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Publication Date

2020

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Patient and Team Experiences of Team-based Primary Care

by
Laureen M. Bauer

DISSERTATION
Submitted in partial satisfaction of the requirements for degree of
DOCTOR OF PHILOSOPHY

in

Nursing

in the

GRADUATE DIVISION
of the
UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

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Acknowledgements

First and foremost, I want to thank my advisor, Dr. Ruth Malone, whose expert guidance was essential to this work. For the past two years, I have had the pleasure of regularly meeting with Ruth to discuss and interpret my data. Her continual encouragement of me to think deeply, to “unpack,” and to find, “in what world this makes sense” led to richer work than I could have ever created on my own. She always had that perfect touch to inspire and push me “onward.” I will forever be grateful for her guidance and inspiration.

Thank you to Dr. Patricia Benner, for her scholarly work that introduced me to the world of interpretive phenomenology. Her research and publications had a profound influence on this work and that of my current professors. I also would also like to thank the other UCSF faculty that I’ve had the privilege to learn from: Dr. Susan Chapman for agreeing to accept me as an advisee and for skillfully guiding me through my qualifying exam; Dr. Catherine Chesla for planting the seed that led to a deep love of qualitative research; and to Drs. Roberta Rehm and Janet Shim, who steered me through my early efforts to conduct qualitative research. I’m also grateful for my fellow students: Meg Martin, Linda Bawua, Ariel Baria, Debra Hemmerle, and Daniel Linnen, our small but mighty PhD cohort, for being supportive to me and each other over the years.

I’m deeply grateful for the primary care clinic leadership, teams, and patients who participated in this study. I so appreciate their openness and honesty as they shared with me their heartfelt and personal stories. If this dissertation strikes a cord with readers, it is the richness of their narratives that have made this work so meaningful.

Special thanks to Dr. Thomas Bodenheimer, for supporting my career and showing me new ways to imagine a transformed primary care system. I am grateful to have had the privilege

of working with him, along with the exceptional team at UCSF's Center for Excellence in Primary Care: Dr. Kevin Grumbach, Rachael Willard-Grace, Amireh Ghorob, and Dr. Danielle Hessler. This work draws on the excellent foundation that they have built.

And finally, I want to thank my family and friends who went along with me on this journey. To my many friends who have encouraged me, and have always been there for a bike ride or a workout. A special shout out to Bridget Quinn for her encouragement, support, and advice on how to develop a writing practice. I'm grateful for my sons, Scott and Will Bauer, and my daughter-in-laws, Audrey Nguyen and Amber Richard, for never doubting that I would finish. Thank you to my parents, Les and Mary Meier, who were always there for me, and who told me that I could do anything I put my mind to. But most of all, I want to thank my one and only, my life partner, Doug Bauer, who has been my biggest cheerleader. Thank you for believing in me and supporting me.

Funding Acknowledgements

This dissertation was supported by:

- The University of California, San Francisco Graduate Dean's Health Science Fellowship
- Fletcher Jones Fellowship, University of California, San Francisco
- Julius R. and Patricia A. Krevans Fellowship, University of California, San Francisco
- Sigma Theta Tau International, Alpha Eta Chapter – Dissertation Funding Support
- Graduate Dean's Dissertation Completion Fellowship – Dissertation Funding Support

The content is solely the responsibility of the author and does not necessarily represent the official views of any of the funding agencies.

Patient and Team Experiences of Team-based Primary Care

Laureen Bauer

Abstract

Purpose: The purpose of this multi-sited, interpretive phenomenological study was to explore the team-based care experience for patients with type 2 diabetes and their primary care teams.

Background: Over a decade ago, policy makers began to sound the alarm about an impending workforce crisis in primary care. This crisis endures today, as the supply of primary care providers has not kept up with the high demand from population growth, and an aging population with high rates of chronic disease. Primary care workforce and delivery issues are magnified in the care of patients with chronic conditions, particularly patients with type 2 diabetes.

Consequently, patients report frustration with the care they receive, their inability to receive timely access to a primary care provider, and the rising costs that they increasingly share. As primary care workload complexity and demand increase, primary care practices are restructuring to team-based models of care by including interdisciplinary members such as registered nurses, pharmacists, behavioral health specialists, health educators, medical assistants, community health workers, and health coaches on the team. While there is ample and growing evidence of the benefits of team-based care, specifically for patients with type 2 diabetes, little is known about how patients experience team-based care or how it impacts engagement with their care.

Methods: An interpretive phenomenological approach was used to explore this issue within a purposive sample of clinics (n=5) selected to represent different types of primary care and team settings. Forty-one participants from the 5 clinics were recruited, including 17 patients with diabetes, 6 primary care providers (physicians, nurse practitioners, physician assistants), 2 clinic administrators, 4 registered nurses, 2 health educators/wellness coaches, 8 medical assistants and

2 front desk representatives. Four data collection strategies were triangulated: individual semi-structured interviews with clinic patients, team focus groups, targeted observations of team-patient and team interactions; and clinic documents. Interviews were recorded, transcribed and analyzed using an interpretive approach.

Results: The majority of patients experienced team-based care as an enhanced sensation of support: like a family, a net, a support, or a feeling of being surrounded. Team members provided an authentic, nurturing presence for patients to express their suffering, challenges, frustrations and confusions. Patients felt that they entered into a caring community where they felt understood and those caring for them were “there for them.” Team members felt equally supported by a team environment through mutual learning, a shared awareness of patient care responsibilities, and an enhanced sense of joy in practice. Barriers to patients’ engagement with teams include team conflict, poor team communication and organization, inadequate staff training and overly complex or large teams. Several critical practices of high-performing health care teams were revealed: shared commitment (to each other and to their patients), value and care of teammates, mutual learning, trust in each other to perform their roles in the team and strong inter-team communication.

Conclusion: This research provides important insights into the experience of team-based care from within the teams’ and patients’ worlds to highlight what patients value in their health care experience, and how team-based primary care may provide a means to achieving greater patient engagement and satisfaction with their care, while sustaining a more fulfilled and joyful primary care workforce.

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Chapter 1

Introduction and Background

Over a decade ago, policy makers began to sound the alarm about an impending crisis in primary care (Bodenheimer, 2006). This crisis endures today, as the supply of primary care providers has not kept up with the high demand from population growth, and an aging population with high rates of chronic disease (American Association of Medical Colleges, 2015; Schwartz, 2012; Petterson et al., 2012). Patients are frustrated with the care they receive, their inability to receive timely access to a primary care provider, and the rising costs that they increasingly share. These factors continue to concern policy makers today as evidenced by the numerous health care proposals dominating the political landscape.

Primary care workforce and delivery issues are magnified in the care of patients with chronic conditions. One in six of all adults in the U.S. have at least one chronic condition contributing to 70% of all deaths in 2014 and comprising 90% of annual U.S. health care expenditures (Center For Disease Control, n.d.; Raghupathi & Raghupathi (2018). Chronic disease care that is poorly coordinated and managed results in high disease burden, mortality and health care costs (Anderson & Horvath, 2004).

This study focuses on the experiences of patients with a common chronic disease - type 2 diabetes. Diabetes prevalence in the U.S. has significantly increased in the past 30 years, impacting over 34 million adults at a cost of nearly \$245 billion per year (Center for Disease Control [CDC], 2020; American Diabetes Association, 2013). An increasingly aging and diverse U.S. population, high obesity rates, and lower diabetes mortality rates contribute to a projected increase in diabetes prevalence from 9% in 2012 to as high as 30% by 2050 (Boyle, Thompson, Gregg, Barker, & Williamson, 2010; Center for Disease Control [CDC], 2020).

Type 2 diabetes was chosen as a focus of the study because it is a highly prevalent

chronic disease that requires frequent contact with the health care system and incurs significant national, state and personal costs. Health care providers, administrators, governmental and private payers, and policy makers are struggling to find ways to care for this ever-growing population within the already strained U.S. primary care system. One solution to the impending shortage of primary care providers and the high cost of chronic disease care is the adoption of team-based models of primary care.

New Models of Primary Care

There has been a growing awareness over the past 30 years of the challenges that primary care providers face to provide all the necessary care for their patients with chronic disease (Ostbye et al., 2005; Yarnall et al., 2009). Research conducted in the 90's revealed that providers were not following guidelines for optimal clinical care of these patients (Wasson, et al., 1992; Cohen, Tripp-Reimer, Smith, Sorofman & Lively, 1994). This was attributed to the culture and structure of medical practice, which is oriented to acute patient needs, and the limited time providers have to meet all the clinical and self-management needs of patients with chronic disease. Providers recognized that patients with chronic conditions not only needed appropriate clinical care, but also support to help them manage their illnesses, adhere to recommended treatment and engage in health promoting activities such as exercise and healthy nutrition. A traditional 15-minute primary care visit is not sufficient to address all the behavioral, social and psychological needs of chronically ill patients and their caregivers (Saba, Villela, Chen, Hammer, & Bodenheimer, 2012).

In the mid 1990s, policy makers proposed a new approach to improve how patients with chronic disease receive their care: The Chronic Care Model (Wagner, Austin, & Von Korff, 1996). Wagner (1996) noted that to effectively manage patients with chronic disease, patients

needed to receive appropriate clinical care as well as assistance coping with and managing their illness. This novel way of delivering care required restructuring existing primary care practices with an emphasis on team-based care, patient self-management support, and clinical information systems designed for population health management and decision support (Figure 1.1).

The Chronic Care Model was developed in response to the failure of typical primary care systems in supporting patients' self-care management. Health care providers were often too rushed to assess patients' ability to function and their understanding of their illness or to provide them with the information or supportive services they needed. The model described four essential patient engagement, or self-management tasks that patients needed to do to achieve successful outcomes: 1) engage in activities that promote health (e.g. exercise, nutrition, stress management, sleep), 2) interact with health care providers and systems and adhere to recommended treatment, 3) self-monitor physical and emotional states and make appropriate self-management decisions, and 4) manage the impact of their illness in the day to day reality of work and relationships (Wagner, Austin & Von Korff, 1996).

Researchers found compelling evidence that interventions based on components of the Chronic Care Model improved process and outcome measures for patients with diabetes (Bodenheimer, Wagner, & Grumbach, 2002b). The Chronic Care Model describes a redesigned system of primary care in which an informed, "activated" patient interacts with a prepared, proactive practice team supported by a health care system that is organized to support the patient. Activated patients have the knowledge, skills and confidence to manage and participate in their own health to self-manage symptoms and problems; engage in healthy lifestyle activities; be involved in shared treatment decision-making; collaborate with providers and the health care team; make informed health care choices based on performance or quality; and navigate the

health care system (Bodenheimer, Wagner, & Grumbach, 2002a; Hibbard, Stockard, Mahoney, & Tusler, 2004).

Building on the Chronic Care Model, in 2007 four major primary care physician organizations developed and endorsed the Joint Principles of the Patient-Centered Medical Home (PCMH) (Kellerman & Kirk, 2007). This model of primary care promoted seven care attributes: enhanced access, continuity, comprehensiveness, team-based care, care coordination and management, a systems-based approach to quality and safety, and reimbursement reform (Arend, Tsang-Quinn, Levine, & Thomas, 2012). In 2008, the National Committee for Quality Assurance (NCQA) and several other organizations started medical home accreditation programs. The Commonwealth Fund (2014) launched the five-year Safety Net Medical Home Initiative funding 65 community health centers to redesign their practices into patient-centered medical homes. The passage of the Patient Protection and Affordable Care Act (ACA) in 2010 provided significant funding for medical home demonstration projects, workforce development and training, and primary care delivery innovations (Blumenthal, Abrams, & Nuzum, 2015).

The PCMH movement gained momentum across the country, particularly with health maintenance organizations, federally qualified community health centers, the Veterans Health Administration, and private integrated delivery systems such as Group Health and Geisinger Health, who had payment mechanisms to support many of the PCMH transformations. Since the initiation of PCMH accreditation, more than 13,000 practices have received NCQA recognition, with more than 100 payers supporting NCQA recognition through financial incentives or coaching (National Center for Quality Assurance, n.d.).

NCQA's checklist approach to the PCMH recognition process has been criticized for being overly prescriptive and not necessarily leading to the fundamental changes that primary

care practices need to make to achieve gains in improved quality, patient experience and reduced cost. The evidence on patient-centered medical homes' impact on quality outcomes and cost reduction is mixed, ranging from no association with changes in quality (Fifield, Forrest, Burleson, Martin-Peele, & Gillespie, 2013; Friedberg, Schneider, Rosenthal, Volpp, & Werner, 2014); insufficient evidence to determine effectiveness (Hoff, Weller, & DePuccio, 2012; Jackson et al., 2013; Peikes, Zutshi, Genevro, Parchman, & Meyers, 2012); modest improvements in quality (Kern, Edwards, & Kaushal, 2014, 2016; Solberg, Asche, Fontaine, Flottemesch, & Anderson, 2011); and significant associations with improvement in care (Driscoll et al., 2013; Reid et al., 2010). Clearly, even with attempts to standardize the process of PCMH transformation and recognition, there is a wide variation in redesign success.

In 2010, in an effort to understand the essential elements for successful primary care transformation, investigators from UCSF's Center for Excellence in Primary Care (CEPC) conducted a review of 23 high-performing primary care practices throughout the United States. From studying these exemplary practices, they developed a model (10 Building Blocks of High Performing Primary Care), which describes the main elements of transformation necessary for improved clinical outcomes and patient satisfaction (Figure 1.1) (Bodenheimer, Ghorob, Willard-Grace, & Grumbach, 2014). These building blocks incorporated Starfield's (2005) four pillars of primary care (first-contact care, continuity of care, comprehensive care, and coordination of care), and the Joint Principles and PCMH recognition standards. Team-based care is a foundational element of the model, and teams are considered essential to be able to deliver all the care required for patients with chronic disease. Through their study of exemplar practices, the researchers found that many practices added capacity by using well-trained non-clinicians who shared in many routine chronic care tasks. This involved all members of the team

working to the top of their licensure or education to proactively care for patients. New payment models that reward value (improved patient outcomes at reduced costs) instead of volume (visits, lab tests, or procedures) were introduced to support the adoption of team-based care (Haas & Swan, 2014).

Team-based Care Workforce

Just as the introduction of the Chronic Care Model caused a paradigm shift in care for patients with chronic disease, the team-based feature of the 10 Building Blocks model fundamentally changes concepts of the primary care workforce, organizational structures and payment. Team-based care is defined by Naylor and colleagues as:

the provision of health services to individuals, families, and/or their communities by at least two health providers who work collaboratively with patients and their caregivers—to the extent preferred by each patient—to accomplish shared goals within and across settings to achieve coordinated, high-quality care (Mitchell et al., 2012, p. 5).

Historically, family physicians and general internists practiced adult primary care (Saba et al., 2012), but during the past 50 years, the new professions of nurse practitioners (NPs) and physician assistants (PAs) emerged. These professionals are now practicing in nearly half of all U.S. physician offices (Peterson, Phillips, Puffer, Bazemore, & Petterson, 2013). As the U.S. primary care physician workforce declines (U.S Department of Health and Human Services, 2016; IHS Inc., 2017; American Academy of Family Physicians, 2013), the number of NPs entering the workforce each year is projected to increase by 84% between 2010 and 2025 (Auerbach, Staiger, Muench, & Buerhaus, 2013), with roughly half of NPs currently working in primary care settings (Spetz, Fraher & Bates, 2015). The number of PAs entering the workforce is also growing, although less rapidly (Auerbach et al., 2013). If these trends continue, the proportion of primary care practitioners who are physicians will drop from 71% in 2010 to 60% in 2025, as the proportion of NPs will jump to 29% and continue to rise (Bodenheimer & Bauer,

2016). A cross-sectional analysis of Medicare claims found that patients with type 2 diabetes cared for by NPs had significantly improved outcomes compared with primary care groups staffed solely by physicians, suggesting that NPs are providing high quality diabetes care as primary care providers (Lutfiyya et al., 2017). In this manuscript, the phrase “primary care provider” (PCP) refers to primary care physicians as well as NPs and PAs who are authorized to diagnose and treat, who can bill for their services, and function as the team leader for a panel of patients.

As primary care workload complexity and demand increase, primary care practices are restructuring to team-based models of care by including interdisciplinary members such as registered nurses, pharmacists, behavioral health specialists, health educators, medical assistants, community health workers, and health coaches on the team (Saba et al., 2012). Collectively, the health care team is empowered through systems and processes that allow team members to work to the top of their licensure, education or training to proactively care for a panel of patients. These processes include co-location of team members, setting team goals, mapping team workflow, clarifying team expectations, communication through team meetings and huddles, and developing standing orders or standardized procedures (Ghorob & Bodenheimer, 2012).

Patients with diabetes and depression or other mental health issues have poorer self-care (Lin et al., 2004), more diabetes-related complications (Lin et al., 2010), higher number of diabetes related hospitalizations (Chwastiak et al., 2014), and higher mortality (Park, Katon, & Wolf, 2013) than patients with diabetes alone. There is also growing recognition of the benefits of collaborative care for patients with type 2 diabetes and co-occurring mental health issues (Chew, Vos, Metzendorf, Scholten, & Rutten, 2017; Hunter et al., 2018). Stroschal (1998) defines collaborative care as behavioral or mental health providers working with primary care,

and integrated care as behavioral health working within primary care, as a part of the primary care team. Integrated behavioral health interventions are also being successfully implemented using behavioral health specialists or integrated care managers on primary care teams to work with patients with depression or complex behavioral health disorders to improve medication adherence (Bogner, Morales, de Vries, & Cappola, 2012), to improve glycemic control for patients in safety net settings (Chwastiak et al., 2017), and to reduce depressive symptoms (Johnson et al., 2014).

Registered Nurses

Nursing practice in the United States has deep roots in the provision of primary care, as illustrated by Lillian Wald's visits to poverty-stricken European immigrants in lower Manhattan at the beginning of the 20th century, and the visiting nursing services provided to underserved populations in rural areas through the American Red Cross and the U.S. Public Health Service (Buhler-Wilkerson, 1993; Keeling & Lewenson, 2013). After many years where the majority of registered nurses worked in hospitals, there is a renewed interest in the value of registered nurses working in primary care settings (Bauer & Bodenheimer, 2017; Bodenheimer & Bauer, 2016).

The 3 million RNs in the United States represent the country's largest health profession, which is projected to grow by 15% between 2016 and 2026, positioning RNs to assume greater roles in primary care settings (Smiley et al, 2018; U.S. Bureau of Labor Statistics, n.d.). RNs are providing three important emerging primary care functions: managing the care of patients with chronic disease (e.g. hypertension and diabetes) by helping them with behavior change and adjusting their medications according to physician-written protocols; leading complex care management teams to help improve and reduce the cost of care for patients with multiple diagnoses who are high users of health care services; and coordinating care between the primary

care home (also known as the patient-centered medical home) and providers of other health care services (Bodenheimer, Bauer, Syer, & Olayiwola, 2015).

When caring for patients with type 2 diabetes, registered nurses often assume the role of care manager to provide patient education, self-management and medication support. In 2015, a total of 43% of U.S. physicians worked with registered nurse (RN) care managers for patients with chronic conditions (Osborn et al., 2015; Spetz, Fraher, Li, & Bates, 2015). In a systematic review of 41 interventions to improve the management of diabetes in primary care, researchers found that the involvement of a nurse care manager was associated with improved clinical outcomes, and the studies in which nurses partly replaced physicians in providing diabetes care demonstrated a positive impact on glycemic control. (Renders et al., 2001). A review of RN care managers in primary care found equivalent or better outcomes of care in patients working with nurses rather than primary care providers (Watts & Lucatorto, 2014). Other studies demonstrating improved diabetes outcomes associated with the involvement of registered nursing care include interventions such as motivational interviewing regarding diet, exercise and weight loss (Aneltiangco, Adelman, Dellasega, & Gabbay, 2012); in-person and telephonic self-management support (Katz, Mesfin, & Barr, 2012); insulin initiation and protocol based titration (Blackberry et al., 2014; Capaldi, 2007; Swanson et al., 2015); administering diabetes protocols for glucose, blood pressure and cardiovascular risk control (Cleveringa, Gorter, Van Donk, & Rutten, 2008; Kengne et al., 2009); and support for medication adjustment and adherence (Farmer et al., 2012; Lin et al., 2012).

Pharmacists

As the burden of diabetes care continues to strain the primary health care system, primary care providers find the support of pharmacists to be particularly effective in the care of patients

with type 2 diabetes (Smith, Bates, Bodenheimer, & Cleary, 2010). The initiation of the pharmacy doctoral degree (Smith, 2007) has facilitated a role that expands beyond dispensing medications and counseling on adverse effects to include initiating and managing insulin therapy (Rochester, Leon, Dombrowski, & Haines, 2010; Sisson & Kuhn, 2009), managing medications for patients with high A1C or severe insulin resistance (Hess, Brandon, & Johnson, 2016), supporting other team members such as community health workers (Rojas, Gerber, Tilton, Rapacki, & Sharp, 2015), and assuring patients are following recommended protocols for cardiovascular disease risk reduction (Gee, Rodriguez, Ramirez-Estrada, & Lin, 2014).

The addition of pharmacists on primary care teams has been shown to improve clinical outcomes for patients with type 2 diabetes (Wubben & Vivian, 2008). A systematic review of pharmacist interventions to manage type 2 diabetes showed a greater reduction of A1C (a blood test that measures average blood glucose levels in the preceding 3 months), improvements in systolic and diastolic blood pressure, and a reduction in 10-year coronary heart disease risk when compared to usual care without a pharmacist intervention (Pousinho, Morgado, Falcao, & Alves, 2016). A study of HMO patients reported that patients managed by a team that included a pharmacist were nearly four times more likely to attain A1C goals, and twice as likely to achieve low-density lipoprotein (LDL) cholesterol goals or blood pressure reduction than usual care (Ip et al., 2013). Hess et al. (2016) found that pharmacist interventions were particularly effective for patients with severe insulin resistance, decreasing A1C from 9.7% to 8.6% after 6 months of follow-up (normal A1C is less than 5.7%; diabetes is diagnosed at greater than 6.5%). A 10-year Kaiser evaluation of the cost effectiveness of pharmacists on the primary care team found that adding pharmacists to the team improved long-term care management and reduced costs of care for patients with type 2 diabetes (Yu, Shah, Ip, & Chan, 2013). Several evaluations of

pharmacists' effectiveness in improving medication adherence, however, showed mixed results (Antoine, Pieper, Mathes, & Eikermann, 2014; Kocarnik et al., 2012; Mino-Leon, Reyes-Morales, & Flores-Hernandez, 2015).

Diabetes Health Educators

Diabetes health educators, health care professionals who focus on helping people with diabetes achieve behavior change goals through self-management education, are increasingly found on health care teams. They work collaboratively to help people with diabetes gain the knowledge and skills to modify their behavior to improve their health (Boren, Fitzner, Panhalkar, & Specker, 2009). In the United States, a certified diabetes educator can be a clinical psychologist, registered nurse, occupational therapist, optometrist, pharmacist, physical therapist, physician (M.D. or D.O.), or podiatrist holding a U.S. license; a dietician or nutritionist, certified exercise physiologist, or certified health education specialist; or a health professional with a master's degree in social work meeting the professional experience and examination requirements for certification by the National Certification Board for Diabetes Educators (n.d.).

Diabetes educators have additional training and expertise to assist patients in developing knowledge, skills and confidence to manage their diabetes through improved nutrition, increased physical activity, blood glucose self-monitoring, medication management, and insulin therapy initiation and support. They often are able to spend more time with patients than primary care providers or other team members who assist with the daily patient schedules (Gucciardi, Espin, Morganti, & Dorado, 2016).

Diabetes self-management education provided by diabetes health educators or nutritionists has been shown to be a cost effective way to assist patients to improve health behaviors (Boren et al., 2009; Ellis et al., 2004; Gary, Genkinger, Guallar, Peyrot, & Brancati,

2003; Mitchell, Ball, Ross, Barnes, & Williams, 2017; Norris, Lau, Smith, Schmid, & Engelgau, 2002; Yamashita, Kart, & Noe, 2012) and health outcomes such as improved glycemic control, lipids, and blood pressure (Chomko, Odegard, & Evert, 2016; Mitchell et al., 2017; Moller, Andersen, & Snorgaard, 2017). Robust diabetes education programs are being systematically implemented in Canada's single payer health system (Gucciardi et al., 2016), as well as throughout Europe (Hurley et al., 2017), but are still only accessed by one-third to one-half of patients with diabetes in the U.S. due to lack of insurance coverage, lack of available trained educators and clinic and patient logistical barriers (Peyrot, Rubin, Funnell, & Siminerio, 2009).

Medical Assistants

There has been considerable interest in the role of medical assistants (MAs) in primary care teams (Bodenheimer & Laing, 2007; Bodenheimer & Willard-Grace, 2016; Bodenheimer, Willard-Grace, & Ghorob, 2014; Chapman & Blash, 2017; Sheridan et al., 2016). Medical assistants are an ethnically and racially diverse and growing workforce in the United States, projected to increase 29% by 2026 (U.S. Bureau of Labor Statistics, n.d.; Snyder, C., Frogner, B., & Skillman, S., 2018), faster than many health care professions (Chapman, Marks, & Dower, 2015). Medical assistants are unlicensed personnel who work under the license of a physician and possess either a certificate or high school diploma combined with on-the-job training. Medical assistant scope of practice varies by state, but typically includes the ability to provide information to patients from pre-approved sources and follow physician-approved protocols with training and supervision (Dower, 2013).

For diabetes care, newly expanded roles for medical assistants include panel management and self-management support through health coaching. As panel managers, they often work with diabetes registries to identify care gaps such as overdue laboratory tests for A1C or lipid panels

(Sequeira, McNamara, Yang, D'Afflitti, & Mishuris, 2016; Van der Wees, Friedberg, Guzman, Ayanian, & Rodriguez, 2014), or conduct outreach to patients who do not present for care.

Medical assistants, often working in small teamlets (pairs) with primary care providers (Bodenheimer & Laing, 2007), also prepare providers for the patient visits by highlighting and communicating the patient care gaps, such as missing preventative screenings or vaccinations, when patients present for their primary care visits.

The American Association of Diabetes Educators (AADE) (2011) recognizes the value of non-licensed professionals, such as medical assistants, to provide diabetes education, self-management training, and support. Research has shown that trained medical assistants working as health coaches are effective in helping patients become prepared for goal setting with their primary care providers (Buhse et al., 2017), increase trust with their primary care providers (Thom et al., 2014), improve their chronic care experience and satisfaction with their care (Thom et al., 2015), and improve clinical outcomes such as glycemic control and LDL cholesterol (Willard-Grace et al., 2015). Medical assistants have the potential to expand outreach to underserved populations in low-resourced primary care practices through language concordance and shared racial, ethnic and cultural backgrounds, since they often come from the communities they serve (Ruggiero et al., 2014).

In a review of 15 case studies of expanded roles of MAs in primary care, Chapman & Blash (2017) identified additional MA roles as medical scribes, translators, health navigators, cross-trained flexible roles (such as phlebotomist or radiology technician), and supervisors. Implementation of these new roles often requires extensive training and salary compensation adjustments.

While research demonstrates the viability of medical assistants working in expanded roles in primary care, several studies highlight barriers to MAs being able to be fully utilized in these roles. Due to competing MA responsibilities during primary care visits, many practices find it difficult to allocate time for provider introductions or dedicated MA health coaching time (Sheridan et al., 2016; Van der Wees et al., 2014). Lack of standardized training and scope of practice consensus have also been barriers to expanded roles for medical assistants in primary care (Chapman, Marks, & Dower, 2015).

Community Health Workers

Community health workers, also known as health navigators and promotores, are increasingly employed in primary care settings to link patients and community members with clinical services, help with patients' economic, cultural and language barriers to reduce disparities in care, and promote positive health behaviors. Community health workers come from a wide variety of backgrounds and training (Chapman, Okwandu, Schindel & Miller J. (2016). As trusted members of the local communities, they have knowledge of cultural values, health beliefs and behaviors that can help reduce the impact of diabetes for patients from vulnerable populations working within the traditional health care system. They can help to increase health knowledge and patient-provider communication through outreach, education, culturally competent and tailored counseling and social support, health care navigation, and advocacy (Witmer, Seifer, Finocchio, Leslie, & O'Neil, 1995).

Community health workers are often incorporated into health care teams to engage patients with chronic diseases like diabetes to promote health behaviors and manage chronic conditions (Carey et al., 2014; DePue et al., 2013; Gary et al., 2009). They have successfully been trained to provide education on diabetes complications, healthy lifestyles, nutrition and

healthy food choices, blood glucose monitoring and medication adherence (Perez-Escamilla et al., 2015). There is growing evidence of the effectiveness of trained community health workers to provide self-management support for patients with diabetes to improve clinical outcomes (Babamoto et al., 2009; Collinsworth, Vulimiri, Schmidt, & Snead, 2013; Loskutova et al., 2016; McDermott et al., 2015; Norris et al., 2006; Otero-Sabogal et al., 2010; Perez-Escamilla et al., 2015; Spencer et al., 2011), although some studies have had mixed results (Chan et al., 2014; Gary, Bone, et al., 2003).

Peer Educators and Coaches

Peer educators and coaches are typically lay volunteers that have the same disease as the people they serve. Given the time intensive nature of self-management support, peer coaches have been proposed as a way to provide support to patients with type 2 diabetes within the existing time constrained primary health care system. Peer coaches share their experiences to provide practical, emotional and ongoing behavioral support (Boothroyd & Fisher, 2010; Fisher, Earp, Maman, & Zolotor, 2010), which have been shown to be important factors for sustained behavioral change for patients with type 2 diabetes (Brownson & Heisler, 2009; Satterfield, Burd, Valdez, Hosey, & Shield, 2002). There is evidence that peer support and coaching can improve clinical outcomes (Gatlin, Serafica, & Johnson, 2017; Lorig, Ritter, Villa, & Armas, 2009; Thom et al., 2013; Thom et al., 2014), self-efficacy and patient activation (Lorig et al., 2009).

Team-based Care's Impact on Quality

By using teams in primary care, administrators attempt to improve quality by maximizing the skill sets of clinicians and support staff in the practice. Highly trained physicians, pharmacists and registered nurses are used where needed, and non-licensed personnel provide

support where appropriate (Hopkins & Sinsky, 2014). The care team composition and methods for access to care can be customized to meet patient needs. For example, a person with poorly controlled diabetes might require more extensive and on-going monitoring (provided by a registered nurse or pharmacist), and/or self-management support provided by a peer health coach, medical assistant, or community health worker who has been trained in health coaching (Thom et al., 2013; Willard-Grace et al., 2015).

Team-based primary care shows promise to improve quality of care, reduce provider burnout, and increase patient experience and engagement, especially for patients with chronic diseases (Bodenheimer et al., 2014; Hopkins & Sinsky, 2014; Willard-Grace et al., 2015). An Australian study describes an inter-disciplinary team (consisting of an endocrinologist, diabetes educator, registered nurse, psychologist and podiatrist) delivering high quality care to patients with diabetes over twelve months, dropping their mean blood glucose levels significantly. The patients stated they felt included in their team, therefore increasing their morale and motivation to adhere to their medical plans (Hepworth, Askew, Jackson & Russell, 2013). Similar findings in hypertension management showed that a multidisciplinary team's approach and interventions positively impacted patients' adherence to medication and other psychosocial behaviors, thereby improving their blood pressure. The researchers saw a nearly 5% decrease in diastolic blood pressure compared to usual primary care after a 4 month team-based intervention (Kravetz & Walsh, 2016). In a study of 27 integrated practices in Utah, Reiss-Brennan and colleagues (2016) found that patients had a higher adherence to a diabetes care bundle and documentation of self-care plans in a team-based care model compared to usual care.

However, there is limited research about how team-based care is perceived by patients with chronic disease (Bodenheimer & Willard Grace, 2016). Patient experience is a primary

measure of patient-centered care and a cornerstone of high-quality care (Anhang Price et al., 2014; Institute of Medicine, 2001). Therefore, understanding patients with diabetes and their teams' experiences with team-based care may inform ways to improve practice, and develop policies that sustain and promote team-based care. This study seeks to understand the meaning of team-based care for patients with type 2 diabetes and how their experience of team-based care shapes their health care experience. This study will a) explore how patients with type 2 diabetes and their health care team perceive and understand team-based care, b) understand how the experiences influence patients' engagement with their care, and c) compare different models of team-based care and understand how the differing models impact the patient experience.

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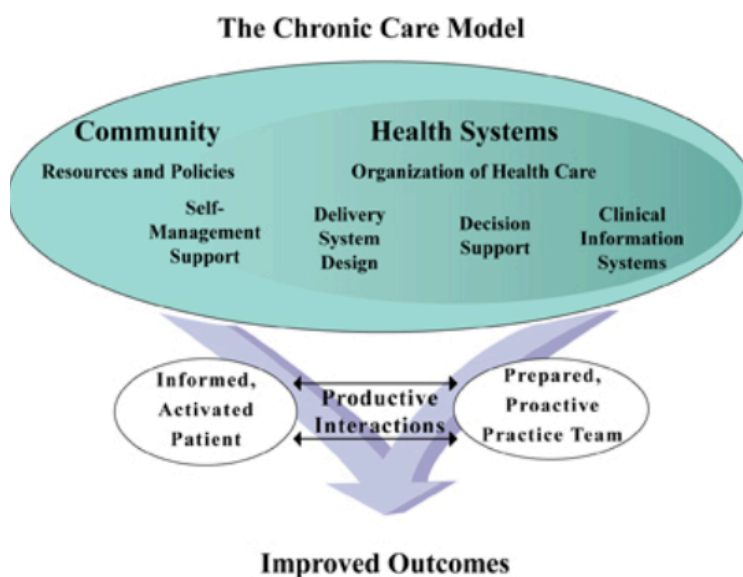
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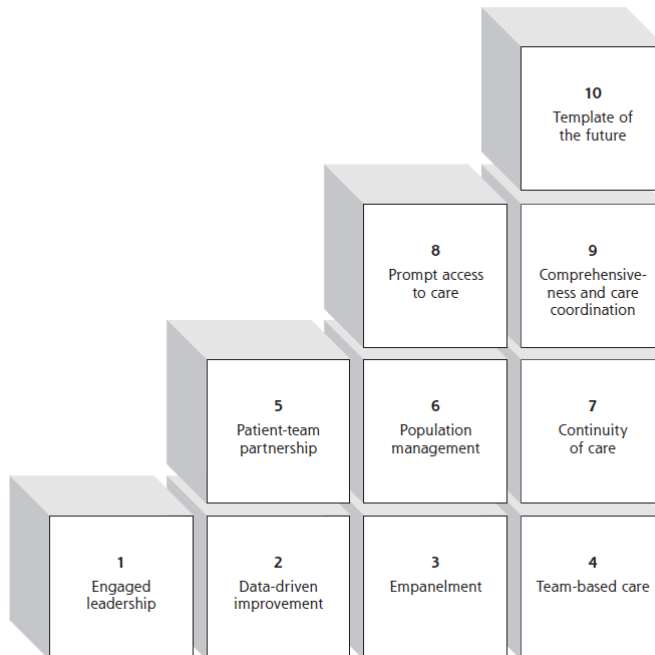
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The 10 Building Blocks of High Performing Primary Care



Bodenheimer, T., Ghorob, A., Willard-Grace, R., & Grumbach, K. (2014). The 10 building blocks of high-performing primary care. *Annals of Family Medicine*, 12(2), 166-171. doi:10.1370/afm.1616

Figure 1.1 New Models of Primary Care

Chapter 2

Patients' Experiences of Team-based Care in the Literature

While there is ample and growing evidence of the benefits of team-based care, specifically for patients with type 2 diabetes, little is known about how patients experience team-based care and how it impacts the engagement with their care. Patient experience is a primary measure of patient-centered care, which has been identified as one of six major dimensions of quality of care and a component of the Triple Aim of improving quality and patient satisfaction, population health, and reducing per capita cost of the U.S. health care system (Anhang Price et al., 2014; Berwick, Nolan, & Whittington, 2008; Institute of Medicine, 2001). Patient experience describes how patients interact with or “experience” the health care system, and is distinct from patient satisfaction, which focuses on patients reporting being “happy” or “satisfied” with their care, rather than experiences that occur or do not occur during a health care encounter. Research has shown that patient experience is associated with improved clinical outcomes, patient adherence to treatment, and loyalty to physician practices (Browne, Roseman, Shaller, & Edgman-Levitan, 2010).

Literature Review Methods

Search Terms

Five databases were used to conduct a literature review on team-based primary care for patients with type 2 diabetes: PubMed, Embase, CINHALL, Web of Science, and the Cochrane Database of Systematic Reviews. Multiple combinations of eleven MeSH and keywords—“primary health care”, “primary care”, “patient care team”, “team based care”, “interdisciplinary team”, “multidisciplinary team”, “team care”, team*, diabetes, and “diabetes mellitus, type 2” were used to conduct literature searches in the selected databases. A preliminary background search on team-based primary care in PubMed yielded more than 2100 articles. A more focused

search of the five databases with terms specific to team-based primary care for diabetes yielded 669 articles, with an additional 14 articles from reference lists and expert searches. Table 2.1 describes the literature search term used in each database and the corresponding results in detail. [Table 2.1: Search Terms Used in Team-based Primary Care for Patients with Type 2 Diabetes Literature Review].

Inclusion and Exclusion Criteria

Studies were included if all of the following criteria were met: (a) available in English full text, (b) included team-based care delivery for patients in primary care settings (c) targeted adults with type 2 diabetes and (d) demonstrated quantitative or qualitative empirical analysis. Articles were excluded if they described study protocols, treatment guidelines, specific therapies, medications or devices, evaluations of specific care delivery such as group visits, telehealth, virtual clinics, specialty or hospital-based care, non-type 2 diabetes (pre-diabetes, gestational diabetes, type 1 diabetes), physician, nurse-practitioner or physician assistant only practice settings, and medical education. After a review of titles, 234 articles met the inclusion criteria.

Literature Review Results

The results were categorized based the on abstract reviews. I focused on studies providing evidence of patients with type 2 diabetes experiences with team-based primary care, with the relevant remaining articles included as background context for concepts and themes. After full text review of 21 articles, the review ultimately includes 11 studies on patients with diabetes experiences of team-based primary care. The details of the study selection process are described in Figure 2.1 based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram by (Moher, Liberati, Tetzlaff, & Altman, 2010). [Figure 2.1 PRISMA Flow Diagram to Select Studies Included in the Literature Review]

Quality Appraisal

Table 2.2 shows the results of the quality appraisal using criteria adapted from the Integrative Quality Criteria for Review of Multiple Study Designs (ICROMS) tool (Zing et al, 2016). The ICROMS tool allows an evaluation of quality across different study designs for mixed study systematic reviews. Table 2.2 shows a summary of the methodological strengths and weaknesses of each study using a selection of the ICROMS criteria.

All of the studies included in the review were deemed of sufficient quality to be included in the review, and all of the qualitative reviews except one met the minimum mandatory ICROMS criteria of clear aims, and design and sampling appropriate to aims for qualitative studies. The study that did not meet the mandatory aim was a qualitative arm of a mixed method study with three open-ended questions, but was included because of the large sample size and quality of analysis (Dejesus, Vickers, Howell, & Stroebel, 2012). Because ICROMS criteria for cross-sectional studies have yet to be developed, I incorporated some additional quality criteria for these studies and highlighted their strengths and weaknesses.

Study Characteristics

Eleven studies met eligibility criteria for inclusion (Tables 2 and 3). Nine studies utilized qualitative methods (two of which were sub-studies of mixed methods studies with interviews or open-ended questions added to a survey), and two used cross-sectional descriptive surveys. Studies were conducted across five countries: United States (n=4), the U.K. (n=3), Australia (n=2), Germany (n=1) and Oman (n=1). The studies from the U.K. and Australia explored patient experiences after nationwide initiatives to transfer care from hospital-based specialty practices to primary care settings. The studies from Germany and Oman describe more traditional models with some elements of team care.

The team composition in the primary care settings was typically the primary care provider and a registered nurse or a medical assistant, with only several studies utilizing a full team of allied health providers. In general, the teams were not well defined, but in addition to the primary care providers, the most common team members mentioned were registered nurses (called practice nurses in the U.K. and Australia), health care assistants or medical assistants, diabetes educators or health educators, and care managers. Only one study assessed patient perspectives of full team care (Foster & Mitchell, 2014).

Discussion

Researchers explored the experiences of patients with type 2 diabetes in team-based primary care settings, and in some instances included both patients' and primary care providers' perspectives (Table 2.4). An overview of the major patient and provider themes related to patient experience with teams is described below.

Continuity, trust and rapport. Patients placed a high value on the relationships that they had with their primary care providers. Patients valued face-to-face time with a trusted professional through a continuous relationship (Långst et al., 2015). They valued the rapport that they had with providers, feeling that providers knew them as individuals. "It's the rapport, 'cause we talk about all sorts of things, motor cars, holidays, as well as my complaints...we've just got a good rapport, that's all" (Johnson, Baird & Goyder, 2006, p. 250). In an Australian integrated care model, trust in clinicians influenced how patients engaged with the clinic and their self-care. They valued seeing familiar clinic staff and considered it to be a benchmark of quality in their care (Lawton, Rankin, Peel, & Douglas, 2009). "They know me. They speak as if they've known you for a long time" (Burrige et al., 2017, p. 1035). Patients welcomed

positive and respectful clinician attitudes that were not prescriptive, alarmist or aloof and thought this enhanced engagement in their care.

The continuous relationships that patients had with their primary care providers helped ease the transition from specialist to primary care in the U.K. and Australian studies (Burridge et al., 2017; Lawton et al., 2009; Johnson, Baird & Goyder, 2006). However, some patients who had developed trusting relationships with specialists felt that this transfer to primary care represented inferior and less frequent care (Lawton et al., 2009). In a study of team care in Australia, while patients recognized that team care can be more thorough and reassuring and help relieve time pressure on their general practitioners (GPs), they feared it could have an impact on the quality of GP interactions (Foster & Mitchell, 2015).

Some studies also identified resistance to registered nurses taking on roles traditionally held by physicians, with some patients fearing that it would result in less contact or worsening relationships with their primary care provider (Dejesus et al., 2012; Lawton et al., 2009). Other patients formed strong bonds with diabetes nurse specialists who initiated them on insulin or helped them with fluctuations in glycemic control (Johnson, Baird & Goyder, 2006). Lawton et al. (2009) found that many patients saw advantages of receiving diabetes care from nurses who were perceived to be highly competent and “particularly approachable and able to give clear information and advice about diabetes and its management” (p. 139). They valued the opportunities to ask questions during clinical interactions of nurses that they hesitated to ask their time-pressured GPs.

