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Extra/ordinary medicine: Toward an anthropology of primary care

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Abstract

Primary care is at the forefront of healthcare delivery. It is the site of disease prevention and health management and serves as the bridge between communities and the health care system. As ethnographers of primary care, in this article we discuss what is gained by situating anthropological inquiry within primary care. We articulate how anthropologists can contribute to a better understanding of the issues that emerge in primary care. We provide a review of anthropological work in primary care and offer empirical data from two ethnographic case studies based in the United States, one focused on social risk screening in primary care and the other examining the diagnosis and care of people with dementia in primary care. Through these cases, we demonstrate how research of and within primary care can open important avenues for the study of the multidimensionality of primary care. This multidimensionality is apparent in the ways the medical field addresses the social and structural experiences of patients, scope of practice and disciplinary boundaries, and the intersection of ordinary and extraordinary medicine that emerge in the care of patients in primary care.

Keywords

Anthropology; Dementia; Extra/ordinary; Primary care; Qualitative methods; Social determinants of health

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Alissa Bernstein Sideman: Writing – review & editing, Writing – original draft, Validation, Supervision, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Na'amah Razon:** Writing – review & editing, Writing – original draft, Validation, Supervision, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization.

Declaration of competing interest

None.

1. Toward an anthropology of primary care

Primary care brings a unique lens to healthcare: it emphasizes long-term relationships with patients while also serving as a bridge between the community and the health care system (Saba, 1999). In the international context, the Alma Ata Declaration established primary care as central to health care systems, stating, primary care is “essential health care ... made universally accessible to individuals and families in the community ... through their full participation and at a cost that the community and country can afford” (Kruk et al., 2010). Primary care emphasizes health promotion and disease prevention prior to the clinical manifestations of illness, the coordination of multiple elements of patient care, and a holistic understanding of patients across the life course (Starfield et al., 2005).

Primary care is the foundation of the health care system and is present in a diversity of settings. Yet medicine, especially in the US context, through its specialties, curricula, funding streams, and training, orients healthcare towards disease processes or anatomical sites. Primary care plays a critical role in the health of the population and in addressing health disparities, yet it is also a discipline that is underfunded and undervalued (Starfield et al., 2005). Anthropologists are in the position to intervene and respond to this marginalization of primary care. In this article, we examine the contributions of prior literature in anthropology focused on primary care. We then present two ethnographic cases centered in primary care. We argue that anthropologists can open important avenues of investigation by centering their work in primary care. It is within primary care where individuals (i.e., health practitioners, patients, caregivers) experience and shape the ordinary/extraordinary process of health and illness and where the scope and boundaries of different medical practices are negotiated (Kaufman, 2015; Wool, 2015).

Throughout this paper, we use the language of ordinary/extraordinary from Zoë Wool who describes the daily practice of US veterans learning to live with their injured bodies after war (Wool, 2015). The process these veterans undergo, while extraordinary, is found within the daily, seemingly ordinary, manifestations of living: reconnecting with family and community, navigating the healthcare system, and caring for their bodies. In Wool’s work, there is a blurring of the extra/ordinary, where the ordinary is ever-present within extraordinary spaces and circumstances. Tracking where the ordinary continuously appears and disappears matters because it is at this tenuous flexion point where we can understand key domains such as how social relations come to matter and how people make sense of their lives amidst the most extraordinary circumstances.

Primary care is similarly a site where the ordinary and extraordinary co-exist. Many of the daily practices of primary care are exceedingly ordinary and routine at first glance, particularly when juxtaposed with specialty care and its technological complexity. Yet, it can take extraordinary efforts to manage the complexity of caring for individuals – not just as organs or diseases, but as entire beings rooted in social and cultural lives, complex medical systems, and communities. This extra/ordinary is present in the daily spaces of primary care – where patients come with ordinary coughs and fevers, aches, and pains. The boundaries of the ordinary exist in primary care both when facing a challenging diagnosis, but also through the everyday handling of complex circumstances, such as social risks and patient

context. These all require primary care providers (PCPs) to shift between the ordinary and extraordinary. Throughout this paper we illustrate how this tension between the ordinary/extraordinary emerges in primary care as clinicians navigate the social lives of patients beyond the biological model of disease, as well as the dynamics between values and deficits and strengths and barriers in primary care as it encounters other disciplines. If ordinary and its extra are crucial to understanding the contours of medicine and social lives, then primary care is a site where this can be meaningfully studied because it is a site where this line of extra/ordinary is constantly being negotiated.

We thus highlight the various scales and tensions that co-exist in primary care and the role anthropologists can play in studying and supporting primary care. We demonstrate how research of and within primary care can open important avenues for the study of the multidimensionality of primary care that are apparent in the ways the medical field addresses the social and structural experiences of patients, scope of practice and disciplinary boundaries, and the intersection of ordinary and extraordinary medicine that emerge in the care of patients in primary care.

