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# NONGOVERNMENT SECTOR FIGHTING CANCER IN ROMANIA

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***Abstract:*** *The burden of cancer is increasingly affecting patients in all European countries. The paper draws a landscape of the Romanian non-profit sector involved in tackling cancer. A descriptive analysis was done on two databases (the national registries of associations and foundations in Romania), for delineating the extent and the type of the NGOs' involvement in the cancer fight. Results show a cancer civil society still in its infancy stage, displaying an imbalanced situation in terms of goals' orientation and territorial distribution. Financially helping patients is a prevailing orientation, whilst there is not enough focus on prevention, education, rehabilitation and palliation. The paper raises concern for policy-makers to include NGOs as partners in national-cancer control programmes.*

***Keywords****: nongovernment organisations; cancer; survivorship; return to work.*

## Introduction

As part of civil society, nonprofit organizations can have a remarkable influence on the population's health status and on the health issues in general (Hawe and Shiell, 2000; Olafsdottir, Bakhtiari and Barman, 2014; Anheier, 2009). The NGOs involvement in health can either take the form of substituting services that governments fail to provide, or to complement services and functions offered by welfare states. More specific, civil society can influence health in several ways: by becoming direct service providers, by engaging in advocacy or by providing social capital through associational opportunities (Giarelli, Annandale and Ruzza, 2014).

The types of involvement and the benefits of civil society participation in health are stated by several studies (Giarelli et al. 2014). Especially in transitional or development

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countries with a welfare state having a weaker force, civil society actors can make the difference with regard to improving health in the short and long run. Apart from advocacy, they can significantly contribute to prevention through information and education campaigns, they can improve diagnosis and treatment by facilitating the access to services that are either not provided by the government or not accessible and they can provide services such as rehabilitation or palliation.

The NGOs involvement in cancer care is not only beneficial, but it has been shown to be essential, by providing technical knowhow, skills and resources relevant for cancer care and research (WHO, 2002). Here too, their role is most needed in developing countries due to the limited resources the health care systems have. A vital and active nonprofit sector can substitute missing public services, can reduce disparities and therefore can even inequalities in cancer care and control. The landscape of NGOs involvement in cancer is eclectic. Examples of good practice stand next to cases of minimal or non-existent implication. For example, the NGOs dramatically contributed in U.S. to the evolution of public agenda and its gradual shift in focus from the understanding of cancer as an individual problem generated by woman's choices concerning her lifestyle (e.g. diet, delayed pregnancy) to the framing of cancer as an environmental and institutional neglect for which the government and economic actors should be held responsible. This change in the framing of breast cancer has greatly impacted on the federal spending of cancer research and on the public discourses about the epidemic of a breast cancer (Kolker, 2004). On the other side, there are countries whose civil society cannot assume an active role due to lack of maturity or missing knowhow.

The nonprofit involvement in health care is usually a result of the features and particularities of the health care system in the country and it should be considered accordingly. Several articles, for example Serapioni and Matos (2014), are analysing citizen participation or civil society implication in health, by discussing first the opportunities and challenges of the health care system. In Eastern European countries, where the health systems face considerable resources constraints and organizational difficulties, the NGOs involvement is expected to be different than in Western countries. According to Eikemo and Bambra (2008, p. 5), the Eastern European welfare state type of regime Romania has is struggling to make the shift from the universalism of the communist state towards marketization and decentralisation. The ongoing health care system reform has provided in the last years several measures towards an increasing involvement of the local communities, i.e. public hospital decentralisation, community medical assistance (Popa, 2014a; Popa, 2014b). Through these measures, the framework for involving the civil society actors begins to be set up, but actual involvement is still low. Essential mechanisms for participation are still missing, as well as a culture of participation and volunteering.

How is the involvement in cancer care and control of NGOs in Romania? This is the main question this article is trying to answer. The analysis will focus on associations and foundations in Romania. More specific, we are addressing four directions when drawing a landscape of the Romanian nonprofit sector involved in tackling cancer: the role in cancer care and control, the cancer areas they are involved in, the territorial discrepancies in involvement and the support offered for cancer survivors, mostly the

