XML-Based Self-Mapping of ALS (Lou Gehrig's Disease) Patients for Environmental Analysis and Community Building

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ABSTRACT

The Internet-based nature of many support networks, chat rooms and information sources for terminally ill patients, caregivers and health care providers makes the web environment a unique place for gathering spatial data about disease and raising awareness of environmental risk factors. This paper details the online visualization and spatial database components of Mapping People with ALS project (M-PALS). M-PALS is a grassroots project focused on building an online spatial database and forum for visualization of ALS patient locations with respect to environmental indicators. XML and GIS techniques are combined with a series of online forms to provide real time mapping and analysis of patient information from an expanding spatial database. Patients are encouraged to map themselves into the system and browse overlay maps of possible environmental triggers. Responding to an extensive grassroots network and a international web radio broadcast, ALS patients enter information about their residences, occupations, relocation history and diagnosis into a series of online forms. Users can explore online interactive maps to analyze ALS patient locations, including their personal self-mapped information, with respect to the spatial distribution of environmental toxins and other possible geographic influences and disease triggers.

Online mapping of patient point layers with reference and analysis layers is performed in an XML-based mapping system called AxioMap. The system uses Vector Markup Language and Scalable Vector Graphics, which allow for encoding and scripting of graphic primitives in standard HTML. Upon form submission, XML point coordinate files, which display on a map of symptom development and diagnosis locations, are updated to include the new data. Database coordinate files update in real time through the CGI form submission scripts. Environmental layer overlay and patient location visualizations encourage increased consideration of the linkages between

environmental causality and spatial relationships that could lead to documentation of likely ALS disease triggers.

***Keywords and phrases*:** Amyotrophic lateral sclerosis, Internet mapping application, XML, self-mapping, environmental risk

1.0 INTRODUCTION

The Internet-based nature of many support networks, chat rooms and information sources for terminally ill patients, caregivers and health care providers creates new ways of generating and gathering data about disease and raising awareness of environmental risk factors. This paper details the online visualization and spatial database components of Mapping People with ALS (M-PALS) project. M-PALS is a grassroots initiative focused on building an online spatial database and forum for visualization of ALS patient locations with respect to environmental indicators (http://superfund.sdsc.edu/als/). XML and GIS techniques are combined with a series of online forms to provide real time mapping and analysis of patient information from an expanding spatial database. Patients are encouraged to map themselves into the system and browse overlay maps of possible environmental triggers.

Amyotrophic lateral sclerosis (ALS) is a degenerative muscle disease with no known cause or cure that affects hundreds of thousands of people globally (Chiò, 2000a; Chiò, 2000b; Dietrich-Neto *et al.*, 2000; Galasko *et al.*, 2000; PVARALS 2001; Thijs *et al.*, 2000). Epidemiological studies have focused relatively sparsely on the spatial characteristics of the disease. Although possible significant spatial clusters of patients have been identified in Japan and Guam (Galasko *et al.*, 2000), ALS has long been considered a spatially random phenomena and geographic applications are not considered top priority for continued research (Swash, 2001). In the U.S. perceived clusters were noted in communities in Massachusetts and Texas in the early 1990's (Annegers *et al.*, 1991; Proctor *et al.*, 1992). Recently, patients and caregivers have suggested locations for suspiciously non-random clusters of cases in the states of Texas and Michigan and research has increasingly pointed to environmental risk factors (Armon, 2001; Brooks, 2000; Chiò, 2000a; Chiò, 2000b; Mitchell, 2000). Due to the possible role of geographically traceable triggers for the disease, the M-PALS project explores development of a spatial database for environmental analysis and the use of visualization and GIS in ALS research.

2.0 SELF MAPPING ENVIRONMENT

Extensible Markup Language (XML), one of the most heralded software technologies of recent years (W3C 1998), has influenced all areas of Internet computing, including online cartography. As online maps are becoming interactive representations of distributed information systems, they increasingly rely on XML for discovery, integration and presentation of multimedia spatial content. In this project, XML encoding of spatial data plays the central role as a means of passing and storing information entered by the users in CGI-based input forms, and of online interactive map rendering where patient maps are generated as virtual XML documents to display updated user input.

Responding to an extensive grassroots network and an international web radio broadcast (VoiceAmerica 2001), ALS patients enter information about their residences, occupations, relocation history and diagnosis into a series of online forms at the project Web page (details of form processing are below). Users can explore online interactive maps to analyze ALS patient locations, including their personal self-mapped information, with respect to the spatial distribution of environmental toxins and other possible geographic influences and disease triggers. Multiple locational entries per patient facilitate analysis of spatial and temporal dynamics with respect to symptom development and diagnosis. Our goal is to develop complete residence and employment patient histories, while previous epidemiological studies have primarily focused on location of death as a geographic component (Seljeseth *et al.*, 2000).

