

Joy and Challenges in Improving Chronic Illness Care: Capturing Daily Experiences of Academic Primary Care Teams

Julie K. Johnson, MSPH, PhD¹, Donna M. Woods, PhD², David P. Stevens, MD³,
Judith L. Bowen, MD⁴, Lloyd P. Provost, MS⁵, Connie S. Sixta, PhD⁶, and Ed H. Wagner, MD, MPH⁷

¹Centre for Clinical Governance Research, Faculty of Medicine, University of New South Wales, Sydney, NSW, Australia; ²Feinberg School of Medicine, Northwestern University, Chicago, IL, USA; ³The Dartmouth Institute for Health Policy and Clinical Practice, Hanover, NH, USA; ⁴Oregon Health & Science University, Portland, OR, USA; ⁵Associates in Process Improvement, Austin, TX, USA; ⁶Sixta Consulting, Inc., Houston, TX, USA; ⁷MacColl Institute for Healthcare Innovation, Group Health Center for Health Studies, Seattle, WA, USA.

BACKGROUND: Two chronic care collaboratives (The National Collaborative and the California Collaborative) were convened to facilitate implementing the chronic care model (CCM) in academic medical centers and into post-graduate medical education.

OBJECTIVE: We developed and implemented an electronic team survey (ETS) to elicit, in real-time, team member's experiences in caring for people with chronic illness and the effect of the Collaborative on teams and teamwork.

DESIGN: The ETS is a qualitative survey based on Electronic Event Sampling Methodology. It is designed to collect meaningful information about daily experience and any event that might influence team members' daily work and subsequent outcomes.

PARTICIPANTS: Forty-one residency programs from 37 teaching hospitals participated in the collaboratives and comprised faculty and resident physicians, nurses, and administrative staff.

APPROACH: Each team member participating in the collaboratives received an e-mail with directions to complete the ETS for four weeks during 2006 (the National Collaborative) and 2007 (the California Collaborative).

KEY RESULTS: At the team level, the response rate to the ETS was 87% with team members submitting 1,145 narrative entries. Six key themes emerged from the analysis, which were consistent across all sites. Among teams that achieved better clinical outcomes on Collaborative clinical indicators, an additional key theme emerged: professional work satisfaction, or "Joy in Work". In contrast, among teams that performed lower in collaborative measures, two key themes emerged that reflected the effect of providing care in difficult institutional environments—"lack of professional satisfaction" and awareness of "system failures".

CONCLUSIONS: The ETS provided a unique perspective into team performance and the day-to-day challenges and opportunities in chronic illness care. Further research is needed to explore systematic approaches to integrating the results from this study

into the design of improvement efforts for clinical teams.

KEY WORDS: chronic illness; team; joy in work; graduate medical education; ambulatory training; interprofessional training.

J Gen Intern Med 25(Suppl 4):581-5

DOI: 10.1007/s11606-010-1408-8

© Society of General Internal Medicine 2010

BACKGROUND

Chronic diseases account for 59% of the 57 million deaths annually and 46% of the global burden of disease.¹ In the United States, chronic illness is the most common reason for seeking health care and it accounts for over 70% of all health care expenditures.² Efforts to improve care for people with chronic illness are increasingly focused on the chronic care model (CCM). Successful implementation of the CCM results in superior outcomes for patients.³⁻⁵ The overwhelming burden of chronic disease is coupled with increasing evidence of a physician workforce that is increasingly disillusioned with primary care as a career choice, and fewer people who choose primary care as a specialty.^{2,6}

Two chronic care learning collaboratives—a national Academic Chronic Care Collaborative and a subsequent California Collaborative—were conducted by a partnership between the Institute for Improving Clinical Care of the Association of American Medical Colleges (AAMC), and Improving Chronic Illness Care, a national program based at Group Health Cooperative. The purpose was to facilitate implementing the chronic care model (CCM) in resident continuity practices. The CCM provides an evidence-based framework for chronic illness care based on elements for improving care at the level of the community, organization, practice, and patient.^{7,8}

