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THE CARE FOR PEOPLE WITH RARE DISEASES IN DENMARK IN THE FIRST HALF OF THE 1920S: SAMFUNDET OG HJEMMET FOR VANFØRE, DIAKONISSEHUSET ST. LUKAS STIFTELSENS HOSPITAL, KOLONIEN FILADELFIA, DANSK RØDE KORS AND SILKEBORG BAD**Abstract**

Introduction and aim: History of healthcare in the range of rare diseases is not well described. The aim of the analysis of reports of a few Danish hospitals and sanatoria from the first half of the 1920s is to characterize medical care on people suffering from rare diseases.

Material and methods: The analysis of activity of Samfundet og Hjemmet for Vanføre in Copenhagen, Diakonissehuset Sankt Lukas Stiftelsens Hospital in Hellerup, Kolonien Filadelfia in Dianalund, sanatorium of Dansk Røde Kors in Bækkelund and Silkeborg Bad in Silkeborg was undertaken using reports (primary sources) attached to Ugeskrift for Læger, the journal of the Danish Medical Association (Den Almindelige Danske Lægeforening).

Results: Among patients of described hospitals and sanatoria there were persons with rare diseases, e.g. osteogenesis imperfecta and rare neoplasms as gliomatosis cerebri, vaginal cancer and retroperitoneal sarcoma.

Conclusion: Medical care given by hospitals and sanatoria included treatment of rare diseases.

Keywords: Rare diseases, medical care, Denmark, history of medicine

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OPIEKA NAD CHORYMI NA CHAROBY RZADKIE W DANII W PIERWSZEJ POŁOWIE LAT 20. XX WIEKU: SAMFUNDET OG HJEMMET FOR VANFØRE, DIAKONISSEHUSET ST. LUKAS STIFTELSENS HOSPITAL, KOLONIEN FILADELFIA, DANSK RØDE KORS I SILKEBORG BAD**Streszczenie**

Wstęp i cele: Historia opieki medycznej w zakresie chorób rzadkich nie jest dokładnie opisana. Celem analizy raportów kilku duńskich szpitali i sanatoriów z pierwszej połowy lat 20. XX wieku jest charakterystyka opieki nad chorymi na choroby rzadkie.

Materiał i metody: Analiza działalności Samfundet og Hjemmet for Vanføre w Kopenhadze, Diakonissehuset Sankt Lukas Stiftelsens Hospital w Hellerup, Kolonien Filadelfia w Dianalund, sanatorium Duńskiego Czerwonego Krzyża (Dansk Røde Kors) w Bækkelund i Silkeborg Bad w Silkeborg była przeprowadzona z wykorzystaniem raportów (źródła pierwotne) załączonych do Ugeskrift for Læger, czasopisma Duńskiego Towarzystwa Lekarskiego (Den Almindelige Danske Lægeforening).

Wyniki: Wśród pacjentów i kuracjuszy opisanych szpitali i sanatoriów były osoby chorujące na choroby rzadkie, np. osteogenesis imperfecta i rzadkie nowotwory jak glejakowatość mózgu, rak pochwy i mięsak przestrzeni zaotrzewnowej.

Wnioski: Opieka medyczna w duńskich szpitalach i sanatoriach w pierwszej połowie lat 20. XX wieku obejmowała leczenie chorych na choroby rzadkie.

Słowa kluczowe: Choroby rzadkie, opieka medyczna, Dania, historia medycyny

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1. Introduction and aim

In majority rare diseases are poorly known disorders. That is because of the low prevalence in populations. Nowadays there is a precise definition of rare disease in European Union, namely a disease less frequent than 1 : 2000 people in the country [1]. The analysis of reports of a few Danish hospitals and sanatoria from the first half of the 1920s enables to achieve the preview on medical care on people suffering from rare diseases. Documents were annexed to the journal of the Danish Medical Association (*Den Almindelige Danske Lægeforening*) entitled *Ugeskrift for Læger*. The journal published from the year 1839 is one of the most important medical periodicals in Scandinavia.