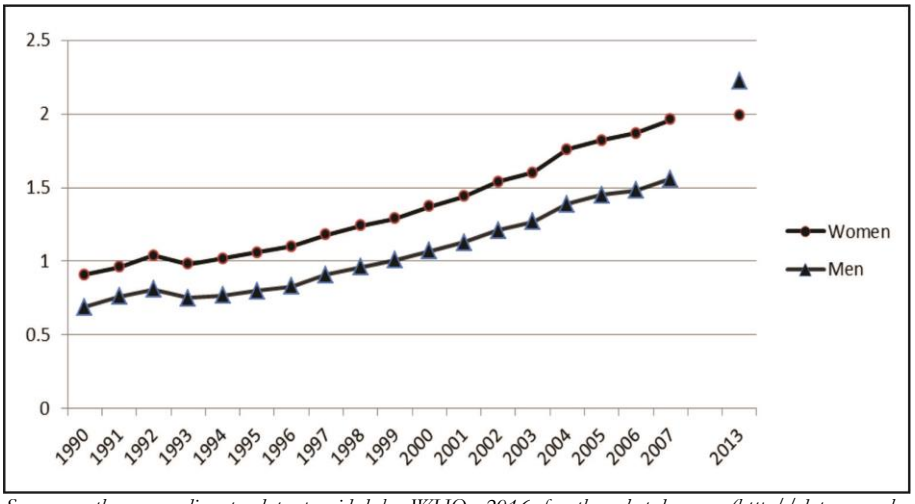
support for returning to work. The study also tries to address the limits NGOs encounter when fulfilling their goals. We will conclude by synthetically presenting the Romanian NGOs' role in cancer care and control, against the background of the current provision offered by the state.

## Cancer in Romania – incidence, prevalence, survivorship

The cancer is the second cause of mortality in Romania, although the total number of cases is smaller than in other European countries (Dégi, 2011). In 2012, the leading types of cancer in Romania were lung, colorectal and prostate cancer, for men, and breast, colorectal and cervix uteri cancer, for women (Ferlay et al. 2013). The number of avoidable deaths is high, indicating the need for more prevention programmes and more involvement from the relevant social actors (including NGOs).

During 2003-2011, the incidence of cancer increased in Romania with 32.36% and the mortality due to cancer increased with 9.67%. Cancer's prevalence in Romania displays a steady upward trend in the past two decades throughout which it has been growing from 0.85% in 1990 to 2.07% in 2012 according to World Health Organization (WHO, 2016). Based on WHO's European health for all database, Dégi (2013) draws attention to the fact that in Romania every year 52.000 new cases of cancer are diagnosed while about the same number of cancer-specific deaths are reported. Cancer prevalence by gender shows similar upward trends.

***Figure 1**: Cancer prevalence (in%) in Romania by gender for the years 1990-2007 and 2013*




*Source: authors according to data provided by WHO, 2016 for the selected years (http://data.euro.who.int/hfadb/param.php)*

Overall, Romanian women seem more affected than men by cancer disease, except for the most recent reported data concerning the prevalence of cancer for the year 2013 when there is a shift in the pattern with women being less frequently diagnosed than their male counterparts, as shown in the next figure. In the last years, the government begun to address the higher prevalence of cancer in women through several programmes and policies targeted to prevention and early detection of cervical and breast cancer. In the same time, a significant number of NGOs in Romania are focusing on women with cancer, offering information or various types of support, as we will show next.

In this context of increasing prevalence but lower mortality, the number of people surviving cancer is higher every year in Romania: in eight years (2003 – 2011) it has increased 8 times. Part of the needs of these patients are related to treatment and we will analyse below how many NGOs are offering support for treatment. When finishing treatment, patients face the social and psychological effects of cancer, therefore the need for adequate assistance prevails.

Within the number of patients newly diagnosed with cancer every year, a considerable part are of working age. In 2012, 50.27% of the newly diagnosed patients were of working age in Romania (Globocan, 2012b). This points to the acute necessity of addressing their work-related needs (resuming work, job retention). This type of support is only scarcely offered by the state, therefore NGOs could play a significant role for helping cancer patients to return to an active role on the work market.