Forty-one teams, representing 37 teaching hospitals, participated in the learning collaboratives.⁹ Learning collaboratives are communities of practice, where groups of people who share concern or passion about a topic, deepen their knowledge and expertise in the topic by interacting on an ongoing basis.^{10,11} As the first conducted within academic settings,

participants in the Academic Chronic Care Collaboratives (ACCCs) assembled around the current state of primary care and a shared commitment to redesign chronic illness care and resident practices based on the CCM. Participants agreed to collect and report data on a series of disease specific clinical outcome and process of care measures to monitor collaborative improvement efforts.⁹ They also agreed to monitor educational improvements using measures designed for that purpose.¹²

OBJECTIVE

We conducted a qualitative evaluation of the ACCCs to understand and describe the drivers that facilitate changes in practice. We developed an electronic team survey (ETS) to provide a unique perspective into how primary care teams function and the day-to-day challenges and opportunities of providing care for patients with chronic illness with an emphasis on the challenges on implementing the CCM in academic settings.

DESIGN

The ETS is based on the Electronic Event Sampling Methodology developed by Amabile and colleagues to collect information about specific events that might influence team members' daily work and subsequent outcomes on projects requiring creativity.¹³ Electronic Event Sampling Methodology is an adaptation of the Experience Sampling Methodology developed by Larson and Cshikszentmihalyi, where participants are asked to interrupt their current activity to make notes of their experiences in real time.^{14,15} In contrast, using the Electronic Event Sampling Methodology, e-mails are sent daily to the study participants asking that they complete a survey related to what they experienced that day. Our research team proposed that Electronic Event Sampling Methodology would be more practical in busy academic clinical settings. The ETS was based largely on one of the "free response" items in the survey questions from Amabile and colleagues.¹⁶ Participants were prompted to "Briefly describe ONE event that stands out in your mind from today's work related to providing care to patients with chronic health problems. Describe your feelings about this work, your experience of this work, or your team's experience of this work. The event you describe can be positive, negative, or neutral."

PARTICIPANTS

Forty-one residency programs from teaching hospitals participated in the ACCCs. Faculty and resident physicians, nurses, and administrative staff composed the participating teams. All team members were eligible to participate in the ETS. In the National Collaborative, there were 138 possible respondents. In the California Collaborative, there were 194 people possible respondents. To establish a unique identifier for each person participating in the ETS, a team "liaison" provided names and e-mails of their team members.

APPROACH

Participants learned about the ETS during quarterly collaborative learning sessions and monthly conference calls. To minimize respondent burden and to enhance response rate,

we limited the survey reporting periods to one week per month during four consecutive months. Prior to each reporting period, e-mails were sent to each team member as a reminder of the upcoming reporting period, to communicate the secure login and password for the survey, and to confirm participation in the study. The number of eligible participants varied for each reporting period, because at the time of e-mail reminders, some participants indicated an inability to participate because of absence from the clinic due to other professional obligations. In the National Collaborative, the number of potential respondents ranged from 94 to 125 (of 138 eligible respondents) across the four reporting periods. In the California Collaborative, the number of eligible respondents ranged from 150 to 185 (of 194 eligible respondents) across the four reporting periods.

Reminder e-mails were sent each day of the data collection week, pointing the participants to the secure web-site and asking that they complete the survey. Each data collection week was Monday to Friday (5 working days). The ETS was managed via a web-based tool housed at the University of Chicago.

One member of the research team (JJ) received responses to the ETS, grouped narrative entries according to participating site and de-identified all responses so that the respondent would remain anonymous. A database of all responses was created and the data was entered into Atlas.ti 5.2, a qualitative analysis software, to facilitate retrieving, coding and sorting the data.¹⁷

The ETS response rate was calculated at the team level and included teams that had responses across all four reporting periods of their respective collaborative (either the National Collaborative or the California Collaborative). For example, if the ETS data from a team did not encompass all 4 reporting periods then that team was considered non-responsive for the purpose of calculating the response rate.

The design of the qualitative analysis was based in a grounded theory approach, with text-based constant comparative analysis performed on the narrative entries to determine emerging themes.¹⁸ With this inductive method, two qualitative researchers (JJ and DW) coded a small sample of narrative entries with no a priori assumptions during an initial coding process. The narrative responses were then compared across the entries to integrate them into themes and categories. Emerging themes were discussed with the ACCC research team for feedback during a regularly scheduled conference call. The coding scheme was then consistently applied to all the narrative entries by one researcher (JJ).¹⁹ Themes and examples of verbatim ETS responses were presented to the respondents (i.e., collaborative participants) during the in-person learning sessions that were held quarterly.

