Reaching out Medical College library services to patients through E-Health libraries: An ongoing work in progress

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Abstract

Introduction: Library information science has traditionally existed in libraries but with evolution of digital online literacy the traditional role of a librarian can be expanded to healthcare through trained patient-information-managers or E-health-librarians delivering information and knowledge to rural and urban patients unable to access traditional health-care resources in hospitals or health centres.

Methods: LN Medical College, Bhopal, E-Health libraries are managed by interested and trained library and information science as well as other background volunteers designated, 'patient information communication managers.' These E-health library volunteers typically reside in the same community drained by the E-health library and their job is to create detailed electronic health records of de-identified patients (after signed informed consent), share the records across an online-global, participatory-healthcare, learning-ecosystem, contact the 'local-doctors' in their area and share inputs from the Global doctors on each patient thus obtaining conversational and evidence based clinical decision support input to benefit those patients with the records.

Results: This is a pilot intervention of an open-online-health-record system, de-identified as per HIPAA guidelines, that has enabled one hospital unit managed by a physician team to regularly engage in informational continuity of their patients, through a patient-information-manager (aka E-health-librarian) supported online-network of 1500+ physicians and patient-information-communication managers working both in the hospital as well as rural and urban communities. A qualitative thematic analysis of insights from selected cases over one year of starting this system was assessed. Almost all the online-records shared over the physician's social network received multidisciplinary inputs from multiple specialists and generalists toward facilitation of a valuable informational support for the physicians managing the patients in the online-records. Most of the patients with online-records generated during hospital stay were able to maintain better continuity of care with their hospital physicians through the patient-information managers.

Conclusion: A gratifying response from the pilot users of the system indicates that this model can be scaled by many more physicians in hospitals globally through larger in-hospital pilots and also utilized for continuing evaluation of patient-care not only in the hospitals but also in the community through patient-information managers (aka E-health librarians) working both in the hospital as well as E-health libraries in rural and urban communities.

Introduction

"Traditional libraries have been often considered temples of learning where silence is valued and protected but they are nothing but isolated learning environments where the single individual has no access to a second opinion from another person, no access to a complementary perspective, or external critique, neither does s/he have any chance to get complementary literature from anyone which might have a different reference library." The above was brought by Mikael Wiberg in an extensive article about online-learning (Wiberg 2007).

"In modern libraries it is perhaps easier to break past this 'silence' barrier where the library user predominantly browses an electronic information network rather than a paper based disconnected media.

Unfortunately, this advantage of the modern library is underutilized as even systems for online universities, or distance education may not have adequate support or encouragement for social interaction. Most of these systems assume a centralized communication model in which the learning peers (i.e. the students) mostly communicate with one central peer (i.e. a mentor or advisor). This leads in many cases to communication related to the structure rather than the content of an online education and does not support spontaneous, creative social learning processes." (Wiberg 2007).

Learning schools are redirecting the focus from what has been labelled "traditional computer-based learning environments" towards user-driven learning networks supported by social internet based applications. The assumption that computer-mediated learning will occur in the classroom, managed by a teacher, is now being challenged, not by schools and educational software developers, but by the consumer growth of personal technologies such as those that support learning around health information requirements. (Sharples 2002).

User driven learning is a form of conversational experiential learning between networked users in web space and user driven health care aims at improved healthcare through clinical problem solving utilizing concerted experiential learning in conversations between multiple users and stakeholders, primarily patients, health professionals, and other actors in a care giving collaborative network across a Web interface. (Biswas 2008).

Our team has tried to extend the above concepts here at LN Medical college LNMC, Bhopal through a pilot intervention of an open-online-health-record

system, de-identified as per HIPAA guidelines, that has enabled one hospital unit managed by a physician team to regularly engage in informational continuity of their patients, through a patient-information-manager (aka E-health-librarian) supported online-network of 1500+ physicians and patient-information-communication managers working both in the hospital as well as rural and urban communities. (Purkayastha 2015). We describe below an operational plan on sustaining and scaling our current workflow through the patient-information managers (aka E-health librarians) supported model.

