COMMONWEALTH OF AUSTRALIA

Official Committee Hansard

SENATE

COMMUNITY AFFAIRS REFERENCES COMMITTEE

Reference: Services and treatment options for persons with cancer

WEDNESDAY, 11 MAY 2005

CANBERRA

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SENATE

COMMUNITY AFFAIRS REFERENCES COMMITTEE

Wednesday, 11 May 2005

Members: Senator Marshall *(Chair)*, Senator Knowles *(Deputy Chair)*, Senators Humphries, Hutchins, Lees and Moore

Substitute members: Senator Cook for Senator Hutchins

Participating members: Senators Abetz, Allison, Barnett, Mark Bishop, George Campbell, Carr, Chapman, Colbeck, Coonan, Crossin, Denman, Eggleston, Chris Evans, Faulkner, Ferguson, Ferris, Forshaw, Greig, Harradine, Lees, Lightfoot, Ludwig, Mackay, Mason, McGauran, McLucas, Murray, Nettle, O'Brien, Payne, Tierney, Watson and Webber

Senators in attendance: Senators Cook, Humphries, Knowles, Lees, Marshall and Moore

Terms of reference for the inquiry:

To inquire into and report on:

(a) The delivery of services and options for treatment for persons diagnosed with cancer, with particular reference to:

  (i) the efficacy of a multi-disciplinary approach to cancer treatment,

  (ii) the role and desirability of a case manager/case co-ordinator to assist patients and/or their primary care givers,

  (iii) differing models and best practice for addressing psycho/social factors in patient care,

  (iv) differing models and best practice in delivering services and treatment options to regional Australia and Indigenous Australians, and

  (v) current barriers to the implementation of best practice in the above fields; and

(b) How less conventional and complementary cancer treatments can be assessed and judged, with particular reference to:

  (i) the extent to which less conventional and complementary treatments are researched, or are supported by research,

  (ii) the efficacy of common but less conventional approaches either as primary treatments or as adjuvant/complementary therapies, and

  (iii) the legitimate role of government in the field of less conventional cancer treatment.

WITNESSES

Committee met at 5.03 pm

MAHER, Professor Jane, Chief Medical Officer, Mount Vernon Cancer Centre, London, UK

KOHN, Dr Michelle, Complementary and Alternative Medicine Adviser, Macmillan Cancer Relief, London, UK

Evidence was taken via teleconference—

CHAIR—Welcome. You can probably hear the bells in the background. Unfortunately the Senate has just been called to a division. I am the only one that is paired at present, so I might have some initial discussion with you informally until the rest of the committee returns. This is most unfortunate, but the timing of these things is out of our control.

Senator COOK—As I am not there, I cannot hear the bells, if that makes any difference. I could start with some questions, if that does not interfere with anything at your end.

CHAIR—That would be fine, if you want to do that.

Senator COOK—I wonder whether Professor Maher and Dr Kohn have an opening word or two to say about their specialities.

Prof. Maher—I have been a practising oncologist for 20 years at Mount Vernon Cancer Centre. I am a senior lecturer at University College London and Professor of Cancer and Supportive Care at Hertfordshire University. I sit on the Joint Council of Oncology for the Royal College of Radiologists and the Royal College of Physicians. I am Chief Medical Officer at Macmillan Cancer Relief, and I sit on the Scientific Committee of Population and Behavioural Sciences for Cancer Research UK. That describes what I am. Do you want me to go on and talk about my experience with complementary therapy or do you want to leave that until a bit later?

Senator COOK—I am a senator and a member of this committee, but I am not in the parliament at the moment: I have cancer—a melanoma—and I am at a retreat, where I am getting some treatment. I think it is fair to say that I probably had most to do with getting this reference before the Senate. What I am most interested in really is, firstly, why you have moved into the field of complementary treatment. I also would like to know how you define complementary treatment. Making some assumptions about your answers now, I would also be interested to know whether you see this as an approach to dealing with cancer that does not just treat the disease but treats the whole person and therefore is likely to be a stronger approach to cancer treatment in the future than it is now. Those are my three questions.

