

ORIGINAL RESEARCH

Teaching caregiver care to advanced practice nurses: The intersection of technology, online support communities and social capital

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ABSTRACT

Aim: The primary goal of this study was to pioneer the role of clinicians learning from online patient communities as a situated learning discussion board activity.

Methods: Online patient support groups provide a novel approach for providing situated learning experiences for advanced practice nursing students enrolled in distance education programs. This study examined the pedagogy of incorporating an online patient support group forum into a situated learning discussion board activity for nurse practitioner students. Curated conversations from Smart Patients™ were used to teach a cohort of Adult-Gerontology Nurse Practitioner students how to provide care for caregivers and to recognize signs of caregiver stress.

Results: The integration of an online support community to support active learning in an advanced practice nursing distance education program demonstrated the role and connection between patient-centered care, caregiver care, technology and virtual patient support groups.

Conclusion: The integration of an online support community to support active learning in an advanced practice nursing distance education program demonstrated the role and connection between patient-centered care, caregiver care, technology and virtual patient support groups.

Key Words: Caregiver, Social capital, APRN education, Online communities, Technology

1. INTRODUCTION

In 2011 America’s 77 million Baby Boomers started turning 65 years of age.^[1] Each day since that time and for the next 15 years, between 7 to 10 thousand individuals will turn age 65.^[2] This increase in the number of older adults is unprecedented.^[3] While often thought of as a United States (US) phenomenon, this shift toward an increasingly older population is actually occurring worldwide.^[3,4]

In most parts of the world longevity is increasing and fer-

tility rates are declining.^[3,4] By the year 2050, for the first time in history, there will be more elderly persons than children under the age of 15.^[3] While advances in science and medicine allow people to live longer, living longer is still associated with chronic illnesses, functional decline and poorer health.^[4]

The acceleration of population aging poses numerous challenges for national economies, health care systems, policy-makers and families.^[3] One major concern is how to care for

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the elderly. Worldwide, more than 46% of people 60 years of age and older have disabilities and more than 250 million older people experience moderate to severe disability.^[3] How to care for the elderly is a global question.^[5]

A caregiver, also known as an informal or family caregiver, provides unpaid assistance to an individual, usually a family member or friend with a chronic or disabling condition.^[6] The caregiver role is becoming more burdensome and stressful due to a myriad of factors such as: older age of caregivers, increased disability of care recipients, higher financial costs and less formal care.^[6] Moreover caregivers often lack formal education in caregiving and need information and support services.^[7]

There is an urgent need to alleviate the significant stresses and burdens associated with caregiving. Primary care providers must have the knowledge and skills to identify, support and treat caregivers. As primary care providers, nurse practitioners (NPs) in particular, will be central to these efforts. Therefore, NP students must be given the knowledge and skills to effectively provide care, support, and advocacy for caregivers. This paper explores how curated conversations from Smart Patients™ online patient community will be used to teach a cohort of Adult-Gerontology Nurse Practitioner students how to provide care for caregivers and to recognize signs of caregiver stress. Social capital will be used as a concept for linking technology, online support communities, patient-centered care and care of the caregiver.

Background

Thirty-nine percent of American adults are caregivers.^[6] It is expected that in the next 20 years the demand for caregivers will rise by 85%.^[6] Major drivers of this rising trend are: a) an aging population; b) decreased hospital lengths of stay; and c) changes in insurance reimbursement.^[7] In addition, while the incidence of cancer is decreasing, the number of people who have cancer is increasing.^[8] Individuals who have cancer often live at home.^[8] More than 50% of caregivers who take care of individuals with cancer take care of patients with metastatic disease or with severe comorbidities while they are undergoing treatment.^[6]

While caregiving affords personal fulfillment and satisfaction, it is also associated with numerous physical, psychological and financial burdens.^[9] Strategies to alleviate burdens, promote self-management, and improve overall quality of life are essential to caregivers.^[6,7]

