Using Positive Deviance and the Citizen Healthcare Model for Coproduction

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Research Report

Using Positive Deviance and the Citizen Healthcare Model for Coproduction

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Authors' Note:

Our paper is novel because it examines a new approach to co-production. Many standardized group care models exist that are medically focused and/or led by healthcare staff. These care models have shown improvements in health outcomes but few have assessed the impact of a patient and support person led group model and its potential to create change. This study introduces a process to create such a group of patients; families and healthcare teams who have learned to succeed despite great obstacles. By using positive deviance methods and citizen health organizing techniques this group was assessed through a mixed methods approach of qualitative interviews, quantitative data assessment and social network analysis. To our knowledge, this topic has not been published in a major scientific journal. Neither author has any conflicts of interest related to this paper. We look forward to your review and response. In the meantime, please let us know if you need anything else.

Conflict of Interest:

None of the authors has any reportable conflicts of interest related to this research study.

Abstract

Background. Many standardized group care models exist that are medically focused and led. These care models have shown improvements in health outcomes but lack in coproduction.

Methods. Using a combination of a citizen health care model (CHCM) and a positive deviance (PD) approach Epsom Family Medicine (EFM) identified two positive deviant patients to coproduce a new approach to address complex diabetes. Quantitative analysis using statistical process control methodology was used to assess electronic medical record data. A Semi-structured qualitative interview was conducted. Direct observation notes were
recorded. A Social network analysis questionnaire was used to assess pre-and-post strength and relationship development.

Results. 40 participants attended at least one meeting out of ten. Qualitative interview identified influence on: Peer support, support system, peer led vs. medical led differential and a new role for the medical team. The quantitative data showed only one individual with a statistically significant reduction in weight and blood pressure that correlated with 2 sequential meetings attended. The social network analysis showed a new social connection with each member to the group focused around information. Co-production to invite support people to office visits and improve access to health food occurred.

Conclusions. PD and CHMD approaches focused on personhood and empowerment of patients and their support people can be applied to generate: coproduction initiatives to flatten hierarchy, creative solutions to individual behavioral struggles and to address health system inadequacies in addition to filling community gaps to achieve health.

Implications. A low-cost process for developing coproduction in healthcare was identified.

Keywords. Coproduction, Positive deviance, citizen healthcare

Introduction

Healthcare is transitioning from a medical professional model to one of coproducing healthcare. Several group models exist currently. In the structured Stanford Chronic Disease Model (SCDM), the script is patient led with chronic disease training. In the Community Oriented Primary Care (COPC) model, providers collaborate with community members to improve community health. In COPC, while the community members aid the providers, the community health relies on the provider who remains in a hierarchal relationship within the community. Although, the SCDM and COPC group models have displayed potential, other relevant approaches are needed as we transition to a coproduction model of healthcare wherein the hierarchal nature of the provider is flattened.

Care models that are collaborative, patient and family centered and involve community based approaches have been advocated by leading healthcare organizations. Two community organizing approaches that have shown promise to level provider hierarchy are: Positive Deviance (PD) and the Citizen Health Care Model (CHCM). PD is an asset-based collaborative approach that identifies individuals and/or groups whose uncommon behaviors and strategies allow them to find better solutions to problems than their peers despite having access to similar resources and struggling with similar obstacles. It has been used to identify solutions within healthcare and patient community to address issues ranging from hospital-acquired infections, diabetes management, maternal and child health, iron deficiency anemia, acute myocardial infarction, hypertension, immunizations, and cystic fibrosis. Since the solution comes from within the community, it’s likelihood for sustainability, affordability and success is high in PD.
CHCM engages with patients, families and communities as co-producers of health and healthcare. In this approach, health professionals apply community organizing skills to partner with individuals, families and the communities to build health and healthcare that better serves their needs. CHCM has been applied in multiple settings to address diabetes and has shown reductions in hemoglobin A1c, blood pressure and weight. CHCM recognizes social support and group oriented sequences as more valuable to participants than structured program content. These initiatives have been sustainable for over a decade without relying on external funds to achieve targeted changes. PD and CHCM approaches thus allow patients and healthcare professionals to coproduce the group experience and for professionals to serve as facilitators. These less structured approaches find local solutions to problems and capitalize on existing resources. This asset based approach is different than the deficit model which assumes the patient is the one either lacking knowledge or motivation. (See supplementary material Appendix A for core principles of PD and CHCM).