2. Anthropology and primary care in the literature

What constitutes primary care and where it takes place is multidimensional. It brings together well-child visits, diabetes management, housing needs, cancer screening and survivorship, mental health, dementia care, and end of life discussions. Is it defined by its space? By the practitioner delivering care? Or by the care that is delivered? Because of the diversity of settings and experiences that comprise primary care it means that primary care does not always have distinct disciplinary boundaries. The literature we present brings together an eclectic group of researchers and sites. Some are anthropologists working in departments of anthropology, others are clinicians using ethnographic methods to study primary care, while still others are social scientists embedded within health care systems. Attending to this broad literature and textures of care highlights the contours, challenges, and benefits of spending time exploring primary care ethnographically as anthropologists.

In the following sections we highlight (1) the history of primary care, (2) the contributions of anthropologists conducting ethnographic research of primary care, and (3) clinicians, anthropologists, and other social scientists working within healthcare systems using anthropological methods to study primary care. Although anthropologists of primary care are situated in different academic or clinical spaces and write for different audiences, their work has been important for thinking about the ways primary care engages with communities, how to conceptualize complexity, and the boundaries of primary care in different contexts.

2.1. Histories of primary care

Situating the anthropology of primary care requires understanding the emergence of a disparate medical field that transverses multiple specialties, localities, and histories and the anthropological engagement with these areas. In global health settings, primary care became a central focus of development and anthropological study due to the ideologies set forth by the Alma Ata Declaration of 1978. Alma Ata emphasized the importance of community

health and primary care within health care systems as a means towards attaining health as a human right and as a way to build community participation in health (Walley et al., 2008).

Anthropologists Closser et al. (2022) and Abadía-Barrero and Bugbee (2019) trace the trajectories anthropologists have taken in the study of primary health care, noting that Alma Ata led to a shift away from the single disease programs of the late 1970s and towards work focused on primary health care. Nonetheless, they highlight that even up until the early 1990s, work in the anthropology of primary care focused heavily on disease models, cultural health beliefs, and cultural logics of disease. These authors and others also discuss the shift to studying primary care through a political economy framework, e.g. Closser et al. (2022) on healthcare planning and delivery; Abadía-Barrero and Bugbee (2019) on power dynamics, political structures, and market-based justifications for primary care; Morgan (2001) and Smith-Nonini (1998) on the challenge of community participation in health care.

In the US, primary care emerged at the intersection of several specialty fields. In the early 20th century, the Flexner Report encouraged growing funding and support of primary care to strengthen the workforce, although with severe consequences for the Black physician workforce (Flexner, 1910). The field of family medicine became the 20th medical specialty in the US in the late 1960s, aligned with the social justice movements occurring at the time (Saba, 1999). Over the subsequent decades, family physicians and researchers within primary care adopted anthropological methods to investigate the social and longitudinal aspects of care and the complexity of primary care (Crabtree, 2006; Kobrin and Rendle, 2017; Like and Steiner RP, 1986; Scott et al., 2008).

2.2. Ethnographic studies that center on primary care

Anthropologists and physicians using ethnographic methods have investigated a range of topics relevant to primary care, including time (Guzmán, 2020; Satterwhite, 2019), professionalization (Culhane-Pera KA et al., 2000; Saba, 1999), diagnosis (Heritage and McArthur, 2019); financial and performance measures (Magrath and Nichter, 2012; Manelin, 2020); electronic medical record (Ventres et al., 2006); and collaborative care models (Stewart et al., 2015). Several ethnographic studies include a focus on primary care through the lens of community health. For example, Briggs and Mantini-Briggs (2009) studied the *Misión Barrio Adentro* program in Venezuela to explore the development of a neighborhood clinic program that intended to provide primary care to citizens. Schepers-Hughes (1992) and Smith-Nonini (1998) examined the role of community health workers providing primary care, particularly in rural, impoverished communities. Smith-Nonini highlighted the tensions between the Ministry of Health, international aid, and local organizations delivering primary care in post-war El Salvador. In Cuba, where primary care is the central to the health care system, Graber (2022) explored how patients received what would normally be considered “specialty” health care (i.e., cancer immunotherapy and participation in clinical trials) in primary care centers. Anthropologists have also looked at the ways that primary care is delivered through sites outside of typical primary care clinics, such as the emergency department (Hanssmann et al., 2022; Kline, 2019; Whitmarsh, 2008).

In work on the political economy of primary care, anthropologists have looked at the ways global health agendas focused on single-disease projects have drawn resources away

from primary care and structural determinants of health (Graham, 2016). They have also examined how neoliberal health reforms have led to the privatization of health such that citizens have had to pull together healthcare on their own using a combination of both public and private options (Abadía-Barrero, 2015; Waitzkin et al., 2007), as well a shift towards pharmaceuticalization and judicialization of care (Biehl, 2021; Kalofonos, 2021).

2.3. Ethnographic and qualitative studies of primary care from within clinical settings

Another group contributing to an anthropology of primary care are anthropologists employed by and working within health systems. These anthropologists' audiences often extend beyond anthropology. Several of these studies have centered in the Veterans Affairs (VA) health system. For example, Fix et al. (2023) published a reflexive piece about the role and practices of anthropologists working within the VA. Anthropologists and sociologists in these settings have shared their work focused on the implementation of the VA's patient-centered medical home (Forman et al., 2014; True et al., 2014; Tuepker et al., 2014), examined culture shift and language (Howard et al., 2016), the role of non-clinicians such as clerks (Solimeo et al., 2016), and the implementation of new care teams (Tuepker et al., 2014). For these social scientists, the VA has provided a fruitful space to study the culture of primary care and to translate findings into practice and policy recommendations.