Healthcare providers, family, friends, and co-workers were once the points of contact for caregivers seeking health-related information and advice.^[10] However, over the last decade, the emergence of health-related online support com-

munities has created a virtual place for the anonymous sharing of information and support that defies time and geographic constraints.^[11] Online support groups provide the means for caregivers to reach outside of their interpersonal and community sphere of resources for much needed advice and support.^[11]

Online support communities promote building, bridging and linking social capital for caregiver support.^[11] Fifty-two percent of caregivers with internet access report that online resources help with their ability to cope with the stress of being a caregiver.^[12] When controlling for age, income, education, ethnicity and overall health, caregivers are more likely than other adults to go online to find others with similar concerns as theirs.^[12]

Caregivers face the risk of becoming sick themselves.^[6,7] The literature reports that caregivers have higher rates of depression, have at least one chronic illness, and suffer financial hardships.^[6,7] However, caregivers are often not recognized or valued by health care professionals for their hard work.^[6] It is essential that Advanced Practice Nurses (APRNs) are able to identify caregivers, recognize the ways in which they are at risk, manage their care, provide recourses and discuss strategies for support.^[7] NPs will be central to these efforts and NP students must be given the knowledge and skills to effectively provide care, support and advocacy for caregivers.

In order to prepare NP students to meet the challenges of practicing in a rapidly evolving healthcare environment, educational experiences must be focused on the patient's experience.^[13] Online patient communities, such as Smart Patients™ represent a rich collection of patient experiences from which clinical students could learn. Smart Patients™, an online community which supports patients and caregivers affected by serious illnesses, has the potential to be a powerful teaching tool for online NP students.

2. METHODS

2.1 Population

The population consisted of Adult-Gerontology Primary Care Nurse Practitioner students (n = 26) who were enrolled in an Introduction to Practice for the Adult-Gerontology Primary Care Nurse Practitioner course and who volunteered to participate in this study.

2.2 Setting

The pilot study was conducted during week 14 of the 15 week course. The course was designed so that during most weeks of the semester, students completed self-paced lectures and/or learning activities, utilized supplemental resources and participated in an asynchronous discussion board forum.

2.3 Study design

This was a descriptive mixed-methods pilot study to establish the role of de-identified conversations from an online patient community to teach caregiver care to Adult-Gerontology Nurse Practitioner students.

Objectives

- Examine the pedagogy of online delivery by comparing learner satisfaction with a narrated PowerPoint lecture vs. an situated learning discussion board activity
- Explore the integration of an online oncology support community to support active learning in an NP online program
- Demonstrate the importance of reflection to introduce, connect and solidify emergent themes

Hypothesis

Online patient support groups provide a novel approach for providing situated learning experiences for students enrolled in distance education programs.

Social capital was used as the concept for linking technology, online support communities, patient-centered care and care of the caregiver (see Figure 1).

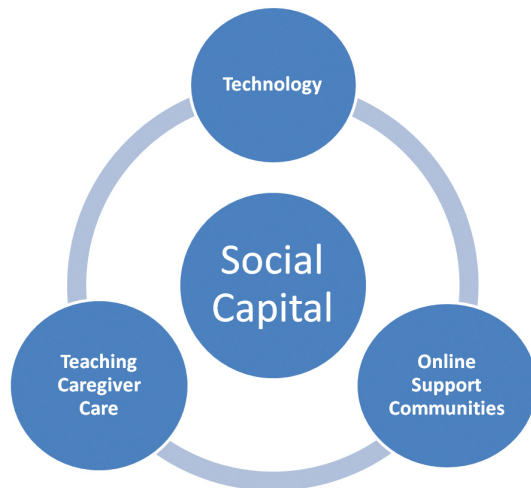


Figure 1. Social Capital as a Concept to link key Components of the Study

Smart Patients™ is an online patient community where patients and caregivers learn from each other. The site is free and open to all patients and caregivers who join the site. Only patients and caregivers who register with Smart Patients™ and establish a username and password can access the site. Participants start conversations on any topic of interest and tag those threads with keywords so that others can then follow.

