginal because of shortages of radiation oncologists, radiation therapists and medical physicists. These services have had difficulties meeting current demand and are below capacity to meet levels of service to provide for the estimated 50–55 percent of cancer patients potentially requiring radiotherapy and the increasing number of patients with cancer.

There are also gaps in other cancer treatment disciplines such as medical oncology where there are shortages of trained oncology nurses and pharmacists. There are less well quantified gaps in other workforce groups that contribute significantly to cancer care including pathology, surgery, general practice and community health workers. Further work is needed to identify the problems in these areas and their impact on cancer treatment.

The demand for cancer treatment will increase because of population growth and the ageing population. It is imperative that a co-ordinated and comprehensive strategic approach is taken to quantify gaps across current cancer control services, determine future staffing requirements and ensure that education and training resources are there to match those needs. The plan needs to ensure that there are sufficient numbers of trained Māori and Pacific cancer control professionals to assist the needs of these population groups.

Recommendations

- Conduct a comprehensive stocktake of workforce requirements across the continuum of cancer control services.
- Develop a comprehensive registry/inventory of cancer control personnel with annual reporting.
- Provide regular communication of workforce data and recommendations to all funding and cancer care provider agencies.
- Develop a strategy for workforce development to correct current deficits and meet future needs.
- Provide a focus for increasing involvement of Māori and Pacific cancer health professionals.
- Develop processes to determine and implement workforce planning standards by all professional groups, taking into account care delivery systems, practice models, technical change and workforce evolution.
- Ensure co-ordination between cancer treatment providers and training organisations to determine training requirements and opportunities for human resource development and deployment.
- Research issues of compensation, benefits, work/life satisfaction and career development for cancer professionals to improve the attractiveness of career opportunities and enhance recruitment and retention of staff.

Candidate Priority Action 4: Cancer patients should have access to the best available treatment technologies, surgery and drugs

Introduction

To achieve optimum outcomes for survival, tumour control and quality of life for patients with cancer there needs to be access to the treatments that, on the basis of current evidence, are known to provide the best outcomes. The cancer treatment technologies include procedures for diagnosis and staging (radiology and pathology), surgery, radiation treatment, chemotherapy and other drug therapies. Some treatment procedures such as bone marrow transplantation are very complex and expensive.

To achieve good cancer treatment outcomes for the population, there has to be sufficient access to the existing treatment technologies. There also need to be processes that enable access to newer treatments as the evidence emerges to support their use. A process for the evaluation and introduction of new chemotherapy drugs is emerging through an evolving PHARMAC process. However, this process only addresses new pharmaceuticals and does not deal with other cancer treatment technologies.

In New Zealand, high-standard cancer treatment is available, however, problems with capacity mean that there are inequalities in access to these treatments. These can be measured by delays patients experience in receiving treatment and difficulties experienced by population groups such as Māori and Pacific peoples. There are difficulties with introducing new treatments and treatment approaches throughout New Zealand because of a lack of agreed processes and funding support. Many of the newer treatments are considerably more expensive. A process is required that carefully evaluates the costs against the additional benefits and in turn evaluates this against other cancer treatment priorities.

Cancer is a complex disease that requires the collaboration of a number of health disciplines for its diagnosis, treatment and follow-up. Close collaboration between these disciplines or multidisciplinary management has been shown to provide better outcomes (Department of Health [London] 1995). This is thought to be due to more appropriate diagnosis and better selection of patients for treatment, in particular surgical treatments. The fact that surgery and post-operative care takes place in skilled and experienced hands, in hospitals equipped to support these difficult problems, is important. Substantial benefits of specialisation have been shown in studies of people with oesophageal, gastric and pancreatic cancer in terms of choice of tests and treatments, and on survival (Backmann et al 1999). Similar benefits have been found in the treatment of other cancers by high volume specialised teams (Selby et al 1996; Hannan et al 2002). The expertise of the surgeon performing the surgery, the frequency with which he or she does the operation and the availability of an experienced team are all important in terms of outcomes.

Multidisciplinary teams and specialised treatment centres are not necessarily essential for the management of all cancers, but optimum management requires the different levels of service to function in a co-ordinated way. How to achieve this in a country with the geography and the small population of New Zealand is not yet clear. The development of multidisciplinary clinics has already occurred in some centres for some cancers such as breast and soft tissue tumours and discussions have begun on other cancers, in particular oesophageal, gastric and pancreatic. Effective liaison within a clinical group can be achieved by regular discussion of patient problems through face-to-face meetings, or for those practising away from major centres, through televideo links or other forms of online communication.

The transfer of patients with certain cancers to a specialised unit will have an impact on the base hospital. Workforce issues may arise with staff recruitment and retention. There will also be an impact on the patient being transferred, their family and friends in terms of support, travel and accommodation. Nevertheless, the benefits of some specific cancers being treated at a specialised unit needs to be explored.

Recommendations

- Continue to develop standards for the utilisation, replacement and addition of radiation oncology equipment.
- Develop a nationally co-ordinated and consistent process for the introduction of new technologies and drugs in cancer treatment.
- Develop a process to prioritise management of specific cancers with new treatment approaches.
- Expand the use of multidisciplinary management and explore the place of specialised treatment units including surgical.
- Improve systems for consultation and referral of patients for specialised surgery and multidisciplinary care.
- Establish specialty surgical oncology networks through regional oncology programmes to facilitate continuing education activities for surgeons, communication between surgeons and cancer centres, and to support research projects.

References

Backmann M, Alderson D, Peters T, et al. 1999. *Survival, clinical practice and costs in patients with pancreatic, oesophageal and gastric cancers: influence of doctor and hospital volumes*. Report to NHS National Cancer research and Development Programme.

Department of Health [London]. 1995. *The Calman-Hine Report: A policy framework for commissioning cancer services*. London: HMSO.

Hannan EL, Radzyner JD, Rubin D, et al. 2002. The influence of hospital and surgeon volume on in-hospital mortality for colectomy, gastrectomy and lung lobectomy in patients with cancer. *Surgery* 131: 6–15.

Selby P, Gillis C, Haward R. 1996. Benefits from specialised cancer care. *Lancet* 348: 313–18.

Candidate Priority Action 5: All treatment providers should follow defined standards of integrated care for the management of cancer patients

All patients receiving cancer treatment need to have access to a consistent standard of care if the best outcomes are to be achieved. Various approaches can ensure this occurs. These include the application of national and local guidelines, treatment given within clinical trials and the use of multidisciplinary clinics. To ensure application, these processes need to be continuously monitored by developing key process indicators and measuring outcomes.

Currently, application of guidelines is variable and there are no systematic processes for monitoring outcomes. Access of patients to clinical cancer treatment trials is limited.

