

## After the treatment's over...

### Measuring the rehabilitation needs of Europe's growing army of survivors

→ Peter McIntyre

As more cancer patients survive longer, the need for rehabilitation services is rising up the political agenda, driven by patients who want their lives back, and by policy makers who want people to get back to work, or at least become as independent as possible. To improve services we need to measure rehabilitation needs and service capacity – but that's easier said than done.



The odds that at least one person in a group like this is living with cancer are high and increasing. Many will need help to get back on their feet after their treatment ends

By 2030 an estimated 75 million people will be living with cancer diagnosed within the previous five years, almost 20 million of them in World Health Organization European region. The number of people in Europe living with a diagnosis of cancer is already rising by about one million people a year, as the number of new cases continues to outstrip the number of people dying with cancer.

This is not only a health challenge. In an era of financial turmoil and underfunded pensions, the prospect of an ever increasing number of people living for a long time with a potentially disabling disease frightens policy makers.

Rehabilitation is a hot topic. On the one hand it is an unexplored, expensive and growing cost; on the other hand, if rehabilitation reduces dependency on acute health services and allows millions of people to return to work and an active life, it could prove highly cost-effective.

As one European expert who has been considering rehabilitation needs put it,

politicians want to know “whether to do rehab or build 50 kilometres of highway.”

In 2008 the European Commission launched EUROCHIP 3 to enable meaningful comparison of the needs of cancer patients and the capacity of cancer services between countries and regions, with a view to promoting equality of cancer care across Europe. Under one of the work packages, experts were commissioned to draw up a list of indicators that would enable assessment of rehabilitation needs in the 27 member states.

According to the brief, the indicators had to be based on data that could be collected on a population basis via existing cancer registries, and they had to provide an indication of psychological, clinical, psychiatric, nutritional and social services rehabilitation needs.

This has proved a thankless job. The experts found no agreed definition of who needs or gets rehabilitation, while cancer registries collect little data that can be used to assess need. There is not even agreement on what rehabilitation means.

### DIFFERENT NEEDS

People have different needs according to their cancer, the success or otherwise of treatment, their age and gender. For some, the treatment is completely successful while for others the disease or treatment changes what they can do, and even the way they look. Some need physiotherapy; others need surgical reconstruction or psychosocial counselling.

People also have different aspirations. Some want to return to work. Others want peace and dignity in their remaining time. Young people with cancer may have a need for fertility advice and treatment.

Everyone quotes the World Health Organization’s definition of rehabilitation, but it hardly helps to define what is needed. “Rehabilitation of people with disabilities is a process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels. Rehabilitation provides disabled people with the tools they need to attain independence and self-determination.”

### PREVALENCE

Piret Veerus from the National Institute for Health Development in Estonia is leading the expert group and points out that since rehabilitation is a process rather than an endpoint, no single indicator can map patient needs. She told the group, “Prevalence is easily collectable and can be a proxy indicator for the number of patients who need rehabilitation, but maybe prevalence by cancer site or by gender and age group is more important.”

Hans Bartsch, medical director of the Tumour Biology Centre at Albert-Ludwigs University, Freiburg, in Germany, heads the working group on supportive care, rehabilitation and social medicine for the German Cancer Society. He doubts that prevalence is much of a guide to rehabilitation needs unless more detail is captured. “The spectrum of rehabilitation needs changes over time. In the first year after treatment there are a lot of physical needs and acute psychosocial aspects. After a time the physical needs decrease and long-term recurrence fears arise.

“Lung cancer patients survive two years at best and they have a lot of rehabilitation needs to keep them as independent as they can be. But only 15% of

lung cancer patients receive rehabilitation. Of breast cancer patients, I guess 60% receive rehab.”

Gill Hubbard, reader at the Cancer Care Research Centre in Stirling, Scotland, agrees that prevalence on its own is not a good measure of the need for rehabilitation. Her centre is pressing the Scottish Government to collect data on recurrence of disease. “Qualitative data on people living with cancer shows that fear of the disease coming back is so strong. You can tell people there is an 80% survival rate, but what they really want to know is what is the chance of my disease coming back. Patient representatives are keen to keep recurrence as an issue. The cancer data people are not so keen, because it is difficult to collect.”

