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Article

Big data, dementia prediction and knowledge organization

Big data, predicción de la demencia y organización del conocimiento

Big data, previsão de demência e organização do conhecimento

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Abstract

This paper uses principles of knowledge organization to explore the application of big data algorithms to the task of predicting dementia diagnoses. Using the principles of domain analysis, the paper argues that domains, as distinct from academic disciplines, provide a more flexible, and therefore more useful way of understanding the different discourse communities involved in dementia prediction. Using the distinction between the epistemological, applied and sociocultural dimensions of knowledge organization, the paper extracts a series of important questions and ambiguities that face both technology-related and dementia-related domains in the area of dementia prediction.

Keywords: DEMENTIA; BIG DATA; PREDICTION; DOMAIN ANALYSIS

Resumen

Este artículo utiliza los principios de la organización del conocimiento para explorar la aplicación de algoritmos de big data a la predicción de diagnósticos de demencia. Utilizando los principios del análisis de dominio, el artículo argumenta que los dominios, a diferencia de las disciplinas académicas, ofrecen una forma más flexible y, por lo tanto, más útil de comprender las diferentes comunidades discursivas involucradas en la predicción de la demencia. A partir de la distinción entre las dimensiones epistemológica, aplicada y sociocultural de la organización del conocimiento, el artículo extrae una serie de preguntas y ambigüedades importantes que enfrentan tanto los dominios tecnológicos como los relacionados con la demencia en el ámbito de la predicción de la demencia.

Palabras clave: DEMENCIA; BIG DATA; PREDICCIÓN; ANÁLISIS DE DOMINIO

Resumo

Este artigo utiliza princípios de organização do conhecimento para explorar a aplicação de algoritmos de big data à tarefa de prever diagnósticos de demência. Utilizando os princípios da análise de domínio, o artigo argumenta que os domínios, diferentemente das disciplinas acadêmicas, fornecem uma maneira mais flexível e, portanto, mais útil de compreender as diferentes comunidades discursivas envolvidas na previsão da demência. Utilizando a distinção entre as dimensões epistemológica, aplicada e sociocultural da organização do conhecimento, o artigo extrai uma série de questões e ambiguidades importantes que se colocam tanto aos domínios relacionados à tecnologia quanto aos relacionados à demência na área de previsão da demência.

Palavras-chave: DEMÊNCIA; BIG DATA; PREDIÇÃO; ANÁLISE DE DOMÍNIO

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1. Introduction

In 2024, the Government of Canada's Research Coordinating Committee announced its New Frontiers in Research Fund, designed to support "world-leading interdisciplinary, international, high-risk/high-reward, transformative and rapid-response Canadian-led research" (CRCC 2024). Funds such as these attest to a growing awareness in research communities across the world that many of the world's problems are not only multinational in scope but multidisciplinary in nature. Whether addressing pandemics, global warming, political unrest, poverty or social injustice, researchers are conceding and even embracing the realization that some degree of cooperation is necessary between disciplines of study. This cooperation might be multi-disciplinary, in which each community retains its own assumptions and methods; it might be interdisciplinary, in which the different fields synthesize their approaches; it might even be transdisciplinary, causing the emergence of a new field of study (Choi 2009, 351).

Such ventures, exciting as they are, create significant challenges in knowledge organization, necessitating the design of new systems that facilitate the smooth integration of information retrieval and access across different databases, catalogues and platforms, frequently using different vocabularies, classification systems and metadata standards. Furthermore, beneath these logistical challenges we frequently find intractable differences in perspectives, a priori assumptions, objectives, values and methods of inquiry. In this paper, I hope to argue that the field of knowledge organization has much to offer: the theories and methods of knowledge organization have the potential, not to resolve such differences, but to bring them into the light and arrange them in a meaningful way that robs them of their potentially insidious effects and enables researchers to address them productively.

Among the world's many pressing challenges, dementia research in particular is rapidly evolving into a multi-disciplinary activity as the world's population ages and as the consequences of the rising burden of dementia cases make themselves felt upon governments, health care systems, communities and families. Dementia is notoriously difficult to predict and to diagnose; many treatments are only effective in the very early stages; and the rising incidence of dementia across the world is placing a serious strain on local, national and international health systems. And researchers across the spectrum of academia, inspired both by compassion and the prevalence of funding, are stepping up to address the challenges.