Online mapping of patient point layers with reference and analysis layers is performed in an XML-based mapping system called AxioMap (ELZA Research 2000; Zaslavsky, 2000). The system uses Vector Markup Language (as implemented natively in Internet Explorer 5+) and Scalable Vector Graphics (as implemented in the Adobe SVG plugin for multiple browsers) to retrieve XML-encoded spatial data, and render and manipulate interactive vector graphic content in a Web browser. Compared with server-side mapping architectures, XML encoding and rendering of geographic information emphasizes dynamics, interactivity and interoperability for geographic data, while avoiding high costs and poor scalability and interactivity associated with map server solutions.

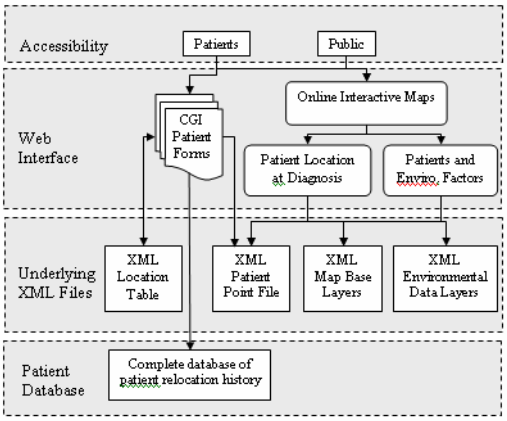

Figure 1. System diagram of publicly accessible user interface and underlying files.

The overall schema of the system is shown in Figure 1. Upon form submission, XML point coordinate files, which display on a map of symptom development and diagnosis locations, are updated to include the new data. Database coordinate files update in real time, as the form submission CGI script searches a prepared postal code database and matches the submitted address with postal code coordinates. In order to emphasize privacy and facilitate several submissions per postal code region in the visualization (US postal zip codes encompass approximately 30-50 sq km), the system contains a randomization routine that offsets coordinate locations around the appropriate postal code centroid (Figure 2). As a result, submissions from one zip code are shown on a map as a cluster of randomly located points (a point per submission), rather than as one point at zip code centroid.

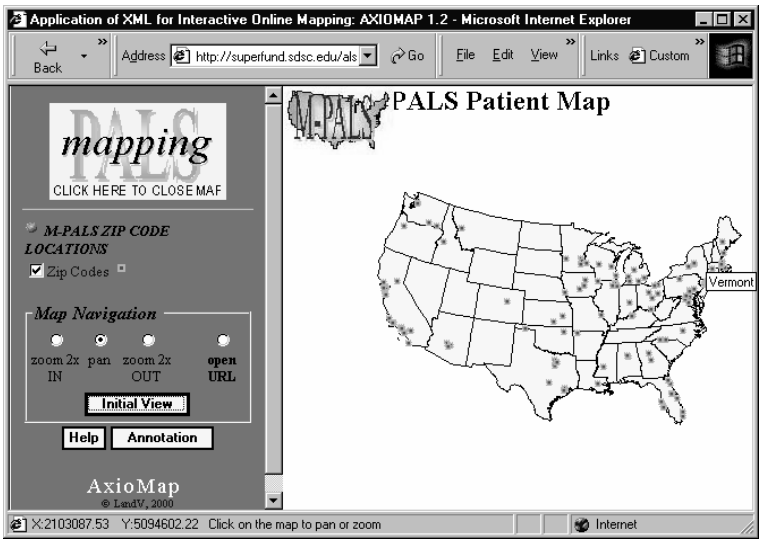

Figure 2. Sample postal code-based map of patient locations.

3.0 ENVIRONMENTAL GIS LAYERS

Our mapping system generates several patient maps from a single XML store of patient locations, including point maps, and multilayer maps where patient point locations can be juxtaposed with a variety of environmental and demographic variables. The respective spatial layers are constructed in a GIS (ArcView GIS), and generalized and converted to XML format for ease of display in the online environment. Reference data include state boundaries and general population characteristics within the contiguous United States. Environmental risk factor layers include both point and non-point source locations. US Environmental Protection Agency National Priority List Superfund sites, where large quantities of environmental toxins are documented, as well as county agricultural chemical use of fungicides, herbicides, insecticides, and desiccants, are among the initial environmental data layers. A

