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An Ontological Framework to Improve Surveillance of Adverse Childhood Experiences (ACEs)

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Abstract. Adverse Childhood Experiences (ACEs) have been proven to be linked to increased risks of a multitude of negative health outcomes and conditions when children reach adulthood and beyond. To better understand the relationship between ACEs and the associated health outcomes and eventually to pan and implement preventive interventions, access to an integrated coherent actionable data set is crucial. In this paper, we introduce a formal reusable ontological framework to capture the knowledge in the domain of Adverse Childhood Experiences to improve ACEs surveillance and response.

Keywords. Ontologies, Adverse Childhood Experiences, Public Health Surveillance, Semantics

1. Introduction

In the past 20 years, Adverse Childhood Experiences (ACEs), a set of negative events and processes that a person might encounter during childhood and adolescence, have been proven to increase the risks of a variety of diseases and health risks such as substance abuse [1] or impaired memory [2]. Most ACEs studies focus on adults' years after the ACEs have taken place and give a retrospective picture [3] while there are only a few studies on children and the short- and medium-term effects of ACEs on them. There is also not much consensus on how and when a medical and clinical approach is preferable to a community-based method and vice-versa [4]. To facilitate the collection, and exchange of the ACE-related data across different disciplines and systems and to improve ACEs surveillance, clinicians, health providers, researchers, and policymakers require to access a coherent integrated knowledge source. Due to several ethical, privacy and legal concerns, not all relevant pieces of data being used and shared in the same way; (e.g. personal information, and criminal records may have been assigned restricted access rights). To facilitate capturing, integration and sharing the data in the field and to maintain interoperability between different data sources we implemented the Adverse Childhood Experiences Ontology (ACESO). Ontologies offer a standardized structure to represent and reason about the data [5], improve semantic interoperability, i.e. the ability to use multiple data sources concurrently, and facilitate the distribution of knowledge across different actors and disciplines. Finally, ontologies enable us to deduce more information from the existing data through reasoning and inference. Formal Ontologies

have been extensively used in biomedical and health informatics to improve surveillance of both infectious [6, 7] and non-infectious [8, 9] diseases.

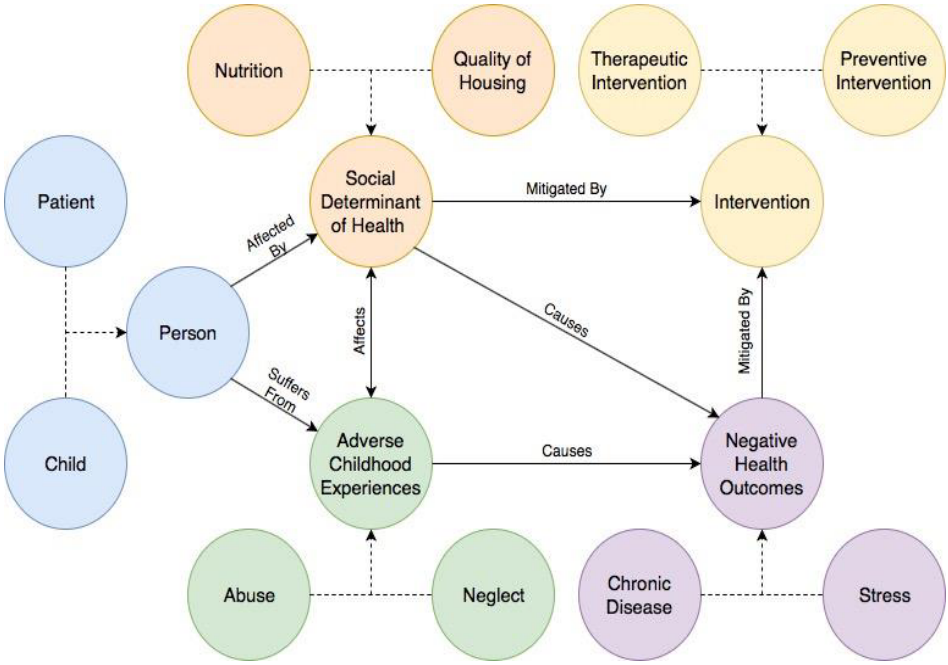

Figure 1. The top conceptual model for the ACEs ontology.