The advent of machine learning methods commonly referred to as "big data" has brought computer scientists and statisticians into collaboration with researchers in medicine and the health sciences. The professional practices we refer to as prognosis and diagnosis, classifications based on a sensitive analysis of evidence, bear a striking resemblance to the way various machine learning methods process the evidence of different variables to perform their own acts of classification. With health systems around the world facing daunting logistical challenges, it is tempting to see machine learning systems as a way to accelerate professional practices with computational power, using algorithms that their designers hope will be unhindered by the biases that afflict even the most conscientious human judgment.

As this paper will show, early efforts to use big data methods to predict the onset of dementia have encountered both promising results and perplexing challenges: challenges which do not stay confined to a single discipline. Knowledge organization as a body of theory has a significant contribution to make in framing these challenges in two primary areas. First, the concept of knowledge domains as developed by Birgir Hjorland and Hanne Albrechtsen (1995) enriches our understanding of the interactions taking place in multidisciplinary and interdisciplinary research. Second, the axes of the conceptual triad presented by Guimarães and Dodebei (2012) enable us to stratify the challenges in a revealing way. These challenges are, in a very real sense, knowledge organization challenges. And while our field cannot, as it has in the past, impose a "universal" consistency, it can nonetheless make it easier for stakeholders to find their own solutions.

2. The Dementia Problem

The term "dementia," as defined by the Diagnostic and Statistical Manual (DSM), the U.S. National Institute on Aging, and the World Health Organization, refers not to a disease but to a group of symptoms: "a cluster of neurocognitive disorders … characterized by the presence of cognitive deficits that are the most prominent and defining features of the condition" (Sachev, et al. 2014, 635). These symptoms are caused by a range of possible underlying diseases or disorders. For this reason, determining the cause and producing a reliable diagnosis takes time, and involves testing across the full range of neurocognitive domains recognized by the DSM: not just memory, but language, perceptual motor function, social cognition, complex attention and executive function. These tests frequently seek, not to detect a presence but to confirm an absence: to eliminate possibilities patiently and systematically, until the clinician is left with a reasonable, if not decisive, confirmation.

Because of this complexity, differential diagnosis is challenging, and misdiagnosis is an ongoing and grave concern. Symptoms of Alzheimer's Disease are similar to those of other causes such as Lewy Body or Frontotemporal dementia. They can also arise from causes beyond dementia, as side effects of other ailments. Cases of Fronto-Temporal Dementia, for instance, have been initially diagnosed as Alzheimer's disease, organic dementia, Lewy body dementia, Cerebrovascular disease, Parkinson's disease, corticobasal degeneration, multiple system atrophy, small vessel disease, normal pressure hydrocephalus, psychiatric disorder, space occupying lesion, progressive supranuclear palsy, paraneoplastic syndrome and Huntington's disease (Brzezicki, et al. 2019, 296).

3. The "Big Data Solution"

The term, "big data," refers to the practice of applying machine-learning algorithms to large volumes of data for purposes of discovery, inference and prediction. This practice has entered widespread use as "predictive analytics," a technique which has been adopted in various domains, ranging from insurance to banking, human resources, medicine, policing and aviation, among others, and which has made us all familiar with "the algorithm": a faintly-understood process that pushes advertisements our way and shapes what we find on search engines and streaming services. Much of the popular appeal of predictive analytics stems from its startling assertion that correlation can be separated from causation. As stated by Mayer-Schoenberger and Cukier in their popular apologia, *Big Data*, "there is a treasure hunt under way, driven by the insights to be extracted from data and the dormant value that can be unleashed by a shift from causation to correlation" (2013, 15). Such a split has its uses in basic research which is striving for new and unforeseen insights: many large-scale research programs now incorporate big data to some extent as a means of guiding us to unexpected solutions to complex problems by highlighting unexpected correlations. Beyond academia, splitting causation from correlation has also led to fanciful and attractive conceits of entrepreneurial magic. Eric Siegel's book on predictive analytics, for instance, carries the catchy subtitle: "The Power to Predict Who Will Click, Buy, Lie, or Die," and promises to show, for instance, that early retirement leads to shorter life expectancy, and that vegetarians miss fewer flights (2016).

Given the stakes involved, medical and health care practitioners are understandably more cautious in their use of big data and machine learning. For these communities, big data serves various functions: it is used in efforts to discover new treatments, new cures, new methods of addressing ongoing and persistent challenges. More important for my purposes, it is also used in efforts to enhance the delivery and effectiveness of medical and health care services, including those involving the diagnosis of dementia. As David Snowdon discovered in his famous "Nun Study," large archives of longitudinal data can be statistically analyzed to yield important insights (2001).

