

CONCEPT MAPS IN CANCER RESEARCH: FROM DESCRIBING COMPLEX DATA MODELS TO PATIENT EDUCATION

Rodrigo Carvajal, Amber M. Skinner, Paige W. Lake, Monica L. Kasting, Susan T. Vadaparampil, Damon R. Reed
Moffitt Cancer Center & Research Institute, USA
www.moffitt.org

Email: {Rodrigo.Carvajal, Amber.Skinner, Paige.Lake, Monica.Kasting, Susan.Vadaparampil, Damon.Reed}@moffitt.org

1 Introduction

Cancer research requires collaborations among patients, caregivers, clinicians, basic and populations scientists, and health care providers. Development of cancer research applications involves the integration of complex and heterogeneous data sources that require data transformations and aggregations to satisfy the interests of cancer investigators with different expertise and interests. Software engineers and data scientists struggle on how to better gather requirements and how to better communicate with their users about the development of their apps and how the data is presented and analyzed. As a second case, research has demonstrated that cancer patients want to be informed, specially the newly diagnosed, of their disease and its potential impact on their life, yet they continue to report unmet information needs. Benefits of access to meaningful information include improved ability to cope and make informed health decisions during the diagnosis, treatment, and post-treatment; reductions in anxiety and mood disturbances; and improved communication with care givers, friends, and family members. In both cases, concept map-based knowledge models have been developed at the Moffitt Cancer Center & Research Institute (MCC&RI) to facilitate the communication among data scientists, cancer researchers, and clinicians; and to educate patients, caregivers, and their families about cancer.

2 Data Modeling and Concept Maps

Concept Maps have been used as the graphical tool to support the Software Development Life Cycle (SDLC) of complex systems that involves electronic medical records, molecular characterizations of disease, patient-generated data, and survey data among other data sources. Concept Maps have been widely used at MCC&RI to gather system requirements, describe and navigate the complexities of the data model and the metadata associated to several data elements, document applications, and train users.

DM-Cmap Tool was developed to describe, enhance, and share complex data models among software engineers, data scientists, and cancer investigators. Seventeen (17) cancer researchers were interviewed during the development of the tool to identify their data sources and how their projects intersected (in terms of common? data elements) with other projects in the research institute. Concept Maps were used during the interviews to model the data. DM-Cmap Tool connects to the data warehouse to automatically generate concept-map based interfaces that facilitate the navigation of data dictionaries (aka codebooks) that replace the entity-relationship (ER) diagrams. *Figure 1* depicts a concept map that describes the Microarray table and its interactions with other data elements within the data warehouse or main database. Microarrays are chips that contain collections of microscopic DNA that measures gene

expression. Original output included in *Figure 1* was slightly modified to be included in this article. Each concept refers to a database table, the two resources associated to concepts are a) Text file with the description of the table in the Data Definition Language (DDL) and b) link to a concept map with the description of the table. Using DM-Cmap Tool a collection of 600 tables was represented as concept maps.

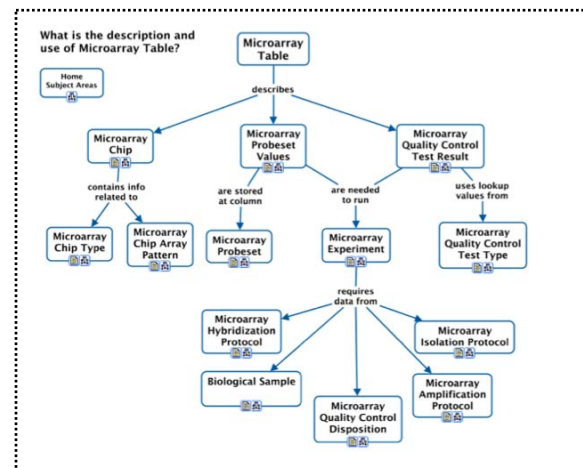


Figure 1. A concept map representation of a database table

3 Concept Maps Uses in Patient Education

It's well documented that some populations have limited access to credible and reliable cancer related information. In response, concept map-based knowledge models were developed at MCC&RI using IHMC CmapTools program. Concept Maps have been used as the graphical tool for organizing and representing information about the Adolescent and Young Adult (AYA) Program at Moffitt Cancer Center and the "Fertility and Reproduction in AYA Genetics: Improving Learning and Education" (FRAGILE) project.

3.1 Adolescent and Young Adult (AYA) Program

A multidisciplinary team developed a concept map-base knowledge model to illustrate and describe the AYA program purpose, operation, services provided to cancer survivors, patients and their families, the unique needs of AYA cancer patients, and the key stakeholders involved with the program. In addition to knowledge elicitation sessions with an AYA researcher, the director, and the coordinator of the AYA program, a revision of the strategic plan and literature review was used to construct the knowledge model. This tool has been used in multiple presentations internally to educate MCC&RI staff on the program services, population served by the program, and resources available to cancer patients between the ages of 15-39.

3.2 Fertility and Reproduction in AYA Genetics: Improving Learning and Education (FRAGILE)

A knowledge model to address the concerns of cancer patients and oncologists regarding the intersection of fertility, genetics, and reproductive decisions in AYA cancer patients and survivors is under construction. Main topics were identified through qualitative data analysis of the transcripts from 17 cancer patients and 18 oncologist interviews. The knowledge base contains concept maps that answer questions such as how is cancer genetic risk determined?, what does a cancer genetics counselor do?, what is the impact of a cancer diagnosis on my fertility?, does cancer diagnosis impact my future biological children?, and what is Preimplantation Genetic Diagnosis (PGD)?

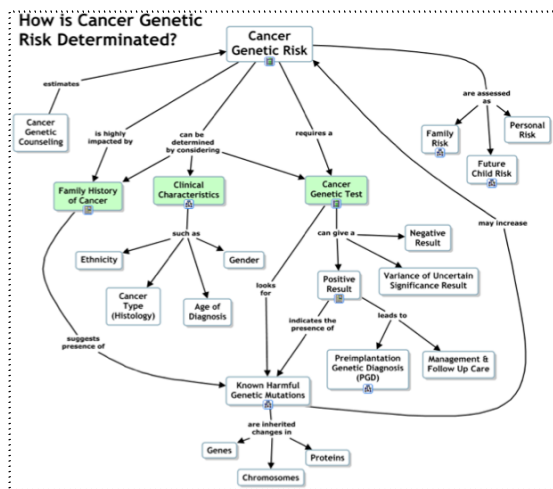


Figure 2. Cmap on how cancer genetic risk is determined

4 Summary

Concept maps are an efficient methodology for knowledge sharing of complex data models, for synthesizing the complexity of the AYA program, and for facilitating the communication among cancer research experts, data scientists, oncologists, cancer patients, caregivers, and staff members of MCC&RI.

Patients' and oncologists' concerns were classified in 33 themes that include topics such as cancer treatments, access to educational information, genetics and cancer (risks for children, beliefs, testing, counseling), family planning, discussions with health care providers (genetic risk conversations, reproductive health), and many other topics. In addition to the qualitative analysis of the interviews, the methodology, carried out by a multi-disciplinary team, included an extensive literature review, knowledge elicitation sessions with AYA cancer experts, genetic counselors, oncologists, and fertility preservation experts.

The future work includes the recording of a set of videos clips of experts providing further explanations. Other digital resources such as images, web pages, and documents will be linked to the concept maps as well.