Perceived competency. Patients with type 2 diabetes valued diabetes care provided by knowledgeable providers and staff. Some patients felt that primary care doctors and nurses did not have enough “specialized” knowledge in diabetes care (Abdulahdi, Al Shafae, Freudenthal,

Östenson, & Wahlström, 2007). In one U.K. study, some patients expressed frustration that good diabetes control meant they no longer received specialist care. They attributed this to the possible rationing of care due to the resource constraints in the U.K's National Health Service. Some patients felt valued that someone senior was investing their time with them and appreciated the attention they received. Other patients who transferred to primary care felt reassured that their care no longer warranted specialist care, meaning that their diabetes was under better control (Lawton et al., 2009).

Similarly, knowledge of diabetes management and chronic diseases in general were the most sought after qualities of a care manager for both patients and providers (Dejesus et al., 2012). Specific training in diabetes or a degree in a medical field were also high on the list of qualities looked for in care managers. Many considered registered nurses as a complement to a primary care provider, rather than a replacement, and felt reassured when they saw nurses discussing their case with their primary care providers (Lawton et al., 2009). When providing medication education, patients found health care assistants to be more approachable than their primary care providers, but felt that they did not have diabetes-specific knowledge regarding their medications. The assistants themselves expressed a need for more training to be able to take on greater responsibility in providing medication-related information (Längst et al., 2015).

Patient-clinician communication. Communication related issues with health care clinicians were seen as both enablers and barriers to perceived quality of diabetes care in primary care settings. A Mayo clinic study found that good communication skills were high on the list of the most valued characteristics of care managers (Dejesus et al., 2012). In a study exploring patients' perceptions of factors to enhance medication information provision (Längst et al., 2015), patients felt that tailored information using lay language in a stepwise and repeated way

that considered patients' resources and capacity enhanced medication education. Patients in integrated care practices in Australia highly valued communication between team members and their primary care providers, which allowed them to experience continuity of care with their general practitioners (GPs) (Burridge et al., 2017). These patients also appreciated open communication and reciprocal relationships that encouraged them to be more active in managing their diabetes. "I went in there this morning to see [the diabetes educator]...my GP will have those details this afternoon" (Burridge et al., 2017, p. 1035).

Physicians recognized that communication difficulties, such as language barriers, explaining treatment recommendations, and not following up with patients, impeded treatment relationships (Beverly et al., 2012). In a U.K. study of patients with diabetes, up to a third of patients had to rely on family members to translate information during clinical encounters (Wilkinson, Randhawa, & Singh, 2014). Physicians were aware of their patients' struggles to achieve treatment goals, but expressed uncertainty as to how to improve their care. "I think sometimes we don't really understand why what we're saying is not making sense to them" (Beverly et al., 2012, p. 1182). Patients in a primary care setting in Oman identified communication barriers such as not being greeted or feeling welcomed during a visit; poor attention and eye contact exacerbated by the use of an electronic health record; not feeling listened to, encouraged to ask questions or express concerns; and not receiving information on lab results as impeding perceived quality of care (Abdulahdi et al., 2007).

Patient education and empowerment. Collaborative care involves patients interacting with multiple health professionals and engaging with ongoing diabetes management. Two themes concerning collaborative care for type 2 diabetes emerged from the studies: patient education/empowerment and self-care management support. Patients represented in these

studies overwhelmingly valued personalized, content-relevant information and advice (Abdulhadi et al., 2007; Burrige et al., 2017; Ganguli, Orav, Weil, Ferris, & Vogeli, 2017; Längst et al., 2015; Lawton et al., 2009; Wilkinson et al., 2014). Patients had positive experiences with health educators, and would like to have had them available more than just a few months after initial diagnosis (Abdulhadi et al., 2007). Patients' trust in the health care team was enhanced when patients perceived that medical information they were receiving was of high quality (Burrige et al., 2017). This is especially apparent in the provision of medication information. Patients valued timely, tailored, face-to-face, and responsive medication information that considered their health conditions and life situation (Längst et al., 2015). Many patients perceived that the provision of medication information was not sufficient (especially regarding side effects), involved too much technical jargon, or conflicted with outside sources, particularly those found online (Längst et al., 2015). Patients felt that this created an unnecessary dependency on the provider.

Wilkinson et al. (2014) noted that the timing of information for newly diagnosed persons with diabetes was significant. Often the amount and timing of information was problematic, such as information overload just after diagnosis. Patients felt that it might be more useful for education to be delivered in a staggered way: "It was an awful lot of information to take in...there's a lot there I'm sure they didn't take in, because the older you get, the less you retain anyway" (p 3).

Written materials were of limited value to patients with low health literacy (Abdulhadi, Al-Shafae, Östenson, Vernby, & Wahlström, 2006). Patients with low literacy felt that this impeded diabetes management, and that they were required to accept what was provided to them

because they weren't educated. "Doctors only decide what to do because they know better. We don't know, we are not educated" (Abdulhadi et al., 2006, p. 6).

Conversely, primary care providers found that the erroneous information that the patients sometimes received via unverified online sources was challenging for patient education. They complained that patients often forgot the information provided during medical encounters. In some cases, patients wanted more information on side effects than providers were willing to provide in the fear that it would interfere with medication adherence. "If I tell forty side effects for each medication...nobody will take it" (Längst et al., 2015, p. 1436).

Self-care management support. Self-care management support is helping patients set goals and gain skills to address the concerns of having a chronic illness (Foster & Mitchell, 2015). Dejesus et al. (2012) found that patients felt that dietary management, blood sugar control, and weight management were some of the most challenging aspects of patients' diabetes self-care. Supporting patients with self-management, however, includes more than just addressing the medical needs related to diabetes. In a survey of what high risk patients value in care managers, Ganguli et al. (2017) found that the top "very helpful" activities for care managers were discussing medications and side effects (60.9%), answering questions (48.0%), identifying causes of stress (41.3%) coordinating care (44.1%), addressing family, home life or living situations (38.8%), identifying preferences for care (35.6%) and asking what makes it hard to take care of health (33%).

Medication self-management, defined as the range of tasks that patients have to undertake to successfully manage their therapeutic regime and sustain safe medication use over time, was particularly challenging for patients with type 2 diabetes (Längst et al., 2015). Patients found it challenging to fit a complex schedule of medications into their lives. They

often forgot to take their medications, were unsure what to do if they missed a dose, found changes in regimes difficult and needed more support with insulin administration. In spite of the identified need to individualize complex medication regimes to family and occupational circumstances, medication self-management often received little attention in the patient-provider communication. In one study, patients found that their providers focused more on fulfilling therapy and medication management responsibilities and they had little expectations from patients for medication self-management (Längst et al., 2015).

When patients were considered to be partners in their ongoing care they felt that their standing as a patient in the clinic was respected. “I was someone that they were genuinely interested in, that they were as ecstatic about my results as I was. They were as invested as I was, and that was a spiral of good” (Burrige et al., 2017, p. 1035). When health care professionals approached unmet goals with a positive attitude and motivational supports, it helped patients get back on track (Beverly et al., 2012). “The most important thing for me is being supported” (Foster & Mitchell, 2015, p. 884). These perceptions of support were magnified for non-white and less educated patients (Jackson, Weinberger, Hamilton, & Edelman, 2008). In a Veterans Health Medical Center (VAMC) study, non-white patients with diabetes had more than twice the odds (OR=2.3, CI 1.28-4.05, $p<.05$) of indicating that their experience with the VAMC was consistent with the chronic care model, defined as the provision of self-management support, the organization of care within integrated teams, the use of tools to support evidence-based care, and the availability of clinical information systems. Those not completing high school had nearly three times the odds (OR=2.97, CI 1.15-7.63, $p<.05$), and also had more than twice the rates of patient activation (OR=2.12, CI 1.0-4.5, $p<.05$), perception of care teams (OR=3.8, CI 1.28-11.08, $p<.05$), collaborative goal setting (OR=3.2, CI

1.34-7.69, $p < .05$) and collaborative problem solving (OR= 3.1, CI 1.11-8.71, $p < .05$) (Jackson et al., 2008).

Patients recognized their own role in self-management, and felt that difficulty of self-management led to feelings of insecurity. They acknowledged that they often had poor adherence to medical recommendations because they ate traditional foods, were in family situations that were not supportive, or did not alter how they cooked or prepared foods (Abdulhadi et al., 2007). This often led to feelings of self-blame, hopelessness, discouragement, depression and defeat. When patients saw their disease progressing, they expressed feelings of wanting to give up.

“I think you just give up...it’s such a baffling disease...How do I feel? Discouraged. And I ask myself, ‘Why can’t I do it?’ And, often the time comes when you’ll say I’m lazy. I don’t want to give up what I like. And that’s selfishness also. And that’s the reason I think that I can’t reach it...Because I think I’m such a bad patient” (Beverly et al., 2012, p. 1183).

Patients found a collaborative approach to diabetes care engaging and motivating, particularly with a relationship with open communication and a positive attitude (Burrige et al., 2017). Team care reinforced personal obligations and a sense of duty for self-care in daily routines. Patients were doing more and pushing themselves to get the most out of supportive relationships. They felt an obligation to comply with expert advice and do their best. Some felt the need to be more proactive “developers” of their care by searching out information and being directive coordinators of their care (Foster & Mitchell, 2015). Patients valued the motivational role nurses played in diabetes management, and both patients and providers felt that a willingness to collaborate was a highly valued skill in a care manager (Dejesus et al., 2012). Patients valued the praise, encouragement and reassurance that health care team members offered: “Because while I know I’m managing it, but it’s good to hear somebody else say,

y’know, that I’m managing it well”...“just maybe a wee bit of reassurance that you’re doing your tests...and that’s alright you know, and you’re doing things right.” (Lawton et al., 2009, p.143).

Accessibility. The type of setting and organizational structure described in the studies often influenced how patients experienced their diabetes care. In several of the U.K. and Australian studies, the patients had recently changed from receiving care from specialists to their primary providers and they were able to compare the differences between the two settings. In other studies, the patients described care they received from smaller and more traditional provider-nurse or provider-assistant team care. In the U.K and Australian studies, patients were positive about the changes to primary care in terms of convenience, location, accessibility, waiting times, and communication with their providers (Burrige et al., 2017; Dejesus et al., 2012; Foster & Mitchell, 2015; Lawton et al., 2009; Johnson, Baird & Goyder, 2006). They appreciated the flexible clinic appointments, continuity of relationships with staff and rapid feedback to their general practitioners, and felt that the care was more oriented to their needs instead of expecting them to adapt to the health care system (Burrige et al., 2017).

Visit length and waiting time. Patients valued the time they spent with their primary care providers. They preferred longer visits and a more intimate style of consultations about treatment decisions (Lawton et al., 2009; Johnson, Baird & Goyder, 2006). In general, the patients felt that the contact with their primary care providers was insufficient – they wanted more time to receive tailored information, as well as praise, encouragement and affirmation of adherence to treatment (Burrige et al., 2017; Lawton et al., 2009). In clinics with longer waiting times, it was felt that health service organizations did not always recognize that time was a finite resource for patients (Abdulhadi et al., 2007).

Team-based care. Team-based care was seen as a relief to the harried primary care provider. In a study of perceived responsibility and self-blame in type 2 diabetes in the Boston area (Beverly et al., 2012), primary care providers expressed a sense of failure, inadequacy, frustration and fatigue when patients didn't meet treatment goals. They recognized that they were not reaching out frequently enough to patients and wanted to track their patients better, especially those who may not come in for visits in fear of disappointing their providers. They asked themselves what more they could be doing to help their patients – have better relationships, more time, provide more resources, or more clearly communicate challenges, issues and goals for patients to work on. “What we're asking patients to do is hard and it's continuous. I think that the failures largely are due to [providers] setting expectations that are insurmountable ” (Beverly et al., 2012, p.1182).

When working in team-care arrangements, patients appreciated that there was a network or team of clinicians working on their behalf and considered this to be thorough and reassuring (Foster & Mitchell, 2015). Patients appreciated the availability of staff like a nurse care manager (Dejesus et al., 2012), and the frequent, face-to-face time team care could provide (Ganguli et al., 2017). Team care meant more dedicated time and tailored information. This dedicated time allowed patients who were newly diagnosed with type 2 diabetes more time to process their unique emotions which can include upset, fear, confusion, denial or acceptance and assisted with engagement in their care (Foster & Mitchell, 2015).

“It has taken a load off GPs. Time is something that GPs don't have. They'll talk to you while they think it is necessary but they will shut you out as quickly as they can because they have got ten patients waiting to come and see them whereas if it is broken up into other individuals they can devote more time to what they are doing...you are learning a lot more and being told more by the different people involved.” (Foster & Mitchell, 2015, p.884).

Some patients found that they were sometimes more inclined to ask a team member for information than their primary care provider during medical encounters (Längst et al., 2015).

“She [the practice nurse] never makes me feel that she’s rushed because somebody else is waiting to come in... Well, you can like sit down and talk to them better than, more than what you can at t’hospital, somehow, I feel more confident, calmer” (Johnson, Baird & Goyder, 2006, p.250).

However, not all patients appreciated receiving care from team members. Some patients felt that care was more fragmented when there were multiple allied health providers involved in their care (Johnson, Baird & Goyder, 2006). They needed to be convinced about the benefits of team care, and many would not go if they had to pay out of pocket (Foster & Mitchell, 2015). “I think they just follow protocol... as far as they are concerned they have done what they have to and then it is up to you” (Lawton et al., 2009, p5).

Literature Review Limitations

There are several limitations to this review of the literature. Even though inclusive search criteria were used, there were few studies that explored the experiences of patients with type 2 diabetes with team-based care. The studies that were included in this review were heterogeneous, from specific topics such as medication education or attributes of care managers to broad-themed qualitative reviews of patient experiences. The small number of studies necessitated including a mix of qualitative, quantitative and mixed methods studies, making the findings across studies varied. In spite of these limitations, the analysis and synthesis revealed cohesion of themes in experiences with team-based care.

Gaps in the Literature

As this systematic review demonstrated, there was a limited amount of existing literature on patients’ with type 2 diabetes of experiences with team-based primary care. Of the eleven studies reviewed, only one explicitly described the experience of patients with type 2 diabetes

with a full health care team (Foster & Mitchell, 2015). The majority of the studies described patient experiences with small teams of the primary care provider and a nurse or medical assistant, but failed to fully describe how the teams functioned, and what the team represented to the patient in relation to their care.

However, even with the limited number of studies of this topic, several recurrent themes emerged: effective diabetes care requires continuous, sustained and trusting clinician relationships (BurrIDGE et al., 2017; Längst et al., 2015; Lawton et al., 2009), time and accessibility to trained health care professionals and staff (Abdulhadi et al., 2007; Lawton et al., 2009), and confidence building through tailored self-management support and shared goals (Beverly et al., 2012; Dejesus et al., 2012; Foster & Mitchell, 2015; Jackson et al., 2008). Many of these themes are echoed in the related literature on what patients with type 2 diabetes want in their relationships with health care providers.

Table 2.5 shows a synthesis of types of enablers to team-based care cited by participants in the reviewed studies. In spite of the heterogeneity of study designs, which included quantitative, qualitative and mixed method studies, there were some unifying characteristics of what study participants felt enhanced team-based care. Participants in all eleven studies mentioned some form of self-management support in their description of team benefits (or barriers if lacking). In ten of the eleven studies the relationship with the primary care provider and/or team was perceived to be of high importance (Abdulhadi et al., 2007; Beverly et al., 2012; BurrIDGE et al., 2017; Dejesus et al., 2012; Foster & Mitchell, 2015; Ganguli et al., 2017; Längst et al., 2015; Lawton et al., 2009; Wilkinson et al., 2014). Other important enablers of team-based care included clinic organizational structures and time spent with health professionals, which were often linked in the discussions (Abdulhadi et al., 2007; BurrIDGE et al., 2017; Foster &

Mitchell, 2015; Längst et al., 2015; Lawton et al., 2009). This is consistent with related literature that suggests that as the complexity of primary care increases, the time that it takes to manage a panel of patients has become beyond what a typical primary care provider can achieve on their own (Bodenheimer, 2008; Grant, Pirraglia, Meigs, & Singer, 2004; Ostbye et al., 2005; Yarnall et al., 2009; Yarnall, Pollak, Ostbye, Krause, & Michener, 2003).

There were several questions that were not answered in the literature. Specifically, if patients strongly prefer continuity of care with a primary care provider, what does the desire for continuity mean for team-based care when the care is shared among a team of professionals? How does team-based care impact the primary care provider-patient relationship? Does the patient's primary relationship need to be with the primary care provider, or can it be with another trusted member of the team? As the results of this review demonstrate, understanding team structure, composition, and organizational structure with respect to teams will enhance this research.

Another gap in the literature is a clear understanding of how patients experience teams in primary care settings. Only several studies specifically mentioned patients' awareness of teams (Burridge et al., 2017; Foster & Mitchell, 2015), partly because those studies were evaluating the changes to new, integrated models of care. What is not known is the meaning of working with teams for patients with type 2 diabetes, and whether this meaning is impacted by awareness of a team-based approach. Does working with a team change how patients approach their own self-care and diabetes care management?

Team-based diabetes care shows promise to solve many of the patient-stated desires for adequate and timely information, self-management support, and additional time with health professionals, but we lack information on the views and priorities of patients to know how it

impacts their engagement in their care. It remains to be seen if team-based care can also deliver better long term care of patients with type 2 diabetes. Team-based care, proposed as a solution for better care, can fulfill these promises if the patients' perspectives, expectations and concerns are incorporated into delivery designs.

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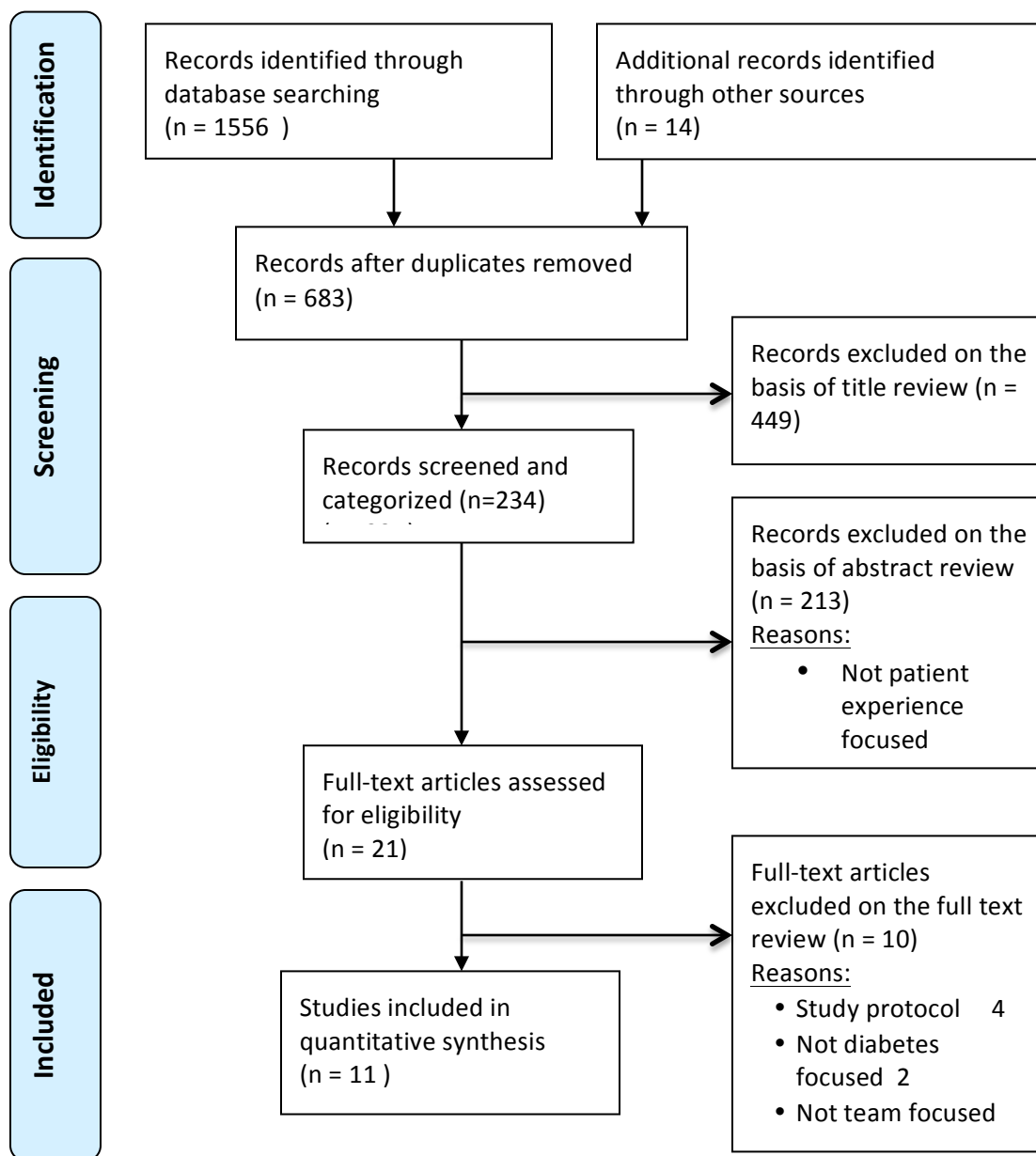


Figure 2.1 PRISMA Flow Diagram to Select Studies Included in the Literature Review

Table 2.1

Search Terms Used in Team-based Primary Care for Patients with Type 2 Diabetes Literature Review

Database Search Engine	Search Terms	Results
	Primary Care Teams Background Search	
PubMed-	"Patient Care Team"[Majr] AND "primary health care"[majr] – Mesh background search	1903
	("patient care team" OR "team based care" OR "team-based care" OR "interdisciplinary team" OR "multidisciplinary team" OR "team care") AND ("primary health care" OR "primary care") NOT medline[sb] – Mesh search translated to keyword search to find non-indexed articles in PubMed	209
	Primary Care Teams and Type 2 Diabetes Focused Search	
PubMed	"Diabetes Mellitus, Type 2"[Mesh] AND "Patient Care Team"[Mesh]	278
	"Diabetes Mellitus, Type 2"[Mesh] AND "Patient Care Team"[Mesh] AND "primary health care"[mesh] diabetes AND ("patient care team" OR "team based care" OR interdisciplinary team) AND ("primary health care" OR "primary care") NOT medline[sb] – non-indexed articles search diabetes AND ("patient care team") AND ("primary health care" OR "primary care") – English only - keyword search	319
	"Diabetes Mellitus, Type 2" AND primary health care AND team* - keyword search	353
Embase	'Type 2 diabetes' AND ('patient care team'/exp OR 'interdisciplinary team' OR 'multidisciplinary team'/exp) AND 'primary health care'/exp AND [english]/lim AND [2007-2017]/py	490
CINHAL	"Type 2 diabetes" patient care team [mesh] OR "team based care" OR "team-based care" OR "care team" OR "multidisciplinary team" OR "interdisciplinary team" "primary care" OR "primary health care" OR "primary	60

	healthcare"	
Database Search Engine	Search Terms	Result
Cochrane Database of Systematic Reviews	diabetes "primary care" "multidisciplinary team" - 1 (duplicate with team) diabetes "primary care" "team based care" - 3 (all duplicates with team) diabetes "primary care" "team-based care" - 5 (all unique) diabetes "primary care" "interdisciplinary team" 0 diabetes "primary care" "patient care team" - 1 (duplicate with team) diabetes "primary care" "team"- 5 (all unique)	10
Web of Science	(TS="Type 2 diabetes" AND TS=("primary care" OR "primary health care") AND TS=("patient care team" OR "interdisciplinary team" OR "multidisciplinary team" OR "care team" OR "team based care" OR "team-based care")) AND LANGUAGE: (English)	46
Other Sources	CDC, CMS, RAND, Commonwealth Fund, Kaiser Permanente, and Reference list review	15

Table 2.2
Quality Appraisal of Team-based Care Experiences Literature

Study	Country	Aim	Design	Measure	Sample Size	Quality Review +/- (1)
Quantitative Study Designs						
Ganguli et al., 2017	United States	Explore participants' with T2DM awareness and perceived utility of care management program	Cross-sectional	Telephone survey	1220 patients	+Clear study aims +Clear rationale for participant inclusion + Large sample size +Represents successful care management model +Limited non-response bias observed +Limitations addressed -Cross sectional design limits causal inferences about associations -Single health system -Low response rate
Jackson et al., 2008	United States	To assess potential racial/ethnic and educational level differences in degree which diabetes care corresponds to the Chronic Care Model	Cross-sectional	Survey	189 patients	+Clear study aims +Clear rationale for participant inclusion +Ethnically/racially diverse sample population +High response rate +Limitations addressed -Cross sectional design limits causal inferences about associations -Small sample size -Single health system (VAHS) -Primarily male sample population
Qualitative substudies (of mixed method studies)						
Dejesus et al., 2012	United States	Ask physicians and patients with T2DM what qualities they look for in a care manager	Qualitative sub-study (mixed methods)	3 open-ended questions from 20 question survey	175 patients 22 physicians	+Clear study aims +Limitations addressed +Conclusions clear and justified -Design appropriate to aims -Sampling appropriate to aims -Data collection appropriate to research aims

Study	Country	Aim	Design	Measure	Sample Size	Quality Review +/- (1)
Burrige et al., 2017	Australia	Explore patients with T2DM views of integrated care	Qualitative sub-study (mixed methods)	Semi-structured interviews	25 patients	+ Clear study aims + Design appropriate to aims + Sampling appropriate to aims +Data collection appropriate to research aims +Limitations addressed +Conclusions clear and justified
Qualitative Study Designs						
Abdulhadi et al., 2007	Oman	Explore perceptions of patients with T2DM regarding medical encounters and quality of interactions	Qualitative	Focus group discussions	27 patients	+ Clear study aims + Design appropriate to aims + Sampling appropriate to aims +Data collection appropriate to research aims +Limitations addressed +Conclusions clear and justified
Beverly et al., 2012	United States	Explore physicians and patients with T2DM experiences and difficulties achieving diabetes treatment goals	Qualitative	In-depth interviews and observation	34 patients 19 physicians	+ Clear study aims + Design appropriate to aims + Sampling appropriate to aims +Data collection appropriate to research aims +Limitations addressed +Conclusions clear and justified
Foster et al., 2015	Australia	Investigate the views of primary care patients receiving Medicare-funded team care for chronic disease management	Qualitative	Repeat in-depth interviews	23 patients	+ Clear study aims + Design appropriate to aims + Sampling appropriate to aims +Data collection appropriate to research aims +Limitations addressed +Conclusions clear and justified

Study	Country	Aim	Design	Measure	Sample Size	Quality Review +/- (1)
Johnson et al., 2006	U.K. England	Explore views and experiences of patients with T2DM after diabetes care transferred from hospital to primary care clinic	Qualitative	Semi-structured interviews	12 patients	+Clear study aims +Design appropriate to aims +Sampling appropriate to aims +Data collection appropriate to research aims -Limitations not clearly addressed - Conclusions not clearly justified
Längst et al., 2015	Germany	Investigate which factors physicians and patients with T2DM perceive to enhance or impede medication provision	Qualitative	Semi-structured focus groups	25 patients 13 physicians 19 health care assistants	+Clear study aims +Design appropriate to aims +Sampling appropriate to aims +Data collection appropriate to research aims +Limitations addressed +Conclusions clear and justified
Lawton et al., 2009	U.K. Scotland	To examine patients with T2DM perceptions and experiences over time of change from specialty to primary care	Qualitative	Repeat in-depth interviews	20 patients	+Clear study aims +Design appropriate to aims +Sampling appropriate to aims +Data collection appropriate to research aims +Conclusions clear and justified -Limitations not addressed
Wilkinson et al., 2014	U.K. England	To investigate patients with T2DM experiences upon diagnosis in light of new self-management innovations of care	Qualitative	Interview	47 patients	+Clear study aims +Design appropriate to aims +Sampling appropriate to aims +Data collection appropriate to research aims +Limitations addressed +Conclusions clear and justified

(1) Criteria in bold: Mandatory ICROMS quality criteria for qualitative studies

Table 2.3

Summary of Literature of Provider and Patients' with Type 2 Diabetes Team-based Care Experiences

Study	Country	Aim	Design	Measure	Sample	Setting Type
Abdulhadi et al., 2007	Oman	Explore perceptions of patients with T2DM regarding medical encounters and quality of interactions	Qualitative	Focus group discussions	27 patients	Primary care centers in Muscat Oman
Beverly et al., 2012	United States	Explore physicians and patients with T2DM experiences and difficulties achieving diabetes treatment goals	Qualitative	In-depth interviews and observation	34 patients 19 physicians	Diabetes clinics in Boston MA
Burrige et al., 2017	Australia	Explore patients with T2DM views of integrated care	Qualitative sub-study (mixed methods)	Semi-structured interviews	25 patients	Primary care clinics in Brisbane
Dejesus et al., 2012	United States	Ask physicians and patients with T2DM what qualities they look for in a care manager	Qualitative sub-study (mixed methods)	3 open-ended questions from 20 question survey	175 patients 22 physicians	Primary care internal medicine clinic
Foster et al., 2015	Australia	Investigate the views of primary care patients receiving Medicare-funded team care for chronic disease management	Qualitative	Repeat in-depth interviews	23 patients	1 urban and 1 rural general practice clinics in Queensland
Ganguli et al., 2017	United States	Explore participants' with T2DM awareness and perceived utility of care management program	Cross-sectional	Telephone survey	1220 patients	Boston-area primary care clinics
Jackson et al., 2008	United States	To assess potential racial/ethnic and educational level differences in degree which diabetes care corresponds to the Chronic Care Model	Cross-sectional	Survey	189 patients	North Carolina based VA primary care clinic
Johnson et al., 2006	U.K. England	Explore views and experiences of patients with T2DM after diabetes care transferred from hospital to primary care clinic	Qualitative	Semi-structured interviews	12 patients	4 primary care practices in Sheffield
Längst et al., 2015	Germany	Investigate which factors physicians and patients with T2DM perceive to enhance or impede medication provision	Qualitative	Semi-structured focus groups	25 patients 13 physicians 19 health care assistants	Primary care clinics
Lawton et al., 2009	U.K. Scotland	To examine patients with T2DM perceptions and experiences over time of change from specialty to primary care	Qualitative	Repeat in-depth interviews	20 patients	Primary care clinics

Study	Country	Aim	Design	Measure	Sample	Setting Type
Wilkinson et al., 2014	U.K. England	To investigate patients with T2DM experiences upon diagnosis in light of new self-management innovations of care	Qualitative	Interview	47 patients	18 primary care clinics in 3 locations

Table 2.4
Findings of Providers' and Patients' with Type 2 Diabetes Team-based Care Experiences

Study	Country	Setting Type	Team Composition	Major Findings
Abdulhadi et al., 2007	Oman	Primary care centers in Muscat Oman	Physicians and nurses in traditional roles Limited exposure to health educators and dieticians	Identified weaknesses and overall dissatisfaction with care Patient-provider barriers <ul style="list-style-type: none"> - not feeling welcomed - interruptions during the visit - poor attention and eye contact exasperated by the EHR - patient not encouraged to ask questions - inability to participate in medical dialogue due to lack of information - lack of continuity - long wait times with short visit length Self-described patient barriers <ul style="list-style-type: none"> - poor compliance with diet - families not supportive with cooking and preparing food - don't want to be seen as problematic - consider self not educated and doctors know better
Beverly et al., 2012	United States	Diabetes clinics in Boston MA	Not described	Physicians' perceived responsibility for patients' difficulty achieving treatment plans <ul style="list-style-type: none"> - self-reflective, recognition of own barriers with language, time constraints, not reaching out or following up with patients, feeling rushed, not enough time or doing enough, feeling like a failure, inadequacy, frustration and fatigue Patients' self blame for difficulty achieving treatment goals <ul style="list-style-type: none"> - patients blamed themselves for lack of progress, direct frustration and disappointment inward
Burridge et al., 2017	Australia	Primary care clinics in Brisbane	Transferred from specialist to GP-led integrated diabetes care Access to diabetes educator	Structural elements of care <ul style="list-style-type: none"> - increased convenience, flexibility, communication, tailored care Patient-clinician relationships <ul style="list-style-type: none"> - new model focuses on patients' engagement and self-care, patients found collaborative approach engaging and motivating, additional time to address individualized needs - some resistance to changing

Study	Country	Setting Type	Team Composition	Major Findings
				to new provider
Dejesus et al., 2012	United States	Primary care internal medicine clinic	Primary care provider Nurse care manager	Qualities in care manager valued by patients and providers: <ul style="list-style-type: none"> - being knowledgeable, having good communication skills, having certain personality traits, accessible (patients only) Qualities of concern by providers: <ul style="list-style-type: none"> - Not a team player or not knowing practice limitations
Foster et al., 2015	Australia	1 urban and 1 rural general practice clinics in Queensland	GP and allied health services Podiatry, PT, dietician, diabetes educator, practice nurse	<ul style="list-style-type: none"> - Patients found team care to be thorough and reassuring - Felt obligations for self care in the structured care routine - Given financial incentives to engage in team care - Optimized experience if patient expectations and preferences are considered - Overall positive about team care
Ganguli et al., 2017	United States	Boston-area primary care clinics	Primary care provider Care manager (defined as someone who helps you with your medical care)	<ul style="list-style-type: none"> - N= 1220 ; Response rate = 45.8% - White race=89.8%; Female = 60.8% Below poverty level=9.5% - Attended some college=65.8% Medicare 66.6% - Overall high care manager awareness (74%) - Reported at least one interaction in previous year as very helpful (81.3%) - The higher the awareness of the care manager, the higher odds of reporting very useful interactions - (OR=2.77, CI 2.15-3.56, p<.05) - Very helpful interactions included post-hospitalization follow-up, addressing barriers to self-care and medication management - Patients report worrying about families and financial issues
Jackson et al., 2008	United States	North Carolina based VA primary care clinic	Not described	<ul style="list-style-type: none"> - Survey Results n= 296 ; Response rate = 69% - Non-hispanic white=57.1%; African American=38.1%; Male=97.9% - Less than high school education=20.1% Non-VA

Study	Country	Setting Type	Team Composition	Major Findings
				<p>health insurance 31.8%</p> <ul style="list-style-type: none"> - Patient Assessment of Chronic Illness Care (PACIC) regression n=189 - PACIC summary score = 43.9% of patients indicating CCM implementation (scale score ≥ 3.5); Mean=3.1 (1.1) range 1-5 - Non-white population twice the odds of reporting care is in line with CCM (OR=2.28, CI 1.28-4.05, $p < .05$) - Non-white more likely to have help with problem solving (OR=1.57, CI 1.14-2.16, $p < .05$) and follow up (OR=2.86, CI 1.41-5.82, $p < .05$) - Patients with less education three times more likely to report care in line with CCM (OR=2.97, CI 1.15-7.63, $p < .05$)
Johnson et al., 2006	U.K. England	4 primary care practices in Sheffield	Transferred from specialist to GP-led diabetes care Practice Nurses	<ul style="list-style-type: none"> - Patients were unaware of policy changes in diabetes care - GP-based diabetes care acceptable to patients if support is continuous - Seen as more accessible in location and time - Acceptable if full range of diabetes care available to address needs - Patients value rapport, listening, continuity, personalized care - Mixed opinions on nurses, but value their time to support patient education
Längst et al., 2015	Germany	Primary care clinics	GPs Health care assistants (not defined)	<p>Factors to enhance or impede medication provision</p> <p>Enabling factors (high agreement between patients and providers):</p> <ul style="list-style-type: none"> - important to deliver tailored information, face to face delivery, have a trustful and continuous patient-provider relationship, regularly reconcile meds, provide tools for med management, have a team approach <p>Barriers (low agreement between patients and providers):</p> <ul style="list-style-type: none"> - inadequate or conflicting information – patient concerns about insufficient information and information overload or use of jargon

Study	Country	Setting Type	Team Composition	Major Findings
				<ul style="list-style-type: none"> - not having medication reconciliation - lack of support for self-management - patients forgetting information or family interference (physicians)
Lawton et al, 2009	U.K Scotland	Primary care clinics	Transferred from specialist to GP-led diabetes care Practice nurses	<ul style="list-style-type: none"> - Reassurance that transfer signified well-controlled diabetes - Resentment that better control meant “inferior” or less frequent care - Concerns about interrupted continuity - Ambivalence about nurses taking on roles of physicians
Wilkinson et al., 2014	U.K. England	18 Primary care clinics in 3 locations	Not described	<p>Experiences of care for patients newly diagnosed with diabetes</p> <ul style="list-style-type: none"> - 45% report unmet support and information needs at diagnosis - 17% felt that they didn't need support - 17% had negative view of care regarding information giving, support and communication - suggest recent quality improvement interventions not successful

GP=General Practitioner; AHP= Allied Health Professional

Table 2.5
Team Care Enablers Identified by Patients with Type 2 Diabetes

Study	Team or Provider Relationship	Continuity	Team or Provider Trust	Perceived Competency	Communication	Time	Self-care Support	Clinic Structure
Abdulhadi et al., 2007	x	x		x	x	x	x	x
Beverly et al., 2012	x				x		x	
Burridge et al., 2017	x	x	x		x	x	x	x
Dejesus et al., 2012	x			x	x		x	
Foster et al., 2015	x					x	x	x
Ganguli et al., 2017	x						x	
Jackson et al., 2008							x	
Johnson et al., 2006	x	x			x	x	x	x
Längst et al., 2015	x		x		x		x	x
Lawton et al., 2009	x	x		x	x	x	x	x
Wilkinson et al., 2014	x				x		x	

Chapter 3

Methodological Reflections and Methods

Human experience is the ultimate source and justification for all knowledge.
- John Shook, *Free Inquiry*, 2008

This chapter outlines the methodological foundations and justification for an interpretive phenomenological study of patients with type 2 diabetes and their health care teams' experiences with team-based primary care. In this chapter, I discuss the unique contributions that a qualitative investigation of this topic can yield. Interpretive phenomenology is proposed as the method that best suits an exploration of the meaning and experiences of team-based care for patients with type 2 diabetes and their health care team. I describe the qualitative methods employed to collect, organize and analyze my data and conclude with a discussion of methodological rigor and the limitations of my methodological approach.

Methodological Approaches to Social Science Inquiry

The field of social science research has a long history of tension surrounding the value and relevance of qualitative versus quantitative methods of inquiry for the study of social worlds and phenomena. The quantitative-qualitative paradigm debates of the 1980s ushered in a flourishing qualitative research movement with a proliferation of scholarly publications, journals, handbooks and lectures on feminism, post-modernism, post structuralism, and post positivism (Denzin & Lincoln, 2017).

The basic tenets of quantitative inquiry (here called positivism) are beliefs in the preeminence of the scientific method for knowledge production. Traditional positivist scientific research privileges "theory-neutral" observations and empirical quantitative data to seek universal truths (Schumacher & Gortner, 1992). The positivist approach asserts that universal truths exist and are achievable through verification and replication of observable findings.

Hypothesis testing, randomization of sampling, standardization of data collection, and the anticipation of generalizable and replicable evidence form the backbone of positivist inquiry. Attempts are made to eliminate any bias effects of the researcher and research subject by attempting to assure objective and standardized data collection procedures.

Positivist methods of inquiry promote understanding of the laws of nature, physics, chemistry, and physiology, but qualitative researchers argue that they are less suited to understanding complex human and social differences of race, ethnicity, gender and social class (Denzin, Lincoln & Giardina, 2006). Qualitative researchers wish to enhance traditional ways of knowing by using methodologies that privilege alternative “knowledges, voices and experiences” (Smith, 2005, p.87).

In this historical moment, science-based research is particularly challenged by the politics of truth – how facts (and fiction) are asserted and manipulated for political purposes. It is possible that the move to more positivist, analytical approaches represents a “backlash against the deep and moving portraits of social injustice, racism and myriad forms of oppression operating under the apparently ‘just’ fabric of American social life” (Denzin, Lincoln & Giardina, 2006, pg 773). Quantitative research is not immune to the politicization of knowledge, as political ideology often determines what is believed to be true or false. In this instance, all scientific inquiry, regardless of methodology, is in jeopardy of being destabilized and devalued. As the consequences of political devaluation of scientific research unfold, we may begin to see further entrenchment of methodological ideologies, especially if research funding becomes scarce.

It is within the context of these tensions that I elaborate the use of a qualitative research methodology to explore how patients with diabetes experience team-based primary care and

articulate the potential for a unique contribution to the understanding of the delivery of primary care in the United States.

Qualitative Research

Unlike most rational-empirical positivist approaches, the qualitative researcher does not have an a priori hypothesis that is being tested. Qualitative research focuses on the perceptions, meaning and concerns of those being studied. Denzin and Lincoln (2005) describe qualitative research as a “situated activity that locates the observer in the world” (pg.3). The focus is on everyday reality, and research is conducted in naturalistic contexts that result in thick descriptions of the person experiencing their situation. The discovery is iterative, ongoing and changing, and analysis is concurrent with the data collection. The data collection methods used in qualitative research, such as open-ended interviews and observations, may allow partial access to the life worlds of participants. The relationship between the researcher and the researched is engaged, transparent and reflexive (Schwartz-Shea & Yanow, 2012).

Four ontological, epistemological, axiological and methodological philosophical assumptions underlie qualitative research (Denzin & Lincoln, 2011). Ontologically, there is the belief that multiple realities and multiple forms of evidence and perspectives can coexist. Epistemologically, qualitative researchers value the subjective experiences of individuals as a source of knowledge and conduct studies in the field to minimize the distance between the researcher and those being researched. Axiologically, values are made transparent, and researchers actively report on their biases to position themselves in the study. Methodologically, knowledge production is inductive and not handed down from the theory or perspective of the researcher. Qualitative researchers stay open to the possibility of the research question changing

during the study to better reflect the types of questions needed to understand the research problem.

Qualitative research questions are exploratory and explanatory, and there is no anticipation of determining causation. Theory sensitizes the researcher to the situation being studied, but does not structure the research. Research questions arise from practical and clinical experience, and gaps in understanding (Schwartz-Shea & Yanow, 2012).

In positivist research, objects are studied independent of their context, and the researcher attempts to maintain objectivity while employing a deductive logic of inquiry. Alternatively, the qualitative researcher relies on context for understanding a concept, studying objects in their situated states. This inquiry is iterative and recursive, as if solving a puzzle, during which a comprehensive picture reveals itself in the course of the research. This requires reflexivity and examination of the self and presuppositions to move toward a deeper understanding of the puzzle.

Both quantitative and qualitative researchers seek knowledge on the merits of evidence, but how that evidence is assembled is a fundamental difference between them (Schumacher & Gortner, 1992). Most contemporary researchers would consider themselves to be post-positivist, and acknowledge that metaphysical considerations are outside of scientific realms. This post-positivist, post-modern paradigm concedes that there are factors that can't be observed that may explain observable phenomena, and recognizes that multiple perspectives lead to a plurality of understandings of social phenomena. It is in this space where qualitative research finds its current home in a world that is dominated by quantitative research.