KEY RESULTS

During 2006–2007, 41 teams from 37 teaching hospitals participated in the ETS. The response rate for participating in the ETS was 87%. The 1,145 narrative entries provided a window into how collaborative participants care for patients with chronic illness, work as part of a team, and teach.

Several themes emerged from the analysis of the qualitative data. The six most frequent themes from the ETS responses were (1) mindfulness of patient care, (2) changes in work attributed to the ACCC experience, (3) greater focus on patient education, (4) multi-disciplinary team function, (5) mindfulness of learner interactions, and (6) reflection on action (e.g.

the ability to have new understanding based on a reflection of a recent experience).

The themes from the ETS narrative entries for teams focusing on improving diabetes care were then linked to the quantitative clinical outcomes that were submitted as part of the monthly reports that were required from participants in the ACCCs.⁹ We used the Assessment Scale for Collaboratives to rank the team performance on a scale of 1 to 5.²⁰ This scale evaluates participating teams for evidence of (a) implementing the CCM for the patient population of focus, with at least one change implemented for each of the six components of the Care Model, (b) making significant improvement in two of three required outcome measures (percent of population with HbA1c <7, LDL <100, blood pressure ≤130/80), (c) reaching at least 50% of goal for all required process measures (percent of patient population with up-to-date retinal examinations, foot examinations, and establishment of patient self management support), (d) planning for spread of improvement efforts; and (e) monitoring at least 90% of the population of focus using a disease registry. A score of 4 served as the cut-off for high performance, which is defined as “Significant Improvement”. Specific results of collaborative measures are reported elsewhere.⁹

To consider whether there were any differences, as indicated by the qualitative themes, related to different levels of quantitative performance, we compared the sites that scored the highest on the assessment scale to those that scored the lowest. Five sites met criteria for high performance, using a score of “4” or “significant improvement” as the cut-off. The five sites ranking the lowest on the scale were grouped as low performing sites. The themes between the two groups were the same, except for one theme that emerged in the higher performers—professional work satisfaction (i.e. a sense of “joy in work”)—and two themes that emerged exclusively in the poorer performers which reflected the effect of providing care in difficult institutional environments—“lack of professional satisfaction” in work as evident by interference with ability to deliver good chronic illness care and awareness of “system failure” within the microsystem. Themes and illustrative verbatim quotations are described in the following sections.

“Mindfulness of Patient Care,” where the respondent identified and described an event from the day that was directly related to patient care, was the most frequent theme that emerged.

Took care of a pt. who was here with syncopal episodes, bradycardia and SOB. This is 89 year old pt. with a H/O CHF, HTN and several other problems. She had to have several tests done and she ended up being admitted on a tele floor for further evaluation. I spent about 90 minutes plus my lunch hr with this pt. The whole team—RN, MA, the collaborating physician, the pt. and her spouse was involved with everything we did. It was a group effort to get her to floor. This was a very satisfying visit, since I felt I could do something for her and reliev[e] ve some of her symptoms. [Physician]

“Changes in Work” was the second most frequent theme, and provided the Collaborative faculty insight into real-time changes that were occurring in response to the Collaborative.

The group visit attracted two patients who had not been seen recently in the clinic and were due for a routine

doctor visit. Their resident physician has graduated. I was able to assign new doctors for these two Change Team patients today. Appointments are being arranged with residents who will be trained in the chronic care model during next month’s rotation. This will ensure planned visits will be scheduled for residents during the month. Not only does this promote continuity of care with the nurse practitioners providing team based care with the residents, it also provides residents with patient who need updated care. [Member of the Administrative Staff]

The next most frequent theme was “Patient Education”:

Per MD request, met with a 21 yr old type 1 DM who has been non compliant with diet, exercise, blood sugars... plus drug usage. I was able to utilize knowledge of young adults in approaching her to establish rapport and goal setting. She has agreed to weekly f/u with me for teaching and coaching. Patient open to teaching. [Nurse]

In the theme, “Multidisciplinary Team Function,” the respondent identified and described an event from the day that was related to working as part of a multidisciplinary team to provide chronic illness care.

