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Do cancer patients change their diet in the e-health information era? A review of the literature and a survey as a proposal for the Italian population

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ABSTRACT

In recent years, there has been an explosion in the amount of available information on cancer in parallel with an ever-increasing number of cancer survivors. Cancer patients and long-term survivors are known to be more sensitive to health-related information and dietary changes could represent a potential consequence of this huge availability of messages. In our review about dietary changes after cancer diagnosis, we found that this topic is particularly investigated among the breast cancer population. The literature examined show that breast cancer patients modify their eating habits after diagnosis in a percentage that varies between approximately 30% and 60%. The most reported changes were an increased consumption of fruit and vegetables, a decrease in the consumption of red meat, fats and sugary foods. Patients who reported changes were more likely to be younger, with higher educational levels and with a longer period of time since their diagnosis of cancer. It also emerged that cancer patients are often more likely to use supplements.

This topic has not been investigated in cancer patients in Italy, therefore, we propose an approach to explore it with a structured questionnaire: The “ECHO SURVEY - Eating habits CHanges in Oncologic patients”.

1. Introduction

According to GLOBOCAN, in 2012, 14.1 million new cancer cases occurred worldwide. Lung cancer is the most common cancer in the world, both in term of new cases (1.8 million cases, 12.9% of total) and deaths (1.6 million deaths, 19.4%) due to its high mortality. Breast cancer is the second most common cancer overall (1.7 million cases, 11.9%) but ranks 5th as a cause of death (522,000, 6.4%) due to its relatively favourable prognosis; these two are followed, in terms of incidence, by colorectal cancer, prostate cancer, stomach cancer and liver cancer. These six cancers account for 55% of the global incidence burden in 2012 (Ferlay et al., 2015).

The Italian Association of Cancer Registries (AIRTUM) estimated that over 365,000 new cases of cancer would be diagnosed in Italy in

2016. In Italy, breast cancer is the most common cancer in terms of new cases (14%), followed by colorectal, lung, prostate and bladder cancers. In terms of mortality, lung cancer remains the primary cause of death by tumour followed by colorectal and breast cancers (AIRTUM, 2016).

The high incidence of cancer, coupled with improvements in early detection and initial treatments, has led to an ever-increasing number of cancer survivors. In Italy, the number of people living beyond a cancer diagnosis reached nearly 3 million in 2015 (4.9% of the population). Based on these trends, cancer survivors' health is rapidly emerging as a major public health concern (Jones & Demark-Wahnefried, 2006).

Although non-modifiable risk factors influence the incidence of cancer, most differences in the cancer risk between people is due to factors that are not inherited. Lifestyle factors have long been

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recognised as potentially important determinants of cancer risk: avoiding tobacco products, maintaining a healthy weight, staying active throughout life and following a healthy diet may greatly reduce a person's lifetime risk of developing or dying from cancer (Norat et al., 2015).

The most extensive review of the existing evidence on diet and cancer is the 2007 World Cancer Research Fund/American Institute for Cancer Research (WCRF/AICR) report and its subsequent updates (Wiseman, 2008). Lifestyle recommendations for cancer prevention were drawn up on the basis of nutrition-related factors judged to be convincingly or probably related to cancer, according to predefined criteria for judging the strength of the evidence regarding causality.

A growing body of evidence also suggests that diet, exercise and body weight status can influence cancer survivors' health (Pekmezci & Demark-Wahnefried, 2011). Due to the complexity of this field of research, evidence is too limited to develop specific recommendations; therefore, current recommendations for cancer survivors are based on primary prevention recommendations and emphasise achieving and maintaining a healthy weight, regular physical activity, a diet rich in vegetables, fruits and whole grains and limited in red meat and alcohol (Rock et al., 2012).

1.1. Sources of health-related information

Thanks to the advances in new communication technologies, there has been an explosion in the amount of available information on cancer (Viswanath et al., 2012). This knowledge is not exclusively available to health professionals, since modern communication channels, such as the Internet, are changing the nature and speed of information and interaction between individuals and health organisations (Davis & Walters, 2011).

The readily available, large amount of information has enormous potential to influence what people know about cancer, but the main challenge is the difficulty in separating quality from quantity of cancer information (Viswanath et al., 2012).

