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Editorial Comment

Behavioural and social science research in cancer: time for action

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The diagnosis of cancer leads to a significant emotional burden, which current health services often fail to address. There is a paucity of behavioural and social science research to underpin approaches to more effective, behaviourally-focused preventive strategies for cancer, and improved psychosocial support for cancer patients. Patients with unmet needs typically show higher psychological and symptom distress. Further, this extends well beyond the patient; issues of cancer survivorship have equal salience for carers and family members. Family caregivers frequently lack support, are given to feelings of isolation, and experience considerable anxiety.

In this issue of the *European Journal of Cancer*, an expert group has outlined a strategy for research in the behavioural and social sciences to improve cancer control and care [1]. The aim of the strategy is to enhance research capacity in Europe in the behavioural and social sciences. The work has been supported by the European Commission, has involved a wide, consultative process, and has brought together experts from a wide range of disciplines, in keeping with the broadness of the Group's remit.

This is an important development; the Group outlines a coordinated plan of research into the various behavioural aspects of cancer control at all stages of the journey, from early detection and screening, to active treatment stage and late palliation. At all stages the message is clear; adequate attention must be given to psychosocial and behavioural factors if we are to develop cancer strategies which are truly focused on individuals with cancer, their families and carers. New service developments in this field must be supported by an adequate research base.

1. Research capacity and coordination

There is a strong case for a more coordinated approach to cancer research capacity building in behavioural and social sciences; these areas lack effective European-wide coordination and collaboration. Initiatives such as European Union (EU)-funded Networks of Excellence have the potential to bring together leading European researchers and enhance the integration of research in this area. There are promising national developments which may serve as useful models; the United Kingdom (UK), for example, has established the National Cancer Research Institute (NCRI) [2] with the aim of developing more effective research investment strategies, and improving coordination between the major funding bodies such as the Medical Research Council and Cancer Research UK. For the first time, it has been possible to take stock of current cancer research funding, and identify areas of research which have been neglected. Importantly, national clinical studies groups have been established to coordinate and build research capacity in areas including primary care, palliative care and psychosocial health. The NCRI also has a strong focus on strengthening links with key European and North American cancer research agencies.

2. Role of primary care

Primary care has a central and growing role in the health systems of EU member states, and there is growing interest in organisational developments in European primary care to better incorporate patient perspectives and psychosocial aspects of healthcare [3]. Family doctors and other primary care providers are concerned with the comprehensive, coordinated, and

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continuous care of individuals, families, and, increasingly, populations. It is critical, therefore, that the role of primary care in cancer prevention and management in Europe is maximised. There is a growing recognition that primary care has a vital role to play in the provision of psychosocial care to patients with cancer [4]. Further, many opportunities for cancer prevention exist in primary care. Nevertheless, lack of research and evidence about effective social and behavioural strategies hinders progress.

3. Cancer screening

Much psychological and behavioural research into cancer screening has focused on strategies for improving uptake rates, and this work needs to continue. However, the concept of informed choice is the focus of much current research effort. For European screening programmes to be 'successful', many would argue that we need not only good uptake rates, but also participants who are truly informed of the risks and benefits in a way which supports patient autonomy. We currently lack adequate measures of informed choice [5], and effective strategies for incorporating informed choice in the delivery of screening programmes.

4. Future trends

In the context of important initiatives such as the Europe Against Cancer Programme there are declining cancer rates in Europe [6], but there remains ample scope for efforts targeting preventive behaviours and psychosocial support. At present, Europe lacks the evidence base to implement widespread initiatives in these areas; hence, the need for a research capacity building strategy.

In the future, it is likely that more people are going to be diagnosed with cancer, and that they are going to live longer with the disease. Strategies for psychosocial support for cancer patients will need to take into account the aging population of cancer patients, and the growing perception that cancer is a chronic illness. It is likely there will be a much greater need for better psychosocial care, particularly with the breakdown of community and family structures in Europe, and the growing number of people living alone. There will be a growing emphasis on quality of life (and death), with demands for greater choice in when and how to die.

Cancer patients in Europe will also have access to unprecedented amounts of information about their illness and treatments. They will likely be linked to treatment centres making use of novel information technologies. None of these developments will obviate their need for psychosocial care; indeed, there will be a call for technology-based solutions to help address issues such as isolation, anxiety and depression [7]. In parallel, the need for human contact and the demand for face-to-face interaction may become greater.

5. Benefits of research

The growing focus on quality of life (QOL) issues in cancer services is an obvious and tangible benefit of previous research efforts; incorporating standardised health-related quality of life assessments in cancer patient care can heighten the awareness of these issues amongst healthcare providers. The European Organisation for Research and Treatment of Cancer (EORTC) has taken a leading role in developing valid instruments to assess quality of life, and this has led to widespread application in research and clinical settings [8]. The scope and application of research needs to be widened; there is a need for a European mobilisation of activities and resources. Behavioural and social science research is currently fragmented and there has been little cross-country participation. Yet there is a particular imperative that these issues are addressed at a European level. There is a need to generate change in health systems and health policy and foster partnerships to advocate for improved resources. Further, there is a need to integrate the resources, infrastructure and expertise of leading researchers in Europe, to attract investment, and better coordinate activities. The result will be better social and psychological outcomes for cancer patients throughout Europe, improved quality of life and, it would seem, further improvements in survival.

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