The ACEs ontology aims to provide a basis for the representing the ACEs data model and hierarchy and to empower query answering and reasoning. In order to facilitate the inclusion of existing sources, the ontology reuses concepts from many existing ontologies and defines new ones when necessary.

2. Building the ontology

The study of adverse childhood experiences, their causes, their detection, their prevention, and their consequences are linked to concepts and terminologies coming from a multiple domains and disciplines; from medicine to community responses, from legal justice to personal behavior, etc. As a result, developing an ontology encompassing the whole range of relevant subjects is far from trivial.

We classified the ontological knowledge into five different key domains namely, person, adverse childhood experiences, social determinant of health, negative health outcomes and interventions. As shown in Figure 1 the plain arrows represent relations between domains while the dotted ones denote inclusion. *Person* represents human subjects, e.g., the *Children*, the *Patients*, their family members and the rest of their social network. *Adverse Childhood Experiences* contains the ACEs, as defined by Felitti et al. [1]. They include various kinds of *Abuse* and *Neglect*. *Persons* suffer from *ACEs* at different level of granularities, e.g., divorce or separation of parents affects all the

children in a family while only some of them might be victims of emotional abuse. *Social Determinants of Health* (*SDHs*) are environmental factors that can affect *Persons* and how *ACEs* affect them. Like *ACEs*, *SDHs* act at various granularities, e.g., having mold in a house is household-specific while the quality of public transportation has impact on the entire neighborhood. *Nutrition* and *Quality of Housing* are also *SDHs*. *Negative Health Outcomes* are the medical and surgical consequences of the *ACEs*, e.g., *Stress* or *Chronic Diseases* (e.g. diabetes). *Interventions* are therapeutic or preventive programs that outside actors, e.g., social workers, implement to prevent or mitigate the negative outcomes.

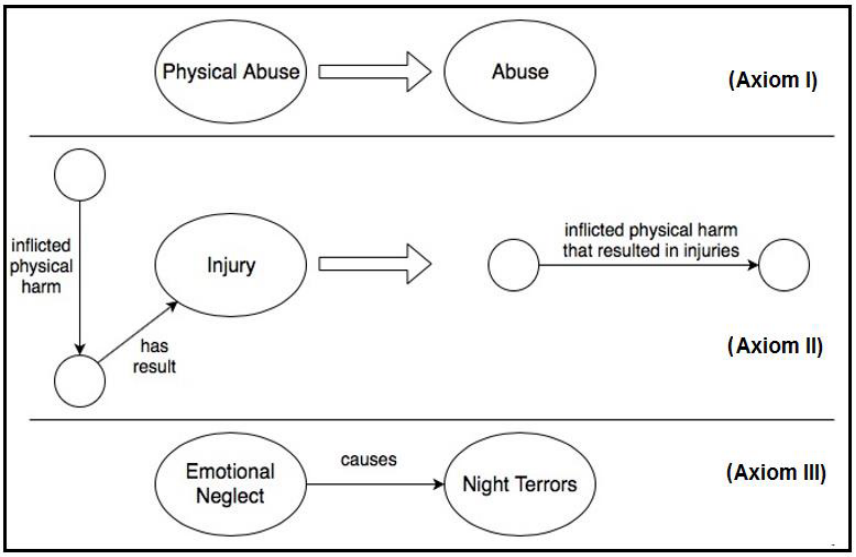

Figure 2. An abstract representation of some of the axioms that can be expressed in the ontology.

Many key concepts, e.g., abuse or mental illnesses, have already been defined in the existing ontologies or controlled vocabularies. So, we imported these definitions from their source ontologies; e.g. from SNOMED CT[1] and the National Cancer Institute Thesaurus (NCIT)[2]. We then add additional concepts and relations that are required to study ACEs.

