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Creating an Efficient System of Data Collection on the Patients' Adherence Level- with a Special View of the Fbih Health System

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Abstract:-

- ***Objectives:***

Improving the system and methods of collecting data related to the adherence level is one of the biggest problems not only in measuring the level of non – adherence, but also in assessing its impact on all participants in the health care system. An innovative approach to the application of existing methods using the information systems (IS) can in many ways help to increase the volume and reliability of data. Implementation (ICT) in Sarajevo Canton can be a pilot project in Bosnia and Herzegovina (BiH), or in Federation of Bosnia and Herzegovina (FBiH), as an opportunity to improve the methods of collecting data related to non-adherence level, by obtaining more precise and accurate information about the role and importance of adherence in the health system, without investing significant financial resources.

- ***Methods:***

Comparison of the method of measuring the degree of adherence of the previous research results in the world and the practical application of the health system in the Sarajevo Canton.

- ***Results:***

Applying modern information technologies (IT) and information systems (IS), together with the creation of a unique data collection methodology with a number of sources, obtained through various methods, it is possible to obtain data and information from much larger sample with different characteristics (economic, social , demographic, type of disease, therapy, etc.).

- ***Conclusion:***

By improving data collection methods, it is possible to get accurate and precise data on the adherence level, or provide a better insight into the role and importance of adherence.

Keywords:- *Patient Adherence, Data Collection, Integrated System, Adherence Metrics.*

I. INTRODUCTION

Adherence is one of the important factors that can greatly affect the outcome of the therapy. Adherence is the key mediator between medical practice and patient outcomes (1). A larger number of studies clearly demonstrates the benefits (2, 3) of adherence high level, whose importance is recognized by the WHO (World Health Organization) (4). Patient's non adherence is caused by a greater number of barriers (5, 6) that occur within the dimensions of adherence (7). In order to create an adequate strategy and measures for increasing adherence level, it is necessary to develop reliable and valid measures of adherence behaviors (8). Methods currently in use for measuring the adherence level refer to direct and indirect methods (9). The choice of a method for measuring the adherence level depends on a number of factors, however, unfortunately, an adequate model of adherence measurement has not yet been found which will collect the necessary information, but at the same time which will be easy to use and will not require significant financial resources (10).

II. PATIENTS AND METHODS/MATERIAL AND METHODS

Measurement of patient's adherence level is possible through the use of indirect and direct methods (11, 12, 13). Due to the complexity and large number of factors (14), no method allows obtaining of complete and accurate data with the optimal use of resources, primarily the financial resources. The Table 1. shown below, gives an overview of the available methods for measuring adherence level, with their advantages and disadvantages.

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MEASUREMENT METHOD	STRENGTHS	LIMITATIONS	Advantages	Disadvantages
Directly observed therapy	A very reliable method that, with the application of modern technologies, can enable the collection of reliable methods and information	The biggest disadvantage is the amount of costs necessary for the implementation, and the size of the sample which cannot be significantly large compared to other indirect methods.	Most accurate	Patients can hide pills in the mouth and then discard them; impractical for routine use
Biomarkers	The method is precise and does not require a significant period of time for each subject individually.	The method may require significant financial resources, under certain circumstances, the results may be inaccurate.	Objective; in clinical trials, can also be used to measure placebo	Requires expensive quantitative assays and collection of bodily fluids
Patient recall*	A simple method for applying on a larger sample	Data can be unreliable because patients can often be forgetful and provide incomplete information.	Simple; inexpensive; the most useful method in the clinical setting	Susceptible to error with increases in time between visits; results are easily distorted by the patient
Patient surveys	A very commonly used method that does not require significant financial resources. Extremely easy to use and does not require significant time to implement the same.	Data collection may be incomplete and incorrect, because it does not require additional verification. Data collected is data that the respondents recall. Certain respondents may be dishonest and provide different information than the actual ones.	Simple; generally easy to perform	Factors other than medication adherence can affect clinical response
Patient diaries (paper or electronic)	It does not require significant financial resources and it is possible to apply modern technology in order to gather data more easily.	Data collected using this method can be incomplete, and sometimes incorrect.	Help to correct for poor recall	Easily altered by the patient
Pill counts/inhaled dose counters/ weighing canisters**	Easy to use, with the use of modern technology, it is possible to increase the level of reliability of the collected data.	Patients can affect the outcome of the result and in this way collected data may not reflect the true state of the adherence level.	Objective, quantifiable, and easy to perform	Data easily altered by the patient (e.g., pill dumping)
Prescription refill rates	Simple method to use. It is possible to create a system that will be connected with pharmacies and medical institutions.	The correct take-up of prescribed drugs does not imply that the patient is adherent. The adherence is influenced by a number of factors, such as the time period of drug conduction, quantity of drugs, maintenance of other regulations of doctors, etc. which are not collected by this method.	Objective; easy to obtain data	A prescription refill is not equivalent to ingestion of medication; requires a closed pharmacy system

Table 1:- (15, 16, 17): Direct and Indirect Methods for Measuring Adherence

*Patient response to an open-ended question. **For example, electronic pill boxes, sensors in pill bottle caps or devices attached to inhalers that record the date and time each time they are activated

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Direct methods enable the collection of data that is most accurate and complete, however, the cost and size of the sample constitutes a significant limitation (18), in contrast to indirect methods that can be applied to a larger number of patients, but unfortunately reliability is much lower in comparison to direct methods, causing multiple problems when evaluating the impact and importance of adherence on therapy.