Prof. Maher—My colleague Dr Michelle Kohn probably has the broadest view of what is happening nationally and internationally, but I will start with talking about my experience. I became involved in complementary therapy because when I was first appointed as a consultant in 1986 I conducted a piece of work to ask my patients what they wanted researched in the future, and complementary therapy came out as a priority amongst the patient population—and I found that a significant percentage of them were using complementary therapy. So over a period of two years I developed a partnership project between patients and carers and health care

professionals to develop a facility essentially to support patients during their cancer treatment at a cancer centre. We then opened an integrated facility which included complementary therapy as part of a care package. We developed a centre which had a combination of lay volunteers, cancer health care professionals, psychologists, psychiatrists, counsellors and complementary therapists. They worked in a centre which was integrated with part of the routine cancer centre behaviour.

If I think about what I have valued most over that period, I have observed that the complementary therapists with whom we have worked have particular skills in developing therapeutic relationships with patients. I can see the value of a large number of their interventions, and they have certainly helped patients to develop a different perspective on illness, involving mind, body and spirit. There is no doubt that that has been helpful for people. But I think there are a number of challenges, first of all in developing a shared language. Quite a lot of complementary and alternative therapists use language and concepts which are completely unfamiliar to me as a medical scientist. It is then very difficult to develop a shared concept of what you are doing. That makes it quite difficult to develop appropriate evaluation that is acceptable to other medical practitioners. I do not know if that is the sort of thing you are after.

Senator COOK—From that answer, Professor, I have interpreted that you started down this course as a medical scientist, because—

Prof. Maher—And I am still a medical scientist.

Senator COOK—that is where the patients want to go.

Prof. Maher—Correct.

Senator COOK—Could you for a moment dwell on what you regard as complementary therapy—could you explain that?

Prof. Maher—There are a variety of definitions, but in general I would use ‘complementary therapy’ to describe those therapies that are used in association with and complementary to other more orthodox forms of medicine. Today’s alternative therapy is tomorrow’s complementary therapy.

Senator COOK—Yes. Can you name some of those?

Prof. Maher—The therapies we are very comfortable using are acupuncture, homeopathy, aromatherapy, massage, reflexology, shiatsu and the Alexander technique. We have just started working with nutritional interventions. We have not used spiritual healing up until now, because we have not been able to develop a shared language. I wonder if it would be more helpful perhaps if Michelle came in here, on the definitions between alternative and complementary therapy?

Dr Kohn—Would you like me to give you a bit about my background first?

Senator COOK—Yes, please.

Dr Kohn—I am a physician who trained in London. I qualified in 1990 at University College and Middlesex School of Medicine. I always had an interest in pharmacology. Early on in my medical career when I was working on the HIV-AIDS unit many of my patients were using complementary therapies. We did not always know what the answers were or what was going on, but they said that things like shiatsu massage or the herbs they were taking seemed to make them feel better. So there was this openness and curiosity to try to work out what was helping them, and I think that is where my interest first arose.

I then went on—when I was doing my member of the Royal College of Physicians exam—to work with Professor Maher at Mount Vernon Hospital. I saw there that patients were benefiting from some of the therapies that she has described—touch therapies such as aromatherapy and mind body therapies such as relaxation. Patients said that these therapies helped them go through their treatment and give them a different perspective. That was when I saw this within the cancer setting. I should mention that I worked for a few years in clinical trial development and drug research, so I was always curious to see how that could be applied to these other therapies that had different diagnostic frameworks and different models in terms of how one would conduct a clinical study. Some of my exposure since then has been in the United States, where I visited various models.

I want to pick up on this point about the different levels of complementary therapies. In the UK we describe complementary therapies as therapies working alongside orthodox treatments—those would be things like mind body therapies, touch therapies and acupuncture. The phrase 'alternative therapies' we tend to use to describe therapies that are used in place of orthodox cancer treatments. It is purported that they have an effect on the cancer. The difficulty lies in the fact that most of those therapies today remain unproven rather than disproven. So as physicians we feel that to justify their use we want to see more robust research evidence, to make sure that they work and that they are safe.