Figure 2 shows some examples of the axioms described in the ontology. These axioms can define how two concepts are related, e.g., the first axiom says that every instance of *Physical Abuse* is also an instance of *Abuse*. Similarly, the axioms can be used to define relationships, e.g., Axiom II states that if something *inflicted physical harm* that *has result* an *Injury*, then that thing *inflicted physical harm that resulted in injuries*. Axioms can express inclusions, as shown in Axiom I, as well as equivalencies, as demonstrated in Axiom II. They can also express knowledge about causality patterns, e.g., the third axiom states that *Emotional Neglect* may causes *Night Terrors*. These axioms are deduced from the data and will be incorporated into the ontology.

[1] https://www.snomed.org
[2] https://ncit.nci.nih.gov/ncitbrowser/

While developing an ontology one needs to decide about its expressivity. A highly expressive ontology allows representing the knowledge in more details, which demands more complex reasoning and maintenance tasks. For this reason, many biomedical ontologies choose less expressivity to gain more computability. We choose to support several versions of the same ontology with different level of complexities and expressivities to be employed for different use cases. This, however, makes the maintenance task more difficult. We present two versions of the ontology on BioPortal[3]. The main version, labeled 1, is expressed in the description logic $\mathcal{ALCRIQ(D)}$, a sub-logic of OWL 2 [10]. The difference in expressivity between the two logics lies in the absence of nominals that are used to express assertions about individuals, e.g., *Person* (Albert) that states that Albert is a Person. $\mathcal{ALCRIQ(D)}$ is an expressive logic and thus the complexity of reasoning is high. In order to reduce the complexity, it is possible to avoid the use of datatypes used for dates and frequencies; counting quantifiers used to define the ACEs scores; or simplify the role hierarchies. The version labeled "Light" is modified in this way and thus expressed in $\mathcal{ALC}$. The ACEs ontology currently contains more than 280 classes, 90 object properties, and three data properties.

3. Applications

In order to show the usability of the ontology, we present an application scenario in a public health setting. A neighborhood association aims to improve the quality of living for the residents through appropriate interventions. In order to do so effectively, the association needs to collect data on the current state of the neighborhood as well as the potential interventions that it could enact. The association itself has access to some data provided by its members about the problems they face but this source of data is not necessarily perfect. For instance, members of the association may not be representative of the residents of the neighborhood. There are many other possible sources of data that could be used such as transportation data, energy consumption, crime data, school or church attendance, hospital admissions, and so forth. This information is spread through scattered heterogeneous data sources. The use of the ontology we can facilitate data integration, harmonization and querying more efficiently. Obviously due to privacy and security concern, the pieces that are available are not at the personal or household level but at the aggregated/group level, e.g., the school district, and the ontology is required to integrate the data in a meaningful way. Additionally, information about the possible interventions, as well as their required resources and their effectiveness and outcomes, need to be formatted in a uniform way to be compared with the resources available to the association and the expected outcome. Again, the ontology makes this task easier. Finally, the ontology can be used to reveal hidden dependencies among elements in the causal pathway (of a disease or condition) through logical inference. For instance, some of the characteristics of a neighborhood may point towards a higher than average risk of suicide attempts for its residents.

[3] https://bioportal.bioontology.org/ontologies/ACESO

4. Discussion and conclusion

In this paper, we presented an ontology to improve the surveillance of Adverse Childhood Experiences. The main task of the ontology is to provide a framework to uniformly capture and represent the domain knowledge as well as improve data acquisition, exchange, querying and reasoning for more effective ACEs prevention and treatment. We presented two different versions of the ontology with different expressive powers and thus different complexities for reasoning and maintenance. The ontology is meant to be used by actors throughout the ACEs community, within different applications from the diagnosis of individual experiences, to the discovery of connections between ACEs and its negative outcomes, to the design of policies to prevent ACEs. The ontology is still under active development and more concepts, relationships and axioms will be added to describe constantly expanding universe of ACEs and answer more complex exploratory and explanatory questions.

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