For all the promise implied by big data algorithms when applied to dementia prediction, they pose some formidable questions in the way they bring questions of computer science, mathematics and statistics into close proximity with medical research, medical practice and health care in general. In particular:

-Are machine learning algorithms substitutes for acts of human judgment or as supplements to them?

-To what extent do the inferential processes of these algorithms resemble the processes of diagnosis and prognosis?

While knowledge organization theory cannot answer those questions, it can parse and stratify them in a useful way.

4. From "Discipline" to "Domain"

Understanding academic communities—or any community, for that matter—requires that we go beyond formal declarations of policy to unearth those a priori "obvious" assumptions that are deemed too obvious to articulate. Philosopher Charles Taylor has suggested that much of the conceptual scaffolding that supports our knowledge comes, not from formal and explicit articulations of philosophy, theory or metaphysics, but rather from partially submerged implicit structures of understanding that he calls "social imaginaries" (Taylor 2004). In a more narrow and focused sense, Hjorland and Albrechtsen (1995) presented to the knowledge organization community the concept of the "domain." Related to, but not confined to academic disciplines, domains are

Thought or discourse communities, which are parts of society's division of labor. Knowledge organization, structure, cooperation patterns, language and communication forms, information systems and relevance criteria are reflections of the objects of the work these communities and of their role in society. (Hjorland & Albrechtsen 1995, 400).

By defining domains as "thought communities," Hjorland and Albrechtsen gave us the means of defining a wider variety of associations that could produce discursive consistency. While a domain might be a discipline, Hjorland (2017) insists that "it need not be; it can be distributed in multiple disciplines or specialties or be a non-discipline, such as a hobby … (It is) a specialization in the division of cognitive labor that is theoretically coherent or socially institutionalized" (439).

In the area of dementia prediction, we can detect a number of loose associations of thought consistency and potential ruptures between such associations:

-Communities of prediction: including researchers in computer science and statistics, as well as in economics, business and public policy;

-Communities of empirical inquiry: including medicine, science and technology;

-Communities of care: including health providers, community advocates, and families

Individuals may belong to different communities at different times, and may stand simultaneously within multiple communities. Domain analysis provides us with the necessary flexibility to see these communities as loose associations with less-than-rigorous consistency. Within such flexibility, however, we can detect in dementia research, and dementia prediction particularly, two loose domain aggregations:

-Technology: those domains concerned with the capacities and potential of big data analysis, including computer science, mathematics and statistics. This area also includes, less formally, apologists for big data in the world of business and economics, advocating for its use in all areas of human activity.

-Dementia: those domains concerned with the prediction, diagnosis and treatment of dementia, including medicine, nursing, public health, as well as associations, communities and families intimately concerned.

5. The Three Dimensions of Knowledge Organization

Various efforts have been made in the intervening years to define the distinct dimensions of domains. This paper takes the triple distinction offered by Guimarães and Dodebei in their Introduction to the Proceedings of the 2011 Meeting of ISKO-Brasil (2012). In this triadic model, the processes of knowledge organization—its classification systems and vocabularies and ontologies—are formed and operate along three dimensions:

-The **epistemological** dimension (*dimensão epistemológica*) which addresses the conceptual, historical and methodological bases of a domain);

-The **applied** dimension (*dimensão aplicada*) dealing with the models, formats and structures of a domain;

-The **sociocultural** dimension (*dimensão social e política*) dealing with ethics, culture and identity.

What, then, are the processes involved in dementia prediction using big data algorithms and methods? And how can we assess the domain interactions along these three dimensions?

6. Prediction Processes

The processes that machine-learning systems employ to predict the onset of dementia typically draw from one of three different datasets:

-Image modality based datasets, which analyze brain imaging data such as magnetic resonance imaging;

-Clinical-variables modality based datasets, which draw on clinical data drawn from medical tests and clinical records;

-Voice modality based datasets, which test for disorders through changes in voice patterns typical of various cognitive disorders. (Javeed, et al. 2023, 5-6).

This analysis will confine itself to tests carried out on clinical variables modality-based datasets, which often offer the greatest breadth of longitudinal data, having been accumulated, in many cases, over many years. In such analyses, the system performs calculations on tests performed in clinical settings such as questionnaires and cognition tests. This data might include such variables as demographic information, family history, medications, results of physical examinations, neurological exams, cognitive tests, geriatric depression tests and clinical assessments (James, et al. 2021, 3).

