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Thema: 2 General practice / Family medicine

Titel: **A user-friendly software tool empowering patients to improve medical pedigree accuracy and completeness**

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Text: **Introduction**: Family history collected during clinical examination reveals important information about hereditary traits. We hypothesized that the pedigree acquired by the patient as the most knowledgeable expert of his own kinship would be more accurate than the physician's documentation.
Method: Between July and August 2019, twelve patients (mean age: 70) underwent a medically indicated, complete clinical examination in a single medical office of general internal medicine that was videotaped for research purposes. The physician documented the number of relatives, year of birth, aliveness, age at death, cause of death and lifetime disease history. The observed examination process and the obtained result were analyzed and a user-friendly, digital family tree tool *(DiFaTreeT)* was designed. In November 2019, the same patients used *DiFaTreeT* to document their medical family history on their own. Data obtained from the *DiFaTreeT* and the physician exam (=*standard of care*) were compared.
Results: Two of twelve patients (17%) were unable to use the software and needed assistance. On average, patients recorded 10 family members in 21 minutes whereas the physician devoted 2.5 minutes for 8 family members. Only 55% of data points fully matched in the patient's and physician's report. Remarkably, *DiFaTreeT* was clearly superior to the physician's recording for all structural elements of a pedigree: number of relatives (18 vs 3% more relevant data with *DiFaTreeT* vs *standard of care,* respectively), the year of birth (74% vs 0%), aliveness (18% vs 2%), age of death (39% vs 0%) and even cause of death (55% vs 7.5%). In the crucial section of lifetime medical disease history, *DiFaTreeT* data were at least equivalent to the physician's registration (29% vs 25%). In one family, it was only the patient's report that contributed a so far overlooked hint to a hereditary disorder. As an unexpected side-benefit using *DiFaTreeT*: patient's pedigree members all carried their real names, ensuring that future changes will be precisely allocated to the proper individual.
Conclusion: Patients are able to manage certain parts of their electronic health record equally well or better than a physician. An adequate tutorial may guide patients to a further improved recording of their own medical family history. *DiFaTreeT* could boost genomic medicine since the patient's medical pedigree is an indispensable source of information about a genetic origin of disease.

Gewählte Präsentationsart: **Poster oder Vortrag**

Konferenz: SGAIM Frühjahrskongress 2020 · Abstract: A-1159-0002-00324 · **Status: Übermittelt**

Drucken Zurück