Self-report measure is the cheapest and most commonly used method, that can together with Patient surveys provide information related to the reasons which cause patient's non - adherence (19). Table 2. presents the MAQ used in Patient surveys and can be easily implemented in the IS health system.

		No=0	Yes=1
1	Do you sometimes forget to take your pills?		
2	People sometimes miss taking their medications for reasons other than forgetting. Thinking over the past two weeks, were there any days when you did not take your medicine?		
3	Have you ever cut back or stopped taking your medication without telling your doctor, because you felt worse when you took it?		
4	When you travel or leave home, do you sometimes forget to bring your medication?		
5	Did you take your medicine yesterday?		
6	When you do feel your disease is under control, do you sometimes stop taking your medicine?		
7	Taking medication every day is a real is a real inconvenience for same people. Do you ever fell hassled about sticking to your blood pressure treatment plan?		
8	How often do you have difficulty remembering to take all your medications? Never/Rarely -0; Once in a while -1; Sometimes -2; Usually -3; All the time - 4		

Table 2:- (20): MAQ (Medication Adherence Questionnaire)

The application of modern technology usually refers to Electronic monitors, which serve as effective strategy in reducing non-adherence. However, the key defects relate to the impossibility of assessing adherence to all aspects of the treatment, as well as complexity of collecting and utilizing this type of data, since electronic monitors do not guarantee that the behaviour was performed, and there is the possibility that monitoring data can overestimate adherence (21, 22). Also, additional limiting factor is the fact that cost of electronic monitoring is not covered by insurance, and thus these devices are not in routine use (23), since not all users can afford them. Although electronic monitors provide a potentially powerful tool for identifying problems with adherence, this method also has a number of constraints for which it is necessary to find possible ways for reducing or eliminating the same (24).

We believe that no single method is sufficient to collect accurate and reliable data, especially on a larger sample. For this reason it is necessary to create an integrated data collection system that will be implemented at the level of the entire health system.

III. RESULTS

The data and results of the adherence level, collected by various different methods, in most cases, are not stored in unique databases, but the results of the same are presented in individual professional articles, books, etc. Even in developed countries, the records of the adherence level, as well as its barriers, are not entered into the patient's cardboard, primarily because built-in data collection system, that is defined and adopted by the healthcare system, does not exist at all.

Due to the lack of an integrated system of data collection on adherence level and obstacles that patients face, we consider that the role and importance of adherence is underestimated. Suggestions and methods for reducing the level of non-adherence are created "sporadically", respectively, in most cases, are mere recommendations / conclusions of the research authors. The lack of unique data and the methodology for collecting them make it impossible to obtain the necessary data on the basis of which it is possible to accurately determine the importance and impact of adherence for the health system. There are only available cost estimates and estimates of reduced therapy effects due to patients' non - adherence (25, 26).

Applying modern information technologies (IT) and information systems (IS), together with the creation of a unique data collection methodology with a great number of sources, obtained through various methods, it is possible to obtain data and information from much larger sample with different characteristics (economic, social, demographic, type of disease, therapy, etc.). Using modern technology (e.g. BI - business intelligence) which has the ability to process a large amount of data from the DW (Data Warehouse), it is possible to create reports and indicators which can be helpful not only when creating strategies / measures / suggestions for increasing adherence, but also for monitoring and tracking trends. The collected data does not have to be used only in relation to the patients' adherence, but can be applied in a number of segments inside and outside the medical system. Data sources in the concept of an integrated data collection system are multiple, and one of the potential models is presented in Figure 1.