In terms of classification, that has shifted quite a bit. As I said, we tend to use the word 'complementary' in the UK, but I think a model that is emerging out of the States is coming more towards the UK now, because patients are saying they want to know if there are things that might help their cancer apart from helping them feel better. Something that might be of value in this framework is that we have our main cancer cell killing strategies—things like surgery, chemotherapy and radiotherapy—and then the alternative cancer cell killing strategies. Those are the alternative therapies I mentioned—the alternative pharmaceuticals, things like hydrazine sulfate, alternative diets such as Gerson and alternative immune therapies. The problem there, as I mentioned, lies in the fact that most of those have not had robust evidence to date.

You then have complementary cancer cell killing strategies. They could involve vitamins, nutrients, herbs and things like *Panax ginseng*, which might help alongside the orthodox treatment and have an effect on the cancer. But most of the work that has been done to date remains early laboratory work. The other type of complementary therapies are complementary host defence building—things like diets and supplements which people use to enhance the immune system—and mind, body and spiritual therapies, again which people think might have a psycho-immune effect, giving them overall spiritual care and some sort of transformational process. Those therapies can normally be used safely alongside orthodox cancer treatments.

One of the problems which Professor Maher alluded to is that some of the wording that is used, such as 'immune boosting', is used very freely, but we have not yet got enough scientific evidence to know exactly what we mean by it. There is great potential here but we do need to scientifically investigate it further.

Senator COOK—Obviously, I have a million questions coming out of this, but, speaking as a cancer patient with a fairly dismal diagnosis, it seems to me that the paradox is that my surgeon and oncologist will tell me what they know as medical scientists, which is proven, but that what is proven does not offer me much of a shot at it. Therefore I want to know what the next level is—what will be proven in 10 years. What is coming up the slope that is the best and most likely winner, most likely to become a proven therapy within 10 years? I want it now. It seems to me that treating the whole person—their diet, their emotional state and their psychological state, and getting them into a situation where they have a positive view of life and so forth where they can relax and allow their immune system to take over—has a positive impact. If I can bring this to the point, this seems to be resisted by the orthodox medical field. My oncologist is a top bloke, but is a bit sneering towards them. Can you tell me whether you have encountered resistance to moving down this avenue of approach and, if so, how you have overcome it.

Prof. Maher—You have described that very well, and in describing it you have used a number of different words and phrases which are in common parlance but for which there are precise medical definitions and which people get very nervous about using unless they have the evidence base behind it. The way that I would have taken it—I certainly have taken it—is step by step: first of all, on a practical level, introducing complementary therapy and alternative treatments one at a time, focusing on developing a shared language to describe it, and then focusing on trying to make a connection between what the therapist describes as happening and what has some meaning to a scientist observing it. That sometimes takes quite a lot of work. In the Population and Behavioural Sciences Committee of Cancer Research UK, I have been through endless discussions and debates which have started as stand-offs but then have gradually moved as you have found a connection.

One of the difficulties for a medical scientist is that many of the complementary therapies are complex interventions. It is like a black box: you see the black box but you do not understand what is going on in the black box. Therefore it is very difficult as a scientist to give credence to the approach because you do not understand what it is and you have not got the language or the tools to find out. My experience is that the only way that you make progress is actually to have complementary therapists, alternative therapists and medical scientists who have open minds, working together in reflective practice, and then you find the points of contact.

CHAIR—Are you still finding major resistance? You talk about the general resistance and the need for people to have open minds, but do you think you have actually moved over the barrier where—

Dr Kohn—In terms of our national framework, we are finding that when it is complementary therapy—things such as mind body touch therapies—there does not seem to be resistance. I have noticed quite a shift in the last few years. I conducted a survey back in 1999 when I wrote a report for Macmillan Cancer Relief. At that time many of the doctors that were interviewed were saying things such as, 'Oh well, it keeps patients out of the surgery.' They were very nonchalant and not really encouraging or supportive; they were quite dismissive. Five years on, we are

finding that they really appreciate that we need to be addressing quality of life, symptomatology—that it is also about expanding life, not just extending it. This really does resonate with patients. They have been guided by the patients' voice. We are finding now that over 90 per cent of our cancer services are offering some sort of complementary therapy. We published a directory a couple of years back and we found that most hospices, hospitals and many voluntary sector organisations were offering these therapies. At the top of the list in the UK are the touch therapies, mind body, acupuncture, energy therapy. Medicinal nutritional therapies are still offered but at a much lower rate.

