

Unmonitored Patient Demographic Data Changes can Lead to Bias in Reported Outcomes and Data Registry Development

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Received on: 27 September 2022; Accepted on: 26 October 2022; Published on: 31 December 2022

Keywords: Clinical data, Data registry, SDOH, Social determinants of health.

Journal of Foot and Ankle Surgery (Asia-Pacific) (2023): 10.5005/jp-journals-10040-1273

Each patient is inevitably affected by his or her social determinants of health (SDOH) which plays an important role in the process of decision-making and predicting the outcomes in patients. Often, SDOH has been shown to have meaningful correlations with short- and long-term outcomes of treatments, especially in the field of orthopedic surgery. Therefore, accurate and continuous recording and monitoring the SDOH is vital in developing patient electronic medical records and registry systems. Changes in these determinants including changing the place of living, access to healthcare centers, socioeconomic status, insurance status, aging, mobilization, and transportation status can affect the quality of life, quality of health care, and the prognosis of the disease. In our recent research experience investigating the correlation of SDOH with different orthopedic conditions such as Achilles rupture, ankle fractures, and hallux valgus, we experienced that the patients had changed their place of living and thus their access to healthcare center was affected. These changes in the place of living as well as changes in the insurance, job, and socioeconomic conditions of the patients hindered us from an accurate analysis of data and unbiased report of the correlation of SDOH and the treatment outcomes of these orthopedic conditions. Although much progress has occurred in recent years to track SDOH, in our experience there was still a considerable number of missing data leading to concerns for biased outcomes.¹ As an example, our hospitals failed to keep track of patients' relocations, thus making it impossible for researchers to find any correlation between the place of living and the outcomes of Achilles repair in patients who suffered from acute Achilles rupture. Two indices that are commonly used for the assessment of SDOH include the social vulnerability index (SVI) and area deprivation index (ADI) scores; both factors are highly dependent on the living location of the patient. The SVI is affected by the socioeconomic status, household, composition and disability, minority status and language, and housing type and transportation.² This score is used to determine how vulnerable the communities are and how to prepare personnel accordingly in case of an emergency. ADI is based on 17 census variables that describe the SDOH in an area.² It allows the user, in this case being the health care provider, to determine resource allocation based on geographical need. However, these scores are not 100% reliable either. There is evidence of embedded bias within the scores secondary to the calculation methods. In fact, one study, in particular, found that the ADI calculation decreases in reliability as the vulnerability score increases.³ In our experience, due to a lot of missing data,

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How to cite this article: Lucaciu A, Hendriks JRH, Baker R, *et al.* Unmonitored Patient Demographic Data Changes can Lead to Bias in Reported Outcomes and Data Registry Development. *J Foot Ankle Surg (Asia-Pacific)* 2023;10(1):216–217.

Source of support: Nil

Conflict of interest: None

we were not able to provide the complete set of data needed for SVI and ADI as some of the patients were relocated during the healing course and we did not have any records of their previous living places.

Other than developing valid and reliable registry systems, demographic data and SDOH are being highly valued and used in predictive models.⁴ Scientists believe that the accurate and reliable prediction of the outcomes such as outcomes of a treatment or

prognosis of a diseases as well as the quality of healthcare, highly relies on patient's characteristics and SDOH. However, if the health records of the patients are not accurate and not monitored longitudinally during time, the predictions can be biased and not precise. In our experience, we tried to detect the associated factors impacting patient's recovery time in cases of acute Achilles tendon rupture. The time between injury and proper surgical intervention varied drastically in our dataset. Although one of our aims was to assess the correlation between the place of living, access to healthcare, and the quality of healthcare among our patients, due to lack of data on patients' previous addresses, and due to the fact that some of the patients had changed their addresses during the healing course, we failed to achieve our aim. Investigating other datasets showed us that this problem is widespread among various health care centers in our area which raised a major concern for modifying the methods of admitting the patients, updating their data regularly in each visit, and providing reports of the alterations of SDOH during time. This is also necessary when these centers want to report SVI, ADI, or other SDOH-related reports to the authorities and policy-making entities.

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