2. Material and methods

The analysis of lists of diagnoses of patients of a few Danish hospitals and sanatoria was based on annual reports of Samfundet og Hjemmet for Vanføre, hospital in Copenhagen (1921 and 1923), Diakonissehuset Sankt Lukas Stiftelsens Hospital in Hellerup (1921), Kolonien Filadelfia, the hospital and sanatorium in Dianalund (1922-1923) and two sanatoria: the agency of Dansk Røde Kors in Bækkelund (1922) and Silkeborg Bad (Silkeborg Vandkuranstalt) in Silkeborg (1922). All of these reports were published as some attachments to *Ugeskrift for Læger* (the list below):

- Lægeberetning for Samfundet og Hjemmet for Vanføres Klinik for Aaret 1921. J.H. Schultz A/S Tryk., København. Annex to *Ugeskrift for Læger* 1922(41) [2],
- Guildal P.: Lægeberetning for Samfundet og Hjemmet for Vanføres Klinik for Aaret 1923. J.H. Schultz A/S Tryk., København. Annex to *Ugeskrift for Læger* 1924(42) [3],
- Diakonissehuset St. Lukas Stiftelsens Hospital. Annex to *Ugeskrift for Læger* 1922(48) [4],
- Lægelig Aarsberetning fra Kolonien Filadelfia 1922-1923. Duplex Trykkeriet, København 1924. Annex to *Ugeskrift for Læger* 1924(25) [5],
- Beretning fra Dansk Røde Kors: Folkekuranstalten ved Hald 1922 pr. Bækkelund St. Beretning om Folkekuranstalten Virksomhed i 1922. Frederik Møllers Bogtrykkeri, Viborg 1923. Annex to *Ugeskrift for Læger* 1923(11) [6],
- Faber A.: 40de Aarsberetning for Silkeborg Bad (Silkeborg Vandkuranstalt). Græbes Bogtrykkeri, København 1923. Annex to *Ugeskrift for Læger* 1923(10) [7].

3. Results

Among patients of described hospitals and sanatoria there were persons suffered from for instance gliomatosis and osteogenesis imperfecta and some disorders that may be components or sequelae of rare diseases or syndromes as caecitis (typhlitis) or intellectual disability.

Patients of Kolonien Filadelfia suffered from neurological and mental disorders of various categories, mainly with epilepsy treated with potassium bromide, phenobarbital and disodium tetraborate (borax). In 1922 there were 3 persons with intellectual disability (orig. imbecilitas, imbecility). Amongst patients who died in 1922 there were 1 person with muscular dystrophy (dystrophia musculorum progressiva) whose death was caused with bronchopneumonia and 1 person with Huntington's disease who died because of pneumonia in the course of influenza. In the year 1923 there was a patient died because of brain disorder noted as emollitiones cerebri. The total numbers of patients were 684 in the year 1922 and 770 in 1923 [5].

The majority of patients of Samfundet og Hjemmet for Vanføre were people with diseases of skeleton, except acquired many congenital bone deformities, for example of hand and foot. They were treated with surgery or only on observation. In the year 1921 there were 3 patients

with spina bifida, including 1 with this defect associated with valgus (left) and club-foot (right), and two years later 4 patients with this type of defect, 1 of them had paraplegia and another one, 6 year old boy, with the enormous spina bifida associated with incontinence and uremia, which was a cause of death. The total numbers of patients were 1778 in 1921 and 2123 in 1923. In two described years 1921 and 1923 there were also patients with osteogenesis imperfecta (3 in 1921 and 1 in 1923), persons with muscular dystrophy (dystrophia musculorum progressiva) (8 in 1921 and 7 in 1923) and 2 patients with intellectual disability (orig. imbecilitas, imbecility) (1923) [2], [3].

Patients of Diakonissehuset St. Lukas Stiftelsens Hospital were treated in two hospital wards – internal and surgical. There were a few persons affected with rare diseases in 1921 (table 1). The total number of patients in this year was 1068 [4].

Tab. 1. Patients with rare diseases or health disorders related to rare diseases in Diakonissehuset St. Lukas Stiftelsens Hospital in Hellerup in the year 1921 (from 1 January to 31 December) [4]

| Health disorder | Male | Female | Total | Discharged | Dead |
|-------------------------|------|--------|-------|------------|------|
| vaginal cancer | 0 | 2 | 2 | 2 | 0 |
| peritoneal sarcoma | 0 | 1 | 1 | 1 | 0 |
| retroperitoneal sarcoma | 0 | 1 | 1 | 1 | 0 |
| typhlitis | 0 | 1 | 1 | 1 | 0 |
| male breast tumor | 1 | 0 | 1 | 1 | 0 |

In 1922 in the group of 349 visitors of the sanatorium of Dansk Røde Kors in Bækkelund there were 11 persons suffering from myopathies (various but unspecified) and 1 patient with gliomatosis (table 2). At all they were people of various age and occupational activities, among others housewives, fishermen, seamen, smiths, farmers, painter, nurses, teachers, telephone operators and children, from almost all parts of the country. There were many kinds of physiotherapeutic treatments undergone, e.g. massage or gymnastics, vibrations, salt bath, carbonic acid bath, electric shower and carbon-arc light [6].