## The Romanian nonprofit sector – opportunities and limits

The limitations NGOs come across are even more severe and visible in the European countries challenged by institutional fragmentation, scarcity of financial resources and a short history of citizen participation (Serapioni and Matos, 2014). By the end of 1990s Romania registered around 5.000 non-governmental organizations, a reality which can be described as a promising revival of civil society after the long censorship triggered by the brutal control of the state over the informal associations, and its detrimental effects on people's private initiatives to set up non-profit organizations during the communist regime. An early systematic analysis of NGOs profile in the post-socialist Romania has shown that the main areas of non-profit sector were tied to peculiarities of the national context characterized by a high presence of international organizations and international funding, a moderate collaborative relationship between NGOs and state in some fields (e.g. sport, culture, environment), and a sense of pride Romanians have for their cultural heritage and the beauty of nature. In this context, some fields like health, recreation and housing were lagging far behind areas like education, advocacy or social services (Johnson and Young, 1997). In their analysis carried out on the 499 NGOs self-registered in the *Catalogue of Nongovernmental Organizations in Romania: 1991-92* provided by the Soros Foundation for an Open Society (Bucharest), Johnson and Young (1997) identified only 11 non-profit organizations in the health domain, in spite of large flows on international funds channelled into health institutions in Romania. A more recent study (Petrescu, 2014) dealing with the regional disparities and evolution of

social economy in Romania shows that NGOs ranks first in the top of such entities with a number of 29,226 organizations found in the REGIS database (2010) provided by the National Institute of Statistics. According to the same source, there was a rapid increase in the number of NGOs during the decade 2000-2010, in some regions the share of growth being amounting to 400% (South-East) and even 800% in Bucharest-Ilfov. To this dynamic, the changes in the legislation might have had also a major contribution. The legislation concerning the creation of associations in Romania has made visible progresses in that it shifted from the excessively bureaucratic conditions of the Law 21/1924 (e.g. it required 21 persons in order to form an association and the approval of the ministry under the area of which the association intended to exert its activities) to less restrictive conditions specified within the Ordinance 26/2000 (e.g. a minimum of 3 members to set up an association and at least the double of the minimum gross wage as initial patrimony).

The number of employees working within NGOs has tripled during the past decade, reaching 17,268 in 2010. A Romanian NGO employs on average 2,3 persons, although there are significant regional discrepancies both in the number of employees and in average revenue by entity. Concerning the number of employees, the most developed NGOs appear to be found in Bucharest-Ilfov, the West and the South-East regions, while Bucharest-Ilfov, South Muntenia and the West are leaders according with the earned revenues (Petrescu, 2014). So, although these organizations are, in theory, associated with poor economic performance of those areas where vulnerable groups are most present, the Romanian case suggest that NGOs are more developed in regions that perform better in terms of economic and human capital. Social capital, as both a premise and an outcome of the membership in associations, is also less developed in regions like Moldova (North-East), compared to other ethnically mixed regions of Romania where people claim more often that they trust others, unlike their Moldovan counterparts who are more ethnically homogeneous and tend to limit their trust and exchanges to their kin (Sotiropoulos, 2005).

Within the cancer field, the civil society had some achievements by taking part in the fight against women cancers. Although along the years the incidence of cancer was constantly higher among women than among men (Fig. 1), the relatively lower prevalence of cancer among Romanian women lately could be partly accounted for by the increased awareness of women concerning the available screening for early detection of the most current forms of cancer (breast cancer and cervical cancer). The Romanian NGOs may have played a considerable role to the achievement of this outcome by challenging the traditional culture of care which has long relied on the private or family support for recovering from most diseases given the stigma and shame associated with ill-health in general, and cancer in particular (Dégi, 2013). Some NGOs campaigns, such as "Pearl of Wisdom", engaged in reducing cervical cancer, became popular in Romania through the implication of several organizations (e.g. The Association of Cancer Patients, The Romanian Cancer Association, The Romanian Health Psychology Association) that have contributed to the spread of information and the broadening the access through free services allowing better coverage also for the less fortunate groups of women (e.g. those with low incomes, those living in remote and isolated areas witnessing a lack of care facilities) (Geană, 2012).

There remain however many issues to be addressed by civil society, especially its NGOs, with regard to the promotion of cancer patients' rights, the continuous and up-to-date information regarding screening procedures, population's awareness toward the benefits of adopting healthy lifestyles and reducing of health-compromising behaviours, the quality and coverage of care and emotional support services throughout all stages, from prevention to rehabilitation. Frequently, the limits they encounter hinder the realization of these goals. If the scarcity of financial resources and the dependence on external financial aid, as well as their capacity to attract funding are usually the main limits, other problems appear too. The shortage of human capital (e.g. volunteers and other human resources) with appropriate knowledge and skills to deal with physical and psycho-social needs of cancer patients, or the lack of appropriate means to reach out to those vulnerable groups. Moreover, the organizational culture and role awareness within the NGOs in Romania are still sensitive points; Many of them are still learning how to shape health care reform and policy, whereas a significant part are assuming mere fundraising tasks or provide communities for helping their members, however are still not aware of the possible role in influencing health.