Administrators at Smart Patients™ moved actual conversation threads to a separate website for clinicians and trainees, which was designed exclusively for educational purposes and called Learn from Smart Patients™.

Coded conversations were organized and grouped to form case studies that met the five student learning outcomes:

- Identify physical, psychological and financial burdens for caregivers
- Determine unmet needs of caregivers
- Determine caregiver sources of support, coping strategies, resources and self-care measures
- Discuss how web-based technology is an evolving social collaboration tool for caregivers
- Discuss how virtual communities can contribute to building, bonding, bridging, and linking social capital for caregivers

Smart Patients™ administrators and school of nursing (SON) faculty developed questions to insert into the conversations at critical points to create breakpoints that: a) guided and directed student learning based upon the expected outcomes and b) allowed for reflection and student discussion of the relevant issues.

The pilot study was incorporated into the course in a format that matched the usual weekly format (self-paced learning materials, supplemental resources and a discussion board forum for student participation and discussion). Commencement of the week-long learn from Smart Patients™ discussion board activity was preceded by a narrated Power Point lecture on caregiver care. On the last day of the study, students were asked to complete an anonymous questionnaire (see Table 1).

2.4 Ethical considerations

This study was approved by the University’s Internal Review Board and all participants provided voluntary consent to participate. Faculty in the SON collaborated with administrators at Smart Patients™ to create a discussion opportunity where NP students accessed curated and de-identified conversations from the SmartPatients™ online community and were informed that they could discontinue participation at any time. Participation and/or non-participation did not in any way affect a student’s grade or standing in the class.

Administrators at Smart Patients™ asked participants in the curated conversations if they would be willing to share selected and de-identified posts with students and educators. Only online posts from participants who explicitly agreed were used for this pilot study. All identifying information was removed from curated conversations, and caregivers were given fictitious names to maintain the confidentiality of

selected forum participants. The risk of students copying and pasting direct quotes into an online search engine to identify participants was mitigated as access to information on

the Smart Patients™ site requires a username and password and Smart Patients™ conversations do not appear in online search engine results.

Table 1. Anonymous Questionnaire

1. How would you rate the effectiveness of the Narrated PowerPoint for teaching you about Caregiver Care?				
Very poor	Poor	Average	Good	Excellent
2. How would you rate the effectiveness of Online Patient Communities for teaching you about Caregiver Care?				
Very poor	Poor	Average	Good	Excellent
3. Have you seen Caregiver Assessment Tools used in practice by physicians or nurse practitioners?				
a. Yes				
b. No				
4. Do you believe that online support communities have the potential for direct participation and/or facilitation by healthcare providers?				
a. Yes				
b. No				
5. What were the benefits of participating in the learning from online patient communities?				
6. What did you enjoy most about participating in the Learn From Smart Patients™ forum?				

3. RESULTS

All participants (100%) agreed the narrated PowerPoint was an effective teaching tool to introduce and explain caregiver care. A majority (82%) agreed that the Learn for Smart Patients™ forum was an effective teaching tool. Additionally, all participants, (100%) believed that online support communities have potential for practitioners to learn from patients about caregiver care. None of the participants had observed Caregiver Assessment Tools being utilized in the clinical settings they were assigned for student patient care experiences.

Two researchers independently employed thematic analysis to extract common concepts from the student discussion board posts and six themes were identified: Social Capital, Support to Caregivers, Community of Care, Caregiver Activation, Empathy and Holistic Person-Centered Care (see Table 2).

4. DISCUSSION

All participants agreed the narrated PowerPoint was an effective teaching tool to introduce and explain caregiver care. Whereas 82% agreed that the Learn for Smart Patients™ forum was an effective teaching tool. It is important that NP educators help students to understand and appreciate the deep learning that occurs actively within a social context.^[14] Moreover, methods of teaching should mimic real-life and should focus on the patient’s experience.^[13]

Six themes emerged from the qualitative analysis that strengthen and solidify the importance of educators providing the scaffolding for students to actively construct their own learning^[14] (see Table 2).