To get around the difficulty of collecting recurrence data, various proposals have been put forward for deriving information on recurrence from prevalence data using statistical modelling. The expert group considered the concept of ‘conditioned survival’, which shows the statistical chances of a former cancer patient dying in the 12 months after each year of survival. They also recommended ‘qualified prevalence’ as a proxy indicator, which models how many patients will have complications, relapse or metastases. These and other modelling concepts are being worked on at the Istituto Nazionale dei Tumori in Milan from where Paolo Baili is providing technical support.

### RETURN TO WORK

There was a strong feeling that something beyond prevalence was also needed. Miklós Garami, head of Paediatric Oncology at Semmelweis University, Hungary,

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said, “What people want to know is: will I be able to work or not? Can I have children or not? These things are easy to measure but nobody measures them.”

Bartsch agreed. “Return to work is the major issue in Germany. The pension fund is responsible. Politicians always ask: what is the percentage going back to work after rehabilitation?”

But most cancer patients are at or beyond retirement age and work may not be at the top of a cancer patient’s own list of priorities. Josette Hoekstra-Weebers, head of supportive care at the Comprehensive Cancer Centre Netherlands, in Groningen, suggests that financial pressure may drive the agenda. “Whose need is it really to return to work? The costs of healthcare are going through the roof and in the Netherlands health insurance companies are giving less and less money for rehabilitation.”

Despite such reservations, it is still felt that return to work could be an important indicator. Both France and Belgium are looking at how to link different databases to discover how many cancer patients do go back to work.

However, Elke Van Hoof, director of the Belgian Cancer Centre, suggests that ‘return to normal life’ would be a better test, less open to political pressure. “No-one was interested in the past because most cancer patients died. Now everyone wants to know who is going to pay for our pensions.”

## QUALITY OF LIFE

Quality of life has been identified as a priority issue, which could be measured using a questionnaire developed by the EORTC (European Organisation for Research and Treatment of Cancer) that is widely used in research. Because of technical, legal and ethical challenges, in some countries collecting these data would require primary care doctors to act as a go-between with patients, and it was feared that the

**How do you quantify rehabilitation needs and capacities? Exercise programmes like this one can be important to regain fitness after cancer treatment, but different survivors need different types of help at different times, from different service providers**



response rate might be low, making samples unrepresentative. Hoekstra-Weebers pointed out that the Netherlands and other European countries use a psychosocial screening tool developed by the National Comprehensive Cancer Network (an alliance of twenty-one cancer centres in the US), but until this is used more widely, she said, it cannot be adopted as an EU indicator.

An attempt was made to find a measure of existing resources devoted to cancer rehabilitation, but social systems were too diverse to find common threads. Moreover the quantity of resources may be secondary to the quality.

## MEASURING QUALITY

The Belgian Cancer Plan finances support from nutritionists and social workers and others, but Van Hoof says not enough attention has been paid to quality. “There are 300 psychologists counselling cancer patients in Belgium, but only 10% are trained in cancer issues. So far, we don’t have any data on qual-

ity of care. Most psychologists are not prepared to deal with the specific issues, fears and problems that are experienced by patients. They had an idealistic notion that they were going to help cancer patients, but they see that some cancer patients die or have problems and some are running away from this. It is very important that staff are well-trained and receive support to cope with their own feelings.”

Bartsch strongly agrees. “It is not a question of how many psychologists you have, it is what they are doing. In Germany this is work in progress. We have 90 psychosocial centres but only 20 are in a programme of evaluation to look at what they did. I miss in these indicators the qualitative aspects of rehabilitation. The danger is that the commission will say we will give so many millions to each country for psychologists and social workers, but that will not improve the situation.”