Epsom Family Medicine (EFM), a rural primary care clinic within the Concord Hospital Medical Group (CHMG) had difficulty in getting their largest patient population those with type II diabetics under diabetic control. EFM had a higher volume of percent of complex diabetic in its total patient panel in comparison to other clinics within CHMG (Fig. 1). This population comprised of 90 patients with mean Hemoglobin A1c (HbA1c) of 9.2±1.1. Several attempts by provider teams to attain diabetic control did not materialize and lacked care coproduction, i.e. EFM did not have any care processes that directly included patients, family members or the community. Lack of coproduction motivated the healthcare teams to develop a new care process. The EFM physician teams sought to apply PD and CHCM as a different approach to the complex diabetic patient population to coproduce health with two broad aims: (1) to bring together a group of patients to (a) improve the health and quality of life of patients through shared wisdom and support, to (b) enhance EFM by the group partnering with the healthcare teams to create better quality care, to (c) enrich the community by building and tapping into its resources and relationships, and (2) to flatten the hierarchy of provider-patient relationship by allowing patients to lead and for providers to facilitate the group and offer resources as needed and when asked. Since high volume has been shown and recommended to be an important feature of value creation in healthcare, we sought to assess the value of group support approach in complex diabetic patients seen at EFM.

Methods

1. Group formation & PD Process

Groups were formed by PD. PD process was initiated by developing a PD definition within a specified community. Electronic health records where used for PD patient group identification. The process included assessment of necessary risk factors in positive deviant patients as study inclusion criteria. The risk factors included comorbid diagnoses of depression, anxiety, specific medications to treat either or both conditions, patient social vulnerability based on home address and either being single and/or unemployed.
2. Patient identification & inclusion criteria

Complex diabetic patients, family members who had overcome obstacles to achieve patient health, and staff willing to engage in designing patient experience were identified and classified as important players for their wisdom and credibility to flatten the prevalent expert provider hierarchical culture. Additionally, patients were required to have at least one HbA1c greater than 9.0 during the past three years and to have their two most recent HbA1c less than 8.0. Lastly, to ensure identified patients made behavioral changes, only patients with medication dose reductions and maintained diabetic control were included. When all the above qualitative inclusion criteria where applied, six patients were identified in the PD group.

3. Exclusion criteria

Qualitative patient screening was conducted with patient’s primary care provider teams who were asked to exclude any patients that were not positive deviant. One patient was ruled out in this process due to a prolonged hospitalization. The five remaining patients were classified as positive deviants, two of whom agreed to design a peer support and learning experience (Fig. 2)

4. Perspectives of positive deviant patients

EFM team met with the two classified positive deviant patients and asked them to design a learning experience for peers that they would attend if they had difficulty managing their diabetes. The positive deviant patients identified the following peer learning elements: (1) inclusion of support people as it is difficult to face the condition alone, (2) peer support meeting time to be accommodating to the majority of working people, (3) semi structured support groups to express patient struggles and for peers to share wisdom with struggling patients, (4) willingness of patients and support people to bring healthy meals for group meetings.

5. Patient recruitment

Positive deviant patients recommend the following to recruit peers to attend support groups: (1) use of existing relationships between healthcare teams and patients to call patients or to have discussions during an office visit, (2) allowing a clinical liaison to facilitate group meetings. While the EFM team suggested focusing recruiting efforts specifically on patients who were interested in lifestyle change to control their diabetes. All EFM teams were asked to identify a core group of patients that would fit the profile based on the transtheoretical model such that the identified patients would not be pre-contemplative but rather would themselves be interested in a support group to make lifestyle changes. This selection approach has previously demonstrated improvement in diabetic self-efficacy. Providers crossed off patients that had uncontrolled diabetes and considered them pre-contemplative based on their patient relationship.
6. Coproduction

Healthcare teams contacted motivated patients remaining on the list through phone calls or met them during office visits. The first meeting was physician facilitated and was led by a group member. It occurred in June 2015 with 11 participants in attendance. The group meetings subsequently occurred once a month for two hours each until April 2016 for a total of ten meetings and had at least one clinical liaison as facilitator. During the last three meetings, three patient coleaders, who received formal facilitation training provided by the hospital, volunteered to facilitate the group. Thus creating more patient lead group self-reliance.

7. Keeping the group moving

The following suggestions were documented during the first meeting to keep the group moving: (1) any gaps in group knowledge to be addressed by a speaker, (2) the group recognized patients were not the only ones who made meals or did grocery shopping and many lifestyle interventions involved their support people, therefore, an audacious goal to market a health system wide effort to invite patient support persons to all office visits to improve quality of care was put in place (3) consensus to provide support to caregivers so they can help make behavioral changes with the patient, (4) in addition to the healthcare teams inviting new members, the group members agreed to initiate invites to friends and family to participate in the meetings, (5) a call tree to remind all members to attend meetings, and (6) attendance list and group consent forms to be filled at each meeting for confidentiality.

