ISLAMIC REPUBLIC OF IRAN

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Research Affairs

Disease Registry Unit

In the Name of GOD

Registry system for evaluation and therapeutic intervention of childhood fatty liver in Iran

Non-alcoholic fatty liver disease (NAFLD) is a chronic liver disease caused by the accumulation of excess fat in the liver. Non-alcoholic fatty liver disease is the most common liver disease in children and is also very common in obese children because of its close association with obesity. In recent decades, NAFLD has been one of the symptoms of liver transplantation in adulthood (1). Numerous studies have shown that the prevalence of the disease in the general population of children is 3 to 10 percent, which increases to 60 to 70 percent in patients with metabolic disorders. However, the prevalence of NAFLD varies widely depending on geographical location and diagnostic methods (2). In Iran, a study of 952 children and adolescents aged 6-18 years reported that the incidence of fatty liver by ultrasound was 28.8% in overweight and obese children (3). Due to the prevalence of NAFLD among children and adolescents in Iran, determining the most effective and sustainable method of evaluation and therapeutic interventions for NAFLD is one of the health priorities of the country. In many children, NAFLD is associated with insulin resistance, central obesity, and dyslipidemia, which is characterized by high triglycerides and low HDL (4, 5). Evaluation of clinical course of pediatric NAFLD and evaluation of their effectiveness and effectiveness in this field is only possible through the establishment of a registry system. Using a high quality data collection system to collect data on pediatric non-alcoholic fatty liver disease, this system provides the opportunity to identify best practices for improving the treatment of pediatric NAFLD and its complications and to plan for its implementation nationally.

Registry Objectives (what is it you are specifically looking at, trying to reach?)

The main goals of registry system include: determining the abundance of NAFLD among children, determining the clinical course and complications of determining the abundance of NAFLD among children, determining and evaluating health care services in this area and increasing the quality of care, developing a health care system to prevent and control of NAFLD and its complications, design and implementation of epidemiological studies to identify factors associated with the exacerbation of NAFLD, collecting and recording data for clinical trials in this field

Registry Design (participants, data collection, statistical analysis plan, etc.)

All people 18 years and younger that initial medical assessment in physicians' offices, hospitals, clinics and health centers located throughout the country if they have NAFLD are entered into the system. The information about the entered persons is collected according to the software questionnaire such as demographic information, anthropometric measurements, laboratory results, diet, risk factors for childhood NAFLD, interventions performed, outcomes and complications. All this information is provided by the relevant authorities in each center. At the Information Coordination Center, the person or persons informed and expert to monitor the information entered on a regular basis and, if there is any confusion, contact the relevant center and the registrant or speak to the patient if necessary. In this system the detection method will be inactive. After placing NAFLD on the list of reportable diseases, medical practitioners, nurses, and health care providers across the country after defining diagnostic procedures and ensuring the type of disease complete the standard pre-designated form provided to all units for this purpose. In order to evaluate the quality of data collection at specified intervals (three months), several records are randomly selected and the accuracy of their data entry is examined by referring to the origin of the file or patient question.

The registration system will be active for 10 years, during which time the information of eligible people will be entered. All steps in setting up and running the system will be carried out under the supervision of the Strategic Committee. The task of the Strategic Committee is to determine the strategies needed to achieve the predetermined goals. The Data Coordination Center, which is overseen by the Strategic Committee, is responsible for controlling the quality of information, how it is accessed, and how the database outputs for analysis. In addition, individuals are involved in the program to collect information or other information that all individuals are aware of in committee decisions through the Data Coordination Center.

Timeline for your Registry project (project deadlines set by you and your mentor)

	1	2	3	4	5	6	7	8	9	10
Proposal submission	*	*	*							
Designing Registration system				*	*					
Coordination with other focal point for registration						*	*	*	*	*
Registry duration set 10 years										
Each 10 years data will be evaluated and results use in researchers and articles to improve patient's conditions.										

Who will provide support and feedback and how often will this occur?

Shahid Beheshti University of medical science provides financial support for the registry of Iranian registry of ALF databases system clinical outcomes research.

Also, some experts plan to collect information or other items in the program, all of which are in the committee's decisions through the coordinating center strategic committee formation, preparing the internet system for patient registration. To inform all the pediatricians, gastrointestinal pediatricians, neonatologists, surgeons. Also, other experts will be invited to participate.

References:

1. Vos MB, Abrams SH, Barlow SE, Caprio S, Daniels SR, Kohli R, et al. NASPGHAN clinical practice guideline for the diagnosis and treatment of nonalcoholic fatty liver disease in children: recommendations from the Expert Committee on NAFLD (ECON) and the North American Society of Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN). Journal of pediatric gastroenterology and nutrition. 2017;64(2):319.
2. Mann JP, Valenti L, Scorletti E, Byrne CD, Nobili V, editors. Nonalcoholic fatty liver disease in children. Seminars in liver disease; 2018: Thieme Medical Publishers.
3. آتوسا ا, رويا ك, ابوالفضل ب, حميدرضا ص, محمد ط. بررسي فراواني كبد چرب در كودكان مبتلا به اضافه وزن و چاقي در مقايسه با گروه طبيعي (يک مطالعه مقطعي در اصفهان).
4. Schwimmer JB, Deutsch R, Rauch JB, Behling C, Newbury R, Lavine JE. Obesity, insulin resistance, and other clinicopathological correlates of pediatric nonalcoholic fatty liver disease. The Journal of pediatrics. 2003;143(4):500-5.
5. Lavine JE, Schwimmer JB. Nonalcoholic fatty liver disease in the pediatric population. Clinics in liver disease. 2004;8(3):549-58, viii-ix.