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SPECIAL ISSUE

Older Adults' Access to Health Care and Provider-Patient Interactions in Later Life

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OLDER ADULTS’ ACCESS TO HEALTH CARE AND PROVIDER-PATIENT INTERACTIONS IN LATER LIFE

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Older Patients’ Experiences with Medical Care and Caregiving: Editorial

Eva Kahana PhD, *Editor-in-Chief*

When I was asked to become Editor of the *Journal of Elder Policy* (JEP) in 2019, I considered the invitation to be an honor and looked forward to addressing important policy issues related to needs and care of older adults. I did not anticipate that so many of the topics addressed by the JEP would pertain to me personally.

At the time of starting as Editor, I was 78 years old and had been married for 59 years to my collaborator and the love of my life, Dr. Boaz Kahana. In the four years since I accepted the editorship, COVID descended on the world and turned older adults’ social relationships upside down. My husband Boaz passed away in November of 2020 and I needed to learn to live alone. For most older adults, COVID heralded an era of loneliness (Groarke et al., 2020). Although the acute phase of COVID has passed, there is still much ambiguity for older people about continuing or diminishing precautions related to COVID. I personally just started sparingly going out to restaurants and inviting friends into my home.

I have also grappled with disabling health challenges due to arthritis in my hip that caused pain and limited my mobility. Last year, I was awaiting the decline of COVID to schedule my hip replacement surgery, which could potentially enhance my mobility and reduce my pain.

I am still working full time as a professor and greatly enjoy my work. I requested to continue teaching online this semester due to my mobility issues and fear of contracting COVID. It was challenging to get the permission from my university, as all courses are now back to being taught in person. But eventually, my supportive dean prevailed, and I am currently teaching my class on Stress and Coping online. I have 20 students and instructing them is a highlight of my week. I also continue to supervise doctoral students and work on my research. As I write this editorial for the current issue of JEP, I realize how much my work and lived experiences are intertwined. I also learned that personal perspectives can deepen one’s understanding of healthcare-related issues and challenges.

I had my long-postponed hip replacement surgery in Philadelphia mid-July 2022. Now, I am eagerly working toward recovery and toward fully regaining my mobility. I have positive visions of walking unassisted and traveling again. I am still a bit unsteady on my feet, but have recently graduated from the walker to the cane. So, the current issue of JEP that is focused on “Older Adults’ Access to Health

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Care and Provider-Patient Interactions in Later Life" is closely related to my lived experiences.

The articles included in this issue address older patients' experiences in navigating the complicated health care system. They recognize that older patients are confronting a bureaucratic system that varies greatly from their earlier life experiences and from their expectations (Rourke, 2021). I will introduce my discussion of these issues by sharing my lived experiences as an 81-year-old woman undergoing hip replacement surgery.

As I mentioned, I decided to have my surgery in Philadelphia where my younger son, Michael, and his family live. He was aware of an excellent orthopedic surgeon, Dr. Javad Parvizi. Having my surgery in Philadelphia instead of Cleveland ensured the availability of high-quality formal health care and the proximity of family caregivers, as my older son Jeffrey was also spending the month in Philadelphia with his family while his children attended summer camp.

The Rothman Center, affiliated with Jefferson Hospital where Dr. Parvizi practices, is a busy orthopedic center that exuded an optimistic air. My care was excellent during my brief, two-day hospital stay. After my discharge, I spent three weeks recovering at a Residence Inn near my son's home. I was using a walker and initially needed help to get on and off the bed. I hired homecare workers from a recommended home care agency to help me out when family members were unavailable during my convalescence.

The nighttime caregivers came for a 12-hour shift, from 9 p.m. to 9 a.m. Daytime caregivers came from 9 a.m. to 5p.m. The caregivers helped me get dressed and to walk for exercise in the lobby. I paid $30 per hour to the agency, resulting in an expense of $600 per day for 17 days, or a total out-of-pocket personnel cost of $10,800. It is likely that the homecare workers were paid only a fraction of this cost. Most of the caregivers were immigrants to the U.S. Some came from the Bahamas, others from Nigeria. All were married women, with families, and were active participants in church activities.

Most caregivers helped whenever they were specifically requested to do so. Only a few took the initiative to help with a shower or with meals. The nighttime assistants initially helped me get on and off the bed, allowing me to walk to the bathroom. As I became stronger and more independent in getting on and off the bed, they generally left me to my own devices, with some asking: "Are you alright?" Most of the night-time caregivers watched TV in the living room until late and then went to sleep with their clothes on in the bed adjacent to mine. If I asked for help to get out of bed at night, most responded, awakening to my request. A few slept very soundly and did not awaken when I asked for help. I later learned that the caregivers were expected to stay up, but it was tacitly understood that most go to sleep. My daytime caregivers spent a lot of time talking to their friends on the telephone. My experience underscored the limitations of support by paid caregivers.

After returning home to Cleveland, I no longer required caregivers and had a local hospital-based physical therapist visit twice a week for about half an hour to help me improve my walking. There were only a few minutes of exercises included in each visit. Half of the visit was spent with the therapist checking my vital signs. I recently started outpatient physical therapy that appears far more professional. The therapist spends a full hour with me and explains the rationale for the exercises I do.

Reflecting on my experiences with hired care after my surgery affirms the concerns addressed by JEP regarding difficulties of older patients in obtaining responsive healthcare, particularly when personal care is called for. Private agencies offer limited oversight and control when supervising care staff. Even reputable hospitals have difficulty ensuring a high quality of care provided by homecare workers, such as physical therapists.

The personalized and continuous care of yesteryear has nearly disappeared and has been replaced by a fragmented and cost-conscious system (Stange, 2009). Care by physicians is often substituted with less fully-trained healthcare providers (Montenegro et al., 2011). Indeed, the physician is now generally referred to as one of a multiplicity of "providers."

Changing Patterns of Healthcare Delivery

The articles in this issue also address the fragmentation of health care and the challenges they pose for policy. To describe this problem in depth, our issue includes patient, researcher, and health care provider perspectives. We also continue to publish multidisciplinary papers written by clinicians and researchers. On a macro level, this edition of JEP also offers insights into regional and international differences in health care and policy. Our examples include focus on underserved populations in Appalachia, geriatric doctors in Italy, and patients recently diagnosed with diabetes in Baltimore.

Several papers are based on patient narratives and use qualitative approaches. They call attention to the shortcomings of our current health care system in providing senior-friendly policies. Trust between patients, physicians, and family caregivers comprises an important and often unrecognized element of successful medical care. The current issue of JEP includes in depth longitudinal studies of such relationships. Given the complex needs of geriatric patients, integrating informal caregivers in the health care team enhances the success of care provision. One study we include is focused on physicians' perceptions of family caregiver trustworthiness, and identifies domains where caregivers provide particularly strong support.

Continuity of care has long been a positive mantra in describing desirability and expectations for high-quality medical care. Most employed people, at least among middle-class Americans, obtain health insurance from their workplace and get their usual care from an internist or family physician affiliated with one of the major hospitals in town. As patients age and develop chronic health and mobility problems, they look for a referral to a specialist to further treat them. However, there have been dramatic changes in the delivery of healthcare in the past ten years, particularly since the onset of the COVID pandemic in 2020. Obtaining in-person appointments with primary care doctors has become much more difficult, with long waits now being the norm. Communication has morphed to online contacts and even online appointments (Fox & Rainie, 2002). Visual inspection and assessment by the doctor has become secondary. Given the fear of COVID, especially by older adults, some of these changes are understandable.