# Theoretical considerations

## *Role of NGOs in cancer care and control*

Although recognizing the essential role governments have in fighting cancer, WHO urges all key stakeholders in society to take action in cancer control activities, including NGOs (Dunn, Herron, Adams and Chambers, 2013). In theory, NGOs could involve and have impact in all areas of cancer control, that are primary prevention, early detection and secondary prevention, diagnosis and treatment, survivorship and palliative care (Beaulieu, Bloom, Bloom and Stein, 2009). In fact, the NGOs involvement depends on so much variables that it greatly varies across countries and regions. Different countries achieved important results in some areas of cancer control mostly through the contribution of the nonprofit sector. Although the impact the nonprofit sector can have on various areas of cancer control can vary in a great extent, the idea that the government and the nonprofit sector should complement each other in their effort to fight cancer, is widely accepted.

In spite of growing recognition by states that there is a necessity for a genuine partnership between governments, NGOs and other civil society's organizations, some authors show that there are few national cancer control plans which clearly state the role of NGOs in fighting cancer beyond a cursory acknowledgment in their introduction. Dunn et al. (2013) infer that this collaborative goal between various sectors of society remains more a rhetoric than an effective commitment in most countries. On the other hand, other studies suggest that there is visible progress in some advanced resource settings. For instance, Klawiter (2004) illustrate the changes of disease regimes and their impact on the illness experience of a woman diagnosed twice with breast cancer in San Francisco Bay Area where breast cancer movements embedded in broader social movements (e.g. feminist activism, environmental

organizations) have transformed medical practices, legislations and subjectivities. The author emphasizes the importance of the concept of *disease regime* she defines as  the institutionalized practices, authoritative discourses, social relations, collective identities, emotional vocabularies, visual images, public policies and regulatory actions through which diseases are socially constituted and experienced' (Klawiter, 2004, p. 851). Civil society can play a crucial role in the transformation of disease regimes through the activities of NGOs and the mobilization of various resources and shared sensibilities of communities that can become powerful sources of change for both medical practices and cancer patients' empowerment.

Grey and McMikel (2013) emphasize the need for enhancing the advocacy role of NGOs in developing countries because these collective actors have a great potential to address the aspects of cancer care which are often sidelined or neglected by other stakeholders (e.g. physicians, industries, governments). NGOs could play an influential role in improving the cancer-related policies and in raising awareness about the exposure to life-threatening habits characterizing the rapidly expanding modern lifestyles (e.g. unhealthy diet, sedentary behavior).

## *Territorial discrepancies in the role played by NGOs*

There is a wide recognition of the high discrepancies between and within countries concerning cancer incidence and cancer mortality (Jones, Chilton, Hajek, Lammarino and Laufman, 2006). Aside of these notorious aspects, there are also under-researched cross-country discrepancies in the role played by non-governmental organizations (NGOs) in cancer control.

The civil society involvement and role in health issues depend on the country development level and on the type of the welfare state. According to country development level, NGOs were found to play a major role in assisting hospitals and medical staff in providing direct medical services in low income countries, while in more developed countries they have broader purposes that go beyond clinical information and include emotional support, engagement in research activities and advocacy, especially in high income countries (Azenha et al., 2011). Similarly, NGOs involvement matters more in societies with weaker welfare systems, i.e. in transitional and developing countries (Olafsdottir et al., 2014). Such disparities might reflect not only the availability and inequality of resources that shape the quality of health care services and the profile of NGOs in this field, but also the maturity of cancer civil society. As an illustration, Azenha and colleagues (2011) show that in low income countries, NGOs' founders were more likely to come from health care professions, contrasting with the case of higher income countries where the share of cancer survivors-led NGOs gradually increase. This positive gradient could reveal that there is a strong association between the level of available resources and the capabilities of cancer survivors to mobilize resources through grassroots associations in order to disseminate the idea of cancer as curable disease, to dispel misconceptions and

population's fatalist attitude towards cancer, as well as to advance more effective cancer-related policies.

Apart from the discrepancies between countries, there are significant differences between regions within a country in the territorial coverage with NGOs working on health issues. The accretion of health NGOs mainly in urban areas and capital cities in post-socialist countries is explained by Dill (2014) as a resultant of the fact that most of them relied on some form of connection to professional service providers and institutions at their inception. They were either founded by health care professionals, or attracted members from the patients in public health care services, which reinforced the disproportioned location in urban areas.