Lots happening today... Absolutely awesome Interdisciplinary Team Meeting with residents presenting complex patients. Great interchange between disciplines about patient barriers, medication adjustments and coordinating follow-up for continuity. Improvement in show rates for planned visits was also reported as a result of nurse practitioner telephone interventions. Residents discussed a team approach to patient care as a follow-up from the Team Meeting. [Physician]

“Mindfulness of Learner Interactions” emerged as a prevalent theme:

Worked with a 4th year medical student this afternoon in clinic and had a ton of no-shows (all acute visits), but the patients who did show up were all my chronic care patients, many of them diabetic. I was able to teach the med student about following DM trends with our clinic flowsheet and go through some self-management goal setting with the patient while med student was present. She thought it was fantastic and wishes she had been exposed to this earlier [Physician]

“Reflection-on-action” is a theme where the respondent described an event from the day that was related to his or her own reflections about caring for patients with chronic illness. This theme represents comments displaying consciousness about the future, goals, and how to improve care. The “reflective practitioner” is not a new concept and “reflection-in-action” and “reflection-on-action” were central to Schön’s efforts to describe what professionals do.²¹ Reflection-in-action is reflecting on the process while engaged in the process. Reflection-on-action is something that occurs later, after the event. Given the nature of our data collection process where

the narrative entries captured the event of the day, post hoc, reflection-on-action best describes the category.

Today I saw a young patient with poorly controlled Type I diabetes. She has been very cooperative and enthusiastic about establishing care with me and getting her DM under control. Yet her A1c is 12.4. She has limited income and really would benefit from seeing an endocrinologist in the area. I'm excited to work with her, but sometimes I feel somewhat overwhelmed with the complexities of her care and the limited economic means she has. I know that if we get her DM under control that will be a huge achievement for her, myself, and the entire team. This event reminded me to share my frustrations with my residents, so that they see that attendings also have difficulties with their patients at times and we can all work to motivate each other. [Physician]

Whereas the previous six themes were the most frequent across all participating sites in the collaborative, separating the high performing teams from the lower performing teams based on clinical indicators resulted in two key differences. The high performing teams had an additional theme of "Professional Work Satisfaction" that could be best described as events that brought "joy" to the provider in their day-to-day work of providing care for patients with chronic illness. These ranged from simple to more complex interactions, but overwhelmingly described an enthusiasm resulting from the work, environment, and interactions that we termed "joy and work".

A patient that we have been calling weekly to titrate insulin came today with perfect sugars. She was happy and so were we. We called the nurses in to look at her logbook! It takes a village to take care of a patient. [Physician]

In contrast to the theme of Professional Satisfaction, "Lack of Professional Satisfaction or Joy in Work" characterized events that resulted in frustration for the respondent.

Due to an overcrowded faculty meeting agenda I was unable to discuss the [collaborative] activities currently underway. We learned that another faculty member is leaving at the end of June. We are extremely short of physician faculty. In the face of these stresses, not being able to keep the [collaborative] activities in front of the faculty lets them drift [to] the background. When you are focused on just getting the essentials done, anything new seems less important. My limited time working on the [collaborative] in this residency give[s] me a Sisyphus-like experience. You push it to the top of the hill only to have it fall back to the bottom. [Physician]

"System Failures" describes events that can be characterized as trying to work within a larger system that sets up barriers that are perceived as insurmountable.

I created a new flow sheet for insulin titration in the clinic. It has evidence based guidelines built right in and it looks good. Now I have to turn it over to the forms committee and it will take months to be approved and patient care will suffer as a result. I think our forms

committee is awful and causes unnecessary delays in patient care. What do you say to residents in systems like ours? Any good idea you have today will be delayed because of a draconian hospital committee? [Physician]

DISCUSSION

Our qualitative study used a daily electronic survey of members of the clinical team to capture events that stood out at the end of each day, when these events were still close to the time of the patient and/or team interaction. Furthermore, using the quantitative performance indicators reported by the collaborative teams as a "filter" we were able to consider qualitative differences between events experienced by teams that performed higher and lower on the clinical indicators.