Recommendations

- Encourage best practice according to regional and national guidelines and protocols.
- Conduct interdisciplinary patient management through multidisciplinary conferences and clinics.
- Increase the proportion of patients who receive treatment within clinical trials.
- Establish regional and national networks to develop standards (service specifications) for cancer treatment and symptom control.
- Improve the provision for rehabilitation and support for survivors of childhood cancer including the early identification of late effects.
- Improve regional links to an enhanced national cancer registry.
- Obtain commitment from cancer treatment provider health records and resources to develop minimum data set abstraction and registration.
- Develop surveillance with treatment process indicators and outcomes reporting.
- Continue to improve access to regionally co-ordinated palliative care services.

Candidate Priority Action 6: To improve the quality of care delivered to adolescents diagnosed with cancer and their families and whānau

Introduction

Adolescents with cancer present special problems for carers.

1. The psychosocial and emotional problems faced by adolescents are unique.
2. The types of cancer encountered straddle the paediatric and adult age groups.
3. Responsibility for consent varies over time and between patients from almost complete dependence on adult caregivers to patient autonomy.
4. There is no clear, widely-accepted definition of adolescence.
5. Outside of large cities, the absolute number of cancers seen in this age group is relatively small.

The management of cancer in childhood (0–14 years inclusive) has received priority attention through the Ministry of Health-funded national Paediatric Oncology Steering Group. In New Zealand, there is no consistent, equitable pattern of referral and management for adolescents with cancer; they ‘fall into the gaps’, receiving treatment in either paediatric or adult oncology units. Often, neither environment is suitable. These criticisms and subsequent recommendations pertain to all adolescents in New Zealand: Pākehā, Māori and Pacific peoples.

Definition of adolescence

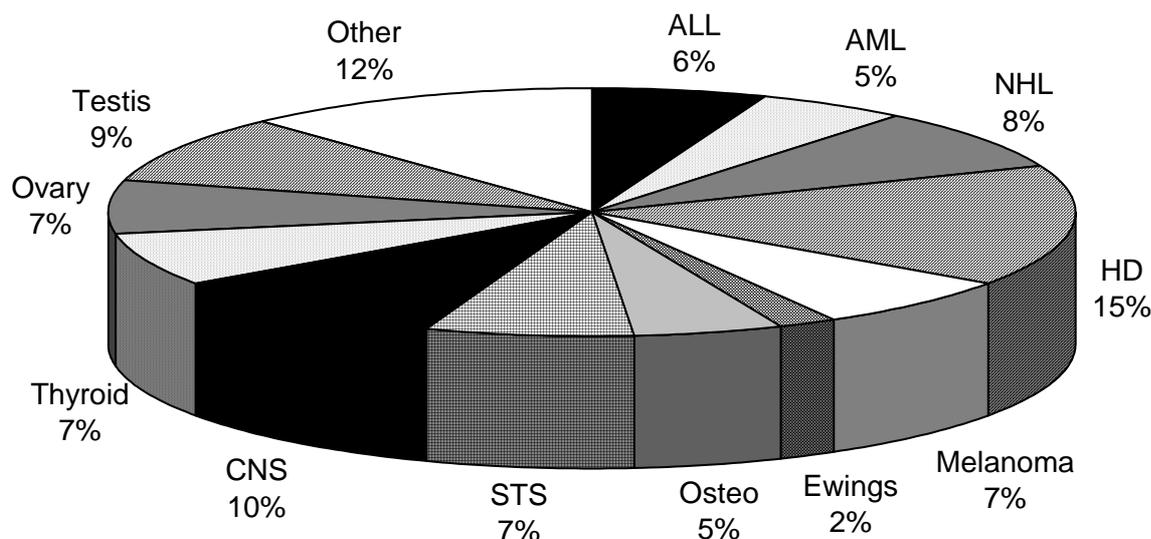
The World Health Organization defines adolescence as spanning the 10–19 year age group, further dividing this period into early (10–14 years) and late (15–19 years) adolescence. Cancer statistics derived for adolescents address the 15–19-year-old age group. In New Zealand, the decision whether an adolescent is treated in either an adult or paediatric oncology unit is usually based on:

1. to whom the primary oncology referral was made
2. the age of the patient (<15 years to paediatrics, ≥ 15 to the adult service)
3. an informal judgement of the physical and, sometimes, emotional maturation of the patient.

Data on incidence, diagnosis and outcome

Incidence exceeds 200 new cases per million aged 15–19 years per annum. This is greater than that in children (~140/10⁶/annum 0–14 years old) but considerably less compared with the young adult. Applying SEER (NCI Surveillance, Epidemiology and End-Results) incidence data to statistics from the 1996 population census, approximately 58 of 284,985 New Zealanders aged 15–19 will develop cancer annually. The distribution of cancer types is as follows.

Figure 1: Cancer in adolescents 15–19 years, SEER 1975–98



Hodgkin's disease is the commonest diagnosis (15 percent) followed by acute leukaemia (ALL and AML together constitute 11 percent). However, the majority (over two-thirds) are a miscellany of solid tumours with brain tumours and germ cell tumours of the testis and ovary predominating. Only bone tumours (osteosarcoma and Ewings sarcoma) are relatively specific to this age group with peak incidence in the second decade of life.

The incidence rate for adolescent cancer in the US during the 1990s was the highest reported since the SEER programme began in 1973, increasing by over 30 percent from 1973 (an average increase of 0.9 percent per annum (Bleyer 2002)). This is mainly accounted for by an increasing incidence of germ cell tumours and NHL (and, to a lesser degree, osteosarcoma and acute lymphoblastic leukaemia).

Registry data based solely on organ of origin are unhelpful. Classification systems should include histological diagnosis.

The burden of adolescent cancer

The distribution of cancer mortality in adolescence indicates that leukaemia (29 percent) and CNS tumours (16 percent) are the major contributors (Sith et al 2002). SEER data point to leukaemia being the primary contributor to mortality burden from cancer (function of incidence and survival).

Patterns of referral and treatment

In contrast with childhood cancer, there is no infrastructure for the care of adolescents with cancer in New Zealand. As a result, referral is ad hoc depending on the interest of the oncologist, a judgement of maturity of the patient and the nature of the malignancy. Treatment patterns and outcome data are not available for New Zealand. The following data is from the US (Bleyer 2002).

- Whereas 90 percent of children with cancer are treated at institutions that participate in NCI-sponsored clinical trials, the figure for 15–19-year-olds is 20 percent.
- There is a close correlation between patient participation in clinical trials and outcome. In contrast with paediatric oncology (where trial entry approaches 60 percent), fewer than 10 percent of adolescents benefit from participation in clinical trials of anti-cancer treatment.
- For those with ALL entered on clinical trials, six-year EFS was superior for those treated on a paediatric protocol (CCG – 64 percent) compared with an adult trial (CALGB – 38 percent).
- Comparing overall five-year survival rates during two periods (1974–76 and 1989–95), improvement was 38 percent in 10–14-year-olds compared with only 19 percent for 15–19-year-olds.

The quality of survival – psychosocial issues and late effects

Adolescence is a transition from childhood to adulthood, the latter attained when a number of maturational tasks are accomplished.