## *Areas of involvement of NGOs in fighting against cancer*

Several areas are mentioned with regard to the NGOs participation in health in general: providing information on health, diseases, lifestyle; aggregating social actors and groups based on their interests regarding health issues; monitoring health care services and policies provided by the state or the progress in the enactment of various changes; resolving crises in health care; contributing to policy design and implementation or representing the interests of the vulnerable population (Giarelli et al., 2014; Schmidtke, Falge and Ruzza, 2013; Guta et al., 2014; Mulvale, Chodos, Bartram, MacKinnon and Abud, 2014).

Regarding cancer in particular, similar areas can be targeted. Analysing the activity of the breast cancer civil society, Azenha et al. (2011) found that NGOs worldwide are involved in activities related to providing information, raising the community awareness, early detection campaigns, direct medical services, emotional support, research, basic material provision, advocacy, financial support, and legal rights. Although the accent should be put on prevention, Different types of interventions can be done throughout the cancer care and control continuum.

Looking from a different angle, the civil society can be part of a more complex intersectoral partnership. Dunn and colleagues (2013) argue the fight against cancer cannot be successful unless civil society organizations are involved from the planning stage of the programmes and policies and then all the way through the process of implementing an effective policy or programme. A legal and structural framework facilitating their inception and functioning has to be set up, in order for them to be empowered partners with full responsibilities.

## *Involvement in supporting survivors, particularly work reintegration of cancer patients*

As longer cancer survivorship is more and more a reality today, NGOs should address the particular needs of the patients which come out of the treatment and engage on the difficult path of rehabilitation. Usually, cancer is approached in a medical manner, giving full consideration to proper diagnosis and treatment, but leaving the patient that

has completed the treatment with almost no support for the social and psychological needs of survivorship. The situation regarding this type of support differs from one country to another, but since the medical system is focused on prevention and treatment, NGOs could become a key actor in providing the services in this area.

Work is one component of survivorship that is often overlooked by individual or institutional stakeholders engaged in tackling cancer. But as the number of working-age cancer survivors is continuously growing, the work reintegration of cancer patients is providing not only individual benefits, but societal also. The literature on how NGOs can help with the return to work of cancer patients is limited, but there are voices stating that NGOs can partner with public and private employers in order to facilitate this outcome (Feuerstein, 2009). Rather, there are papers asserting the challenges and difficulties NGOs face when involving in cancer survivorship activism (Errico and Rowden, 2006; Durstine and Leitman, 2009).

## Data and method

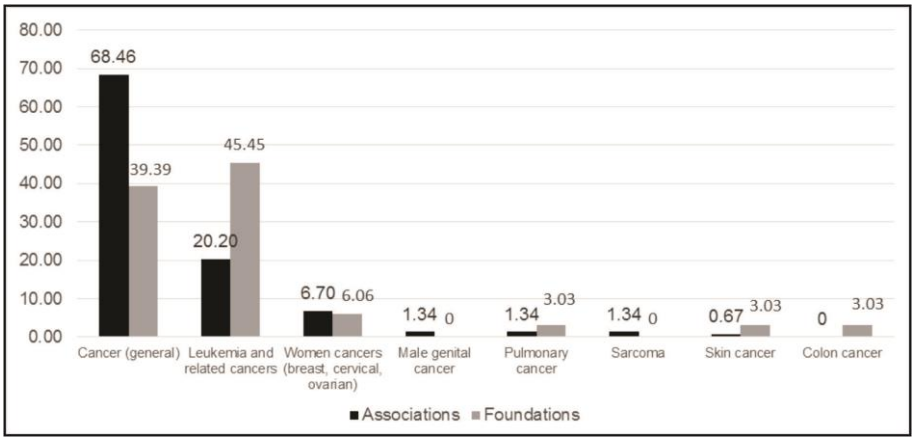
The data for this study are drawn from the National Registry of NGOs (Ministry of Justice, 2016). This is a public available database with information about all types of organizations with no patrimonial aim. Our search focused on associations and foundations as specific types of not for profit organizations. The database for associations has 70938 entries from which we targeted the organizations addressing cancer problem. Also, the database for foundations has 18464 entries from which we targeted the foundations addressing cancer problem. In order to identify these types of NGOs some keywords were used for our search: "cancer", "neoplasm", "neoplasia", "carcinoma", "leukemia", "melanoma", "lymphoma", "sarcoma", "blastoma". The search triggered 135 cases for associations and 33 cases for foundations.