Many hospital systems have also encouraged patients communication with their doctor through an electronic portal such as MyChart (Rainie & Fox, 2000). The monitoring of these portals has often been left to clerical staff, and questions addressed to doctors have also been increasingly handled by assistants. Indeed, physicians' assistants and nurse practitioners have gained primary roles as healthcare providers (Kleinpell, Ely, & Grabenkort, 2008). The customary, old-fashioned practice of primary care doctors calling and notifying their patients of test results has fallen by the wayside. Results are now conveyed via e-mail, or if necessary, by a medical secretary who does not personally know the patient. This practice eliminates the opportunity for the patient to maintain contact and ask questions of their familiar doctor. Also absent is the reassurance coming from a long-term advocate. The changes outlined here occurred both prior to and during the Pandemic, and clearly made obtaining health care more challenging. The articles published in this issue reflect these health care challenges.

Current Articles Elucidating the Challenges of Coordinated Health Care Delivery

Our first article reflects the divide between physician aspirations to deliver personalized care and obstacles to such care delivery. Written by two physicians and a director of community health, the manuscript by **Stange, MD, PhD, Gaglioti, MD, MS, and Bindas**, **MBA** skillfully maps out the benefits of comprehensive health care for older adults. This paper is unique as it explores and interprets three case studies where the authors share personal reflections of managing the health of older adult patients. The second half of the paper builds on these case studies, and shares the findings from a survey asking: “What matters in health care?” From this survey, the authors identified domains of care “that represent the essence of high-quality primary care, from the perspective of those receiving or providing care.”

These expectations include accessibility to primary care, focus on the whole person, and family in context. This involves forming relationships with the patient over time, learning the most important aspect of care for the patient, prioritizing communication among health care teams to manage multiple chronic illnesses, being an advocate for the patient, and focusing on prevention rather than treatment. The domains encourage health care providers to act as generalists so that they can recognize problems and prioritize their actions to promote health and healing and personalize care for the individual. The authors conclude their paper with policy recommendations that promote primary care, relationship-centered models of care, and non-reductionist research methods.

Medical expertise directed at older persons is represented by care offered by geriatricians. The paper by **Degiuli, PhD** considers the roles of geriatric physicians in the U.S. and in Italy, offering a cross-cultural perspective on geriatric care. Based on qualitative interviews with geriatricians and participant observations at geriatric conferences, the author explores the roles these specially trained physicians play both in acute and long-term care settings. She concludes that geriatricians have a very limited presence in both Italy and in the U.S. This underrepresentation of physicians most highly-trained in chronic care needed by elderly patients offers a unique and important explanation for the underserved characteristics of this group. Degiuli calls for macro-level solutions in order to provide better care for chronic illnesses of late life.

The paper written by **Chard, PhD**, **Girling, PhD, Harris-Wallace, PhD, Henderson, PhD, Roth, PhD,** and **Eckert, PhD** in this issue of JEP focuses on diabetes diagnosis pathways and implications for health policy. Type 2 Diabetes is a chronic health condition that concerns many older adults. While screening and prevention are common topics in the literature, the process of diagnosis is often ignored. This important paper explores the pathways in which older adults find themselves diagnosed with diabetes. Utilizing narratives from 47 older black and white adults, the authors reveal that their participants only learned of their disease after suffering a health event and/or experiencing alarming symptoms (e.g., losing consciousness while driving). Surprisingly, only 13 percent of participants were diagnosed during their annual health care visit. Other avenues of diagnosis were through worksite or community testing. In all instances, the participants appeared to be caught off guard by their diagnosis. This paper calls attention to the importance of diagnosis before health events occur, and the need for providing access to screening, particularly in underserved communities.

The paper by **Rao and Minakshi, PhD** examines an understudied but central topic of physician trust in family caregivers. The authors utilized qualitative interviews with 20 physicians to explore how they develop trust in family caregivers, how they perceive whether a caregiver trusts them, the role that culture plays in trust-building, and perceived barriers and facilitators of integrating caregivers into the health care team. Findings from their study revealed that physicians' assessment of trust in family members included competence, fidelity, and reliability. Physicians felt that they could trust family caregivers if they perceived that the caregiver was able to carry out tasks related to the patient's needs, if they advocated for the patient, and if they seemed engaged in the patient's care. In terms of perception of caregivers' trust in them, physicians utilized verbal signals (expressing gratitude) and non-verbal cues (body language) and noted the way in which caregivers asked questions. Additionally, physicians felt that if they were culturally sensitive to their patients, caregivers tended to trust them. Telehealth visits and use of FaceTime helped involve the family member in the patient's care. Lastly, the importance of family caregivers was revealed when physicians expressed that they trust other physicians for objective data, but that family caregivers were able to give them a clearer picture of the patient's symptoms and provide context. Rao and Minakshi conclude with policy recommendations that support integration of family caregivers into the health care relationship.

Hicks Patrick, PhD, Pullen, MA, Ibrahim-Bacha, BS, and Spencer, PhD consider the important link between place and functional disability in Rural Appalachia. Using data from the Centers for Disease Control and Prevention's (CDC) Behavioral Risk Factor Surveillance System (BRFSS), they explore how demographic social determinants of health (age, gender, education, and income) impact access to healthcare and functional ability among 4,867 adults living in West Virginia. Their analysis indicated that being male, younger, and of lower income was associated with more difficulty in accessing medical care. In terms of functional ability, only income was found to impact one's functional levels. Additionally, more access to medical care was associated with lower levels of functional ability, suggesting that greater access leads to more diagnosis and care. The authors suggest that these results may indicate that expanded Medicaid coverage and other social programs are reaching the intended recipients. Their paper underscores the importance of continuing programs of Medicaid expansion in states such as West Virginia where the population is growing older. They also emphasize that Medicaid programs should be expanded to include prevention rather than just treatment in order to combat functional disabilities in later life for those who are younger and middle-aged now.

Bravo, PhD, MPH, Gutierrez, PhD, MPH and Levy-Storms, PhD, MPH address patient-provider relationships (PPR) in a geriatric program serving older adult foreign-born Latinos with multimorbidity. In-depth interviews were conducted in Spanish on three separate occasions with 13 Spanish-speaking patients over the course of one year. Doctor-patient relationships were based on technical knowledge, trust, and advocacy in a hierarchical order. Over time those doctors demonstrating the best relationships exhibited expertise, trust and advocacy. Accordingly, good doctor patient relationships demand constructive actions by doctors on patients' behalf. These findings support the work of Clarke, Bennett and

Korotchenko (2014), in which patients reported that they received inadequate care due to the personal failings of their physicians and constraints of medical consultations.

The Evolving Nature of Health Care Policies

In considering the diverse perspectives and healthcare locations in this volume of JEP, one must be impressed by commonalities in health care and by deficiencies identified that call for innovative policies. We are also impressed by the value of qualitative as well as quantitative approaches to the study of health care delivery, especially as it occurs in late life. We also learn to appreciate the roles played by family members and other informal caregivers in impacting the health and functioning of older adults.

It is important to recognize that services to older adults evolve through a combination of planned improvements and evolving opportunities. Many services do not reflect planned policies, but rather the evolution of organizations and professions. In considering the diverse perspectives and healthcare locations in this volume of JEP, one must be impressed by commonalities in health care and in deficiencies identified that call for innovative policies. We also note the value of qualitative as well as quantitative approaches to the study of health care delivery, especially as it occurs in late life. We also learn to appreciate the roles paid by family members and other informal caregivers in impacting the health and functioning of older adults. Family caregivers are invested in caring relationships in ways that are hard to find among paid caregivers.

We are pleased that our publication retains an international perspective focusing on older adults and health care providers in diverse cultural contexts. We recognize cultural differences, but are also impressed by commonalities across cultures. In particular, there appear to be similarities in the importance of investment of health care personnel in enhancing satisfaction with care among elderly patients. Even with advances in health care delivery, relational aspects of health care assume paramount importance in old age. It appears that deficiencies continue to exist in health care delivery to older adults. To the extent that collective solutions have not been prevalent, individual proactivity among older adults can hold great value (Kahana, Kahana, & Lee, 2014).