Hubbard from Stirling says that collecting data on rehabilitation capacity is very complex. The UK has a pyramid model with specialist rehabilitation at the top and general rehabilitation at the bottom. “Capturing data on that is difficult even in our country. We are saying every health and social care professional needs to have some low-level conversation with the patient to ask about work and assess their needs. The patient might then get referred to the specialist. The capacity you want to measure needs more conceptualising – is it specialist or general rehabilitation?”

Palliative care is another issue that divided the group. Jeanne-Marie Bréchet from the French National Cancer Institute pointed out that the (quite high) proportion of cancer patients who die within a year of diagnosis have a need for palliative care that can be considered as a specialised form of rehabilitation. Magdalena Bielska-Lasota from the National Institute of Public Health in Warsaw

## “A major part of the national growth is going to cancer treatment, and rehabilitation is required to get the benefit”

agrees. “This is a discipline of oncology which is developing in its own way, but in Europe not much attention is paid to it and it is not funded sufficiently.” In Poland palliative care development is included in the National Cancer Plan and the main objective is to improve quality of life for patients with advanced disease. Priority has been given to the development of high-quality palliative care centres and information about pain relief. There is also special support for patients and families in a system known as ‘hospices at home’. “The number of hospices is recognised as an important indicator and I would like it to be included,” she said. However, there was also a view that hospices are a distinct speciality that should not be considered as part of oncological rehabilitation.

### SOME PROPOSALS

Despite these difficulties, the group has come up with a short list of proposals.

- Two- and five-year prevalence should be collected by cancer site, age and gender. The list will include qualified prevalence and conditioned survival and if these cannot be calculated then the proportion of patients who have not (yet) been cured will be included.
- Quality of life has been given a high priority but will require pilot studies to test the methodology. Return to work will also be included if links can be made between databases and if the data protection problems can be overcome.
- Palliative care will be discussed with the European Association for Palliative Care.

- One innovative idea is to collect data on specialised care – speech therapy for patients with head and neck cancer, physiotherapy for breast cancer patients, dietician support for colon cancer patients, and psychological support for all cancers.

Alongside the recommendations for data collection will be a mapping report and a scientific paper for the *European Journal of Cancer* or other prestigious journal. A recommendation will be made to the European Commission that rehabilitation be given a higher profile within European research.

In Germany, the rehabilitation system – which originated 50 years ago as a fitness and nutrition programme in former TB centres in the countryside – led the way in providing psychological support for patients, and Bartsch says they need to become better at measuring outcomes.

“As we recognised during these meetings, the differences are tremendous and the infrastructure is still a developing process. Countries like the UK or France or especially the Netherlands are almost not comparable to countries like Slovenia or Bulgaria. A good result would be that we could identify major areas for research and major areas of development to at least give a basic kind of support to cancer patients.”

### VALUE FOR MONEY

It is critical to show that rehabilitation is good value for money, he adds. In Germany the cost of rehabilitation is covered by the pension fund, and cancer patients are the only ones who are enti-

tled to draw on this even if they are retired – something that has recently generated a heated debate. “We have about 1 million rehabilitation patients for different kinds of diseases and about 18% of those – 100,000 to 180,000 people – are cancer patients. How can we justify this money?”

Garami, from Semmelweis University, Budapest, says that, despite the difficulties, the EUROCHIP initiative is crucial. “In the European Union we do not have a general rehabilitation system and we do not even provide a definition for rehabilitation. A major part of the national growth is going to oncology treatment, and rehabilitation is required to get the benefit, which means we have to get patients back in the work field or help them to get a normal life.

“Health services should offer in different countries different kinds of possibilities, but definitely they should offer basic treatment, such as physical rehabilitation, to help people return to work or even to a basic social life or emotional life.

“In major countries of the EU they do not have the right to rehabilitation. When active treatment is finished the patient is left alone.”

With Europe in financial crisis, ‘softer’ areas of treatment and care are particularly vulnerable to cutbacks. Although it was not so obvious when the group was assembled, one key outcome might be to create a climate where the rehabilitation needs of patients diagnosed with cancer are seen as equally legitimate as the need for curative forms of treatment.