In the last couple of years we have had national guidance published within our NICE—the National Institute for Clinical Excellence—which looked at supportive and palliative care. Complementary therapies were one of 11 topics. Again, it validated it as part now of supportive and palliative care. So I think things definitely have shifted. The next stage, which is what you have been describing, is: how are we as physicians, as health professionals, going to respond to patients who want to do that bit more, who are looking for other treatments, other ways of helping with their illness, especially if orthodox medicine does not seem to have that much to offer?

CHAIR—What our committee would like to do is effectively to map out a strategy that leapfrogs the hurdles and barriers that are put in place in order to get to what should be considered the leading edge of the treatment of cancer. We do have a very conservative medical profession in this country. While a lot of words are said about integrated medicine and the way it is treated by involvement with everybody, it rarely actually happens. I think we really want to see what is happening in the UK and in the US. If we can shortcut that natural evolution that others have already gone through, and save ourselves several years, it is probably where we want to be.

Dr Kohn—I was recently in the States and I brought along a copy of the national guidelines that were published by the National Council for Hospice and Specialist Palliative Care Services with the Prince of Wales's Foundation. These were guidelines on how to set up and maintain services, dealing with all the issues such as qualification of therapists and an evidence base for the therapies used. Our American friends said, 'This will be tremendously helpful to us so that we don't reinvent the wheel.' So I think we could use some of these initiatives across countries, adapting them for local needs.

The other important point is to look for local clinical champions. People like Professor Maher have been instrumental. If you can find people with a very solid, orthodox background who have that open-mindedness, who are willing to get involved, to be actively supportive, who really can investigate this in a thorough way, that definitely moves things along in a very helpful direction.

CHAIR—I have been rejoined by my colleagues, so I will hand over to Senator Humphries.

Senator HUMPHRIES—I am sorry to have missed much of what you have said, but I am looking forward to reading the transcript and catching up. You may have already covered this issue, but I was wondering if you could recommend what kind of process, if any, we would establish in Australia, based on the experience you have had over there, to deal with potentially harmful applications or uses of complementary or alternative medicines. We have been given evidence that there are some settings where these applications could be not just neutral in terms

of a patient's therapeutic progress but potentially quite harmful. Distinguishing between harmful and innocuous therapies is obviously very important. Is there any particular advice you can give us about how to deal with that issue?

Dr Kohn—That is a key concern here amongst physicians. We held a research symposium last June and had a panel of clinicians who said that they did not have the information at their fingertips. They did not know whether some of these therapies might, for instance, interact with orthodox therapies and negate their effects. What we do need is to provide better information. Studies are coming out in this area. There was a study published in England last year looking at interactions with orthodox therapies. When studies like that appear, we try to encourage people to find a way to really make them come through the mainstream so that clinicians are alerted. Charities such as Macmillan Cancer Relief in the UK and others that have been involved in this field will probably be looking more and more at how we can educate physicians. We need to make it as easy for them as possible to give the information to hand. Otherwise the dialogue between patients and physicians is not going to occur.

Prof. Maher—I agree with Michelle there. I think there are three processes. The first thing is that you need to have and make use of the documentation that has been produced by other countries—particularly in the UK—relating to standards in terms of delivery, process, what therapies work and what therapies do not work, and to have this backed up with a piece of good information on safety. The second thing is that you need to think seriously about having some form of national research behaviour such as the one that has been set up in the United States, the one that started off with MCAM. There is actual research activity. And the third thing is the possibility of having some sort of exemplar centre, exemplar place, that is associated with a very highly respected cancer centre. I think those three things are important: the organisation process stuff, the research, the basic information and some sort of exemplar site.