- Becoming comfortable with their own bodies.
- Working towards physical and emotional independence.
- Developing new and meaningful relationships.
- Developing a personal value system.
- Learning to rationalise and verbalise conceptually.

Two-thirds of parents report adolescence as the most difficult period of child-rearing. It would seem that this difficulty is not new.

‘Our youth ... have bad manners, contempt for authority. They contradict their parents and ... tyrannise their teachers’ (Plato quoting Socrates, fifth century BC)

The diagnosis of cancer in the adolescent threatens and opposes many of the maturational tasks desirable to attain adulthood. This results in:

- increased dependence on caregivers
- reduced peer contact and acceptance
- disturbance of physical maturation and appearance
- profound effects on developing sexual identity
- interrupted education and career plans.

The net result is loss of self-esteem. One in three adolescents diagnosed with cancer suffers post-traumatic stress disorder (Barr 1999). Adolescent males often reject their mothers and one in five mothers develop post-traumatic stress disorder.

An infrastructure that cares for adolescents with cancer and their families

We need to create an infrastructure in New Zealand for the care of adolescents with cancer and their families that:

1. addresses a meaningful definition of adolescence based on developmental stage, not age. There is considerable overlap between an older child and an adolescent, and a young adult and an adolescent. One of the hallmarks of the adolescent is the propensity to oscillate between various phases of development, particularly evident during times of stress such as the diagnosis of a life-threatening condition. So the definition has to be broad, and care-givers must recognise that considerable developmental changes may occur during the time-span of anti-cancer therapy and follow-up for an individual patient
2. addresses their psychosocial needs. When previously admitted adolescents were surveyed, 53 percent felt out of place in a children's ward and 81 percent on an adult ward (Kain 1999). Seventy-seven percent said they would prefer designated facilities which have been shown to improve health outcomes through:
 - improved compliance
 - improved behaviour
 - shorter duration of stay
 - reduction in psychosocial morbidity
 - improved educational performance.

General adolescent wards have not proved successful in Melbourne and Brisbane for a number of reasons including dilution of specialist nursing expertise. At Manchester Children's Hospital, nurses with expertise in adolescent psychosocial development were able to recognise and treat aberrant behaviour in adolescents with ALL, compared with untrained oncology nurses (Evans 1996)

3. encourages the most appropriate medical personnel to treat a designated cancer. 'The present dispersal of adolescents throughout different specialty wards caters for the convenience of the medical staff rather than the needs of the patient. Designated areas should be sited where both paediatric and adult oncology and haematology is practised. There is a danger that professional rivalries may interfere with their development ... In order to succeed there needs to be agreement between paediatric oncologists, medical oncologists, radiotherapists, clinical haematologists and surgical oncologists, *but no one of these groups has the skills to manage all the various cancer diagnoses*' (Lewis 1996)

4. ensures maximal entry onto age-specific clinical trials. The Children's Oncology Group (US) Adolescent and Young Adult Subcommittee is presently co-operating with a number of adult study groups to develop clinical trials relevant to this age group (A Bleyer, personal communication, 2002). Presently, Children's Oncology Group (COG) trials include patient participation up to 21 years of age. Starship has institutional membership of COG; the Wellington and Christchurch Child Cancer Units became members in 2002. Participation in COG trials requires stringent data management; this has been addressed nationally by the Paediatric Oncology Steering Group
5. ensures fiscal responsibility and minimises disruption of family dynamics and finances through travel but respects equity of access. These issues were addressed for paediatric oncology by the Child Cancer Foundation and Health Funding Authority in 1999–2000. The result was an infrastructure that consisted of a 'hub' child cancer unit in three centres (Auckland, Wellington and Christchurch) with travel and accommodation arrangements for patients and their families and whānau, and outreach and regional support by medical personnel ('shared-care') that minimised disruption. It is logical to assume that the same applies to adolescents with cancer and their families and whānau
6. ensures prospective collection of data on adolescent cancer incidence, treatment and outcome in New Zealand.

Recommendations

1. An adolescent should be identified as someone who has embarked on, but not completed, the physical, intellectual and emotional transition to adulthood.
2. Adolescents with cancer should be treated by a multidisciplinary team with expertise in psychosocial issues unique to that age group. This would naturally develop if areas specific to adolescent cancer treatment were designated.
3. The appropriate medical personnel with expertise in particular tumour types should be 'imported' to treat adolescents within the optimal environment for the patient.
4. Adolescents with cancer should be treated where expertise in clinical trial entry and data management exists.
5. Designated adolescent care areas should be created within either child cancer or adult oncology units in Auckland, Wellington and Christchurch. It may be optimal for these services to be 'grafted onto' the existing paediatric oncology infrastructure – this will minimise cost and permit effective 'shared-care' for patients from regional centres.
6. Include data on adolescents in the newly created New Zealand Child Cancer Registry.

References

- Barr RD. 1999. On cancer control and the adolescent. *Medical and Pediatric Oncology* 32: 404–10.
- Bleyer WA. 2002. Cancer in older adolescents and young adults: epidemiology, diagnosis, treatment, survival and importance of clinical trials. *Medical and Pediatric Oncology* 38: 1–110.
- Evans M. 1996. Interacting with teenagers with cancer. In: P Selby, C Bailey (eds) *Cancer and the adolescent* 251–63. London: BMJ Publishing Group.
- Kari JA, Donovan C, Li J, et al. 1999. Teenagers in hospital: what do they want? *Nursing Standard* 13(23): 49–51.
- Lewis I. 1996. Cancer in adolescence. *British Medical Bulletin* 52(4): 887–97.
- Sith MA, Anderson BD, Ries LA. 2002. Continuing improvements in outcome for children with cancer in the United States 1979–98. *Proceedings of the American Society of Clinical Oncology* 1551.

Candidate Priority Action 7: The integration of conventional and complementary care for cancer patients

Introduction and definitions

A population health objective of the New Zealand Health Strategy (Minister of Health 2000) is to reduce the incidence and impact of cancer. For New Zealanders who develop cancer, the goal of treatment is to increase the quantity and quality of life.

This candidate priority action proposes ways in which the health sector can support cancer patients to make better-informed choices relating to their treatment.

There are three groups of therapies. A complementary therapy is, by strict definition, one that adds benefit to the orthodox, conventional or scientific therapies provided through the health system. An alternative therapy is one that by implication is used instead of an orthodox treatment. Sometimes complementary and alternative medicine (CAM) are considered together because both are perceived to require more scientific evidence.

The fundamental difference of opinion between the practitioners of scientifically based medicine and alternative medicine lies in the criteria they consider applicable for establishing effectiveness of treatments. Scientific medicine lays down universally applicable criteria that define and describe what is to be achieved by a treatment. A treatment must have a measurable statistical probability of effect that is based on empirical data and not on individual cases.

