Nursing, professional curiosity and big data cocreating eHealth

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Nursing, Professional Curiosity and Big Data CoCreating eHealth

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Abstract. This paper describes work that has taken place over the past three years in the form of an annual deep dive study track within a national conference setting. The work explores the changing influence that big data, and in particular population and social determinants of health data, makes upon the generation of co-created eHealth within a nursing domain. Working with delegates, many of whom returned year after year, the paper reports the discussion themes and ideas that evolved over time. The paper is presented as an example of connected reasoning and personal development by all those involved and is offered as a distributed think tank for further discussion and debate.

Keywords. Nursing, professional curiosity, context based care, population health data, social determinants of health, health inequalities.

1. Introduction

The past few years has seen a massive growth in the availability of medical and health related data and information. The data is being entered into electronic health records (EHR) by clinicians as they complete their patient related tasks. Some of this data is coming from administrative systems as the patient is processed through our systems. A subset of data is coming from the patient themselves perhaps entered through personal health records or uploaded from mobile applications. Currently, there are additional sources of data to consider when thinking about patient and population health. This data comes often, but not exclusively, from external systems that describe the social determinants of health such as the environment in which a patient lives, or the economic status of a community, or the transportation infrastructure, or the ability to access food, or the climate and pollution levels to which one is subject. Much of this data and information is freely accessible from community level datasets that need to be paired with electronic health record data to fully understand the health risks of patients and populations. Our research question is how will this understanding happen and what does nursing affect as the trend of increasing access to data and information is expected to continue as the sources increase and improve in terms of accuracy and timeliness.

This explosion of data that paint a more holistic image of patients and populations should be of importance to nurses. Nursing has a unique role within the healthcare professions in that the work of nurses (in the widest sense) is one with the greatest

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number of contact opportunities with the patient, their relatives, care givers, and friends [1]. It is within this role that there is need for a cross-over between the immediate patient information generated during an acute episode of care or during the management of a long term condition and the wider sociobehavioral and population information that may be community or patient specific in order for nursing to have a better understanding of the relationship between care provision, context of living, and optimal health and wellness.

Over the past three years, a deep dive track has been offered within the Summer Institute of Nursing Informatics hosted by the School of Nursing, University of Maryland in Baltimore, USA. The track was designed to develop professional curiosity, promote constructivist learning, and increase exposure to skills around the importance of considering the context of living for those receiving care. It is rewarding to note that many of the 35 to 40 delegates who joined the first deep dive track session three years ago have returned to the track each year. This allowed a natural progression in knowledge development and an incremental enhancement in thinking, which improved the discourse about how to accomplish a full understanding of this ocean of data and information. This progression in learning also fostered a healthy debate about what knowledge and skills are needed by informaticians and nursing professionals alike to promote a co-creation of eHealth which has informed this paper.

Nursing has become highly skilled in the science of care, the application of justified interventions to meet diagnostic need, and in the ability to record such care given in system designed tools such as the EHR. This process describes a common activity of nursing worldwide and reflects to some degree a common understanding of the role of the nurse. However, the deployment of nurses does vary at both at regional and country levels. For example in Europe there are instances where nurses are part of the community within which they work. These nurses frequently visit patients and their carers in their own homes; whereas there are other countries in which the acute intervention is more prevalent. Regardless, the need to view the patient as more than a receiver of a medical service at a point in time but as a whole biopsychosocial individual is a core component of all nurses wherever they work and wherever they live. Thus the need to consider what other data besides what may be extracted from episodes of care captured in an EHR is needed to paint that full patient or population picture. Herein lies the struggle – how to capture this data and what do we do with it once captured?

The question for development within the deep dive track became one around professional curiosity, how well do we, as nurses, know the context for those in our care and if we do know the context for those in our care how might this knowledge affect the care interventions prescribed? Of particular interest was where the care and context meet which is generally at the time of discharge following a health episodic intervention during which a nurse is to be preparing a patient to move to another level of care which can greatly influence ongoing wellbeing. The accepted notion being that appropriate discharge for an individual following an acute intervention will reduce the requirement for re-admission and thus present a potential cost saving and a better experience for the individual patient.

The term 'professional curiosity' comes from social care and in particular issues around child safeguarding [2], it charges of us to look beyond the current state and behaviors of those in our care so that a more complete 'picture' of the issues and circumstances are fully understood, as some would say "no stone unturned".

Add to nursing and professional curiosity a third dimension, that of freely accessible population data and the opportunities of care in context becomes a closer reality.

2. Methodology

In the first year (2015) approximately 40 delegates were invited to explore population contexts across three domains, rural, semi-urban and urban. In three groups, one for each domain, they self-selected a geographical location and then using a well-known search engine found out as much as they could about the context of their selection. It was interesting to note that many of the data sources identified by delegates as impinging upon the health context included non-medical care sectors such as social, economic, environmental agricultural and physical. There were many 'ah-ha' moments which led to further exploration of available data sources to give a holistic view, indeed the professional curiosity appeared to know no bounds and led to the publication of results as a poster presentation at the Nursing Informatics 2016 world congress [3].