Experiencias de los pacientes mayores con la atención médica y la prestación de cuidados: Editorial

Eva Kahana PhD, *Editora en Jefe*

Cuando me pidieron que me convirtiera en editor de *Journal of Elder Policy* (JEP) en 2019, consideré que la invitación era un honor y esperaba abordar importantes cuestiones de política relacionadas con las necesidades y el cuidado de los adultos mayores. No anticipé que tantos de los temas tratados por la JEP me tocarían personalmente.

Al momento de comenzar como Editora, tenía 78 años y llevaba casada 59 años con mi colaborador y el amor de mi vida, el Dr. Boaz Kahana. En los cuatro años desde que acepté la dirección, el COVID descendió sobre el mundo y puso patas arriba las relaciones sociales de los adultos mayores. Mi esposo Boaz falleció en noviembre de 2020 y necesitaba aprender a vivir sola. Para la mayoría de los adultos mayores, la COVID anunció una era de soledad (Groarke et al., 2020). Aunque la fase aguda de la COVID ha pasado, aún existe mucha ambigüedad para las personas mayores acerca de continuar o disminuir las precauciones relacionadas con la COVID. Personalmente, comencé a salir con moderación a restaurantes e invitar a amigos a mi casa.

También he lidiado con problemas de salud incapacitantes debido a la artritis en la cadera que me causaba dolor y limitaba mi movilidad. El año pasado, estaba esperando el declive de COVID para programar mi cirugía de reemplazo de cadera, lo que podría mejorar mi movilidad y reducir mi dolor.

Sigo trabajando a tiempo completo como profesor y disfruto mucho de mi trabajo. Solicité continuar enseñando en línea este semestre debido a mis problemas de movilidad y miedo a contraer COVID. Fue un desafío obtener el permiso de mi universidad, ya que ahora todos los cursos se impartirán de forma presencial. Pero finalmente, prevaleció mi decano solidario, y actualmente estoy enseñando mi clase en línea sobre estrés y afrontamiento. Tengo 20 estudiantes e instruirlos es lo más destacado de mi semana. También continúo supervisando estudiantes de doctorado y trabajo en mi investigación. Mientras escribo este editorial para el número actual de la JEP, me doy cuenta de cuánto se entrelazan mi trabajo y mis experiencias vividas. También aprendí que las perspectivas personales pueden profundizar la comprensión de los problemas y desafíos relacionados con la atención médica.

Tuve mi cirugía de reemplazo de cadera pospuesta durante mucho tiempo en Filadelfia a mediados de julio de 2022. Ahora, estoy trabajando con entusiasmo para recuperarme y recuperar completamente mi movilidad. Tengo visiones positivas de caminar sin ayuda y volver a viajar. Todavía estoy un poco inestable sobre mis pies, pero recientemente me gradué del andador al bastón. Entonces, la edición actual de JEP que se enfoca en "El acceso de los adultos mayores a la atención médica y las interacciones entre el proveedor y el paciente en la vejez" está estrechamente relacionada con mis experiencias vividas.

Los artículos incluidos en este número abordan las experiencias de los pacientes mayores al navegar por el complicado sistema de atención médica. Reconocen que los pacientes mayores se enfrentan a un sistema burocrático que varía mucho de sus experiencias de vida anteriores y de sus expectativas (Rourke, 2021). Presentaré mi discusión sobre estos temas compartiendo mis experiencias vividas como una mujer de 81 años que se sometió a una cirugía de reemplazo de cadera.

Como mencioné, decidí operarme en Filadelfia, donde vive mi hijo menor, Michael, y su familia. Conocía a un excelente cirujano ortopédico, el Dr. Javad Parvizi. Tener mi cirugía en Filadelfia en lugar de Cleveland garantizó la disponibilidad de atención médica formal de alta calidad y la proximidad de los cuidadores familiares, ya que mi hijo mayor, Jeffrey, también pasaba el mes en Filadelfia con su familia mientras sus hijos asistían a un campamento de verano.

El Centro Rothman, afiliado al Hospital Jefferson donde practica el Dr. Parvizi, es un centro ortopédico ocupado que emana un aire optimista. Mi atención fue excelente durante mi breve estadía de dos días en el hospital. Después de mi alta, pasé tres semanas recuperándome en un Residence Inn cerca de la casa de mi hijo. Usaba un andador y al principio necesitaba ayuda para subirme y levantarme de la cama. Contraté trabajadores de atención domiciliaria de una agencia de atención domiciliaria recomendada para ayudarme cuando los miembros de la familia no estuvieran disponibles durante mi convalecencia.

Las cuidadoras nocturnas vinieron para un turno de 12 horas, de 9 p.m. a 9 a. m. Las cuidadoras diurnas venían de 9 a. m. a 5 p. m. Los cuidadores me ayudaron a vestirme ya caminar para hacer ejercicio en el vestíbulo. Pagué $30 por hora a la agencia, lo que resultó en un gasto de $600 por día durante 17 días, o un costo total de desembolso personal de $10,800. Es probable que a los trabajadores de atención domiciliaria se les pagara solo una fracción de este costo. La mayoría de las cuidadoras eran inmigrantes en los EE. UU. Algunas venían de las Bahamas, otras de Nigeria. Todas eran mujeres casadas, con familias y participantes activas en las actividades de su iglesia.

La mayoría de las cuidadoras ayudaron cuando se les solicitó específicamente que lo hicieran. Solo unas pocas tomaron la iniciativa de ayudar con la ducha o con las comidas. Las asistentes nocturnas inicialmente me ayudaron a subir y bajar de la cama, permitiéndome caminar hasta el baño. A medida que me volví más fuerte e independiente para subir y bajar de la cama, generalmente me dejaban sola, y algunas me preguntaban: "¿Está bien?" La mayoría de las cuidadoras nocturnas veían la televisión en la sala de estar hasta tarde y luego se iban a dormir con la ropa puesta en la cama contigua a la mía. Si pedía ayuda para levantarme de la cama por la noche, la mayoría respondía despertando a mi pedido. Algunas dormían muy profundamente y no se despertaban cuando pedía ayuda. Más tarde supe que se esperaba que las cuidadoras se quedaran despiertas, pero se entendía tácitamente que la mayoría se iba a dormir. Mis cuidadoras diurnas pasaban mucho tiempo hablando con sus amigos por teléfono. Mi experiencia resaltó las limitaciones del apoyo de los cuidadores pagados.

Después de regresar a mi hogar en Cleveland, ya no necesité cuidadores y tuve una visita de un fisioterapeuta del hospital local dos veces por semana durante aproximadamente media hora para ayudarme a mejorar mi forma de caminar. Solo se incluyeron unos minutos de ejercicios en cada visita. Pasé la mitad de la visita con el terapeuta revisando mis signos vitales. Recientemente comencé la fisioterapia ambulatoria que parece mucho más profesional. El terapeuta pasa una hora completa conmigo y me explica la razón de ser de los ejercicios que hago.

Reflexionar sobre mis experiencias con la atención contratada después de mi cirugía confirma las preocupaciones abordadas por JEP con respecto a las dificultades de los pacientes mayores para obtener atención médica receptiva, particularmente cuando se requiere atención personal. Las agencias privadas ofrecen supervisión y control limitados cuando supervisan al personal de atención. Incluso los hospitales de renombre tienen dificultades para garantizar una atención de alta calidad proporcionada por trabajadores de atención domiciliaria, como los fisioterapeutas.

La atención personalizada y continua de antaño casi ha desaparecido y ha sido reemplazada por un sistema fragmentado y consciente de los costos (Stange, 2009). La atención de los médicos a menudo se sustituye por proveedores de atención médica menos capacitados (Montenegro et al., 2011). De hecho, ahora se hace referencia generalmente al personal médico como uno de una multiplicidad de "proveedores".

Cambios en los patrones de prestación de atención médica

Los artículos de este número también abordan la fragmentación de la atención de la salud y los desafíos que plantean para las políticas. Para describir este problema en profundidad, nuestro número incluye las perspectivas del paciente, el investigador y el proveedor de atención médica. También continuamos publicando artículos multidisciplinarios escritos por médicos e investigadores. En un nivel macro, esta edición de JEP también ofrece información sobre las diferencias regionales e internacionales en la atención y las políticas de salud. Nuestros ejemplos incluyen el enfoque en poblaciones desatendidas en los Apalaches, médicos geriatras en Italia y pacientes recientemente diagnosticados con diabetes en Baltimore.