Data from this pioneering study indicated that APRN education can be improved by employing structured and supervised interaction with the dialogue present in contemporary online communities of caregivers. Several times during the activity, student responses were so authentic and sincere that they needed to be reminded by the faculty that this was not a live virtual encounter.

Additionally, the data indicates that the Learn from Smart Patients™ model may substantially enhance APRN education that aligns with the evolving trend of patients seeking support from online communities rather than “in-person” support groups.

The need for more research to understand the value added to healthcare education, combined with the potential for reciprocal learning between caregivers and APRNs, and the need for clinical education to evolve, resulted in the model shown in Figure 2. New Pedagogy for Teaching Healthcare Providers. The model involves interprofessional education and practice and is the plausible next step to test the new model for expansion to all clinical areas of practice, such as Physician Assistant, Physical Therapy, Medicine, and Pharmacy.

Table 2. Qualitative Themes Developed from Student Discussion Forum Posts

Theme	Discussion Board Post Exemplar
Social Capital	<ul style="list-style-type: none"> • Peer groups do something providers can't, they help heal, provide kinship, hope, possibility and worth • We are part of the patient's collaborative community, which is becoming more non-traditional in terms of helping them find their "new normal" • Many times patients/caregivers do not share their fears & frustrations with people who have not experienced or dealt with the same issues • Sometimes they can be intimidated by providers • Reaching out to the online caregiver community to get their opinion because people who have not gone through this cannot understand • Burdens for caregivers are often not brought out or discussed
Support to Caregivers	<ul style="list-style-type: none"> • Caregivers may not be able/willing to articulate when they are not coping in their caregiving roles • It is astonishing to see how pervasive caregiver concerns are and how broad the spectrum of these worries can be • Numerous forms of support are needed, some will be evidenced based and others more motivational, inspirational. The ability to adapt is one of our greatest strengths • Caregiving can make you feel socially isolated, depressed, overwhelmed and trapped • There are multiple "red flags" here, he is reaching for help • Providing this atmosphere of recognition, encouragement and reinforcement can lessen isolation and distress. It can make the individual feel empowered
Continuity of Care	<ul style="list-style-type: none"> • Even though our (Providers) recommendations seem simple, caregivers under stress may not be able to think through simple things they need guidance and direction • This forum demonstrates how we as providers critically analyze, synthesize and evaluate information • This much information is usually not shared during office visits
Caregiver Activation	<ul style="list-style-type: none"> • I wonder why we don't screen patient caregivers? This would be a proactive approach, should be part of the medical history • Consideration of the health and well-being of care providers will also promote positive and trusting relationships for those involved in the care • Recommend assessment of the caregiver as part of the initial patient assessment • Patients/caregivers have specific wishes that cannot easily be fulfilled because they are using the tools they always have, but reaching outside their reality can generate new interpretations and possibilities • It's important to explore caregiver values and preferences. By understanding their personal feelings, we can begin to understand why caregivers make certain choices • We need office visits for this, establish rapport, take a psycho-social history and we may not get it all one visit. We need to think about how we practice
Empathy	<ul style="list-style-type: none"> • Helps providers build-out a capacity for empathy or at least improve it. (This kind of) reflection is a great way to evaluate myself and review how I interact with patients • I believe we got to the heart and soul of medicine/nursing this week • It is important for us to acknowledge what a big step she/he is taking by reaching out for help
Holistic Person Centered Care	<ul style="list-style-type: none"> • My greatest take away is to treat the entire family and not just the patient • I love the idea of coaching someone/caregiver through a major illness or diagnosis, it can be therapeutic for both parties • Support groups provide a great source for encouragement and advice from people dealing with the same situation • Important to assess the various needs in terms of psycho-social footing, coping approaches and respite

4.1 Limitations

There are several limitations to the study. A sample of convenience was used for this study. Future studies should be conducted using large scale randomized national population samples. The ability to generalize the study's results are

limited in that students in an Adult-Gerontology Primary Care Nurse Practitioner Program may differ in important ways from students in other NP population foci or from other health professional students and/or practicing clinicians.