Tab. 2. Patients with rare diseases or health disorders related to rare diseases in the sanatorium of Dansk Røde Kors in Bækkelund in the year 1922 [6]

| health disorder | male | female | total | healthy | better | without change |
|----------------------|------|--------|-------|---------|--------|----------------|
| myopathies (various) | 2 | 9 | 11 | 3 | 7 | 1 |
| gliomatosis | 0 | 1 | 1 | 0 | 1 | 0 |

In the summer 1922 Silkeborg Bad hosted guests from almost the whole country and a few persons from abroad (in total 373 persons). Amongst bather of the sanatorium there were two persons whose health problems might have been symptoms of rare diseases: a child with chorea minor (Sydenham's chorea) and man with brain disorder noted as emollitio cerebri. Following physiotherapeutic treatments were used in Silkeborg Bad: salt bath, spruce bath, carbonic acid bath, hot air bath, diathermy, electric shower, light therapy and others [7].

4. Discussion and conclusions

Work on reports of hospitals and sanatoria activities taking rare diseases under consideration is one of basic proofs of the interest in giving help people with uncommon health problems. That is also evidence for the fact of medical care for persons from this group provided by medical professionals. The not small number of patients with rare diseases mentioned in

examined reports and information about treatment of them prove that Danish surgery, conservative treatment and physiotherapy were open to solve non-routine health problems. As is clear from the introduction to Kolonien Filadelfia report, the tetany and the need for treatment with calcium were taken into consideration in making decisions on the treatment of epilepsy [5]. The real number of patients suffering from rare diseases could have been bigger as disorders noted in reports could have been parts of pictures of diseases unknown in the analyzed period. For example an underlying disease of patient with chorea minor (Sydenham's chorea) might have been among others Lesch-Nyhan syndrome, Wilson's disease or Huntington's disease and intellectual disability could have been a symptom of many genetic diseases as phenylketonuria (untreated).

It could be speculated that medics' work was as careful as it was possible basing on medical knowledge of that time. Many diagnostic and therapeutic methods, including radiography and advanced surgery, were available [2], [3], [4]. Moreover two described sanatoria have localization in the vicinity of forests and lakes. The agency of Dansk Røde Kors in Bækkelund is situated near the lake Hald (Danish: Hald Sø) in a small distance from the town of Viborg and hydro-sanatorium Silkeborg Bad (Silkeborg Vandkuranstalt) – on the outskirts of the town of Silkeborg close to mineral springs called Arnakkekilden, near the lake Ørnsø (Danish: Ørnsø) [6], [7]. There were people of many occupations involved in management and maintenance of health care institutions, except medics there were among others clergymen, bookkeepers, cooks and helpers [4]-[6].

These examples of hospitals and sanatoria prove that in the first half of the 1920s Danish medical care on persons with rare diseases was on a comparable level with that for people with common disorders.

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References

- [1] European Commission Health & Consumer Protection Directorate-General: Useful information on Rare Diseases from an EU perspective, JMO/C5/81.
- [2] Lægeberetning for Samfundet og Hjemmet for Vanføres Klinik for Aaret 1921. J.H. Schultz A/S Tryk., København. Annex to Ugeskrift for Læger 1922 (41).
- [3] Guildal P.: Lægeberetning for Samfundet og Hjemmet for Vanføres Klinik for Aaret 1923. J.H. Schultz A/S Tryk., København. Annex to Ugeskrift for Læger 1924 (42).
- [4] Diakonissehuset St. Lukas Stiftelsens Hospital. Annex to Ugeskrift for Læger 1922 (48).
- [5] Lægelig Aarsberetning fra Kolonien Filadelfia 1922-1923. Duplex Trykkeriet, København 1924. Annex to Ugeskrift for Læger 1924 (25).
- [6] Beretning fra Dansk Røde Kors: Folkekuranstalten ved Hald 1922 pr. Bækkelund St. Beretning om Folkekuranstalten Virksomhed i 1922. Frederik Møllers Bogtrykkeri, Viborg 1923. Annex to Ugeskrift for Læger 1923 (11).
- [7] Faber A.: 40de Aarsberetning for Silkeborg Bad (Silkeborg Vandkuranstalt). Græbes Bogtrykkeri, København 1923. Annex to Ugeskrift for Læger 1923 (10).