A content analysis on the aims provided in the National Registry database by all NGOs helped us draw the next categories of information: types of cancer addressed by NGOs, whether cancer is the main or the secondary goal of the NGO, the demographic categories targeted by NGOs (adults or children, male or female), the existence of goals targeting the return to work of cancer patients, as well as the main goals relevant for the cancer fight, proposed by each NGO. County (location) for each NGO is another variable included in our databases. We performed descriptive analysis on the two databases resulted.

## Results

Our analysis shows that within the 70938 association in Romania, 135 (0.19%) address the problem of cancer either in general, or for specific types of cancers. Around two thirds of these associations are addressing cancer as a main goal and one third as a secondary goal. 83% are targeting adult cancer, whilst 17% try to tackle cancer in children. The majority of association aims to tackle cancer in general, but apart from them, the main types of cancer Romanian NGOs are fighting against are leukemia, breast and cervical cancer (see Fig. 2)

***Figure 2**: Types of cancers addressed by associations and foundations in Romania (percent)*




*Source: National registries of associations and foundations in Romania*

Regarding the foundations, there are 18464 foundations in Romania and 33 foundations (0.17%) are working on the problem of cancer. A little more than a half (57.6%) are addressing cancer as a main goal, and the rest put other goals on their agenda and also cancer. The majority of them tackle child cancer (54.5%), 39.4% address cancer at all ages (unspecified age) and 6,1% fight against women cancer.

## *Areas of involvement and role in cancer care and control*

Glancing at the goals stated by the associations activating in the cancer field in Romania, three large categories are apparent: goals targeting the needs of the patients, goals concerning the problem of cancer in general and goals directed to the health care system. The first category is considerably more consistent than the others, with the great majority of organizations being interested in addressing the needs of the current and potential patients, e.g. offering support of any kind, improving care or support for patients with rare cancers. Of the total number of occurrences, two thirds are goals related to patients. Within the category, raising money for cancer patients and offering material support is an aim embraced by many organizations. Far less mentioned (around 15% of the total occurrences) are the goals related to fighting cancer in general, e.g. research on cancer, changing attitudes about cancer, or developing policies. Even less present (12%) are the aims related to the health care system: reforming the system, establishing social services or support for oncology institutions.

**Table 1**. Goals' orientation of associations and foundations in Romania

| Categories of NGOs' goals | Specific goal | Number of occurrences for associations | Number of occurrences for foundations |
|---|---|---|---|
| Goals addressing the patients | Support for cancer patients (of any kind) | 57 (33.1%) | 4 (9.3%) |
| | Support for children with leukemia/cancer (of any kind) | - | 15 (34.8%) |
| | Raising money for helping cancer patients | 24 (13.9%) | - |
| | Information/education regarding cancer (prophylaxis, symptoms, treatment) | 20 (11.6%) | 2 (4.6%) |
| | Advocacy for the rights/interests of cancer patients | 16 (9.3%) | 2 (4.6%) |
| | Prevention, prophylaxis of cancer | 15 (8.7%) | 8 (18.6%) |
| | Support for work and social reintegration of cancer patients | 9 (5.2%) | 1 (2.3%) |
| | Counselling/psychotherapy for cancer patients | 8 (4.6%) | 1 (2.3%) |
| | Improving quality of life of cancer patients | 7 (4.0%) | 1 (2.3%) |
| | Support for diagnosing and treatment of cancer | 6 (3.4%) | 8 (18.6%) |
| | Offering care/improving care for cancer patients | 6 (3.4%) | - |
| | Rehabilitation of cancer patients | 2 (1.1%) | - |
| | Support for patients to be treated abroad | 1 (0.5%) | - |
| | Support for patients with rare cancers | 1 (0.5%) | - |
| | Informing the population regarding prevention and fighting skin cancer | - | 1 (2.3%) |
| Goals addressing the problem of cancer in general | Supporting and promoting cancer research on cancer | 15 (40.5%) | 4 (100%) |
| | Decreasing the mortality rate from cancer and ease its burden | 15 (40.5%) | - |
| | Changing attitudes regarding cancer and cancer patients | 5 (13.5%) | - |
| | Developing policies, in accordance with the European policy and regulations in the field | 2 (5.4%) | - |
| Goals addressing the health care system for cancer | Improving quality and access to medical services/ Reforming the system | 8 (27.5%) | - |
| | Establishing/developing social services (social work services, support groups) | 8 (27.5%) | - |
| | Support for oncologists (promoting profession, training) | 5 (17.2%) | - |
| | Establishing/developing oncological centres (for diagnose and treatment, registries) | 5 (17.2%) | - |
| | Support for oncology medical institutions/wards (donations, equipment) | 3 (10.34%) | - |
| | Information, education of medical staff regarding prevention and fighting skin cancer | - | 1 (50%) |
| | Social, medical and humanitarian services for children with cancer | - | 1 (50%) |