Postmodern and Poststructural Approaches to Qualitative Inquiry

This section seeks to further elucidate current postmodern and poststructural thought, and

how they will influence my qualitative inquiry. The underpinnings of qualitative research lie in the postmodern belief that an ultimate truth is unknowable, and that multiple perspectives are valid. Postmodern thought is inherently difficult to describe, but is essentially a collection of positions that discards the idea that society is orderly and coherent, and embraces “multiplicity, fragmentation, and indeterminacy” (Best & Kellner, 1991, pg. 4). It rejects grand theories, metanarratives and universal truths to recognize that multiple perspectives and plurality of understandings and meanings exist (Cheek, 2000). Common assumptions, “truths”, and taken-for-granted aspects of the established reality become suspect. Postmodern researchers seek to ensure that all points of view are heard, and multiple voices and positions are celebrated rather than cast aside as a statistical anomaly. There is acknowledgement of the importance of researchers’ awareness of their own positions and interests and how they frame their research – from the questions that are asked (or not asked), to whom they are asked and how they are asked.

Postmodern health care researchers insist that no single representation of health care practice can capture a universal truth of that practice. A postmodern research lens can reveal organizational strategies in health care, and illuminate how these strategies promote certain understandings and experiences of health.

The postmodern analysis offers the possibility for new and/or different discourses to surface in the health area. It enables the potential for the multi-dimensional and multi-perspective nature of health care to be represented through the frames of multiple discourses. A postmodern perspective allows for the analysis of why health care practices have been shaped in the way they are, and why certain players and practices in health care have been relegated to the margins, often designated as “other “ rather than “another” (Cheek, 2000 pg. 35).

Related, but distinct from postmodernism, poststructuralism is the theoretical perspective that focuses on the analysis of literary and cultural texts as representations of reality (Cheek, 2000). Poststructural research is concerned with the underlying assumptions found in language, and proposes that language is “both constituted by, and constitutive of, the social reality that it seeks to represent” (Cheek, 2000 p. 40). In the health care arena, the way that health care is organized, delivered and financed represents pre-established views and assumptions about how health care is practiced. Poststructural research challenges the accepted ways of acting, thinking and representing the current system as one true accepted reality.

This is to take a step back in the depth of the research to be undertaken. Rather than accepting the reality of the clinical or health setting as a given, that very reality itself is made the focus of research (Cheek, 2000, pg. 41).

Interpretive Phenomenology

Interpretive phenomenology is a hermeneutical inquiry of interpretation and understanding of human concerns and practices. The principal purpose of phenomenology is to understand individuals’ common or shared experiences and capture “everyday skills, habits, and practices by eliciting narratives about the everyday” (Benner, Tanner & Chesla, 2009, p. 351). Human actions are observed in meaningful contexts. This methodology is derived from the phenomenological traditions of Heidegger (1962/1927), and is further illuminated by Bourdieu (1977), Dreyfus (1991) and Benner (1994). Heideggerian phenomenology is concerned with ontology, the study of being, as well as the meaning or interpretation of human experience. Humans are recognized as self-interpreting beings that can relate to their own self-identities. Humans have an understanding of the world that is founded in their actions. These meanings are

created, shared and limited by a particular language, culture, and time and place in history (Dreyfus, 1991).

Hermeneutics, the methodology of interpretation, forms the backbone of interpretive phenomenology inquiry. This holistic inquiry attempts to study individuals in a situation and avoids breaking down personal and situational characteristics in isolation. In hermeneutic analysis, data are collected from individuals who have experienced the phenomenon and the investigator circles back and forth between partial understanding and the more complete whole throughout the study process to understand the phenomenon in a deep way, often looking for comparisons. The hermeneutic circle describes the movement back and forth between an overall interpretation and the details in a given text. The new details can modify the overall interpretation, causing new details to stand out as significant, creating a circle of interpretation that leads to an ever richer interpretation of the text (Dreyfus, 1991). Neither the whole text nor the individual parts are interpreted without referencing each other. The shifting back and forth between the parts and the whole reveals new themes, issues and questions that are generated through the process of understanding the text (Benner, 1985).

Hermeneutic inquiry has been used to understand everyday practices, meanings and knowledge embedded in health and illness, stress and coping, as well as skills and practices (Benner, 1994; Tanner, Benner, Chesla & Gordon, 1993). “The essence of human existence is hermeneutic, that is, our essence of human understanding of the everyday world is derived from our interpretation of it” (Dahlberg, Drew, and Nystrom 2008). The understanding of a phenomenon is gained through shared knowledge and experiences within their linguistic, cultural and historical contexts.

Three main phenomenological concepts will form the structure of this inquiry. The first is that humans are situated within their worlds through significant activities, relationships, and commitments that establish both opportunities and limitations for their lives. The situated state of “being-in-the world” occurs in a particular time in history, within a culture, and within the context of community and family where humans find themselves (Dreyfus 1991). Humans participate in activities and relationships that are meaningful to them based on their place in the world - within a family, a culture, a workplace or a community. By being raised and living in a particular situated context, humans develop a certain way of seeing and responding to the world around them. Through these situated circumstances, certain perceptions and responses may or may not present themselves to individuals. “Being situated means that one is neither totally determined or constrained nor radically free in how one acts” (Benner, Tanner & Chesla, 2009, p. 436).

The second concept concerns the ways that individuals live in and interpret their worlds. Several modes of being characterize these activities (Heidegger, 1962/1927; Dreyfus, 1991). The ready-to-hand mode of being is when humans are engaged and involved with the world through everyday functioning, without reflection or awareness. The ready-to-hand mode is captured through an understanding of the commonplace, mundane or taken-for-granted way that people live their everyday lives. Objects, equipment and interactions become the background of day-to-day life, and fade in one’s consciousness. In contrast, unreadiness-to-hand occurs during malfunction or breakdown, such as in illness, equipment failure, or in the case of health care delivery, breakdown in care processes. It describes any contrast to normal functioning, and serves to make conspicuous the inconspicuous. Narratives of situations where things go wrong and how individuals cope with disruptions to their lives often serve to illuminate this mode of

being as well as the experienced situation. The present-at-hand mode of being is when individuals pause to reflect on their taken-for-granted activities. The everyday practical activity stops while the individual detaches in a stance of curiosity or reflection. Activities and objects that were invisible in the ready-to-hand mode, become visible substances with properties through abstract thinking. When learning new skills, adaptations, or behaviors individuals are often in the present-at-hand or unready-to-hand modes of being.

The third significant concept informing this methodology addresses human concerns. The way that individuals engage in the world is established and bounded by what matters to them. The concerns, or things that matter, will influence and structure how the person approaches, perceives (both the seen and the unseen), and acts in a situation (Benner, 1994). For example, when one is caring for an infant who is ready to crawl and explore their surroundings, hazards become visible – potentially dangerous objects within reach, heavy equipment that could be pulled down, stairs or surfaces that could result in a tumble, as well as potential interactions with pets and other children in the home. Creating a safe environment becomes paramount; therefore attention and action follow these concerns.

Applying Interpretive Phenomenological Methods

A postmodern approach to studying patients' experiences with team-based primary care is complementary to the contemporary focus on patient-centered care. The term "patient-centered", defined by the Institute of Medicine (IOM), 2001) as being respectful of, and responsive to, individual patient preferences, needs and values and ensuring that patient values guide all clinical decisions. The idea of including patients' and providers' perspectives in research is hypothesized to improve the likelihood that patients achieve the desired outcomes of

their care (Frank, 2014). Interpretive phenomenology, which has underpinnings in postmodern philosophy, is a useful methodology to study patient experience.

Plager (1994) states that “the question asked and the self-understanding held are crucial issues in how a research project is approached” (p. 65). While a number of both quantitative and qualitative methods could be used to understand team-based care, I feel that a postmodern approach using interpretive phenomenology provides the most meaningful way to understand how patients experience team-based primary care. Interpretive phenomenology, applied as a methodology to the understanding of experience, helps answer the epistemological questions of how we know what patients with type 2 diabetes perceive and understand about team-based primary care; and how we know how their experiences with team-based care influences engagement with their care. From an ontological standpoint, interpretive phenomenology uncovers the experience of the phenomenon of team-based care, and provides a structure for the analysis of the experience. This hermeneutic methodology fills the gap in understanding from empirical studies of patient experience, which are predominantly found in psychometric analyses through patient surveys.

The shortcomings of traditional positivist philosophies become apparent as we attempt to understand the experience of team-based care for patients with chronic illness such as type 2 diabetes. Positivism is not able to deal with the subjective aspects of persons nor with perceived relationship processes (Schumacher & Gortner, 1992) as one would encounter attempting to understand an experience of care.

In the study of patient experiences of team-based care, there has been a growing interest in using patient experience survey data to measure the effects of primary care practice transformation efforts such as the adoption of Patient Centered Medical Homes (PCMHs) and

Accountable Care Organizations (ACOs) (Scholle et al., 2012). Both of these new primary care delivery models are built on a foundation of team-based care. Two existing patient experience measures, the Clinician and Group Consumer Assessment of Healthcare Providers and Systems Survey (CG-CAHPS) and the Consumer Assessment of Healthcare Providers and Systems Patient Centered Medical Home Survey (CAHPS-PCMH) are used for exploring patient experience with primary care, and have some preliminary constructs that could apply to team-based care (Fumagalli, Radaelli, Lettieri, Bertele, & Masella, 2015). In future studies, a mixed methods approach using psychometric research could be complementary to a postmodern interpretive phenomenological study design, and allow the team-based care constructs developed through an initial qualitative inquiry to be used to create a survey instrument to quantitatively evaluate patient experiences of team-based care.

Study Design and Methods

Research Questions and Aims

This study seeks to describe and understand the meaning of team-based care for patients with type 2 diabetes and how their experience of team-based care shapes their health care experience. This study will a) explore how patients with type 2 diabetes and their health care team perceive and understand team-based care, b) understand how the experiences influenced patients' engagement with their care, and c) compare different models of team-based care and understand how the differing models impact the patient experience. Understanding the common team experiences of patients with diabetes and their providers may inform ways to improve practice, develop policies, and develop a deeper understanding about the phenomenon of team-based care to potentially increase the likelihood of patients achieving their desired outcomes of care.

Study Design

An interpretive phenomenological approach was used for the data collection, analysis, and interpretation phases of the study. I sought to understand how team structure and functioning were experienced from the patients' as well as the team members' perspectives. Patients' and providers' interactions with their health care team were explored to illuminate how these interactions influence patients' healthcare experiences. I received institutional review board (IRB) approval from UCSF for this study (IRB # 18-25311).

An initial pilot study was conducted including semi-structured interviews and observations of patients and their primary care teams from two primary care practices. For the full study, I recruited patient and provider participants from three other primary care clinics that have well-established team-based care, to understand how team composition and structure impact team care experiences.

Forestructure

This study of team-based primary care was shaped by my prior experience and observations working with primary care clinics' leadership teams in the process of practice transformation. My pre-understandings of team-based care and patient engagement directed my approach to this study, as well as the stance I took with study informants, my mode of inquiry and interpretation of narratives. In the Heideggerian tradition, my prior understanding is presumed through the hermeneutic process. There is no point from which I can have a "privileged" foundational view of the world (in my case, of team-based care). I have a world and exist in a historical time just as my participants do. As a result, there is no way to have external truths that correspond to "things as they are" (Dreyfus, 199a; Heidegger 1927/1962). I must be critically reflective of how my forestructure (personal knowledge and background)

influences my understanding of team-based care. I do not claim to know or completely understand my participants' worlds as they navigate type 2 diabetes while being cared for by their teams.

My interest in primary care teams comes from my longstanding history with the health care system - both professionally and personally. Over time, I have developed a belief system that primary care is the key to a more compassionate, just, and less expensive health care system than what we have now in the U.S.

I received my bachelor's degree in nursing and realized even during nursing school that I disliked the hierarchy in hospitals, and particularly the nurses' status within the system. As a result, I went on to work primarily in public and community health settings. After working as a registered nurse for several years, I obtained a Masters in Health Administration in Policy and Planning. I went on to work in health care management consulting for major hospital systems and outpatient group practices throughout the western U.S.

One of my most transformative personal experiences of team-based care was when I worked as the District Nurse in East Palo Alto, a low-income community in the San Francisco Bay Area. It was there that I experienced what it was like to be on a team that was functioning at a high level. My "team" was composed of two nursing assistants, and the front desk staff at the eleven schools in my jurisdiction, a Stanford University pediatrician and her assistant, and the local community health center pediatricians. That team soared. Over the five years that I worked there, we tackled low immunization rates and achieved the highest rate in the region (even higher than the nearby high-income cities of the south bay), and instituted asthma, fitness and nutrition educational programs for the students and parents. I applied for and received grants and other funding of more than a half a million dollars for the school's health services program. We all felt

that we were a part of something big, and although the work hours were long and tiring, it was the most satisfying work of my career.

I moved on to a position as a quality and compliance director at the local community health center in the same city. I couldn't get the same traction for the five years that I worked at this health center. The center was in a constant state of change and chaos that left the staff burned out and frustrated. As a part of the federally qualified health center community, I attended multiple trainings on quality and started to read the current literature on primary care.

In my last position, I worked as a practice coach and trainer for UCSF's Center for Excellence in Primary Care (CEPC), under the direction of Dr. Thomas Bodenheimer, the author of many of the primary care publications that I had read about while at the health center. While there, I learned about teams in primary care, and how the empowerment of registered nurses and medical assistants on teams improved quality and staff satisfaction in primary care. I consulted with five San Francisco based primary care clinics to help implement many of the elements of team-based care. I also led trainings on health coaching (motivational interviewing) in primary care settings and practice coach trainings.

Many of my thoughts and understandings about primary care also come with from my everyday life as the spouse of a primary care physician. I have seen first-hand his frustrations: working in a system without the benefit of teams, having to do many of the things that are done by other team members in some of the clinics I've seen. I see him work at home in the evenings before and after clinic days to enter data into the electronic medical record and have seen his frustration trying to coordinate care for his hospitalized patients.

I've also witnessed the continued degradation of primary care, continuing the downward spiral since Bodenheimer's (2006) publication calling out a crisis in primary care in the U.S.

I've seen the medical center move the primary care offices from the heart of the campus, to a building harder for patients to reach, being replaced by the higher paid surgical and medical subspecialties.

Being an RN also impacts how I perceive team-based care. Before working for CEPC, I viewed the work of medical assistants with fear about the quality of their work. I worried about their expanding scope, particularly in primary care settings where I saw them perform many of the functions that were typically in the domain of nursing: giving medications, assisting with procedures, answering questions of patients, or providing health education. It was only after training many medical assistants about the basics of chronic disease care and health coaching that I came to appreciate the skill that they could bring to helping patients make lifestyle changes. Often the medical assistants attending the trainings were more skilled at health coaching than the more highly educated nurses and physicians in the trainings. I realized that many nurses and physicians, myself included, had a hard time getting out of the "telling" patients what to do, or imparting our wisdom, instead of entering into a dialogue by asking questions of patients. I learned to appreciate this additional team member role and what they could bring to the medical teams in primary care.

Being a public health and health policy professional, practice coach, motivational interviewing instructor, registered nurse, and a doctoral student is part of the "forestructure" that I bring to this inquiry. My findings show up in relation to my prior understandings. These understandings helped determine why I asked the questions that I asked, not only about the patients' experiences, but also about their goals, their idea of an ideal visit, and if they felt that they were on a team.

Data Collection

Eligibility and Recruitment. To begin the clinic selection process, I chose clinics that had a reputation of having robust team-based care, through first-hand knowledge from prior research studies or interactions, meetings with clinical leaders during mutual participation in learning collaboratives, or attending presentations at professional association meetings. Recruitment began by contacting the clinical and administrative leadership of the clinics to seek approval for the study. After receiving clinic leadership approval, and a letter of support from the clinics, I sought IRB approval to add the additional clinics to the study. One clinic required approval from their internal IRB committee. I then worked with the clinical leadership to identify primary care providers and team members who might potentially be interested in participating. I sent the primary care providers an email describing the study and gave them a copy of the general interview questions.

Once a team agreed to participate, I provided an informational flyer for the PCP to make available to patients with diabetes. Patients expressed interest in the study by responding to informational flyers posted in the clinic or given to them by their primary care provider. I then conducted a brief phone screening with interested patients to explain study objectives in greater detail. At the phone screening, I determined if the patient met eligibility requirements through patient self-report of diabetes diagnosis.

Patients were eligible if they were 18 years of age or older, English-speaking, active patients of the clinic for a minimum of 12 months, and had self-reported type 2 diabetes. The primary care providers were eligible if they were a primary care provider (MD, NP, or PA) at one of the five participating clinics, worked for a minimum of 1 year at a minimum 40% full-time equivalent (FTE), and had an assigned panel of patients. The team members were eligible if

they were a clinician or other primary care team member assigned to a study participants' primary care team on an ongoing basis. If a participant and or team were eligible, we decided upon mutually convenient times, dates and locations for the individual participant and team focus group interviews.

Enrollment. On the date of the first patient interview, the process of informed consent using a consent form was first conducted with the patients prior to any interviews or observations. Verbal consent was obtained before observing each patient-provider interaction, and patients were notified that they could refuse the observation. Providers and clinical staff were also consented using a consent form specifically tailored to the health care team. The interviewee's telephone contact information was collected to facilitate scheduling. The interviewee was reminded that the research was completely voluntary. The interviewee was provided a telephone contact number for the investigator. Each interviewee was thanked for their time and given a \$25 gift card after each interview.

Interviews. Data collection methods included informal and semi-structured interviews. I conducted individual interviews with 17 patients with type 2 diabetes (Table 3.1) in five clinic settings throughout the U.S. (Table 3.2). As noted in Table 3.1, the population sampled was mostly women (n=11, 65%), 55 and older (n=15, 88%), majority non-white (n=9, 53%), with at least some college education (n=10, 59%). Patients with type 2 diabetes (average years duration of diabetes n=14.5) were interviewed about their experiences with the care team and to explore the nature of their interactions with the primary care team. The semi-structured interviews lasted up to one hour, and were conducted using a set of open-ended questions (Appendix A and B).

When possible, I attempted to find interview locations outside of the clinic setting, as I believed that interviewing in the clinic could have the potential to inhibit patient responses,

especially since informants were discussing interactions with their providers and team members.

I conducted four interviews by telephone.

Focus Groups. I conducted four focus groups with the patients' primary care providers and team members (n=24) to elicit experiences from the primary care team. Staff recruitment at one of the clinics was not possible because their patients were recruited as a follow up to another study. Overall team members consisted of 6 primary care providers (MDs, NPs, and a PA), 4 registered nurses, 2 wellness coaches/health educators, 8 medical assistants, 2 patient services/front desk staff and 2 administrators (Table 3.2).

Table 3.1
Patient Participant Characteristics

Demographics	Site 1	Site 2	Site 3	Site 4	Site 5	Total
N	4	2	6	2	3	17 (100%)
Female	1	1	4	2	3	11 (65%)
Age range						
<35	0	0	1	0	0	1 (6%)
36-45	0	0	0	0	1	1 (6%)
46-55	0	1	1	1	0	3 (17%)
56-65	2	0	3	1	0	6 (36%)
>65	2	1	1	0	2	6 (36%)
Race/Ethnicity						
White	3	0	3	1	1	8 (47%)
Asian	1	0	0	0	0	1 (6%)
Black	0	2	0	0	0	2 (12%)
Latino	0	0	3	1	1	5 (29%)
Native American	0	0	0	0	1	1 (6%)
Education						
Did not graduate	0	0	0	0	0	0 (0%)
High school/GED	0	0	1	2	1	4 (24%)
Some college	0	2	2	0	1	5 (29%)
Bachelors/Masters	2	0	2	0	1	5 (29%)
Did not report	2	0	1	0	0	3 (18%)
Average years T2DM N(range)	14.24 (3-27)	23 (23)	11.9 (1.5-25)	6.5 (3-10)	19.7 (15-24)	14.5 (1.5-27)

Provider and team focus group meetings were held at the convenience of the staff and food and beverages were provided as an incentive for participation. The semi-structured focus groups lasted up to 60 minutes. I used a set of open-ended questions to explore topics presented in the patient interviews and to elicit descriptions about the structure, composition, and communication methods of team-based care at that specific primary care setting (Appendix C).

Table 3.2
Clinic Characteristics

	N
Total Sites	5
Organizational Structure	
Community Health Center (CHC)	3
University-based primary care	1
Independent Practice Association (IPA)	1
Location	
West Coast	4
East Coast	1
Setting	
Urban	2
Rural	2
Mixed	1
Team structure	
Expanded	4
Teamlet	1
Participating team members (all sites)	
MD (PCP)	3
Nurse Practitioner (PCP)	2
Physician Assistant (PCP)	1
Registered Nurse	4
Health Educator/Wellness Coach	2
Medical Assistant	8
Patient Services/Front Desk	2
Administration	2

Each interview and focus group was digitally recorded, allowing for verbatim transcription of the interview and review of the conversation by the investigator at a later time for the purpose of checking for accuracy, extracting narratives, themes or quotations. All transcripts and documents identifying team structure were kept on an encrypted UCSF computer and electronic versions of the transcripts were stored in password-protected files on the UCSF secured network. Transcripts were de-identified of person and place names. Audio-recordings and contact information will be destroyed upon completion of the study.

Observations. When possible, interviews were supplemented by visit observations to observe patient interactions with their care team. Several team huddles were also observed before patient visits. Field notes were taken as soon as possible after the observations and huddles.

Additional data. Supplementary data included strategic planning documents, annual reports, patient brochures and administrative or planning documents describing clinic team structure.

Data Analysis

MaxQDA qualitative data analysis software was used to assist with the qualitative research process such as transcription review, coding, text interpretation, and content and discourse analysis. I used data triangulation to gain insights and generate a range of perspectives regarding team-based care. Comparing observational field notes, semi-structured and informal interview notes, as well as administrative documents describing the team structure to identify commonalities and differences from patient perceptions achieved data triangulation. Three narrative, phenomenological methods were employed to interpret the data: paradigm cases, thematic analysis and exemplars (Benner, 1994; Smith, Flowers & Larkin, 2010). These analytic

strategies are designed to provide the basis for entering practical worlds and understanding socially embedded knowledge (Benner, 1994). In order to maintain confidentiality of the clinics and patients, the results and quotes are presented with fictitious patient, staff and clinic names, approximate patient ages, and intentionally obscured clinic location details.

Coding. The analysis began with coding interview transcripts in the phenomenological tradition with direct quotes, personal notes about my response to the text or the informants to allow me to more fully understand my perspectives and blind spots, which was especially important given my personal background in coaching clinics on team-based care. Additionally, I coded with both theoretical and interpretive notes, particularly noting any reference to the three main constructs of situatedness, ways of being in the world, and patient concerns.

I also coded for themes and marked aspects of the text that seem to be about a specific topic. From the larger codes I looked for sub-themes and continued to rework the analysis until it formed a coherent story. My initial coding attempts in my pilot study identified several broad themes: (1) team structures can promote or inhibit team-based care, (2) trust as a key element for patient acceptance of team care; (3) training, scope, and perceived competency is key to the primary care provider and patient trust in team care; (4) caring team relationships encouraged patient engagement.

Memo Writing. I used memo writing as an analytical tool to capture developing thoughts, concepts, theories and interpretations from early data collection through interpretive analysis. They served as a useful iterative documentation of my reflective and interpretive process. As described by Lempert (2007), the memos served as “the narrated records of [my] analytical conversations with [myself] about the research data” (p 247). I wrote memos after memorable interviews to describe patient narratives about their experiences and my reflections to

those narratives. For example, in this memo I described a patient's reaction to finding her family through DNA testing:

This patient talked about finding her family members recently. She was an adopted only child, and both parents had died, her mom when she was 22, and her dad 8 years ago. "I'm all alone". After finding her family, she said "So now, I know something about my health history, and I know my whole family history, and everybody at the clinic shared all of it with me." She shared her intense joy of finding her family with all the clinic staff. She shared the joy of selling her stressful business with the staff. Then she went on to say, "They're really like my family."

Memo writing allowed me to enter the hermeneutic process by going back and forth between the data and interpretation, and by recognizing gaps and contradictions in the data for further analysis. It served as an analytical technique to analyze narratives and document emerging patterns and my global impressions of the text.

Narrative Analysis. Narrative analysis, or the study of human stories of experience, can be considered both a type of data collection as well as a method of inquiry in interpretive phenomenology. Narrative inquiry is built on Dewey's (1938) idea that experiences are continuous and interactive, and if reflected on may yield insights to human meaning-making. Narrative depictions of events allow investigators to examine the complexity and full range of human experience in a holistic way (Webster & Mertova, 2006). It is through the telling of stories that people make sense of their lives. Narratives are fluid and constructed over time by personal, family, community and historical events and represent a temporal impression of an experience. In describing the power of the narrative, Bruner (1987) states that retelling a story of one's life is an interpretive event that is susceptible to cultural and interpersonal influences.

Sandelowski (1991) saw humans as narrators and their stories as texts to be interpreted in a post-modern deconstruction of “how experience is endowed with meaning” (p 165).

In this interpretive, phenomenological inquiry, the narratives illuminated what mattered to the participant in a particular situation - the small and larger concerns (for-the-sake-of which). Narratives about negative events revealed what was perceived to be a stress or difficult in a situation. In instances of breakdowns, they uncovered what was available to the participant to return to a smooth flow (ready-to hand way of being). How the participant coped within a situation, as well as what emotions, skills and learning showed up in their coping became key questions to consider. How the participant made sense of the experience, or changed their thinking about their life and relationships provided rich analytic clues to the meanings of team-based experiences. Throughout my analysis, I provided exemplar and paradigm cases to highlight the themes and findings.

Ensuring Rigor

In discussing rigor in qualitative research, it is beneficial to reconsider the tensions between qualitative and quantitative research, and the epistemological and ontological sources of those tensions. In positivist research, standards of quality and rigor concern whether the chosen indicators measure what they are supposed to measure (validity), whether the measures are stable regardless of researcher effect (reliability), and if the research findings are replicable. These traditional constructs of validity, reliability and replicability have been deemed to be inappropriate measures for defining qualitative rigor due to the non-fixed, situated and iterative nature of qualitative research (Schwartz-Shea & Yanow, 2012). The positivist concept of validity assumes that careful research design will uncover universal, objective truths. In contrast, interpretive qualitative research does not attempt to measure phenomena or find universal truths,

but seeks to understand subjective meanings while valuing situational knowledge. Reliability, replicability and generalizability are not deemed to be significant research goals because qualitative research findings are assumed to be dynamic, historically situated, and multi-vocal (Schwartz-Shea & Yanow, 2012).

Attempts have been made to describe and translate positivist notions of validity and reliability to defend the merits of qualitative research (Lincoln & Guba, 1985; Popay, Rogers & Williams, 1998; Whitmore, Chase & Mandel, 2001). Whitmore, Chase & Mandel (2001) provide a synthesis of the concepts of validity in qualitative research, differentiating between primary (credibility, authenticity, criticality and integrity) and secondary (explicitness, vividness, creativity, thoroughness, congruence, and sensitivity) criteria.

The four primary criteria are considered necessary to ensure validity in qualitative research. The first, credibility, is the assurance of an accurate interpretation of the meaning of data so that the research reflects the experience of participants in a believable way. Lincoln and Guba (1985) consider credibility to be the overriding goal of qualitative research. Authenticity is achieved when the research reflects the lived experiences and meanings of participants, while remaining aware of the commonalities and difference of multiple voices. Criticality refers to efforts to systematically and critically structure all aspects of the investigation including design, hypotheses, potential biases and evaluation of evidence. Finally, integrity is the assurance that interpretations are grounded in the data and not overstated.

Secondary criteria allow room for differing philosophical and methodological emphasis in the definition of validity (Whitmore, Chase & Mandel, 2001). For example, high quality research using interpretive phenomenology focuses on explicitness, vividness, and thoroughness. Explicitness allows one to follow the interpretations of the researcher through a documented

audit trail (Lincoln and Guba, 1985). Vividness refers to thick descriptions with “artfulness, imagination and clarity” (Whitmore, Chase & Mandel, 2001, p 531). When thoroughness is achieved, the informants and their situations have been adequately sampled, interrogated, and analyzed.

Morse (2015) identified five phases to the approaches of rigor (Denzin & Lincoln, 2017) - prior to 1960 when rigor discussions weren't formalized, the 1970s initial responses to positivism, the 1980s to mid-1990's adoption of Guba and Lincoln's criteria, the mid-1990s to mid-2000's adoption of checklists and standards, and the 2005 to the present's focus on internal methods of building rigor and overall appraisal of completed research. Lincoln and Guba's (2013, pp. 70-71) recent description of quality criteria for hermeneutic inquiry challenges a one-size-fits-all approach to quality. Contemporary thought on qualitative rigor and quality is that rather than something that is *a posteriori* bestowed by an external research review, it is built into or developed within the research (Morse, 2015).

These validity criteria were applied to this study of the team-based primary care experience of patients with type 2 diabetes. Credibility was established through thorough and systematic data collection from informants, their providers and team members. Revealing participant direct quotes and narratives ensured authenticity. Following the hermeneutic interpretive tradition, interview transcripts were reread, compared and contrasted throughout the study. In an attempt to achieve thoroughness, perspectives from clinics in different stages of team-based care development were sought. To improve rigor, the raw transcript data and emerging interpretations were shared with interpretive research colleagues, mentors, and my advisor in on-going meetings. This collaborative review supported criticality and integrity.

Discussion

This study of patients with type 2 diabetes and their health care providers' experiences with team-based care blends three domains of research: chronic disease, the practice and delivery of health care, and skill acquisition. Interpretive phenomenology has precedents as a research methodology in each of these domains.

Since interpretive phenomenology is the study of everyday experiences in both normal as well as disrupted states, researchers have recognized its applicability to the understanding of patients' experiences with health and illness (Benner, 1994). The study of health and illness from a phenomenological perspective is concerned with the experience of individuals with their illness in the context of their day-to-day lives. Phenomenology has been used to understand the ways that chronic illness experiences are "storied" in written accounts or in research interviews (Katz & Mishler, 2003).

Benner's seminal research spanning several decades used interpretive phenomenology as a way to understand practice in health care, particularly study of nursing practice (Benner, Tanner & Chesla, 1992). The value of soliciting narrative accounts in the study of practice is recognized. In the study of nursing practice, the authors note, "highly skilled performance, pragmatic activities and human concerns are highly relational." One would anticipate these relational concerns to be even more evident in team-based delivery systems.

Benner, Tanner & Chesla (2009) used interpretive phenomenology to further the understanding of nurses' progression from novice to expert, demonstrating applicability to the adoption of new skills and behaviors. Benner (1985) saw the power of interpretive phenomenology to study action and behavior that may be applicable to the support for behavior change often evident in team-based practice.

At issue is the understanding that the existence of or freedom from disease may be a necessary condition for certain behavior, but a sufficient condition would be the presence of disease together with the person's experience of the disease and the environment, which constitute together a teleological (goal oriented) antecedent (p.3).

Benner (1985) notes that teleological laws (the philosophical study of nature by attempting to describe things in terms of their purpose) are transactional and require the "systematic inclusion of meanings and self-interpretations in the study of health, illness and suffering." The use of interpretive phenomenology shows promise as a methodology to study the goal-oriented nature of team-based care interactions.

A final consideration worth noting regarding the study of team-based care in primary care settings is the historical context in which this study is taking place. Many of the payment reforms that support team-based care have been enacted as a result of the Affordable Care Act: fee-for-service add-on payments for wellness visits and chronic care management, the Merit-Based payment system (MIPS), and funding supporting Accountable Care Organizations (Basu, Phillips, Bitton, Song, & Landon, 2015; Pittman & Forrest, 2015). With the last U.S. election, and the resulting attempts to weaken the Affordable Care Act, it is not known whether these payment reforms will survive. This threat may have impacted my research on team-based care in unknown ways, yet to be determined.

Van Manen (1990) states that the research method one chooses should maintain a "harmony with the deep interest" (p.2) that an investigator brings to the research. My aim is congruent with interpretive phenomenology's: "to construct an animating, evocative description of human actions, behaviors, intentions, and experiences as we meet them in the lifeworld" (van Manen, 1990, p.19). The human science approach described in this paper highlights the

congruence of an interpretive, phenomenological, hermeneutic approach to make sense of the lived experiences that patients with diabetes have with team-based primary care. As team-based care becomes a central transformational strategy in primary care settings, it is important to understand and reflect on the meaning and experience for patients and their primary care team.

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Chapter 4

Characteristics of Participating Clinics

If you want to build a ship, don't drum up people together to collect wood and don't assign them tasks and work, but rather teach them to long for the endless immensity of the sea. – Antoine de Saint-Exupéry

Five primary care clinic systems are represented in this study (Table 4.1): three federally qualified community health centers (FQHCs): one rural (Mountain View Health Center), one urban (Franklin Community Health Center), and one statewide rural/urban (Warren Health Center); a university-based clinic (Northpoint Primary Care Center); and a rural primary care clinic affiliated with an independent practice association (Harrison IPA Primary Care Clinic). Each clinic had a team composition structure that was unique to their patient population, workforce, physical size, configuration, and reimbursement system. To better understand team and patient dynamics, in this section I will describe each of the five clinics that participated in the study, starting with the three FQHCs. Sources of information about the clinics were obtained from the clinic websites, annual reports, discussions with clinic leadership, and team focus groups. The names of the health centers, health center staff, and patients have been changed and the locations and demographic data of the clinics and patients have been deliberately obscured to preserve confidentiality.

Federally Qualified Community Health Centers (FQHCs)

Three of the clinic systems included in my study were federally qualified community health centers. Federally qualified community health centers (FQHCs) provide primary care to over 8% of the adult U.S. population, a third of people living in poverty in the U.S., and over 10% of U.S. children (Health Resources and Services Administration (HRSA), n.d.). Many of the patients served by FQHCs have been subject to systematic disadvantage, such as poverty,

lack of health insurance, homelessness, marginal or unsafe housing, mental illness, and substance abuse.

The community health center movement began in the mid-60s through the vision of Dr. Jack Geiger from Tufts Medical School (DeBuono, B., Gonzalez, A.R., & Rosenbaum, S., 2007). Fresh from volunteering during the Freedom Summer in 1965, Dr. Geiger realized that many of the forces that made people get sick were social rather than medical in nature. With support of Tufts Medical Center, he traveled to Washington DC to request funding for a community health center. His initial \$30,000 request for a feasibility study grew to \$1.2 million to fund two inaugural clinical sites – one in Boston’s Columbia Point Housing Project and the other in Bolivar County, Mississippi, which at the time had one of the poorest black populations in the country (DeBuono, B. et al., 2007). As a result of their early success serving vulnerable populations, community health centers received federal funding to open more clinics around the country. There are now over 1,400 health centers in the U.S., serving over 29 million people (National Association of Community Health Centers, n.d).

The early work of community health centers focused not only on medical care, but also on the root causes of illness. When sick and malnourished children arrived to the Bolivar County clinic, doctors wrote prescriptions for food for infants and their siblings, offered as a “loan” that was reimbursed by the health center’s pharmacy department. They secured foundation funds to help families rent and buy vacant farmland left barren by cotton acreage restrictions imposed by the government. Recognizing the conditions that were leading to deadly infant diarrheal disease, they obtained funding to dig wells and sanitary privies, improve housing and reduce pesticide exposure (DeBuono et. al., 2007). Many health centers today lead nationwide efforts for integrating behavioral and medical health, as well as healthcare for

homeless populations, and substance use and addiction resources (National Association of Community Health Centers, n.d. a).

Federally qualified community health centers are funded through a combination of federal grants (330 grants), billing through Medicaid, Medicare, the Children's Health Insurance Program (CHIP), other state and regional initiatives, and grants from private foundations and state and local municipalities (Rosenbaum, S., Sharac, J., Shin, P. & Tolbert, T., 2019). Patients pay a small fee for care on a sliding scale based on family size and income and are not denied health care services if they are unable to pay. Health centers have historically had bipartisan congressional support by demonstrating that the benefits of their services outweigh the costs. It has become a source of pride for politicians to receive funding for health centers in their districts. Health centers typically receive more reimbursement on a per visit basis than traditional primary care practices to provide wraparound services for their highly complex patient populations. For this reason, they are often able to fund additional staff such as registered nurses, health educators, community health workers or health navigators, hence, a team of healthcare clinicians.

Community health centers vary widely in size and services, and are typically tailored to the populations they serve. Beginning in 1974, health centers were required to have their boards comprised of at least 51% of health center patients (DeBuono, B., Gonzalez, A.R., & Rosenbaum, S., 2007). This has led the centers to be responsive to the populations they serve – such as urban, rural, indigenous groups, or communities of various racial and ethnic demographic mix. Due to the complex problems that many health center patients face, many health centers collaborate within their communities to provide resources for their patients and families.

From their inception, the health center movement founders recognized that they needed to demonstrate the effectiveness of their efforts to justify funding support from state and federal agencies. They instituted a standardized method of measuring quality of care through a unified data system (UDS) - chronic and preventative disease quality measures collected in a standardized way across all health centers. By tracking quality measures, health centers have indeed proven that they provide high quality care. In 2018, over 80% of health centers across the nation met or exceeded Healthy People 2020 quality goals for one or more clinical standards (National Association of Community Health Centers, n.d. b). For diabetes care, 67% of health center patients with diabetes controlled their blood sugar levels (A1C <9%), which exceeded the national average of 60% (Bureau of Primary Health Care, 2019).

While federally qualified community health centers share basic funding and organizational structures, each health center tailors its staff composition, programs and operations to fit the cultural and linguistic needs of the communities it serves. For this study, I interviewed patients at community health centers from three different regions: a large urban health center, a rural health center, and a statewide urban/rural community health center (Table 3.2).

The Team Dance - Mountain View Community Health Center

The only way to make sense out of change is to plunge into it, move with it, and join the dance. *Alan W. Watts, British writer and philosopher*

So, we did a team dance, and we all got to learn about each other's roles, how to prep a huddle, to talk to your team members and try to communicate and work things out amongst each other (Eileen, RN, Mountain View CHC).

The Mountain View Community Health Center was founded over 40 years ago and serves over 10,000 medical patients and nearly 2000 dental patients at multiple locations in a rural west coast area. They have over 200 employees who provide primary care, reproductive

and obstetrical care, wellness, health education and behavioral health services, substance abuse resources and treatment, HIV/AIDS care, healthcare for the homeless, teen and transgender populations and senior care. Over 50% of their patients have Medi-Cal, and 10% are uninsured. Nearly half of their revenues come from fee-for-service billing, and another 40% from grants and contracts from private, state and county funding.

The clinic received funding from various state and local organizations to expand team-based care to include registered nurses (RNs), usually one RN shared by two teams. The teams include the care team representative (front desk staff), the medical assistant, an RN, and the primary care provider. The clinic also has three behavioral health counselors and a psychiatrist one day a week.

I interviewed the team at one of the health center's smaller outlying clinics that had six part-time primary care providers. Most of the clinic's primary care providers worked part-time, but the other team members, such as the registered nurses, medical assistants and patient service representatives, worked full time and shared their time with several primary care providers. I interviewed five team members of one team in the staff lounge – the PCP (Jean, PA), the RN Manager (Meg), the registered nurse (Eileen), the medical assistant (Linda) and the care team representative (Robert). Most of the members of this team spoke Spanish, which comprised about 30% of the clinic's patients. Jean, the PCP, and Eileen, the RN, have worked at this clinic for nearly 20 years, but have only been paired together consistently on the same team for the past 5 years.

The participants were comfortable with each other while talking about their work as a team. There wasn't a sense that one team member had more to contribute than another: what the

care team representative (front desk staff person) had to say was just as important as the primary care provider, and he substantially contributed to the discussion.

Going “Team-based”

The staff talked about “going team-based” five years ago. “Going team-based” was facilitated by a training, which they called “the team-dance” training. They learned about each other’s roles, how to prepare for and conduct a huddle (a short meeting before a clinic session to discuss the patients that are on that day’s schedule), how to communicate with team members and problem solve with each other.

The purpose of the training was an attempt to reduce the chaos that is often present in busy clinic settings. It helped the team members worked in a synchronized manner through an understanding of each other’s roles and improved and streamlined communication. This was likened to a well-choreographed dance, with team members anticipating each other’s moves as they went through the clinic session.

We had like a half a day with a PowerPoint, and then we had some practice runs of how to huddle together and so forth. We watched a video on a team practice at some place else in the country (Meg, Mountain View CHC RN manager).

In fact, part of the training that we had when we first started doing teams was learning what the other people were doing. Well, it's kind of like a dance ... a lot of role-playing. We broke out in little groups for case scenarios, to learn like, when you have this situation you go to your medical assistant, if you have this situation you go to the nurse. And who does the provider go to for certain things (Jean, Mountain View CHC PCP)?

The change to team-based care involved assigning specific staff to work as consistently as possible together, and scheduling patients so that they saw the same primary care provider when possible. Defining a team structure created an organizational structure that was consistent, so that staff members throughout the organization could make sense of who did what. It reduced

the chaos, and added clarity to the roles of not only individuals, but their relationships to the clinics' patients.

[Before teams], if I was trying to get somebody to help me, it was kind of a free-for-all. Who's answering the phone today? Who's around? I owned my practice, but the medical assistants would kind of rotate through, depending on who worked the day that I was around (Meg, Mountain View CHC RN manager).

That was huge with teams, so that you actually know who to go to. And the beauty is that we all know our patients. We also know which family that person belongs to. That's the beautiful thing about having a team, because the team knows who we are. When I say go ask Robert up front, that makes it easy too (Meg, Mountain View CHC RN manager).

Within their teams, there was a sense of joint responsibility of the care for the provider's panel (group) of patients. "Going team-based," meant that the patients were no longer the responsibility of just the PCP and his or her nurse, but care responsibilities were shared across the team and extended to the medical assistant and the front desk staff.

Creating teams allowed patients to know the specific staff members that were assigned to their care, and the staff to get to know the patients and their families, and develop relationships with them. The ownership of care created a sense of responsibility that was lacking without teams. Without team assignments, a patient care task could float unassigned and unheeded, without a sense of responsibility or urgency toward solving the problem for the patient. With teams, all of the team members felt responsibility for the patient.

"Going team-based" also meant a change in nursing practice at Mountain View clinic. The clinic went from two registered nurses to five, nearly one registered nurse per PCP, and one additional triage nurse. They were able to fund additional nurses through funding from grants and initiatives from the county's managed Medicaid program. Registered nurses provided much of the health education, coaching and care coordination for patients with diabetes. "The

beautiful thing about community health centers is that we actually have registered nurses. [In] private practice, it's incredibly rare" (Eileen, RN, Mountain View CHC).

The clinic staff described itself as having a non-hierarchical organizational structure, with continuous learning happening between team members of different roles. Registered nurses were encouraged to spend time with the medical assistants so they could appreciate the skills and knowledge that they brought to the team. This taught them to value their teammates' abilities and work closely together.