By the 2016 iteration of the track there had been increased public and professional awareness of health inequalities and social determinants of health [4, 5]. The delegates further considered community planning models as they related to reducing health inequalities and to improving health providers' ability to meet expected health care demand. It became clear that a number of key issues were starting to emerge, some already well known but seemingly not yet embedded into the professional lives of nurses in practice. In collaboration with HIMSS some cases outlining a person's journey to include a health episode were presented at HIMSS 2016 during the Interoperability Showcase

In 2017, the track concentrated upon the development of tools for connected health. Delegates engaged in discussion with those who were attempting to use these data sources co-create eHealth. Delegates experimented with tools that connected various data sources which provided a foundation to create collaborative context based care, or as found in the title of this conference, co-created eHealth where this is taken to mean working across professional boundaries and with the patient (or carer) to meet the best level of health outcomes supported by information and communication technology appropriate to the context for the individual patient. Through a constructivist process that used guided small group work, the delegates developed a requirements list that must be considered in order for the broad variety of data and information to be fully used to form knowledge that will provide collaborative eHealth:

- Acknowledge the nurse's professional curiosity role in contextualised healthcare that includes more than consideration of EHR medical data.
- Develop a standard curriculum to prepare nursing and inter-disciplinary students in an academic setting to view, assess, and plan for the person as a whole in their population (context).
- Obtain Leadership buy-in to promote change to optimize collaborative care; identify motivators for change. This may include a broader view of reimbursable nursing activity, responsibility, and role.
- Strengthen the skills and role of nurse informaticians in progressing context based collaborative care [6]. Provide the nurse informatician with the competencies in big data manipulation and management, data science, data analytics, and visualization in order to provide the direct care nurse with the tools to activate collaborative eHealth.

3. Discussion

In line with the unique role that nurses hold within the body of healthcare professionals it increasingly became clear during the discussion that nurses are in a prime position to drive this agenda and to take it outside the direct healthcare setting. However, in order to achieve such a goal, nurses need to develop some basic competencies particularly around the importance and use of data (analytics). In addition there must be recognition that a healthcare episode in most people's lives is but a moment in time in their life and that there may be a number of factors that led to need to seek medical advice and that there will be many external factors that significantly impact the success of that patient outside of the walls of medical care. It was suggested by one group that there needs to be more exact science behind the relationship of diagnosis and care; nurses need to base care upon co-morbidities, social, spiritual and socio-economic perspectives so that we can prioritize the avoidance of harm first.

In all aspects of nursing education, from pre-entry courses through to doctoral level study there needs to be inclusion of data comprehension and analytical techniques offered so that nurses are able to recognize and work with such data to improve patient outcomes. Education is changing, there is a reduction in the need to hold knowledge as before towards that of being able to find and appraise information then to use it in a knowable and connected way [7]. Health care is no different. Every country is well aware of the need to reduce the costs of health and social care whilst at the same time not disadvantaging any particular social group, in order for this to happen data must be used to inform decisions both at the individual patient level and at the regional/organizational level. One area that highlighted the link between micro (individual patient) and macro (regional/organizational) social determinant information was that of discharge following an acute episode of care. The scenario offered concerned a patient of 62 years old, female, slightly obese who had undergone successful keyhole surgery for removal of her gall bladder; one aspect of her post discharge care was that she should build an exercise regime, a leaflet was handed to the patient outlining the staged development of the expected exercise regime. The nurse considered that the micro element had been successfully completed. The patient looked at the leaflet and became distressed for although she understood all the information contained within the leaflet, in her neighborhood no one walked around the block as suggested due to the high level of crime in her area. Thus the nurse did not consider the context of living (macro) for the patient in preparing the discharge formalities. There was the potential for the patient to return for a further in-care episode due to lack of exercise.

Nurse informaticians have a significant role to play in incorporating data analytics into the workplace and helping professionals understand how the documentation of key elements (social determinants) bridges greater understanding of populations and the advancement of healthcare in context to living. It was strongly stated that micro level social determinant information could be gleaned from data fields already present in the EHR without further data fields added; the macro level social determinant information could be gleaned from external data sources such as *https://www.communitycommons.org*. The expertise will be found in mapping links between the micro and macro levels to improve patient outcomes and this has the potential to reduce expenditure.

4. Conclusion

Three years of deepening discussion at the Summer Institute in Nursing Informatics with thoughtful and engaged nurse informaticians has led to an acknowledgment of significant gap and recommendations in order to optimize the oceans of data and build continents of knowledge for co-created eHealth. First, there is much discussion about the importance of using medical as well as social determinants of health data in order to plan for a successful post-acute care life for patients [8]. Nurses are taught to consider the whole person in their foundational courses but somewhere along the way, this is lost and the singular focus becomes the assessments and intervention based on medical need. There needs to be an emphasis on considering the whole patient when assisting that patient in preparing for optimal wellness. This will require a re-education on the data and information that are above and beyond that found in an EHR. Secondly, nurse informaticians also understand the importance of considering the whole patient but many lack the foundational knowledge and skills in data science and analytics to make that ocean of data into a continent of knowledge. Lastly, it will be up to thought leaders to map that pathway to ensure that all can co-create eHealth.

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