Senator HUMPHRIES—Some of the evidence we received suggested that in some areas there was ample evidence of the therapeutic value of certain alternative or complementary therapies but that orthodox medicine was not actually interested in looking at it—that it was not dished up to it, in a sense, through the training they received in medical school, so it was largely ignored.

Prof. Maher—That is correct.

Senator HUMPHRIES—Is there any way around that? Should there be some kind of umpire, for example, to whom we systematically refer alternative and complementary medicines for assessment?

Prof. Maher—I think that has certainly been a problem in this country in terms of prioritisation. There is a sort of inbuilt bias against something which comes with the label 'complementary' or 'alternative'. I think that still is there. Would you agree, Michelle?

Dr Kohn—Yes, but now that we have our NICE guidance framework alongside other supportive and palliative care methods of treatment, I think it is shifting. One of the concerns has been over the regulation of the therapies. Again, there has had to be quite a bit of attention focused on that. For example, in the UK, only osteopathy and chiropractic are currently statutorily regulated, but there are now moves, which are quite evolved, towards acupuncture

and herbal medicine being regulated by the state and some of the other therapies ultimately being self-regulated. That should help them with this whole concern about safety—both the therapies and the practitioners offering them.

As Professor Maher said, there are four key strands here. One is service delivery and making sure that de novo you can come up with guidelines for practice for centres and have as many exemplars as possible. Do not forget that there will be different models according to what the setting is—whether it is a hospital or hospice and how many things it will be able to offer. Beyond that you also want to have an information strategy—how to get the information across both to health professionals and patients, and education, chiefly for professionals—and finally a research infrastructure to underpin it.

We are pleased that in the UK we now have, within our National Cancer Research Institute, a complementary therapies clinical studies development group. Within that group we are looking to which areas we should be prioritising and what sorts of studies we should be conducting to really show the effects. We feel that if we conduct some high-quality studies it will attract more of the establishment to the realisation that these things can be done successfully and with good outcomes. Beyond that, we need to ensure that things are implemented when we have the research.

Senator LEES—I also apologise for having to go to a division; hopefully we will not have any more. You may have answered this question, but how do people find you? One of the issues we have in Australia is that there are some good centres, but you do not find them unless your GP refers you. How does it work in the UK? If someone's GP does not recommend that they go to you, can they still access your services?

Prof. Maher—My centre is a drop-in service. For certain things, you can drop in and automatically be assessed. We addressed this through Macmillan Cancer Relief by commissioning Michelle Kohn to develop a directory of available visitor services with documentation on what they provide. There are two issues there. The first is knowing about the services at all and providing some sort of directory of services that is available to patients and can be viewed by anyone. The second is being able to access the service and how it is paid for. At the moment there are very few services that can be accessed through the NHS. The majority of services in the UK are still funded largely through charity and private, out-of-pocket expense, rather than through state delivery.

Dr Kohn—A good thing about the directory was the feedback. People were telling us that, if they looked in their particular area and there was not much going on, they were able to use it as ammunition for their service commissioners to say, 'Look, there is a gap in our area; we do not have anything, whereas much more is provided in such-and-such place.' Conducting a mapping exercise certainly had its benefits. The other points to mention from our analysis of the findings is that most services were free of charge, as Professor Maher has mentioned, and that many of the services also offered therapies to carers and staff. That is an important point: we should be looking after carers where possible. Once staff receive the benefits, it helps with burnout and helps them understand what is going on and then they are more sympathetic towards their patients.

Senator LEES—In the UK do you have any differences between how a person with one type of cancer is treated versus another? Here in Australia we seem to have made quite a lot of advances in the treatment of breast cancer, but a raft of other cancers seem to have been left behind. Do you have any of those barriers or distinctions?

Prof. Maher—Yes, and I think that a lot of it is to do with perception. I think it is still the case in this country that higher-educated women with chronic relapse and remit type cancers tend to access complementary therapies. I think that is still the case, isn't it, Michelle?

Dr Kohn—Yes, absolutely. In fact, there are a couple of studies that were commissioned by our Department of Health, one of which Professor Maher has been involved in, looking at the drivers of CAM use: perceptions, experiences and why people are using it. The emergent findings are that it tends to be women with breast cancer who are using the therapies. One of the other studies focused particularly on men to find out what the barriers were and why they were not using it. It is important to really come to grips with that.