*Source: authors' analysis on data provided by the National Registry of NGOs*

Note: *one association/foundation can propose more than one goal within the cancer fight.*

When referring to the cancer care continuum, a deeper examination of the first category shows that most of the goals are targeting the diagnosis and treatment component, followed by aims regarding rehabilitation and social/professional reintegration. Prevention is less frequently present in the NGOs objectives, while screening and

palliation as explicit goals are not at all envisaged. This distribution is also prevailing in the aims declared by foundations.

Within the disease-centred goals, supporting research on cancer seems to be the most recurrent. Some goals are vaguely or inadequately enunciated, with no other details provided, which makes difficult to categorize them.

### *Territorial discrepancies*

Looking at the geographical distribution of the NGOs locations, apart from the capital city which has the higher number of associations, the rest of them are distributed around the whole country, except the South region where there are eight counties with no NGO registered. The Central, West and North West regions are the best represented with associations. This distribution is consistent with the regions' development level, level of social capital and trust (Voicu, 2005). Also interesting is the fact that the distribution is rather unequal, as five counties have the highest number of associations (6-15) and 27 counties have lower numbers (1-4). This distribution should be carefully considered, as 21.5% of all NGOs in the database have no specified county.

For the foundations, two counties (one is Bucharest) accumulate 60% of the Romanian foundations proposing goals related to cancer (they have eleven and six foundations respectively). Ten counties have one or two foundations and the rest (29 counties) have no foundations activating in the cancer field.

### *Involvement in survivorship and work*

Most of the Romanian NGOs present in the cancer area are targeting the diagnosis and treatment directions. They raise funds and offer support mainly for covering the medical needs of the patients. We looked how many of them have goals related to survivorship, i.e. offering services and support for rehabilitation, psychological, social or professional/career related needs. Less than a quarter (18,5%) are interested in offering counselling/psychotherapy services, or establishing/developing social services (e.g. support groups), or rehabilitation, or improving the quality of life of cancer patients. These are explicit goals related to survivorship, but many NGOs are stating goals in a general way, so that survivorship can be implicit (for example 'offering support of any kind for cancer patients').

Regarding helping survivors to return to work, nine associations and one foundation declare this aim. The small number reflects a marginal preoccupation with work challenges cancer patients face in their struggle with the disease.

## Discussion

In the context of increased burden of cancer and considerable pressure on the health care systems to decentralise the services, the local level should gain a significant role in fighting cancer. Shifting responsibilities from government to civil society becomes not a preference, but a necessity. Countries in Europe are struggling to provide a more

consistent role for the civil society and to make it a partner with full responsibilities. Dunn and colleagues (2013) show this is not an enterprise without difficulties, as most countries don't even mention explicit roles in their national plans for fighting cancer for the civil sector. Romania is no exception in this regard. A previous analysis (under publication) on the legal documents for the national health programme for cancer proves that civil actors (associations and foundations in Romania) are not once mentioned as partners of the government in the fight against cancer. The government assumes all the roles and does not officially envisage any responsibility for NGOs.

In a health care system oriented largely on diagnosing and treatment, the civil society could assume a steady role on prevention (by informing and educating population) and also on rehabilitation and palliation. Romanian associations and foundations are already doing some activities in this range, although they are legitimated by the government. Still, a consistent share of their activities are oriented to supporting patients for their treatment. Therefore, the treatment component is over-represented, and the rest are not enough covered. Analyses (Azenha et al., 2011) show that in lower-middle income countries, the most common program activities of NGOs included community awareness (76%), early detection campaigns (71%) and information (65%), whereas in Romania, around 50% are oriented towards financially helping patients. This is an urgency and crisis approach, not one oriented in long-term improvement of cancer situation.

