Parents of children with oncological diseases and the employment market in Bulgaria

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Abstract

The problem with the employment of parents of children with oncological diseases is not new and with so many supporting organizations and media influences is expected to be solved, but it is not the case. We asked ourselves are employers familiar with the professional abilities, physical and psychological health of parents of children with malignant diseases? Are there any preferences and programs equally effective for the employers and the employees? The research of the team of the current study draws to the conclusion that currently, the social integration of disadvantaged and vulnerable groups of the population in the labor market is one of the most significant problems in Bulgaria, which is ever growing in scale and tends to affect more and more people. The neglect and downplaying of this problem has led to the emergence of many other socially significant problems including poverty, high social tensions and conflicts, which have a negative impact on the demographic processes in the country and inhibit its development.

Keywords: employers; employees; malignant diseases in children; parents; supporting campaign.

Introduction

Every year, 250,000 children and adolescents under the age of 20 worldwide are diagnosed with oncological diseases, making the statistics a current medical, social and socio-economic issue. The problem with the employment of parents of children with oncohematological diseases is not new. In recent years, with the development of a market economy that presents greater demands to the workforce, the problem keeps getting worse and it is becoming increasingly difficult for this vulnerable group of the country's population to find job opportunities and to be competitive in the labour market, while in active working age[1].

Today, in a free market environment, the range of jobs and professions is dynamic and practically unlimited, but just how accessible are these jobs to parents of children with disabilities and to parents of children with oncohematological diseases? [2]

The purpose of this study is to assess the current awareness and readiness of different categories of employers to employ parents of children with oncological diseases and to be a truly active party in the dynamic processes of socio-economic integration.

Materials and methods

For the purposes of this pilot study, a questionnaire has been compiled for use in a sociological survey among employers, presented in Table 1. The subject of this study are 172 employers, business representatives, regionally selected from the biggest cities of Bulgaria - Sofia, Varna and Plovdiv, where the three centres for treatment of children with oncohematological diseases are located, covering the whole territory of Bulgaria. Two of the suggested questionnaires were filled in incorrectly.

Following the population density in the regions covered by the three centres the 48.42% of the questionnaires were filled in the capital Sofia; 28.82%
A division of companies/enterprises has been made according to the European Commission's (EU) 1996 guidelines, based on three main criteria: employment, turnover and total assets on the balance sheet[3]. Based on the above criteria, the companies are divided into:

1. micro-enterprises (economically independent companies/enterprises, no more than 250 workers, turnover - no more than BGN 40 million and total assets on the balance sheet - no more than BGN 27 million) (based on the employment criterion - no more than 10 people, with enterprises that have no staff, but are characterized by the so-called self-employment by the owner of the company, included in this group)
2. small enterprises, with a staff of 10 to 49 employees and
3. medium-sized enterprises with a staff of 50 to 249 employees. [4,5]

This study included 36 micro-enterprises (21.17%), 29 small enterprises (17.05%) and 65 medium-sized enterprises (38.23%).

The distribution of surveyed employers based on the type of trader/commercial company is as follows:

- 23 (13.37%) work or manage a Joint-stockCompany (AD),
- 31 (18.2%) hold the position of CEO of a Limited LiabilityCompany (OOD),
- 19 (11.5%) are in the position of CEO of a SingleMember Limited LiabilityCompany (EOOD),
- 15 (8.72%) are "Associates" in a Company under the Obligations and Contracts Act (OCA),
- 64 (37.21%) are SoleTrader (ET) owners. The study also included 18 (10.47%) representatives of various non-governmental organizations (NGOs).

Results

The results of the study are summarized in several important areas of research interest, including:

Employers' awareness of the problems of vulnerable population groups, parents of children with disabilities, parents of children with oncological diseases, willingness to provide jobs, awareness of preferential social programs for hiring unemployed persons.

Question 1, aimed at the employers: "Are there any employees who are also parents of children with malignant diseases in the company/enterprise you are managing?", was intended to determine how many of them are generally familiar with the issue, the professional abilities and skills of this vulnerable group of parents, and how many of them have appointed a parent of a child with an oncohematological disease in the company/enterprise they manage. A significant percentage of 95.8% of respondents, however, gave a negative answer.

Parallel interviews with parents of children with oncological diseases at the three treatment centres show that a large number of parents have not been directed to job opportunities and therefore do not even register with the Labour Office. The employers' results presented in Figure 1 also complement the statistics which show that 46.51% of them are aware of the issue, 40.12% require more information and 13.37% report that they would not hire a parent of a child with an oncological disease at all [6,7].