Goal: Patient centred care delivery through empowerment of patients and E-health librarians along with local caregivers connected through a global information network.

Key objective: Management of chronic disease patients through trained E-health librarians working with local and global doctors toward best quality evidence based information communication for patients.

People Needed: Trained E-health librarians, Local and Global doctors to care locally and learn globally. We have been running a volunteer driven institutionally funded project for the last few years to impact a sample local population served by patient-information managers (aka E-health librarians) and local doctors through global networking.

The role of a doctor comes in checking the information upload and correcting the patient-information managers (aka E-health librarians) as and when alarms due to remarkable situations come up. This also funnels patients to the tertiary centres as medical college hospitals for further rigorous tests and treatments.

Key Expected outcomes in health parameters

Detection and screening: An open case-record of patients integrated into a mobile health database can be accessed from anywhere, anytime by both patients and care-providers.

E-rounds: Significantly reduces time/effort for busy consultant-doctors.

Home-healthcare: better coverage and assessment of chronic disease patients at their home settings.

Follow ups: Patients in remote locations can be accessed and helped further through high-definition video calling systems.

Economic impact (reduction in lost wages, travel costs etc): Project will not only significantly reduce travelling cost for multiple follow-ups but also reduce lost daily wages often suffered by patients who have to sacrifice their workdays to attend hospital OPDs.

– Possible reduction in tertiary care load but bigger coverage. The project will reduce number of visits to tertiary hospital based care and add more value

to better monitoring and evaluation in community based home-healthcare settings.

– Possible reduction of cost of care per patient. Travel cost, physician time, better co-ordination, improved care delivery, quicker diagnosis and referral system with increased patient involvement in care.

Training of patient-information managers (aka E-health librarians): Hands on training in identification of disease from patient's history and clinical findings and investigations and creation of open-case-records for each of their patients. Apply information driven evidence based clinical problem solving. Learn various protocols guided by online evidence toward management of diseases.

Training to care for the whole patient and be driven by patient requirements rather than solely by disease requirements. Learn to communicate information obtained by them from the patients (as well as online resources validated by Global online experts) to the local physicians in the patient's village. Learn to collaborate with the local physicians to develop a collaborative approach to patient care. Formative assessment through regular online interactions and documentations.

Call/Advertisement for Training of patient-information managers (aka E-health librarians)

Eligibility

Computer literate Library information science and other science graduate with strong language skills in English, Hindi and other local languages.

Methodology

100% practical hands on learning which will be documented and stored in paper as well as archived online for formative assessment at the end of the course (also see section on 'assessment' and 'course-content' below and E-health library workflow plan).

Objectives of the Course: Train course participants to effectively utilize Information and Communications Technologies ICT toward applying information driven clinical problem solving for improving patient health outcomes in the community. Become efficient tele-health practitioners by collecting patient information through telephone and email and further processing of the data by gathering and adding evidence based solutions from medical consultants using store and forward techniques with e-mail, phone as well as face to face meetings.

Become efficient health journalists by researching and writing up case studies around interesting clinical problems as well as write health reviews to spread health awareness in local languages.

Duration: Assessment driven.

Assessment of Course participants: A system of formative Assessment will evaluate student generated data/learning points arising from their experiences during the course of their online learning interactions with virtual patients and faculty. This means there will be multiple weekly assessments and validation/corrections of the candidate's learning through a dialogue between the facilitator and the student all of which will be recorded on the web site. At the end of the course all these formative assessment data shall be qualitatively analysed for an overall assessment. There will be no formal exam/summative assessment at any point of the course.

Sample Online-learning portfolios of current patient-information-managers (aka E-health librarians) for assessment:

http://userdrivenhealthcare.blogspot.in/2016/03/assessment-of-patient-information_28.html

http://userdrivenhealthcare.blogspot.in/2016/03/assessment-of-patient-information_87.html

http://userdrivenhealthcare.blogspot.in/2016/03/assessment-of-patient-information.html

http://onlinelearningportfoliointern.blogspot.in/2016/03/internship-medicine-posting-1-month.html

http://userdrivenhealthcare.blogspot.in/2016/03/experience-patients-are-interviewed-by.html

Course Content and learning outcomes: At the end of the course students will be able to obtain.