Anthropologists in clinical settings outside the VA have also examined primary care innovations. Anthropologist Crabtree led two large studies focused on primary care: the Direct Observation of Primary Care (DOPC) study and the Prevention and Competing Demands in Primary Care (P&CD) (Crabtree et al., 2011). These studies led to an examination of the complexity and uncertainty of primary care. Crabtree also studied cancer survivorship in primary care (Rubinstein et al., 2017), patient and provider trust, and the care of elderly patients (Adams et al., 2002).

Our goal in bringing together these different literatures that focus on primary care is to build on this diversity of anthropological engagements with primary care. We now turn to our case studies that center primary care through two different domains: social risk screening and dementia care in primary care. Throughout we draw on Wool's ordinary/extraordinary framework to study and make sense of the range of care and tensions that exists in primary care.

3. Methods

In the two case studies we describe we used ethnographic methods, including interviews and participant-observation, in primary care settings in the United States between 2015 and 2022. Interviews involved primary care providers (PCPs), including medical doctors (MD), nurse practitioners (NP), doctors of osteopathic medicine (DO), and physician assistants (PA), as well as patients, caregivers, and specialty medical providers. More details about participant selection, sample size, and analytical strategy are integrated into the sections below for each case. All studies discussed in this paper received IRB approval from the University of California, San Francisco. We engage with different areas of primary care and show the multifaceted possibilities of engaging ethnographically with primary care. We use Wool's framework of the ordinary and extraordinary to explore key areas that emerge in

the anthropological study of primary care: primary care's engagement with patients' social contexts and with other medical specialties.

4. Results

4.1. Case Study 1: The extra/ordinary work of addressing social risk in primary care

For PCPs, understanding the social context and community of their patients is a central part of the extra/ordinary work of caring for patients in primary care. The social is not viewed as an additional complexity, but rather it is a core part of addressing illness and promoting health. As one primary care physician explained to our team:

This kind of stuff is the stuff that this place has been attuned to for a long time. I mean, before we were calling things social determinants of health . . . the idea of advocating around those issues and the idea of trying to have the resources has been kind of long-standing.

It is therefore reaffirming to many PCPs, like the one quoted above, that a growing body of policy and research focuses on the significance of social barriers to health. Studies suggest that nearly 50% of an individual's health is due to social context—such as physical environment and structural determinants of health (Schroeder, 2007). As a result, the broader healthcare system has tried to better characterize and address this social context, attending to the extraordinary complexity of health and the health system within the ordinary sites of clinical visits. For example, some health care programs are collaborating with municipalities to address housing insecurity (Enterprise Community Partners, n. d.), several projects are offering medically tailored meals to address food insecurity (Berkowitz et al., 2018), and efforts are underway to support transportation needs (Wolfe and McDonald, 2020).

One approach to better characterize social context is the development of tools that systematically identify social risks (De Marchis et al., 2020; Garg et al., 2021; Henrikson et al., 2019). These efforts, known as social risk screening, involve screening questionnaires aimed to identify: (1) Population level prevalence of social risks such as housing insecurity or food insecurity in a defined community; (2) Individual patients facing social risks with the goal of connecting them with social services. As I discuss more below, social risk screening is part of a broader effort to identify individuals who may not be able to fully engage in the healthcare system or achieve optimal health because of their social context. For example, a patient with diabetes may not be able to optimize their treatment if they lack regular access to healthy food. A patient with end-stage kidney disease may not be able to get to their appointments for dialysis or to their kidney transplant evaluation if they do not have reliable transportation.

In what follows, I [NR] examine how the integration of social risk screening into community health practices unintentionally decouples the social context from PCPs' clinical care and changes how PCPs understand and learn about the social. I build on the Yates-Doerr's (2020) analysis of the limitations of the social determinants of health to specifically examine the impact of social risk screening in primary care. I write of the intersection of the medical and social not only as a medical anthropologist studying primary care, but also as a primary care physician integrating the social into medical practice.

4.1.1. Methods—I draw on the qualitative data collected as part of a convergent mixed-methods study of four community health clinics (CHC) in Texas focused on social risk integration. Sites were eligible to participate if they were screening all or most of their patients using a standardized, multi-domain social risk screening for at least six months prior to study initiation. The providers included in the analysis below were providing direct clinical care (physicians, nurse practitioners, physician assistants, and dentists). The research team conducted semi-structured interviews remotely via zoom. The interview guide was developed collaboratively based on existing literature and pilot testing to best probe individuals' knowledge and perspectives on social risk screening tools and broader social care activities taking place in the clinic. Deidentified audio recorded interviews were transcribed and coded using inductive approach to develop an initial codebook identifying shared themes across sites. Details about the broader study methods, full interview guide, and participant demographics are described in a prior publication (De Marchis et al., 2023).