8. Approach & Data Collection

We used a mixed-methods approach to assess the impact of the coproduced support group intervention. Quantitative data were collected from electronic health records in a continuous format. We gathered recordings of personal observations of physicians who attended each meeting. We used a semi-structured qualitative interview focus group, after the 10th meeting, to assess the impact of the group experience on participants. Perspectives were prompted through one focus group interview with five participants who attended at least three meetings. During the interview the use of open, direct, verbal questions was used to elicit stories and case oriented narratives. Pre-and post-support network questionnaire was developed based on data from a systematic review establishing improved diabetic outcomes associated with increase in social support. (Supplementary material appendix D)

9. Measures

The outcomes included: (1) number of people participating in meetings, (2) patient data on HbA1c, weight, blood pressure, emergency visits, and hospital admissions, (3) responses of qualitative interview with group participants, and (4) recordings of physicians who attended each meeting. The process measures included: (1) pre-and post-support network analysis.
10. Data Interpretation & Analysis

Two external qualitative volunteer researchers independently coded the data using the open coding method\textsuperscript{31} marking text excerpts of interest and giving them descriptive labels. The codes were combined to form themes. The preliminary themes were examined and finalized by the research team. The data were reexamined for confirming and disconfirming evidence for the identified themes. Any differences in interpretation were resolved through discussion.\textsuperscript{32} Data was collected in a pre and post questionnaire format evaluating social network connection. The data was then analyzed using R statistical software to create social network diagrams. Using statistical process control charts and an iterative process\textsuperscript{33}, electronic health record data was collected in a continuous format and analyzed via statistical process control chart rule methodology.\textsuperscript{33}

Human subjects protection

A group consent of confidentiality was signed by each member before participation. The qualitative, quantitative and social support survey of patient data was approved by Concord Hospital’s Institutional Review Board.

Results

In our 90 patient panel with complex diabetes, the average age was 58 years, and depression and anxiety were common comorbid conditions. Forty participants, both patients and support people attended ten group meetings. Half of the 40 participants belonged to health systems outside of CHMG. Ten out of 20 EFM patients, who were remotely monitored during office visits, had attended more than one meeting. One patient who attended six meetings showed statistically significant reductions in weight and blood pressure, based on statistical process control chart rule criteria.\textsuperscript{33} Nineteen patients who attended less than six meetings did not shown any statistical difference in weight, HbA1c, or blood pressure.

Statistical process control data on three sample patients are summarized in (Fig. 3). Panel A presents patient one who attended six meetings and showed a statistically significant reduction in weight and blood pressure that corresponds to attending two sequential meetings. Panel B depicts patient 2 with no statistically significant changes. Panel 3 depicts patient 3 who showed a reduction in weight due to hospitalizations rather than the group intervention. The qualitative interview identified several key patterns, the main categories and their corresponding sub-categories are outlined in Table 1.

Based on the physician recordings, the group developed a health system wide marketing campaign for patients to bring their support people to appointments. The group through multiple meetings with the EFM care teams co-produced a marketing “Bring your support person” letter approved on May 17\textsuperscript{th} 2016 by the Concord Hospital Patient Relations
Committee and the Practice Operations Committee (Supplementary material Appendix B). Additionally, the group worked with multiple stakeholders within New Hampshire to increase healthy food donations in local food banks (Supplementary material Appendix C).

The pre-and-post social network support analysis on three patients who attended at least three meetings illustrates a new social support connection through the group as a whole (Fig. 4).

Discussion

Our study assesses the impact of patient and support person led coproduction for complex diabetic by merging PD and CHCM models via mixed-methods approach. Our Qualitative assessments revealed multiple benefits of peer led and peer centered groups, from patient empowerment, to hope, generation (e.g. leaving a legacy), whole personhood acknowledged, active engagement, creative problem solving, enhanced learning and coping skills, and expanded patient comfort zones. The peer meetings helped the patients’ support persons to become more empathetic and aware of patient struggles. Patients encouraged other similar patients to join to learn from their wisdom which could in turn help them. Our findings are similar to those observed with asset models such as PD and citizen healthcare. In contrast, the medical-led lecture group with a focus on what not to do, rather than what needs to be done resulted in only mandatory passive participation because the medical professional was perceived as the expert.