However, it is not as simple as that. The evidence for various therapies differs greatly in quantity and quality, and this evidence is often complex and difficult to interpret. The cancer patient faces further difficulties because the advantages and risks of all potentially relevant therapies are not usually discussed together. Thus it is at present very difficult for the patient to make fully informed choices about the best and most comprehensive treatment plan.

Background

There has been a substantial increase in belief in and use of complementary and alternative therapies for cancer. Factors responsible for this include in general the rising prevalence of chronic disease, increased public access to health information of variable veracity, reduced tolerance of paternalism, increased sense of entitlement to quality of life, declining faith that scientific breakthroughs will in the short term have relevance to the personal treatment of disease, increased interest in personal spirituality and, in particular, the wish of cancer patients to consider and choose from the full range of therapies that may be helpful to them. The trend is unmistakable and has been comprehensively reviewed ('Hype, Hope and Healing', *New Scientist*, 26 May 2001, www.newscientist.com). Many now believe there is potential for public health gains using complementary and alternative medicine (O'Brien 2002).

Healing goes beyond curing. For cancer, curative treatments may prove impossible. Yet, even as the disease progresses, an inner healing process (emotional, mental and spiritual) can be astonishingly powerful in the patient's life and in those of their loved ones (Lerner 1996). Patients will inevitably search for possibilities that offer hope. The strategy should help and support them in this endeavour.

The New Zealand cancer control strategy should encourage patients to play an active role in their own health. Indeed, Principle 9 of the cancer control strategy draft of 27 August 2002 states that:

'accurate and comprehensive information should be available to enable all people who experience cancer, their carers, their family and whānau to make informed choices about their treatment, support and care.'

Some health professionals and the popular media present conventional therapy and complementary and/or alternative therapy as diametrically opposed and mutually exclusive. Instead, the emphasis should be on careful evaluation of evidence and utilising their potential for synergy to maximise opportunities for healing by the patient.

The Medical Council of New Zealand in its *Guidelines on Complementary, Alternative or Unconventional Medicine* (1999) states:

'There cannot be two kinds of medicine – conventional and alternative. There is only medicine that has been adequately tested and medicine that has not, medicine that works and medicine that may or may not work. Once a treatment has been tested rigorously, it no longer matters whether it was considered alternative at the outset. If it is found to be reasonably safe and effective, it will be accepted. But assertions, speculation and testimonials do not substitute for evidence. Alternative treatments should be subjected to scientific testing no less rigorous than that required for conventional treatments.'

But what of complementary therapies which, to deserve that classification, are widely agreed to have some benefit? For these there may be little or substantial evidence of benefit, but usually less than full scale clinical trials. Such complementary therapies would include: diet and nutrition, exercise, meditation, massage, aromatherapy, acupuncture, psychosocial and spiritual support, and herbal medicine. How should advice be given on these modalities so that they will indeed be complementary to the other therapies prescribed?

Overseas trends

In the UK 75 percent of citizens support access to CAM, and 14–25 percent with chronic disease consult a complementary and alternative therapy practitioner (Coates et al 1998).

Of 503 patients at a cancer centre in the USA, 16 percent had considered using alternative therapy for cancer after a diagnosis had been made, two-thirds felt that CAM should be encouraged by the medical profession, and 85 percent felt that alternative care should be offered at the cancer centre as part of oncology treatment (Coss et al 1998).

Between 48 and 64 percent of Australians use some form of CAM, and between 20 and 44 percent visit CAM practitioners (Maclennan et al 1996).

A poll in Canada found that two-thirds of citizens felt that the Government should be advocating the use of CAM to potentially reduce costs to the health care system and 70 percent felt that the Government should cover the cost of such treatments (Angus Reid Group Inc 1998).

The National Institutes of Health in the US has recently expanded the research programme budget for the National Center for Complementary and Alternative Medicine. Its goal is to incorporate CAM practices that have been proven safe and effective into mainstream medicine through research, training and career development. Its director has noted that in 1997 42 percent of Americans used one or more complementary modalities, up about a third in six years:

‘The public chooses these practices because they believe, and some evidence suggests, that some of them sustain and improve health. But they need guidance about which practices are safe and effective.’

The Treatment Working Group of the Canadian Strategy for Cancer Control recommended that the following principle be included in the Canadian strategy: ‘It is the patient’s right to pursue complementary and alternative health care. Their choices should be respected and, where pursued in conjunction with conventional health care, management should be developed co-operatively between the patient and practitioners safely, knowledgeably and in the context of accurate record and evaluation’. The present proposal argues that this should also form part of the New Zealand cancer control strategy.

Concurrent developments in New Zealand

Traditional healing

Central Auckland hospitals are actively considering the use of traditional Māori healers and medicine to provide services that better accommodate the needs of Māori patients. The Auckland District Health Board is considering draft guidelines aimed at the spiritual, emotional and physical wellbeing of Māori patients and their whānau.

Proposed therapeutic products legislation

There is currently active public debate about proposed legislation being developed by the Ministry of Health for regulation of what are currently called dietary supplements that are dealt with as foods rather than medicines. Submissions have just closed on a discussion paper and a decision whether or not to proceed will be made in late 2003 or early 2004. If this initiative proceeds, legislation is expected in 2005. The proposal is to create a Therapeutic Products Agency. A list would be prepared of substances for which ‘low level’ health claims (eg, aids digestion, aids sleep) will be allowed. To be on the list the supplier must certify that they hold evidence to support the claims (eg, incorporation in a herbal pharmacopoea, historic evidence of traditional use, reference to in text of homeopathy).

However, 'high level' health claims will still be able to be made for registered medicines for which evidence from double blind, placebo controlled clinical trials will continue to be required. It seems therefore that the proposed Therapeutic Products Agency and its list may help identify preparations that have no evidence of therapeutic value (by not listing them), but will not provide a mechanism for testing and thus establishing benefit as a complementary therapy.

Ministerial Advisory Committee on Complementary and Alternative Health (MACCAH)

In June 2001, at the instigation of the Green Party, the Minister of Health established a Ministerial Advisory Committee on Complementary and Alternative Health to undertake a four-year project. The committee chair is Professor Peggy Koopman-Boyden and its terms of reference are:

- a) to provide information and advice to the Minister of Health on complementary and alternative health care
- b) to provide advice on how complementary and alternative health care can improve outcomes in the priority areas signalled in the New Zealand Health Strategy
- c) to provide advice on the need, or otherwise, to regulate complementary and alternative health care practitioners in order to protect consumers who use complementary and alternative health care
- d) to provide advice on consumer information needs and, in particular, advice on the benefits, risks and costs of complementary and alternative therapies
- e) to review overseas evidence-based research, identify priorities for the development of New Zealand evidence-based research on the safety and efficacy of specific complementary and alternative therapies, and support the development of guidelines
- f) to provide advice on whether, and how, specified complementary and alternative health practitioners should be integrated into the mainstream health system.

At the time of writing this paper MACCAH had released a discussion document on policy issues related to complementary and alternative health care. More information about MACCAH is available from <http://www.newhealth.govt.nz/maccach.htm>.

