A Study Proposing a Data Model for a Dementia Care Mapping (DCM) Data Warehouse for Potential Secondary Uses of Dementia Care Data

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ABSTRACT

There is growing emphasis on sharing and reusing dementia care-related datasets to improve the quality of dementia care. Consequently, there is a need to develop data management solutions for collecting, integrating and storing these data in formats that enhance opportunities for reuse. Dementia Care Mapping (DCM) is an observational tool that is in widespread use internationally. It produces rich, evidence-based data on dementia care quality. Currently, that data is primarily used locally, within dementia care services, to assess and improve quality of care. Information-rich DCM data provides opportunities for secondary use including research into improving the quality of dementia care. But an effective data management solution is required to facilitate this. A rationale for the warehousing of DCM data as a technical data management solution is suggested. The authors also propose a data model for a DCM data warehouse and present user-identified challenges for reusing DCM data within a warehouse.

KEYWORDS

Data Management, Data Warehousing, DCM, Dementia Care Mapping, Dementia Care, Grounded Theory, Secondary Use of Data

INTRODUCTION

In 2015 there were 46.8 million people estimated to be living with dementia worldwide (Prince et al., 2015) an increase of more than 10 million since 2010. The numbers of people with dementia globally are estimated to rise to 74.7 million in 2030 and more than 131.5 million in 2050 (Prince et al., 2015). There are 9.9 million new cases of dementia every year, indicating one new case every four seconds. This figure is 30% higher than the annual number of new cases estimated for 2010 by the World Health Organisation in their 2012 report (Prince et al., 2015). Currently about 800,000 people

with dementia live in the UK and the number is expected to double in the next 30 years (Department of Health, 2015). Dementia is a progressive disease and there is currently no cure. In addition to research focused on the cause and cure of dementia, improving the quality of life and quality of care for people with dementia is a major global concern (World Health Organisation, 2012) and is a national priority in the UK (Department of Health, 2015a). The G8 Dementia Summit in 2013 highlighted the importance of progressing initiatives for sharing and reusing existing large research and healthcare datasets (Department of Health, 2013) for this purpose, thus instigating the concept of 'big data' for dementia research (Deetjen et al., 2015).

Big data for dementia research includes a combination of both medically driven and non-medically driven data. The term 'non-medically driven data' here refers to data about people's lifestyles, diets and food choices. It is suggested that the medical and non-medical dimensions, considered together, could support improvements to the care of people with dementia (Deetjen et al., 2015). While the current focus of the 'big data' proposal is to enhance research to support better dementia diagnoses, as well as cures and treatments, dementia care related data could also provide a resource for understanding, assessing and improving the existing care provision for people with dementia. However, to facilitate this dementia care related data with the potential for reuse needs to be identified and made available in electronic and integrated formats in order for it to be possible to be considered part of a 'big data' initiative.

This paper will argue that Dementia Care Mapping (DCM) (Bradford Dementia Group, 1997; 2005; 2014), an internationally used dementia care quality improvement tool, offers a dataset which has potential to be used for secondary purposes as part of a 'big data' research solution for improving health and social care provision for people with dementia. Further, it is argued that data warehousing is the most appropriate technical solution for facilitating this within a data management framework. This paper will also propose a data model for a DCM data warehouse based on requirements collected from potential end users and existing data management solutions for DCM data.

Background

Dementia Care Mapping (DCM) (Bradford Dementia Group, 1997; 2005) is an observation tool to assess, monitor and improve the quality of care of people with dementia in formal care settings such as care homes, day centres and hospital wards. Only trained individuals called 'mappers' can use the DCM tool. The observations carried out using the DCM tool are called mapping. Mapping is usually conducted by one or more mappers, depending on the number of participants being observed, with each mapper typically continuously observing five to eight participants for a specific time period (Bradford Dementia Group, 2005). The length of mapping is variable, depending on the mapping purpose, ranging from short maps of 30 minutes to longer maps of six-hours or more.

DCM Data

During observations, both quantitative and qualitative information (DCM data) is collected. The quantitative information is collected as pre-defined codes that reflect participants' behaviour (called Behaviour Category Codes; BCC), mood, engagement levels (called Mood and Engagement levels; ME) in every five-minute period (time-frame) and the quality of interactions (Personal Enhancers; PE's and Personal Detractions; PD's) with staff, as and when they occur. During each mapping a large amount of qualitative notes are also written by mappers to give a context to the formal coding frames and additional information on the environment of the care setting, such as the noise levels, temperature and overall ambiance where the mapping is taking place. Alongside DCM data, a limited amount of additional information is also collected as a standard component on the DCM data collection sheets (i.e. DCM raw data sheets (Bradford Dementia Group, 2005)). This includes the date and time of mapping, location of mapping, mapper and participants' name/code.

Following data processing, analysis of the DCM data is undertaken to help identify areas for potential improvements in existing practices and for the future planning of care. The DCM 8 user's

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