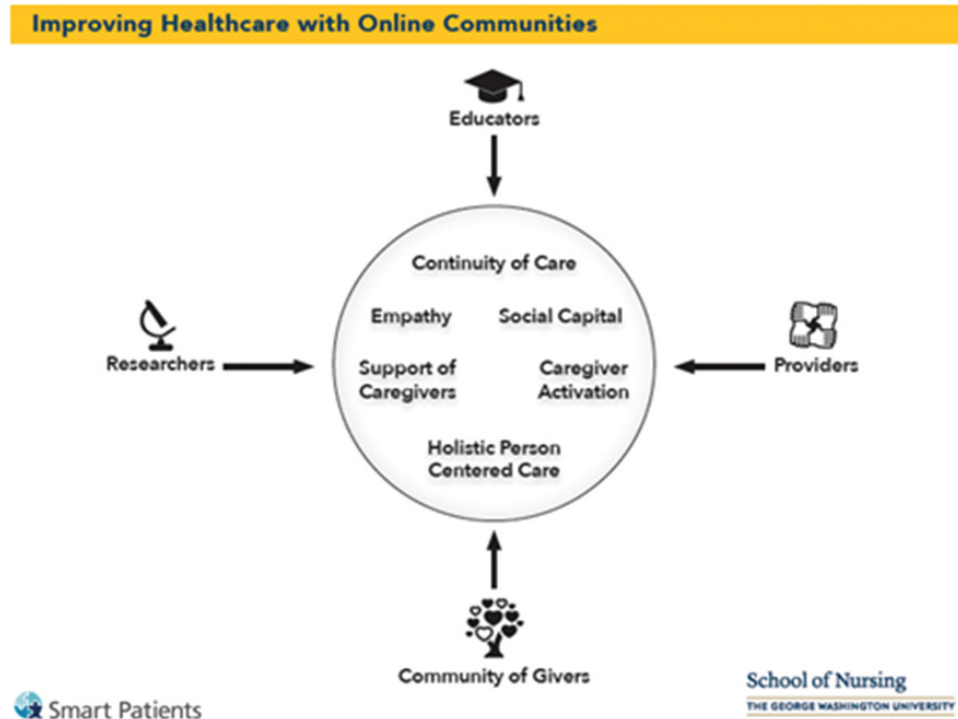


Figure 2. New Pedagogy for Teaching Healthcare Providers: Incorporating the Patient and Caregiver Perspective into Clinical Education

4.2 Relevance to clinical practice

APRN education is distinguished by the achievement of core clinical competencies. Typically, these competencies include the mastery of care to individuals with chronic disease conditions, which often require the services of a caregiver.

The Canadian Association of Schools of Nursing defines the scope of education for nurse practitioner students through a set of "Guiding Principles and Essential Components" which includes "effective communication and collaboration skills to prepare students to work with other health professionals, people requiring care and their families, and with relevant community organizations".^[15] A similar educational "domain" exists for nurse practitioner students in the United Kingdom (UK), requiring higher educational institutions to respond to "evolving healthcare/societal issues, that impact advanced nursing practice".^[16] The Australian nurse practitioner education standards specify that program content includes "online components" and "advanced holistic health

assessment and diagnostics".^[17]

This is also reflected in the American Association of Colleges of Nursing learning strategy's for faculty to "create an educational experience using data focused on a clinical issue that has evidence-based guidelines" considered essential to nurse practitioner education.^[18]

5. CONCLUSION

It is clear that teaching caregiver care to APRNs by accessing online support communities through technology addresses the competencies required globally for NPs. Engaging students in active learning that simulates real patient experiences deepens the understanding of the patient, caregiver and provider relationship. In addition, it expands the potential to add a new dimension to their graduate education.

CONFLICTS OF INTEREST DISCLOSURE

The authors declare that they have no conflicts of interest.

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