The complementary and alternative medicines database

The Ministry of Health is to develop an Internet database of research-based information for individuals and health professionals on the safety and effectiveness of complementary and alternative therapies. This project has an ongoing budget of \$150,000 per year. Cancer therapies will be included.

The database will be online by June 2003. The information available will consist of summaries of research derived from Medline and the Cochrane Collaboration and may be searched according to particular cancers and/or particular therapies.

The database will start small but will become more comprehensive as information is added progressively. A major challenge will be to ensure that the information is comprehensible to interested laypeople, while still being sufficiently comprehensive and detailed to adequately inform health professionals.

Potential for significant health benefit

Integrating complementary and conventional therapies would provide benefits to cancer patients. It would:

- allow positive involvement of patient, partner and family in the care of the cancer patient and reduce the psychological and emotional impact of cancer
- reduce the risk of unproven or ineffective treatment or of treatments which compromise conventional therapy thus increasing the impact of cancer
- allow patients to get the best possible information as a total package and so have maximum opportunity to select the treatment regime which is most appropriate for them
- reduce the risk of the patient receiving uninformed or dangerous advice.

Likelihood to influence change in practice

There is progressive acceptance of complementary therapies by the public and growing acknowledgement of this by the conventional health professions.

Potential for addressing gaps

Incorporation of this priority action would lead to provision of comprehensive and more balanced information for cancer patients and their families and whānau about which therapies are available and the evidence for their effectiveness.

This would increase the participation of the patient and family and whānau in cancer care and reduce the burden of cancer on them.

Recommendations

That the agency or agencies responsible for the implementation of the New Zealand cancer control strategy:

- ensure that the Ministry of Health Complementary and Alternative Medicines Database includes high-quality and comprehensive information which clearly defines the benefit or lack of benefit of therapies believed to have effects complementary to conventional cancer therapies
- ensure that both government and non-government organisations with an involvement in cancer develop a national mechanism for disseminating information about effective and ineffective cancer therapies to cancer patients and their families and whānau, and to health professionals involved in cancer care

- commission research to determine the most efficient and effective way for cancer treatment services and organisations to provide comprehensive advice on all therapies that may be of benefit to their cancer patients, and to determine a timetable for their implementation
- expect cancer treatment services and cancer care organisations to report periodically on progress toward the integration of complementary and conventional therapies in their jurisdictions.

How to proceed

This is a complex issue and will take time to implement. It is of particular relevance to cancer patients. The bodies responsible for implementation of the New Zealand cancer control strategy will need to establish working parties. These will research and develop a framework for the integration of conventional and complementary cancer care so that the public are well informed about these matters. Health professionals involved in cancer care will also be able to provide informed, comprehensive and explicit guidance to their patients.

This process would involve:

- defining the perspectives on complementary cancer care of the various components of the public and private health system, non-governmental organisation providers of cancer care and advice, and cancer care professionals
- investigating, developing, testing and implementing a process for integrating complementary and conventional cancer care
- developing innovative public and professional education programmes to encourage and facilitate integrated models of cancer care
- ensuring that the curriculums of institutions educating health professionals include consideration of complementary and alternative cancer care, evaluation of their effectiveness, and the integration of complementary and conventional care
- convening a national conference to examine and make recommendations regarding an optimal framework
- developing an agenda to guide research into complementary and alternative cancer therapies.

The Canadian, Australian and English proposals for integrating complementary therapies suggested various ways that this could occur.

- Conventional clinicians should be encouraged to work co-operatively with cancer patients who choose to integrate complementary therapies with mainstream treatments.
- Developing a framework to guide research into the co-operative development of complementary therapies and conventional medicine.
- Regional health authorities investigating, developing and implementing processes for a co-operative model.
- Regional authorities implementing strategies for implementation, for example, through a support and information centre alongside treatment hospitals (eg,

Memorial Sloan-Kettering Cancer Center in New York has an integrative medicine centre which offers and conducts research into reflexology, reiki, Swedish massage, meditation, mind/body therapies, and art, music and sound therapy).

- Developing public and professional education systems to include the concept of integrated cancer care (eg, Australia's Swinburn University has a department of integrative medicine).
- Holding a national conference to examine and make recommendations for an optimal agenda and framework for research into the co-operative development of complementary and conventional cancer care.

Expected outcomes

Better integration of conventional and complementary cancer therapies will have a positive impact on morbidity and mortality for cancer patients.

The specific outcome(s) most easily measurable for this proposed objective would be assessment of patient satisfaction with advice received, and possibly improved quality of life.

Would New Zealanders prefer complementary therapy to be available alongside conventional therapy at their cancer treatment centre? Would they like authoritative advice on complementary and alternative therapy to be available from their health professionals? The answer to both questions is likely to be a resounding yes.

Conclusion

There is a growing awareness of complementary and alternative therapies for cancer and their use is increasing steadily. There is:

- a need for guidance about which practices are beneficial
- a preference that they be integrated with conventional therapy
- a desire for patients to have access to the widest range of therapies available.

There is already widespread and growing support in the community for complementary care. Its choice as a priority within the New Zealand cancer control strategy would therefore be a popular one with the public. Identifying the specific steps, which should be taken to implement and measure the effectiveness of this proposal, would require further discussion and refinement by the body responsible for the implementation of the New Zealand cancer control strategy.

References

Angell M, Kassirer JP. 1998. Alternative medicine: the risks of untested and unregulated remedies. *New England Journal of Medicine* 339: 839–41.

Angus Reid Group Inc. 1998. *Use and Danger of Alternative Medicines and Practice: Parts I and II*. Consumer poll conducted by CTV/Angus Reid Group.

- Coates JA, Jobst KA. 1998. Integrated health care: a way forward for the next five years? *Journal of Integrated Health Care* 4: 209–27.
- Coss RA, McGrath P, Caggiano V. 1998. Alternative care: patient choices for adjunct therapies within a cancer center. *Cancer Practice* 6: 176–81.
- Lerner M. 1996. *Choices in Healing*. Cambridge, MS: MIT Press.
- Maclennan AH, Wilson DH, Taylor AW. 1996. Prevalence and cost of alternative medicine in Australia. *Lancet* 347: 569–73.
- Medical Council of New Zealand. 1999. *Guidelines on Complementary, Alternative or Unconventional Medicine*.
- Minister of Health. 2000. *New Zealand Health Strategy*. Wellington: Ministry of Health.
- O'Brien K. 2002. Problems and potentials of complementary and alternative medicine. *Internal Medicine Journal* 32: 163–4.
- Treatment Working Group of the Canadian Strategy for Cancer Control. Integration of Conventional/Alternative Health Care. URL: <http://www.cancercontrol.org>.

Candidate Priority Action 8: Empowering patients

Promoting a patient-centred approach to care

Introduction

This paper describes issues to be addressed within a model of care delivery that would empower patients receiving cancer treatment and improve treatment outcomes.