4.1.2. Results—Across the four CHCs, the study team conducted twenty-seven interviews, of which fifteen (15) were with primary care providers. Of these, the majority (13/15) were under the age of 45. Two-thirds (10/15) identified as female. We solicited race/ethnicity self-identification given the link between social risk and the experience of racism. Four participants self-identified as non-Hispanic Black, four participants identified as Hispanic, six participants identified as Asian, and one participant identified as non-Hispanic White. Participants had a range of practice experience, with two practicing less than a year, seven practicing between one and five years, and six with over five years of clinical experience.

4.1.3. Social context as the extra/ordinary care in primary care—Among the clinicians we interviewed, addressing the social context of health was something already embedded into their practice. Clinicians felt strongly that addressing the social context of health was a core component of providing primary care. As one pediatrician shared with us:

When I got here ... they [clinic leadership] talked about treating the whole person in a holistic view and providing wraparound services. And so having social work, talking about resources, trying to connect with resources, partnering with other agencies, that was something that the folks here were already attuned to and doing when I got here. So when things came up in the course of treating patients or working with patients, it was very much felt to be part of their care for us to try to connect them with resources and stuff ... There's been a very broad view of what health is at the clinic ... There was no question for anybody at the organization that these were important things to be asking about or doing, the idea that their upstream drivers of health is what we're founded on.

Like this clinician, for the PCPs we spoke with, understanding and addressing social context was part of the core of caring for patients. This was seen as ordinary work in the day-to-day practice of seeing patients, especially within the safety-net setting, but also required extraordinary efforts.

PCPs discussed the embedded manner by which social settings influence health and shape daily care delivery, even prior to the implementation of social screening.

We deal with that [social risks] every day, all day long, and medications and things like that. If you don't have insurance, we'd have to work something out to figure out how you're going to pay for it, how you're going to get the medication. That was before these studies and what have you. That's just a part of medicine.

Other clinicians emphasized that not only was addressing social needs part of their routine practice of care, but it was critical to addressing health care issues.

I think the social determinants of health definitely have a huge role in my ability to provide care, and the patient's ability to improve their health. Especially in the population that we work with, people do have a lot of barriers like transportation, or housing, or food insecurity. And knowing about those and being able to do something is important to me because I think I can prescribe all the medications that I want and talk to people about changing their lifestyle all I want, but nothing's going to happen unless I address some of these things. And it usually is more important to address the social determinants than whatever I'm talking about first.

PCPs often assessed patients' social needs within the actual visit, as an extension of the medical issues discussed because this social context was seen as critical to knowing what medications to prescribe, how patients were able to access food, or their ability to refrigerate medications. For example, one clinician explained how the development of his understanding of social context unfolded in his practice:

I'd say it depends on when the patient's presenting, and I think time is always a factor, so getting into the weeds of the social determinants can be an inhibiting factor, depending on what they're presenting on. So, if they're coming in for cough, colds, or sniffles, the social determinants aren't as much of a factor, but if they're coming in for mental health disorders, then that social determinants can be higher on the list of things that I'm thinking about.

Although clinicians described the intimate place that understanding and asking about social risk played within their practice, the introduction of social risk screening changed some of this dynamic. As an unintended consequence, the implementation of social risk screening tools drew attention to social context away from PCPs by removing it from the clinician's sphere.

4.1.4. The extraordinary efforts to integrate social risk screening into primary care—The clinics participating in our study had already integrated social screening into their clinic for at least six months. Yet, many continued to struggle with key areas of implementation: Where and who should conduct the screening? Which of their patients should be prioritized for screening? Where should social risk data be integrated into the electronic medical record? Who is responsible for follow up? In some clinics, medical assistants completed the screening, at others the front desk provided patients with packets to complete, bundled with other intake forms about medical history and demographic information. As one clinician explained regarding the complexity of integrating social risk screening into routine medical visits:

It's good and bad. It's good in the sense that, definitely, these are important factors that influence medical health, the patient's healthcare, but at what cost that we're using all this time to input this data, versus treating the patients?

By placing social risk screening into intake packets, these forms were made into ordinary bureaucratic paperwork. Yet they also asked about the extraordinary circumstances many patients navigated in getting medical care: insurance, sick leave, juggling multiple jobs, speaking languages other than English, or navigating documentation status.

Separating social risk screening from the actual encounter with a clinician (i.e., the office visit) meant that in some cases clinicians did not know that social screening took place in their clinic, while other clinicians, despite being aware of screening happening never saw their patients' social risk data. As one clinician involved in the social screening process shared: "A lot of the screening they [ie non-clinician staff such as community health workers or front desk] do, doesn't get communicated back to me." This meant that the social risk screening process actually detached the social context of patients from the clinical encounter, having the opposite of the intended effect. Social risk screening was inadvertently removing, or duplicating, the more intuitive and embedded social assessments that PCPs did as a part of their social history and rapport building from primary care encounters. It was inputted into a population health measure— of how many individuals were screened, what social risk existed in the community— and removed from the ordinariness of primary care.

PCPs discussed social screening as an important process yet felt it to be different from their typical care of patients. Social screening, they felt, was about metrics, which were different from what they learned about patients while building relationships and getting to know their patients during their ordinary clinical encounters, similar to the distinction between "population management" and "good doctoring" Manelin's (2020) discusses in his work on quality metrics in primary care. One clinician explained how he learns of social risks:

It usually comes up in the talk, when we start talking about stressors, we'll go from there. And usually a big stressor is either food or housing, transportation and then we'll try to address whichever one comes up in that conversation.