Figure 2 summarizes the motives of the employers who have employed a parent of a child with malignancy at their company/enterprise. As the leading motives in making their decision, employers point out: civic empathy, emotional engagement and personal motivation to the parent's problem.

In order to maximize objectivity regarding employers' attitudes and awareness in employing parents of children with oncohematological diseases, the participants in this study were asked questions regarding the employer's assessment of the professional qualities and employability of the contingent of parents as a work force (question 4.). The lack of information undoubtedly hinders employers in recruiting parents of children with oncological diseases, which in most cases is detrimental to said parents. The attitude of employers to take specific action and address the issue of employing members of vulnerable groups may also stem from the fact that most of them think that this group of people is discriminated against in terms of employment, which is confirmed by the answers to question 5. What's positive is that 94.16% of employers answer question 6: "If you as a company/enterprise manager are better informed about the problems of the parents of children with malignancies, would you take specific action to open jobs for people with such problems?" with "YES" and only 5.88% respond negatively, which proves that employers are generally willing to take specific action to create jobs for such parents, they just need to be better informed about the issue.

The results of the answers to questions 7, 8 and 9 show
that 70% of employers do not feel confident about the role of the state in solving issues related to the social integration of parents of children with oncohematological diseases. They believe that there is still no stable social policy that would stimulate them to participate more actively in these integration processes.

Table 1. Employers’ sociological survey questionnaire

| Employer Questionnaire | Questions:                                                                 | Answers:                                                                                  |
|------------------------|-----------------------------------------------------------------------------|-------------------------------------------------------------------------------------------|
| Question 1.            | Are there any employees in your company/enterprise who are also parents of children with malignant diseases? | YES / NO                                                                                  |
| Question 2.            | Have any parents of children with malignant diseases turned to you as a company/enterprise manager when looking (on their part) for employment opportunities? | YES, SEVERAL TIMES ONLY ONCE NO                                                            |
| Question 3.            | If you have assigned/saved a position/ in your company/enterprise for an employee who is also a parent of a child with malignancy, what was your main motivation for this? | Please answer freely in a few words:                                                      |
| Question 4.            | As a company/enterprise manager and an employer, do you consider that an employee/worker who is also a parent of a child with malignancy is sufficiently competitive in seeking employment opportunities? | I AGREE I PARTIALLY AGREE I PARTIALLY DISAGREE I DON'T AGREE OTHER: Please answer freely in a few words: |
| Question 5.            | Do you think there is some form of discrimination against parents of children with malignancies in terms of their employment (considering the possible absences from work related to the need for additional care, the physical or emotional problems of the parent)? | YES, THERE IS THERE IS IN PART THERE MOSTLY ISN'T ANY NO, THERE ISN'T OTHER: Please answer freely in a few words: |
| Question 6.            | If you as a company/enterprise manager are better informed about the problems of the parents of children with malignancies, would you take specific action to open jobs for people with such problems? | YES / NO                                                                                  |
| Question 7.            | Bulgaria is a member of the European Union since January 1st, 2017. Do you think that Bulgaria is working sufficiently towards integrating patients with malignancies and their parents in society? | YES IN PART NO OTHER: Please answer freely in a few words:                               |
| Question 8.            | Statistics from international surveys show that about 55% of parents of children with malignancies remain temporarily or permanently unemployed. What do you think are the main reasons this problem exists? | Please answer freely in a few words:                                                      |
| Question 9.            | The Employment Agency has developed programs that provide preferences for employers when recruiting unemployed people. Are you familiar with them? | YES IN PART NO OTHER: Please answer freely in a few words:                               |
| Question 10.           | What do you think needs to be done to solve the problems with the employment (recruitment/preservation of work position) of parents of children with malignancies? | Please answer freely in a few words:                                                      |
Discussion

Our results show that the majority (94.11%) of the employers, representatives of micro, small and medium-sized businesses in the three most populated cities of the country, have the positive attitude about actively participating in solving the issues related to the social and economic integration of parents of children with oncological diseases by providing job opportunities. Only 4.11% of the surveyed 170 employers been directly confronted with the problems of parents of children with oncohematological diseases and have employed such an employee/parent. The results can be explained by the fact that malignancies account for 2% of all childhood illnesses, a small percentage of total childhood morbidity. However, an explanation can also be found in another aspect to which the answers to question 2 direct us. The results of question 2 confirm the conclusions of previous international and regional studies [6,7], focusing on the psychological assessment of parents, who are in the process of active treatment of the child. Given the high anxiety, emotional lability, depressive tendencies and low working capacity, keeping employed and looking for work is not a priority for the surveyed parents, but the lack of employment leads to additional and significant economic burdens for affected families. It is reasonable to conclude that if the above-mentioned parent group was better informed about the labour market and more flexible job opportunities, parents would be much more active in seeking out contacts with employers, and employers would also be more involved in solving the problem of employment.