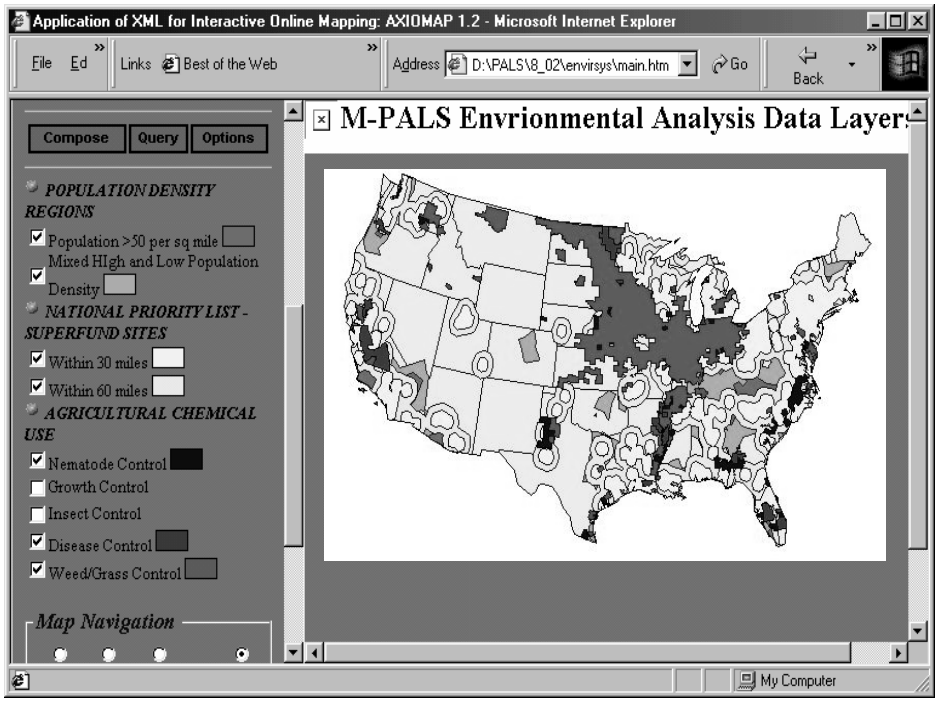

Figure 3. Sample environmental data layers for overlay with patient locations in the M-PALS interface.

snapshot of the map interface with environmental risk factor layers and locations entered by ALS patients, is shown in Figure 3. The interface allows for simple layer manipulation (turning layers on and off, choropleth mapping), as well as retrieving information about individual patient locations. Interactive features of the map interface include tooltips associated with all geographic features, ability to reposition map elements (legend, annotation), and – in the VML version - speech-enabled tooltips (available if a plug-in from www.speaksforitself.com is installed).

4.0 COMMUNITY FOCUS

The M-PALS project seeks to empower individuals to give their personal case history to researchers with the goal of visualizing themselves in the research community and research process. The patients deliberately and literally "put themselves on a map", to establish their previously ignored presence. The benefit of real time visualization is that interest continues as patients check map updates and converse with project coordinators through email and chat rooms. The project Web pages are careful to point out that data is preliminary and no conclusions can be drawn from juxtaposing patient data and environmental layers at such small spatial scales. Nevertheless, as patients, care givers, and those interested in the ALS community visualize the spatial pattern of responding patients with environmental factors, they gain better understanding of the scope of the disease and the extent of community affected by it. The environmental visualization also encourages ideas of linkages between environmental causality and spatial relationships that could lead to documentation of likely disease triggers. In fact, some of the more valuable documents of the project are email communications from ALS patients or their relatives in which they describe their personal disease histories vis-à-vis environmental factors in the area. While hardly a reliable source for statistical analysis, these individual cases may lead to new hypotheses about previously unexplored environmental factors of the disease.

5.0 PRELIMINARY IMPLEMENTATION RESPONSE AND RESULTS

This project involves balancing patients' privacy concerns with the building of an accurate database. In the first year of our project, which began in August 2001, we have had approximately 450 patient record entries. Approximately 98 percent of these patients requested that we contact them as soon as updates on our project were available. Close to 95% of patients included both their first name and home street name when asked to do so in the interest of project accuracy. We found that 97% of respondents preferred that their self-disclosed information be made available to other ALS researchers and in no way restricted our use of their case histories.

We also sought to maintain a balance between the need to elicit a community focus on environmental explanations and the threat of potential misinterpretation of environmental factors with the distribution of ALS as depicted on the online maps. 3-5% of the initial submissions were accompanied with detailed case information often associating environmental triggers with possible disease clusters, establishing leads for further research.

6.0 CONCLUSIONS

ALS is a disease of global concern for which environmental triggers may exist. Internet technologies, such as XML mapping capabilities as implemented in AxioMap, offer an effective means of encouraging patients to map themselves into an extensive spatial database. Both the technology and the characteristics of ALS lend themselves to the spatial analysis of environmental risk factors in an interactive online setting.

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