The New Zealand health care system offers a comprehensive range of treatments and support for people with cancer. These services are provided by a variety of tertiary disciplines, including medical oncology, radiation oncology, haematology, paediatrics and surgical specialties, and by a number of community-based initiatives including general practices, community and rural nursing services, marae-based health centres and Cancer Society support services. It is expected that most patients with cancer will use a number of these services throughout their cancer experience.

Concern has been expressed, however, that despite the high standard of care offered by many of these services, not all patients are comfortable using them and, of those who do, not all patients achieve the expected outcome. This has been noted particularly in Māori and Pacific communities (Minister of Health and Associate Minister of Health 2002).

To improve the health outcomes and quality of care of all patients with cancer we need to deliver cancer services in a way that responds to individual patients' needs. A number of barriers have been identified with the current model of care delivery that may prevent some cancer patients from effectively accessing or receiving the best care. These are outlined below.

Negotiating health care services

First, there is concern that patients find negotiating the labyrinth of health care services difficult. Currently GPs and medical specialists are the most likely to refer patients through the various services involved in cancer care. This system relies on the assumption that such medical services have the resources to follow up on referrals and to ensure that they are processed in a timely manner. It also assumes that the patient will be proactive about the type of care they want and has the initiative and ability to follow up on referrals should they fail to obtain an appointment.

No studies have been conducted in New Zealand to determine how well this referral system meets the needs of people with cancer but there is anecdotal concern that people are falling through the cracks. Further, a study designed to elicit the needs of people with cancer and their support people in the Wellington region did determine that patients who are unable to maintain an effective relationship with a health professional, felt less able to express choices or opinions about services (Litchfield et al 1995).

Canada and Britain have also identified poor co-ordination of referrals and treatment as a barrier to some patients receiving effective care. These countries have looked to assigning responsibility for the co-ordination of care to specific people or services. This option has recently been taken up in the New Zealand Palliative Care Strategy (Minister of Health 2001) which has recommended that patients receiving palliative care be assigned a co-ordinator to work with them. This system is yet to be evaluated to determine patient satisfaction and improved outcomes.

Information provision

Another barrier to the effective utilisation of cancer services is that patients do not always receive appropriate information about their cancer, its treatment or the various care options that they have. This is recognised as a particular problem for Māori and Pacific peoples. The need for information is often recognised as one of the most pressing needs of people with cancer. As a consequence there is a lot of high-quality information available for patients. Hence this issue is not one of sufficient information, rather it is about how patients source credible information that is delivered in a style that meets their needs (Litchfield et al 1995).

As a multicultural society, we often translate health material to ensure that all patients are receiving consistent information and health messages. Concern has been expressed, however, that the translation of existing material alone is not an effective way to deliver accurate health information. Rather, current thinking now suggests that health professionals and members of the recipient community should rewrite the information together in the language of the recipient (Finau 2000). This will ensure the accuracy of the information and increase use of, and compliance with, the material as there will be a sense of ownership of the information among patients and communities.

It should also be recognised that many patients prefer that information be delivered face to face (Barthow 1991). This is particularly true for Māori. Telephone calls and letters fail to provide clarity and often lead to misunderstandings about treatment and support information. This one-on-one style of information-giving is not currently a reality of cancer care. It is a time-intensive initiative which current staffing levels cannot address.

Care and treatment in homes and communities

Cancer is a chronic condition that may affect people over a number of years, hence patients tend to prefer treatment options that have the least impact on family, social and work commitments such as home- and community-based care. In recent years there has also been a move to shift traditional in-patient cancer treatments to the ambulatory setting which has further increased the number of patients who can realistically receive ambulatory or community-based cancer treatments. The complexity of many aspects of cancer care requires that these patients be cared for by health professionals who are knowledgeable and experienced in the care of people with cancer. Also, even though most patients cared for in the community receive much of their care from partners, whānau or friends, they and their support people need to know that they can contact an appropriately trained health professional at any time. Similarly, access to the sorts of specialist equipment currently found in a hospital setting is equally important.

Practical assistance

Practical assistance is also necessary. Travel and accommodation needs of cancer patients who have to travel for treatment have recently been addressed. A number of other aspects of practical patient support also require attention such as assistance with household chores, child care and so on (Lichfield 1995; Budge and Carryer 2001).

Holistic care

Delivery of appropriate care is also about more than competent delivery of treatment modalities. It is about holistic care and being able to meet all the patient's health care needs. For Māori and Pacific peoples, and patients from other cultural groups this is particularly important. The 1999 report on the needs of Māori affected by cancer recommends increasing the Māori workforce in cancer centres and training Māori health workers in cancer treatment and care.

Training

Finally, in whatever setting patients receive care, appropriately trained health professionals should care for them, whether this is in a medical ward in a tertiary hospital or in a rural health setting. This is currently a problem in New Zealand, not only due to well publicised staff shortages in many disciplines, but also due to poor access to advanced training, particularly for nurses working with cancer patients. In light of a recent study which offers evidence that increasing nursing skill mix can ensure better health outcomes in a hospital setting (Lamkin 2001), the issues of nursing numbers and level of preparedness must be addressed in New Zealand. Currently, there are no nationally recognised 700 level papers on offer to nurses in New Zealand.

Recommendations

Co-ordinate delivery of care

- Ensure that patients in all hospital and community settings have access to cancer nurses and other health professionals who have received training in cancer care.
- Evaluation of different systems of care co-ordination should be undertaken to determine whether they:
 - improve access to and transition through current cancer services
 - ensure that patients are more aware of treatment options
 - promote patient choice
 - decrease duplication in service.
- A decision can then be made on which approach to co-ordination of care would best meet the needs of New Zealand patients.

Delivery of information in an appropriate manner

- Standards should be developed to guide delivery of health information, particularly information to Māori and Pacific peoples.
- Evaluation of patient understanding should be an ongoing part of the information process.
- Evaluation of the effectiveness of information should be based on how the patient found the information and upon style of delivery.
- Consumers and relevant parties should be consulted to develop new information and improve the old.

Improve resources to the community

- Resource allocation to the community must be improved. Areas of need include:
 - practical assistance
 - access to skilled and experienced cancer nurses and other health professionals
 - provision of equipment necessary to continue to remain in the home and community as safely as possible.

Ensure a standard of training to those people involved in delivery of care

- New Zealand needs to develop courses in cancer care to meet the needs of patients and health professionals working in cancer care.
- This is of particular urgency for Māori and Pacific health services which need development of their workforce.
- The development of a basic post-graduate course in cancer nursing needs to be explored by the Health Workforce Advisory Committee.

Conclusion

An empowering model of care for cancer treatment patients would need to address:

- training and credentialing of health workers involved in cancer care
- workforce issues
- standards for information-giving
- a continued shift to community-based care
- resources for community care, especially access to experienced cancer nurses
- development of the Māori and Pacific workforce
- development of a culture that is inclusive and consultative
- evaluation of various approaches to co-ordination of cancer care.