Team Learning Practices

The team interview highlighted several team practices: mutual support or "having your teammates' back," valuing what all team members brought to the team regardless of their educational backgrounds, and mutual learning through practice. There was an intention to be supportive, as expressed by this team RN, who sought to point out that "having someone's back" wasn't limited to the other RNs or providers in the clinic. This created a feeling of support for all the team members. Instead of a sense of competition between team members of different professions, or some team members vying to show that by nature of their education and experience that they had more power within the team, they intentionally created a "we're all in this together mentality."

Yeah. I'd say for my team, I feel like we all have each other's backs to a certain extent. And then I know that the MAs don't feel like there's that hierarchy of the providers up here and the MAs here or the nurse there (Eileen, RN, Mountain View CHC).

This was my first actual MA job. So, coming here and working as a team, it was very welcoming. Just getting support from every side, it was good (Linda, Mountain View CHC team MA).

This team's practice went beyond intentionally supporting each other. Being intentionally supportive was the baseline behavior that they built on. The next level was for the

team members to recognize the value that their colleagues brought to the team. This was on display in their team meetings, where the entire team's input was encouraged. In the team huddle that I observed, Robert brought up that he needed to have some insurance forms signed at that visit, and the medical assistant mentioned that the patient usually came in with a family member. Everyone's input was valued, which added not only to the understanding and care of the patient and the social determinants that impacted their care, but to the smooth functioning of the clinic.

I don't know what it's like at another clinic, but if you had a staff meeting or something, it feels very collaborative, and like he's saying, not hierarchical. Part of the culture is to have everyone's voice count. Let's hear what the medical assistant has to say. They really care. It's just totally valid (Jean, PA, Mountain View CHC PCP).

“Having everyone's voice count” served to flatten the organizational structure, with team members being attentive to each other beyond their prescribed roles. All team members felt that that had a role that mattered, and that they added a contribution to the team. Providing mutual support, and valuing what each team member had to contribute, led this team to take team practices a step further. Team members described how they encouraged mutual learning from each other. In many health care settings, training occurs with staff members and clinicians working within their professions to learn from more experienced practitioners. But in this clinic, team members were not only learning within professions, but were encouraged to learn across roles and professions. Nurses were able to learn and hone new skills by seeing how things were done on other teams. The nursing manager also encouraged the registered nurses to spend time with the medical assistants, with the express intent to learn from them. She recognized that medical assistants might be more skilled than nurses at doing some of the manual tasks that used to be the sole domain of nursing in primary care. Registered nurses working in primary care now tend to do more care management, health education and coaching, and have less practice than in

the past with the manual skills associated with day-to-day clinic visits, such as drawing and processing labs, administering vaccines and other medications, and assisting with office-based procedures.

And the nurses [on the other team] sometimes are doing things way differently, and it's like, 'Huh! Look at what Meg just did,' when she did the huddle. So, we learn things that way too (Jean, PA, Mountain View CHC PCP).

This mutual learning environment broke down defenses, and opened possibilities for learning and thinking about things in a new way. Seeing someone do something in a new way wasn't seen as threatening in this team.

And as the new nurse manager, one of the things I try to really instill with the nurses, especially the new nurses is, 'Hey, go to the MAs in the lab. They have lots of knowledge.' They're doing tasks that the nurses aren't doing as much. We're doing more case management. So, I feel like there's a team environment instead of, go ask the MA, or go ask the nurse. I feel like I try to keep it more team-based. I feel you just work better together (Meg, Mountain View CHC RN manager).

The nurse manager recognized that the team worked better together when they were learning from each other. There was a humility that occurred when they were sharing practices. Even learning from each other was less hierarchical, and knowledge flowed in all directions.

Interviewer: And did you feel like you were learning from each of the other team members? Was there one person in charge of training?

Linda: No. I feel like it is one care team, it's like we're all a team. That's how it feels here" (Linda, Mountain View CHC MA).

In this clinic, the mutual training was a demonstration of the value and care that the team members felt for their teammates. The continuous co-learning was how they fed and nourished the team.

The Integral Health Educator Role - Franklin Community Health Center

Franklin Community Health Center serves more than 50,000 patients spanning several urban west coast counties and seven cities, offering pediatric, adult and geriatric primary care

services as well as urgent care, wellness and health education, pre/post natal care, substance abuse treatment, care coordination and transitional care, case management, chronic disease care, mental health, health care for the homeless, senior home care and dental services. The health center participates in community-based research on areas of concern for patients living in urban areas, such as the effects of environmental stressors for people with asthma.

The Franklin Community Health Center has been in existence for more than 40 years, much with the same leadership. One of the most distinguishing features of the health center is its emphasis on health education and extensive use of health educators for patients with chronic disease. Unlike some of the other clinics that primarily use medical assistants or registered nurses, health educators are a part of the core primary care team for patients with diabetes.

When a patient with diabetes comes to the clinic for their primary care visit, they see the health educator first, in the same exam room as the primary care provider. The visit begins with the health educator, and then the primary care provider comes into the exam room. There is a short dialogue between the two with the patient in the room so patients see that the team members are talking to each other about their progress and goals. The patient's overall visit is longer, but more convenient because they aren't required to schedule and attend a second visit. This results in a seamless visit for the patient in one room with the different clinicians coming and going.

I was unable to interview the staff at this clinic location, but the patients with diabetes that I interviewed who had experience working with these health educators praised their extensive knowledge of diabetes and nutrition. "They [PCP and health educator] confer and plot strategy for my care" (Marshal, 67 years, Franklin CHC patient).

I've never ever had a healthcare team like here. Those two individuals [health educator and nutritionist] are incredible. We used to have a nutritionist here called Lucille...

mercy, oh incredible. That lady could tell you the exact content of [anything], it was just really how she was. Between the two of those people, my knowledge about diabetes increased exponentially (Marshal, 67 years, Franklin CHC patient).

The patients felt a strong sense of a team working on their behalf, as they “plotted” or discussed their care. They knew that their team thought about their care beyond the time spent in a visit. The patients valued the support that they received, and saw it as supplemental to what they would receive from their primary care providers alone. Lily, a patient of the Franklin Community Health Center, spoke of her health educator: “She’s the type that can get me to do anything that I didn’t want to do. She could get me to do it. She would be like... try.” (Lilly, 53, Franklin CHC patient). The health educators did not ask for perfect adherence to a nutrition or exercise plan from their patients, just to “try” new ways to control their diabetes. By asking them to test out new ideas without an expectation of perfection, patients felt empowered to attempt new self-management skills.

Empowering the Team - Warren Community Health Center

Warren Community Health Center is a large, statewide community health center system that has been in existence for more than 40 years, initially starting as a free clinic. It now serves nearly 150,000 patients at hundreds of locations, providing primary care, dental and behavioral health services. This community health center offers a wide array of services for patients with HIV/AIDS, LGBT-focused primary care, healthcare for the homeless, substance use and addiction, wellness classes and services, as well as a large number of school-based health centers. They have an extensive, centralized quality improvement department as well as a well-staffed IT department.

One of the distinguishing features of Warren Community Health Center is their commitment to provider and staff training. They have a medical assistant training program,

family nurse practitioner (NP) training residencies, and a research and innovation center that focuses on the needs of underserved and specialty populations. They host several case-based training initiatives on Hepatitis C, HIV, behavioral health opioid dependence and chronic pain.

Warren Community Health Center has invested heavily in training for team-based care, particularly in expanding the roles of medical assistants and registered nurses. Their teams are co-located in pods of two primary care providers, two medical assistants, and a shared nurse. Also available to the teams are behavioral health specialists, and certified diabetes educators.

Medical Assistants: A Central Part of the Team

Medical assistants had an integral role on the team at Warren CHC. They were paired with a primary care provider and co-located in the same pod shared with another PCP/medical assistant and a shared registered nurse for the two PCPs. Medical assistants were trained in chronic disease care basics and to use a daily dashboard (report provided by the clinic's technology department) to determine what patients needed for preventative and chronic disease care. They had standing orders for activities that were within their scope of practice. All the medical assistants were also trained in motivational interviewing, so the primary care providers, medical assistants and nurses all communicated with patients with the motivational interviewing guiding principles in mind.

The MAs assist as well because they have a dashboard that they review every morning. And so if there's A1Cs that are needed, anything related to their particular care, then they are also putting it in the chart. So either they're performing it or advising the provider if something is needed that's beyond their scope of practice that they need to put in. But they can order the A1C without the providers because the order's there. We will talk if I notice something or if they notice something. And even the MA can chime in and say, "Hey I've noticed this." And we can have a discussion around it (Maria, RN, Warren CHC, Nurse manager).

The medical assistants were empowered and encouraged to speak out about what they noticed about the patients, and didn't feel that they had to wait until the PCP or nurse brought

something up. They all discussed the mutual concerns that they had concerning their patients. The team empowered MAs to “notice,” to go beyond their typical tasks of rooming patients or taking vital signs, to be aware of what was happening in patients’ lives.

An Expanded Role for Registered Nurses

Warren CHC made a significant investment in registered nursing by providing a shared RN for each team. The RNs had extensive knowledge of chronic disease management and independently assisted patients to meet chronic disease management goals. They provided nursing assistance to the team’s panel of patients, as well as care management by referral for particularly complex patients. In the team interview, I saw team practices unique to the role of registered nurses working in primary care settings: guided autonomy supported by standing orders and standardized procedures, an emphasis on personalized patient care by creating individualized solutions to patient problems, and a heightened sense of team communication.

The nurse manager, an experienced primary care nurse, described the autonomy that registered nurses were given as they work under the direction of standing orders, sometimes called standardized procedures. Standing orders are written guidelines that describe care for a given diagnosis, and are jointly developed with the medical and nursing staff, approved by the clinical leadership. This organizational system of using standing orders allowed nurses independence while providing assurance to both the primary care providers and nurses that they could use their own judgment in executing clinical actions. The nurses felt secure that they were bounded by the parameters of the care that they could legally give, which gave them confidence and facilitated trust with the primary care providers. The nurses felt that they could freely propose a plan of care based on their observations without waiting for instructions from the primary care provider.

In this following example of a patient with diabetes, the focus of the plan of care was on the individual patient, to help her reverse the trend of rising blood glucose that the nurse observed. With the independence afforded by standing orders, the nurse was empowered to make a plan of action that took into account what worked best for the patient including the frequency, location, and type of visit.

As a staff nurse, we have a lot of autonomy and our clinical judgment is often trusted, which is very nice. We have a set of standing orders that are there so that we have our own nursing visits, we can approach the provider and say, 'Hey this patient I'm reviewing....' Let's say we're huddling in the morning and I'm looking to see who needs vaccines. I also notice that they're diabetic so I happen to look to see what their last A1C was, and then I may notice that there's a trend upward in the last eight months of results. So I would go to my provider [and] say, "Hey Dr. Mutha [PCP], Claire [MA], I'm noticing a trend. I would like to enroll them in care coordination and see how we can assist in helping this patient get back to where they need to be (Maria, RN, Warren CHC nurse manager).

Here we see more “noticing,” of patients, this time by the registered nurse, who as a team member, was empowered to look beyond her narrow role and make suggestions to the PCP. This careful attention includes an assessment of whether or not the patient was ready for behavior change.

At that point, the provider will tell me yes, I can see them every two weeks. They would make that note. And however I see fit, I could bring that patient back or I could give them a phone call and check in and see how they're doing. We can establish self-management goals if they're ready, do motivational interviewing (Maria, RN, Warren CHC nurse manager).

Complex care coordination was a chief role of the nurses in this clinic system. A formalized system of care activated nursing care coordination. The primary care provider or the nurse could initiate referrals to the program. Nurses did an independent assessment of the patient's medical and social needs. If the patients' needs were complex, they could present their case to an in-house case-based educational and training program where individual cases were discussed. Nurses decided which cases they presented to the program.

They have a program here that's complex care coordination, which they can ask us if we want to refer or we can just say, "I want to enroll this person in care coordination," and then they will take them on and just look at what it is they are needing, what are the barriers. I will share with them what I think the barriers are but they [the registered nurses] do a lot of their own stuff and they have [an interdisciplinary training program], where they work on care coordination and discuss cases (Maria, RN, Warren CHC nurse manager).

In identifying patients' barriers to care, the nurse is demonstrating that she has an understanding of her patients' worlds, the particular circumstances in their lives that are preventing them from managing their diabetes. She knows her patients in a deep way, and discusses the barriers that she witnesses with other members of the team.

In the example below, a primary care provider described the value that she felt a nurse added to the individualized care of a patient with diabetes. The awareness of a patient's particular problem would have typically been overlooked in a busy primary care office. But with the availability of nursing care, they were able to work with the patient to come up with a customized plan that met his desires not to do his own blood sugar testing, while using the expensive insulin that he had available to him at home. The primary care provider valued the personalized care given by the team nurse. Having a team member care for this patient allowed the time to creativity think of solutions to adapt to the patient's unique situation.

But we have had patients, specifically with diabetes, for example. Somebody who's unwilling to check their sugar at all but is not a candidate for anything other than insulin. One gentleman has a large amount of insulin at home and he doesn't want to have to buy anything else so he wants to use that. But he doesn't ever want to check his sugar, so she arranged for him to come in every day, have his fasting sugar checked by her, and then she would follow up with him on it (Audrey, NP, Warren CHC PCP).

The RN-PCP relationships varied from individual to individual, and expanded as the relationships grew. One nurse described how she was able to make a significant impact in the lives of patients with diabetes at one clinic setting, only to have difficulty gaining the same

traction at another site. She described how the trust between the nurse and provider grew over time as they observed the assistance that nurses could provide for their patients.

Registered nurses had their own schedules that were filled by the patient services representatives (PSAs) according to protocols. For example, if a patient called with symptoms of a urinary tract infection, they were under 60 years of age, female, and the symptoms were not reoccurring, then they were put on the nurse's schedule. Nurses also saw patients for vaccines, blood pressure checks, spirometry, and retinal screenings. The PSAs had visit length guidelines so they know how to schedule accordingly. Nurses also scheduled their own patients, and PCPs requested nursing visits for follow-up appointments.

Maximizing Technology for Daily Communication

Unlike the other clinics participating in this study, Warren Community Health Center replaced the daily huddle with a more flexible approach using technology as a way to communicate. The clinics had a high no-show rate (patients scheduled for an appointment who did not come in), so in the past, the team members spent a lot of time prepping for patients who didn't come in. With the new system, the visit preparation was done the morning before the session started, and was on-going throughout the day. The team members reviewed the schedule, and put notes in the EMR with relevant details about latest lab results or what was needed for the patient for that visit. They also used an instant messaging system that worked through the EMR for on-going communication throughout the day. A provider messaged an MA while they were in the room if they needed something. I observed a PCP message an MA to copy pages from a health education resource and bring them to her during an exam. The provider didn't need to leave the room to make a request of her MA and could stay focused on the patient.

Pas de Deux: The Art of Partnering - Northpoint Primary Care Clinic

Definition of “pas de deux” (Merriam-Webster)

1. : a dance or figure for two performers
2. : an intricate relationship or activity involving two parties

For over thirty years, Northpoint Primary Care, a university-based primary care clinic, has provided acute, chronic and preventative services, prenatal care and dermatology services to patients of all ages. They refer specialty care to the university-based specialists within the same health system.

This clinic has seen many iterations of care delivery, and in the past had a more traditional structure with a primary care provider supported by a medical assistant primarily for rooming patients and taking vital signs. The clinic tried multiple efforts to improve operations and efficiency over the years, and at one point designed a staffing system to maximize flexibility of medical assistants, so they were no longer assigned to one physician. This resulted in fluctuating staffing arrangements, with the physician and medical assistant pairs changing daily depending on staffing needs.

About five years ago, the clinic medical and administrative leadership implemented a team-based model of care, consistently pairing small teams (teamlets) of co-located primary care providers and medical assistants. Because many of the primary care providers had other research and teaching obligations and were in the clinic half time or less, most of the medical assistants were paired with several physicians. The primary care provider usually had the same medical assistant, but the medical assistant worked with several providers in a typical week.

The clinic used licensed vocational nurses (LVNs) to draw blood, and give immunizations and injections, as well as several registered nurses, who conducted care coordination and triage. The LVNs and RNs were not assigned to specific teams, but rotated

where needed. The clinic also had health navigators who worked with patients who were high clinic and hospital/ER utilizers. There was a nutritionist on site about two days per month, whose services were often not covered by most patients' insurance, requiring them to pay out of pocket for her in-clinic services. Front desk receptionists greeted patients, answered phone calls, and triaged phone and electronic messages.

In the past, Northpoint had a reputation for high turnover and low morale among the staff. Moving to the teamlet model has been a positive change for this clinic, which is now receiving some of the highest patient satisfaction scores in the university system. Co-locating the medical assistants and the primary care providers allowed the teamlets to easily communicate about patients and conduct huddles before each clinic session. Co-location provided many opportunities for two-way education – the provider taught the medical assistant about clinical conditions impacting patients, and helped them to become familiar with their desired working styles and what was important to them as providers. Sitting next to the primary care provider allowed medical assistants to more easily share with the providers what they learned about patients' lives, and their thoughts about barriers to their care. Based on clinic survey data, staff morale in the clinic has improved and accountability has increased with this new model of care. The medical assistants were assigned to their providers' specific panels of patients and were expected to track the required preventative and chronic disease care for those panels. They were given monthly reports on their patients' progress on these metrics. The university's clinical administration had a narrow interpretation of medical assistants' scope of practice which limited their role to rooming patients, taking vital signs, managing the provider's in-box, and drawing blood (if they received phlebotomy training). They were not allowed to provide any health education or coaching, or give immunizations or injections.

I interviewed Dr. Hill, and his medical assistant, Ms. Smith, when they worked together as a teamlet at Northpoint clinic. Dr. Hill and Ms. Smith shared the same office space and their desks were next to each other. Ms. Smith roomed the patients, took their vital signs, reviewed current medications to update the medication list, assisted between visits by answering emails to providers sent through the patient portal, and reached out to patients who hadn't been coming in for their visits or labs.

There was a sense of ease and trust between Dr. Hill and Ms. Smith. She considered his style to be easy-going, and their communication to be effortless. "I know exactly what he wants as far as with diabetes patients. He really doesn't need to tell me exactly what he needs" (Ms. Smith, Northpoint Clinic medical assistant). They approached their working relationship assuming the other had their best intentions in mind. They watched out for each other, and often double-checked each other's work as a safety precaution. There was a sense that they had each other's backs.

I just assume that [she] has already looked at all these things, and then if the patient needs a foot exam, she does it. I will look at it afterwards while I'm in the room with the patient at some point, but even if she's pended things [placed an order in the EMR], sometimes I'll just want to make sure. But for the most part, you know, she takes care of all those things, and I don't, besides signing the orders (Dr. Hill, Northpoint PCP).

Teams in this setting not only knew their patients, but they got to know each other. Throughout the interview, both Dr. Hill and Ms. Smith acknowledged and recognized each other's contributions to the care of their patients. It was understood that Ms. Smith felt that Dr. Hill's patients were her patients, that they were jointly sharing patient care. Dr. Hill seemed to be at ease with letting go of some of the details of his patients' care to Ms. Smith. Under the university-based system rules, the medical assistant can "pend" certain orders in the EMR, and the provider then signs the orders to let the medical assistant know that they were approved.

This letting go seemed to free up Dr. Hill's time to have a deeper relationship with his patients, to be more present in their company, and for them to feel a connection when they were with him in the room. In one visit, I observed Dr. Hill unhurried conversation with a patient: he sat directly across from him, and had a long conversation before examining him or consulting the medical record. It wasn't until after the exam that he consulted the EMR.

Creating Time and Space for Building Trust

During my interview, we discussed several stories of patients with type 2 diabetes, and Dr. Hill and Ms. Smith jointly added to the narratives. We also discussed how they worked together as a team. The first story that they chose to share with me was about a patient who they had seen that morning who brought in a cake as a going away gift for Dr. Hill (they both laughed at the irony of a patient with diabetes bringing in a cake). The patient was in his 50s, worked full time, had type 2 diabetes and high blood pressure. He had been reluctant to accept that he had a chronic disease because he felt so healthy most of the time, but his A1C was extremely high when he first came to see Dr. Hill. He rarely stayed with the same doctor for long, and rejected most types of care, including doing blood tests or taking medications.

And his wife tells me, "This is the longest he's ever gone to a doctor. He usually just gives up at some point." They come and see me every three months. We don't make huge changes. We haven't made huge strides, but we made a little bit. His blood pressure is really well controlled, and I am so happy about that. His diabetes is not -- still not super well controlled, but that being said, now every time they come in, they like the routine of it. Sometimes they remember to get labs ahead of time. I would call this all relationship building. That we had to build a relationship, and he had to trust me. I'm sure that's true for most people, that I think people want to make sure that you are on their side and that you're not going to do anything that's going to hurt them (Dr. Hill, Northpoint PCP).

Woven throughout the interview, Dr. Hill talked about how he approached the care for his patients with diabetes. He was less concerned with outcomes in the traditional sense that one would expect (reduced A1C, weight loss, reduced cholesterol levels, up to date on

all the health maintenance items). His focus was on developing relationships with his patients, gaining their trust, and jointly working together with them in their own time and pace, to achieve the goals that they wanted to achieve. The interview showed a deep sense of “knowing” his patients – not just about their physical health but also about their lives, families, motivations, and desires.

Tanner, Benner, Chesla and Gordon (1993) similarly describe the sense of “knowing the patient” in their research on expert ICU nurses. Knowing the patient goes beyond the knowing physical manifestations, but encompasses knowing about their lives and their emotional responses to their disease. Dr. Hill could see that this patient, a man in the prime of his life, didn’t want to be defined by his diabetes. He preferred to change doctors rather than be constantly reminded that needed to make changes in life: taking daily medications, daily monitoring his blood sugars, or changing his lifestyle. Dr. Hill “knew” his patient was approaching his disease from within his own perspective, or worldview, which was to seek normalcy. He didn’t want to be seen as a diabetic, but as a person with diabetes, in which diabetes was a small part of his full and active life.

In a typical relationship between a primary care provider and a patient with a chronic disease, there isn’t sufficient time during the visit to focus exclusively on trust-building. Did the fact that Dr. Hill’s medical assistant was empowered (through standing orders and training) to concentrate on many of the routine preventative and chronic disease care free up space and time for the primary care provider to develop deeper relationships with his patients? Or was it how this particular practitioner chose to practice, and he would have done this regardless of the types of team arrangements at the site where he was working? Surely one could imagine that freeing up his time and mental energy from some

of the routine care has had an impact on his morale and work satisfaction, making him more available to his patients and willing to provide individualized care.

Well, we tried metformin, and he kept having side effects with metformin. We tried extended release. He still had side effects with extended release. And, you know, I said, 'Even though this is what is probably the best thing, if you're not going to take it, then you're not going to take it.' So, you know, and he felt comfortable telling me he wasn't taking it, which took a long way to get to that point too, and so, then we've, you know, gone out of the box and tried other stuff (Dr. Hill, Northpoint PCP).

Having a trusting relationship based on deeply knowing the patient allowed Dr. Hill to creatively work with the patient to try different medications, to try "out of the box" solutions that were tailored to his patient's needs.

Teaching Beyond the Routine

When Ms. Smith, the medical assistant, described her role in the same patient's care, it revealed a different type of relationship with the patient. She said that she felt like she knew him well, and knew about his life and challenges, but in her time with him, she focused on the tasks at hand, taking the vital signs and labs, making sure everything was done that was highlighted in the electronic health record's health maintenance bar. She recognized that the wife tended to do most of the talking during the visit. When I asked Ms. Smith about her role with this particular patient, she described the tasks involved in rooming the patient and making sure that everything that was needed for the visit was performed. It was clear that she also knew this patient, his work schedule and routine, and even his vacation schedule.

Well, I confirm that it's a diabetes visit, go over the health maintenance bar [in the electronic medical record], what he's due for. Mr. K. tends to forget, like Dr. Hill said, going to the lab to get his lab work. I get the feeling that he's a real busy person and doesn't want to miss work to come here and doesn't want to miss work to go to the lab. So, he likes -- the wife, first thing she said, "Poke him." [Laughs]

I think the convenience of us being able to poke them right away and get the A1C is a big plus, especially for patients like that who don't admit they have diabetes, don't want to go to the lab, don't want to miss work to come to the appointment. As a matter of fact, he's

on vacation today, and that's the only reason he came in -- I mean this couple of weeks. They said he went fishing. He went to Las Vegas. He's very funny because he doesn't do any of the talking. It's the wife that does all the talking. [Laughs] They're a cute couple (Ms. Smith, Northpoint MA).

While the medical assistant clearly felt a rapport with the patient, and knew him well, I observed a teaching moment between Dr. Hill and Ms. Smith during this interview. Dr. Hill explained to Ms. Smith, that although the patient's wife does most of the talking, it was important to focus on what he had to say as a way to build rapport and understand his feelings and desires. He even gave Ms. Smith some examples of questions that she could ask him so that she could hear from him directly and not be spoken for by his wife. He subtly encouraged Ms. Smith to think about how she worked with this patient as an individual. This type of teaching, or coaching, of the medical assistant was aided by a pre-existing rapport and trust between the primary care provider and the medical assistant. The primary care provider cared enough about the on-going development of the medical assistant to explain some of the more subtle ways to build rapport with patients.

I think another rapport-building strategy with him was really focusing on him. Even though his wife is happy to talk for him, and he's happy to have her talk, I think I'm very clear about talking to him, "But how do *you* feel about it? Do *you* really want...?" You know. I think it's true for almost everyone. You have to kind of find how you're going to work with that person specifically.

I think my goal is to get them to come back. But I would say for everyone, though, the goal is that this is a long-term thing here. It's not like we're going to do something today. I'm not a surgeon. I'm not going to fix your diabetes today. This is going to take a long time, and so, we have to build a relationship. That way, you'll continue coming back, and we'll make changes because some things will work for a while. Then they stop working, and you do something else. Set that groundwork. So, really, my goal is always to get people to come back (Dr. Hill, Northpoint PCP).

What is striking in this narrative is how much Dr. Hill had earned the trust of this patient who had a history of not coming to see doctors and out of control diabetes (did have an A1C of 12%, now down to 9%). The wife reported that it was the longest he'd ever been coming to the

same doctor, so what was it about Dr. Hill that made him different for the patient? His wife told Dr. Hill that he usually “gives up.” Dr. Hill put any changes on the back burner while he developed a relationship with the patient, and got to know him as a person. He listened to him about his side effects and didn’t dismiss his concerns. He let the patient know that how he reacted to the medication was important, and encouraged him to be honest about whether he was taking it or not. He celebrated the successes of what was working well, such as getting his blood pressure under control. The provider’s encouragement of the patient’s honesty about his experiences, and willingness to tailor approaches based on his individual response, built a spiral of trust.

Dr. Hill was patient and willing to give his patient all the time that he needed to develop a trusting relationship. What clearly mattered to the PCP, his “for the sake of which”, was relationship-building. This seemed to take precedence over rapidly improving his A1C, adding new medications, or checking blood sugars, which ultimately all depended on repeated visits with the provider. The PCP was on a limited assignment at the clinic, but even so, was able to treat his patients as if the long-term relationship was the most important aspect of care. For Dr. Hill, relationship building was the foundational groundwork of his care.

If the lack of time was a barrier to develop a trusting relationship, it seemed that Dr. Hill was able to find ways to create the time and space for the relationship to develop. He developed enough trust with the patient that he came back every three months. Dr. Hill made changes to the plan at a pace that was comfortable for the patient. Getting him to take a medication that made his A1C go from 12% to 9% was an accomplishment, especially for a patient who was reluctant to accept his diabetes diagnosis. Dr. Hill was able to do this by not pushing him to the point that he didn’t want to come back, and by allowing the him the permission to be honest

about taking medications, even phrasing it in such a way as “if you don’t take it, it doesn’t do any good, so I’d rather have you be honest with me.”

While this narrative shows a strong trusting relationship between the PCP and the patient, the medical assistant’s role seemed secondary. The medical assistant’s role on this team showed that she anticipated what the PCP needed for the particular visit, knew the patient well enough to know that an in-house (point of care) A1C would be more convenient for him. However, the primary relationship in this clinic is with the PCP. It is possible that the close working relationship and trust that he has with his medical assistant freed up time for him in the visits to focus more intently on patients.

Mutual “Tuning-in”

This relationship between Dr. Hill and Ms. Smith conjures the image of “co-performers” in a “pas de deux,” – both working within the clinic structures to smooth the way for the meaningful relationship that existed between Dr. Hill and the patient. In this team relationship, sharing space through co-location played a role in the nature and quality of their interactions.

In their interactions, Dr. Hill and Ms. Smith acted in ways that were mutually understood. Communication was transmitted through a common vocabulary with the clinic and scope of practice rules guiding their interactions. This communication gave a glimpse into the meaning of team interactions. The medical assistant in this narrative was able to do much more than one might expect in a typical medical assistant role because of the ability to use technology (the electronic medical record) to guide her on what health maintenance and diabetes specific labs and exams were due and how often the patients should be returning. She was also able to communicate directly with patients via the patient portal, and easily relay messages between the provider and the patient. She reported that she felt comfortable working within her bounds, or

scope, as a medical assistant, and the provider demonstrated that he felt comfortable with her role guided by the electronic health record.

In recent years health care team communication has transformed by adopting unique ways of communication powered by technology- through electronic medical records, registries, patient portals, email, and messaging (Swee-Lin Tan, Goonawardene, 2017). Many patients actively engage in seeking out information about their health, their medical conditions, lab results, and visit appointment and health maintenance reminders (Dubbin, Chang, & Shim, 2013). They are no longer content to passively receive health care advice - they often come to the health care encounter with ideas, questions, and insights powered by research into their own conditions. The relationship power dynamic is flattening as information becomes more transparent to all participants in the relationship.

In this narrative, the Ms. Smith astutely recognized how different patients responded to having a chronic disease, and identified her role as helping to reassure or motivate patients.

Well, you have patients like Mr. K. that don't really think they have diabetes, doesn't want to even think about taking their medication, and then you have patients that are constantly coming in, 'I want my A1C checked.' I said, 'Well, you just had it checked last month.' So, we get different patients. There is a lady that is not on my panel with Dr. Hill, but on my other doctor who is constantly asking for her A1C to be checked. She wants her feet checked because she's getting pain.

I tell her these are done annually. There's nothing that I can do but take her shoes off, so the doctor can take a look at them. There's not really one patient that way (Ms. Smith, Northpoint medical assistant).

Here is another example of where the provider took a moment during the interview to teach the medical assistant some subtleties of patient experiences with anxiety around their chronic disease. Ms. Smith described a patient who repeatedly wanted to have her blood sugars checked. Dr. Hill identified that the patient was anxious. Again, he gave her some phrases to use to reassure the patient. He recognized that the medical assistant could be empowered to tell the

patient directly the typical schedule for lab tests, so that they can mutually reinforce expectations for the patient. He recognized that it is to his benefit as a provider to have a medical assistant know these things, so that they can help to alleviate the patient's anxiety.

You hear a story like this, and it sounds like this person is very anxious even though actually it's not related to her health problems, but she knows she has diabetes, and that's something you can put a name to and can ask questions. It is so wonderful to have a support staff that is empowered to just handle these problems on their own and say, 'Well, actually, you had this test done six months ago. You don't need another one. Things don't change that fast.' And Ms. Smith can just say that, and that doesn't have to go to the doctor and deal with that problem (Dr. Hill, Northpoint PCP).

When Dr. Hill put a name to what the patient was feeling, Ms. Smith acknowledged that not only this patient, but many patients with diabetes felt anxious and afraid. She heard many patient stories of their fears of losing their eyesight or limbs to the disease. In this narrative, she is telling Dr. Hill that she recognizes this anxiety in patients, and that she understands their fears. This mutual acknowledgement of patients' fears reinforces their working relationship, based on this mutual understanding of their patients' experiences.

She's using [the patient portal] all the time. [I'm] constantly telling her that you're not due for the test. I let her know that A1Cs only can be checked every three months. That's it. And you get patients where they're scared. They're scared of what this disease can do to them. 'I'm going to lose my feet. I'm going to lose my eyesight.' Or they have a friend or a family member that are missing their toes. You know, they're very frightened of having this chronic disease. They're very panicky, and they want the doctor to take a look right away (Ms. Smith, Northpoint MA).

Ms. Smith was tuned to the patient's non-verbal expression of her anxiety expressed by seeking out frequent visits or contacts with the health care system. She demonstrated a high level of understanding of the patients concerns, perhaps though her experience, perhaps by working closely with Dr. Hill over the past year.

Being Out of Step

I interviewed a second teamlet at Northpoint clinic, Dr. Roberts and his medical assistant, Ms. Lopez. While I heard many examples of mutual respect and recognition of each other's strengths, there was a fundamental difference in how this teamlet worked together. Instead of a sense of ease, clear communication and smooth functioning of their team's practice, Dr. Roberts was consistently running behind, causing the patients to have long waits in the waiting room and the exam room when they went to see him.

Working in an academic medical center, Dr. Roberts often had medical students working with him. He enjoyed working with them, and was giving of his time to teach them. In the dialogue below, we see that Dr. Roberts didn't feel that his medical assistant was capable of assisting him fully in his practice.

Then they [the medical students] understand, because they're going to be out there doing this type of work and they need to understand how frequent it is the patients don't follow and how gratifying it is when they do. I could, I suppose, ask my nurse [referring to his medical assistant] to do it. I do ask my nurse to do those things sometimes for particular patients but there's a limit to how much you can ask them to do because they have a lot of other things to do (Dr. Roberts, Northpoint PCP).

Dr. Roberts had been a primary care provider at Northpoint for several decades, and had experienced the periods of low morale and high staff turnover. He discussed that he was not able to fully benefit from the teamlet model of care, mostly because he felt that his medical assistant hadn't been adequately trained to be able to do some of the expanded roles that other medical assistants were doing. He still spent much of his time going over the medical record before patient visits, looking up past lab values, and putting orders in the medical record for his medical assistant. As a result, he was usually very behind during the course of the day.

In some ways, the medical assistant I have now is easy because she's always very nice. The patients love her because she's so nice, but she's just different. She doesn't cross all

the t's, and dot all the i's, and she doesn't grasp the importance of a medical finding that she might notice. She doesn't share the same kind of urgency I do about certain things. That leads me not to trust her as much. So I don't leave as many things to her (Dr. Roberts, Northpoint PCP).

Dr. Roberts had trouble trusting his medical assistant, believing that she had inadequate training or the capacity to learn. Ms. Lopez felt that she was capable of assisting patients more than she was allowed to do, and expressed a strong desire for more training. She contrasted the difference between the two physicians that she is paired with, showing appreciation for both.

It's good. I think I'm their balance. They're very different personalities. Both doctors, both men are great people, great doctors, physicians and very different also. I think I appreciate both of them for different reasons.

Well, they have very different personalities in the sense where like Dr. Roberts, he means well. He's very stern, very precise. Just he has his way of doing things and Dr. James on the other hand; he's a great physician as well. He just has a different outlook and so he's a lot more relaxed, a lot more easy-going and kind of 'Let's take the moment as it comes.' Whereas, with Dr. Roberts we do a lot of preparation, a lot of chart prepping especially on his end. By the time I come in I know exactly what's in his notes and they're very extremely detailed. I already know what to look for (Ms Lopez, Northpoint MA).

Ms. Lopez behaves quite differently depending on the primary care provider that she is working with that day. With Dr. Roberts, she waits and expects to receive detailed orders about what she should do for each patient.

With Dr. James, I kind of take the bull by the horn and I manage our huddle, which means I put in our notes. So I wait for him or if he's running late and he's not there, I kind of eyeball our schedule and I'll try and predetermine what I think the patient might need and anticipate it beforehand. When Dr. James comes in I'll just double check with him and run it by him. Usually it works okay just like it works fine just the same. With both of them it's very different. It's not standardized. Like some of the other MAs here, they know what to expect (Ms. Lopez, Northpoint MA).

With Dr. James, she "takes the bull by the horn," and anticipates what he would want. You can see that she is thinking of the patients and what they would need as they wait for him,

which doesn't occur with Dr. Roberts. Here we see the fluid concept of a team, which is not only situated within a clinic structure, but also within the individuals making up the team.

When a team structure is small as in a teamlet model, there is a risk of the two individuals making up the team not being in synch. There is less of a buffer than one would expect with a larger team where there is a variety of team strengths. With another team member, there would be more possibilities for mutual and cross learning, to make up for some of the skills or knowledge that one team member might not possess. When Dr. Roberts was asked what would be an ideal type of clinic structure, he said:

A bigger team of people to check in with people more frequently and people that are trained well enough to really ask the right questions. And know what the answers mean. Medical assistants often don't have quite enough training to really know, but we hope if they stay with us long enough they actually do eventually learn most of those things (Dr. Roberts, Northpoint PCP)

The ability of the team members to grow and learn is key to a high functioning team. Dr. Roberts hopes that with time his medical assistant can learn what she needs to do to be helpful in his practice. But in his current practice, his lack of trust in his MA means that he feels compelled to do many of the activities himself, putting him further behind, so the cycle of non-learning and non-trust continues.

“No Wrong Doors” - Harrison Independent Practice Association Primary Care Clinic

Harrison IPA is an independent practice association that has been serving Harrison County since the mid-90s. An IPA is an association of physicians that contract with independent care delivery organizations that provide services on a negotiated per capita rate. Harrison IPA provides administrative, claims processing and medical management services for three health plans: an HMO, an employer-sponsored medical and dental health plan, and a retirement fund HMO.

The Harrison IPA Primary Care Center opened nearly 10 years ago and provides primary care and same day services to patients in the small town and the surrounding communities. The clinic also offers nurse-led care coordination, support, and coaching to patients at risk for overutilization of expensive health care resources. After the first year of operation, Harrison IPA was awarded a foundation grant to provide funding for a community-wide collaborative for transitions between the local hospital and the clinic. A multidisciplinary team of nurses, providers and social workers from the two sites, as well as the emergency department (ED), hospitalists, and county mental health meets monthly to encourage high utilizer patients to receive care in the primary care provider's office rather than the ED. By the end of the first year of the program, ED visits had reduced by half and inpatient admits reduced by over a third after enrollment in the program.

A Rich Mix of Team Roles

The Harrison IPA Primary Care Clinic team consists of a nurse practitioner (NP), who serves as the clinic's main primary care provider (PCP), a medical director (MD), three medical assistants (MAs), an RN care coordinator, a marriage and family therapist/addiction specialist, a certified diabetes educator, two wellness coaches/personal trainers, and a front desk staff member.

The Harrison IPA Primary Care Center is explicit in its team approach. It is mentioned in their patient brochure, and new patients are told at their initial meeting that they work in a team.

I like to explain, every time I explain what we do and the team approach. I start getting excited just about that. I tell them what a wellness coach is, and what we're not. And then I might refer, if they don't have a primary care provider, to (the PCP) if they don't have primary care, or counseling, or they have a medical assistant they can work with (Marie, Harrison IPA wellness coach).

In contrast to traditional primary care practices, the PCP saw herself as a consultant on the team. During an office visit, she told patients that they would see her again in several months, but in the meantime, she knew that they would be seeing the wellness coach, and that the coach would let her know how things were going with the patient. The wellness coach was a conduit to her if they needed to reach her for anything.

The RN care coordinator worked with the care transitions team at the local hospital to care for complex patients at risk of hospitalization or frequent emergency department use. The RN care coordinator saw patients at the hospital, rehab center or in their home, as well as attended clinic visits with the patients. The clinic had several certified diabetes educators working with patients. Their primary role was to provide nutrition and blood glucose monitoring and health education to patients with type 2 diabetes. The position was vacant at the time of my site visit, and many of those functions were shared with the RN care coordinator and the wellness coaches.

The clinic had two full-time wellness coaches who were both trained in kinesiology and motivational interviewing. The primary role of the wellness coach was to help patients achieve their health care goals. The goals were patient driven, and could be as diverse as improving balance and mobility, increasing exercise, improving nutritional awareness by reading labels, assisting with weight loss, providing smoking cessation counseling and support and coaching for medication adherence. The coaches had their own exam rooms with exercise equipment and a large monitor for patient education. The meetings with a wellness coach lasted up to 30 minutes or longer. They saw both the clinic's patients as well as patients referred from outside providers in the IPA. This service was covered for HMO and IPA patients, and others were charged a small visit fee for their services.

Medical assistants took vital signs, height and weight, AIC labs, roomed patients, and remained during to visit to function as scribes. They occasionally read back notes from prior visits, such as previous goals, weight or lab values. Patients were told that MAs functioned as the team captain and to contact them for any needs or questions. There was also a front desk staff member who scheduled patients' visits, registered and checked them in, answered phones, answered patient questions and directed inquiries to different team members.

The staff considered patients to be team members and drivers of their own care. There was a discussion during the focus group interview regarding whether or not patients felt that they were a part of the team. The staff acknowledged that the idea may have been foreign to patients, but that they continually worked to make patients feel empowered and in charge of their own care – even with something as simple as asking if it's ok to take their weight. Some patients reportedly expressed surprise at the request, saying that they didn't know that they could refuse. Staff continually reminded patients that they had every right to say no to anything that they didn't want to do - that it was their experience. This concept of patient as the driver of their care was expressed by all the team members, and most strongly by the PCP. "We're consultants to the patients...offering advice and counsel" (Margaret, NP, Harrison IPA PCP).

A hallmark of the Harrison IP Primary Care Center was the emphasis on shared decision-making and motivational interviewing. All of the team members, including the front desk staff and medical assistants, were trained in motivational interviewing, which they attempted to use consistently in their patient interactions. Motivational interviewing shaped the team members' thinking to create a collective understanding and common language. They asked the patients what goals they wanted to work on before they discussed specific topics or goals.

I certainly try to make them feel that way [that they are on the team]...I really try not to just talk *at* them. I try to get their ideas because we know that's how

they're going to end up being successful. I'll steer the conversation, but they really are the ones driving. If I think that they need to lose weight first, I'm wrong. I want to know what they want to do first, and then we kind of go from there (Marie, Harrison IPA wellness coach).

Marie emphasized that it is the patients who drive their approach to care. It is patients' goals that are primary, no matter what she might think or propose. There is a mutual understanding that approaching behavioral changes from within the patients' lives and world that leads to long-term change. It's not a top-down, "do it my way" approach to care.

Team roles at this clinic were intentionally less hierarchical than most primary care clinics. The MAs in particular had an empowered role – they attended every visit, both to scribe, and document the overall plan. Leadership roles, such as the "team captain" were flexible in this setting, with the MA being in charge of communication for the team. "We try to make it pretty clear to the patient [that] this is your team captain. This is the person that you can contact any time when you need something" (Margaret, NP, Harrison IPA PCP). Patients were paneled to the medical assistants and not to the PCP; however, with only one PCP, all patients by default were on the PCP's panel. MAs also did intake visits for new patients and had standing orders for normal wellness labs that could be ordered before seeing the PCP.