Senator LEES—What did they find? We have the same breakdown here of who is using services. If they are provided, men seem very reluctant to access anything you would call complementary or alternative.

Dr Kohn—To my knowledge, that study has not yet been reported on. It is still in progress.

Prof. Maher—There is an issue of access and association. When we started to provide a lot more financial advice in our support and information centre we found that the men began to come in and then they began to take up some of the services that were associated with it. It is not an automatic thing for men—certainly Englishmen—to seek supportive therapies.

Dr Kohn—One colleague who runs a very successful service in an oncology centre in the north of England said that because his service is physically integrated—it is actually within oncology—he gets as many men as women from across the range, including the lower socioeconomic classes. It is quite an interesting finding: his view is if you make it integrated enough and the oncologists know that it is literally next door, as opposed to patients having to go to another building or go somewhere else, they are likely to use it. They then see it as much a part of the service as any of the other oncological features.

Prof. Maher—I would agree with that. That has certainly been our experience.

Senator LEES—My final question relates to the research you are or are not able to do and the funding for looking at outcomes where people have been able to access complementary therapies.

Prof. Maher—That has been one of the greatest challenges. We have just completed a multicentre, randomised controlled trial, looking at the simplest of things, such as aromatherapy massage, and we are about to report on that with a positive result. But developing that protocol and getting it funded and getting it through with the appropriate amount of funding for a multicentre, randomised controlled trial was a big challenge. The sort of money that is required for big studies is quite difficult to obtain, because it is just not prioritised by research teams. Having said that, there is no doubt that there is an increase in research, certainly in phase 1 and

phase 2 studies, and randomised controlled trials have commenced. But I think you do need ring-fenced money if it is going to take off, and I think that has been the American experience. Would you agree with that, Michelle?

Dr Kohn—Absolutely. We held a research symposium last summer to bring together researchers, funders, policy makers and practitioners and it helped just to hear the views. Some of the things we were hearing were that people did not know where to go to get the funds, and within the funding bodies they did not have people with suitable experience for peer review or to judge the protocols. So, until these things are addressed, it is unlikely that the field will evolve. Now that we have a complementary therapy group within the National Cancer Research Institute, that again gives more of a focus on this area. A key factor that was mentioned, however, is that we must not progress to randomised controlled trials too quickly. For many of these therapies we need to do a lot of early exploratory and pilot work. Otherwise, we progress too quickly and we end up with meaningless trials. What we need is collaboration across research and practice communities to make sure that those trials are meaningful in their design.

Prof. Maher—I would like to add that the Medical Research Council in the UK has developed the concept of complex medical interventions—that is, interventions where there are multiple elements to the treatment—and you do not necessarily understand which is the important part of it and which is the important domain. In order to explore that, so you fully understand the therapy or the treatment that you are delivering, needs quite a lot of preresearch. That is also the area for which it is often difficult to get sufficient funding. The risk with that is that you end up doing a study which investigates the wrong bit, using the wrong outcome on the wrong population, because you have not clearly understood exactly what the therapy does. So I think that a very important area is to make sure that there is adequate funding for the prepilot work.

Dr Kohn—We also have to think in terms of the outcome measures to ensure that what we are measuring is meaningful and really descriptive of what the therapies are doing. We so often find, as Professor Maher described before, that it might be that the symptomatology is still there—for example, the patient still experiences pain—but they say, 'I feel better able to cope.' There has been a transformation. Through many of the therapies and by using an integrative approach, there is a possibility for transformation and other things happening that really make people feel better that might not be captured with conventional outcome measures.

Senator LEES—My final question is: is it so important to break down the various parts of what people are doing? For example, someone who may find massage very helpful may also, without necessarily talking to researchers, have changed their diet, be taking vitamins or be doing a range of other things as well.

Prof. Maher—I think we do need to have an idea of exactly what is going on.