A 2023 review shows a set of 12 machine learning algorithms in use to derive a set of features that have the greatest predictive power for the later onset of dementia (Javeed, et al. 2023, 10). Four typical examples include:

-Logistic regression: a specific form of multiple regression, adapted for cases in which the outcome variable is a dichotomy. It is therefore commonly used in medical cases for predicting binary outcomes, such as assessing whether a proposed treatment is likely or unlikely to cure the patient (Kelleher, et al. 2015, 353);

-Support vector machine modeling (SVM): this model resembles logistic regression, except that SVM also pays attention to the width of the margin on either side of the decision threshold: the greater the margin, the more reliable the prediction (Kelleher, et al. 2015, 377);

-Random forest modeling (RF): this model works on the principle of the decision tree, in which a model is derived from a training data set, involving a series of tests. The test begins with a root node and moves through 0 or more internal nodes to arrive at a prediction. The forest algorithm applies the decision tree process to a collection of randomly-selected subsets of the data. The results are collated, and the majority verdict constitutes the prediction (Kelleher, et al. 2015, 165);.

-Gradient-boosted trees (XGB), is similar to random forest modeling, but uses a sequential system of testing, enabling each subsequent test to learn from the previous iteration (Kelleher, et al. 2015, 121).

In a study conducted on memory clinic data in the United States between 2005 and 2015, logistic regression proved more effective in predicting the onset of Alzheimer's disease than did non-machine-learning tests such as the CAIDE dementia score, while the support vector model was effective in predicting Lewy Body disease (James, et al. 2021, 11-12).

While these processes clearly show promise, their use brings certain inherent problems in dementia prediction to light.

7. The Epistemological Dimension

7.1 Prediction vs. Diagnosis

If we look at the epistemological implications of algorithmic prediction, we find distinctions of great importance in the dementia domains that must be maintained. First, while it is very useful to have accurate predictions that dementia will occur, a prediction is not the same as a diagnosis. The Diagnostic and Statistical Manual explicitly distinguishes the two when it urges clinicians to base their diagnoses on symptoms, not on risk factors (Sachev, et al. 2014, 638). Obesity, for instance, may increase the likelihood of developing diabetes, but the mere fact that a patient is obese does not alone constitute grounds for diagnosing diabetes. Predictive algorithms based on clinical data were never intended to replace clinical diagnosis; they aimed rather to bring that diagnosis about sooner, thereby reducing the stress on patient and family, and reducing the number of intrusive, costly and intimidating tests that might be run.

7.2 Binary vs. Continuous Variables

Second, the models were designed to predict a binary outcome: a diagnosis of dementia. This is totally understandable, from the point of view of the doctor, who has to prescribe some sort of treatment in the face of the verdict, and of the patient, who has important decisions to make. It's important, however, to recognize that diagnostic standards such as DSM-5 have three categories and not two: normal cognition, mild neurocognitive impairment, and major neurocognitive impairment, which we typically call dementia (Sachev, et al. 2014, 637). In a very real sense, dementia occurs along a continuum: the machine learning models are imposing cut-off points along that continuum, typically called "decision thresholds," thereby turning a continuum into a binarism.

8. The Applied Dimension

In applying these predictive models, there are several reasons why we should be cautious: not because of the models themselves but because of the popular belief in their infallibility and their freedom from bias.

To begin with we must recognize that the models do not do away with professional medical expertise. Much of the clinical data comes not merely from tests that were founded upon clinical knowledge, but also from a clinician's interpretation of those tests, along with experience-based observation of the patient's decline in functioning. Clinical judgement is embedded into these models and forms a crucial aspect of the training of the algorithms.

Second, the specific nature of the population should be taken into account. Machine-learning prediction is typically carried out on datasets drawn from individuals in clinical settings such as memory clinics, where the average age is likely to be high, and many of the patients were expressing some concern over observed changes in cognition. This is not a matter of reading the palms of healthy 25-year-olds to predict "who will lie and who will die," as Eric Siegel would put it. The algorithms are typically exercised on a sample that generalizes to a population for whom the results have the greatest chance of being reliable and useful.

Finally, we must remember the problem of scale. Big data works on large datasets, where a certain allowance is made for small errors and approximations. There are undoubtedly occasions, as Meyer-Schoenberger and Cukier assert, when "two plus two equals three point nine. And that's sufficient" (2013, 35). But there are other occasions where two plus two needs to equal four point zero, and nothing else will do. Dementia diagnosis is fuzzy enough as it is: we can't expect families to show much empathy for the overall accuracy of the big picture when the small picture is hanging in the balance.