Take for example Dr. T, a family physician who has practiced for over a decade. He cared primarily for uninsured and low-income individuals. For Dr. T, primary care was about "getting people what they need." Rather than centering around a particular disease diagnosis or a social situation, primary care provided what his patients needed that day.

In the Community Health Center, what the [patients'] need may not be medication necessarily, or a referral to a specialist. It may be just giving a place to stay and having access to food. So, *to me it's expanding how we view healthcare.* Midstream, upstream kind of approaches [emphasis added].

Because Dr. T's clinic was in the process of integrating social risk screening tools, our conversation shifted to the process of social risk screening in the clinic and how this knowledge was integrated into the delivery of health services.

Interviewer: Do you have a specific role in your clinic around social risk screening? And kind of referral to resources?

Dr T: I mean I think as a primary care provider we all do. Given we work in community health centers and that's a portion of our patients' health and well-being ... Like if I had a Type 2 diabetic that's out of control, then I realize that there's food insecurity issues and they're actually only able to afford junk food. I wish I could find out some of that through that social needs tool. I could actually apply that in terms of my plan in addition to making the referrals ... And let's take a diabetic with food insecurity, I'm not going to spend a lot of my energy on their medications if they ... Let's say they're in unstable housing and don't have access to food. The other issue is, let's say they don't have access to a fridge, how are you going to give them insulin? So, I think your strategies do change depending on what you learn [from social screening tools]. I mean, to me it's, I got to address the housing issue first. So, let's get them connected to a lawyer, let's get connected to the social worker, whomever else. You can talk all you want about, "Oh, you need a healthy diet before getting evicted," but they're not thinking about that.

Dr. T highlights the critical links between social risk and health care delivery. He referred to this process of addressing housing, financial instability, and food insecurity as "medical decision making" and suggested that integrating the social and medical is work "we all do." Yet, if this is work that is integrated routinely into medical care why has the healthcare system needed to reintroduce the social through interventions such as social risk screening? And what is the social that primary care physicians already account for and what do they miss?

Interestingly, he finds that *patients* don't necessarily imagine the doctor to be able to address these issues when given the social risk screener, even though in everyday clinical encounters between patients and primary care clinicians these topics emerge frequently in less of a structured way. Thus, the model of healthcare has not only limited medical care but also patients' expectations of what can be delivered.

Taken together, these interviews highlighted the distinctions between how PCPs think about social risk and how a tool like a social risk screener is reshaping the definition of social risk and the role clinicians have in identifying and addressing these risks. By placing our research within primary care clinics, we have learned how much of this work already takes place, how screening tools aiming to quantify social risk may unintentionally be removing the social from healthcare visits, and how PCPs integrate the medical and social. Although healthcare systems and payers have increasingly turned attention to addressing social risk, primary care as a site of inquiry provides a lens into practices that have already been doing this work and opportunities to strengthen and define social risk integration.

4.2. Case Study 2: Addressing social context and disciplinary boundaries in primary care work in dementia

As discussed in Case Study 1, for PCPs, understanding the social context of their patients is central to the care they provide, though there are complexities that emerge when tools are introduced that reshape clinicians' roles. In what follows, I (ABS) look at one area of primary care – dementia – that requires specific types of engagements with patients' social

contexts, while raising anthropological questions of expertise, disciplinary boundaries, and the blurring of the ordinary and extraordinary.

There are over six million people with dementia in the US, a number that is expected to reach 13 million by 2050 (“2023 Alzheimer’s disease facts and figures,” 2023). Currently, PCPs are often the first to recognize that a patient has a cognitive problem, and much of dementia care happens in primary care (“2020 Alzheimer’s disease facts and figures,” 2020; Drabo et al., 2019). Yet there are major delays in detecting and diagnosing dementia in primary care because of the competing concerns PCPs navigate, but also because there are typically long wait-times to see a cognitive disorder specialist after getting a referral. Discussions of barriers to dementia care, disciplinary boundaries, and scope of practice are frequent, and knowledge and demands often move from specialty to primary care, reflecting a common power dynamic in the healthcare system. PCPs, strapped for time and resources, are often asked to take on the work of specialists across many different fields of medicine. For example, cognitive disorder specialists have developed new tools and programs to support PCPs in detecting and diagnosing dementia because there are not enough specialists to meet the growing needs of the aging population. Additionally, there are new FDA-approved disease modifying treatments that are becoming available, though currently with limited efficacy and high cost. With potential new therapeutic options, PCPs may eventually need to help identify patients who are eligible for treatments. In what follows, I explore the oscillations that I traced when examining the place of social context and its connection to disciplinary boundaries in primary care work in dementia.