Dr Kohn—The problem with diet and vitamins is that you want to make sure that there are no negative interactions with orthodox therapies. For much of this, what we do respect is that patients value some form of self care. They want to be doing things for themselves. The key question they often ask is: 'What else can I do? Are there other things out there?' It is the 'I' factor. They want to be involved in their own care. To a degree, there has to be that respect, but we also want to ensure that what they are doing is not going to actually be harmful.

Senator LEES—Can we make just a general comment, such as that people who are involved in their own care, who are doing something positive for themselves, have better outcomes than people who do not?

Prof. Maher—I do not think you can say that. Unfortunately, although intuitively one would say that that was correct, I do not think you can say that it is completely correct, because there are people who do all of those things and nevertheless do badly. So it is not a universal thing, unfortunately. I do not know if you would agree with that, Michelle.

Dr Kohn—Yes, I do. But I think there is no doubt that, even if ultimately they do badly, if they are saying that they have periods where they are feeling much better—they have hope; they have energy; they have those things that matter to them—that is very important. We do acknowledge that, if these therapies are helping them to get through the uncertainty, to live better with their cancer, then there is no doubt that that is something that is of great importance.

Prof. Maher—I think from your health service point of view, there are two points related to that. The first thing is that, if people feel supported and feel better, they comment less negatively on every other aspect of their life and their care. So if they feel supported—and there is no doubt that in those centres that have complementary therapies associated with them they do feel supported—they will comment less negatively on everything else that happens in association with that treatment.

Dr Kohn—A point that I would like to make is that for us, as orthodox physicians, complementary therapies are helping us reassess the basic tenets of good care, such as the value of things like good healing partnerships. This is not just about compliance. Patients will often say they have a wonderful therapeutic relationship with their complementary therapy practitioner. So there is a lot that orthodox medicine can learn from this, too.

Senator COOK—Most of the questions I want to ask now have been asked, but in slightly different ways, so just bear with me. Coming back to where I concluded my line of questioning, can I say this by way of preface. I am a politician. I understand the difference between perception and fact, and I understand that perception wins. You say that your patients led you down the path of complementary care. You have now been investigating this for some time. Are you in a position to say, when this type of approach is compared to just a straight orthodox approach, what your investigation shows as the better outcome in either life extension or healing?

Prof. Maher—I think that, having become involved in working with complementary and alternative therapies, there is no doubt in my mind that they bring a different dimension to care. I have probably learnt more from them than they have learnt from me in terms of cancer and whatnot. I think that complementary and alternative treatment brings a different dimension to the care of cancer patients.

I am increasingly aware of the fact that the disease trajectory of cancer is changing. It used to be that you were very well and then you got cancer and you died. It was a very clear disease trajectory. We now have a lot more people living with cancer and they usually have one or two other illnesses—diabetes and heart disease. It is much more of a chronic illness than it was before. Because it is a chronic illness, there is a lot more about keeping with the illness rather

than just going in there and killing it. My belief and my experience in doing research is that complementary and alternative treatments are going to provide us with much better ways of dealing with chronic cancer than we had before.

Dr Kohn—If I could pick up on that point, rather than looking mechanistically for just a single magic bullet what we are appreciating, probably more and more, is that by combining different modalities and attacking things on different levels there might be synergies that ultimately may lead to increased longevity. This is something that does need to be investigated but at the moment it is too early to say.

There have been a couple of studies on, for example, group support. A study was done some years ago which indicated that patients with breast cancer who were given group support lived longer than those who were not. They replicated that study and did not get the same response for survival, even though patients had fewer symptoms and felt better. It is complex. The reasons why it was not replicated are numerous and it is difficult to draw concrete conclusions. One of the conclusions was that the climate has changed. People now access support in all sorts of other ways. The climate is not the same as it was in the eighties, where if you offered one intervention it was likely to be the only support that the patient had access to. So, with that changing climate, it is quite difficult at this junction to ascertain the question of longevity.

Senator COOK—Do you think you are far off knowing the answer to that question?

Dr Kohn—It is a difficult thing in trials. Professor Maher was talking about setting up clinical trials and the costs of trials. When one is looking for those sorts of hard outcome measures, they are costly and difficult trials to construct. It is something that is obviously required, but it depends on what intervention one is looking at. It is easier to say that one would look at a hard alternative therapy as opposed to some of these complementary interventions.

