
Infant mortality and nationwide newborn bloodspot screening programs in the European Union

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Abstract

The infant mortality rate in Albania (7.9/1,000) more than doubles the EU-28 average (3.9/1,000), whereas the infant mortality in Germany (3.3/1,000) and Great Britain (3.8/1,000) is slightly under it. Both countries have a newborn bloodspot screening system adjusted to their respective health systems, whereas Albania lacks any kind of a newborn bloodspot screenings system. Since the introductions of the newborn bloodspot screening in the 1970s, infant mortality rates have dropped tremendously in the investigated countries, whereas it is questionable whether newborn bloodspot screening was the deciding factor for this. By comparing Albania to similar countries regionally and economically, the need for a newborn bloodspot screening program becomes clearer.

Keywords: bloodspot, infant mortality, screening.

Introduction

Since the introduction of Newborn Screening by Wilson & Jungner in the late 1960s, newborn bloodspot screening programme is an important tool in order to screen for autosomal-recessive inherited metabolic and hematologic diseases in a population (1). With the introduction of tandem mass spectrometry in the late 1980s (2), the process of newborn bloodspot screening was revolutionized once again, since one dried spot allowed the screening for multiple autosomal recessive diseases (3).

With the technological and medical advantages in the last 47 years, newborn screening became more and more complex and efficient at detecting autosomal-recessive inherited disorders, such as Medium-Chain-Acyl-CoA-Dehydrogenase-Deficiency, which has a reported mortality rate of 20-25% (4). This observed rise in complexity and efficiency resulting in a reduced infant mortality as one of the many positive outcomes (5).

The aim of this paper is to investigate the newborn bloodspot screening programmes available in Germany, Great Britain and Albania and compare them to the infant mortality statistics in the respective country. Infant mortality is one of the most important statistically measurable healthcare indicators – nothing influences the future and demographic change of a nation as much as its infant mortality rate. According to Eurostat, the 2013 infant mortality rate per 1,000 live births in Germany was 3.3 and in the United Kingdom 3.8, both slightly under the EU-28 average of 3.9. The 2013 infant mortality rate per 1,000 live births in Albania however nearly doubles the EU-28 average, by 7.9.

This paper focusses on Albania, Germany and the United Kingdom for several reasons: Albania is a prospective country for an EU accession in the near future. With the enlargement of the EU eastwards and the inclusion of more and more countries, it is important to exchange best practice amongst the (potential) member states. Germany and the United Kingdom incorporate a newborn

bloodspot screening program into two different healthcare systems, the Bismarckian model in Germany, where either private or public health insurances take over the costs for medical treatment and healthcare (6), and the Beveridge model in the United Kingdom, where the complete healthcare sector is run by the state. Germany and the United Kingdom have infant mortality rates under the EU-28 average. This paper evaluates what Albania can learn from the two national newborn bloodspot screening programs in Germany and the United Kingdom in order to reduce its own infant mortality rate towards the range of the EU-28 average.

Methods

The way this paper is approaching the topic is in the fashion of a literature review with a systematic approach. The paper is based on the available data by statistical databases, such as Eurostat and on international journal publications. The aim of this paper is to point out differences in the newborn bloodspot screening programs of the Germany, the United Kingdom and Albania, find possibilities of best-practice exchange and reveal knowledge gaps. The sources for the materials used in this paper are diverse: The statistical data will be retrieved from Eurostat. An important factor hereby is the publication date, whereas recent data is preferred. In cases, where some of the countries provided data for a more recent time period than others, the last period in which all three countries provided data will be taken into consideration in the comparisons.

The relevance of journal publications taken into account in this paper will be sorted by publication date of the article, aiming at reducing the number of outdated references in this paper. Journal articles used are acquired from the online database “PubMed” and the search engine “Google Scholar”. Keywords that assisted the search were the following terms: “Newborn Screening”, “Effectiveness of Newborn Screening”, “Infant

mortality in (Germany / the United Kingdom / Albania)", "Newborn bloodspot screening programs in (Germany / the United Kingdom / Albania)" and others. Due to the fact that Albania is not part of the EU yet, but a possible candidate for a membership in the next years, incomplete and unavailable data regarding Albania might still exist, although only very few gaps were found during this research.