We observed that participants in the ACCCs who came together with a focused common goal, a method to reasonably achieve that goal, and participate in a team working toward this common goal were often reminded of their individual and institutional missions as care providers. The emerging themes from the qualitative analysis supported this observation. Team members reported events characterized as mindfulness of patient care, changes in work attributed to the ACCC experience, greater focus on patient education, multi-disciplinary team function, mindfulness of learner interaction, and reflection-on-action.

Of note, we saw an additional emerging theme—professional work satisfaction or "Joy in Work"—in the high performing teams. Joy in Work appeared to be an important contributor to the success of the ACCCs and to the success of the clinical team. Joy in Work, as a construct, as well as its impact and origination, has been relatively unexplored and undefined, yet we can draw on the organizational behavior literature related to positive affect, flow, and creativity.^{16,22-24} Clearly what brings joy may differ from one person to the next, but similarities emerged across different participants with different roles on the clinical care team.

The narrative reports submitted in response to our daily query suggest that physicians often derive joy from work with patients that bring specific clinical measures under better control reflecting that these measures may have a meaningful relationship to health for both the physician and the patient. Other components of the CCM appear to be contributing to joy as well, such as better communication among team members and the recognition of non-physician team members contributing to the care of the patient.

I am responsible for scheduling our diabetic patients for our Chronic Disease Management Visit Clinic... this is such an important task and a lot of our success hinges upon what I do. [Administrative Staff]

We speculate that further insights about what brings joy to work might be gained from providing patients with the opportunity to report on their experiences managing their chronic illnesses with their physicians and care team.

Finally, for clinicians who have chosen to practice in academic settings, we need to know which teaching experiences bring joy, for example celebrating when a resident demonstrates self-management goal setting as a new skill, or when a resident addresses the entire diabetes guideline when

discussing a patient, or (particularly) when a resident considers changing a career focus to primary care because of the experience working on a CCM team.

Importantly, we found that two themes emerged among the participants whose team didn't perform as well on the Assessment Scale for Collaboratives. It would be misleading to suggest that top performing teams don't experience "Lack of Professional Satisfaction" and "System Failures", indeed these themes were also present in the top performing sites, but not frequently enough to emerge as one of the top themes.

Further research is needed to understand what brings joy in primary care settings and in caring for patients with chronic illness. The first step is to acknowledge that there are certain experiences that increase professional satisfaction and bring joy in work. In contrast, other experiences detract from the potential satisfaction that might come from work. The next step is to collect the stories—both positive and negative experiences—and to recognize that these stories are a potential platform for thinking about design and redesign of chronic illness care. The question becomes, how do we feed these stories back into the improvement process to further enhance professional satisfaction and continue to improve outcomes for our patients?

LIMITATIONS

The ETS, as a method, provides a preliminary look at what team members report as joy and challenges in work in academic primary care teams. Whether these observations can be generalized to other teaching settings or to non-academic settings will require wider tests of this theory and methodology. Given the qualitative nature of the study and results, transferability may be a more appropriate concept than generalizability, in which we consider the implications of the results in a different setting.

Asking participants to report on one event that stands out from each day may result in a collection of narratives that is not necessarily representative of daily work in primary care. We attempted to address this limitation by collecting the data over multiple days throughout the duration of the collaboratives. Validity from these types of methods comes from the repetitive nature of the data collection, so that patterns start to emerge from the narrative entries.

CONCLUSIONS

Narrative reports, such as those gathered through the ETS, provide a new lens through which to view the work of improvement, the work life of chronic care team members, and outcomes for people with chronic illness. This project points to future research to determine the contribution of the construct "Joy in Work" to effective organization of healthcare teams and positive healthcare outcomes for the patient. In addition, further research is needed to explore systematic approaches to integrating the results from the ETS into the design of improvement efforts for clinical teams.

Acknowledgements: *The national staff and faculty for the Academic Chronic Care Collaboratives were supported by generous grants from the Robert Wood Johnson Foundation and the California HealthCare Foundation. The work reported in this manuscript was*

presented at the Academy Health Annual Research Meeting, June 28, 2009, Chicago, Illinois.