Varios artículos se basan en relatos de pacientes y utilizan enfoques cualitativos. Llaman la atención sobre las deficiencias de nuestro actual sistema de atención médica para brindar políticas amigables para las personas mayores. La confianza entre pacientes, médicos y cuidadores familiares constituye un elemento importante y, a menudo, no reconocido de una atención médica exitosa. El número actual de la JEP incluye estudios longitudinales en profundidad de tales relaciones. Dadas las complejas necesidades de los pacientes geriátricos, la integración de cuidadores informales en el equipo de atención de la salud mejora el éxito de la prestación de atención. Un estudio que incluimos se centra en las percepciones de los médicos sobre la confiabilidad del cuidador familiar e identifica los dominios en los que los cuidadores brindan un apoyo particularmente fuerte.

La continuidad de la atención ha sido durante mucho tiempo un mantra positivo para describir la conveniencia y las expectativas de una atención médica de alta calidad. La mayoría de las personas empleadas, al menos entre los estadounidenses de clase media, obtienen un seguro de salud en su lugar de trabajo y obtienen la atención habitual de un internista o médico de familia afiliado a uno de los principales hospitales de la ciudad. A medida que los pacientes envejecen y desarrollan problemas crónicos de salud y movilidad, buscan una derivación a un especialista para que los trate más. Sin embargo, ha habido cambios drásticos en la prestación de atención médica en los últimos diez años, particularmente desde el inicio de la pandemia de COVID en 2020. Obtener citas en persona con los médicos de atención primaria se ha vuelto mucho más difícil, y las largas esperas ahora son el problema. norma. La comunicación se ha transformado en contactos en línea e incluso citas en línea (Fox & Rainie, 2002). La inspección visual y la evaluación por parte del médico se han vuelto secundarias. Dado el miedo al COVID, especialmente por parte de los adultos mayores, algunos de estos cambios son comprensibles.

Muchos sistemas hospitalarios también han fomentado la comunicación de los pacientes con su médico a través de un portal electrónico como MyChart (Rainie & Fox, 2000). La supervisión de estos portales a menudo se ha dejado en manos del personal administrativo, y las preguntas dirigidas a los médicos también han sido manejadas cada vez más por asistentes. De hecho, los asistentes médicos y las enfermeras practicantes han adquirido roles principales como proveedores de atención médica (Kleinpell, Ely y Grabenkort, 2008). La práctica tradicional y anticuada de los médicos de atención primaria llamando y notificando a sus pacientes los resultados de las pruebas se ha quedado en el camino. Los resultados ahora se transmiten por correo electrónico o, si es necesario, por una secretaria médica que no conoce personalmente al paciente. Esta práctica elimina la oportunidad de que el paciente mantenga contacto y haga preguntas a su médico familiar. También está ausente la tranquilidad proveniente de un defensor a largo plazo. Los cambios descritos aquí ocurrieron antes y durante la pandemia, y claramente hicieron que obtener atención médica fuera más difícil. Los artículos publicados en este número reflejan estos desafíos del cuidado de la salud.

Artículos actuales que aclaran los desafíos de la prestación coordinada de atención médica

Nuestro primer artículo refleja la división entre las aspiraciones de los médicos de brindar una atención personalizada y los obstáculos para dicha prestación. Escrito por dos médicos y un director de salud comunitaria, el manuscrito de **Stange, MD, PhD, Gaglioti, MD, MS y Bindas, MBA** describe hábilmente los beneficios de la atención médica integral para adultos mayores. Este artículo es único ya que explora e interpreta tres estudios de caso donde los autores comparten reflexiones personales sobre el manejo de la salud de los pacientes adultos mayores. La segunda mitad del documento se basa en estos estudios de casos y comparte los hallazgos de una encuesta que pregunta: "¿Qué importa en el cuidado de la salud?" A partir de esta encuesta, los autores identificaron dominios de atención "que representan la esencia de la atención primaria de alta calidad, desde la perspectiva de quienes reciben o brindan atención".

Estas expectativas incluyen la accesibilidad a la atención primaria, el enfoque en la persona en su totalidad y la familia en contexto. Esto implica formar relaciones con el paciente a lo largo del tiempo, aprender el aspecto más importante del cuidado del paciente, priorizar la comunicación entre los equipos de atención médica para manejar múltiples enfermedades crónicas, ser un defensor del paciente y centrarse en la prevención en lugar del tratamiento. Los dominios alientan a los proveedores de atención médica a actuar como generalistas para que puedan reconocer los problemas y priorizar sus acciones para promover la salud y la curación y personalizar la atención para el individuo. Los autores concluyen su artículo con recomendaciones de política que promueven la atención primaria, los modelos de atención centrados en las relaciones y los métodos de investigación no reduccionistas.

La experiencia médica dirigida a las personas mayores está representada por la atención que ofrecen los geriatras. El artículo de **Degiuli, PhD**, considera los roles de los médicos geriatras en los EE. UU. e Italia, y ofrece una perspectiva intercultural sobre la atención geriátrica. Basado en entrevistas cualitativas con geriatras y observaciones de participantes en conferencias geriátricas, el autor explora los roles que desempeñan estos médicos especialmente capacitados tanto en entornos de atención aguda como a largo plazo. Ella concluye que los geriatras tienen una presencia muy limitada tanto en Italia como en los EE. UU. Esta subrepresentación de médicos altamente capacitados en la atención crónica que necesitan los pacientes mayores ofrece una explicación única e importante de las características desatendidas de este grupo. Degiuli pide soluciones a nivel macro para brindar una mejor atención a las enfermedades crónicas de la vejez.

El documento escrito por **Chard, PhD, Girling, PhD, Harris-Wallace, PhD, Henderson, PhD, Roth, PhD y Eckert, PhD** en este número de JEP se centra en las vías de diagnóstico de la diabetes y sus implicaciones para la política de salud. La diabetes tipo 2 es una condición de salud crónica que preocupa a muchos adultos mayores. Si bien la detección y la prevención son temas comunes en la literatura, el proceso de diagnóstico a menudo se ignora. Este importante artículo explora las vías en las que los adultos mayores se encuentran diagnosticados con diabetes. Utilizando narraciones de 47 adultos mayores blancos y negros, los autores revelan que sus participantes solo se enteraron de su enfermedad después de sufrir un problema de salud y/o experimentar síntomas alarmantes (p. ej., perder el conocimiento mientras conducían). Sorprendentemente, solo el 13 por ciento de los participantes fueron diagnosticados durante su visita anual de atención médica. Otras vías de diagnóstico fueron a través de pruebas en el lugar de trabajo o en la comunidad. En todos los casos, los participantes parecían haber sido tomados por sorpresa por su diagnóstico. Este documento llama la atención sobre la importancia del diagnóstico antes de que ocurran los eventos de salud y la necesidad de brindar acceso a la detección, particularmente en las comunidades desatendidas.