The analysis presented in Table 1 allows us to infer that grassroots organizations in Romania give more consideration to cancer when the disease is already in place and to the main actor of this problem which is the patient. Support is rather understood and given in direct ways to people (money, other types of material help) and is less focused on developing or improving the system, which could indirectly help a larger number of patients. Many associations conceptualize their contribution as short-term rather than long-term help, by activating less on areas potentially decreasing the burden of cancer in the long run (e.g. research, policy). This picture is consistent with the pattern observed in the cancer policies available in the Romanian National Health Programme for Cancer, where significant consideration is given to early detection, diagnosis and treatment and far less to prevention, or the components ensuring better cancer control in the long run (developing cancer registries, research, etc).

The results further show that cancer civil society is still in its infancy stage, displaying an imbalanced situation in terms of both goals' orientation and territorial distribution. Following the results of Azenha and his colleagues (2011), Romania could illustrate the position of lower-middle countries where NGOs' efforts are mainly invested in the goals of alleviating the consequences of disease through rather medical services and personnel associated to hospitals. The primacy of these goals reflect in fact the structural constraints faced by the nascent civil society during the recent post-socialist history, as well as the urgency to tackle most arduous facts (e.g. pain relief, care provision for cancer patients) by complementing the low-quality healthcare services provided within the hospitals. These limits are compounded by the low sustainability of NGOs' activities in a context of structural barriers for securing the necessary resources to engage in broader awareness campaigns, advocacy and research programs. Efforts are usually limited in scope and space and are supported by narrow networks of

community members revolving around friendship, kinship and other relatively strong ties. Public discourses that attend to larger and groups and policy-makers are not yet capable of mobilizing public support and emotional vocabularies that can attract the interest of people across a wide range of age, class, ethnic, residential areas and so on. Such weaknesses and struggles have been also stressed by studies in other European post-communist settings, like the analysis by Fagan (2005) with respect to the obstacles faced by the development of civil society in Czech Republic. The latter author pointed to the critiques usually faced by NGOs in post-socialist countries given their long-term dependency on international donors and the disconnection with the local communities whose interests they should serve. For these reasons, NGOs in European post-communist countries may witness more difficulties in garnering recognition and credibility from the communities they are based in and may differ in regard to the pathway of becoming rooted in these social, cultural and political realms. By fear of being cut their scarce international aid, some NGOs may propose goals that are not actually reflecting local preoccupations, but rather aims which are dictated by their international donors, irrespective of the actual circumstances in the sphere of their local area of intervention.

The results regarding the territorial discrepancies show an unequal distribution of NGOs in Romania, but specific features can be identified for the regions where they are located. First, these regions have more developed economy and higher incomes, which is a favourable environment for the emergence of such organizations. A similar situation is present in other Eastern European countries, with NGOs led by highly educated and professional individuals (Dill, 2014). In this context, we consider that further research analysing the process of establishing these structures (the characteristics of the people developing them, on what grounds are they established, what are the barriers for their growth, where do they activate or the number of cancer survivors involved and the intensity of their activism in such associations), is necessary. Second, the entrepreneurial skills, usually hold by highly educated people, are an important component in establishing and managing organizations. Studies (Fagan, 2005) show the importance of knowledge and skills related to fundraising and mobilizing community resources. This know-how is accrued in larger cities and infrequent in rural areas.

# Conclusion

Using a descriptive approach, we have presented the landscape of NGOs activating in the cancer field in Romania. Results show a massive focus on patients undergoing treatment (mostly helping and supporting but also informing) but less on other stakeholders such as survivors, physicians, researchers. Furthermore, of the cancer control areas, the diagnosis and treatment are particularly emphasised and in some cases prevention, but there are fields almost not covered such as rehabilitation (physical, professional, etc) and palliation. The results can be partially explained by the structural barriers Romanian civil society faced in the aftermath of the communism fall: low incentives for civic responsibility after decades of learnt ignorance, dependence on international donor funds, disconnection with local communities, widespread suspicion and mistrust.

The paper raises two major concerns. First, it urges policy-makers to include NGOs as partners in national cancer control programmes. In the absence of guidance and legitimation from governments, NGOs make uncoordinated efforts that may not respond properly to the real needs in a specific society. The tendency is to focus on the urgent needs of current patients and to disregard the long run objectives that have no immediate benefits. This is particular important for NGOs in post-communist countries which have less experience on advocating in the health field. Second, NGOs development seems to be dependant of a set of local social and economic characteristics (social capital, social trust, economic development). The consequence is that in regions where these characteristics are less present, the civil society is weaker or absent. The lesson that should be drawn is that additional support is needed in such regions for setting up NGOs and maintaining their functionality.

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