Conflict of Interest: *None disclosed.*

Corresponding Author: *Julie K. Johnson, MSPH, PhD; Centre for Clinical Governance Research, Faculty of Medicine, University of New South Wales, Sydney, NSW 2052, Australia (e-mail: j.johnson@unsw.edu.au).*

REFERENCES

1. World Health Organization. Preventing Chronic Diseases: A Vital Investment: World Health Organization; 2005.
2. **Bodenheimer T, Chen E, Bennett H.** Confronting the growing burden of chronic disease: can the U.S. Health Care Workforce do the job? *Health Aff.* 2009;28(1):64–74.
3. **Bodenheimer T, Wagner EH, Grumbach K.** Improving primary care for patients with chronic illness: the chronic care model, Part 2. *JAMA.* 2002;288(15):1909–14.
4. **Bodenheimer T, Wagner EH, Grumbach K.** Improving primary care for patients with chronic illness. *JAMA.* 2002;288(14):1775–9.
5. **Coleman K, Austin B, Brach C, Wagner EH.** Evidence on the chronic care model in the new millennium. *Health Aff.* 2009;28(1):75–85.
6. Council on Graduate Medical Education. Physician Workforce Policy Guidelines for the United States, 2000–2020. Rockville, MD: COGME2005.
7. **Wagner E, Austin B, Von Korff M.** Organizing care for chronic disease. *Millbank Quarterly.* 1996;(74):511–44.
8. **McCulloch D, Price M, Hindmarsh M, Wagner E.** Improvement in diabetes care using an integrated population-based approach in a primary care setting. *Dis Manag.* 2000;3:75–82.
9. **Stevens D, Bowen J, Johnson J, DM W, Provost L, Holman H, et al.** A Multi-institutional quality improvement initiative to transform chronic illness care and education in resident continuity practices. *J Gen Intern Med.* 2010(XX:XX–XX).
10. **Braithwaite J, Westbrook J, Ranmuthugala G, Cunningham F, Plumb J, Wiley J, et al.** The development, design, testing, refinement, simulation, and application of an evaluation framework for communities of practice and social-professional networks. *BMC Health Serv Res.* 2009;9(162).
11. **Wenger E, McDermott R, Synder W.** *Cultivating Communities of Practice.* Boston: Harvard Business School Press; 2002.
12. **Bowen J, Stevens D, Sixta C, Provost L, Johnson J, DM W, et al.** Developing measures of educational change for collaborative teams implementing the chronic care model in teaching practice. *J Gen Intern Med.* 2010(XX:XX–XX).
13. **Amabile T, Whitney D, Winstock J, Miller L, Fallang C.** *What Really Happens in Creative Projects: Event Sampling Through Electronic Data Collection.* Cambridge: Harvard University; 1997.
14. **Csikszentmihalyi M, Larson R.** Validity and reliability of the experience-sampling method. *J Nerv Mental Dis.* 1987;175:526–36.
15. **Larson R, Csikszentmihalyi M.** The experience sampling method. *New Dir Methodol Soc Behav Sci.* 1983;15:41–56.
16. **Amabile T, Barsade S, Mueller J, Staw B.** Affect and creativity at work. *Adm Sci Q.* 2005;50(3):367–403.
17. Scientific Software Development Company G. ATLAS.ti. Berlin, Germany.
18. **Boeije H.** A purposeful approach to the constant comparative method in the analysis of qualitative interviews. *Qual Quant.* 2002(36):3392–40.
19. **Strauss A, Corbin J.** *Basics of Qualitative Research.* 2nd ed. Thousand Oaks: Sage Publications; 1998.
20. Institute for Healthcare Improvement. Assessment Scale for Collaboratives. Boston: Institute for Healthcare Improvement; 2004.
21. **Schon D.** *The Reflective Practitioner: How Professionals Think in Action.* USA: Basic Books, Inc; 1983.
22. **Csikszentmihalyi M.** *Creativity: Flow and the Psychology of Discovery and Invention.* New York: Harper-Collins; 1996.
23. **Amabile T, Hadley C, Kramer S.** Creativity under the gun. *Harvard Business Review.* 2002;80(8):52–61.
24. **Bakke D.** *Joy at Work: A Revolutionary Approach to Fun on the Job.* Seattle: PVG; 2005.