El documento de **Rao y Minakshi, PhD**, examina un tema central pero poco estudiado de la confianza del médico en los cuidadores familiares. Los autores utilizaron entrevistas cualitativas con 20 médicos para explorar cómo desarrollan confianza en los cuidadores familiares, cómo perciben si un cuidador confía en ellos, el papel que juega la cultura en la construcción de confianza y las barreras y facilitadores percibidos para integrar a los cuidadores en el equipo de atención médica. . Los hallazgos de su estudio revelaron que la evaluación de los médicos sobre la confianza en los miembros de la familia incluía competencia, fidelidad y confiabilidad. Los médicos sintieron que podían confiar en los cuidadores familiares si percibían que el cuidador podía llevar a cabo tareas relacionadas con las necesidades del paciente, si defendían al paciente y si parecían comprometidos con el cuidado del paciente. En cuanto a la percepción de la confianza de los cuidadores en ellos, los médicos utilizaron señales verbales (expresando gratitud) y señales no verbales (lenguaje corporal) y observaron la forma en que los cuidadores hacían preguntas. Además, los médicos sintieron que si eran culturalmente sensibles a sus pacientes, los cuidadores tendían a confiar en ellos. Las visitas de telesalud y el uso de FaceTime ayudaron a involucrar al familiar en la atención del paciente. Por último, la importancia de los cuidadores familiares se reveló cuando los médicos expresaron que confían en otros médicos para obtener datos objetivos, pero que los cuidadores familiares pudieron darles una imagen más clara de los síntomas del paciente y brindarles contexto. Rao y Minakshi concluyen con recomendaciones de políticas que apoyan la integración de los cuidadores familiares en la relación de atención médica.

Hicks Patrick, PhD, Pullen, MA, Ibrahim-Bacha, BS y Spencer, PhD consideran el vínculo importante entre el lugar y la discapacidad funcional en los Apalaches rurales. Utilizando datos del Sistema de Vigilancia de Factores de Riesgo Conductual (BRFSS) de los Centros para el Control y la Prevención de Enfermedades (CDC), exploran cómo los determinantes sociales demográficos de la salud (edad, sexo, educación e ingresos) afectan el acceso a la atención médica y la capacidad funcional entre 4867 adultos. viviendo en Virginia Occidental. Su análisis indicó que ser hombre, más joven y de menores ingresos se asoció con más dificultades para acceder a la atención médica. En términos de capacidad funcional, solo se encontró que los ingresos afectan los niveles funcionales. Además, un mayor acceso a la atención médica se asoció con niveles más bajos de capacidad funcional, lo que sugiere que un mayor acceso conduce a más diagnósticos y atención. Los autores sugieren que estos resultados pueden indicar que la cobertura ampliada de Medicaid y otros programas sociales están llegando a los destinatarios previstos. Su artículo subraya la importancia de continuar con los programas de expansión de Medicaid en estados como West Virginia, donde la población está envejeciendo. También enfatizan que los programas de Medicaid deben ampliarse para incluir prevención en lugar de solo tratamiento para combatir las discapacidades funcionales en la edad adulta para aquellos que ahora son más jóvenes y de mediana edad.

Bravo, PhD, MPH, Gutierrez, PhD, MPH y Levy-Storms, PhD, MPH abordan las relaciones paciente-proveedor (PPR) en un programa geriátrico que atiende a adultos mayores latinos nacidos en el extranjero con multimorbilidad. Se realizaron entrevistas en profundidad en español en tres ocasiones separadas con 13 pacientes de habla hispana en el transcurso de un año. Las relaciones médico-paciente se basaron en el conocimiento técnico, la confianza y la defensa en un orden jerárquico. Con el tiempo, aquellos médicos que demostraron las mejores relaciones exhibieron experiencia, confianza y defensa. En consecuencia, las buenas relaciones médico-paciente exigen acciones constructivas por parte de los médicos en nombre de los pacientes. Estos hallazgos respaldan el trabajo de Clarke, Bennett y Korotchenko (2014), en el que los pacientes informaron que recibieron una atención inadecuada debido a las fallas personales de sus médicos y las limitaciones de las consultas médicas.

La naturaleza evolutiva de las políticas de atención médica

Al considerar las diversas perspectivas y ubicaciones de atención médica en este volumen de JEP, uno debe quedar impresionado por los puntos en común en la atención médica y por las deficiencias identificadas que requieren políticas innovadoras. También estamos impresionados por el valor de los enfoques cualitativos y cuantitativos para el estudio de la prestación de atención médica, especialmente cuando ocurre en la vejez. También aprendemos a apreciar los roles que desempeñan los miembros de la familia y otros cuidadores informales para impactar la salud y el funcionamiento de los adultos mayores.

Es importante reconocer que los servicios para adultos mayores evolucionan a través de una combinación de mejoras planificadas y oportunidades en evolución. Muchos servicios no reflejan políticas planificadas, sino más bien la evolución de organizaciones y profesiones. Al considerar las diversas perspectivas y ubicaciones de atención médica en este volumen de JEP, uno debe quedar impresionado por los puntos en común en la atención médica y las deficiencias identificadas que requieren políticas innovadoras. También notamos el valor de los enfoques cualitativos y cuantitativos para el estudio de la prestación de atención médica, especialmente cuando ocurre en la vejez. También aprendemos a apreciar los roles que desempeñan los miembros de la familia y otros cuidadores informales para impactar la salud y el funcionamiento de los adultos mayores. Los cuidadores familiares están comprometidos con las relaciones afectuosas de formas que son difíciles de encontrar entre los cuidadores pagados.

Nos complace que nuestra publicación conserve una perspectiva internacional centrada en los adultos mayores y los proveedores de atención médica en diversos contextos culturales. Reconocemos las diferencias culturales, pero también nos impresionan los puntos en común entre culturas. En particular, parece haber similitudes en la importancia de la inversión del personal de atención médica para mejorar la satisfacción con la atención entre los pacientes de edad avanzada. Incluso con los avances en la prestación de atención médica, los aspectos relacionales de la atención médica adquieren una importancia primordial en la vejez. Al parecer, continúan existiendo deficiencias en la prestación de servicios de salud a los adultos mayores. En la medida en que las soluciones colectivas no hayan prevalecido, la proactividad individual entre los adultos mayores puede tener un gran valor (Kahana, Kahana y Lee, 2014).

老年患者的医疗护理体验：社论

Eva Kahana 博士，主编

当我在 2019 年受邀担任《老年政策杂志》（JEP）的编辑时，我将邀请视为一种荣幸，并期待应对与老年人的需求和护理相关的重要政策问题。我没有预料到 JEP 涉及的诸多主题会与我个人有关。

在开始担任编辑时，我已经 78 岁了，并且与我的合作者兼一生挚爱 Boaz Kahana 博士结婚 59 年。在我接受编辑职位后的四年里，新冠病毒（COVID）席卷全球，颠覆了老年人的社会关系。我的丈夫Boaz于 2020 年 11 月去世，我需要学会独自生活。对于大多数老年人来说，COVID 预示着一个孤独的时代（Groarke et al., 2020）。尽管 COVID 的急性期已经过去，但继续或减少与 COVID 相关的预防措施一事对于老年人来说仍然存在很多不确定性。我个人刚开始很少去餐馆吃饭，也很少邀请朋友来我家。

我也努力应对一系列因髋部关节炎引起的疼痛和行动不便而产生的致残性健康挑战。去年，我在等待 COVID 疫情减缓，以安排我的髋关节置换手术，这可能会增强我的活动能力并减轻疼痛。

我仍然以教授的身份全职工作，并且非常享受我的工作。由于行动不便和害怕感染 COVID，我请求本学期继续进行在线教学。让我所任教的大学允准这一请求并非易事，因为所有课程现在都恢复了线下授课。但最终，支持我的院长带来了好消息，我目前以网络的方式教授压力和应对（Stress and Coping）课程。我有 20 名学生，指导他们是我每周的重头戏。我还继续指导博士生并从事我的研究。当我为本期 JEP 撰写这篇社论时，我意识到我的工作和生活经历在多大程度上交织在一起。我还意识到，个人观点能加深对医疗相关问题和挑战的理解。

2022 年 7 月中旬，我在费城进行了推迟已久的髋关节置换手术。目前，我正渴望康复并完全恢复活动能力。我对独立行走和再次旅行抱有积极的愿景。我的脚仍然有点不稳，但最近已经从助行器过渡到拐杖。本期JEP聚焦于“老年人在晚年的医疗保健获取和医患互动”，因此与我的生活经历密切相关。