1. An overview of clinical problem solving (The student will learn to prepare a patient problem list, identify an anatomical and etiological diagnosis and as one of the stakeholders in the patient's care facilitate a positive relationship between the patient and his/her primary-secondary-tertiary health professionals through efficient and optimal knowledge sharing between all these stakeholders).
2. Master Clinical history taking and examination (The student will learn to assist and facilitate the process of examining the patient's narrative and other information obtained through physical examination with and without the help of modern technological tools such as radiological imaging and laboratory parameters reflecting the patient's internal chemistry).
3. Master the Essentials of anatomy, radiology, physiology and biochemistry (This is necessary to reach an anatomical, functional and molecular diagnosis for a given clinical problem at hand. Students will be taught to discover these essentials while practicing online clinical problem solving beginning with the case at hand and traveling right down to basic anatomy, physiology and biochemistry in context of case-based information collected from clinical, radiological

and laboratory data.) Students will learn an approach to solve problems around diseases of:
   – Cardiovascular system (Cardiology).
   – Respiratory system (Pulmonology).
   – Renal and genitourinary system (Nephrology, Urology).
   – Hematological system (Hematology, Immunology).
   – Nervous system (Neurology).
   – Gastrointestinal system (Gastroenterology).
   – Reproductive system (Men's and Women's health).
   – Skin and Integumentary system.
   – Cognitive system (Psychology, Psychiatry).
   – Musculoskeletal system (Rheumatology, Orthopedics).
4. Master Essentials of pathology and microbiology (Necessary to reach an etiological diagnosis and students will be taught to discover these in the context of solving their patient's problems).
5. Master Essentials of Pharmacology, EBM and Net-searching (Necessary to formulate a solution and treatment plan and students will be taught to discover these in the context of solving their patient's problems).

Course Faculty: Will comprise of Health Professional Consultants and Professors and health professionals include health information sciences professionals originating from library information sciences. Course timings: Onsite: 9-4 PM and virtual 24x7.

Workflow of the patient-information managers (aka E-health librarians)

The patient-information managers (aka E-health librarians), screen individual rural and urban patients from different districts for various diseases.

THWs create detailed electronic health records of identified patients (after signed informed consent and HIPAA de-identification).

THWs share the records across a global participatory tele-healthcare learning ecosystem.

THWs contact the 'local-doctors' in their area and share inputs from the Global doctors on each patient and invite inputs and queries from the local-doctor and feed-back those to the global doctors.

Obtain conversational and evidence based clinical decision support input to benefit those patients with the records Value Addition to LN Medical College LNMC group:

1) Increased inflow of patients seeking health care services from LNMC Group.
2) Transparent and Informed health care for patients will mean better health outcomes for patients and better financial outcomes for LNMC Group.
3) This is a novel project and perhaps the need of the hour. This will also provide an opportunity for a training program in this area and developing a

future work force for this form of health care delivery.

Risks:
1) As this is novel and aims for transparency and better health care outcomes for people it may upset other stakeholders with different motives.
2) Extreme care shall be required to nurture patient privacy according to HIPAA guidelines: http://cphs.berkeley.edu/hipaa/hipaa18.html and at the same time promote transparency.
3) We would have to have a strong and committed network of health professionals to sustain the high standard of 'care' we are promising.

Study design and Outcomes assessment

This project will employ a case-study-design, integrating units of single-patient-case-studies that will be guided chiefly by the M-health specialist, doctors and research analysts covered by the project budget. They will thematically analyze individual patient records created by the THWs including their updates and prepare situational, problem-based, patient-case-studies based on the SOARC model linked here: http://www.qihub.scot.nhs.uk/knowledge-centre/quality-improvement-tools/case-study.aspx. They shall integrate similar single-patient-case-studies to achieve insights into suitable scale-able strategies that can best prevent and optimally manage such cases in future.

Situation (S of SOARC)
- What was the background to the current state?
- What was happening?
- What was the problem?
- How was this identified?