The "Results" part of this paper shows facts and figures about the infant mortality and the newborn screening systems in the respective countries. The following "Discussion" part will point out the possible solutions for best practice exchange amongst the (potential) EU member states referred to in this paper and state further possibilities to reduce infant mortality in the respective newborn bloodspot screening systems.

Results

Newborn bloodspot screening in Germany

Newborn bloodspot screening in Germany is integrated into a series of "Kindervorsorgeuntersuchungen", which can be directly translated by "prevention examinations for children". These preventive examinations are accompanying a child in Germany from his day of birth until the last examination, taking place between the 17th and 18th year of age. The newborn bloodspot screening takes place between the second and third day of life of the infant. The costs are covered by health insurances (7).

The newborn bloodspot screening includes test for several autosomal-recessive inherited metabolic diseases, such as Phenylketonuria, MCADD, LCADD, VLCAD, Maple Syrup Urine Disease, Isovaleric Acidaemia, Glutaric Aciduria Type 1, Hypothyroidism, Congenital Adrenal Hyperplasia, Biotinidase Deficiency, Galactosemia and deficiencies of the Carnitin cycle. All of these diseases can lead to complications during the early lifetime of a child, leading to lifelong disorders or in the worst case scenario death. On the other side, most of these consequences can be easily prevented by simple

dietary change in the early uprising of the child, e.g. by reducing lactose and galactose for Galactosemia, or reducing proteins in order to prevent mental deficits resulting from Phenylketonuria (7).

Infant mortality in Germany

The infant mortality in Germany at the moment is at the lowest level since the beginning of the records. In the early 1970s, shortly after the introduction of a nationwide newborn bloodspot screening program under the guidelines from Wilson & Jungner, infant mortality was 25 out of 1,000 newborns (8), whereas the latest Eurostat data from 2013 shows an infant mortality rate of 3.3 out of 1,000 newborns. Newborn Bloodspot screening is definitely a factor in this evolution, nevertheless most of this progress can be attributed to the increased research of antibiotics in the 1970s and 1980s (8). A trend that can be observed here is the fact that the decline in the infant mortality rate is still rising, but not as fast as it used to be: While from 1970 to 2002 the decrease was nearly 20/1,000, the last decade only showed a decrease of 0.9/1,000 (9).

Newborn bloodspot screening in the United Kingdom

The screening program in the United Kingdom is similar to the one build up in Germany. The costs are covered by the NHS, the blood sample is taken by a midwife up to five days after the birth of the infant and the process of newborn bloodspot screening is highly recommended, but not compulsory (10). In the United Kingdom, screening is carried out for fewer diseases than in Germany, nevertheless, both countries overlap in most diseases. The only disease the newborn bloodspot screening program of the United Kingdom takes into account which is not screened for in Germany is Homocystinuria, other than that the United Kingdom screens for Phenylketonuria, MCADD, Maple Syrup Urine Disease, Isovaleric Acidaemia and Glutaric Aciduria Type 1 (7).

Infant mortality in the United Kingdom

In the United Kingdom, a similar trend can be seen as it is the case in Germany. After the introduction

of newborn bloodspot screening in the late 1960s / early 1970s, the death rate dropped enormously, yet again the introduction of antibiotics most likely played a role as well (11). A similar trend can be seen in the UK as in Germany, whilst the decrease was enormous in the early 1970s, over the last decade only a decrease from 1.4/1,000 could be observed (9).