Many times, we can schedule what we call MA intake. They start with the MA first. Then MAs have standing orders for normal, wellness labs, if you will. They can order, say, a CBC prior to the patient seeing Margaret. So by the time they see Margaret, their labs are in the system as well (Jill, RN, Harrison IPA care coordinator).

"No Wrong Doors"

Patients could come at any point of entry to the clinic – they weren't required to establish care with the PCP before being offered other services. MAs, RNs and wellness coaches could all refer patients for wellness and education services. With the shortage of primary care providers in the area, the team could start new patients with services while they were waiting for the PCP

visit. Patients could start with wellness visits, have labs drawn, provide health and medication histories, and get to know the practice. The patients that needed to see a PCP sooner were triaged and seen sooner. By the time a patient saw the PCP, they may have already been a well-established client of the wellness coaches and their lab results in the system.

I know for me, when I'm doing a patient's intake, like meeting them for the first time, and they're trying to work on weight loss or any issue that wellness can help them, or if they're smoking, I have a team member I can refer them to a program that we actually have here. Or if they're having problems with depression, anxiety, I could offer wellness as well, but also Ruth, who's a counselor that works here, too (Susan, Harrison IPA medical assistant).

Knowing that they have the full weight of a diverse team to support the patients is reassuring to the staff and the patients as well. It also opens up access to services in a timely manner.

People come to wellness in either direction to either start with us and then they get set up with other people, like counseling or Margaret. Or they start with Margaret or somebody and come to us. Either way, there's no wrong door (Karlyn, Harrison IPA wellness coach).

That's why it's so nice to know that there's no wrong door, because we can send it up the ladder or we can send it any direction. I think it's reassuring for patients to feel like they're in. They're waiting to see the primary care provider, but they're already establishing a relationship right away (Marie, Harrison IPA wellness coach).

“No wrong doors” provided a welcoming, accessible, reassuring atmosphere for patients. Team members saw their roles as fluid and sometimes overlapping. “No wrong doors” meant that if a patient was in need of a service, they didn't have to wait for a particular staff member to link them to that service. The focus was on meeting patients' needs, not on the team members and their roles in the clinic. “No wrong doors” meant removing obstacles and allowing patients to immediately engage with care on their own terms, all while providing an open and welcoming atmosphere to the patients.

One could imagine a typical primary care office where staff had such strictly defined roles that they wouldn't be able to help patients if the task didn't fall into their job description. This is unfortunately typical of many primary care clinics where triage is a major function of the RN role. When there is impaired access (not enough schedule availability) to see a patient on the same day that they call, they may be assigned to see or talk to a triage nurse. Often, a visit to a triage nurse results in a delay seeing the primary care provider, further exacerbating the lack of access, and creating further delays in care. This is in effect pushing the patient away, or creating a sanctioned delay since a professional nurse triaged the patient who was deemed sufficiently healthy to wait for care. With "no wrong doors," one could visualize a room with doors on each side, wide open, welcoming patients to enter. The staff inside is available to patients to get care started without delays while they wait for time for the primary care provider.

Visible Team Communication

Communication between team members was highly visible to the patients at this clinic. They knew that the team was communicating because team members referred to the notes left by other team members. They were aware of goals set by the patient and either the MA or the wellness coach.

They don't have to repeat their whole story every time they see somebody new. I say, 'I just got the referral from [the PCP]. I read through some of her notes. This is what I know about you, where would you like to start?' (Marie, Harrison IPA wellness coach).

The team also had weekly team conferences, of which the patients were aware. Because the clinic was in a small town in a rural area, they were careful to ask patients' permission to discuss sensitive issues in conferences. Patients may be staff, family members, or friends of employees, so they were cautious about using names and keeping sensitive information limited to as few staff as needed.

A sense of team was reinforced through team members recognizing the unique skills of their teammates. The PCP acknowledged that while she might only see her patients every six months, in the meantime, they would be seeing Marie for wellness coaching, and she would be letting her know how things were going. This interaction was made explicit to patients.

I know you're seeing Marie...and if there's anything that she needs from me when you're at a visit with her, that's a good conduit to get messages to me..." (Margaret, NP, Harrison IPA PCP).

Margaret helped patients understand and navigate team roles and patients' relationship to the team, all while speaking highly of her teammate. The interview with the team showed many instances of mutual respect and recognition for what each member brought to the team. When asked to give some stories about patients, the team had a discussion among themselves about which patients they wanted to discuss. The medical assistant demonstrated the same level of comfort and involvement in the team discussion as the primary care provider.

Yeah, I think we do a lot of managing up. Talk really well about our teammates. I also think that we kind of made it a point from the beginning, from our first meetings with the patient to tell them we work as a team. 'This is your team. This is Susan, and she's going to be your team captain, you need anything, start here. Also know that everybody's on your team you are seeing' (Margaret, NP, Harrison IPA PCP).

The team was explicit in telling patients that they all work as a team and anyone that they see is a member of that team. One could imagine being somewhat confused by going from one provider to a team of people working with you. This clinic made explicit how the team structure worked on their behalf. Describing the nominal fee paid by some patients for the wellness coaches, "that gets you an hour with a wellness coach who is a personal trainer and certified in coaching. You know, pretty good deal. You wouldn't find that out in the community (Margaret, NP, Harrison IPA PCP).

The sense of mutual respect and admiration for their teammates was demonstrated throughout the interview. I could sense that the staff appreciated their teammates, felt that they could ask them questions, and could go to them for help and advice. Patients from this clinic noticed this as well.

The Fluidity of Team Structures

As demonstrated by the five teams that I studied, team structures can vary widely by primary care setting – from tight team structures of one primary care provider and one medical assistant (the teamlet), to larger teams incorporating additional nursing, nutritional, pharmacy and behavioral supports. Team member functions were also fluid between settings. For example, many of the clinics trained medical assistants to perform panel management activities to assure that all preventative and chronic disease screening and lab tests are performed for a panel of patients. Medical assistants, health educators, registered nurses, and primary care providers performed motivational interviewing. Three of the clinics (Mountain View CHC, Warren CHC and Harrison IPA) trained all their staff in motivational interviewing, allowing flexibility in staffing and increasing availability for patients who needed this support. Two clinics (Mountain View CHC and Warren CHC) invested heavily in registered nurses to provide medication management and counseling for their patients with chronic disease and complex needs.

Regardless of their team structure and composition, the clinics represented in this sample exhibited common team characteristics: an emphasis on communication between team members, mutual learning and support, and recognition practices, to promote an effective and supportive clinic environment.

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Table 4.1
List of Team Characteristics

Clinic name*	Franklin CHC	Mountain View CHC	Warren CHC	Northpoint Primary Care Clinic	Harrison IPA
Location	West Coast	West Coast	East Coast	West Coast	West Coast
Setting	Urban	Rural	Mixed urban and rural	Urban	Rural
Clinic Structure	Community Health Center	Community Health Center	Community Health Center	University- based primary care	Independent Practice Association
Team structure	Expanded team	Expanded team	Expanded team	Teamlet	Expanded team
Core team composition	PCP:Health Educator	PCP:RN & MA	PCP: Multi team	PCP: MA	PCP: Multi- team
Team supports	MA, front desk	MA, front desk	MA, RN (shared), diabetes educator, registered dietician, podiatry, chiropractor	LVNs, RNs (shared), nutritionist, health navigators, front desk	MA, RN (shared), wellness coaches, diabetes educator, front desk
Staff names*	PCP – Dr. Keene Health educators – Lucile and Cynthia	PCP-Jean, PA RN- Eileen RN Manager- Durelle MA- Linda Front Desk- Robert	PCPs – Dr. Mutha & Audrey, NP; RN – Maria MA - Claire	PCPs – Dr. Hill Dr. Roberts MAs – Ms Smith Ms Lopez	PCP – Margaret, NP RN – Jill Wellness coaches – Marie and Karlyn MAs- Sarah and Manuela

* Clinic and staff names have been changed to maintain confidentiality

Chapter 5 The Makings of a Team

A good team, like a good show, comes into being when the separate individuals working together create; in essence, another separate higher entity - the team - the show - which is better than any of those individuals can ever be on their own.
- Gary David Goldberg, American writer

Most people would agree that putting a group of people together and asking them to work together doesn't automatically make them a team. Identifying the elusive qualities that make a team is one of the aims of this research. I started this research with the basic understanding that to be a team, individual members must first identify as a team, and then use their individual skills and talents for a common goal. In primary care, the common goal is to promote health by preventing illness and injury, diagnosing, and treating episodic and chronic disease, and supporting patients and families to make the best decisions to achieve and maintain health (Starfield, 2005). In the care of patients with chronic disease, the common goal is to help them manage their condition within the complicated context of their lives. During this research, my understanding of what it is to be a team evolved. I found that a team is not just a collection of the individuals and their skills that make up the team. A team is a new entity.

The clinics chosen for this sample were selected because they had a reputation for having robust team-based primary care. Some teams worked together more effectively than others, and were able to achieve high quality care and experience for their patients, while maintaining a high level of team cohesion and smooth operational functioning. In these high performing teams, the primary care providers and staff felt supported and they felt that they had teammates to go to if they needed help or advice about challenging patient situations. The primary care providers appreciated having supportive, well-trained and dependable staff that they could rely on to care for their patients. This chapter focuses on the teams themselves, and describes the staff

perceptions of team-based primary care, practices that enhance team awareness and strengthen teams, and barriers to patient engagement with teams.

Staff Perceptions of Team-based Care

Feeling Like You're Not Alone

Clinicians that I interviewed had positive things to say about working in team-based practice settings. In this current era of high clinician burnout, emotional exhaustion, and cynicism, these staff members described a different type of working arrangement (Willard-Grace, Hessler, Rogers, Dube, Bodeneimer & Grumbach, 2014; Friedberg et al., 2017). They had others to turn to for information, support and advice and no longer felt alone and solely responsible for the myriad of care needed for their patients.

But I think, for me, the importance of having a team is this idea that, "Okay. I don't need to solve it all. I don't need to figure it out. I literally have resources on hand, and so if I can't come up with something, I have at least, in a pod, I have at least six other people that I can tap into. That's not counting the outside resources (Maria, RN, Warren CHC nurse manager).

The reason that I'm working here is because we have a team. For 18 years, I worked in private practice in Internal Medicine. I was on my own to take care of patients. I had a medical assistant who was there to get the patient in the room and work with me during that eight to five. It was usually them and me there until eight or 9:00 at night. Filling out forms, answering questions, calling people back, finishing dictations, all that kind of stuff, and thinking "I have no idea how to get this patient this medicine or they desperately need a social worker or a counselor" (Margaret, NP, Harrison IPA PCP).

Other team members felt that they had someone to talk to when situations were hard, as Margaret describes:

I always feel like I've got someone to commiserate to or someone to listen, who will listen to me. That's really a great feeling (Margaret, NP, Harrison IPA PCP).

Team members went to each other for advice and counsel, another dimension of teams that was less tangible and harder for the clinicians to describe. Just as patients valued being listened to, teammates valued being listened to by their teammates.

I do think there's a sense, also, of *that other layer* of team. Dr. Hill [another PCP] knows I will go to her all the time and say, "What do you think about this?" (Dr. Mutha, Warren CHC PCP).

Having Someone to Go to For Help

The feeling of not being alone to solve patient issues went beyond obtaining information and advice. When a team member needed help with a patient in the course of a visit, the other team members were ready to assist.

Then feeling like I have all these wonderful teammates who say, 'Oh no everything's fine, sure I'll do that,' and we figure it out (Margaret, NP, Harrison IPA PCP).

Helping each other was a team practice that was highly valued. Being available to each other for help was a practice that was intentionally cultivated. This extended to all members of the team: from the medical assistants to the primary care providers.

I feel like I can certainly go to Gayle [the PCP] or another coworker and we work together. It's the same thing, except if they needed me to help with something I'll certainly be able to go, and that's the nice thing to have as well (Claire, Warren CHC MA).

Knowing That Patients are Receiving Needed Care

Just as valuable as knowing their teammates were there for them, the team members felt pride in knowing that by working in a team with diverse skills and knowledge that their patients were receiving better care. Working in a team meant that they felt that they were working together with others to provide all the care needed for their patients. The bigger the team, the more the primary care provider felt that they had the resources needed to provide high quality and comprehensive care.

I like it. I think it's great. Being able to care for the patient from all aspects. Everybody does their part to contribute to the patient, so I think it's great (Audrey, NP, Warren CHC PCP).

I know for me, when I'm doing a patient's intake, like meeting them for the first time and they're trying to work on weight loss or any issue that wellness can help them, or if

they're smoking, I have a team member I can actually refer them to a program that we have here. Or if they're having problems with depression, anxiety, I could offer wellness as well, but also Marilyn, who's a counselor that works here, too (Sarah, Harrison IPA MA).

For the clinics that had expanded teams, such as Warren Community Health Center and Harrison IPA, the patients had access to a range of roles and services in one location. The proximity of support services enhanced the team members' sense of having the capability to address the myriad of needs that patients with chronic disease required. The team members were invested in the care of their patients beyond their physical needs, and expressed satisfaction about the possibilities of additional services they had available from an expanded team.

I love it. It seems like our patients love it too. This was the first practice I worked in that has team-based care. We have wellness coaches, a counselor, nurses and just a lot of support. *Not only I feel better about that, but I think patients do too* (Sarah, Harrison IPA MA).

I would say basically all of the situations I can think of, patients have just been grateful to have everybody. Not like, "Why is this person talking to me?" but they're happy that there's somebody else. They feel that sort of wraparound help (Audrey, NP, Warren CHC PCP).

Practices that Enhance Team Awareness

Awareness of the team occurred when the staff was explicit about practicing in teams and mentioned or introduced patients to other teammates, and when patients observed team members communicating with each other and treating each other with respect.

Explicitness About Team-based Care

Primary care providers and staff members were asked if they thought that their patients knew that a team cared for them. Most of the team members interviewed hoped that the patients would feel they were members of the team, but weren't sure that they did. Some teams emphasized it more than others to their patients, and made sure that they knew that they, as the patient, were the leading their team.

I say that frequently in the visits, ‘Thank you for letting us be on your team.’ *You're the captain of this team.* We all know a lot of things about different health things, *but we don't know you and your life.* To be honest that's one of the things that we give them. Being honest in recognizing that you are leading this team (Margaret, NP, Harrison IPA PCP).

Margaret explicitly empowered patients to be the captain of their team. She asked patients to open up to help the team better understand the complexities of their lives that might impact their health. They were opening up their worlds to the team.

Jean, the Mountain View PCP, contrasts how patients used to relate to their primary care providers with their new roles members of their health care team:

In the old days, a patient would come in and say, let me figure out everything that my primary care provider wants to hear from me, and then I'm not going to be really who I am. I consider the patients as part of the team. Sometimes we're not happy with the team members. Sometimes the team members aren't happy with us. But yeah, it's about them.

There used to be a culture of a doctor was a man, and a man was God, and you came to the doctor, and the doctor told you what to do, and you just sat there patiently and *walked out with your Valium.* And that's not true anymore. We ask a lot of our patients. So, it's got to be about the patient. I do a lot of motivational interviewing. ‘Okay, so you don't like poking your fingers and we don't know, where does that leave us? What would you like to do? Can you make one little change?’ (Jean, PA, Mountain View CHC PCP).

This example of a patient “walking out with Valium” conjures the image of numbing patients, as if to say ‘here, take this pill and go away,’ without taking the time to address the underlying causes of their anxiety. The team behaviors described by the clinics in this study were the opposite of pushing patients away. They wanted to get to know patients as persons, learn more about their particular circumstances in their lives, and draw them in. This cultural shift in in team practice that encourages patients to be open and honest has changed the role expectations for both patients and their teams.

Many of the staff thought that the patients would know that a team was caring for them because they frequently referred to other team members, either by reading what was written in

the electronic medical record, or mentioning that they talked to them about their care.

I think they see the team. Because if I make a call and I'm like, "Hey, I just got your lab results from Dr. Mutha and she wants me to let you know that x, y, and z. So, we want to get you back in and her MA will see you, and we'll run another A1C in a couple of weeks. Come back and I can come in and talk to you about setting a goal." So that you're always making the connection like, "Hey, this person told me," or "I was talking to your PCP about this," and so they're all talking to each other (Maria, RN, Warren CHC nurse manager).

For Marie, Harrison IPA's wellness coach, patients' awareness of the team was tied into being consistently cared for by the same people.

I think that they feel that they are cared for by the team. [It's] consistency, and knowing that continuity of care, that you could call somebody and something's going to get done. We really try to all use motivational interviewing, so that empathetic ear, I think makes people feel literally listened to and good about their plan. There's a lot of teach back, so we're not just using jargon all the time. There's a lot of making sure we have a plan that we came up with together (Marie, Harrison IPA wellness coach).

Here Marie describes several ways of being with patients that she felt increased patients' awareness of team-based care: using motivational interviewing to elicit questions about patients ideas and feelings about behavioral changes, the avoidance of medical jargon so that patients could fully understand the information provided, and the use of a method called "teach back," which entails asking the patient to tell back to the provider what was agreed, or what the plan is to be moving forward. By using these methods of communication with patients, Marie felt that patients were made more aware of a team of people taking care of them.

The more deliberate the clinics were about telling patients that they worked in teams, the more patients were aware of team-based care. Some practices used colors to describe their team, or had symbols or letters in the waiting room to help identify them. However, just talking about the team, giving it a color or symbol to identify it, didn't necessarily translate to the patient feeling cared for by a team. In fact, for some clinics, only the staff was aware of the team color scheme, which they used primarily for scheduling purposes.

Sometimes I would say, "Your team is here for you." Just to say, "We're all here for you. This isn't just me. This is literally a community effort" (Maria, RN, Warren CHC nurse manager)

I also think that we kind of made it a point from the beginning from our first meetings with the patient to tell them we work as a team. This is your team. This is Manuela, she's going to be your team captain. You need anything, start here. Also know that everybody's on your team that you are seeing. Sometimes I will tell them if I have a regular visit with them, I'll say, 'In six months I'll see you back, but in the meantime I know you're seeing Marie doing wellness, and she's going to let me know how things are going, and if there's anything that you need from me when you're at a visit with her, that's a good conduit to get messages to me or that kind of thing (Margaret, NP, Harrison IPA PCP).

In the clinics where patients were most aware of teams, the providers and staff coached patients about how they worked together, the nature of the team structure, and how they communicated with each other. PCPs explicitly mentioned the other team members' roles and told the patients that they would be seeing other team-members between visits. By doing this, the PCP's were reinforcing their recognition of the team members' roles and contribution to the team.

Team Communication

Communication was the glue that held these teams together. During a fast moving primary care session, patients were coming and going in 15 to 20 minute increments during which tests were ordered, referrals made, vaccines and medications administered, and health education conducted. There was little to no time during these busy sessions to review plans for patient care, or to plan team functioning as a whole.

The clinics that I observed used multiple communication strategies to plan and guide team functioning prior to patients coming into the clinic, during visits, and between visits. These strategies included technology such as instant messaging or in-time communication devices,

electronic medical records, huddles and weekly or monthly team meetings to discuss patient care plans.

Patients were aware when the team was talking to each other and communicating effectively:

They all communicate with each other to know what's going on with me when I come in and they already know certain things and have it written down. And they're really good about communicating (Melinda, 57, Harrison IPA patient).

Betty: They write visit summaries and they also talk about me.

Interviewer: How do you know they talk about you?

Betty: Because one of them will say, 'I talked to [your primary care provider] and she said...' or 'I talked to [your nurse] and she said' (Betty, 64, Harrison IPA patient).

Sally: They're mutually aware of the same information, and these new computers that they use I think generally support that.

Interviewer: How are you aware that computers support that?

Sally: Well, I'm watching them enter or extract information, and knowing that they all have the same computer with the same access to the same data, I believe (Sally, 68, Mountain View CHC patient).

Pre-huddle communication. Huddles in primary care settings are daily (or twice a day), short, informal team meetings about patients who are being seen that day. Most of the clinics that I observed used huddles as a way to plan their day or session (usually divided into morning or afternoon sessions of four hours). For many of the clinics, communication about the patients' visits began the day before the patient arrived. Team members and primary care providers reviewed the next day schedule to scan what the patients might need for their visit. They put orders into the electronic medical record so they were ready for the medical assistant when s/he put the patient in the room.

We're all looking at those patients before we meet as a group. I print this out, we all print one of these. You come to the huddle with your portion. We know what they're due for before we ever meet, and we're saying, Alison [the PCP] will have ordered something or Jane [the registered nurse] will or I will or something. But we're pretty much all on the same page with that. So, before the huddle, her chart may already be loaded with a foot exam, A1C, lab or whatever they need, and then we'll say, "Oh yeah, they need this and

that" (Jean, PA, Mountain View CHC PCP).

Well, there is a huddle in the morning but there's usually not enough time. So I usually just... to really go over the patients in the way you had wanted to, so when I abstract the chart for the note, I usually just make a list of the things that I want her to do when she checks the patient and she'll do what I want her to do for those patients. Like get them a flu shot, take their clothes off if I want them to have a physical exam or pending certain labs, like if I want her to get a finger stick glucose or a urine test for microalbumin (protein in the urine), or set up a referral for ophthalmology. All those things will be there so she comes, get them set up, so all I have to do is sign them when the patient comes in (Dr. Roberts, Northpoint PCP).

Huddles. Participants in the huddles varied, but the core huddle team was the primary care provider and the medical assistant. Some clinics added registered nurses, front desk and behavioral health staff to the huddle. This took extra planning, as the front desk staff was usually busy checking patients in during the huddles. Some clinics prioritized the front desk staff attending huddles, so that they could make sure patients completed their registration forms for different types of visits with diabetes educators, wellness coaches or primary care providers.

Huddles typically lasted 10-15 minutes, and had a team member who led the huddle, printed out the schedule for the session or day, read off who was coming in for the day, and their reason for coming in. Other staff members added information that they knew might be relevant to the visit for the day, particularly related to family situations and barriers to self-care. Primary care providers gave instructions to the staff about anything that they would like done during the visit – for example, the patient might need preventative care such as vaccines or be due for certain monitoring labs for chronic disease care.

In a huddle, something will come up and we'll say, since so-and-so is coming in, they'll probably have their kid with them who needs to be seen for that. And we just know in all these things we'll tell them to have their husband do this. And when we can we say in the huddles, so-and-so is coming in, and his father is a diabetic, and if he comes with him, fit him in [the schedule]. They're here, we know he gave her a ride, and he needs to be seen or this child needs a well-child exam. And if this family shows up... we also know who's not going to show up (Eileen, RN, Mountain View CHC).

Huddles were a way for the team members to communicate what they knew about a patient beyond just their medical issues. It was during the huddle that team members shared their knowledge of patient family situations, and social determinants that may impact patients' health and ability to care for themselves. It is during this meeting, however brief, that the team members can deeply get to know and understand the patients and their lives.

We can anticipate that and schedule better. In case somebody doesn't show up, we still fill somebody in that spot. *We know there are social backgrounds and worry about them.* Do they need to have a warm handoff with the behavioral therapist today? (Robert, PSA, Mountain View CHC).

That's the one thing about having a care team is that we get to huddle all four of us in the morning when we're all here. Instead of just the MA and the provider huddling on their own, and then they would discuss their day. But now, the nurse is involved, and so is the front office person as well. That way we know, this needs to be done, it could be something that I [the front desk assistant] can do. Instead of putting all the work on the MA or the work on the nurse, if it's something that I am capable of doing (Robert, PSA, Mountain View CHC).

Robert, the front desk assistant, spoke up confidently and frequently during the Mountain View CHC focus group interview. In many clinic settings, operational functions of the front desk staff are separated from clinical care functions. It was clear that Robert understood his role as one that went beyond the typical front desk functions of checking patients, verifying insurance, and taking messages from patients. Robert looked for opportunities to help out the team to alleviate the workload of the clinical staff. He was involved in huddles during which the team discussed patients' lives and social backgrounds. He worried when patients didn't show up. He noticed if someone was in distress and might need to talk to a behavioral health clinician. This involvement with the patients' lives on a deeper level led to a heightened sense of responsibility.

One clinic that I observed did not do a typical in-person huddle. They opted to communicate information about the day's schedule through the electronic medical record. The

staff would review the day's schedule prior to the session, and write notes in the electronic medical record to the various team members so they knew what was needed for the day. They felt that this was a more effective use of their time since the clinic had a high no-show rate, and the clinic session for the day often varied from the printed schedule.

So I think it's really different for every person, or every team. So for me, I used to do an actual kind of review of the entire day, get together with my team and say, 'This is what we're thinking about.' This particular setting has a really high no-show rate and a lot of changes that happen. So some people may still do that. I don't anymore. The nurse is kind of looking at the patients ahead of time and writing some notes in. And then as patients come in, we use Link a lot, so we can link to each other on things. So that's kind of like instant messaging (Audrey, NP, Warren CHC PCP).

We don't do a typical huddle, largely because of the no show rate and the switching in and out. But instead we do that combination of speaking to each other throughout the day and putting things in electronically to be able to see it (Dr. Mutha, Warren CHC PCP).

In this setting, they traded direct face-to-face communication for efficiency. In observing the clinic's operation, I didn't hear about or see any co-sharing between team members of the details their patients' unique personal lives. The medical assistant stayed at her desk during the visit, and scanned for electronic messages from the PCP and patients. This particular clinic had a high staff turnover rate, and as one patient described it, was a "revolving door." I interviewed the staff and observed the clinic the day after the team's registered nurse left the clinic. Several of the medical assistants were "on loan" from other clinics. Perhaps the trade off between face-to-face communication for efficiency created an environment that felt less supportive to providers and staff.

Communication during visits. Communication during visits happened during one-on-one discussions in the exam room, in the hallway, or at the team stations. This occurred more often when the team members shared the same space, particularly when they sat side by side, as

in co-location. When the team was co-located, informal communication about patients happened organically throughout the day.

Warren Community Health Center used a type of messaging system (Links) to communicate in real time. They preferred this type of system because it allowed the communication to be documented in writing to avoid missed communication.

So I will, if a person's coming in, either if my MA and I or the nurse and I are in the same room and we see that person coming in, I'll say, 'This is what we want to do for this person.' Or one of them will come to me and say 'Hey, this person's here. Do you want this done? Or do you think we should do this? And we'll talk about it verbally or we'll do it on Link. And I actually kind of like doing it on Link more, or reinforcing it on Link because I think we're all so busy that you can lose it if it's just verbal. So there's that kind of written communication (Audrey, NP, Warren CHC PCP).

Technology assisted communication. Much communication between patient visits occurred through the electronic medical record. The team members used messaging systems to communicate patient calls, refill requests, or other issues needed between visits.

Monitoring population health, such as common preventative and chronic disease care, happened between visits using a patient registry or data warehouse, which gave clinics the ability to run population health reports. For example, a clinic could run reports of all patients with type 2 diabetes who had not received an A1C in the past 6 months, or those who hadn't been seen in the past year. These reports provided the team with information about patients' latest preventative or disease specific needs and would stimulate outreach for the patient to come in to the clinic, or get lab tests done. The team used written protocols to know how often certain labs were needed for patients with diabetes or other chronic disease.

Another way that the electronic medical records were used between primary care visits was to document the visits to the other team members. Patients' visits to the diabetes or health educators, registered nurses and wellness coaches were documented in the medical record. All

the team members could see what goals the patients were working on from the same record.

Many of the team members complained that current EMRs didn't have a good place to document and share patient goals, and created systems of their own.

Patients used a range of methods to communicate with their teams - either through telephone calls, the patient portal, or in some cases, calling or texting the PCP or team members' personal cell phones. If a patient called a clinic, the calls generated a telephone encounter and were assigned to a member of the team to respond. Typically the front desk staff or medical assistants received the calls, and then forwarded the questions to the appropriate staff members.

Actually, what really helps team-based care a lot is the electronic health record, because you can see what everyone's doing, you can direct messages appropriately, and the team's not just the medical assistant, but it's also the front desk people and the advice nurse. With the Affordable Care Act and the ACO, there are many more people who are around to be part of a team now than there used to be, and they actually have more medical assistants and there's more time for population management. You can have a registry. You can do outreach. All these things are really good for our patients and it's possible actually because of the electronic medical record, to actually be prepared for a patient coming in. You can look at the chart beforehand. Before, you could only look at the chart when you were in the clinic (Dr. Roberts, Northpoint PCP).

Communicating electronically also allowed team members to share patient stories about their personal lives that might impact their care.

They don't have to repeat their whole *story* every time they see somebody new. I say, "I just got the referral from Margaret. I read through some of her notes. *This is what I know about you, where would you like to start?*" And just people are like, "Oh, okay, great" (Marie, Harrison IPA wellness coach).

By saying, 'this is what I know about you,' Marie could reassure her patients that their "story," or the background details about their life that make up the totality of their illness, travelled to all the team members through documentation in the electronic health record. Patients could sense that they were heard in the last visit if a new team member read back what they already knew. They were given an opportunity to expand (or correct) their narratives, so

that they could start from that point in time of their last visit, and not needlessly repeat the same story to each team member. Team communication flowed from one visit to the next.

Team meetings. Some clinics had regular weekly or bi-weekly team meetings during which they discussed complex patients, or reviewed reports on populations of patients, such as all the patients with diabetes on a provider's panel. In contrast to huddles, which focused on the patients coming in for care that day, team meetings were focused on population health, outreach and care coordination. An expanded team, including registered nurses, health educators or wellness coaches, or behavioral health support staff attended these meetings to discuss strategies to improve outcomes for these patients.

We have a team conference every Thursday morning [about] some of these situations where many of us are involved or that are a little bit more complicated. We talk about those patients to try to get the whole team's input (Margaret, NP, Harrison IPA PCP).

Other clinics had quarterly meetings to review their panels and with staff that prepared reports so that the primary care providers could see their own patients' panel data for preventative and chronic disease metrics. The expectation was that they would take this information back to the team to outreach to patients needing to come in for care.

Strengthening Team Practices

Three ways to strengthen team practices were identified: fostering team and patient trust through training, deliberately and explicitly recognizing teammates, and adopting a flattened hierarchical structure.

Fostering Trust

The importance of trust was a core theme throughout my interviews. Fostering trust between team members and providers, and between team members and patients, strengthened team practices. The circle of trust during team-based care practices was complex and covered

multiple dimensions and intersecting components within the health care delivery system. At the core was that the team had all the skills and knowledge needed to assist the patient. Without a competent workforce, trust was more a hope, and there would always be lingering anxiety on the part of the PCP and other team members. If a PCP didn't feel that the team members had the skills, knowledge and attitude to competently function, she wouldn't have confidence to fully allow the team members to share patient care responsibilities. But as skills and knowledge grew, trust grew along with it, and the team was poised to participate more and more in patients' care.

Some primary care providers had more difficulty than others having team members participate in their team's care. Certainly, everyone had their own comfort level with this style of teamwork, but as the team members learned new skills, the primary care providers learned that investing in training and teaching their teammates benefited both themselves and their patients. Working in teams is not a skill that is taught in medical school, and is counter-intuitive for many physicians who have spent hours and hours learning and honing their profession. Some physicians may be reluctant to share or give up their perceived power in the patient relationship or in their clinical settings. The clinicians in the high functioning team practices that I interviewed shared their knowledge with each other, through a process of continual training and on-the job education. Knowledge flowed in all directions as different team members shared their expertise and knowledge, much of which they gained from their deep relationships with patients or shared cultural backgrounds.

One nurse described how her team experience with one clinic was more successful than at another clinic, even within the same health system. She attributed the success at one of the clinics to it being smaller, so the nurses weren't pulled in as many directions. But she also felt that the primary care providers at that clinic valued more what a nurse could do for their patients.

When asked to describe a typical visit for a patient with diabetes, Maria, the nurse manager at Warren Community Health Center said:

Even though the nurse can drive this, it really does depend on the provider's support, and how comfortable they are ... so some providers are like, 'I want to do it all.' And they [the administration] had a little healthy sort of competition, and they kept coming back to the nurses who were doing really well. And so, I had literally enrolled so many patients that they started to look to me to say, "Why is she being so successful?" And so, one of the things I said to them was what I just told you about the provider part, their buying into it was so key to my success there, because they really valued what I was doing with the patient (Maria, RN, Warren CHC nurse manager).

For the nurse to be fully effective in her role, the primary care providers needed to let go of the attitude that they were solely responsible for the patients care. They also had to let go of the notion that they held all the knowledge about the patients. They had to trust their teammates.

Trusting teammates was not necessarily intuitive. Like PCPs, RNs can have similar reactions to sharing care on a team. They too have spent hours learning and applying their knowledge, and may feel that they are more highly skilled than a medical assistant or an LVN. They also may be reluctant to share some of the power of that knowledge with their teammates, feeling it might diminish their role. Although I didn't see this attitude in the clinics I studied, I have seen this often during nursing meetings when they are discussing medical assistant roles.

Medical assistants differ in their responses to being asked to take on more responsibilities on the team. If they come from a setting where they are told what to do and not to question, they may be hesitant to take on expanded roles. They also may feel that the extra responsibilities should be rewarded with extra compensation and career growth. Here we are reminded of Ms. Lopez from the Northpoint clinic, who worked with two different physicians with differing levels of trust, expanding her role for one physician by "taking the bull by the horns," while waiting for orders from the other. Team members working in high functioning teams can sense

the trust of their teammates, and as a result are confident, and develop strong bonds with the clinicians who share their knowledge and expertise.

I feel in my team there's a lot of trust. When I ask my front person to do something, I'm trusting her to totally follow through, and the same with my medical assistant. And I think with that it runs pretty smooth. So, having the support of other people who know what their jobs are, and who are willing to do it, for me it's huge (Eileen, RN, Mountain View CHC).

Just as trust between team members depended on the competence of the team members, trust from the patient to the team was enhanced when the team members were well trained. Several of the clinics I interviewed had extensive medical assistant training programs for primary care settings. Many clinics trained all the staff in motivational interviewing or health coaching, the basics of chronic disease care, and medication management strategies. Patients recognized the value that well-trained and knowledgeable staff can bring to their care. Nelly spoke about what it was like to work with a health educator and a nutritionist:

I loved it, I loved it in the beginning but they [the health educators] are important because they do know the education behind diabetes and so I'm glad that I let myself open up and trust them and their education regarding diabetes (Nelly, 51, Franklin CHC patient).

In traditional models of care, the patient sees and develops a relationship with their primary care provider only. With team-based care, patients may see many team members, and this new model of care may be unsettling to them. Nearly all the patients interviewed were initially reluctant to go to the team members once they had established a strong relationship with their PCP. Many delayed seeing a health educator, wellness coach, or diabetes educator, because they wanted to see only their PCP.

The clinics that I observed used several strategies to show their patients the trust and confidence that the PCPs had in their teammates and encouraged their engagement. First, PCPs recommended to patients that they see another team member for additional help and support

reaching their health goals or for additional health education. Some patients delayed seeing the team members, but their PCP's encouragement finally assuaged their fears. The fact that the PCP kept asking a patient to see the team member showed how much they trusted and valued the team member's work.

Well, when they first asked to tell me about it, the health educator wants to talk to you, before the doctor comes in to talk to you, about your levels, your diet, what else can be done to help you get back on track. I wasn't comfortable with it so they were like, give it a try. *Just try it* (Nelly, 51, Franklin CHC patient).

In some cases, when patients were reluctant to see a team member, the primary care provider used a "warm hand-off", an "in-person" introduction to the team member during the visit. The PCP might walk the patient to the team member's office, or ask them to step into the exam room during a visit, and offer an introduction. The patient could see the interaction between the PCP and the team member, and see how they communicated. The patient entered into the circle of trust the PCP had in the team member in that moment, and could experience it first hand. This often put patients at ease and allowed them to trust as well.

Lily, a Puerto Rican patient of Warren Community Health Center, was initially nervous to see the team nurse for diabetes education.

The first time when I [went to] see her, I'm so nervous, I say "Oh my God, what happens here? What [is] she doing with me, I don't know." But she tried until I'm okay with her because we come from the same country. She started talking about the food over there, I say, oh okay, I like this (Lily, 48, Warren CHC patient).

Lily was familiar with her PCP, but was anxious about what this new person meant for her care. She wasn't sure that she wanted to open up to another person. Fortunately, her registered nurse, who was also Puerto Rican, was able to bridge cultural barriers through a mutual familiarity with the foods that were commonly eaten in their country. She now enjoys going to her appointments, where she often jokes with her nurse, and says it makes her "feel

good.” They were able to connect with food as a shared practice that is associated with caring and sharing. The clinicians that I interviewed felt that when trust was established, they were more effectively able to care for patients and work with them to achieve their goals.

Marshal, a 66 year-old patient from Franklin Community Health Center, was especially resistant to meeting with anyone other than his primary care provider. His PCP asked him multiple times to see the health educator, and he ignored the request. Finally one day, his PCP brought the health educator into the exam room and introduced them.

This was like about nine or ten years ago, he goes, “Well, I want you to meet Cynthia [the health educator].” I said, “I don't want to meet Cynthia.” He goes, “I want you to meet Cynthia.” I said, “Why?” So, I still didn't do it and so then one day he says, “Here's Cynthia. *It's all right*, you follow her” (Marshal, 66, Franklin CHC patient).

The PCP reassured Marshal that it was going to be *all right*, that he was referring him to Cynthia whom he knew and trusted. Contrast this face-to-face introduction to a typical referral made to an unknown clinician. Marshal could have interpreted a referral to a stranger as his PCP pushing him away. The gentle persistence and in-person introduction by the PCP was a form of caring and reassurance to Marshal that he would still be there for him. Marshal eventually went to see Cynthia, and worked with her and Annie, a dietician, for several years. He appreciated their deep knowledge of nutrition and diabetes care.

We used to have a dietician here called Annie... Mercy. Oh incredible. That lady could tell you the exact content of [anything], it was just really how she was. Between the two of those people [dietician and health educator], my knowledge about the diabetes increased exponentially (Marshal, 66, Franklin CHC patient).

Marshal became so knowledgeable and engaged over the years, that he became a peer counselor for other patients with diabetes, and later a part of the clinic's patient advisory council. In fact, he couldn't resist spending part of the interview telling me about sources of hidden sugar in different processed foods. The result of Marshal's engagement first with the health educator

and the dietician, and then as a peer counselor with other patients, extended the team to others in the clinic, creating a community of wellness rather than simply treatment of disease.

Recognition Practices

Another way that team members demonstrated their trust in each other was through recognition practices. Recognition practices are demonstrated when one team member speaks highly or positively about another team member. These recognition practices were especially apparent during team interviews.

A lot of the times that we get praises, they praise the whole team. They don't just say "Oh my god, you're just ... [they say] love this place, love everyone" (Karlyn, Harrison IPA Wellness coach).

Yeah I think we do a lot of managing up. Talk really well about our teammates. I also think that we kind of made it a point from our first meetings with the patient to tell them we work as a team (Margaret, NP, Harrison IPA PCP).

I think it's good to have a team because you're saying that no man is an island and especially the nurses. They're a huge part of the team because we, or I, rely on them a lot, for example, making sure patients are up to date with all their vaccines, or screening tests and stuff like that. I just take it for granted that they're going to take care of it because they are so good. I can depend on them like that. So, I appreciate that with the nurses and with the medical assistants too. They are already on top of the ball, knowing, 'Okay, this is a diabetic patient.' They're already getting all that stuff done ahead of me, going in to see the patient so even though it seems minute, it's not. It's huge, and it makes the process a lot easier (Dr. Mutha, Warren CHC PCP).

These recognition practices occurred even when patients were not present, such as during these focus group interviews. The trust that developed between team members eventually reached the patient through the tone and manner in which the teammates talked about each other, as well as their eagerness to refer patients to their services.

Team Hierarchy

More than one of the highly functioning teams that I interviewed and observed had a horizontal, or flattened, hierarchical team structure. As I discussed in the last chapter, at

Harrison IPA patients had many points of access to the primary care system. Because there was such a shortage of primary care providers in the region, new patients often struggled to find an open primary care practice, and if they did find one, faced long waits for their first visit. To help resolve these waits, the organization allowed access to services on many levels before the patient had the initial primary care provider visit. Patients could come into the system through the medical assistant, who had standing orders for labs for new patients. They could even start working with patients on their health goals, or refer them to either the diabetes educator or the wellness coaches, depending on patient needs. The wellness coaches could ask patients to go the MA to initiate new patient labs as well, and begin working on health goals. By the time the PCP saw the patient, the lab results might be available, and the patient had perhaps already started working on self-directed goals.

This “open doors” approach to new patients sent a signal to patients about the importance of each of the team members’ roles, and showed that they didn’t need to wait for the initial PCP visit for work to begin. The PCP was not the central driver of care as in most traditional primary care practices. In fact, the PCP explicitly told patients that the MA was the team captain. All the team members were empowered to make decisions around patient care. Empowerment came through systems, such as standing orders for A1Cs, or referrals for wellness visits, that were built into the practice to advance patient care. Empowerment was also created through training. Nearly all the staff was trained in motivational interviewing. Any of the clinical staff could work with patients to set goals, which were documented in the medical record. Everyone had an equal voice when it came to patient care.

Then also, just knowing that you're part of a team, and think everyone having that kind of equal voice at our team conferences. Being able to bring up people that are concerning to any one of us if we have a concern about a patient... we have everybody's head in the game for that particular patient (Sarah MA, Harrison IPA).

At Mountain View CHC, the non-hierarchical, collaborative team structure meant the layers of hierarchy that used to inhibit some staff from speaking out were diminished. The front desk staff, medical assistants, registered nurses and primary care providers all equally contributed during team meetings.

I've been doing this for 39 years, and really, in my opinion the beauty of a team is that, especially these guys, medical assistants, front desk, don't come sheepishly to see who is going to bark at them right now. And that's huge, because in my experience over the years, there has been these layers. I don't know any more than anybody else does. I just do something different. *And that has really been elevated with teams.* In fact, part of the training that we had when we first started doing teams was learning what the other people were doing (Jean, PA, Mountain View CHC PCP).

Jean, the primary care provider, expressed humility about her role on the team, and saw the value of “elevating” her teammates. This team practice of humility empowered the team members to feel comfortable to ask questions of their teammates when needed, all to the benefit of the patient and their care. Shifting power from the PCP to the teammates served to also shift the burden of care from one to many.

It's the comfortableness of being able to ask a question without having to worry, is it going to be a dumb question? Or are they going to look at me weird for asking that kind of question? It's more of like, if I need something from the provider or the nurse, I know I have that comfortableness to go ask them, and get a straight answer. Or if they don't know the answer, they'll help me figure it out, instead of just everybody doing their work, focusing on themselves, trying to get through the day and trying to go home. You're actually here trying to get these people in, trying to get the work done, get the referral sent out or make sure they get their labs done, or whatever (Robert, PSA, Mountain View CHC).