At the center of primary care practice are the values of developing long-term relationships with patients and a deep knowledge of their social, family, and community contexts. PCPs in my research felt these values were centrally important to detecting and diagnosing dementia. As one PCP I interviewed explained,

I’m a firm believer that the majority of what we do is more reliant on what’s going on in the community. So much of the impact on a patient’s care is not going to be when I see them for 15 minutes. It’s going to be what’s going on in the outside world. I try and really focus on those connections of who’s important in your life? What are your goals for your life outside of this clinic room? And how can I be supportive in connecting you into those kinds of activities or care that you need in your home, in your community. Those are the connections that I’m trying to make after I’ve done a [dementia] assessment and make sure that I understand as much as I can about what’s going on outside of the clinic room.

In primary care, there is a tension between the strengths primary care offers patients with suspected dementia due to their in-depth knowing of their social contexts on the one hand, and the pressures from specialists alongside health systems constraints that make it challenging to engage in dementia detection, diagnosis, and care. As a medical anthropologist based in a clinical research environment, the desire to better understand how an anthropologist could contribute to an understanding of these tensions, as well of primary care’s voice and values, led me to situate this research within primary care. In what follows, I trace the ways that disciplinary boundaries and scope of practice are blurred surrounding

dementia and its management, with particular attention to the place of the social in the primary care of dementia.

4.2.1. Methods—As an anthropologist based in a clinical research setting, my case study draws on fieldwork from five research studies conducted between 2019 and 2023. These studies focused broadly on understanding and improving dementia diagnosis and management in primary care. Two involved interviews with PCPs about their practices, two explored the implementation of new dementia diagnostic tools into primary care through interviews, focus groups, and observations, and one was an interview study with cognitive care specialty clinicians about their experiences in dementia care at the end of life. I served as the primary qualitative researcher on these studies and helped with study design, conducted interviews, and led data analysis. My work contributed insights into PCPs' experiences, communication with specialists, and barriers and facilitators to tool implementation and care. From an anthropological perspective, being situated across multiple studies enabled me to see dynamics related to social context, disciplinary boundaries, and scope of practice in many different settings.

Participants were eligible to participate if they were primary care clinicians or members of primary care teams (MDs, NPs, DOs, PAs, or Social Workers) and worked in either family medicine or internal medicine or if they were cognitive disorder specialists. The interview guide for quoted data cited in this case study covered practices, attitudes, experiences, barriers, and facilitators in dementia care. Following oral consent, interviews were conducted either in person or remotely via zoom, and were audio recorded and transcribed. An analytic case summary was developed for each interview to document participant and practice characteristics, to develop themes, and to document interviewer reflections. Three coders then analyzed the data thematically using deductive and inductive coding in ATLAS.ti. They familiarized themselves with the data by reviewing the case summaries and developed a preliminary codebook. They then coded three interviews together to establish agreement in approach and code definitions. The remaining transcripts were then divided and independently coded, with seven transcripts double coded. The team met each week to review coding, introduce and define new codes, and resolve any discrepancies. The case summary was updated with exemplary quotes and additional themes during the coding process. Details about the broader study methods, full interview guide, and participant demographics are described in a prior publication (Bernstein Sideman et al., 2021; Sideman et al., 2023). Themes and findings were developed from the coded data and case summaries.

4.2.2. Results—For the interview data cited in this study, we interviewed 39 PCPs across California. 25 (64.1%) were female. 16 (41%) were Asian, 14 (35.8%) were White, 3 (7.6%) were Black or African American, 3 (7.6%) were Hispanic or Latino, 1 (2.5%) was Native Hawaiian or Pacific Islander 1 (2.5%) was East Indian, and 1 (2.5%) was Middle Eastern. The majority (92.3%) reported that more than half of their patients were insured via MediCal, the California Medicaid program serving low-income individuals.

4.2.3. Navigating scope of practice in dementia diagnosis and care—My early encounter with narratives about primary care's role in dementia was not from within primary

care, but rather was from the perspective of cognitive disorder specialists. One neurologist I interviewed described,

My experience is that by the time we see people in the dementia specialty clinic, or I get a request through e-consult, people are-there's not a question about whether they are demented, they are very demented. There's a huge delay in recognition... These people have often had multiple hospital admissions, and I want to say, what did you miss two years ago?

This neurologist repeated a frequently heard trope in the literature and in conversations with specialists about the challenges of timely diagnosis of dementia in primary care (Connell et al., 2004; McLaughlin and Laird, 2020). These delays led some specialists to develop tools to help remedy the identified problem in primary care.

In a focus group with PCPs, we discussed one of these specialty-developed toolkits. A PCP commented about the challenges she would face using the tool,

When people go to the neurologists, they aren't talking about anything else- their knees, their diabetes, bed bugs. PCPs don't have the luxury to say, 'I don't want to hear everything else on the agenda'.

We owe it to the patient to go through their agenda. People come with a list. That's our job.

The dynamics expressed by these two clinicians highlighted the tensions between specialists' expectations and primary care's realities, which involve the many different ordinary ailments and social contexts beyond cognitive concerns.