Newborn bloodspot screening in Albania

Albania is the only country of all EU member states, candidates and potential candidates that does not have its own newborn bloodspot screening program at all. Whilst other countries, mostly in the south-east region of Europe, have no coherent bloodspot screening program but at least single screenings for primary congenital hypothyroidism, Albania has no screening at all (12). Although there is a neonatal hearing screening program in Albania (13), newborn bloodspot screening is not yet a topic in Albania. Treatment costs for possible complications are usually not reimbursed, in the case of Phenylketonuria, Phe-free amino acids and other suitable supplements for a diet based on a low protein intake have to be paid by the parent/guardian.

Infant mortality in Albania

Over the last 45 years, a decline in the infant mortality rate of Albania could be witnessed. According to the Population Reference Bureau 2014 and 2015 World Population Data Sheets, infant mortality dropped from 98.0/1,000 in 1970 to 7.9/1,000 in 2013. Compared to the United Kingdom and Germany, there is one more clear difference to be spotted concerning the infant mortality rate of the respective countries: while in Germany and Great Britain the infant mortality rate is either continuously decreasing or only going up by a very small margin, the Albanian infant mortality rate rose by 2/1,000 from 2008 to 2013. When this trend started, or whether it is expected to go on, is unclear due to the fact that no infant mortality data was assessed from 2009-2012 (9).

Discussion

Comparison of the different newborn bloodspot screening systems

Due to the fact that Albania has no newborn bloodspot screening integrated in the public health services of the country, no comparison of the screening system can be made for the south-eastern European country. In Great Britain and Germany, the newborn bloodspot screening systems are similar, both based on the Wilson & Jungner criteria from 1968, both without additional costs for the patient (or in this case: the parent/guardian) (7). Albania is definitely lacking a newborn bloodspot screening system that would influence the infant mortality rate in the country positively.

The relation between infant mortality and a newborn bloodspot screening program

One has to acknowledge that the most important medical intervention that reduced the infant mortality in the second half of the last century was definitely the scientific progress in the evolution of antibiotics (8). Due to relatively low incidence rates, such as 1/80,000 for Phenylketonuria (14), nationwide newborn screening programs cannot be attributed to major cuts of the reduction in the infant mortality rate. Nevertheless, the introduction of nationwide newborn screening programs surely has had an impact on the national infant mortality rates: Whilst fifty years ago most of the diseases screenable nowadays led to mental retardation and death, Phenylketonuria, Homocystinuria and other metabolic diseases can nowadays easily be treated with a simple dietary change.

Comparing the infant mortality rate in Albania (7.9/1,000) to the infant mortality rate in the neighbouring countries of Montenegro (4.4/1,000) and Greece (3.7/1,000), which both have a very small newborn screening program (12) shows that a high infant mortality rate is not necessarily regionally induced. Another argument for a higher infant

mortality rate might be the social-economic status of a society. Albania has a gross-domestic product per capita of \$4,610 US and is a growing economy. Similar values in Europe can be found in Bosnia-Herzegovina (\$4,598 US) and Serbia (\$5,907 US) (15). Bosnia-Herzegovina and Serbia both have a newborn bloodspot screening program introduced in their country as well (12), and show a significantly lower infant mortality rate than Albania (Bosnia-Herzegovina: 5.0 in 2012; Serbia 6.3) (9). It can definitely be assumed that the significantly lower infant mortality rate in Germany and the United Kingdom is also partly related to the fact that both countries have a higher level of wealth (GDP per Capita in Germany: 44,999; in the United

Kingdom: 39,567) (15). Another reason that has to be taken into account is the historical perspective, where Albania was also affected by the Kosovo War in the late 1990s. Nevertheless, neighbouring countries and countries with a similar GDP per capita have a lower infant mortality rate. Albania would definitely benefit from a nationwide newborn bloodspot screening program, even only a small one, to prevent the most prevalent diseases would already help reducing the infant mortality rate in the country in the direction of the EU-28 average. Both newborn screening programs, in Germany and the United Kingdom, have similar effectiveness and would be suitable as a “role-model” for a future Albanian newborn bloodspot screening program.

Conflicts of interest: None declared.

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