本期收录的文章应对了老年患者在摸索复杂的医疗系统方面的经历。这些文章都认可的是，老年患者正面临一个与其早年生活经历和期望差异巨大的官僚系统（Rourke, 2021）。我将通过分享我作为一名接受髋关节置换手术的81岁女性的生活经历来介绍我对这些问题的探讨。

正如我之前提到的，我决定在我的小儿子Michael和他的家人所居住的费城进行手术。他知道一位出色的骨科医生Javad Parvizi博士。我在费城

而不是克利夫兰接受手术，这确保了我可以获得高质量的正规医疗服务，并且可以近距离接触家庭护理人员，因为我的大儿子Jeffrey也会在费城待一个月，而他的孩子们则参加了夏令营。

罗斯曼中心隶属于Parvizi医生执业的杰斐逊医院，是一个繁忙的骨科中心，散发着乐观的气息。在我短暂的两天住院期间，我得到了很好的照顾。出院后，我在儿子家附近的 Residence Inn 酒店休养了三个星期。我在休养期间使用助行器，并且最初需要帮助才能上下床。在康复期间，我从一家推荐的家庭护理机构聘请了家庭护理人员，以便在家人不在时帮助我。

夜间护理人员从晚上 9 点开始轮班 12 小时至上午 9 点。日间护理人员从上午 9 点工作到下午 5 点。护理人员帮我穿好衣服，让我在大堂散步锻炼身体。我每小时向该机构支付 30 美元，每天花费 600 美元，一共支付了17天，也就是总的自付人员成本为 10,800 美元。家庭护理人员很可能只得到这笔费用的一小部分。大多数护理人员是美国移民。有些来自巴哈马群岛，有些来自尼日利亚。她们都是有家庭的已婚妇女，并且积极参加教会活动。

大多数护理人员在被特别要求时都会提供帮助。只有少数人主动帮忙洗澡或就餐。夜间助理最初帮助我上下床，让我步行去洗手间。随着我在上下床时变得更强壮和更独立，他们通常让我自己动手，有些人问：“你还好吗？”。大多数夜间护理人员在客厅里看电视直到很晚，然后穿着衣服睡在我旁边的床上。如果我在晚上寻求起床帮助，大多数人都会醒来，响应我的请求。有几个睡得很香，我求助时也没有醒。后来我才知道，护理人员是要熬夜的，但心照不宣的是，大部分人都去睡觉了。我的日间护理人员花了很多时间与他们的朋友通电话。我的经历强调了付费护理人员提供支持一事的局限性。

回到克利夫兰的家后，我不再需要护理人员。当地医院的物理治疗师每周拜访我两次以帮助提升行走能力，每次大约半小时。每次拜访中只有几分钟的练习。治疗师使用一半的拜访时间检查我的生命体征。我最近开始接受看起来更专业的门诊物理治疗。治疗师陪我度过了整整一个小时，并解释了我所做练习的理由。

回顾我在手术后雇用护理人员的经历，证实了JEP所应对的关于老年患者难以获得悉心医疗关怀的担忧，尤其是在需要个人护理时。私人机构在监督护理人员时提供的监督和控制是有限的。即使是信誉良好的医院也难以确保家庭护理人员（例如物理治疗师）提供高质量的护理。

过去的个性化护理和持续护理几乎消失了，取而代之的是一个碎片化且注重成本的系统（Stange, 2009）。医生的护理通常被训练不足的医疗保健提供者所取代（Montenegro et al., 2011）。事实上，医生现在通常被称为众多的“提供者”之一。

不断变化的医疗服务提供模式

本期收录的文章还应对了医疗保健的碎片化及其对政策的挑战。为了深入描述这一问题，我们的期刊包括患者、研究人员和医疗保健提供者的观点。我们还继续发表由临床医生和研究人员撰写的多学科论文。在宏观层面上，本期JEP 还提供了有关“医疗保健和政策方面的区域差异和国际差异”的见解。我们的例证关注点包括：阿巴拉契亚地区未获得足够服务的人群、意大利的老年病学医生、以及最近在巴尔的摩被诊断出患有糖尿病的患者。

几篇论文基于患者的叙事并使用定性方法。这些文章呼吁关注当前的医疗保健系统在提供老年人友好政策方面的缺点。患者、医生和家庭护理人员之间的信任是成功医疗的一个重要且往往未被认可的要素。本期 JEP 包括对此类关系的深入纵向研究。鉴于老年患者的复杂需求，将非正式护理人员融入医疗保健团队一事能提高护理服务的成功率。我们收录的一项研究聚焦于医生对家庭护理人员可信度的感知，并识别了护理人员能提供强有力支持的领域。

长期以来，护理的连续性一直是描述对高质量医疗服务的可取性和期望时所使用的积极口头禅。大多数就业者（至少对美国中产阶级而言）从他们的工作场所获得健康保险，并从内科医生或家庭医生那里获得常规护理，这些医生隶属于城镇的一所主要医院。随着患者年龄的增长并出现慢性健康和行动不便问题，他们会寻求转诊到专科医生，以获取进一步治疗。不过，在过去十年中，医疗保健的提供发生了巨大变化，特别是自 2020 年 COVID 大流行爆发以来。获得与初级保健医生的线下预约变得更加困难，长时间的等待是现在最常见的情况。沟通已经演变为在线联系甚至是在线预约（Fox & Rainie, 2002）。医生的目视检查和评估已成为次要。鉴于对 COVID 的恐惧，尤其是老年人对 COVID 的恐惧，部分变化是可以理解的。

许多医院系统还鼓励患者通过 MyChart 等电子门户与医生沟通（Rainie & Fox，2000）。检查这些门户网站的工作通常留给文员，并且向医生提出的问题也越来越多地由助理处理。事实上，医师助理和执业护士已成为医疗保健提供者的主要角色（Kleinpell, Ely, & Grabenkort, 2008）。初级保健医生打电话通知患者检测结果的传统做法已经被搁置一旁。检测结果现在通过电子邮件传达，或者在必要时由不认识患者的医疗秘书传达。这种做法消除了患者与他们熟悉的医生保持联系和提问的机会。同样缺失的是来自长期倡导者的消除疑虑的保证。此处概述的变化发生在大流行之前和期间，并且显然使获得医疗保健一事更具挑战性。本期发表的文章反映了这些医疗保健挑战。

本期文章阐明了协调医疗保健服务提供一事的挑战

第一篇文章反映了医生提供个性化护理的愿望与提供此类护理所面临的障

碍之间的鸿沟。文章由两位医生和一位社区卫生主任撰写，他们分别为医学博士 Stange、医学博士 Gaglioti 和工商管理硕士 Bindas。文章巧妙地描绘了综合医疗保健对老年人的好处。这篇文章的独特之处在于探究和诠释了三个案例研究，作者在这些案例研究中分享了对管理老年患者健康一事的个人看法。文章的后半部分以这些案例研究为基础，分享了一项调查的结果，调查的问题为“医疗保健中什么最重要？”。从这项调查中，作者识别了一系列护理领域，这些领域“透过接受或提供护理的人的视角，代表了高质量初级保健的要素”。

这些期望包括初级保健的可及性、对整个人的关注、以及将家庭考虑在内。这涉及与患者逐渐建立关系，了解患者护理的最重要方面，优先考虑医疗团队之间的沟通以管理多种慢性疾病，成为患者的倡导者，以及注重预防而非治疗。这些领域鼓励医疗保健提供者充当多面手，以便其识别问题并优先考虑相关行动以促进健康和康复并为个人提供个性化护理。作者在结论处提出了政策建议，用于促进初级保健、以关系为中心的护理模式、以及非还原论研究方法。

针对老年人的医学专业知识以老年病学家提供的护理为代表。Degiuli 博士的文章考量了美国和意大利老年病学医生的角色，提供了关于老年护理的跨文化视角。基于对老年病学家的定性访谈和老年病学会议参与者的观察，作者探究了这些受过专门训练的医生在急症和长期护理环境中发挥的作用。她的结论认为，意大利和美国的老年病学家数量都非常有限。这种在老年患者所需的长期护理方面接受过最高级培训的医生的代表性不足，为这一群体服务不足的特征提供了一个独特而重要的解释。Degiuli 呼吁宏观层面的解决方案，以便为晚年的慢性病提供更好的护理。