The staff in this clinic didn't seem to exhibit the typical signs of burnout, such as disliking their jobs or feeling that they were less capable at work, that are so prevalent in many primary care practices (Willard-Grace, Hessler, Rogers, Dube, Bodeneimer & Grumbach, 2014; Friedberg et al., 2017). This was manifested in their employment longevity and the low staff turnover at the clinic – nearly 20 years for Jean, the PCP and Eileen, the registered nurse.

During the focus group, I observed happy employees who were excited to talk about their work.

Barriers to Patient Engagement with Teams

Just as trust between team members promoted patients' trust with the team, the opposite was true. If team members didn't trust one another, the patient had a hard time allowing others into their circle of care. Several ways that I observed or heard about the erosion of team trust was from team conflict, poor team communication, poor coordination, inadequate training of team members, or overly large and complex teams.

Team Conflict

One way that patients' trust with their teams could be eroded was a team member undermining or contradicting other team members. In one interview, a patient who was having trouble connecting to a team, experienced having a physician from outside the team disagree with a treatment plan prescribed by her own PCP. This interfered with the developing relationship with the patient's PCP, and therefore, she did not engage with any of the other members of the PCP's team. The outside-team physician, instead of discussing the patient's care plan directly with the PCP, contradicted the PCP's recommendations and treatment in front of the patient.

The sad part was she [the other provider] said, 'Yeah, sometimes they don't explain everything to you like they should.' 'Okay. Why are you telling me, telling on your other co-workers?' (Melinda, 57, patient).

Likewise, Sally was upset when a nutrition class instructor contradicted another team member. "I think the two of them didn't have a great working arrangement. Didn't support each other perhaps so much. I found it sad" (Sally, 68, patient).

Patients were disappointed when they observed team conflict. When one team member openly contradicted a teammate, the patient was left discomfited, and that feeling extended to the

person that was being contradictory. Such conflicts left them confused and unsettled. This also undermined any trust that the patient had developed with the team.

Poor Team Communication

A second barrier to establishing trust between patients and the team was poor communication between team members. If the patient received conflicting information from different team members, they didn't know who to trust or which advice to follow. It took coordination and good communication between team members to have a consistent message with patients. These messages could have been discussed and reinforced during huddles or team meetings.

Patients could sense even subtle communication breakdowns and tensions within the team. Scott described how an experienced diabetes educator had to subtly let a new diabetes educator know not to talk about weight loss with him – something that he expressly did not want to focus on.

I've made it very clear with my primary care provider at our very first meeting that I am not interested in weight loss. At least not focused weight loss. I'm very opposed to diet culture. I think it's very unhealthy. And she totally understands and is on board with that. She said I'd probably lose weight as a by-product of care and I'm like, 'Yeah, that's fine.' And so, when I met with the diabetes educators for the first time after my diagnosis, like I said there was the outgoing and the incoming [diabetes educator]. And I think the outgoing got that message but the incoming didn't quite. So, she was just there to observe primarily. And she was going through stuff and I think we were looking at her computer screen and clicking through test results and stuff. And at one point there was the BMI chart was visible. And the outgoing educator didn't mention it. And I could tell, she [the new diabetes educator] started to say something. And then the outgoing was like, "Um," like it was just a really quick, awkward thing (Scott, 35, Harrison IPA patient).

Scott noticed that the two teammates were out of step, which made him feel uncomfortable. Instead of Scott leaving this visit feeling supported and empowered, the encounter made it hard for him to have a good working relationship with the new diabetes educator. This diabetes educator left the clinic less than a year after she started, and was no

longer at the clinic when I did my interviews.

Poor Clinic Organization

Institutional barriers can erode team trust. During the course of any primary care day, there are hurdles to overcome to assist patients in receiving the care that they need. Dropped medication refills, lab results not received or followed up on, referrals that aren't made or followed up on, forms not filled out, are all possible kinks that can happen in a typical clinic day. The way that the primary care practice organizes itself to allow these common types of problems to be solved in a seamless manner can promote or inhibit patient trust in the system. If patients feel that more people on the team mean more dropped balls or more chaos, then trust is impaired. Trust in the team also means trust in the system or the practice. Here Robert, the front desk staff member at Mountain View CHC, described poor organization at his former clinic and how it impacted the quality of patient care.

When people would huddle it would always be the medical assistant and the provider only, and they would do it at the medical assistant's desk or at the provider's desk, just between them two. And the front desk people who weren't really assigned to teams, it was more of check-in. So, that middle work would always fall through the cracks, that reaching out to them, making sure the prescription went through or little things like that, they would never really be assigned to anybody, so it would just be in limbo. And then the whole feeling of being... for the patient, *knowing that they actually care* and my voice is heard, that was really never in play in there. It was more of, let's try to see as many people as we can, and try to get them to the best care that we can, without really a structured team. That is the big difference (Robert, PSA, Mountain View CHC).

This “falling through the cracks” can create critical safety issues in primary care – things like abnormal lab results not reaching the PCP, referrals to outside specialists that don't occur, delays in diagnosis and access to needed care. The front desk staff plays a critical role in making sure that the clinic operations are functioning smoothly and safely. Team-based care allowed “care” into the role of all of staff, even those in non-clinical roles working at the front desk.

Inadequate Staff Training

When staff members were adequately trained, primary care providers hesitated sharing patient care responsibilities with that staff member. Dr. Roberts, the Northpoint PCP, didn't feel that he could rely on his medical assistant to do all the preventative and chronic care needed for his patients, and that he needed to check her work.

Yeah, I just find I have to spell out every little thing that I want the team to do. There's no like proactive anticipation of anything. Like I find that if I want something to be done I have to really be very specific and I can't assume that the medical assistant actually did everything. I'm constantly having to check on like is she doing the blood pressure properly? Does she understand what a hemoglobin A1C actually is and what it measures (Dr. Roberts, Northpoint PCP)?

Even well trained team members sometimes needed to demonstrate to the PCP that they had the skills and attributes to assist their patients. Co-location of the PCP and team members helped build trust, as with the case of Maria, the Warren Community Health Center nurse manager, who described working with her PCP. She felt that by sitting next to the PCP, they could observe her work over time and see how she competently managed patients. Over time, she had more and more referrals for help from her PCP and her caseload grew exponentially.

Interviewer: What helps build that trust so that the PCP starts to rely more on the nurse, or understand their value?

Maria: I think as they see how you work through, right? Because you're literally sitting next to them. So, they're hearing you're on the phone, let's say something was happening and you went to report and say, 'Hey this was happening. I did this, I made this call, I found out this.' So, when they see, 'Oh okay, this person literally is thinking through things,' and as they get comfortable with that, hearing and watching you work, and they get telephone encounters from you, too. So, as a provider you get a telephone encounter, and you see everything, the information the nurse is giving you. 'Oh, okay. This is all right. I didn't have to say, 'Hey, can you go back and ask her x'? Or, 'Can you check this?' So I think it's sort of where the provider feels how knowledgeable the nurse is, her clinical judgment. I think that's where it helps the trust (Maria, RN, Warren CHC nurse manager).

Staff that was poorly trained also eroded patients' trust in the team. Melinda, a fairly new patient to the practice, felt judged by a diabetes educator who wasn't adequately trained or

skilled in motivational interviewing. She didn't feel that her methods and charts were helpful.

As of the time of my interview with her, she had not engaged in any of the other many wellness and educational supports available at the clinic either.

A couple of times I tried to tell her that I was doing my best. The other thing is I felt like I was being pushed all the time. You have to do this and you have to do that. *I can't do it that way.* Everybody has a different process of the way they do things.

The diabetes person, the first time I saw her, it was fine because I thought maybe she can help me do stuff. But I just felt like I was overwhelmed with bunches of papers and charts. I don't do very well with those and I just didn't want to tell her that and I haven't seen her again since then (Melinda, 57, patient).

The diabetes educator hadn't taken the time to get to know Melinda as a person with a complex life, and apparently did not comprehend when Melinda tried to remonstrate that she was doing her best. Unable to make sense of Melinda's lifeworld, the health educator overwhelmed her with information and made suggestions that she found impossible to consider. In fact, Melinda knew that she couldn't do things the way they were proposed. Melinda hadn't been back to see the diabetes educator for six months and didn't know that she was no longer at the clinic.

Large or Overly Complex Teams

Overly large or complex teams from multiple organizations can create confusion within teams. Teams interacting with teams from other organizations can have issues with coordination of care. This is particularly true when the team that is interacting with the patient isn't communicating well with the primary care team.

Robert, the front desk staff at Mountain View clinic, described how the large, complex teams caused employee stress at his former clinic, especially when team members were expected to cover multiple teams. One could question whether this team arrangement described true team-

based care or team-based care by name only, but not in practice.

Because, especially there, I feel like there's a lot more people, and there's also a heavier Hispanic population in that location in which I was working in. And there at the time they would have eight or nine providers working. So, you would have three teams, A, B, and C, but in each team you would have four to five providers working at a time. And you would have one nurse for one team. Can you imagine like one nurse taking care of five providers at a time, instead of being able to focus on just that panel for that provider? (Robert, PSA, Mountain View CHC).

In the following exemplar, Dr. Hill, the Northpoint PCP, told a story about a breakdown in care coordination he had recently experienced. The hospital where he admitted one of his homeless patients had its own care coordination team, but they did not coordinate with Dr. Hill about his patient's care. The large number of people assisting this patient created confusion that could have been avoided had someone listened and responded to the PCP who had intimate knowledge of his patient and what medications had worked in the past.

He was homeless, and he had a lot of trouble with medications, and when he was homeless, he really couldn't take anything more than once a day, and most diabetes medications are more than once a day, and somehow, he wound up mostly just taking insulin for the treatment of his diabetes.

And so, we had a lot of people involved in his care including what was called the Care Support Team, which is like a program for high utilizers. It includes a nurse practitioner and a social worker, and he would have outreach with our advice nurse and me and my MA.

We also had a case manager from the homeless outreach team. He had a lot of people involved in his care, and some people would be more focused on his diabetes like the Care Support Team, they took more interest in his diabetes because they felt like that was something actionable and something they could do something about. Sadly, that didn't happen.

My approach to this was very different. My approach was to make it as simple as possible on him because he had all of these restrictions. It took a lot to figure out that he, under no circumstances, would ever take a medication more than once a day. He went to the hospital recently. They put him on a regimen where they were telling him to inject himself with mealtime insulin at every meal, and I saw this.

I was like, "Guys, this is never going to work. Let's help him." Of course, nobody responded to me, and they eventually discharged him on that regimen anyway, and

then he shows up to this visit with me, and he says, "I don't know. They gave me all these boxes of insulin, and I don't know what to do with them." He didn't even know what it was for. He didn't know why he had different kinds of insulin. He thought they were the same.

He easily could have started giving himself fast-acting insulin, which he thought was his long-acting insulin. It did not happen I don't believe. I actually don't know why he died, but I hope that didn't contribute. But I saw this. I was like, "No, this is terrible. You've got to get rid of those." You know?

Well, he got discharged from the hospital to a SNF [skilled nursing facility]. So, I think they were like, 'Oh, at the SNF, they can figure it out.' But then he went from the SNF back to the hospital, and then he was in the hospital for a while longer, and then he insisted on going home rather than going back to the SNF, and no one changed his medicines. [This patient died shortly after the hospitalization]. So, yeah, it was terrible, but I think the point of that story is that no one was -- in terms of that team situation -- *no one was really focused on what actually would have been right for the patient*. And those med things just totally fell through until it came to me. That team had too many members (Dr. Hill, Northpoint PCP).

This is a disturbing example of the dangers of uncoordinated care, even with the best intentions of trying to coordinate care. The PCP's deep knowledge of the patient's life circumstances, gleaned from his longstanding relationship with the patient, meant that he knew the limitations of the patient's precarious living situation, and how it would be a barrier to multiple daily injections of insulin. Even though he spoke up about the proposed unrealistic plan for his patient, the care coordinators on the other team didn't adjust accordingly. While it is unclear why they refused to adjust the plan - whether they were overwhelmed with other patients, or they were insistent on following rigid standardized guidelines, regardless of the reason, their decision to impose on the patient a plan that he was unable to follow had life-threatening consequences.

In this chapter, we saw many examples of highly functioning teams coming together to work together in a new way, in essence, creating a new entity, *a team*, of individuals that supported each other and their patients. It was not just a collection of individuals with diverse

skills strictly staying in their respective roles. The team entity transcended strict roles and provided an opportunity of caring for each other and their patients in a deep and meaningful way.

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Chapter 6

The World of Living with Diabetes

The first time it happened caught me by surprise. The patient I was interviewing was recounting an emotional experience she had with her team members. She cried, describing how her team gathered around her to support her during a difficult time. I was having trouble holding back tears, and at the end of the interview, as I tipped my head to turn off the microphone, a giant teardrop fell on my notes. I started my research wanting to hear about how patients experienced working with teams, and in doing so, saw a glimpse into their world of living with diabetes.

I interviewed a range of patients with type 2 diabetes: some recently diagnosed and others living with diabetes for 25 years or more; some in tight diabetes control and some out of control; patients taking oral medications and others taking insulin. Patients talked about their reaction to receiving a diagnosis of diabetes, family histories, addictions, and difficulties managing their disease.

I learned to have a box of tissues available during future interviews. Patients often cried when telling their stories of their despair at their own diagnosis and the depression that followed, losing loved ones and family members to diabetes, and the struggles that they had trying to control their disease.

Receiving a Diabetes Diagnosis

I interviewed Nelly, a 55-year-old patient of Franklin Community Health Center, in the living room of her apartment. The walls of the living room were decorated with collages made with images of a man playing a guitar - decorations for the memorial service for her fiancé who “passed” 10 years ago. He had been a guitarist in a famous blues band; she was a singer in the band. When I arrived she was on the phone with her granddaughter’s school. She waved me in, and seemed at ease with me being in her home.

Nelly's mother died of diabetes when she was 10 years old. When she was told 22 years ago, when her own daughter was 2, that she had diabetes, she cried in the doctor's office. Her memories were flooded with the distress of losing her mother at such a young age. Now diagnosed with the disease that took her mother away when she was 10 years old, she felt that she was re-living the experience with her own daughter. Her diagnosis thrust her out of her everyday present world into the remembered devastating, unexpected, sudden loss of someone so close on whom she depended.

When I found out, I must have cried for about 30 minutes, but what I liked about that experience is that doctor, he was so kind that he stayed with me. He didn't just [say] okay, you have diabetes so I'm breaking down a client and he goes to the next patient. He didn't do that. He stayed with me and he was really very kind and that made me feel good, but after that I became very closed, very negative, really didn't want to take care of myself. A part of me just was like, so I have it and it was like, whatever. This is what it is and I didn't care what they said so that's how that was (Nelly, 51, Franklin CHC patient).

Nelly's new diagnosis reminded her of a traumatic time in her life, and having to think about it meant re-examining things associated with loss and death. She closed herself off, and experienced her care as pushing her towards her diagnosis, which for her shaped and colored a fearful experience of loss. Going to the clinic and interacting with the clinicians served to reinforce that her life was no longer the same. She especially didn't feel a connection with the nurse who cared for her after her diagnosis, and felt that the nurse wasn't genuinely interested in her or what a life changing impact the new diagnosis had on her life.

I didn't quite care for her. I wasn't getting a good vibe. We didn't connect. Well she came in it's like, she just wasn't the warm-hearted person. When she spoke, it was her tone. Her tone was not a very warming tone. It was very like "How are you?" Not like, "How are you today, how was your day, how have you been, have you been taking care of yourself?" It wasn't like that. Okay, take your vital signs, very dry tone, so I didn't like her because I'm already feeling this down, depressed about it, and hurt. I have a disease my mother had that I don't want and I'm like, "What do I do? You are not helping the situation either with your attitude so now you are giving me an attitude so

now I'm getting very defensive and I don't want you touching me." It was ugly (Nelly, 51, Franklin CHC patient).

Depression was a common reaction to hearing a diabetes diagnosis. Some were reminded of their own loved ones' struggles, others looked inward to how their lives would be changed forever. The diagnosis forced them to take on a new and unwanted identity. Marshal, a 66-year old patient of the Franklin Community Health Center, described it as entering into the dark, as into an unknown world.

I was so despondent because I'd always been really healthy and all of a sudden, there was this... I've never been suicidal or a thought like that but the outlook was so dim so I said, "Well, I guess I have a special diet, so what is it?" It's like stepping into the dark at first because I was so sick (Marshal, 66, Franklin CHC patient).

I'm so worried when she told me I have diabetes. I'm so depressed because I [didn't] expect to have that. And I asked myself, "Why me?" It [was] very hard when my doctor told me (Lilly, 48, Warren CHC patient).

Many patients felt that they were personally responsible for their diabetes. Patients were reflective describing their diagnosis, and described what they thought were contributing factors that led to their diabetes, such as drinking massive quantities of sugary sodas, and stressful, sedentary lifestyles.

I got the diabetes myself and I know what I did. I'm an avid fan of the sugar drinks and I drank tons of that stuff. I'd go to work and drink Mountain Dew. I'd get off from work, I'd drink 20 ounce bottles, or two, or three 20 ounce bottles. Some of them were seven days a week, working at an oil refinery. It's 12 hours a day for 14 days. Plus, I drove two hours home every day back and forth for four hours, two hours each way back and forth (George, 70, Northpoint Primary Care patient).

So, I was drinking Arizona iced tea, definitely high fructose. I'd buy a case of it from the drugstore. Then all of a sudden, I couldn't keep anything down, nothing. I was urinating a lot. It's like endlessly. So, no matter what I put in my stomach, it came back. I lost 112 pounds. It was so rapid until I looked like I was 90 years old. It was really bizarre. I couldn't eat anything, nothing. Finally, just before I was about to walk through the portal, a friend came over and brought some beef bouillon and some crackers. But, I was still on my way out and so they came over, got me and took me to the doctor. So when he [the PCP] walked in that exam room, his expression was like, "Oh God, is it..." So he ran out of the room and came back and he brought a meter. Then he goes, "You've got diabetes (Marshal, 66, Franklin CHC).

Walter, a 64-year-old patient of Dr. Hill's at the Northpoint clinic who suffered a stroke that left him wheelchair bound, talked about how he rarely went to the doctor before his stroke. He had been active, and swam daily, but wasn't fully aware of the risks of ignoring his diabetes. He just wanted to feel normal.

And I rarely went to see my primary physician. I just didn't want to know -- hear any major concern. I just was really stupid about trying -- just thinking exercise was taking care of everything (Walter, 64, Northpoint Primary Care patient).

In the following exemplar, Scott, a 35-year old patient of Harrison IPA, recounts how he discovered he had diabetes by looking up the meaning of his lab value online.

I did the blood test really early and I got an email [with the results]. I was like, "Oh hey, this one's highlighted. This is very high and it's highlighted. I should Google what that means. Oh, I'm diabetic." And I had the soda next to me and I'm like, "I should dump that right now." And I did. It was very scary that first day. Me and my partner went home and we grabbed a laundry basket and just started pulling stuff off of our cabinets and like, "You can't have that anymore" (Scott, 35, Harrison IPA patient).

Scott came to his first appointment with a general knowledge of diabetes, but at the same time, some misunderstandings about what it meant for him, and how his life would change. He thought that he could never eat sugar again. Scott was like many other patients with diabetes whom I interviewed. Most of the patients had a long history of trying every type of diet, and considered themselves to be experts on nutrition. They knew what they needed to do to control their diabetes; they just had trouble motivating themselves to do it.

Many patients talked about how stress impacted their diabetes and saw a correlation between stressful events and out of control blood sugar. Others found that their symptoms such as neuropathies, vision issues, the ups and downs of blood sugar levels, fatigue, and hunger impacted their ability to resist unhealthy foods and exercise.

Family History of Diabetes

Nearly all of the patient study participants had a family history of diabetes - grandparents, parents, aunts, uncles, brothers and sisters - yet many were surprised at their own diagnoses. Some blamed the types of foods that they ate, such as rice, beans and tortillas, which were customarily eaten in their cultures. Those that had family members with the disease were well aware of what their future could hold. Many had lost family members and loved ones to diabetes, and their own diagnosis made them fearful. “Almost all my family’s got diabetes - everybody died from diabetes” (Luisa, 43, Mountain View CHC patient).

I lost my mom and I lost my dad, I lost my two brothers for diabetes and heart attack. But the experience, when the doctor told me that, is so bad. So bad, so sad all the time (Lilly, 48, Warren CHC patient).

Let's see... my father, my son, aunts and uncles on my father's side, and my great-great grandfather. They brought it from Poland to here (Andrea, 57, Warren CHC patient).

People are passing. I've lost two brothers already. [My mom] passed at 50 from a heart attack. It runs in the family. It's all the beans, rice and tortillas. I don't eat those anymore (Isabel, 52, Harrison IPA patient).

But sometimes, you know, we Filipinos love rice... eat rice all the time (Lillian, 60, Northpoint Primary Care patient).

Difficulty Managing Diabetes

Patients described the difficulties they experienced managing their diabetes. It was hard for many of them to devote the time and energy that it took to care for themselves in the chaos of everyday life and complicated family issues. Some were working full time caring for children and elderly family members, others had stressful family lives with young adult children facing addiction.

I had a lot of bad family issues going on at the same time, so it was really hard to keep my diabetes in control. I'm the baker there [at her job], too. So I get to bake all the good stuff and I don't get to eat any of it (Melinda, 57, Harrison IPA patient).

Some patients who had diabetes for many years watched their blood glucose levels

fluctuate, usually rising, as their initial medications no longer became effective. They could be eating strict diets and well controlled for years, but eventually they needed stronger doses, or had to start taking insulin.

I take my medications just like he tells me so. I've been doing that. But I've been taking the same stuff for so long that I don't really think is working that great (George, 70, Northpoint patient).

And part of it also is that the longer you're on [your medications] and the longer you've had the disease, the more difficult it is (Sally, 68, Mountain View CHC patient).

Sources of Motivation.

Patients found motivation to make lifestyle changes from different sources. For some, it was fear of needles and the possibility of having to have daily injections of insulin. For others, it was watching family members suffer with diabetes: losing their limbs, vision or dying prematurely. Some had transformative events that made them engage in their care: near death from pneumonia, death of a parent or a spouse.

Family members and spouses encouraged many of the patients to take better care of themselves, saying that they wanted them to stay around. Both Luisa and Melinda found support and motivation from family members: Luisa from her 5-year old son, and Melinda from her husband.

And he says, "Mom this is not good, you have to eat healthy." He's five years old and he's giving his mom encouragement and advice (Luisa, 43, Mountain View CHC patient).

Sometimes it's really hard to fight the cravings. I've been a lot better now though, just because my husband helps me a lot with that. He doesn't let my buy it for one and tries to not keep it around. He himself tries to do better. And then he helps incorporate stuff, helping me more at home has been the biggest thing. Because before he works, he only works one day more than I do, so he would still come home and just be on his phone all the time, playing on his games. So now he's been helping me more with dishes and cooking and everything. So that helps (Melinda, 57, Harrison IPA patient).

For others there were transformative events that motivated them, such as a life-threatening illness, or the death of a parent or spouse.

But I think the thing that changed me the most was when I got pneumonia. One of those doctors told me I was pretty lucky because it was bad. I tried to make a promise to myself that I was going to do better. Because my dad passed away just a little over a year ago. He also had diabetes, too. So I didn't want to be like him (Melinda, 57, Harrison IPA patient).

Well, my husband passed two years ago. So it's been over a year, but it's still pretty darn tender. So when he passed I said, you know I should really start thinking about myself now. And I've kind of been struggling with avoiding the diabetic educator. Because being diabetic so long, you really do know everything. It's whether you apply it or not. So I just decided last year, you know what, I need to do something, or I'm going to go too, I'm going to go early. So I had quit smoking already for probably four years (Isabel, 52, Harrison IPA patient).

Melinda's serious illness, just after witnessing her own father die of diabetes complications, created the motivation for her own transformation. Isabel's painful experience of losing her husband made her realize that she should start to think about her own health. Both Melinda and Isabel had had diabetes for many years and already knew what they were supposed to be doing but previously they simply couldn't find the motivation to make the changes.

Andrea observed her family not taking care of themselves and what it did to their health. This motivated her to learn more about her diabetes, and make changes in her diet after her hospitalization that brought her blood glucose level down to a normal range.

I'd seen how everybody else in the family did not take care of themselves, so I was getting diabetic magazines with recipes and I just was experimenting with food. I learned to make some really good concoctions that are filling and don't have all that extra stuff you don't need. Yes, because when I was in the hospital, they said [my A1C] was 13-something and then it came down to 7-something in three months. They were pretty impressed with me (Andrea, 57, Warren CHC patient).

The fear of needles was motivating for many patients and resulted in several reactions. Some made changes in their diets to avoid needing to take insulin. Others needed to be convinced to take insulin after dietary changes failed to bring down their blood glucose, or who over time became more and more resistant to medications.

I think in the very beginning, I was more resistant. I think she put me on metformin, and then within three months or so, she was already talking about some kind of injectable,

and I was I was like, “No!” So I think it took me a while to come to the decision that I would take it. And they keep telling me, reiterating to me, that they want my blood sugar to be lower, so I do less damage to my body. They just keep saying it over and over. And finally I'm like, “Okay, you're right. You're right, you're right.” But it takes a long time to ingest it, because, I think, my kind of fear or aversion to the drugs (Maria, 60, Harrison IPA patient).

Maria was initially resistant to taking insulin, but with the support and continual and consistent messaging of the team, finally agreed that it would be better for her health.

This chapter provided a glimpse into the patients' worlds of living with diabetes, including their reaction to receiving a diagnosis of diabetes, family histories, and difficulties managing their disease. Even though these topics were not specifically the focus of the study, patients wanted to share these heart rendering stories about the despair and depression that followed their diagnosis, losing loved ones and family members to diabetes, and the struggles that they had trying to control their disease. It is within this context that we understand the meaning that patients with type 2 diabetes ascribe to their experience with team-based care in the following chapter.

Chapter 7

Experiencing Team Care in the World of Chronic Disease

All I know is that it is different. It's different than where I've ever been before. And I like it because they give you that personal attention, a little touch that you don't normally get (Anna, 66, Mountain View CHC patient).

It was difficult for Anna to put into words what made her experience with teams different from a typical medical encounter. Her care felt *different*, but she couldn't identify what made it seem different. Was the personal touch she experienced a characteristic of the team members in her practice, or something that arose from team-based arrangements that make this type of care experience more likely?

This chapter focuses on patients' with diabetes experiences with team-based care. It begins with patients' perceptions of team-based care: their awareness of being taken care of by a team, whether they felt that they were a member of the team, how their care relationships changed in the context of the team. The second part of the chapter describes the relationships that developed and how patients characterized those relationships. The chapter ends with a description of what patients wanted from their health care encounter.

Patient Perceptions of Team-based Care

Patients perceived a team when they observed communication between team members, coordinated efforts on their behalf, personable interactions, and good rapport between team members.

Awareness of Team Care

How aware were patients of a team of people taking care of them? During my interviews, I deliberately waited to use the word *team* until near the end of the interview to see if patients would spontaneously use the word *team* in describing their care.

My interviews revealed that patients' awareness of teams depended on how the teams were structured, how well they communicated with each other, and how deliberate they were in referring to their care as coming from a team. The smaller the team, as with a teamlet arrangement, the fewer patients were aware of team-based care. While they might have known the medical assistant, they described their care in relation to what was provided by their primary care provider. When patients were asked directly if a team took care of them they would usually say yes. They typically saw the PCP and MA as a part of their team, but it varied with the institution if they saw other team members, such as the registered nurse or health educator as a part of the team.

When Scott, who had been recently diagnosed with diabetes, was asked if he felt the staff that he saw at the clinic was a team, he responded:

I'd say so. I don't often meet with them all together, it's usually every time I meet with one of them it's one on one. But, I think it's obvious that the lines of communication are there. When I see them interacting, there's a really good rapport, really good vibe there (Scott, 35, Harrison IPA patient).

Scott felt an awareness of a team when he saw staff members communicating with each other. He usually met with one member at time, but he could see that they were communicating with each other as they referred to other team members' notes in the electronic medical record. He could also see that the team members got along well together by how they spoke about each other, creating a positive atmosphere in the clinic. One could imagine that it would be a reassuring patient experience to see team members getting along and working well together.

Other Harrison IPA patients also noticed the team. For Maria, the defining characteristic of a team was also communication between team members. She felt that they communicated daily, and that the team shared information about patients with each other. She called it "team

talk.” Team members were explicit with her about talking to each other and sharing information on her behalf.

Yes. I think that they are a team, they seem to be a team. They share information, I think, with each other, on a daily basis. I think they *team talk* about people and they [say], somebody gave me that information (Maria, 60, Harrison IPA patient).

Isabel noticed that team members referenced each other when discussing her care, and that they read each other’s notes in the electronic medical record.

I’m not sure everybody is aware that they’re quite that team. But I am. Because they’re always referring to one another. I might tell [my PCP] ‘I just saw Marie [the wellness coach] yesterday’ and she would say, ‘Oh what did Marie say?’ and then she might even go back and read Marie’s notes (Isabel, 52, Harrison IPA patient).

Jeffrey, a Northpoint clinic patient, sensed a team when he saw multiple staff members coordinate efforts on his behalf.

When you look at the coordinated effort from the moment you step inside to reception to the nurses during the [visit], absolutely, yeah. Those guys - they seem to work together quite well (Jeffrey, 67, Northpoint patient).

Jeffrey also noticed how well the team worked together. It left me wondering, would a group of people working together that didn’t get along as well still be called a team?

When asked who was on their team, their responses were driven by the services that the patients themselves used. Some felt that other physicians with whom their PCP consulted were a part of the team; others felt that family members or extended caregivers were part of the team. Often these family members or caregivers came with them to their appointments, or helped provide transportation. If a patient didn’t use a particular service, such as a health educator or wellness coach, then they didn’t see them as a part of their team.

For Walter, who had a stroke and used a wheelchair, his perception of team expanded to include his 24-hour caregivers.

Well, it’s my primary physician, my care providers. James is the main care provider

who's lived with me for four years. He's a refugee from Uganda who got asylum here. I was coming out of [the skilled nursing facility] and that's who I hired right out of the gate to help me. So he gets me up every morning, helps me get dressed and cleaned up, and prepares my breakfast. It's everyone from the receptionist to the medical assistant to the referral person - she coordinates everything. And my family (Walter, 61, Northpoint patient).

Am I on the Team?

When patients were asked if they were a part of the team, a few patients answered that they didn't know, but some were more equivocal.

I am, but in a different way. I'm kind of an ancillary. Here's the team, and I think *I'm over here*, and that I get pulled in when I come into the office. But outside of that, I don't know. I don't feel as much like a team. I feel like I could call and get information. I don't know. I never thought of it that way - that I was on that team, on my health team. I guess I do kind of feel that way, but not in the same sense that they meet every day and see each other every day.

Well just that I'm part of [the] decision-making process. So that does make me on the team. I'm not looking at all the facts and figures and stats to make that decision. They're looking at that, and thinking of ways to make my life better. And then I'm coming back with information when they ask me about it, as to whether or not I think that's a good thing, or yay or nay, or maybe this, or whatever. So I get to add in, but they're coming up with kind of a plan, and then I come in and alter it, or agree with it based on how they're seeing it. (Maria, 60, Harrison IPA patient).

During this interview, we see that Maria had never thought of herself as a part of the team. She described a sensation of being “over there,” or apart and separate from her team. But as she continued to reflect on the question, she realized that she was indeed a part of the team, especially since she was involved in decision-making about how her care plan was carried out. Many of her reflections showed that she was realizing how she was co-constituted with her team – through the two-way flow of information about her health and the team asking for her opinion and permission around treatment decisions. Patients of clinics that used motivational interviewing or health coaching had the strongest sense that they were a part of the team, as opposed to those who felt that they weren't always following their providers' suggestions.

Scott felt he was a member of the team when working with certain team members, especially the wellness coach who was particularly skilled in motivational interviewing. This gave Scott a feeling that he was actively creating solutions and engaged in his care. With some team members, he also had a feeling of being a separate entity from the team – I am the patient and they are the team.

Depends on who I'm meeting with. I think Marie [the wellness coach] more than anyone takes that approach like I am part of the team. She works with me to create solutions to problems. In my interactions with everybody else, it does feel like I'm the patient and they are the team that's working with me. I'm the one helping build solutions (Scott, 35, Harrison IPA patient).

Other patients definitely felt that they were a part of the team, and that being a part of a team meant being involved in their care, and working with their team to improve their health.

Oh, yeah. She likes my input and she's very happy with the way I try to do the best I can to take care of myself. She's always happy with my A1C; they do it every three months and they give me a copy (Andrea, 57, Harrison IPA patient).

I am on the team. I'm a big part of the team. I'm the one that says, "Okay, if that's what you want to do, *we'll do it*, maybe because, if I don't do it then no part of the team is *winning*. So yes, absolutely (Isabel, 52, Harrison IPA patient).

These patients saw themselves as being the architects of solutions to some of the barriers they faced to their health. They felt that they were ultimately the ones who needed to put the plans in motion, and that “winning” depended on their involvement. “We’ll do it,” meant everyone, especially them. Winning might have different meanings to different patients. The role of the team members was to find out what winning meant in the context of the patients’ lives.

Caring Relationships in the Context of the Team

Feeling cared for by their PCP and team members was highly meaningful to patients, and impacted how they engaged in their own self-care. Ideally, a caring relationship with a PCP

happens in a traditional provider-patient relationship. But how do caring relationships change with the introduction of new team members?

Betty, a patient at Harrison IPA, describes feeling cared for during an impromptu patient visit by her PCP during what was planned as a wellness visit:

I went to see [the wellness coach] a week ago, maybe two weeks ago. And we didn't know if I had a cold or if it was my allergies, but I was really having problems with my nose. And well, we assumed it was a cold because my temp was around 101. And so, I went in to see [the wellness coach] and while I was there, [my PCP] came. [She] knocked on the door, came in and said, 'I heard you're not feeling well.' She did an exam and everything. With no appointment, just I was not feeling well, so she came in to see me. I really felt cared for at the clinic. *Like I matter and my health matters* (Betty, 64, Harrison IPA patient).

When the PCP came to her wellness appointment, it made Betty feel recognized as a person with multiple needs that did not always neatly fit into a scheduled visit of a certain time and place. Betty left the visit feeling like she was truly cared for by the team. They cared enough to give her the care she needed, when she needed it, without the delay and disruption of having to come back for another visit.

What I found in my interviews was that team-based care increased the opportunities for caring relationships to develop, either by allowing for more frequent interactions, or by having more time during visits to develop relationships. The following exemplar highlights these expanded opportunities for connection and caring relationships by contrasting clinics where I conducted interviews – Northpoint clinic, with limited team-based relationships, and the other clinics with more expanded use of team members.

At Northpoint clinic, the relationship focus was on the primary care providers. Both PCPs that I interviewed were attentive and responsive, even giving patients their cell phone numbers or emails so they could contact them directly when they had questions.

George, a 70-year old patient of the clinic, would give advice to others seeking care with Dr. Roberts to “listen to him and do what he says.” He felt that Dr. Roberts cared, sometimes acting “like a mother hen,” when he would call to report his blood results and tell him what he needed to do. George hadn’t noticed any difference in the structure of visits after the teamlet model was implemented at the clinic several years prior to the interview. He still felt that he was seeing a different medical assistant every time he went to the clinic and identified more closely with the person at the front desk who he saw every time he came to the clinic. He couldn’t remember any of the names of the medical assistants who had assisted him in the past, who were essentially interchangeable in his care. They never stood out in his consciousness as a member of his healthcare team.

Dr. Roberts had high quality scores in his practice because he diligently monitored all of his patients’ chronic disease and preventative care needs. But there was little time during the visit to work with patients on their goals or assist them with strategies for lifestyle changes, as in some of the clinics that had more team members available to patients.

I never had a doctor that called me personally before. Usually, that just stops right there at the clinic, but he does. I was complaining about my A1C being high and that I needed to work on that to get it back lower, like I wasn’t staying over above eight. I need to get it down lower. I had it down lower and then it went back up. It’s been like a basketball back and forth. It’s hard for me to control it. He gave me a pen, some kind of pen now that he just ordered it last time. I just got it in the mail yesterday. I’m supposed to give myself shots with it instead of using the Glipizide. I’m supposed to do that. I haven’t started it yet till I see him (George, 70, Northpoint patient).

In this example, the caring PCP relationship had the potential to promote patient engagement, but time constraints limited that engagement. While George valued Dr. Robert’s attentiveness and availability, all the support and education depended on the PCP’s availability. He had to wait for a visit to Dr. Roberts before he knew how to start his medication, which delayed care.

Interviewer: If you could change something to live a healthier life, what might that be?

I wish I knew, watch what I eat, I wish I could walk. I'd exercise more. I used to go to the gym and then they shut the gym down and then they sent us to another place. I went over there one time and then I quit going to the gym. Now, I sit on my butt most of the time, which I'm not supposed to do. But when I walk, I hurt. So, I don't do a whole bunch of walking. I had a bicycle. I used to ride it around the park where I live. I could ride a bicycle. I go to the gym. I tried to do the elliptical. That killed my lower back (George, 70, Northpoint patient).

George struggled to control his blood sugar, but hadn't worked with his PCP on strategies to control it and seemed at a loss to know how to lead a healthier life. He didn't have the knowledge, skills or confidence in his own ability to be engaged in his care, and didn't have the team supports to help him discover ways to change his lifestyle.

A second patient of Dr. Roberts, Lillian, also felt that the PCP was a "good doctor," but would advise friends that if they were to go to this doctor to "be patient" because of long clinic waits. She mentioned the frustration of having to wait during visits several times in the interview. Both Dr. Robert's patients that I interviewed experienced their disease as a mystery: they followed the instructions of their caring doctor; yet felt that they had little control over their lives and their disease.

The patient relationships in other clinics with more extensive team-based care expanded to include other team members, which magnified the patients' perceptions of supportive care. The patients eventually opened up to the team members. This act of "opening up" oneself showed their willingness to allow others to help participate in problem solving. In Nelly's case, she worked with several different team members until she felt comfortable with one.

Then when you find that person, then you *open up* and then you tell them how you really feel about your diabetes and what you are going through, which makes it easy. Because then you're opening up to them and then they are able to help you, to resolve the problem, the issues of whatever you're having (Nelly, 51, Franklin CHC patient).

The caring relationship that developed encouraged Nelly to become more actively involved in her care. For the first time since her diagnosis, she was finally able to control her blood sugar levels to within a normal range.

Many patients talked about the anxiety that living with diabetes caused. When they came to the clinic, they were anxious about what their A1C levels would be. Others were frustrated and disappointed when they saw little progress on their A1C after putting in so much effort with diet and exercise. Some patients didn't want their diabetes to define their lives and preferred to ignore it, so coming to the clinic was an unwelcome reminder that they had a chronic disease.

Like when it's time for me to go in for my three month, then I know I'm going to get my A1C, and I have this anxiety about it. The fact that I know she's a nice person and she's not really going to come down too hard on me, helps me. So I've been consistently going to see her. I'm afraid when I get my A1C drawn. The fear about what it's going to be, because it's been so high and it's like, "Just put me in the coffin." But it feels like she's going to work with me and that she's not going to shame me too bad about whatever my A1C is, and she's going to work with me to help me do something better (Maria, 60, Harrison IPA patient).

Caring, non-judgmental relationships helped patients deal with the anxiety about their disease, and the ultimate fear underlying it: their mortality.

Feeling Seen Through Individualized Care

Patients highly valued being seen as an individual with their own unique needs and life circumstances, which made taking care of their diabetes challenging. "Feeling seen," meant that their symptoms or their disease did not define, or constitute their sense of themselves as a person. Many patients spoke about how the individualized care they received from their team motivated them to work harder to take care of their health.

I have to feel like they hear what I'm saying and I have to feel like they get it. That they're not doing "cookie cutter" care. That I'm not the same as the person who was here before and I'm not going to be the same as the person who is here after me. That I'm me, and I need that individual care (Betty, 64, Harrison IPA patient).

In a traditional, busy practice, with little time beyond the 15-minute visit, one could easily imagine both the PCP and the medical assistant reducing the patient to a personification of a standardized checklist, someone who needs to have periodic A1C and cholesterol labs, blood pressure and foot checks, scheduled for retinopathy screening – all markers of a high quality practice. With individualized care, patients feel seen and heard, complete with their own messy life stories. It is to the messiness of life that patients return home to manage their care.

She works with me, and adjusts my meds, and listens to me, and I feel like she treats me as if I'm an intelligent consumer, or patient. And I do explain to her what's going on with me. Somebody insisting that you do something, I mean, it's very ... I think it's very possible that if someone insisted I did something, and I didn't want to do it, I wouldn't go back. Because I would find that I'm just not going to fight that fight (Maria, 60, Harrison IPA patient).

When care is individualized, there is no longer someone insisting on one solution. It is working with the person through their own individual circumstances and agency, to come up with the best solution to their situation. It's respecting that the patient is situated in a particular place, time, location within the context of their families, culture, race, ethnicity, gender, level of education, and stage of life. Insisting on one solution drives patients away from medical care, but truly seeing a patient within the context of their lives pulls them in and makes them want to engage. Patients knew when a proposed change wouldn't work for their particular lives, whether they verbalized it or not. They experienced resistance and tension when there was insistence on one solution that didn't work for them.

I feel like more doctors' offices and clinics need to understand that, too. I know they're doing that as a medical professional, that they're used to seeing hundreds of patients all the time and so they're kind of like robots in a way, where they think they've got to do this and this, this way. But everybody is different. Everybody has a unique way of doing things. Some people can give up everything. It's easy for them. And others just can't (Melinda, 57, Harrison IPA patient).

A key component of individualized care I observed was the use of motivational interviewing. The ideas for potential areas of change came from the patients' own lives, experiences, and life worlds, thus, were inherently individualized. By using motivational interviewing, staff helped patients explore their own motivations, barriers and solutions, and empowered and encouraged them to come up with their own solutions within the context of their lives. Staff did this by asking questions more than giving advice, and giving advice only when patients asked for it.

Each patient had his/her own narrative about how they adapted their lives to cope with managing diabetes. Some patients had prior injuries that required modifications to exercise, some had food likes and dislikes or cultural food preferences, others were overwhelmed with life events - like new jobs, divorces, children suffering from addiction, a spouse's death, planning celebrations, or recovering from a heart attack. Each situation required a unique plan to help them cope and manage their diabetes.

They've said, "Well, how much can you walk?" I'd tell them how many days a week. I figured well, I can do three half hours between our meeting. So I would try. Some days I could get the whole half hour, other days it took me three days to get the half hour. It still works that way. Some days I could walk part of the mall. Other days, I have to sit down up to six times, and I'm huffing and a puffing (Larry, 66, Harrison IPA patient).

When using motivational interviewing, the staff asked questions of the patients. Patients then decided what actions they wanted to take and how often they wanted to do them. If a patient was stuck in their thinking, there was a supportive, non-judgmental person advising them. It freed them up to ask for help.