Although, the qualitative analysis exhibited a preference for patient and support person driven intervention over medical-led group intervention for complex diabetes control, only one patient out of 19 EFM clinic patients had an improvement in weight and blood pressure. Reasons for not observing higher number of patients adapt healthy behavior change may be that chronic disease processes may require more time to have a broader impact and/or the CHCM recommended meeting frequency of twice a month instead of once a month was not utilized. Projects such as the Family Education Diabetes Series that utilized the CHCM were able to lower weight, HbA1c and blood pressure within six months by meeting twice a month. We took notes on behavioral change suggestions made by members at each group meeting. Despite these suggestions, we are unable to prove that the recommended suggestions were executed by group members. An improved approach could be having each member set SMART (specific, measurable, attainable, relevant, timely) goals prior to leaving the meeting and to check in on progress with each member preceding each meeting.

Our quantitative findings were based on 20 patients in CHMG, we excluded 20 patients and support people who were not in the CHMG system. Thus, there may be patients who may have shown change in quantitative measures that we could not capture. The social support
network of members who attended three plus peer meetings showed an increase in social support through the information characteristic with the group. The evaluation measures for the social network were chosen to capture the complexity of change within a new environment. These approaches have been shown to be validated assessment tools under conditions of complexity during the developmental stages of an initiative. This is also consistent with a prior study that shows correlation between increase in social support and improved diabetic outcomes over time.

The data is limited due insufficient data points on some patients making it difficult to establish a statistical process control baseline. This may have impacted our ability to show statistically significant change. The support network evaluation, although not validated, was created based on current evidence on social support and its impact on diabetic outcomes. We understand causality cannot be delineated with qualitative findings and factors associated. The strengths of our study include the use of PD and CHCM to develop a coproduction intervention for complex diabetic care. We had no funding, the project costs were low as the study was volunteer run. This project made an impact on patients and their support persons lives by empowering them as documented by our qualitative findings. Additionally, the group impacted health system through ‘Bring your support person’ initiative first at EFM and then through a campaign for the entire health system. They also impacted the community through a state-wide conversation related to healthy food access in New Hampshire food banks. The learnings related to a low cost process for developing coproduction in healthcare, pragmatic behavioral habits identified by the group, innovative care processes of including support people in office visits and awareness of healthy food access in food pantries are generalizable.

**Conclusion**

PD and CHMD approaches focused on personhood and empowerment of patients and their support people can be applied to generate: coproduction initiatives to flatten hierarchy, creative solutions to individual behavioral struggles and to address health system inadequacies in addition to filling community gaps to achieve health.

**Funding**

The study was volunteer run.
References

Table 1 Qualitative group interview identified categories and key patterns

<table>
<thead>
<tr>
<th>Peer support</th>
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<td>Peer-led group</td>
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<td>Medical-led group</td>
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<th>Support system</th>
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<td>Medical is expert</td>
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<th>Role of medical team</th>
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<td>Medical is expert</td>
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Core principles of positive deviance and Citizen Health Care Model

Positive Deviance (PD)

- solutions to complex problems already exist within each community and community members possess wisdom that can be harnessed to improve the performance of other community members
- wisdom is derived from within the context and from local resources that exist in the community.

Citizen Health Care Model (CHCM)

- the greatest underutilized resource for improving healthcare is the knowledge, wisdom and energy of individuals, families and communities who face challenging health issues
- people must be engaged as co-producers of healthcare for themselves and their communities not only as patients or consumers
- professionals can play a catalytic role in fostering citizen initiatives after developing skills as citizen professionals in groups with flattened hierarchies
- an initiative that is *owned and operated* by citizens rather than an established program
- local communities must bring their historical, cultural and religious traditions of health and healing into dialogue with contemporary medical systems

a courageous vision, e.g. a big, hairy, audacious goal (BHAH)
Appendix B

Dear <<PATIENT NAME>>: Your <<CHMG PRACTICE NAME>> provider encourages you to bring a support person to your upcoming appointment on <<DATE>> at <<TIME>>. This person may be your spouse, partner, friend or family member — anyone you trust to help and support you in managing your health effectively. Your provider, <<PROVIDER NAME>>>, firmly believes in the value a support person plays in helping you manage your medical condition(s) successfully. Simple acts of support like helping you with food shopping and preparing healthy meals, asking your provider questions you may not think of or assisting you with your medication schedule, have been shown to help patients with chronic conditions meet their health goals. For this reason, we hope you will bring a person of your choosing to your upcoming appointment.
Appendix C  
Stakeholder engagement within New Hampshire to increase healthy food donations in local food banks

Food Insecurity Tool Kit  
Courtesy of: Medicine and Public Health Task Force

**Food Security** is built on three pillars: **food availability** – sufficient quantities of food available on a consistent basis, **food access** – having sufficient resources to obtain appropriate foods for a nutritious diet, and **food use** – appropriate use based on knowledge of basic nutrition and care, as well as adequate water and sanitation.  
– World Health Organization

A Cautionary Paper About Food Pantries & Chronic Illness

1. What are food pantries?

There are a lot of different places where people in need can get food. You may hear of food banks, food pantries, and other food resources. Ultimately, these organizations are there – often operating on minimal resources and the kindness of donation – to supply food to those without, with the best variety they can manage.