由Chard博士、Girling博士、Harris-Wallace博士、Henderson博士、Roth博士和 Eckert博士在本期 JEP 中撰写的文章聚焦于糖尿病诊断途径和对卫生政策的启示。2 型糖尿病是一种令许多老年人担忧的慢性病。虽然筛查和预防是文献中的常见主题，但诊断过程却往往被忽视。这篇重要的文章探究了老年人发现自己被诊断出患有糖尿病的途径。通过使用 47 位黑人和白人老人的叙事，作者揭示，参与者（即这些老人）在经历了健康事件和/或经历了令人担忧的症状（例如，驾驶时失去知觉）后才知道他们的疾病。令人惊讶的是，只有 13% 的参与者在年度医疗保健访问期间被诊断出糖尿病。其他诊断途径是通过工作场所或社区检测。在所有情况下，参与者似乎都对诊断结果措手不及。文章呼吁关注在健康事件发生之前进行诊断一事的重要性，以及提供筛查机会的必要性，尤其是在服务欠缺的社区。

Minakshi 博士和Rao撰写的文章研究了医生对家庭护理人员的信任这一未被充分研究但十分重要的话题。作者利用对 20 名医生的定性访谈，探究了其如何建立对家庭护理人员的信任、其如何感知护理人员是否信任他们、文化在信任建立中的作用、以及将护理人员融入医疗团队一事的感知障碍和促进因素。作者的研究结果表明，医生对家庭成员信任度的评估包括能力、忠诚度和可靠性。医生的感受是，如果其认为护理人员能够执行

与患者需求相关的任务，能为患者进行倡导，并且似乎参与了患者护理，那么他们就可以信任家庭护理人员。在感知护理人员对医生的信任方面，医生利用语言信号（表达感激之情）和非语言暗示（肢体语言），并注意护理人员提问的方式。此外，医生认为，如果他们对患者具有文化敏感性，那么护理人员往往会信任他们。远程医疗访问和使用 FaceTime 有助于让家庭成员参与到患者的护理中。最后，当医生表示他们信任其他医生的客观数据，但家庭护理人员能够让他们更清楚地了解患者的症状并提供背景信息时，家庭护理人员的重要性便得以展现。Rao 和 Minakshi 最后提出了一系列政策建议，用于支持将家庭护理人员融入医疗保健关系中。

博士Hicks Patrick、文学硕士Pullen、理学学士Ibrahim-Bacha、和博士Spencer考量了阿巴拉契亚农村中地点和功能性障碍之间的重要联系。通过使用美国疾病控制和预防中心（CDC）行为风险因素监测系统（BRFSS）的数据，作者探究了健康的人口社会决定因素（年龄、性别、教育和收入）如何影响西弗吉尼亚州4,867 名成年人的医疗保健获取和功能性能力。他们的分析表明，男性、年轻和较低的收入与“更难以获取医疗服务”一事存在联系。在功能性能力方面，只有收入会影响一个人的功能性水平。此外，更多的医疗保健机会与较低水平的功能性能力相关，这表明更多的医疗保健机会导致更多的诊断和护理。作者认为，这些结果可能表明：扩大的医疗补助覆盖面和其他社会项目正在惠及预期的接受者。他们的文章强调了在人口老龄化的西弗吉尼亚等州继续扩大医疗补助计划的重要性。他们还强调，医疗补助计划应该包括预防而不仅仅是治疗，以便让当下的年轻人和中年人在以后的老年生活中防止功能性障碍。

Bravo博士、Gutierrez博士和Levy-Storms博士在一项老年病学项目中应对了患者-提供者关系（PPR），该项目服务于患有多种疾病的、在外国出生的老年拉美裔人。在为期一年的时间里，在三个不同的场合用西班牙语对13名讲西班牙语的患者进行了深度访谈。医患关系是建立在“技术知识、信任和倡导”这一等级顺序的基础上的。随时间推移，那些具备最佳关系的医生表现出专业知识、信任和倡导。因此，良好的医患关系需要医生代表患者采取建设性行动。这些研究发现支持Clarke、Bennett 和Korotchenko（2014）的研究，后者的研究中，患者报告称其得到的护理不足，这归因于医生的个人失误和医疗咨询的限制。

医疗保健政策不断演变的性质

在考量本卷 JEP 中的不同观点和医疗地点时，让人印象深刻的是医疗保健的共性以及所识别的不足之处，后者需要创新政策。同样令人印象深刻的是，医疗服务提供（尤其出现在晚年生活）研究的定性和定量方法所体现的价值。我们还学会重视家庭成员和其他非正式护理人员在影响老年人健康和功能方面所发挥的作用。

老年服务是通过一系列改进计划和不断变化的机会相结合而发展的，认识到这一点很重要。许多服务并不反映所规划的政策，而是反映组织和专业

的演变。在考量本卷 JEP 中的不同观点和医疗地点时，让人印象深刻的是医疗保健的共性以及所识别的不足之处，后者需要创新政策。我们还注意到定性和定量方法对医疗服务提供研究的价值，尤其是当它发生在晚年时。我们还学会重视家庭成员和其他非正式护理人员在影响老年人健康和功能方面所发挥的作用。家庭护理人员在护理关系中的投入是难以从付费护理人员处获取的。

令我们欣喜的是，我们的出版物保留了国际视角，关注不同文化背景下的老年人和医疗保健提供者。我们承认文化差异，但也对跨文化的共性印象深刻。特别地，医护人员加大提升老年患者的护理满意度一事的重要性似乎存在相似之处。即使在医疗保健服务提供方面取得了进步，医疗保健的相关方面在老年中仍占据着最重要的地位。向老年人提供医疗保健一事似乎仍然存在缺陷。在集体解决方案尚未普遍存在的情况下，老年人的个人主动性具有很大的价值（Kahana, Kahana, & Lee, 2014）。

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Integrated, Personalized Care for Older People

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Abstract

Medical science has made magnificent advances by dividing complex problems into their component parts. The strength of clinical trials, and the resulting evidence-based clinical guidelines, is that they isolate a particular phenomenon or therapy from its context to assess its effect without the confounding of diverse contextual factors. However, the health and health care of whole people, and particularly older people who often live with multiple chronic conditions, is context-dependent. Older people are not well served

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by the current fragmented medical knowledge and organization of health care, which is impersonal, often ineffective, and dangerous. More helpful approaches to health care for older people begin with the whole of the person in their family and community circumstance, and then examine the parts of people (including individual strengths, as well as diseases and disabilities) in context.

We interpret three case studies in light of research on what patients and primary care clinicians say matters in health care. What matters are 11 domains of care: accessibility, a comprehensive, whole-person focus; integrating care across acute and chronic illness, prevention, mental health, and life events; coordinating care in a fragmented system; knowing the patient as a person; developing a relationship through key life events; advocacy; providing care in a family context; providing care in a community context; goal-oriented care; and disease, illness, and prevention management.

The health and health care of older people requires contextualized knowledge and personal knowing, supported by integrated systems that treat health care not as a commodity, but as a relationship.

Keywords: health services for the elderly, primary care, care integration

Atención Integral y Personalizada a Personas Mayores

Resumen

La ciencia médica ha hecho magníficos avances al dividir problemas complejos en sus componentes. La fortaleza de los ensayos clínicos y las guías clínicas basadas en evidencia resultantes es que aíslan un fenómeno o terapia en particular de su contexto para evaluar su efecto sin la confusión de diversos factores contextuales. Sin embargo, la salud y el cuidado de la salud de las personas, y en particular de las personas mayores que a menudo viven con múltiples afecciones crónicas, depende del contexto. Las personas mayores no están bien atendidas por el actual conocimiento médico fragmentado y la organización de la atención de la salud, que es impersonal, a menudo ineficaz y peligrosa. Los enfoques más útiles para la atención de la salud de las personas mayores comienzan con la persona en su totalidad en su familia y circunstancias comunitarias, y luego examinan las partes de las personas (incluidas las fortalezas individuales, así como las enfermedades y discapacidades) en contexto.