Sample illustration (from our current patient-records)
Simple Case-scenario (Trunkal Obesity with Diabetes): A 35 year old man with trunkal obesity (abdominal circumference of 130 cm) and a strong family history of diabetes and heart attack is interviewed by our THW in the community and an electronic Personal health record PHR is created along with screening for diabetes and hypertension which are absent. He is found to have fasting blood glucose of 130 mg% and post prandial blood glucose of 200 mg% which establishes the diagnosis of diabetes for the first time. He is found to have a BP of 130/82 mm Hg. On ophthalmological examination he doesn't have any evidence of diabetic retinopathy. His PHR created and updated by the THW serves as a platform to follow him up with 3 monthly preventive advice regarding diet and exercise to reduce his abdominal circumference and record his repeat weekly blood glucose for monitoring

his diabetes and his weekly BP to detect the development of hypertension.

Complex Case-scenario (Diabetes with pain abdomen and diarrhoea and Paralysis of one leg): A 35-year-old man was recently interviewed by our THW in LNMCH for registering into the PHR. This patient had previously presented to a community hospital with eighteen months of chronic abdominal pain. The pain was epigastric, mild, and associated with occasional diarrhoea. After being admitted to the hospital, the patient was diagnosed with Insulin-Dependent Diabetes Mellitus (IDDM) and was started on subcutaneous insulin injections. His condition improved and he was discharged. After a brief respite, he suffered from severe abdominal pain for which he returned to the Primary Health Centre nearest to his village. He was given an intramuscular injection of an unknown substance into the left gluteal region to relieve his pain.

After receiving the intramuscular injection, the patient was unable to rise from a supine position. He discovered that he was unable to move his left leg. The patient returned to the same PHC two days later, where nothing was done for his left leg weakness, but instead he was given another intramuscular injection in the contra-lateral gluteal region. The patient was later admitted to the PHC for thirty days, but no therapeutic steps were taken to resolve the loss of mobility and the patient noticed no improvement in his condition. The patient returned to his home for two weeks, hoping for an improvement in his condition, but there was no change. Six weeks after the injury, the patient presented to a tertiary care hospital with foot drop, mild paraesthesia and tingling sensations in the left leg.

Situation/Problems Bottom-line: Injection nerve palsy, Insulin dependent Diabetes, chronic abdominal pain and diarrhoea.

Objective (O of SOARC)
- What were the aims of the project?
- What was hoped to be achieved?

Sample illustration (from one of our current patient-records): For all our single-patient-case-study projects the broad research questions are: What is this patient's situation/problem and how can we help find better options for him/her and others like him/her?

Simple Case-Objective: Once we identified the above mentioned patient with a definite problem of significant trunkal obesity with strong family history of diabetes making him high risk for heart and brain attacks our primary objective was to reduce his trunkal obesity as that would not only significantly reduce his chances of hypertension and heart or brain attack but also contribute to controlling his diabetes. Our secondary objective was to follow him up with intermittent screening for any further complications such as weekly for BP and annually for retinopathy.

Complex Case-objective: Through the above mentioned patient with paralysis of one leg following an injection, we found that 'injection nerve palsy' was a significant problem in Central India not just for the particular patient who presented to us but also in a few more similar patients we came across and we realized that a fresh approach was necessary to prevent this problem from recurring. Our objective was to reduce this problem by identifying training lacunae in injection practices and instituting training beginning with our own nursing staff and publicize our actions through appropriate channels to scale our action. We also needed to take care of his insulin dependent diabetes by optimizing the dose and frequency of his insulin injections as well as his diarrhoea and pain abdomen by investigating it further. We also needed to follow him up with intermittent screening for any further complications such as weekly for BP and annually for retinopathy.

Action (A of SOARC)
- What action was taken?
- What were the implemented improvements (tools/techniques)?