Zoë Wool's (2015) discussion of the ordinary and the extraordinary is helpful in thinking through these dynamics between primary and specialty care. PCPs are involved in everyday encounters and lived experiences, what Wool calls "the ordinary," the "small acts of daily life." Wool notes that there is a social and moral sensibility that is situated within this ordinariness, which was expressed by PCPs I interviewed regarding their professional values in relation to dementia care. PCPs typically interact with specialists at extraordinary moments, for example, when a patient has an illness that exceeds the PCP's abilities, or when a diagnosis out of their perceived scope of practice is needed. Disciplinary boundaries can make these borders between the ordinary and the extraordinary seem real. One PCP explained this dynamic,

I am terrified that I am missing [dementia] simply because the patient didn't come in, or I missed the opportunity to catch it if the patients do come in. Then if I do catch it, who can help me to manage this patient?...I don't feel like I'm qualified to give them the diagnosis. I feel like the diagnosis should be coming from a specialist who has the training, which I don't. All I can do is find their support to make sure other medical problems are stabilized. I can only encourage the amount of family involvement. I don't feel like I can do anything else. I need help.

Another PCP articulated what she felt would constitute helpful support from specialists in navigating these boundaries,

I want more relationship-building with neurologists, as someone I can trust. If I had a strong relationship with one of the neurologists, I'd feel I could easily curbside – 'I've got this situation, what do you think about this? It may not be worth the patient driving 4 hours to come see you.'

Here, and in other interviews, there was a tension between what PCPs suggested they needed— what would “help”—and what was being provided, which varied by type of practice, health system, and geography. In a way that reflected their own disciplinary values, some PCPs articulated the need for ongoing relationships with neurologists to support communication and learning rather than simply communicating through medical chart notes at the moment of diagnosis. Most wanted time to do an adequate evaluation and address people's social needs, funding structures that would reimburse this extra time, and a team that includes a social worker or other mental health professional to help extend the care and support of the patient and family's social needs. Although some of the tools designed sought to address the important issues of underdiagnosis and lack of time, I found that more work was needed to align specialists and PCPs around primary care's realities, needs, and scope of practice, as well as its strengths.

4.2.4. Blurred boundaries in the centering of the social—However, despite statements and practices that seemed to reinforce disciplinary boundaries, there was also a distinct blurring of these boundaries regarding the question of scope of practice in many of my interviews, particularly when considering the social contexts of their patients. In accounting for their patients' social contexts, PCPs I interviewed shifted towards reflecting on the strengths of primary care. Many felt that a primary care approach was in fact essential to making a dementia diagnosis. In contrasting their work with specialists, PCPs articulated their holistic way of engaging with the complexity of both illness and their patients' social lives, rather than narrowing in on disease. Many felt that knowing patients through long-term relationships and familiarity with the patient's care and social settings were especially important in dementia diagnosis. They also emphasized their role in accounting for a patients' social circumstances, such as language, culture, or logistical barriers such as transportation and insurance in both diagnosis and care in dementia. One PCP explained,

I think that to get the [dementia] diagnosis, you need the primary care provider to basically hand feed the diagnoses to the neurologist because we know the patient. We know the patient in all of the ways a provider should know them, their chronic conditions, their family dynamic, what's going on with them. Many times I can tell you I know the family, I know the dynamic, I know how it has progressed if I've seen them long enough. So, I think primary care is the primary setting to diagnose someone with dementia versus having a neurologist see the patient one time, do whatever testing they need to do, and then say, “Oh, you have this or that.” Like give me the tools to do it because this is the patient that I'm going to follow every two weeks, every month, every three months versus the neurologist who might see them, like, “Come back every three months,” “come back every six months,” “come back once a year.” So, that's kind of my idea about it.

Another PCP echoed this importance of the discipline's understanding of patients' social contexts and history, but also spoke to the power dynamics around expertise between

primary care and neurology. When describing an 80 year old patient who received burdensome testing that was ultimately felt to be unnecessary, a PCP at a safety net hospital explained,

I just think it's important if that's who you have to refer to, a neurologist, is to make sure that you're able, as a primary care provider, to feel comfortable consulting and giving your opinion on what should or should not be done. It's hard with specialists because we have put them in this category where they know a lot more than us, and in a lot of ways they do, but again, thinking about the patient and thinking about what's really truly needed because then we uncover things that might not be anything.

Although PCPs may need specialists as experts who help with the “extraordinary” moment of diagnosis, they felt the knowledge they bring about the ordinary lives of their patients can be central to making a diagnosis, thus showing the ways that the ordinary and extraordinary coexist in these processes. And, in another kind of blurring, cognitive disorder specialists often review primary care notes as an important archive of the patient's medical history and take an in-depth history from a patient and their family members to understand their longitudinal experiences and contexts when trying to pinpoint when symptoms began to make a specific diagnosis. This process reflects some of the orientation of primary care itself. The ordinary lives of patients—and primary care's contributions—are intimately entwined with the extraordinary in diagnostic processes in dementia.

Although some PCPs I interviewed felt that primary care is the ideal place for patients to get a dementia diagnosis because of their knowledge of patient's social contexts, most did not feel confident actually making a diagnosis themselves. Many identified concerns about what they could do clinically for their patients

I feel that there's a gap in consensus on what's the real value of treatment and how do you get the patient and the family members to understand that? And how do you get the medical community to come together...? There's a cost both financial, and the burden of an additional drug, and the side effects. And you take somebody who's frail and you give them nausea. There's a cost to this... That I find incredibly frustrating. So, great neuro[logy]. Thanks for doing the work up. But could you just talk to me about what your thinking was?