The provision of patient-centred care has the potential to improve patient quality of life and satisfaction with care. Therefore, care that is delivered in a more acceptable way to the patient would positively impact on uptake of current treatment options and, ideally, reduce mortality from cancer.

Ensure that all cancer treatment providers follow principles of patient-centred and co-ordinated care

Cancer management has become increasingly complex and demanding for health care providers, cancer centres and patients. This has resulted in fragmented care delivery. Experiences of cancer patients through the cancer care system are highly variable. There is need to create a seamless process for patients through the various cancer providers by enhancing the relationship between the community, secondary specialist providers and cancer centres.

An integrated cancer care system means that every person has access to the full range and combination of cancer treatment services that ensure quality of life and improved survival. This has to address the need of special population groups where there may be difficulty accessing appropriate care. Accessibility is a key component and improved co-ordination needs to be provided from initial diagnosis, through secondary care, tertiary oncology centre care and return to the community once initial treatment is complete. To permit this co-ordination requires improvement of systems and provision of adequate resources. Although there is limited evidence to establish how fragmentation and treatment delays affect patient outcomes, patients and providers clearly support timeliness and continuity of care.

Recommendations

- Develop networks between cancer centres, secondary referrers and community care with providers identifying clear roles and responsibilities in treatment and follow-up of patients with cancer.
- Optimise the communication between care providers and support this with development of electronic records and referral systems.
- Ensure resources to permit co-ordination of patient care through their cancer treatment to avoid unnecessary delays and provide treatment within achievable, clinically acceptable timeframes.
- Improve access of patients to information about cancer care in New Zealand:
 - develop aids to guide patients through the cancer care process
 - enhance patient access to Internet sites for dissemination of information
 - continue to develop educational materials, guidelines and protocols.
- Respect the right of patients to pursue complementary and alternative health care.
- Ensure co-operative management to permit provision of information, safety, accurate records and evaluation when a patient chooses to seek both conventional and alternative treatments.
- Improve the co-ordination of care for adolescents with cancer through multidisciplinary management and specialised units.

References

- Barthow C. 1991. *Breast Cancer: Support in the Wellington Region*. Wellington: Wellington Division of the Cancer Society of New Zealand.
- Budge C, Carryer J. 2001. *Cancer Care: Discharge experiences and needs*. Report to the Regional Cancer Treatment Service, Palmerston North.
- Finau S. 2000. Communicating Health Risks in the Pacific: Scientific construct and cultural reality. *Asia-Pacific Journal of Public Health* 12(2): 90–7.
- Lamkin L, Rosiak J, Buerhaus P, et al. 2001. Oncology Nursing Workforce Survey Part 1: Perceptions of the nursing workforce environment and adequacy of nurse staffing in outpatient and inpatient oncology settings. *Oncology Nursing Forum* 28(10): 1545–52.
- Litchfield M, Clark M, Edwards R, et al. 1995. *A Description of the Needs of People with Cancer and Support People*. Wellington: Wellington Division of the Cancer Society of New Zealand.
- Minister of Health. 2001. *The New Zealand Palliative Care Strategy*. Wellington: Ministry of Health.
- Minister of Health and Associate Minister of Health. 2002. *He Korowai Oranga: Māori Health Strategy*. Wellington: Ministry of Health.

Candidate Priority Action 9: The improvement of cancer treatment for Māori

Introduction

Cancer continues to be a major cause of Māori hospitalisation and mortality. It dramatically impacts on quality and longevity of life and has many financial and social costs. The effects are devastating for the person with cancer as well as their whānau. While prevention is important to the reduction of financial and social costs it is also necessary to address the needs of people with cancer.

Removing some of the barriers for Māori using cancer treatment and support services involve improving appropriate workforce numbers, providing appropriate information and improving understanding of Māori holistic care processes, for example, kanohi ki te kanohi or talking face-to-face with people who have cancer and their whānau. Telephone calls and letters fail to provide clear information which often leads to misunderstanding of care and treatment support. Whānau/family is the essence of the Māori world and therefore has a direct interrelationship with Māori wellbeing.

A report completed in 1999, *Ko To Rourou, Ko Taku Rourou, Ka Ora Te Iwi: The Needs of Māori Affected by Cancer*, suggests a number of objectives to be considered in meeting the needs of Māori. Although this report looked specifically at the services of the Wellington Cancer Society, it could easily apply to other cancer services.

This report suggests:

- improving access to information including having information translated
- providing information that is practical
- providing information on Māori healing processes and where these services can be accessed
- improving the Māori workforce in cancer centres
- training Māori health providers in cancer treatment care
- improving access to support services
- a Māori advocacy service
- clear and accurate information on treatment and care processes
- giving choices about the kind of treatment that is being offered.

To cover gaps and meet the special needs of Māori, a number of issues should be considered. The issues are:

- resource requirements
- Māori workforce development
- access to information and clarity of information
- support systems (whānau, spiritual, community)
- choice or options of joint treatments including traditional Māori healing
- language used, particularly in written material
- access to services
- encompassing the Māori view of health and wellbeing
- a Māori National Cancer database, collecting and analysing information to identify what types of cancer Māori have, their locations and needs
- early detection and treatment through awareness education
- care in the home, including training whānau to care for the patient, for example, bathing, kai, mouth and teeth care.

Objectives

Māori have the right to expect the same level of health care as other New Zealanders. The high incidence of cancer in the Māori population suggests that there are gaps in the way we care for this sector. There are identified gaps in the way we provide health care to Māori. Our obligations under Te Tiriti o Waitangi require that we continue to identify and address the gaps. Significant gaps for Māori in relation to cancer control are listed below, with possible solutions.

The need for a national cancer database to:

- identify types of cancer among Māori
- identify geographic location of Māori with cancer
- identify which geographical areas require what services for Māori.

The potential to improve home care for Māori through:

- training and an educational package available to assist whānau caring for someone with cancer
- increased and improved confidence to care for whānau in the home
- less time spent in institutions.

The potential to improve the Māori workforce by:

- training and education packages developed and implemented in education institutions including Māori institutions, marae-based training packages, medical schools, nursing training
- increasing the professional Māori workforce.

The potential to offer choices of treatment to Māori through:

- resources provided to Māori rongoa providers
- choices for patients, with options considered as part of care plans.

Recommendations

- Improve information dissemination and appropriate language including face-to-face presentation of information.
- Improve the Māori workforce through a co-ordinated training package (between tertiary institutions, hospitals, marae, Māori education institutions) and training of whānau.
- Improve support services including care in the home.
- Establishment of a Māori cancer database.
- Provide treatment choices to use Māori healing methods and medicines.

References

Kokiri Seaview Marae. 1999. *Ko To Rourou, Do Taku Rourou, Ka Ora Te Iwi: The Needs of Maori Affected by Cancer*. A report prepared for the Wellington Division (Inc) of the Cancer Society of New Zealand.