Sometimes, they get amazing things to offer – fresh eggs, gleaned produce, etc. But far and away, they are dependent upon donations, what moves from the shelves, and what keeps well as they have to warehouse and distribute the goods.

2. Why should I know about what food banks and pantries carry?

For a variety of reasons, food banks and food pantries have stayed out of informing and guiding toward “healthy” foods. For one, it would require an extra layer of nutritionally-aware and certified staff, and these organizations and pantries operate on their own, with reliance on donations, grants, and government money. Also, it would mean guiding those who use these services to one good over another – which doesn’t align well with the current warehousing model. It is not that these admirable organizations don’t want to contribute to healthier offerings – but they are donation-dependent, often infrastructure-isolated, and work with the offerings and product sustainability they can obtain.

For these and similar reasons, food pantries actively de-medicalize their offerings. They do not guide people toward “healthy” options. They even, in some circumstances, have patrons sign a waiver, signing away responsibility for what might happen from consumption of what they procure.

We in the medical community can help make this better! First, in identifying our food insecure patients. But then, to make a difference in their security, we need to not only find patients available food, but then give tools to choose and use that food in a wise, healthy manner. Highly preserved and salted foods – e.g. boxed potatoes and pastas – can be available and necessary sustenance for our patients who, at a baseline, need calories. But these foods can also harm patients with chronic diseases such as congestive heart failure and diabetes. Can they find healthier options, and can they use them? Our words can make a difference.

3. What can we do?

We can do so much, built on the foundation of our patients’ stories. Actively work in our communities to discover ways to help food pantries – partner with them², and provide that health insight – and lobby to get better resources (such as refrigeration for fresh produce and eggs) out into the communities. New Hampshire has 225 listed Food Pantries, listed here: [http://nhfoodbank.org/agency-listings.aspx](http://nhfoodbank.org/agency-listings.aspx). Reach out, see if you can understand the food landscape more deeply.

The budget WIC ingredients, and many more – find these and bring them to your patients. Engage your local dieticians in helping your health community. Access is important, but making these right choices will allow our patients to live happier lives, bring community resources and farming closer to bear, and ultimately enhance our ability to relieve chronic disease.
Appendix D
Developed pre and post social network questionnaire

<table>
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<tr>
<th>Your Name:</th>
<th>What type of relationship do you have with this person? Write all letters that apply: Friend (FR) Family (F) Spouse/Partner (P) Healthcare Provider (HC) Diabetes Group Member (GM) Diabetes Group as a Whole (DMG) Other (Please list)</th>
<th>On a scale of -3 to +3 how supportive is this person?</th>
<th>What type of support do they provide? Write all letter(s) that apply: Emotional (E) Tangible (T) Example: Financial, material goods, services Informational (I) Companionship (C) Example: Shared sense of belonging, companion for shared social activities</th>
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<td>Date:</td>
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<td>If a person came with you to the meeting write their name:</td>
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<td>Please list up to 10 names of people who support you (or your partner) in some way related to diabetes:</td>
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Fig. 1 Analysis of means comparing patient volume of complex diabetics in each clinic within the Concord Hospital Medical Group system.
Fig. 2 Patient identification using positive deviance process for coproduction group development
Fig. 3 Statistical process control data on sample patients

Panel A1 Patient 1 overview chart

Panel A2 Patient 1 Weight X-MR chart

Panel A3 Patient 1 Systolic blood pressure X-MR
Panel B1 Patient 2 overview chart

Panel B2 Patient 2 Weight X-MR chart

Panel B3 Patient 2 Systolic blood pressure X-MR chart

Significant changes in measures evaluated in SPC charts and annotated in chart
Panel C1 Patient 3 overview chart

Significant changes in measures evaluated in SPC charts and annotated in chart.

Panel C2 Patient 3 Weight X-MR chart

Panel C3 Patient 3 Systolic blood pressure X-MR chart

Significant changes in measures evaluated in SPC charts and annotated in chart.

as of 2/17 weight loss of 12 lbs
Fig 4. Pre-and-post social network support analysis on three patients who attended at least three group meetings

Panel A Pre-Survey

Panel B Post-Survey