Senator COOK—I will harden the question to one degree but it may not be able to be answered simply. Given your experience in this field and your knowledge of medicine and treatment, is it likely that you will dabble in the complementary and alternative field and move on to something else or is it likely that—to use a word that you used a moment ago—the trajectory of the treatment of cancer patients will increasingly embrace complementary or integrative approaches to healing?

Dr Kohn—I think it is worth looking at other chronic diseases to see the parallels. For example, in rheumatological illnesses, many patients follow the complementary path, again to have their long periods of remission from illness. So, the more we are looking at cancer as an illness with long periods of chronicity, the more we could probably learn from other illnesses where they have been used in that way.

Prof. Maher—I think that many of the complementary and alternative practitioners are extremely skilled in enhancing the placebo effect, enhancing self-management and increasing the ability to deal with chronic illness, and that is where I think their skills lie. I think that there will be an increased integration of complementary and orthodox approaches for that reason.

Senator COOK—In your answer to Senator Lees about the effect of a patient taking greater responsibility for their own treatment you said you got—in my understanding at least—a mixed

response: yes, it has a positive effect but it is not universal. Is that how you want us to understand it?

Dr Kohn—If you are looking at a situation where you are looking not just at the disease but at the disease in a person and looking at the interaction between that person and the disease, inevitably you are not going to get the same response. It is not going to be the same in everybody. It is not like doing a randomised controlled trial and being absolutely certain that you will get the same effect in the same person.

Senator COOK—The comparison is between someone who does not take some responsibility for getting well and puts their entire faith in their doctor and someone who takes some responsibility and tries to manage their disease, find which is the best way for them for healing their disease—

Prof. Maher—Can I quickly give you some evidence on that. There is evidence that if you have a helpless, hopeless approach to disease, you do worse. But there is no evidence that if you have a fighting spirit approach to your disease, you do better.

Dr Kohn—To extend on that point, in the early work they divided people into four basic personality categories—helpless hopeless; stoic; denial; and fighting spirit. We now realise that that is a little oversimplified. Actually what matters is that people are appropriate for their situation. There are times when it would be appropriate not to care about things. One cannot be happy and smiling about it all the time. There are times when negative emotion works at the right time. The construct was changed to positive assertive, positive yielding, negative assertive and negative yielding, meaning that at different times people should react appropriately. But overall it would help not to be hopeless and helpless.

Prof. Maher—I think we are answering the question in a more practical way. I am aware that we have been quite woolly. But from a practical point of view, there is evidence—or certainly a trend to thinking—that there are more people who could benefit from a more self-managed approach. That is, there are probably quite a lot of people who are currently not actively involved in self-management of their illness who would benefit from an approach that involved more self-management.

Dr Kohn—To pick up on that point, I think Professor Maher is absolutely right. One cannot predict. It is not a case where there is a certain personality who will benefit. We often find that people say they never would have thought that this would have been for them; once they have been exposed to complementary therapy, they are surprised in a way by how much they have benefited. I do not think it is, at the outset, a naturally self-selected group.

Senator COOK—I am aware we have been a bit woolly too. I do not have time to go into it in a more defined way, but I have one last question. When you were setting out what you call complementary treatments, you did not include meditation. Is that an omission?

Dr Kohn—It is in there. I would say the main therapies that we include are the touch therapies, reflexology, aromatherapy and massage; mind-body therapies such as visualisation, meditation and relaxation; acupuncture; energy therapies such as reiki spiritual healing; creative

therapies such as art therapy and drama therapy; homeopathy; and medicinal and nutritional therapies.

Senator COOK—Is the nutritional therapy about diet?

Dr Kohn—When we describe them as complementary, we mean that they are going to be dietary modifications used alongside orthodox therapies as opposed to diets used as a treatment regime, such as the Gerson therapy.

Senator COOK—Thank you. I understand.

CHAIR—We will have to leave it there. I thank Professor Maher and Dr Kohn for providing evidence to the committee via teleconference from London.

Committee adjourned at 5.54 pm