Candidate Priority Action 10: The development of treatment guidelines

Introduction

The aim of developing treatment guidelines would be to reduce mortality through ensuring the most effective cancer treatment practices are consistently followed. Secondary aims would include improving quality of life, patient satisfaction and cost benefit. Outcomes should be measured against other populations (eg, OECD countries).

The development of guidelines is complex, time consuming and costly especially in the context of multiple conditions, with an ongoing requirement to keep them up to date in an ever-changing field. However, given that there are already Guidelines on Surgery in Breast Cancer (Collins and Simpson), Early Detection of Breast Cancer for Primary Providers (New Zealand Guidelines Group), and some work has been done in New Zealand on the screening of bowel cancer (Parry 1997), it may be easier to concentrate on breast cancer and bowel cancer, where there is an apparent excess of cancer mortality.¹ Guidance documents and the sharing of protocols should be considered.

There are many types and subtypes of cancers and treatments are continually and sometimes rapidly evolving. From the perspective of cancer mortality, New Zealand has an excess of death from cancer in every age group in comparison to other countries including Australia, a country with similar lifestyles and close affinities in medical practice (Skegg and McCredie 2002). The most excess deaths in New Zealand (in comparison to Australia) are from colorectal cancer in males (104) and three sites – breast (143), colorectal (115) and lung (119) – in females. Those affected by these cancers should be the first target population for any strategy. However, all major cancers should be studied depending on resources available.

Before making changes, however, there should be a study looking at possible reasons for the differences in mortality in comparison to Australia (and perhaps other countries). These might include differences in treatment, environmental risks, delays in referral and/or diagnosis, etc. With respect to breast cancer, New Zealand now has similar treatments to those used in Australia and the same list of drugs, but the use of the drugs has not been uniform across the country.

If significant differences are identified, it would then be appropriate to address these and incorporate the changes needed into treatment guidelines or to use treatment guidance or recommendations already devised by other specialist groups in the United Kingdom, Canada and so on. Any change will be very dependent on an upgrading of information services and databases and accuracy of information. In addition, the six DHB cancer centres servicing the 16 DHBs without cancer centres will need to be given the responsibility of ensuring that the hospitals/clinicians in their areas are kept up to date and are well informed (along with the Ministry of Health).

¹ Lung cancer in females is also associated with excess mortality in New Zealand, but as treatment options are limited, the reasons for the differences should be explored and the prevention of smoking continued as a key target.

Recommendations

- Identify points of difference, if any, between treatments and develop therapeutic recommendations based on any significant differences.
- Consider adapting and adopting a limited number of overseas treatment guidelines if available rather than ‘re-inventing the wheel’. If Australian guidelines are currently available for the above conditions, they might be a starting point.
- Continue the process of sharing protocols, rather than guidelines, between departments. Guidelines are often only regarded as satisfactory if all parties are involved in their production and agree with the final format.
- Consider adopting current guidance documents that arose from the UK Calman-Hine Report which identified deficiency in cancer services (literature review and manual available for each):
 - Improving Outcomes in Breast Cancer 1996
 - Improving Outcomes in Colorectal Cancer 1997
 - Improving Outcomes in Lung Cancer 1998
 - Improving Outcomes in Gynaecological Cancer 1999
 - Improving Outcomes in Upper Gastrointestinal Cancer 2001.

These do not include haematological malignancies at the present time, but there are a number of overseas evidence-based guidelines which could be adapted to the local situation (eg, removing sections where a drug was not currently available for that condition) and/or could provide leverage via the Cancer Treatment Sub-committee of Pharmac for the timely introduction of new therapies (New Zealand Guidelines Group).

- Rather than adopting the total guidance document, some significant action points could be extracted from a limited number of treatment guidelines and used as a basis for funding, information for the public and referring doctors and treatment specialists in small centres and private practices. An example is given as follows:

‘Patients with multiple myeloma < 60 years of age should be treated with moderately intensive chemotherapy (eg, VAD or CVAMP) followed by allogeneic or autologous stem cell transplantation, unless clinically inappropriate.’

One message is that the adoption of any guidance document will need to be met with resource allocation.

- To help improve treatment outcomes, any treatment guidelines or guidance documents should be complemented by active involvement in well-organised clinical trials. This was well demonstrated by the involvement of all tertiary New Zealand haematology departments in the UK AML 10 study which improved the five-year survival from 2 percent to 42 percent from the late 1980s to 1996 (NZ BMT Study Group 2002). A desirable target might be that a certain percentage (eg, 70 percent) of all patients with certain malignancies, be entered into international multicentre randomised studies (eg, as occurs in paediatric oncology nationally and internationally).

- All of the above is dependent on the ability to get new drugs funded in a more timely fashion (eg, Glivec), and the availability of resources (eg, currently there would be problems adopting the guidance recommendations for colorectal cancer because of the rationing/inadequacies in New Zealand of publicly funded colonoscopy services).

Conclusion

The Ministry of Health would need to set standards and monitor any implementation. For example, departments and DHBs could be monitored with respect to the use of guidance documents. Real outcomes should be monitored, such as survival times in relationship to place of residence. (This will be impossible with the inadequate databases currently across the country.)

For some conditions, if treatment guidelines were adopted nationally, the use of recommended treatments could be clinically audited. One example for haematological malignancies might be: the number of myeloma patients < 55 years of age to be treated by stem cell transplantation could be set at a suitable figure (eg, 90 percent per annum) and the departments reviewed with respect to this activity.

A review of mortality in lung, breast and bowel malignancies could be undertaken again in three or five years after the adoption of changes which results from researching the differences in treatments, treatment guidance documents and/or treatment guidelines, benchmarking New Zealand cancer-related mortality against that in Australia and/or other OECD countries. This again is very dependent on the speed and accuracy of reporting to the Cancer Registry.

References

Skegg DCG, McCredie MRE. 2002. Comparison of cancer mortality and incidence in New Zealand and Australia. *New Zealand Medical Journal* 115: 205–8.

Collins JP, Simpson JS. Guidelines for the Surgical Management of Breast Cancer. URL: http://www.nzgg.org.nz/library/gl_complete/nz-only/breastcancer/.

Royal New Zealand College of General Practitioners. 1999. *Guidelines for Primary Care Providers: Early Detection of Breast Cancer*. Wellington: Royal New Zealand College of General Practitioners.

Parry S. 1997. Colorectal cancer screening. *New Zealand Medical Journal* 110: 303–4.

Guidance on Cancer Services: Improving outcomes in breast cancer. Manual update. URL: <http://www.nice.org.uk>. Accessed 30 June 2003.

NZ BMT Study Group. 2002. *Indications for Bone Marrow Transplantation*. Auckland: NZ BMT Study Group.

Hann IM, Stevens RF, Goldstone AH, et al. 1997. Randomized comparison of DAT vs ADE as induction chemotherapy in children and younger adults with acute myeloid leukaemia: results of the Medical Research Council's 10th AML trial (MRC AML 10). Adult and Childhood Leukaemia Working Parties of the Medical Research Council. *Blood* 89: 2311–18.