9. The Sociocultural Dimension

On the sociocultural dimension, we encounter at least one major distinction between the Technology and the Dementia domain groups. Dementia may indeed be a medical condition, and one distinct from “normal aging.” But dementia manifests in the real world within a social context. As the World Heath Organization acknowledges, the key and even decisive criteria for a diagnosis of dementia are socially constructed, and vary according to context. The International Classification of Diseases warns us that certain factors should not necessarily be construed as evidence of dementia:

Dementia produces an appreciable decline in intellectual functioning, and usually some interference with personal activities of daily living. … How such a decline manifests itself will depend largely on the social and cultural setting in which the patient lives. Changes in role performance, such as lowered ability to keep or find a job, should not be used as criteria of dementia because of the large cross-cultural differences that exist in what is appropriate, and because there may be frequent, externally imposed changes in the availability of work within a particular culture. (World Health Organization 1992)

How is the variable “degree of independence” determined? Certain people, particularly those who are wealthy or command privilege, may have fewer calls upon their self-reliance. Similarly, interest in hobbies, while undoubtedly revealing, would vary between the hobby. Some activities, such as music, entail high levels of retained ability and interest, while others are more vulnerable. Is this something that the algorithms that can account for?

10. The Contribution of Knowledge Organization

The field of knowledge organization has two primary ways of contributing to the needs of families who are facing the possibility of dementia. Situated as it is outside of, and distinct from, the various knowledge domains that contribute to dementia research and clinical practice, knowledge organization experts can draw on the insights of these three dimensions to articulate some principles that should underlie the design of information resources, particularly those which offer decision flowcharts or ontological visualizations of dementia studies. In particular, our field is well positioned to insist on the following elements of any dementia-related information system in which big data methods are being used for diagnosis:

-a clear distinction between **risk factors** and **symptoms** associated with dementia;

-the use of visualizations that emphasize continuities between **normal cognition**, **mild neurocognitive impairment**, and **major cognitive impairment**, rather than those that emphasize a binary distinction between **normal** and **abnormal**;

-visualizations of the diagnostic process that emphasize the equal participation of data and **informed clinical judgment**;

In addition to any specific tools, in the form of visualizations, decision guides or ontologies that knowledge organization specialists can provide, our field should insist that all information systems contain a clear and specific glossary of terms: not just those defined in the points above, but those which must be articulated within the particular social context, such as **degree of independence**. Dementia may be a global phenomenon, but it manifests within specific social contexts, and those must be represented in any information provided to patients and their families.

11. Conclusion

Returning to the concept of domains, we find that in dementia research that relies on big data, we are dealing with multiple domains: what's more, we are dealing with loose domain "clusters" that cherish different a priori assumptions. While these assumptions may seem irrelevant in the face of a shared and urgent challenge like dementia, they persist, often at the level of unexpressed assumptions and inclinations. The tools of big data analysis, like all predictive mechanisms, function on principles of probability, and probability has a deep relationship to randomness. As Ian Hacking showed us in *The Taming of Chance* (1990), the shift towards massive data collection in the 19th century moved us away from deistic determinism into the realm of randomness and probability, a realm which, with its statistical qualities of likelihood, probability and central tendency, has a beauty, significance and power all its own. Big data analysis, with its massive data archives and its striking powers of visualization, appears to partake of this beautiful and intriguing realm.

But individuals confronting dementia, like those confronting other terminal diagnoses, or any other unexpected disasters, are experiencing randomness at a more intimate proximity, and at close quarters, randomness can look unsightly and unfair. When you’re watching a loved one’s independence and cognition dwindle into helplessness while your neighbour celebrates her ninetieth birthday by running a marathon, it’s not easy to derive consolation from a grand, sweeping probability distribution.

Big data shows a real potential for improving the diagnosis and treatment of dementia in its early stages. However, the widespread adoption of such methods would raise important questions, and those questions must be answered. We cannot afford to treat these machine learning algorithms like closed boxes: at the risk of looking like fools, we all have to open the boxes and get at least some understanding of how these systems work. And finally, we must never forget that global patterns of the human community inscribe themselves, sometimes brutally, on the most intimate aspects of individual lives. Whatever improvements these tools bring about, we must communicate what we know to patients and their families with honesty, tact and compassion.

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D. Grant Campbell: Conceptualization, Data curation, Formal Investigation Methodology, Project administration, Supervision, Validation, Resources, Writing – original draft, and Writing – review & editing

Data availability note

The data used to prepare the paper can be obtained through request by mail to the author