The evaluation of the participants in the current sociological survey on the issues regarding state policy on the integration of parents of children with oncohematological diseases shows that, in a market economy where the problem of employment is a problem for a large part of the working population of the country, we are not supposed to expect that the solution to the problem of employment of the
contingent of parents of children with oncological diseases is only the employers’ obligation [3,4,8]. Issues related to the economic and social integration of vulnerable groups of the population must be resolved by the whole of society, as is the case in all developed democratic countries [2,7].

Solving these issues implies providing accessible information on the additional work environment requirements, employability assessment, emotional and mental health of the parent group, as well as information on current employment programs in the country. An adequate information environment is a prerequisite for making it easier for employers to take the necessary steps to eliminate the problems concerning the employment of parents of children with malignancies and to look for the optimal options and effective actions to solve the bigger issue - the social and economic integration of people and parents of children with disabilities and diseases that require continuous treatment and rehabilitation. Oncological patients, and in particular the parents of children with oncohematological diseases, are among the riskiest target groups on the labourmarket, despite the antidiscrimination and incentive measures provided by the Bulgarian legislation for employment. Some of the reasons for this unfavourable finding stem from the socio-psychological attitudes of a large number of employers who underestimate the potential of these vulnerable population groups; in the existing public context regarding the malignancy stigma, the lack of or the not clear enough social policy enabling employers to take advantage of the already proven skills and abilities of the above-mentioned contingent of potential employees [9]. It is undisputed that even the unemployed parents themselves need encouragement, proper training and support by career guidance, a secure and accessible information environment, and to be provided with sufficient technical means and services for quality work (which refers to all employees). These problems are extremely complex and require the help of a broad range of institutions - state, regional and local authorities, business, non-governmental organizations and the media.

Summary of the mainfindings

- There is insufficient active dialogue between unemployed parents of children with oncohematological diseases, employers, labour mediators and active institutions in the field of employment;
- Of the surveyed employers, 70% do not know the qualities of this group of parents as a workforce in terms of employability, they are not familiar with the standards for a suitable workplace and with the programs to encourage the employment of disabled people, parents of children with disabilities and parents of children with oncohematological diseases seeking work;
- In order to improve the dialogue between employers and parents of children with oncological diseases, it is appropriate to include resources and representatives of the non-governmental sector (NGOs) related to oncological diseases, their treatment and quality of life, who are well acquainted with the specifics of oncohematological diseases - the accompanying socio-economic burdens and the problems of the work environment.

Limitations of the study

The limitation of our study includes the fact that usually in Bulgarian society the parent taking the leading role as the one who cares for the child in the hospital, therefore is more widely socially accepted for the mother of the sick child to be unemployed and especially not to contradict if she is asked to resign. Some of the companies are comprised mainly by female employees (i.e. in a textile factory). Thus, our results could be true reflection of the situation in more conservative and closed societies in the contrast in the more advanced in gender equality ones.

Conclusion

Currently, the social integration of disadvantaged and vulnerable groups of the population in the labour market is one of the most significant problems in Bulgaria, which is ever growing in scale and tends to affect more and more people[5]. The neglect and downplaying of this problem has led to the emergence of many other socially significant problems including poverty, high social tensions and conflicts, which have a negative impact on the demographic processes in the country and inhibit its development [9]. According to the accepted Standard Rules on the Equalization of Opportunities for Persons with Disabilities – a 1993 UN Resolution: 'The State is obliged and responsible for accepting the principle that all citizens should be allowed to exercise their human rights, in particular in the field of employment, by actively supporting their inclusion in the labormarket' [10]. An active marketing policy and techniques are needed to create an information environment for employers, schemes to stimulate the professional orientation of citizens, to encourage private entrepreneurship to address the problems of vulnerable groups of the population in all aspects of the production activity.
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