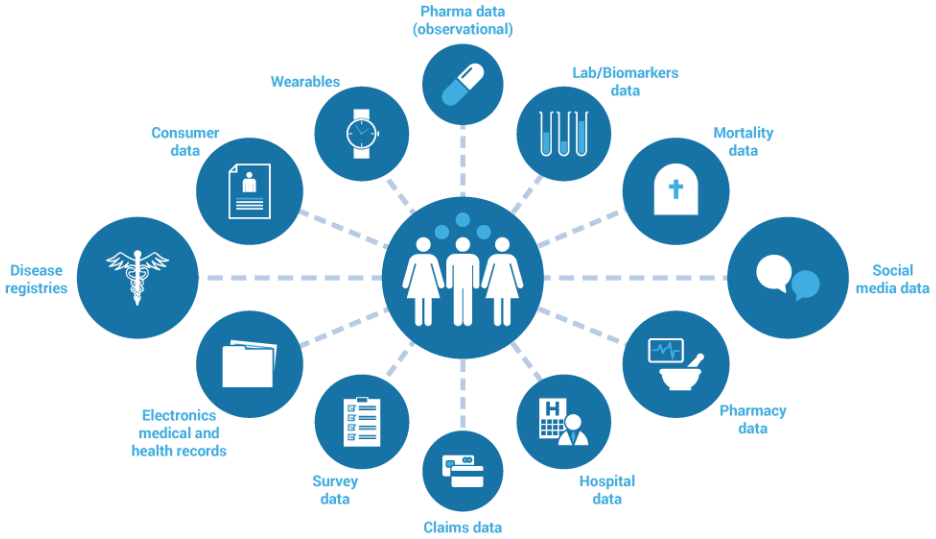

Fig 1:- (27): RWE (Real World Evidence) is Patient-Level Data

It is important to emphasize the role and significance of protecting the privacy of collected data, even though, currently, a great number of systems collect private and personal data that many users are "not aware" of. Social networks are an example of such systems, which collect users' information and, with the help of advanced analytical systems, generate data not related to individuals, but rather data of certain groups with common characteristics (social, economic, geographic, etc.). Due to this, we can conclude that the collection of data related to patients' adherence, with their consent, would not constitute a threat to privacy, but would serve as a basis for improving adherence, and hence therapy effectiveness, as well as health system improvement.

IV. DISCUSSION

We believe there is a great opportunity for improving the system of data collection and, consequently, for increasing the level of adherence in countries that introduce information technology into health systems. The process of implementation and introduction of information systems is a process that requires detailed analysis and preparation, and if the role and importance of adherence are presented in time, we believe that the creation and adjustment of the information system will not cause a significant increase in financial resources. So, for example, the implementation of Information Communication Technology (ICT) (28) in the Sarajevo Canton can be a turning point and a pilot project that, with minor improvement and adaptation, can be used to collect data primarily through the survey method (e.g. questions from Table 2.) and interviews during patient's visits to medical institutions. Flexible IS in healthcare institutions can certainly be expanded in a way that collects data from other sources, respectively other direct and indirect methods that have been previously presented. Ideally, the data would be collected and analyzed from the sources shown in Figure 1.

Benefits and advantages in this case are certainly greater than the necessary investments, especially in terms of long-term period. The data collected in the aforementioned way will provide multiple benefits for many segments in terms of monitoring, improving and analyzing the health system. In the context of adherence, this method of data collection will surely be very useful in creating strategy / measures / proposals for increasing the level of adherence both at the level of the health system, and also at the patient level.

By combining the available methods of collecting data on adherence level, together with other data related to the social, economic, demographic status of the patient and the treatment of patient, it is possible to create a systematic approach for collecting individual and collective data. Each method of data collection on adherence level has its advantages and disadvantages, but by combining them, it is possible to increase reliability level, while the sample size allows obtaining a macro and micro image of the adherence level within the health system, according to the desired search parameters.

V. CONCLUSION

By improving data collection methods, it is possible to get accurate and precise data on the adherence level, or provide a better insight into the role and importance of adherence. Previous research were primarily focused on a smaller sample with specific characteristics. The lack of accurate and reliable information involving a larger number of participants represents a bottleneck in generating a clear strategy, and in obtaining accurate indicators of the costs amount, which consequently increases the number of visits to medical institutions and lowers the effectiveness of therapies, caused by patients' non – adherence.

Previous methods, which are partially presented, have a number of shortcomings, and most of them represent a trade - off between reliability / precision in relation to the

required financial resources. We believe that it is necessary to find an innovative solution and improvement of the existing methods, primarily through the use of information technologies and devices that every participant in the treatment process uses on a daily basis (e.g. mobile devices, IS in health institutions, etc.).

The suggestion of the authors regarding the implementation of an integrated data collection system related to the patient's adherence in the implementation of the IS in the healthcare system represents an innovative approach and the opportunity to create a systemic approach to the collection and processing of data related to the patients' adherence, whose purpose and application can be multiple, both in the macro and micro plan. The improvement of the IS in the first phase is primarily focused on the creation of additional questions that will include issues such as those presented in Table 2., which will be filled/answered during patients' visits to medical institutions, or during a medical examination whose entry should not last longer from e.g. 5 min.

We consider that the authors' proposals in this paper can be implemented in a short period, with the important emphasis that no significant financial resources are needed, because it is required a completely new implementation of the IS, but an upgrade of the existing one.

DECLARATION OF INTEREST

The authors declare that there are no conflicts of interest.

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