Simple Case-Objective: For the problem of 'trunkal obesity' on reviewing the literature, we found that informational interventions that re-iterate the optimization of diet and exercise in individuals with target to reduce the abdominal circumference can be effective and we instituted the same in our patient through weekly follow ups over mobile phone and SMS reminders about diet and exercise and also collected the information on his weekly fasting and post-prandial blood glucose values and his Home BP recordings that was entered into his PHR. The THW was provided with a portable blood glucose monitor and portable BP monitoring standard oscillometric device for initially training the patient on its use as the patient was also expected to buy the same device and learn to operate it on his own at the end of one to two years. Annual Fundoscopy screening was planned to be done through tele-ophthalmology techniques as previously described from India here: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4455409/

Complex Case-objective: For the problem of 'injection nerve palsy' on reviewing the literature, we found that informational interventions that disseminated proper training to develop an anatomical understanding of the sciatic nerve can be effective and we took the nursing staff of our hospital to the dissection room and demonstrated the anatomy of the sciatic nerve along with the measures to prevent such injuries by demonstrating proper techniques (ventro-gluteal in supine position instead of the currently prevalent practice of dorso-gluteal in lateral position) and monitoring the staff as they practised on cadavers. For the patient, an ankle-foot orthosis (AFO) was used to provide foot dorsiflexion during the swing phase and lateral stability at the ankle during stance. Since the patient also complained of paraesthesia, pregabalin was prescribed to manage this symptom. Unfortunately, because of the patient's poor socioeconomic condition, he was not in a position where he could afford these medicines. Hence, to alleviate his pain, less expensive medications, paracetamol and diclofenac were prescribed. Along with these treatments, the patient was put on regular insulin for his IDDM and the dose and frequency was optimized. His diarrhoea was further investigated and basic stool examination did not reveal any abnormality and he was managed as autonomic diarrhoea and pain. Once discharged from our hospital he was followed up by our THW, who collected information not only about his afore mentioned problems but also on his weekly fasting and post-prandial blood glucose values as well as his Home BP recordings using a portable blood glucose monitor and portable BP monitoring standard oscillometric device. Annual Fundoscopy screening was planned to be done through tele-ophthalmology techniques.

Results
- What is the situation now?
- What was achieved through the action(s) and were objectives met?

Simple Case-Result: The patient with trunkal obesity has made good progress over two years and his current abdominal circumference is 95 cm and his blood glucose normalized over 6 months. He hasn't developed hypertension and his annual fundoscopy results obtained through tele-ophthalmology are normal.

Complex Case-Result: The patient with injection nerve palsy is still living with his gait disturbance due to the nerve palsy and is still using a posterior AFO although he finds it uncomfortable while walking. The fit of his AFO is less than ideal, and the authors are searching for financial resources to supply this patient with a model that will fit. His diabetes is well controlled. He still continues to have episodes of abdominal pain and diarrhoea although the duration and frequency is less than before. After training our own nurses in using a ventro-gluteal-supine approach we are trying to scale to propagate this safer injection approach to other nurses and any practitioner who administers injections to patients. We still need to gather more robust evidence through a funded RCT where one can compare the two approaches and establish the superiority of the ventro-gluteal-supine approach as a fool-proof and consequently safer method. This patient was eventually published in an international journal (Shah 2015).

Conclusion
- How is the change sustainable

Simple Case intervention sustainability and scaling: In two years our THWs are expected to identify more than 100,000 patients with trunkal obesity and with their information based intervention to reduce trunkal circumference, they are expected to contribute a substantial impact in reducing the population of people with diabetes and hypertension in central India.

Complex Case intervention sustainability and scaling: In two years our THWs and doctors are expected to scale their informational intervention to promote safe injection practices to not just hospital based nursing staff such as in LNMCH but also similar staff and rural practitioners who regularly inject patients and may not be aware of the fallacies.

Overall Project sustainability and scaling: The most significant contribution of our project we believe is the creation of a usage model for ICT in healthcare that has the promise of generating a patient-centred learning ecosystem comprising of multiple stakeholders such as patients, their primary care-providers ranging from THWs, medical students, local doctors and global online doctors. We already have a working prototype of this ecosystem that has its epicentre at LNMCH along with a strong online presence and our current funded project will scale it further such that we shall be able to attract a lot many new learners into this system who would not have otherwise been made aware of its existence and usefulness.

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