In these dynamics, PCPs expressed a repeated tension between feeling that primary care is the exact right place to evaluate and care for patients with dementia and feeling overwhelmed by the implications of a diagnosis and systemic pressures.

The strengths of primary care— which are also mirrored in its challenges given that PCPs' desired way of working with patients requires more time and resources— make it difficult to expand their scope of practice in dementia even if it is something that is ultimately desired and conceived of as better for the patient. The limitations are often structural—not having enough time, resources, or knowledge to address the needs of their patients, even if their philosophies align. However, these limitations are also relational-requiring better communication and understanding between PCPs and specialists because the solutions that PCPs desire and that specialists offer are not always aligned. In my work, seeing the ways

scope of practice was both produced and blurred between primary care and specialty care from the perspective of primary care enabled an engagement with questions of discipline, primary care values, and patient social contexts. Anthropologists have an important role to play in studying how the ongoing broadening and constriction between primary care and other specialists play out at the boundary of the ordinary and extraordinary in dementia care, and in so many other areas of primary care.

5. Discussion

In this paper, we explored several ways that an anthropology of and within primary care can help to illuminate issues of both anthropological and clinical importance. We thus ask, what are the unique insights that emerge from anthropological research happening within primary care? Primary care is a site where, at its best, connection is ongoing, where relationships are central to care. It is a site where illness is extraordinary and yet becomes ordinary. PCPs, when fully engaged in their values, are “anchored” to their patients’ embodied experiences, as the first point of contact for physical care of the whole body, not just anchored to a single organ or system. With this physically and socially holistic entryway, PCPs are imbued in the ordinariness of people’s lives. This ordinariness is most apparent when patients come in for routine yearly check-ups, straightforward medication management, or “ordinary” illnesses such as colds or other viruses (although COVID-19 created a significant blurring in the ordinary role of primary care the extraordinary circumstances of pandemic). This involvement and attention to the ordinariness of life is also apparent in the ongoing relationships PCPs have with patients and their families.

Primary care is also a site where what could be considered the “extraordinary”—a new and serious diagnosis, for example, is often first identified. Although specialists may be brought in to “mark” the extraordinary of a diagnosis, such as dementia, in many cases primary care is where the management of these extraordinary markers takes place. Primary care is frequently touched by the extraordinary and requires that PCPs “flicker back and forth” between the extraordinary and ordinary problems—what Wool describes as “an unstable oscillation between the extreme and the unremarkable” (21). PCPs may also have a role in finding the relevance of the ordinary in extraordinary circumstances: how does an assemblage of ordinary actions—diet, socioeconomic circumstances, social support networks, patient and family history—come to shape extraordinary diagnoses such as diabetes or Alzheimer’s disease? There is an intimacy in PCPs’ grounding in and blurring of both seemingly distinct spaces, in their knowing of daily life and the physical and embodied anchors of patients’ circumstances that drive the extraordinary.

Primary care, we suggest, is an important site where this instability of ordinary and extra is constantly negotiated. Primary care, precisely because it is seen as the ordinary, is the domain where we come to understand the complexity of care. Who gets referred immediately to the specialist? Who can pay for new treatments? Who has health insurance or time off for sickness? All of this is important not because primary care is mundane but rather because primary care is a space where we can understand the process of being a patient, a caregiver, and a clinician. The inequity of our medical society—that some will have access to treatment and others will struggle with paying for basic laboratory tests

and medicine—are also part of this ordinary practice at the intersection with extraordinary dysfunctions. In this paper, we have shown the ways that the ordinary itself is extraordinary in primary care because of the potential for oscillations, and for being the sites where the physical and the social intersect and emerge in the health care system.

We hope that this paper can serve as a call to anthropologists to continue to build on the strong foundations in the anthropology of primary care and to engage with primary care theoretically and practically. We believe that this work can both advance anthropological work, but also can open avenues for anthropologists to find ways to contribute more broadly to health services, policy, and health workforce efforts to transform primary care. There have been recent efforts in the health care system to address the marginalization of primary care, such as new models developed by the Centers for Medicare and Medicaid Services (CMS), for example, Primary Care First (“Primary Care First Model Options | CMS,” n. d.). Yet, despite the stated values of centering primary care, primary care remains underfunded, and support for the types of care teams that could make more comprehensive social care possible, such as a social worker and a nurse, are often lacking.

Primary care is “primary” because it is both the most important and comprehensive component of the health care system and, in many ways, the most basic. An anthropology of primary care can help to articulate primary care’s values, the “why” behind the work PCPs do, the range of care that takes place in routine and exceptional visits, as well as to highlight people’s experiences in primary care. Anthropologists also have the training to understand the nuances of the constraints on primary care. In this way, anthropologists have an important role to play in highlighting why and how primary care is foundational to the health care system and to people’s experiences of health and illness. The ordinary and extraordinary coexist in these primary clinical spaces, and anthropologists are in the position to tease out the oscillations, tensions, and opportunities that exist in these sites and interactions.

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Data availability

The data that has been used is confidential.

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