Well, like the first diabetic educator, one of the things she did was, my favorite food in the world was sushi. Which is really bad for diabetics, just because of the rice. But she constructed my favorite sushi for me, and we figured out how much of it I could have (Betty, 64, Harrison IPA patient).

What can we do to try to get you to take more readings? What can we do to remember your meds? Things like that, they're always setting goals. In fact, every time I go in there they say, What can we do this time? (Larry, 66, Harrison IPA patient).

A by-product of asking questions as patients grappled with solutions to their barriers was that the team members got to know patients in a deeper way. They knew that the patient's family, work lives, past stressors and life events might be getting in the way of reaching their goals. This familiarity fostered support.

We do a lot of talking about my feelings, and about what I'm doing, like right now, the last month I've been overwhelmed with wedding stuff, and I just go in there and just unload, and then we do deep breathing, and we do some, okay what can we do about this situation, so she's my sounding board, if you will. She does a great job of it too, then we set some goals too, okay so what are we going do to combat this (Isabel, 52, Harrison IPA patient)?

Supportive Team Relationships

What is it like to be cared for by more than one person? What does it feel like to have a team supporting you to reach your goals? Many of my interviews revealed that a team or a group of people working with patients magnified patients' sensation of support. It also amplified their awareness of accountability when setting a goal. That, coupled with a non-judgmental, but curious or problem solving approach to trying to help patients cope with barriers, brought patients back for more support. Some patients said that in spite of having supportive loved ones in their lives, they felt isolated when it came to coping with their disease.

“They’re There For Me”

What does support look like in team based care? Patients described the experience of team care as an enveloping or encircling – in one case literal arms around a patient, as she described receiving a group hug when she expressed suicidal thoughts.

In health care we use the term safely net to describe a health care delivery system designed for the most vulnerable populations. The safety net is both health insurance, like the

ACA or Medicare, as well as a health care system that is available when needed for all. They know that there is a place for them that they can rely on. The net is ready to catch them if they fall. The statement “they are there for you,” describes a safety net personified in a team. The net that team-based care provides serves to support and “gird” patients to strengthen them for the complexity of managing their chronic disease.

Feelings of unconditional support allowed patients to feel free to be honest with the team. Patients experiencing this type of care felt that they didn’t have to be the “perfect patient” during their visits. They could come with their struggles with everyday life, and wouldn’t be judged if they couldn’t attend to their health perfectly: whether following a specific eating or exercise plan, or taking all of their medications. That honesty kept them coming back to the clinic, where in other situations they have would have changed doctors, or avoided coming altogether to avoid feeling judged.

A key to helping patients manage their diabetes was to break through the sense of isolation that they were alone struggling to manage their disease.

Interviewer: And what do you think changed for you?
Just recognition that I wasn't doing it on my own. That I wasn't, even though I thought I could, I couldn't do it (Maria, 60, Harrison IPA patient).

Maria realized the limitations of understanding herself as a sole entity, different, apart from others, and separated by her diabetes from the circle of everyday normalcy. In sharing the experience of coping with diabetes with her team, the team patiently drew her back in and helped her once again feel part of a group, all working to improve her health.

We recall Nelly’s story about her trauma of receiving her diagnosis when her daughter was 2 years old. She eventually left the clinic where she received her initial diabetes diagnosis with her diabetes out of control and started going to a new team-oriented clinic about 10 years

ago. She became very fond of her new physician who suggested that she go to Lucille, the health educator. She didn't want to go at first, but eventually went and has been seeing health educators now for about 5 years.

I have trust issues. Little by little I kind of opened up and I think just because of her kindness and how she dealt with me, she didn't push." She opened the door but she let me walk in the door. Then I was able to be myself and talk to her. *They are there for you* so then you can feel it's nothing to be ashamed of and you don't have to be alone because you have them there (Nelly, 51, Franklin CHC patient).

Nelly felt unable to initially trust Lucille, but through Lucille's patience and kindness, Nelly was moved to share aspects of her world. Lucille responded with understanding and compassion. Once Lucille understood more about Nelly's world, Nelly no longer felt that she was alone. For Nelly, the diabetes diagnosis was accompanied by a sense of shame. Perhaps she felt that this was something that she brought on herself, by not taking care of herself. With Lucille, she could be herself and express her fears and concerns honestly and openly and as a result eventually felt less ashamed about sharing the difficulties of managing her disease.

Perhaps Nelly summed it up best at the end of her interview:

It's not just one person, it's a team. It's a team and it's good to work like that. It's teamwork. It's a variety of people who's coming together to help get your health together to make you feel better, to make your life better. It's not just one... the burden is not on one person, everyone has a job to do to make you feel better and that's what I like about it (Nelly, 51, Franklin CHC patient).

“They Know Me”

Institutions aren't generally known for their ability to interact with people as individuals. In health care, the terms evidence-based, protocols, guidelines, standards and metrics imply that there is a common set of standards that should be met to achieve high quality care. While these standards have helped promote higher quality in health care settings, meeting the desired quality goals may risk depersonalizing care of the people that institutions serve.

By eliciting narratives about patients' experiences, we come to see what is important to them. A striking finding from interviews of patients receiving care in teams is that they felt truly seen and known by their health care team: the people checking them in at the front desk, the medical assistants, registered nurses, and primary care providers. One might assume that with a team, having more individuals involved in a patient's care, there would be less of an opportunity to get to know a patient in a meaningful way. Shuffling care between team members, patients could feel that they didn't develop deep relationships with any of them. But this isn't what I discovered in my interviews, perhaps because with team-based care, there tended to be more exposure to the clinic and staff over time.

Many patients spoke about being recognized, greeted by name, and having their care team know and remember personal details about them as individuals, not just as a patient with diabetes. "With this new model, people get to know you" (Ms. Smith, MA, Northpoint Clinic). When they came in for visits, they would talk about their families, hobbies, and leisure time activities. Many team members were able to develop a deeper relationship with patients and got to know them fully as individuals.

The support staff is so wonderful, friendly, professional and courteous. They're always, "Hi, Jeff." They recognize me (Jeffrey, 67, Northpoint patient).

Yeah, we just talk about her, her grandchildren, my daughter. That's what's so nice up there. I've got a personalized relationship with everybody (Walter, 61, Northpoint patient).

Being truly seen and accepted for who they were provided a validation of patients' lives. They were welcomed into a community in which their life story and all its complexities mattered. Their inclusion wasn't just about their disease, with its clinical parameters. When patients felt known, and their presence noticed or absence missed, they felt a connection to the

team. The interactions with multiple team members made them feel seen and understood. “They get me.”

So then we can talk about that and then, it kind of makes me feel better because, oh, she gets it, *she gets me* (Isabel, 52, Harrison IPA patient).

Interviewer: And can you describe what would make you click with somebody on the team?

Anna: I have to feel like they hear what I'm saying and I have to feel like they get it (Anna, 66, Harrison IPA patient).

While a personalized relationship can and does develop between many primary care providers and their patients in traditional practices, patients often feel the time pressure that their providers are under in a typical medical encounter. The provider has less support; so they may get behind schedule, leaving patients to wait in the waiting room and again in the exam room. The medical encounter is 15 minutes or less with the provider rushing to the next patient, and feels unsatisfying.

Team-based care provides the space and time for patients to get to know their team, and the team to get to know their patients.

I mean, I know that I can really talk about other things and be relaxed when I go to the clinic because they make that decision that the individual client is more important than staying on time. They're going to lean over backwards to make sure that you have the kind of support and understanding and follow-up, all that you need (Sally, 68, Mountain View CHC patient).

Often these relationships are developing through more frequent and sometimes longer encounters that are not possible with a traditional model of care. In some settings, I observed the health educator or nurse use the time before and after the PCP entered the room to meet with patients, do motivational interviewing and provide health coaching and teaching. Even though the PCP may have been scheduled every 15-20 minutes, having multiple team members available to the patient gave them an expanded sense of time during the visit.

Patients often contrasted their care with prior clinics as the opposite of what they were experiencing with their new team-centric clinic.

Now, prior to that [coming to her the new clinic], I didn't do that at all with my healthcare provider. And it wasn't that she wasn't nice. I just felt like she was rushed, and she didn't have a lot of time for me and she didn't seem as concerned about my diabetes, all this kind of stuff. So they really have taken an active interest in my health (Betty, 64, Harrison IPA patient).

So I think people have learned that it's just better not to mention some things, or a lot of times they don't have enough time. So I think it's a learned thing in other kinds of settings. And maybe when they come into this setting, they have more time to talk about what's going on with them and then they get to participate more in the decision making (Betty, 64, Harrison IPA patient).

And they don't rush. That's what I loved about them. My other doctor would be gone. It would take forever to get in the room, spend 10, 15 minutes, and he'd walk out. There, they take all the time in the world. Time doesn't really matter. If I have something to ask or talk about, they take the time (Larry, 66, Harrison IPA patient).

“They All Work as One”

Larry is a former electrician in his mid-60s from a rural town on the U.S. west coast. He was diagnosed with type 2 diabetes twenty years ago. He had two successive heart attacks about three years ago, followed by quadruple by-pass surgery and stents, just before becoming a patient at Harrison IPA. His interview provided a rich contrast to the traditional health care model with his new clinic that provided team-based care. He first met his new team a few days after he was discharged from the hospital. The first visit was with his new PCP and the team RN. Concerned about some of his lab values that were critically out of range, they visited him at home daily that first week. “I’ve never had a doctor’s office do that before. It felt like for the first time somebody in the medical profession cared” (Larry, 66, Harrison IPA patient).

When Larry went to the clinic, he didn’t always see his primary care provider. He noticed that she often “popped in, but she didn’t stay the whole time.” He described all the activities that different team members did: checked him in, took his vital signs, conducted

medication reviews, documented problems in the computer, searched and found past lab results so the primary care provider would see them. Larry also had independent visits with the wellness coaches and a diabetes educator, as well as outside therapists, podiatrists, and ophthalmologists.

Whenever Larry was asked about care at his new clinic, even when referring to his primary care provider, he used the word “they.” He didn’t differentiate his relationship with his PCP apart from the other team members. He considered his primary care provider, the medical assistants, the wellness coaches, diabetes educator, the nurse, the therapist, and the receptionist all a part of the “they” of the team. When asked if his PCP knew him well, Larry said, “I walk in there; *they* all know me by name. They’re very good. They’re all very friendly.”

There was something about the way the team worked with Larry that gave him hope. They didn’t give up on him, and they kept trying new things, encouraging him to do “a little more,” and set small goals.

The way they present what I need to do is at a point that makes me want to try to do it. They make you feel like maybe there’s light at the end of the tunnel. They keep doing things; they always try to educate you. They keep pushing me to do just *a little more*, setting small goals. Each time I achieve one of those goals, I’d feel better. My other doctor wouldn’t do anything and I’d just throw my hand up, and I’d walk out. If I had kept him, I would be in the same condition (Larry, 66, Harrison IPA patient).

When Larry achieved a goal, it gave him confidence to keep trying, and not give up. The team was continually working with him, asking “What can we do this time?” “They ask me what I want to do, they allow me to set them.” Asking Larry what he wanted to do helped him make changes that fit within the parameters of his life. Instead of imposing a standard set of expectations for his behavior, they put him in control of his own disease, and engaged him more fully in his care.

“It’s Like a Family”

“It's almost like a family” (Larry, 66, Harrison IPA patient). Many of the patients interviewed mentioned that their team felt like a family to them, conveying a sense of belonging. You can be yourself when you’re with your family. They know you better than anyone else and see you at your worst and best. You share sorrows and celebrate joys. You have someone to tell when something goes well in your life, just as you have someone to go to when you are struggling.

But I think they become part of your family. It’s like a little crowd of people that come to help, you know. When one comes, the other goes. But you feel that crowd. It's a family. They're my family. They're my healthcare family (Isabel, 52, Harrison IPA patient).

It feels like they're my family. I feel like I can talk to them (Maria, 60, Harrison IPA patient).

I like the fact that they have happy people here, they make you feel like family and friends, you know, comfortable. That's why I'm here. I don't have any family here. I feel like I got my family (Luisa, 43, Mountain View CHC patient).

Why do these patients experience their health care team, a group of people not related to them or to each other, so profoundly as a family who is “there for them?” Several examples from my interviews stood out.

I feel like I got my family. Because one time I don't have money to provide for my kids for Christmas, and I was talking with another assistant, a nurse, she's my neighbor. And I explain what's going on and she came in to speak with Jean [the PCP] and Eileen [the nurse] and everybody raised money and give me money for my kids. So it's something that, you know you're not expecting that from somebody that's not your family. But, it's like my husband was really sick. He was really, really sick. So all the money that we have for, you know to pay the bills, we use and we [didn't] have Christmas (Luisa, 43, Mountain View CHC patient).

Luisa’s neighbor, who worked at the clinic, told the staff that their patient was struggling financially and that they wouldn’t be able to afford any Christmas presents. When the clinic staff donated money to buy presents for the family, Luisa was overwhelmed with their

unexpected outpouring of love and support. This is the type of support she would have expected to come from a family, who is always there for you.

Maria, a 50-year-old patient of Harrison IPA, told me the story of her excitement of finding new family members through DNA testing. She showed me photos of her newly found siblings, cousins, aunts and uncles, even their dog, and told me about meeting them in person and the history of the family's immigration to the U.S. This was even mentioned in her team's interview – the team knew and shared her excitement of finding her family.

So, both of my parents have passed away. My mom died when I was 22, and my dad died in 2011. And I was an only child. I was adopted. They couldn't have children. And so, about five years ago, on Ancestry, I was able to find my mom. I knew that I had a brother, but I couldn't find where he lived. And then I felt like I was able to find my sister. But anyway, I kept putting it off, because I was afraid of the rejection. And of course, I'm all by myself, other than my own nuclear family. My husband and I are separated, we don't live together.

So I wrote [to my sister]. It was Friday at work, and I wrote this really short, little thing. I'm like, "I'm not going to put a lot of information in it." And I put it in the mail, in a pretty card. And that was on a Sunday. And so on Wednesday, I was driving to my girlfriend's house, and she called me, my sister did. And she said, "Hi, this is Sarah." And I'm like, "Sarah? Sarah?" She goes, "Sarah Smith." And I'm like, "My sister, Sarah Smith?" She's like, "Yeah!" [laughing]. Anyway, I found that whole family. So now, I know something about my health history, and I know my whole family history, and everybody at the clinic shared all of it with me. Yeah, so it does kind of feel like they're my family. I feel like I can talk to [them] (Maria, 50, Harrison IPA patient).

Maria's experience of finding her family revealed something about what it might mean when patients refer to their team as a family. Having a family helps you know and understand yourself and your place in the world. Having someone who is always there for you, having a connection that is enduring. Sharing the same core DNA connected her forever to her sister in a deep and profound way that Maria found comforting and thrilling. You could sense her excitement. That she would use the same language to describe her clinic family is telling. She felt a sense of connection to them just as she did to her newly found family.

Andrea, a patient of Mountain View CHC, who had recently lost her home because of fires ravaging the west coast, told some of the team members about her thoughts of driving head-on into a truck on the rural road while driving to her clinic appointment. The clinic mobilized around her, found her immediate mental health resources, and surrounded her in a hug. She compared the support that she received from the clinic to that of a family.

That was a place to go to really be seen and understood. They knew about it, they were supportive. They knew, and they could see it was a pretty major change and loss on my part. That were really there for me, and being witnessed, is a pretty powerful thing. And that in itself is as healing as anything can be other than time (Andrea, 57, Mountain View CHC patient).

Andrea felt the healing power of “being witnessed,” or being seen, fully as a person struggling in life’s arbitrary circumstances. After the fire, when she had trouble finding rental housing after being displaced, Andrea reached out to her estranged sister. After she mentioned to the sister that she thought that it would be better to call her than the suicide hotline, the suicide prevention squad arrived at her door. She was told she could either go to the hospital voluntarily or in handcuffs. Describing her hospital experience, she said, “If I wasn’t suicidal going in [to the hospital], I definitely was leaving.” This was in contrast to the experience that she received from the clinic, where she felt seen or “witnessed” by her team and surrounded by a hug.

Andrea felt that her healthcare team was “better than family”, because they were better trained and had more skills to help.

And then four years ago, he [her significant other] passed on from pancreatic and liver cancer. And I just remember there was an incredible amount of understanding and compassion and kindness those few months after that big transition. And it's more focused, dedicated, and skilled perhaps in an environment like that compared to friends, maybe even family (Andrea, 57, Mountain View CHC patient).

A team that is “better than family” seems to imply that it is the type of family that you can depend on for unconditional support, and with whom you aren’t afraid to be honest without expecting criticism and judgment.

What Patients Want

The Ideal Visit

I asked patients to reflect on and describe what they considered to be an “ideal visit.” The responses fell into three main categories: logistics, caring relationships, and affirmations.

Wanting more time with their care providers and less time waiting was the focus of most of the patients’ logistical wants and needs. Patients did not like long wait times, and of the patients I interviewed, it was only an issue with a few providers. Those that experienced long waits seemed to understand that delays sometimes happened, but wanted to be kept informed about why, or how much longer they would have to wait. One patient expressed confusion about the flow of her visits, and never quite knew when a visit was over.

The wait time is not too long, but if it is a long wait, they come and explain what’s going on, why you are waiting (George, 70, Northpoint patient).

You don't have to wait long, the one thing I have trouble with is knowing when the visit was over cause they'd go run off and get something and I wouldn't know whether I was to stay there and wait. Or just pick up and leave. So maybe some more instructions on what happens next and then when it's time to go (Anna, 66, Mountain View CHC patient).

Patients overwhelmingly wanted to have more time with their providers and to have a relaxed visit with plenty of time for questions so that they could understand their illness.

“Spends time with me. Goes over tests I’ve had” (Andrea, 57, Warren CHC patient) and

“Answer my questions no matter how silly they are” (Betty, 64, Harrison IPA patient) were common statements expressing the desire for more time.

I can talk about other things and be relaxed because they make the decision that the individual client is more important than staying on time (Sally, 68, Mountain View CHC patient).

Patients were aware that a rushed clinical visit meant that they wouldn't be able to fully discuss the issues that mattered to them. This might be especially true for elderly patients, who have multiple health issues to discuss.

Not all patients, however, shared the desire for longer visits. Some patients wanted a streamlined visit to affirm that all was going according to plan, and not have to spend much time in the office. For Scott, a younger patient recently diagnosed with diabetes, efficiency in the visit was paramount for an ideal visit, "in and out the door in 20 minutes max."

Caring relationships mattered a great deal to many of the patients. Patients described the actions that made them feel cared for by their team members: being positive and friendly, listening, being compassionate, empathizing, and trying to understand their particular life circumstances. These actions made them feel supported and important.

If I walk in the receptionist is friendly. The medical assistant makes you feel comfortable. Everyone is positive. Everyone is making you feel comfortable (Nelly, 51, Franklin CHC patient).

Focus on the individual – not give a lot of paperwork and information to read and study at home (Melinda, 57, Harrison IPA patient).

Patients wanted to be listened to in a way that they felt heard and understood. They equated the two actions – being listened to and understood - as part of an overall expression of compassion. Patients also wanted their providers to respond in ways that they could understand. Patients wanted personalized care during which they would receive explanations and answers to their questions. This individualized attention made them feel important and valued. "So I feel like a person who is important" (Luisa, 43, Mountain View CHC patient). Sally, a 68-year-old patient of Mountain View CHC wanted to "feel valued as much as I value them."

Being compassionate and listening to what they're trying to tell you so that you can get a better understanding of that particular person (Melinda, 57, Harrison IPA patient).

Feel like I get heard with what my problem is, with what I have to say. To feel like I'm being understood and to feel like things are explained to me in a way that I can understand (Betty, 64, Harrison IPA patient).

Contrast Nelly's caring visit experience where her team members saw her, sat with her, talked to her, and took time with her, with a more efficient visit of 15 minutes, required by so many institutions and insurers in the name of a misplaced efficiency.

So you feel important. If I don't feel like I'm a meat market, like I'm passed down and not cared for. Everyone on the staff is taking care of me, they are catering to me so I feel important like that. I could go in and say anything that was bothering me because a lot of times our emotions are as fragile as our body parts and they work together. If you have a positive attitude, you feel better and the stress levels you know, with this and that. I could come in and come away feeling that "Oh well, my doctor understands. He knows." We'd talk and he wouldn't necessarily have to prescribe anything (Nelly, 51, Franklin CHC patient).

Nelly recognized how emotions were part of her being, and that they could be as fragile her physical being. Being listened to, feeling that she was understood and important, was a part of the healing process and was as powerful as treatments and medications.

And finally, patients wanted recognition and affirmation of the work that they were doing to control their diabetes. Patients who were able to meet or progress towards their small goals were excited to see results and share them with their providers and team members. Patients highly valued the opinions of their team, and sometimes just knowing that they would be coming back to see them made them work harder on their goals.

They'd say, "You're doing great, keep it up." Keep doing what I'm doing. Don't need to do anything differently (Scott, 35, Harrison IPA patient)

The providers' and team members' descriptions about what they would define as an ideal visit were similar to what patients wanted. The primary care providers and staff would like enough time to establish relationships and support their patients in achieving their goals. They

spoke of having enough time so that patients could relax, confide in them, and trust them enough to talk about serious topics affecting their lives.

Team members recognized that the office visits represented a small slice of patients' lives, and that they would return home to many challenges in managing their disease. Many spoke of wanting the patients to have a positive experience so that they leave the visit activated, engaged, excited to meet their goals and feel better than when they arrived. "If they can leave in a better mood, then it's a success. Look towards the future, give affirmations, help them feel better in the moment" (Marie, Harrison IPA Wellness Coach). They realized the power of hope and optimism in motivating patients. And finally, they saw the power in individualized and personalized care – that there wasn't one approach that would work with all patients.

We have an empathetic ear, we're a safe place for them, they open up, there's a lot of crying, there's a lot of heavy burdens or barriers to why they feel like they can't go on their walk or take their medications. There are so many things that get in the way of the how you're going to do it (Marie, Harrison IPA Wellness Coach).

If they're doing well, I'd like to see them every 6 months. I want to make sure they're getting all of their health maintenance issues and chronic illness issues. I want to make sure they get all their questions answered. I want to make sure they understand what diabetes is and why it's important to be self-managing and to feel supported between visits. To do all the healthy behaviors that they need to do (Dr. Hill, Northpoint PCP).

The Ultimate Goal

Patients were consistent on one dimension of the ideal visit – that they would hear the magic words that they no longer had diabetes or were doing well managing their diabetes. This was paramount above all other goals: to have their diabetes controlled, as well as any other problems that they might have like high blood pressure or high cholesterol. As Larry, the Harrison IPA patient summed it up; the ultimate goal was to "have them tell me I'm well."

Oh, you don't have anything, you don't have [any] infections, you don't have diabetes [any] more. I [would] feel happy (Luisa, 43, Mountain View CHC).

To be knowing that my A1C is going to be really low and she will be like, “Yeah, you don't have to come back for a while” (Melinda, 57, Harrison IPA patient).

“Get on the scale and I’ve lost a pound, my blood pressure is great, my A1C is down, and [the PCP] comes in and says “You’re doing a fabulous job. Look at all this! I’ll see you in three months” (Isabel, 52, Harrison IPA patient).

Being well while living with diabetes meant different things to different people. For some “being well” meant being told that they magically didn’t have diabetes. For others, being well was that they were managing their diabetes and keeping high blood sugars and the subsequent effects on their bodies under control. It meant that their actions were having the desired effect on their health, and that they would be less reliant on the health care system. They were in control of their health, which might mean that they didn’t need to come to the clinic as often.

Jointly Celebrating Accomplishments

And finally, in the ideal visit, patients wanted to have their accomplishments acknowledged and to celebrate with the team. Patients who were able to achieve their goals, both big and small, described the joy they felt when they achieved them. Not all the goals were directly related to their health or diabetes. Maria, a 60-year old patient of Harrison IPA, described the goal that she set with her team to sell her store.

Well, when I started at the clinic, I told them that I felt I was going to die if I didn't unload that store. So this huge goal of mine, it makes me feel like crying when I think about it... the idea of actually following through and doing it. And I had been talking about it for a long, long time, and I was afraid to do it. Having the people who cared for me, cared more about my health and everything, and somehow having that little extra boost of help helped me get through that (Maria, 60, Harrison IPA patient).

It took a year for Maria to come to the decision and then sell her store, but it ultimately resulted in less stress and more opportunity for self-care. The team helped her understand her feelings and fears about selling the business, and she felt supported and cared for.

Patients wanted to celebrate with their teams. By celebrating together, it acknowledged both the accomplishments of the patients' efforts to improve their health, as well as the support that the team provided them to reach that place.

I can celebrate with [my PCP] and [my nurse] and my family (Luisa, 43, Mountain View CHC patient).

It is pure and simple. I got on the scale, and my weight was down. My blood pressure was perfect, my A1C was seven or below. And everybody was happy for me (Maria, 60, Harrison IPA patient)

This was recognition that the patient and the team were one, and that patient success was team success – they were all in it together, working in the same direction towards a common goal.

Sally, the 60 year-old patient of Mountain View CHC who lost her housing as a result of fires, briefly changed clinics to one near her new home. She quickly moved back to her “medical family” at the Mountain View CHC. She didn't feel the same personalized care and connection to the staff at the new clinic. She described why she went back to Mountain View and what she considered to be an ideal primary care clinic.

Well in some ways, I'm leaning on the understanding I have from other people, most of whom are [patients of a large managed care system]. And I guess you either hate or love [the system], but still in all, it feels like it's quite impersonal, and also much more timed. I mean I know that I can really talk about other things and be relaxed when I go to the clinic because they make that decision that the individual client is more important than staying on time. And they've actually spoken of that. I've talked to them about that feeling.

I think that's why they work where they work, 'cause they know that those are the values. Those are the core values of that environment, that it's not about time and money. They have to be aware of it, but they're going to lean over backwards to make sure that you have the kind of support and understanding and follow-up also, that you need. So I really feel like a person who's important, and of course, the big celebration when I decided I would stay, was fun to see that I'm valued as well as I value them. They really were hugging, and doing the happy dance (Sally, 68, Mountain View CHC patient).

“Doing the happy dance” with one another is something we all want to be able to experience – patients, providers, even insurers and institutions. It’s time we set up our health care systems so we all celebrate together. Perhaps supporting and strengthening primary care institutions’ ability to provide team-based care will make this happen.

This chapter described how patients experienced team-based care – their awareness of team care, their role on the team, and how caring relationships and individualized care motivated them to be more fully engaged in their care. Patients felt that team members were there for them, knew them as unique persons, and provided a nurturing, supportive presence, “like a family”. Patients experienced teams as a group of people concerned about them, and wrapping them in an envelope of support.

Chapter 8

Reimagining Primary Care Through Teams

“To bring anything into your life, imagine that it’s already there.”
- Richard Bach, American writer

This research provides guidance for a variety of stakeholders: clinicians working in teams, administrative leaders who develop organizational strategies for team-based care primary care, policy makers, government agencies that determine financial models of care, regulatory bodies and associations that influence clinician scope of practice, and future students in the healing professions as they train in this new system of care.

This chapter begins with a discussion of the ontological questions concerning team-based care – what it means to be a team, and what it means to a patient to be cared for by a team. I then summarize the effective team practices that were observed and discussed during the course of my research. At the end of this chapter, I discuss the implications of team-based primary care given the constraints that we face in the current U.S. healthcare system, and summarize the policy considerations necessary for structuring optimal team functioning, effectiveness, and sustainability.

Imagining primary care transformation through teams may seem both daunting and unrealistic. Our current payment, organizational and educational systems are just starting to support team-based care. When working in teams, there is also the human element: unpredictable people and personalities who must come together to form a cohesive working relationship. Teamwork presents many challenges such as individual egos, misaligned goals, patients’ reactions to working with teams, scheduling difficulties, lack of funds and personnel for training, scope of practice restrictions, funding and reimbursement.

I know from my personal experience consulting with primary care practices that many

people who work in primary care are burned out and tired of the seemingly constant organizational changes required of practice transformation. Even health care professionals who deeply believe that primary care transformation is necessary may feel they do not have the energy and time to make the changes needed for a team culture to thrive. Sometimes this resistance occurs despite the fact that the changes have the potential to make their work lives easier and more joyful.

Many of the practices included in my study have pushed through these challenges to make the changes necessary for teams to flourish. In some cases, such as Harrison IPA, they were able to start from the beginning and develop the ideal team structure from the onset. Others, like Northpoint Primary Care Clinic, worked within their institutional constraints to find solutions with a smaller team structure that worked for them. For other clinics, the clinic leadership believed in a team-based model strongly enough to search out additional sources of funding to make it happen.

The Essence of Team-based Care

The essential ontological question about teams is: What does it mean to be a team? From a phenomenological viewpoint, an essential facet of a team centers on the relationship of the team to the world. The world is the meaningful set of relationships, practices, and language that one has by virtue of being born into a culture (Heidegger, 1962/1927).

This begs the question - what is the culture of health care? The culture of health care is currently undergoing a transition. Traditionally, patients have experienced an imbalance of power, with the doctor as the all knowing and powerful entity where patients enter into their foreign world of healthcare feeling fearful, weak, shamed, vulnerable, and ill-informed. Recall Jean, from Mountain View CHC, describing the transition she has seen in health care culture:

There used to be a culture of a doctor was a man, and a man was God, and you came to the doctor, and the doctor told you what to do, and you just sat there patiently and walked out with your Valium. And that's not true anymore. We ask a lot of our patients (Jean, PA, Mountain View CHC PCP).

The “world of health care” reflects the set of relationships, hierarchies, skills and practices related to that world – its history, culture, language and vocabulary. It is the everyday experiences co-constituted by patients and the team members that make up the team. To understand the essence of team-based care, we must understand and make sense of the world in which the humans engage in teams.

How do I “name” the elusive essence that is called team-based care? What is it that makes it what it is? A team is not just a collection of individuals, or a particular configuration of roles. A team has a fluidity of function that shapes different possibilities for care that feels more human than a particular role or function. In Heideggerian phenomenology, “disclosing,” which is likened to clearing a forest to bring in light, reveals ways of being in whole situations. Disclosing, equated to caring, is the “opening” up of a shared situation. “If I share your situation, it becomes not *my* situation but *our* situation” (Dreyfus, 1991, pg 165). My data showed that teams in primary care allowed new possibilities to show up for the patients and the clinicians. They were no longer bound by hierarchal rules but were interacting and teaching each other in new ways. Teams created a new safe space to try out things that other systems constrained them from doing. When people came together in this meaningful way, health care delivery became something new. What emerged out of team-based care was more than the sum of the individuals that made up the team.

I know from my interviews that there was something “different” about team-based care for patients and the teams themselves. Was the difference when patients encountered a team of people who supported them and each other, and they entered into that world of support? Were

patients entering into a new world where they felt that they were truly the center of focus? Did that change their behavior in some way? When I examined the experience of team-based care from the patients' perspectives, they described an enhanced sense of support. Their narratives allowed me to envision a possible inner dialogue about their new world within the team:

If these people (the team) care so much about me, I must be worthy of care, and I will start to care for myself. I feel obligated to them and I don't want to let them down. We are now joined, or co-constituted, in my world. I have let them in, opened up to them, and now we are in this together. And if I fall, they don't judge me. I can be open and honest with them and my struggles. They will work with me to find ways to do better next time, or try something new. There is something about a group of people who care for me that adds power to the caring. And when I'm cared for, I want to care for myself. In a team I get encouragement, they celebrate with me, we share successes and disappointments. They're rooting for me. It's like having your own fan base - they want me to win. They stick by me through thick and thin. It's like a family, and sometimes, a team is even "better than a family."

What are the words to describe teams? Patients experienced teams as like a family, a support, or a feeling of being surrounded and wrapped around. Team members provided an authentic, nurturing presence for patients to express their suffering, challenges, frustrations and confusions. When they entered into a team, they were entering into a caring community where they felt that those caring for them were "there for them." They felt understood from within their lives in all their complexity and messiness. Team members, in turn, genuinely felt and conveyed a sense of caring.

It was over 25 years ago that the seminal book *Through the Patient's Eyes* (Gerteis, Edgman-Levitan, Daley & Delbanco, 1993) was published, spawning the patient-centered care movement. The authors realized the importance of understanding patient experience in healthcare as a measure of quality of care. Patient experience describes the subjective experiences of human relationships in the act of caregiving, which are more elusive and difficult to capture than the technical aspects of care. Based on over 6000 interviews of hospitalized

patients, the results of this research led to the development of the Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey, which began in 1995 as a program by the Agency for Healthcare Research and Quality (AHRQ). The survey has since been updated and is now widely used for surveying patient experience in both hospital and outpatient settings.

CAHPS became the national standard for evaluating health plans, spurring CMS to require the use of the CAHPS survey as a measure of organizational quality in primary care settings. In spite of the growing push to transform primary care through the use of teams, the CAHPS patient experience survey doesn't address patients' experiences with being cared for by a team, resulting in a gap in understanding patient experience of teams in primary care settings. The aim in this study was not only to find out how patients experienced teams, but what they wanted and needed from the healthcare encounter. In the course of this research, I attempted to understand the experience beyond the boundaries set by my own view as a clinician researcher, and entered into the view of patients as expressed through the narratives that they chose to share.

By including organizations that had highly functioning team-based primary care, I could explore the patients' experiences within well-developed teams. Many patients chose to contrast their current care with care from previous providers that were less team-based. The core finding from my research is that patients were able to feel a team working on their behalf, and it provided a sense of support beyond what one person working alone could provide. This support encouraged patients to more fully engage in their own care. Feeling surrounded, wrapped around, held up, or supported is the hallmark of the experience of team-based primary care.

Putting Patients at the Center

My research aligned with the current literature regarding what patients hope to experience in their relationships with their primary care providers: continuity of care, sufficient

time for medical encounters, the opportunity to ask questions, feeling listened to as a unique patient and tailored care (Pooley, Gerrard, Hollis, Morton, & Astbury, 2001).

Continuous, Caring Relationships

At the core of what patients with type 2 diabetes want of their health care experience is to have a continuous, caring relationship with an individual whom they know (Pooley et al., 2001). Patients preferred to see the same person each time they received care, and felt that their care improved when they had most of their care through one named individual. Continuity, defined as a sustained partnership between a patient and a provider, is associated with improved health outcomes (Cabana & Jee, 2004; Parchman, Pugh, Noel, & Larme, 2002), fewer hospitalizations and emergency department visits (Hussey et al., 2014; Knight, Dowden, Worrall, Gadag, & Murphy, 2009; Nyweide et al., 2015; van Walraven, Oake, Jennings, & Forster, 2010), greater patient satisfaction (Gulliford, Naithani, & Morgan, 2007; Mainous, Goodwin, & Stange, 2004; Nutting, Goodwin, Flocke, Zyzanski, & Stange, 2003; van Walraven et al., 2010), better adherence (Alazri, Neal, Heywood, & Leese, 2006), greater likelihood of receiving recommended care (Atlas, Grant, Ferris, Chang, & Barry, 2009), and lower costs of care (Chen & Chen, 2011; Saultz & Lochner, 2005). These benefits may be even more apparent in patients with chronic disease such as diabetes (Chen & Chen, 2011), where a continuous relationship may increase self-care behaviors and glucose control.

There is growing evidence that patients who have a good relationship with their providers, are able to communicate effectively, and believe that health professionals take a personal interest in their care, are more likely to achieve effective management of their conditions (Pooley et al., 2001). Research by Mainous et al. (2004) found that the provider-patient relationship may be linked to successful management of medical issues, and that patients

with medical conditions like diabetes that require substantial intervention, exhibit a stronger desire for continuity.

A caring relationship is central to what patients wanted from their health care experience. What caring behaviors were on display in team-based care? Caring involved giving of one's time. It was truly listening and understanding, attempting to view the patients' struggles within their worlds, and trying to understand their particular circumstances. The result was that patients felt seen, important, and "like they mattered." Patients knew when someone cared for them.

Team members in effective practices allowed themselves to be open and moved by patient narratives. Recall Mary from Harrison IPA describing, "there's a lot of crying" during medical visits. This entering into and opening themselves genuinely to the patients' lives was experienced by patients as warm and authentic. It showed respect, kindness and care. In *The Primacy of Caring*, Benner & Wrubel (1989) discuss how caring is an "enabling condition of connection and concern" that "places the person in the situation in such a way that certain aspects show up as relevant." Caring was central to effective team relationships. It caused team members to "notice" the patients and each other, and set up the possibility for trust, "that enable[s] the one cared for to appropriate the help offered and to feel cared for" (p. 4).

This entering into the patients' worlds evoked feelings of hope. Larry, the Harrison IPA patient, who was not expected to survive his second heart attack, said that after being cared for by his team, he felt a sense of hope, a "light at the end of the tunnel." This level of caring and empathy allowed patients to accept themselves in their particular situation in life, and to be able to look at their life circumstances with curiosity, compassion and less shame.

Building Trust through Relationships

Continuity and trust are intertwined, as continuous relationships allowed familiarity and increased mutual trust between providers and patients. Thom (2001) described behaviors that are important to the patient for building trusting relationships: being comforting and caring, demonstrating competency, encouraging and answering questions, and explaining what is being done. As trust improves, patients feel more comfortable sharing information about the social factors that impact their care (Parchman, Flannagan, Ferrer, & Matamoras, 2009).

Clinic providers and staff were aware of the importance building trust through relationships. Sometimes, when patients had been avoiding getting care due to prior negative experiences with health care providers, or because they didn't want to have to think about their diabetes, just getting a patient to come back to appointments was considered a success. When patients had a relationship with the staff, and felt that the clinic was a safe place, they returned for care, and were honest about their lives and all the complications that made taking care of their diabetes difficult. This openness allowed the staff a window into the patients' lives so they could understand and motivate them to find solutions to take better care of themselves. Letting the staff into their lives through the relationship was transformative in their care. They felt seen and heard, no longer "just a number" in a clinic, but a person with a life beyond their disease. If patients felt that their team cared about them, they felt worthy enough to take care of themselves. They had the courage to try new things, even when they didn't initially work. They kept coming back for more care, without guilt or shame, but with openness and honesty.

The patients like us generally, and they feel safe to come back to us. So, even if they have been falling off the wagon, so to speak, they'll come in. And they're honest (Eileen, RN, Mountain View CHC).

They know us. It's building a relationship, really. We've all been there where you've been to the places where you've seen a different provider, a nurse practitioner at every visit,

and you just feel kind of like a number sitting there, you don't feel like a person. And I feel for my patients on my team, I've really built that relationship, and I feel in turn there's trust built for that sharing to come out (Jean, PA, Mountain View CHC PCP).

Dr. Hill felt that his relationship to his patients was essential and foremost to the care he provided.

I would call this all relationship building. We had to build a relationship, and he had to trust me. I think people want to make sure that you are on their side and that you're not going to do anything that's going to hurt them. But I would say for everyone, though, the goal is that this is a long-term thing here. It's not like we're going to do something today. I'm not a surgeon. I'm not going to fix your diabetes today. This is going to take a long time, and so, we have to build a relationship. That way, you'll continue coming back, and we'll make changes because some things will work for a while. Then they stop working, and you do something else. Set that groundwork. So, really, my goal is always to get people to come back (Dr. Hill, Northpoint PCP).

Dr. Hill's long-term view of patient care contrasts with the "fix-it" mentality that a surgeon might have. He realized that for a patient to change their lifestyle takes time, patience, and perseverance and that a solid relationship lays the groundwork for those changes.

Asking and Listening Through Motivational Interviewing

In a systematic review of patients' and healthcare professionals' perceptions of self-management support, the authors found that the traditional model of health education was the primary means used by health care professionals to increase knowledge and facilitate behavior change (Ofstedal, Lewis, Willis, Bourke-Taylor, & Smith, 2017). Patients were provided generic information on diabetes management, but they expressed the desire for help in understanding how to apply the information to their own situation. In a qualitative study of patients with type 2 diabetes perceived support from healthcare practitioners, patients valued being heard and appreciated enquiries about their personal life: "It's understandable that they have a 'recipe', but I think some of them should perhaps be better at just listening to what a person tells them about his or her everyday life" (Ofstedal, Karlsen, & Bru, 2010, p. 1504).

These listening interactions are time-intensive, and in traditional models of care, patients and providers struggle to balance medical care needs with the psychosocial needs of patients attempting to manage their chronic disease in their daily lives. For patients living with chronic disease, medical care is a small piece of their overall care. Patients wanted to be seen as unique individuals with their own life worlds and challenges. They wanted to be known and recognized as individuals. Recall the pride that George felt when the front desk staff at Northpoint Clinic recognized him and greeted him as he came in the door, or how Walter felt when he was warmly greeted and they asked about his family.

When patients felt that they were listened to and their thoughts and feelings were taken into account during treatment decisions, they felt respected and valued. When care was individualized, there was an emphasis on the patients' subjective experience of illness within the context of their social, psychological, physical, cultural, and spiritual lives. The individualized care the teams provided looked beyond the physiological state of disease at the impacts of illness on day-to-day living, relationships, self-concept, emotions, practices, and habits. It incorporated how patients understood their illness, responded to it, communicated about it, thought about it, how it altered their lives: in other words, how their illness was situated within their lives.

Motivational interviewing was the tool used by these teams to access the worlds of individuals living with diabetes. When using motivational interviewing, questions were asked of the patients: what did they know, what was their understanding of their illness, what did they want to know, how did treatment and medication options affect their lives? Benner and Wrubel (1989) defined "situated possibilities" as the opportunities or choices that show up to individuals as they are engaged in their own concerns. When teams were asking patients about how their illness impacted their lives, and how they understood their diabetes, they were soliciting deeper

understandings for both themselves and the patients in the context, or situation, of patients' current lives. Certain opportunities showed up as possible within a situation, making some choices stand out. Team members developed a collective response with each individual patient that relied on truly knowing the patient to decide what courses of action to take.

Three of the five clinic sites where I conducted interviews required all members of the staff to get training in motivational interviewing. Team members described their use of motivational interviewing during the focus group interviews:

Go in and openly listen, hear everything, ask a few guiding questions, really hear their story, reflect back and figure out what to do to leave with some kind of plan, some kind of hope, that kind of thing (Margaret, NP, Harrison IPA PCP).

I'll steer the conversation but they really are the ones driving. If I think that they need to lose weight first, I'm wrong. I want to know what they want to do first, and then we kind of go from there (Marie, Harrison IPA Wellness Coach).

By using motivational interviewing, the team members became the sounding board for patients as they attempted to navigate changes to their lives. They entered the session with patients with humility, not as experts, knowing the most lasting solutions would come from the patients themselves. "As medical providers, we are consultants to the patients, not the boss. Offering advice and counsel and remembering that it's ultimately this person that we're looking at who's come here for help...and putting the ownership on them" (Margaret, NP, Harrison IPA PCP). Through motivational interviewing, they were able to be with their patients in a way that acknowledged their personal experience with their illness so that they felt known and supported. Knowing the patient means "getting a grasp of the patient, getting situated, understanding the patient's situation in context with salience, nuances and qualitative distinctions." It was getting to know the person as a person, with "an involved, rather than detached understanding of the patient's situation and the patient's responses" (Tanner, Benner, Chesla & Gordon, 1993, p.

