Educational Challenges: 
Some strategies to provide better cancer care in underserved populations

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Differences in healthcare, whether due to unequal income, to age, education or social factors, remain one of the most important challenges for care providers. At the 2015 MASCC meeting in Copenhagen, the Education Study Group hosted a workshop on providing cancer care to underserved populations. This article is adapted from that workshop.

Social inequalities in health are those systematic differences that are socially produced and unfair. There are many underserved cancer patients in Europe today due to a variety of complex causes, among these are low income, ethnic minority discrimination, cultural and educational differences and lack of support during and after treatment. Studies of the cancer patient experience have found that the young and very old, ethnic minority patients and women report worse experiences in the quality of health care, greater healthcare inequalities and lower patient satisfaction. To reduce inequalities it is necessary to improve in each of the following key areas:

- educational opportunities
- income distribution
- health-related behaviour
- access to healthcare.

There is a wide variance of income between European countries in the West and East, North and South (see map), and further economic differences within countries and regions. In recent years two new factors must also be considered: First, refugees are coming from the Middle East and from Africa – do we integrate these patients into our National Health coverage, and if so,
how? Second, the economic crisis has had a huge impact on cancer patients, particularly on women, the elderly and the poor.

How low- and middle-income levels affect cancer services in the European Nations:

- In low-income European countries there is little awareness that cancer is treatable. There are also inadequate pathology services for diagnosis and staging, and no treatment availability (radiotherapy and drug treatments).
- In middle-income countries there is late-stage presentation of disease and limited data collection. There is poor provision of community access to early detection, diagnosis and treatment, and low prioritisation of cancer control programs within the health-care system.

Elderly people with cancer

In Europe, getting old presents many complex challenges to the individual and to society: These become even more burdensome when a person has cancer; the social security system is under pressure, because there is a decreased younger population in the workforce to pay for the retired. Some of the barriers that older people face include understanding complex diagnoses and higher dependence on relatives. They must often travel to receive chemotherapy (with limited transportation options and cost implications), and spouses are older and less able to be effective care-givers.

Other wider social issues are also a factor: with families getting smaller there is more cost for complex care responsibilities at home; public misconceptions about cancer make people reluctant or unwilling to seek care when early symptoms occur; treatment is too costly for patients to afford (out-of-pocket payments are highest in the poorest countries in Europe).

Evolving solutions for older people living with cancer

Technologies may help, with portable ultrasounds, x-rays, ECG machines, and incentive spirometers, which will facilitate transportation and save time and money.

Strategies for care providers may also include education and training as a way to effectively meet the challenges involved in caring for the aging population; geriatric assessments are another key tool. Legislation on opiates/opioids, palliative care coverage and provision of medications must also be addressed.

Challenges in the healthcare system

In Western Europe, there is a shortage of professional cancer nurses and oncologists due to financial constraints, and an issue around ageing health professionals. Patient/nurse ratios differ greatly from country to country. For example, WHO reported in 2004 nurses ratio across two countries as follows:

- Finland – 1,200 nurses per 100,000 population
- Spain or Portugal – 500 per 100,000.

The contrasts are stark: regions with the highest provision can have 10 times as many per capita than those with the lowest provision, and further regional differences exist within many countries.

Many factors are also pushing nurses to leave their own countries, including: low pay, poor career prospects, political instability and social violence. The strongest push factors encouraging nurses to leave are currently found in Luxembourg, France, Switzerland, Portugal and Spain.

Socio-economic factors

Screening

When it comes to cancer screening programmes for breast, cervical and colorectal cancer, people in poorer inner city neighbourhoods are being screened at much lower rates than people in the richer suburbs. These people are under diagnosed. Among a number of factors influencing this is the fact that poorer self-assessment of health is higher in those of lower socio-economic status, including
Health literacy and communication
Health literacy is considered the single best predictor of the patient’s health status. It is defined as the capacity to obtain, interpret, and understand basic health information and services and the competence to use such information and services to enhance overall health. Poor health literacy puts tremendous adverse financial burdens on healthcare. For example, in the United States, the healthcare costs of a patient with limited literacy is around four times that of those who have adequate health literacy.

Communication is of great importance for people diagnosed with cancer. As the world becomes more racially and ethnically diverse, literacy, cultural and economic sensitivities, language, hearing, vision, and nonverbal communication are some of the issues we should consider in our communication with cancer patients. Providing compassionate care is the first step. We need to listen carefully and provide emotional support. Eye contact is imperative. Through compassionate care, you will establish a trusted relationship.

An initial assessment of the patient by the healthcare professional should include:

1. Can the patient read, if so what level?
2. Are there cultural and economic issues?
3. Are we saying what we mean? How are we saying it? Do they understand our jargon? What is the patient’s primary language? What are their non-dominant local languages?
4. Can the patient hear?
5. Can they see?
6. Be aware of non-verbal communication – are they frightened?
7. Is the person too fatigued to learn?
8. Is the patient so worried about financial issues that they cannot comprehend anything?
9. Does the patient have memory deficits? If so, write things down in an understandable way.
10. Are they elderly?
11. Do they have multiple co-morbidities?

Often fear, anxiety, medications, poor nutrition, fatigue, low education and financial worries mean the patient cannot take in anything else. Healthcare professionals must alter how they teach people who are overwhelmed: speak slowly, teach back, encourage questions, use plain language and examples. Use technology only if appropriate. Do not complicate things. Think about readability of patient materials – length of words and sentences etc., and use visuals relevant to the text.

Often there are networks that can help patients understand and navigate this new world. These may be advocacy groups, peer groups, community collaboration (see box), churches, barbershops/beauty shops, and other activity groups such as bowling, in-home shopping, library and parent groups.

Patients’ abilities to understand what is going on with regard to their healthcare makes a huge impact on their outcomes.

What is Community-Based Participatory Research (CBPR)?
The theoretical and practical approach

Fascinating social health research is occurring particularly on health promotion and disease prevention. However, despite the success of this research, the interventions often show low effectiveness when applied as practice. This may be due to the following:

1. Traditional research institutions and communities differ in their approach to a problem – traditional researchers use different “tools” to address health promotion and disease prevention;
2. Communities are often not consulted on the design and conduct of research projects;
3. Communities often do not have access to research findings or they disregard the research findings as “not applicable” to them, and
4. Academic-community partnerships, when it occurs, often favour the biomedical model and academic expertise rather than participatory research and experiential wisdom.

Community-based participatory research (CBPR) attempts to address these problems. It begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities. “Community-based research” is rooted in the community, serves a community’s interests, and frequently encourages citizen participation at all levels. It aims not merely to advance understanding, but to ensure that knowledge contributes to making a concrete and constructive difference in the world.

(CBPR originated in the 1940s as action research initiated particularly by Kurt Lewin and other European social scientists.)