A study by Hesse et al. has shown that, even though physicians remain the most highly trusted source of information, patients reported first going online for information. This first study provided evidence for the observation that people were turning to the Internet as an information source of first resort (Hesse et al., 2005).

In the United States, periodic telephone surveys of American adults conducted by the Pew Research Center revealed that the percentage of adults who look for health information online increased constantly and those with chronic conditions are likely to report that online searching has affected their treatment decisions and their interactions with doctors (Davis & Walters, 2011). Significant growth in the use of the Internet for health purposes was also found in seven European countries participating in a survey (Kummervold et al., 2008; Kummervold & Wynn, 2012; Santana et al., 2011).

In Italy, a multicentre survey was designed to provide information about Internet use for health-related purposes and to assess the possible behavioural consequences. Internet users accounted for 64.6% of the total sample and the rate of e-health use (use of the Internet for any health-related purposes) amounted to 56.5% of Internet users. The rate of users adopting any dangerous modifications of behaviour based on information found on the Internet was quite high and noteworthy, especially in women and in those with chronic diseases (Siliquini et al., 2011).

In this context, there is a growing interest in health promotion through education and people want to receive as much information as possible; this desire for information about healthy living is undoubtedly an increasing trend among cancer patients and the Internet has become a major source of medical and health information for patients and families (Rutten, Arora, Bakos, Aziz, & Rowland, 2005; Santana et al., 2011).

1.2. eHealth in cancer patients

Little is known about the impact of health information obtained from the Internet (eHealth) on cancer patients' behaviour and choices, as only a few studies have been published in some countries.

A small structured Spanish survey found that the rate of Internet use amounted to 27% for cancer patients and 58% for their relatives. Around half of Internet searchers felt more optimistic after the search, while negative feelings were less reported by the interviewees (Lopez-Gomez et al., 2012).

In Canada, another small survey of radiation oncology patients found similar results and most patients wished their doctors had supplied them with links to medically relevant websites (Katz, Roberge, & Coulombe, 2014).

1.3. Information needs in cancer patients

Since effective communication is known to be a key for optimal health outcomes, understanding *what* patients need to know, *when* during their care pathway and from *whom* they receive this information becomes vital to ensuring the delivery of quality cancer care (Rutten et al., 2005).

Many investigations and reviews of the literature were conducted to identify cancer patients' information needs and the sources used to obtain cancer-related information. In most of these publications, different typology of information needs were created and grouped into categories and subcategories. As would have been expected, one of the most frequently cited categories during the diagnosis and treatment phase was related to treatment options and side effects (i.e. “*treatment-related information*” or “*tests and treatments*”). A greater proportion of cited needs during the post-treatment phase were “*rehabilitation information*”, “*self-care issues/home care during recovery*” and “*health promotion*”. The few studies that investigated the level of information needed about diet and nutrition recorded that around half of the interviewees wanted information about this topic and approximately one in four patients look for information about “prevention of cancer”. When asked, over half of the respondents also reported that they trust Internet-derived information “a lot” or “some” (Beckjord et al., 2008; Rutten et al., 2005; Shea-Budgell, Kostaras, Myhill, & Hagen, 2014).

A study conducted in Boston by the Harvard School of Public Health and the Dana Farber Cancer Institute found that health information-seeking is associated with social determinants. The research shows a relationship between the level of education and need for information about “self-care management” (such as diet/nutrition, staying healthy, etc.). These types of information were sought by 28% of the respondents with less than high-school education and by 60% of those with a post-graduate degree (Galarce et al., 2011).

Most studies on cancer patients and survivors' information needs have been conducted in the United States, while only few investigations have been performed in other countries.

During the period September 2010–March 2011, an online multi-lingual questionnaire was designed and administered to cancer patients in 24 European countries. Among the several options proposed, 80% of the patients strongly agreed or agreed to the statement “I want information on diet and nutrition”. However, over 50% of respondents *strongly agreed* or *agreed* that they wanted information on all of the information suggested in the questionnaire, meaning the results of the study were not very remarkable (Maddock, Lewis, Ahmad, & Sullivan, 2011).

From this background, four points emerge:

1. There has been an explosion in the amount of available information on cancer in parallel with an ever-increasing number of cancer survivors.
2. Cancer survivors could be influenced by this amount of information in terms of subsequent health-related choices.

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