275). Knowing the patient is the foundation of individualized care.

Encouraging “Baby Steps”

Providers recognized that it was important for patients to make small, sustainable changes, or “baby steps” as patients developed trust in them. Providers are often in the role of encouraging patients to try something new, which can be frightening for patients. Taking that first step is sometimes the hardest. The provider and team members asked patients to try, and with their encouragement, promise to be there for them if they fall.

It's very rewarding when you could see them make just a little *baby step* or an improvement, and that they are trusting to tell me things that they probably wouldn't tell a nurse somewhere else. To me, that's really rewarding (Jean, PA, Mountain View CHC PCP).

We recall the Northpoint patient who had difficulty accepting his diabetes diagnosis, and who often changed providers prior to coming to Dr. Hill:

[He] doesn't want to check blood. [He] doesn't want to do anything. So, we just spent a long time building trust, and that proving to him that his goals are my goals, and so, we had a lot of *baby steps* with medications. He told me the medication gave a side effect. I was like, "Not doing it. That medication's terrible" (Dr. Hill, Northpoint PCP).

While this patient gradually navigated his new reality, and as he entered into a new world as a person with diabetes, his initial attempts to manage his medications were like taking “baby steps,” as one would experience with any new endeavor. When taking “baby steps,” initial attempts are tentative, wobbly, and off-balance. You fall often, but you get back up and try again. Gradually, the attempts become more confident with bigger “strides” until walking becomes a taken for granted activity. But it didn’t feel this way at first, and Dr. Hill sensed that it was important not to rush this patient. Dr. Hill assured him that “his goals are my goals,” that they were co-constituted and partners in his care. There

was a sense that they were in this together, not as someone from the outside imposing a solution.

Adequate time

Patients didn't want to feel rushed during their visits and wanted to have time with their primary care providers and team members. Primary care providers acutely feel the lack of time that they are typically allocated to spend with their patients (Bodenheimer, 2008; Saba, Villela, Chen, Hammer, & Bodenheimer, 2012). In a study of patients' and health professionals' views on the management of type 2 diabetes (Pooley et al., 2001), both patients and health care professionals emphasized the importance of having sufficient time during visits to ask questions, give information, and agree on a course of action. The availability of time to discuss the complexities of diabetes care, provide patient education and self-management guidance is central to high quality care and patient empowerment. Yet the traditional practice structure of 15-20 minute visits doesn't allow for the in-depth discussions that are responsive to patients' individualized needs.

In her book, *Elderhood*, Louise Aronson describes the debilitating burnout that she experienced as a primary care physician. She was frustrated at the lack of time to do the myriad activities needed in a primary care clinic visit, many of which could have been shared with a robust and well-trained team.

In most clinics, appointments are scheduled in a one-size-fits all manner that distinguishes only between new and returning patients and not between mostly healthy patients and those with complex conditions. Every aspect of those appointments assumes that the doctor's most important activities are diagnosis, prescriptions, and procedures. This discounts the entire range of critical activities that help clinicians match care to patients' realities and preferences, increasing the chances that they can and will follow their treatment plan and that the plan will help them. Such activities include skilled listening to what the patient is saying, all that isn't being said, and body language. It includes giving the patient time to absorb complex information or terrifying new diagnosis, express their concerns, and formulate questions relevant to their specific lives.

It includes checking for alignment between what was said and what was heard, reading the medical record if you don't know the patient or if they have been hospitalized or seen another clinician since their last visit, establishing truly informed consent, negotiating language and literacy and health literacy barriers, and doing values elucidation, medication review and reconciliation, motivational interviewing, patient education, and counseling" (Aronson, 2019, pg. 236).

Patient-centered care that leads to patient empowerment often requires longer and repeated visits. Often team members other than the PCP may have more time to devote to lengthy discussions. Having adequate time for clinical encounters helps create an environment in which patients feel comfortable to ask questions, builds rapport, and helps patients feel at ease to express their concerns. There is growing evidence that diabetes care can be effectively provided using key non-physician team members, who have the skill and time to address patients' needs (Pooley et al., 2001; Thom et al., 2013). In the U.K., where much of the diabetes care is managed by both general practitioners and practice nurses, or by a practice nurse or diabetes specialist nurse alone, it is often the relationship with the practice nurse that is considered to be the continuous relationship (Alazri et al., 2006; Pooley et al., 2001).

In this research, patients said that team members took the time to understand and respect their values, preferences and needs. Patients experienced this approach as if time was suspended, as if the team members "took all the time in the world." When attention was focused intently on the individual, the patients felt that time expanded to meet their needs.

Non-Judgmental Care

The desire not to be judged came up often during my interviews. Patients wanted to be accepted where they were in their lives, and to have their team understand that they were doing the best that they could. They wanted an acknowledgement that when something didn't work for them it wasn't their fault, but the circumstances that complicated their lives. This non-judgmental attitude opened patients up to be honest with the team about what was working and

what wasn't working. They were more open to trying a new approach, and it gave them hope and motivation to keep trying.

Non-judgmental, flexible care led patients to be more honest with their team, and encouraged them to come back even when they weren't able to meet their goals.

I always told my husband, "If I give up everything, I'm going to sneak. I'm going to go behind your back, I'm going to go behind everybody's back and I'm still going to do it because it's going to be worse for me." So I have to do it this way or I just can't do it (Melinda, 57, Harrison IPA patient).

Interviewer: How do they respond to your ideas to try new things?
I think they're very supportive of me, not doing things that are way on the crazy edge, but it's more, well, let's try it and get back to me in a week, or two weeks, let's see how it's working (Sally, 68, Mountain View CHC patient).

They know I am addicted to coffee and Coke. And that's my problem. That's why normally my sugar is high. I used to drink two liters of Coke every day. So I stopped. Right now I drink like one can or two cans, but like with water - like half water, half Coke. It's not easy. Sometimes I feel like shaky and angry and anxious (Luisa, 43, Mountain View CHC patient).

Instead of giving up everything, which many patients didn't feel that they could do, the team members were able to work with patients where they were, whether trying out something they had heard about, or working with them to cut down, instead of completely give up some foods.

To Be Well

Health care professionals often forget that for patients, visiting a clinic is an episodic event in their lives. Even for patients who have a chronic disease like type 2 diabetes who interact more frequently with the medical system, going to medical appointments is a small fraction of their lives. They leave the visit, and go on to live their lives. The interaction is brief.

So it is not surprising that when I asked patients to describe an ideal visit, they didn't focus on the minor details of waiting times or efficient scheduling. Almost every patient I asked described their ideal visit in terms of their health. They wanted to be well. They wanted their

visit to be a validation of the effectiveness of their treatment, medication, or lifestyle changes that they were making to improve their health. Many wanted to hear good news – that their blood glucose levels were improved, or back to normal, that their weight and blood pressure had decreased, or that their cholesterol was normal. And when they heard the good news, they wanted to celebrate with their team members.

The Art of Becoming a Team

Becoming a team wasn't about magic or luck: it involved a consciously effortful change in identity. In the course of becoming a team, individuals changed their worldview from "I" to "we" as they created the new entity. The team members looked outward rather than inward, scanning for the needs of teammates during and between visits and continually communicating and in-tune with their teammates. When a highly functional team came into being, there was a smooth flow in the workings of the team. Differences in personalities and skills became assets, as each person brought their unique strengths to the team, resulting in a group that could accomplish more than the same number of individuals working on their own. The size of the group didn't matter; more important was the nature of their relationships.

When we allow ourselves to recall a time in our own lives when we experienced working in an effective team, we might remember the joint energy, or collective humming as we all worked toward a common goal. There was periodic checking in to see how our teammates were doing, where we could offer help, or what was needed next. The team that we are remembering may be as small as a partnership or personal relationship, a family, a sports team, or a work team assembled for a short or long-term purpose. To imagine that same sensation of forward movement with a team of people working on behalf of a patient is to imagine a more joyful and authentic caregiving experience.

Skill in the practice of team-based care is not easy to define. The care is not reserved only for patients. A highly functional team cares for each of the members of the team. They recognize each other's strengths, they speak highly of each other, they pitch in to help when needed, and "have each others' backs." In the process of this research, I identified eight essential practices for highly effective team-based primary care: explicitness of patient's role, team visibility, focus on the individual, team commitment, mutual support and respect, effective, continuous communication, and mutual learning.

The Patient's Role Made Explicit

The complex self-care management skills required of patients with type 2 diabetes, such as monitoring blood glucose levels, paying careful attention to diet and physical activity, and following complex medication regimes, require patients to be active and empowered partners in their care. In my research, not all patients realized or felt that they were "on the team." Usually those who were the most engaged knew that their role was important, and that they were "the one helping build solutions."

Traditionally, agency is described as the capacity of a person (an agent) to shape the circumstances in which they live to act independently and to make their own free choices (Sahai, Desantis, Grynszpan, Pacherie, & Berberian, 2019). This assumes a radical freedom, or the ability "to choose any course of action and interpret the meaning of any situation through conscious, explicit choice" (Benner & Wrubel, 1989, p 16). In the phenomenological view, by contrast, people are understood to have "situated freedom" based on their involvement in a web of structural factors, such as social class, religion, gender, race, ethnicity, and education that have an enhancing or limiting influence on their decisions (Heidegger, 1982; Benner & Wrubel, 1989). The patient's world is shaped by their background, which influences their ability for self-

care and engagement (Guignon, 1993). If those self-care actions don't make sense in their world, they don't show up as possibilities. When skilled team members were attuned to patients within the context of their worlds, they engaged them through motivational interviewing, asking, "What can you do?" thereby helping patients identify solutions that made sense within the context of their lives.

Doing things collectively, sometimes called joint agency, is the experience of engaging in cooperative activities under joint control. Some researchers believe that joint agency increases the amount of control between those cooperating in any given situation and that working together towards a common goal causes an increased feeling of agency (Loehr, 2018). Is it possible that working in teams increases a feeling of agency for both patients and clinicians?

Team is Visible and Understood

The clinics with the strongest team culture were explicit about the fact that they worked in teams and helped their patients understand team members' roles. It was easier for patients in smaller clinics to get to know the staff and their roles, but some of the larger clinics overcame this difficulty by displaying team member photos and roles in the exam rooms.

I observed a variety of staffing models, developed in the context of particular institutions and organizational cultures according to the patient population and available staff. Team roles in some clinics were tied to the complexity of care (such as nurses at Warren CHC having their own panel of patients with diabetes), or were intentionally duplicative so that patient concerns took priority over strict role definitions (the "open door" policy at Harrison IPA). Team members at Mountain View CHC provided more than just medical care - they provided social support to patients. There is strong evidence in the literature that social support interventions affect patient self-care and diabetes outcomes (van Dam et al., 2005). These forms of social

support helped patients adjust to their life with diabetes. Social support, diabetes knowledge, health beliefs, and complexity of treatment all influence how patients self-manage their diabetes (Auerbach et al., 2002).

It helped patients feel at ease with teams when they understood the team roles. In primary care, the PCP drives medical decision-making. In some clinics, the PCPs were explicit with patients that the MA was the captain of the team, meaning that they controlled the flow of information to and from the patient to the PCP. Patients were instructed to go to the MA for any questions or concerns. This empowered the medical assistants to feel that they were a valued part of the team.

Focus on the Patient as a Person

The concept of standardization in medicine as a means to optimize the delivery of quality medical care is nearly a century old (Timmermans & Berg, 2003). Its complement, evidence-based medicine, was introduced half a century ago as a formal way of ensuring a scientific approach to clinical decision-making and treatment decisions (Daly, 2005). Yet with all the advances in biomedicine and technology, there is an unsettled feeling about the current state of clinical practice, and a sense that perhaps medicine needs to re-learn what has been forgotten with a century of focus on scientific empiricism (Miles, 2009; Miles & Loughlin, 2011). The acknowledgement of criticisms of evidence-based medicine (Straus & McAlister, 2000) and the call for re-personalization of medicine within the last decade has done little to halt the continued emphasis of evidence-based medicine in medical research and practice. There remains a tension between the desire to provide patient-centered care, and the difficulties and costs of applying evidence to the care of individual patients. In *Why We Revolt*, Victor Montori writes about the de-personalization of our current healthcare system:

Industrial healthcare fails to notice patients. It standardizes practices for *patients like this*, rather than caring for *this patient*. Efficient specialization and narrow job definitions drive industrial healthcare's focus toward organs, diseases, or test results. Rigid protocols and fear of deviating from them miss the person. Systems that prioritize access and volume place very little value on the length and depth of the interaction between patients and clinicians. Forcing encounters to be brief and shallow speeds patients through consultations in which clinicians cannot appreciate their patients' situation clearly (Montori, 2017, p.1).

Does the introduction of teams re-personalize care or does it create an even more complex structure, further de-personalizing care? This risk is real and caution should be considered when developing and implementing teams to make sure that they support patient-provider and patient-team member relationships and are truly focused on patients and their needs. My research revealed that patients often gravitated toward one or several team members, just as one would in everyday life with the people that we meet. The successful practices respected and nurtured those relationships, talked about them, and understood them. Perhaps it was commonalities in age, gender, race or ethnicity, or even hobbies and interests. The teams built and grew those relationships, and used them to foster patients' trust and engagement in their care. When relationships were sustained and developed with stable teams, providers and team members came to know their patients so they could provide individualized care.

Individualized care means providing "just right" information to patients as persons, not cases. Patients wanted information that helped them cope with their illness in the course of their everyday lives that was timely, in the right dose and sequencing, on-going, accurate, and consistent. Some patients were overloaded with information when they were first diagnosed with type 2 diabetes. With the stress of receiving a new diagnosis, this wasn't perceived as the best time to be inundated with information about their illness. Patients also wanted communication about the status of their condition - timely, updated labs, and their progress on A1C and other metrics such as weight, blood pressure, and cholesterol.

Primary care providers lament how the introduction of the electronic health record (EHR) has depersonalized care (Sinsky & Bodenheimer, 2019). EHRs, once believed to be a panacea of efficiency that would increase quality of care, have only made matters worse. Clinicians complain of the time-consuming and confusing aspect of using a system that was primarily designed for billing. Some patients feel that their providers are focusing more on the computer than on them during the office visit (Krist et al., 2014). Some teams used medical assistants as scribes so the providers could focus their attention on the patient during visits (Sinsky & Bodenheimer, 2019).

Team Commitment and Support

A shared commitment to teammates was evident in the teams that I studied. “We have each others’ backs” was the team mantra. Supporting each other meant filling in the gaps that can naturally occur in the course of a clinic workday. In a busy primary care practice, having a team of people working on behalf of patients was like an insurance policy. Even with defined roles and responsibilities, there was an overlap in care. In effective teams, a team member didn’t look the other way when there was a gap in care, saying, “that’s not my job.” They not only did the task, but gently used the opportunity to teach and share their knowledge. They were continuously working to improve, and patients became the beneficiary.

Members of highly functioning teams trusted each other. They trusted that their teammates had their best intentions in mind, and that they were doing things not to put themselves above their teammates, but for the sake of the patients’ wellbeing. Trusting relationships built confidence as team members learned new skills and expanded their roles. Team members learned skills at their own pace, and as they experienced support from teammates, they were patient and encouraging with their own patients.

Mutual Respect and Recognition

In highly functioning teams, teammates built each other up to foster expanding relationships. If a patient saw the respect that one teammate gave to another, they were more willing to work with them on their own care. Patients could see that the team members were speaking highly of each other, both between themselves and to the patients. Team members expressed gratitude that there were multiple people working on behalf of their patients. Multiple people meant multiple life and professional experiences and skills that could be deployed on behalf of patients.

The change in hierarchy that team members experienced came from a sense of appreciation that the team members felt for each other. It was not necessarily that each teammate felt that they were capable of performing to the skill level of the other, but that they experienced support from each other. Team members that were more highly trained had enough humility and self-confidence to teach others on the team. Knowledge wasn't privileged or coveted, but shared.

Leadership in primary care teams tended to be fluid, as team members took on leadership roles for certain functions. The team roles defined where the team members expressed their leadership and each team member developed leadership within their roles. The primary care provider led the medical care of a patient. But there were so many other patient needs beyond the narrowly "medical" - providing social and emotional support, coordination of care with other health care entities, helping patients make lifestyle changes to support their health, helping patients navigate the world of insurance and billing. Team members took on leadership roles with all of these functions. Primary care providers felt relief when they knew that they were not solely responsible for taking the lead in all of these areas of patient need. A heavy weight and

burden was lifted.

Effective Team Communication

Patients were eyewitnesses to how things were actually working in a clinic. They could see how effectively team members communicated and worked with one another. They saw the team sometimes “all in one room”, and knew that they talked to each other about patients.

Patients were also witnesses to communication failures: duplication of efforts creating waste of time and money, team members uninformed about nuances of their care, delays in procedures, labs or treatments, or tasks undone. Lack of communication had the potential to become a safety issue, such as lab orders not followed up on, referrals not tracked and followed, or medication changes not communicated.

When patients felt that team members weren't communicating with each other, they didn't have confidence in the team's effectiveness. It was important to patients that team members delivered consistent messages. Points of discord were confusing and distressing to patients. Some patients intentionally asked multiple team members questions to test this consistency or out of fear and need for reassurance. If the messages that patients received weren't consistent, patients became frustrated and trust in the team eroded.

The diffusion and sharing of clinical responsibility had the potential to complicate communication, but I saw this overcome with formalized ways of communicating, such as with daily huddles or team meetings. In clinics with high functioning teams, communication between staff members was prioritized and visible to patients. A patient did not need to tell one team member what the other team member had done or was doing on their behalf. The functions of front line care, often provided by the front desk staff and sometimes medical assistants, became the face of the clinic when patients asked for help with scheduling, billing, medication renewals,

receiving lab results, communicating messages to providers, coordinating with specialists, communicating with hospitals and specialists. Highly functioning teams respected the value of this work and understood its importance to improve patients' overall experience of care.

Celebrating Successes and Sharing Frustrations

Working in a functioning team in primary care brought a palpable sense of joy to some of the practices that I observed. If a team saw accomplishments on behalf of a patient, they shared the joy and pride in their care. If a team was frustrated with the lack of progress of a patient, the burden was not on one person, but shared with the team. Teams working together for and with a patient to help them achieve their goals shared credit for shared success.

The higher level of involvement within team-based care creates a space where team members and patients' concerns, as well as their response and actions on those concerns, are discovered and noticed. These joyful, celebratory, and supportive social spaces, called "disclosive spaces," are created by the relationships and interactions between the team members and the patients and determine what is noticed, disclosed, and considered. "Clinician and patient bend and respond to the other so that horizons and world are opened and reconstituted so that new possibilities can emerge" (Benner, 2004, p. 190). Celebrating with patients served to validate the co-constituted nature of the relationships between team members and their patients.

In experiments related to how joint action influences joint agency, Loehr (2018) found that when people performed successful joint actions together, they experienced a sense of shared control over their actions. Similarly, Bolt (2016) found that when people coordinated their actions with others they experienced stronger joint agency. Perhaps the sense of obligation to the team is a motivating factor for these types of collaborative efforts. The developmental psychologist Tomasello (2019) found the human sense of obligation may be tied to motivation:

When you and I voluntarily place our fate in one another's hands in interdependent collaboration - scaled up to our lives together in an interdependent cultural group - this transforms the instrumental pressure that individuals feel when pursuing individual goals into the pressure that "we" put on me (who needs to preserve my cooperative identity in this "we") to live up to our shared expectations: a we>me self-regulation (Tomasello, 2019, p.1).

Mutual Learning

Most of the participating clinics emphasized motivational interviewing as a team practice, and required motivational interviewing training of all of the team members, including the primary care providers. Motivational interviewing is a directive, client-centered counseling style for eliciting behavior change by helping clients to explore and resolve ambivalence (Miller & Rollnick, 1991). In phenomenological terms, motivational interviewing is a way of being with a client. It involves reflective listening that clarifies and magnifies the person's own experience and meaning, without imposing one's own opinion. Motivational interviewing leaves patients with the impression that we're "in this together."

In a qualitative study of general practitioners' (GPs) perspectives of type 2 diabetes patients' adherence to treatment, researchers found that GPs felt that working in multidisciplinary teams encouraged better adherence (Wens, Vermeire, Van Royen, Sabbe, & Denekens, 2005). They believed that other team members, such as dieticians, could give better nutrition advice than they could themselves. For the clinics participating in this study, some of the team members most skilled in motivational interviewing were the health educators and wellness coaches. Clinicians often have a hard time going from "telling" or "educating" patients, to the more collaborative nature of motivational interviewing. At Harrison IPA, the PCP recognized how skilled her wellness coaches were and sought them out in difficult patient situations.

I observed other mutual learning opportunities through the teams. This was especially

prevalent in Mountain View CHC where the nurse managers would ask new registered nurses to shadow the medical assistants. Opportunities for mutual learning especially occurred when the team members were co-located, where discussions about patients could take place as they worked side-by-side. Mutual learning took humility on the part of teammates, especially those with more advanced education, to be both teachers and learners from other teammates.

Policy Considerations for Team-Based Primary Care

This research makes the concerns, voice, and behaviors of teams in primary care visible, with a goal to highlight practices and policies that support primary care patients and their teams. There are several significant barriers to the effective deployment of teams in primary care settings. Addressing two major barriers, fee-for-service payment systems that tie payment to the primary care provider visit, and inadequate interdisciplinary education and training, will be critical to the success of team-based primary care in the future.

Payment Systems

The dominant fee-for-service payment system remains a foundational barrier to the full deployment of team-based primary care in the U.S. (Robinson, 2019). Primary care practices paid under traditional fee-for-service reimbursement are not incentivized to promote team-based care (Miller, 2009). Many high value services conducted by members of the primary care team, such as outreach to complex or high-risk patients, health education and coaching, follow-up telephone calls, or other electronic communication are insufficiently compensated under the fee-for-service payment system.

Several recent initiatives implemented as a result of the Affordable Care Act are transforming how we pay for primary care in the United States, which may have an impact on financing team-based care (Mose & Jones, 2018). Newly proposed payment models are moving

away from volume-based, fee-for-service reimbursement to payments based on value (high quality care provided in a cost-effective manner).

In January 2015, Sylvia Burwell, the former Health and Human Services (HHS) Secretary, announced HHS's plans to tie future Medicare payments to value. This was the first time HHS had made specific goals for shifting to payment systems for value-based care. In theory, the new payment models would give providers the resources and flexibility they needed to deliver care without being tied to the provider visit. The goal was to change the way care was delivered through greater teamwork and integration, coordination and improved population health (Burwell, 2015). By 2017, a quarter of all U.S. health care payments were tied to adaptations of the existing fee-for-service system, and a third were tied to value-based reform models (Erikson, et al., 2020).

Many of the new alternative payment models still use some degree of traditional fee-for-service payments with a gradual integration of value-based payments. These include several fee-for-service add-on Medicare payments such as wellness visits, complex care management fees, and the proposed Merit-Based payment system (MIPS), which could have a modest financial impact to support team services (Bauer & Bodenheimer, 2015). With these add-on payment options, the extra revenue generated may be enough to support additional members on the primary care team (Basu, 2015).

Federally qualified health centers (FQHCs) have a hybrid reimbursement model that assists health centers with the costs of team-based care. The FQHCs that participated in my study were able to finance teams through a combination of federal 330 FQHC grants, an enhanced fee-for service reimbursement rate that adjusts for their highly complex range of services, and additional grants from managed care Medicaid and community-based organizations.

As alternative payment models such as Accountable Care Organizations (ACOs) continue to grow as envisioned by HHS, the incentives to improve quality and reduce emergency department use and hospitalizations suggest that ACOs will change how they deliver care and the workforce to meet these goals. Registered nursing, pharmacy and health educator skills that emphasize chronic care interventions, complex care management and coordination and patient engagement are well aligned with the ACO goals (Pittman, 2015). In this study, Harrison IPA contracted with a major insurer in an ACO-type shared risk arrangement to provide care for nearly 20,000 patients in their area. With this contractual arrangement, the organization took on substantial financial risk, but had the potential to earn shared savings if they met quality measures and reduced costs. They also sought out and received additional grant funding to support several of their initiatives. Northpoint Primary Care Clinic also participated in several ACO-type contracts. With this funding arrangement, they hired health navigators to follow patients who frequently were hospitalized or were high users of emergency room services.

Centers for Medicare & Medicaid Services (CMS) is experimenting with other payment models such as capitated per member per month (PMPM) payments (Centers for Medicare & Medicaid Services, n.d). PMPM provides practices with a steady income stream and a reduction in cumbersome billing requirements, which allows practices to invest in additional team members for population health and prevention, chronic disease management, care coordination and motivational interviewing. PMPM payment also allows teams greater flexibility to provide care by telephone, text, or off-hours care (Robinson, 2019). However, for capitation to be sustainable, the fee must be sufficient to cover the expenses incurred in the practice and be adjusted for at-risk patient populations (Erikson, 2020).

In January 2021, CMS will launch the Primary Cares Initiative that will test five payment models focusing on value-based primary care payments. Two of the payment models, called Primary Care First (PCF), are designed to test whether financial risk of primary care providers and performance-based payments will reduce total Medicare payments. PCF provides monthly payments to practices and also includes an option that provides higher payments to practices that specialize in care for high need patients, including those with complex, chronic needs and seriously ill populations. The goal is to support primary care practices and allow flexibility in staffing and reduce administrative burden while reducing hospital utilization, improve quality of care and patient outcomes (Centers for Medicare & Medicaid Services, n.d). The other three payment models involve direct contracting for fee-for-service Medicare beneficiaries for organizations such as Accountable Care Organizations, Medicare Advantage plans, and Medicaid managed care organizations, which involve a fixed monthly payment for a variety of risk arrangements. Participants in the global payment model will bear full financial risk. The goal is to provide practices with a steady stream of revenue to assume responsibility for the total cost of care and health needs of a population in a defined target region.

Partially and fully integrated health care systems such as Geisinger Health Plan, CareOregon health plan, Mayo Clinic, Veterans Administration and Kaiser Permanente already have payment systems that allow flexibility to support team-based care. These integrated systems are financially responsible for the full spectrum of patient care, including primary, specialty, urgent, emergency and hospital care and are incentivized to use team members for health education, population health, prevention, and chronic disease management to keep their patient populations healthy and avoid costly downstream inpatient care.

Unfortunately, the payment systems created to support teams in primary care are not universally accessed by many primary care practices in the United States. To fully support teams in primary care, there will need to be a fundamental increase in the overall investment of primary care, both in training and reimbursement, commensurate with its value to achieve better outcomes and lower costs.

Training and Education

For teams to be fully successful in primary care, team members need the knowledge and skills to meet patient needs and work effectively in teams. To accomplish this, team members must have knowledge of both effective team practices and the provision of primary care. Unfortunately, for many team members, neither primary care competencies nor team practices are adequately taught in within conventional professional educational programs.

Traditionally, the education of medical, nursing, pharmacy and other healthcare professional students was conducted in silos, with few opportunities to prepare students to work in teams and share care responsibilities (Schuetz, Mann, & Everett, 2010). In healthcare, collaborative education first appeared in the 1970s, spurred by the Institute of Medicine's 1972 conference on Education for the Health Team (Schuetz, Mann, & Everett, 2010). Initial funding and grants were eventually phased out, so that by the 1990s and 2000s, only pockets of collaborative education took place in the U.S.

With the advent of the Patient Center Medical Home initiative in 2007, the need for collaborative training and education came back into the forefront (Fiscella & McDaniel, 2018). As a result, in the past 10 years, there has been a renewed emphasis on interprofessional training in the healthcare field. The concept of interprofessional collaboration, originating from the organizational sociology literature, identifies key teamwork competencies such adaptability,

coordination, shared leadership, and conflict resolution as components of effective teamwork (Salas et al., 2009; D'Amour, Ferrada-Videla, Rodriguez, & Beaulieu, 2005).

Much has been learned about team dynamics and effectiveness that can be applied to team training (Salas, Reyes & McDaniel, 2018). Research has demonstrated that team training on effective teamwork can boost learning, teamwork practice and proficiency, and outcomes (Hughes et al., 2016; Salas et al., 2009). Collaborative education, when conducted effectively, enhances understanding of the roles and responsibilities of other health professionals on the team (McInnes, Peters, Bonney, & Halcomb, 2016); Coletti et al., 2019). Recognizing the importance of teams to quality in healthcare, the Agency for Health Research Quality (AHRQ) provides an online platform for training health professionals on team education called TeamSTEPPS (Agency for Healthcare Research and Quality, n.d.). TeamSTEPPS is a program developed from the principles of team science research that aims to optimize performance among healthcare teams. Prior to the implementation of teams at Mountain View CHC, the staff participated in a program similar to TeamSTEPPS, where they learned about team roles, cooperation, coordination, and effective communication.

In addition to learning the skills that promote a positive team culture, effective team-based care requires a competent workforce for trust to develop between teammates and for the patients toward the team (Fiscella & McDaniel, 2018). Team members, particularly primary care providers, want to feel that they can depend on their teammates, and want their teammates to be well trained in their respective fields (Lacerenza, Rico, Salas, & Shuffler, 2014). As we saw with Northpoint Primary Care Clinic, one PCP was unable to fully trust his medical assistant due to his perception of a lack of training, which hampered his and his patients' ability to experience the support of a team.

Patients also wanted to feel confident that the team members knew what they were doing and were trained, skilled and competent in their roles. If they felt that they were in competent hands, they could relax and trust their team members. If they didn't, they were anxious, fearful, tense, and on guard around the new team members. *Do they know what they are doing? Do they have the skills and competency to help me?* The need for competent, well-trained staff is key to the successful implementation of teams.

Teams working in primary care require a different set of skills and knowledge than teams working in other health care settings – specifically an understanding of chronic disease, care coordination and the importance of social determinants of health (Fiscella & McDaniel, 2018; Sinsky, 2019; Bodenheimer, Bauer, Syer, & Olayiwola, 2015). Another core competency, motivational interviewing, is needed in primary care settings. We recall that three of the participating clinics required that all staff receive training in motivational interviewing, which provided a common language for all team members.

Medical assistants need to know the basics of chronic disease, and new skills of panel management to monitor an entire panel of patients of a specific provider for all the chronic disease and preventative care needs (Willard-Grace, et al., 2013). Registered nurses must also learn new skills not traditionally taught in nursing school to be effective in primary care - chronic disease management, care coordination, medication management, as well as the ability to conduct co-visits for conditions that can be treated through protocols (Bodenheimer, Bauer, Syer, Olayiwola, 2015; Bauer & Bodenheimer, 2017). Warren CHC had extensive training programs for their medical assistants and registered nurses. Also, recognizing that many newly trained nurse practitioners needed additional hands-on training, they started a robust NP residency-training program.

Interdisciplinary education can be challenging, and requires managing role negotiation among team members, team conflict, communication, documentation, billing and precepting a diverse group of learners (West, 2016). During interdisciplinary education, health professions students have the opportunity to learn each profession's scope of practice to help understand each of the team member roles. This can expose them to the knowledge and skills of other professions, and lead to better appreciation of their teammates. In a qualitative evaluation study of an interprofessional team-based training program for PCMH practices, Coletti et al. (2019) found that "learners recognized that shared responsibility facilitated better care and that clarifying responsibilities was a complementary rather than competitive process, since 'other professions knew ... things a lot better than we do ... so having them as a resource [is] very helpful.' In addition, observing other professionals helped students imagine their own future professional roles" (p. 3.). These learners appreciated working within interdisciplinary teams and observed that training could improve efficiency and flatten hierarchical team structures to optimize team functioning.

Conclusion

As we reach the 10th anniversary of the Affordable Care Act, we recognize how the law's delivery and payment innovations have moved our nation's primary care system towards the goal of providing accessible, patient-centered, high quality care (Peikes, Taylor, O'Malley & Rich, 2020). Many of these funding sources support the adoption of team-based primary care, yet not sufficiently for the majority of U.S. primary care practices to fully embrace this new model of care. This research provides a glimpse of the experience of team-based care from within the teams' and patients' worlds to highlight what patients' value in their health care experience, and how team-based primary care may provide a means to achieving greater patient engagement and

satisfaction with their care, while sustaining a more fulfilled and joyful primary care workforce.

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Appendix A
UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
DEMOGRAPHICS QUESTIONNAIRE

Study Title:

The team-based care experience for patients with type 2 diabetes and their primary care teams

1. Name: _____
2. Preferred Code Name (to use in study report): _____
3. Age:
 - a. 18 – 25 years
 - b. 26 – 35 years
 - c. 36 – 45 years
 - d. 46 – 55 years
 - e. 56 – 65 years
 - f. 65 + years
4. Gender: Male Female Other Decline to Answer
5. Race/ Ethnicity: _____
6. Highest level of education: _____
7. How long have you been a patient at this clinic? _____
8. Name of current provider: _____
9. How long have you been a patient of your current provider? _____
10. Approximately how often do you come to see your provider? _____
11. What types of services to you use at the clinic? Eg. nutritionist, navigator, care support team, other? _____
12. How long have you had type 2 diabetes? _____
13. Last A1C level _____
14. Other chronic diseases _____

Appendix B
UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
INTERVIEW GUIDE

Study Title: The team-based care experience for patients with type 2 diabetes and their primary care teams

Specific Aims:

Specific Aim #1: Using in-depth qualitative interviews, explore how patients with type 2 diabetes perceive, experience, and engage with team-based care;

Specific Aim #2: Conduct focus groups to understand how the patients' care team members experience being part of care teams

Preamble:

I am interested in learning from you about your interactions with the health care staff as a patient with Type II diabetes. I am interested in what you thought of these interactions and what you think they mean for you. You are free to refuse to answer any question or to stop the interview at any time.

Main question	Probes	Notes
Establish rapport: Tell me a little about yourself?	<ul style="list-style-type: none"> • How long ago were you diagnosed with diabetes? • How has your health been recently? 	
Do you feel like <i>(name of primary care provider)</i> at <i>(name of the clinic)</i> knows you well?	<ul style="list-style-type: none"> • How is relationship going? • Understands what managing DM is like for you? 	
Generally speaking, whom do you see with when you come to the clinic? Tell me about your time with these staff members. What is a typical interaction with them?	<ul style="list-style-type: none"> • Providers? • Other clinical staff? • Front desk/administrative staff? • Anyone else? 	
Do you sometimes talk to anyone from the clinic between visits? If yes, tell me more about your experiences with these staff between visits.	<ul style="list-style-type: none"> • Providers? • Other clinical staff? • Front desk/administrative staff? • Pharmacists? 	

	<ul style="list-style-type: none"> • Call center staff? • How do you get in touch with your providers or the staff if you have a question or a concern? If you have a question about your health, is there a specific person you would call? • When you have a question or concern, how are your questions answered? By whom? Do you feel welcome to call or email? What kinds of things might you like to talk over with your HCP if that was easy to do? • Is there someone specific you know you'll be able to talk to? • Do you get your questions answered? How long does it take to hear back? How do you feel about those interactions? • Do you have a preference for who gets back to you? • How smooth or bumpy is the process of getting in touch with someone? • Can you give a specific example of this being smooth or bumpy when you tried to address a specific concern? 	
<p>Think back to the last time you had some sort of interaction with a staff member at the clinic.</p>	<ul style="list-style-type: none"> • This could be an in-person visit, a phone call, or an email that stood out for you. 	

<p>Tell me a story behind this interaction.</p>	<ul style="list-style-type: none"> • Who was involved? • What happened? • How did your primary care provider respond? • How did the other staff respond? • What were the consequences/impact of this interaction? 	
<p>Tell me about another time that comes to mind when you needed to work with multiple staff members at the clinic to get care/solve a problem.</p>	<ul style="list-style-type: none"> • Tell me more about that experience. • Who did you interact with? • How did the staff members communicate with you and each other 	
<p>Reflecting on these interactions, what do you feel about how these interactions went?</p>	<ul style="list-style-type: none"> • How did your questions/issues get resolved? • How did you feel about these interactions? • Do you feel like you're getting the care you need for your diabetes? Can you tell me more about why you feel that way? 	
<p>In your opinion, is there an example of an ideal interaction with the clinic staff and what would it look like?</p>	<ul style="list-style-type: none"> • How do you feel the staff can best support you with your diabetes care? • What role would the PCP play? • What role would the other staff play? 	
<p>Was there ever a time when an interaction with your health care providers at (clinic name) wasn't ideal?</p>	<ul style="list-style-type: none"> • Can you give an example? • Who was involved? • What happened? • How did your primary care provider respond? 	

	<ul style="list-style-type: none"> • How did the other staff respond? • What were the consequences/impact of this interaction? 	
If you had to give advice to another patient with diabetes on how best to work with your PCP and staff at the (clinic name), what would it be?	<ul style="list-style-type: none"> • How would improve your interactions if you could? • What would you want the HCPs to do differently? • What would you do differently? 	
<p>Has your experience with your health care providers changed in the past year? Do you notice any difference in your care?</p> <p>Do you feel that there is a team that takes care of your health needs?</p>	<ul style="list-style-type: none"> • Was there any difference in the care that you got for your diabetes? Other conditions? • Who do you think is on your team? • Do you feel that all of the aspects of your care are being covered? 	
If you could change something to live a healthier life, what would it be?	<ul style="list-style-type: none"> • Taking medications, exercising, eating healthier, reducing stress, stop smoking, stop drinking 	
Can you tell me about a time when you set a health goal for yourself?	<ul style="list-style-type: none"> • What was the goal? • Have you been able to talk with anyone at (clinic name) about your hope to make this change? • Did anyone help you achieve the goal? Family, friends, health care team members, other? 	
Have any of your HCP asked you about your goals and worked specifically with you to set and reach goals?	<ul style="list-style-type: none"> • What was the goal? • Who did you work with? • How did they help you? 	

<p>If yes, can you describe an experience when you worked with one of your health care team members to reach a goal that you set for yourself.</p>	<ul style="list-style-type: none"> • Did they follow up with you? • Did it work? • What was the result? 	
<p>Thank you so much for your time. In wrapping up, did you have any other comments you would like to share that we didn't touch on?</p>		
<p>A final question, do you have any visits scheduled this coming year? I plan to conduct some observations at the clinic and would like to observe you interacting with your health care providers. May I contact you before your next visit?</p>		

Appendix C
UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
PRIMARY CARE TEAM FOCUS GROUP INTERVIEW GUIDE

Study Title:

The team-based care experience for patients with type 2 diabetes and their primary care teams

Specific Aims:

Specific Aim #1: Using in-depth qualitative interviews, explore how patients with type 2 diabetes perceive, experience, and engage with team-based care;

Specific Aim #2: Conduct focus groups to understand how the patients' care team members experience being part of care teams

Preamble:

I am interested in learning from you about your experience as health care providers and staff for patients with type 2 diabetes. I am interested in your interactions with your team members and how you work together to care for your patients. You are free to refuse to answer any question or to leave the focus group at any time.

Main question	Probes	Notes
Establish rapport: Tell me a little about your practice at (<i>name of clinic</i>)?	<ul style="list-style-type: none"> • What is your typical schedule? • How is your practice structured? • Who do you work with to care for patients with diabetes? 	
How do you like to work with other members of your team?	<ul style="list-style-type: none"> • How would you describe your working style? 	
Tell me about a typical visit for a patient with type 2 diabetes. What would that look like for a patient at (<i>name of clinic</i>)? Who would patients interact with?	<ul style="list-style-type: none"> • Goal setting? • How is that determined? • Health coaching/MI? • Who does the team interact with? 	
Do you sometimes need to talk to patients between visits? If yes, tell me more about	<ul style="list-style-type: none"> • How do you get in touch with your patients if they have a question or a concern? 	

<p>your experiences with patient interactions between visits.</p>	<p>Who do you most often work with on your staff when patients have questions between visits?</p> <ul style="list-style-type: none"> • How do you feel the patient interactions by other staff members go? • Do you feel that patients get their questions answered? How long does it take to hear back? How do you feel about those interactions? • Can you give a specific example of this being smooth or bumpy when you worked with another staff member tried to address a specific concern? 	
<p>Think back to the last time you had some sort of interaction around one of your patients with diabetes that involved another clinic staff member.</p> <p>Tell me a story behind this interaction.</p>	<ul style="list-style-type: none"> • This could be an in-person visit, a phone call, or an email that stood out for you. • Who was involved? • What happened? • How did your patient respond? • How did the other staff respond? • What were the consequences/impact of this interaction? 	
<p>Tell me about another time that comes to mind when you needed to work with multiple staff members at the clinic to get care for a patient or solve a problem.</p>	<ul style="list-style-type: none"> • Tell me more about that experience. • Who did you interact with? • How did the staff members communicate with you and each other 	

<p>Reflecting on these interactions, what do you feel about how these interactions went?</p>	<ul style="list-style-type: none"> • How did your patients' questions/issues get resolved? • How did you feel about these interactions? • Do you feel like your patients are getting the care that they need for their diabetes? Can you tell me more about why you feel that way? 	
<p>In your opinion, is there an example of an ideal interaction that your patients would have with the clinic staff and what would it look like?</p>	<ul style="list-style-type: none"> • How do you feel the staff can best support your patients with their diabetes care? • What role would the PCP play? • What role would the other staff play? 	
<p>Was there ever a time when an interaction with your health care staff at (clinic name) wasn't ideal?</p>	<ul style="list-style-type: none"> • Can you give an example? • Who was involved? • What happened? • How did your primary care provider respond? • How did the other staff respond? • What were the consequences/impact of this interaction? 	
<p>If you had to give advice to another person on how best to work with the staff at the (clinic name), what would it be?</p>	<ul style="list-style-type: none"> • How would improve your interactions if you could? • What would you want the team to do differently? • What would you do differently? 	
<p>For Clinic xxx patients only A couple of years ago, Clinic xxxx put teamlets place.</p>	<ul style="list-style-type: none"> • Did you notice any difference at your clinic? • Do you feel that there 	

<p>What differences did you notice?</p>	<p>as there any difference in the care that your patients got for their diabetes? Other conditions?</p> <ul style="list-style-type: none"> • Do you feel that there is a team that takes care of your patients' health care needs? • Who do you think is on your team? • Do you feel that all of the aspects of your patients care are being covered? 	
<p>If you could change something to help patients live a healthier life, what would it be?</p>	<ul style="list-style-type: none"> • New supports for patients? • New ways of interacting with patients and their team? 	
<p>Can you describe an experience when you worked with one of your patients to set a goal to improve their health?</p>	<ul style="list-style-type: none"> • How is the goal set? • Who did they work with? • How did you/the team member help them? • Did it work? • What was the result? • From your experience what affects patient motivation to meet a goal • What is the process for follow-up, check-ins, renegotiation, setting new goals? 	
<p>Thank you so much for your time. In wrapping up, did you have any other comments you would like to share that we didn't touch on?</p>		

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