Interpretamos tres estudios de casos a la luz de la investigación sobre lo que los pacientes y los médicos de atención primaria dicen que importa en la atención médica. Lo que importa son 11 dominios de atención: accesibilidad, un enfoque integral de la persona en su totalidad; integración de la atención en enfermedades agudas y crónicas, prevención, salud mental y eventos de la vida; coordinar la atención en un sistema fragmentado; conocer al paciente como persona; desarrollar una relación a través de eventos clave de la vida; Abogacía; brindar cuidados en un contexto familiar; brindar atención en un contexto comunitario; atención orientada a objetivos; y gestión de enfermedades, dolencias y prevención.

La salud y el cuidado de la salud de las personas mayores requiere conocimiento contextualizado y conocimiento personal, respaldado por sistemas integrados que traten el cuidado de la salud no como una mercancía, sino como una relación.

Palabras clave: servicios de salud para la tercera edad, atención primaria, integración asistencial

为老年人提供综合的个性化护理

摘要

医学通过将复杂的问题分解成不同的组成部分，进而取得了巨大的进步。临床试验以及由此产生的循证临床指南的优势在于，它们将特定现象或疗法从情境中分离出来，以评估其效果，并且不会混淆各种情境因素。不过，全民的健康和卫生保健取决于具体情况，这对经常患有多种慢性病的老年人而言尤为如此。当前碎片化的医学知识和对医疗的组织无法很好地为老年人提供服务，这种对医疗的组织缺乏人情味，通常效率低且危险。更有帮助的老年医疗保健方法从家庭成员和社区环境开始，然后在情境中分析人的各个部分（包括个人优势、疾病和残疾）。

根据有关“患者和初级保健临床医生认为的重要医疗保健问题”的研究，我们解释了三个案例研究。重要的11个保健领域包括：可及性、详尽的全人关注、急性和慢性疾病、预防、心理健康和生活事件的护理一体化、在分散的系统中协调护理、从人的角度看待患者、通过重要的生活事件发展关

系、倡导、在家庭情境中提供照护、在社区情境中提供照护、目标导向的护理、以及疾病和预防管理。

老年人的健康和医疗保健需要情境化的知识和个人关怀，并得到综合系统的支持，这些系统将医疗保健视为一种关系，而不是商品。

关键词：老年人健康服务，初级保健，护理一体化

Introduction

Healthcare in the U.S. is increasingly fragmented and impersonal (Bergman et al., 2020; Cebul et al., 2008; Hu et al., 2022; Hughes et al., 2020; Stange, 2009a; Stange, 2021). To be sick and old and in need of care often feels lonely and scary (Bayliss et al., 2014; Boult & Wieland, 2010; Kim & Rich, 2016). Amidst flashes of technically brilliant procedures and sparks of personal humanism, the U.S. healthcare is a system designed to deliver commodities rather than to develop relationships (Heath, 2006; Knai et al., 2018; Loxterkamp, 2016; Stange, 2016). The fragmented, frustrating, and depersonalizing aspects of U.S. health care pertain to both those in need of care and those trying to provide it (Horwitz et al., 2013; Rotenstein et al., 2018; Shippee et al., 2018). At the macro level, the U.S. system is the most expensive in the world, while producing a population of below average healthiness and unconscionable inequities (Ellner & Phillips, 2017; Starfield, 2011; Woolf & Schoomaker, 2019).

Moreover, there is a growing sense that many of our efforts at improvement are making things worse (Bujold, 2015; Casalino, 1999; Fisher & Welch, 1999; Ganz et al., 2007; Goodson, 2007; Harrison et al., 2007; McDonagh & Hurwitz, 2003; McDonald & Roland, 2009; Milstein & Shortell, 2012; Wachter & Shojania, 2000; Weyer et al., 2008). Over the past four decades, the U.S. system has moved away from a base of largely independent, small, local care, organized around relationships, reputation, and place. These local systems often were paternalistic, lacked transparency and had no centralized means for knowing about the quality of care. But they have been replaced by consolidated vertically integrated healthcare systems organized around administrative and technological accountability, “productivity,” and pay-for-performance metrics, characterized by rising patient dissatisfaction and workforce moral distress and burnout, with the personal paternalism of the individual physician replaced by the impersonal paternalism of administrators and algorithms (Miller, 2021). The worship of technology and specialism has led to fragmentation and unsustainable costs. The Chronic Care Model (Coleman et al., 2009; Wagner, Austin, et al., 2001; Wagner, Glasgow, et al., 2001) and systematic evidence of the power of prevention (Glasgow et al., 2001) have fostered a "proactive" approach (Bensken et al., 2021; Glasgow et al., 2001) to delivering commodities of care that measures and incentivizes quality of care one-disease-at-a-time, and leaves little time or space for patients' and families' lived experience (Bayliss et al., 2014; Heath et al., 2009).

Into this hurried space, an aging population with multiple chronic and acute illnesses, preventive opportunities, family needs, and social context, faces a growing need for integrated, personalized care amidst a declining sense of being known as a person (Aungst et al., 2019). A recent cross-sector initiative examining the needs of people living with multiple chronic conditions identified the importance of attending to multilevel contextual factors to generate and act on the new knowledge needed to provide personalized, integrated care (Bayliss et al., 2014).

In this paper, we explore opportunities for integrating and personalizing care for older people. We begin with three stories from the authors' personal experience. Then we examine relationship-centered care based on new research from the perspective of clinicians and patients. We close with a discussion of policy possibilities for creating a health system environment in which being known and cared for as a person is a regular possibility.

Case Stories

Serving as an Entrée Point and a Buffer (Anne Gaglioti)

For many years, I took care of my patient Mr. P, whom I met at the community correctional facility where I had developed a program that provided care and aided in the transition out of prison. I continued to care for him once he was back in the community, at my clinic at the University Hospital. He was a complex person—not just because of a laundry list of medical and mental health problems: chronic kidney disease, bilateral below the knee amputations, coronary disease, tobacco use, antisocial personality disorder, insulin dependent diabetes, but also because he tended to get admitted to the hospital a lot and caused trouble when he was there. He wanted to go out to smoke on the telemetry unit; he would trash his hospital room; he would threaten the nurses. Mr. P had burned bridges with his friends and family. Eventually, even the relationship with his mother became eroded. He would still come to see me, though, and I would see him when he came.

One of the residents asked me once how I managed to be his doctor without becoming frustrated. I told her I did become frustrated, but I figured if he was showing up, then I would show up, too, and offer a clean slate of possibilities each time. I told her I suspected I was his most stable relationship and knowing someone was there for you is very good for your health. I remember being in one of many meetings in a hospital conference room with a nurse manager and the psychiatry team about his behavior, the psychiatrist, who I respected, got frustrated with me and said, "You know, he doesn't care at all about you." I was puzzled, because to me, it wasn't my business whether he cared about me or not. We showed up for each other; he came to see me, and I came to be his doctor. I moved out of state and handed off his care to a truly open-hearted colleague and friend; the transition went well. About a year later she called to tell me he had died. I cried and wondered out loud to her if anyone else grieved his death. "I thought you would want to know," she said. I did.

This story highlights a few aspects of primary care that allow clinicians, patients, and communities to thrive. The first aspects are knowing and autonomy. I knew that this barrier existed to care for people in my community, and I had a belief I could help to build a path to care where there wasn't one before. Another aspect is connecting and boundary spanning to work across sectors. I knew I couldn't build that path alone, and we convened and built connections with those who were needed to get the job done. A third aspect is continuity of relationships over time. The continuity that led to trust with community partners was foundational to the success of the effort, and the continuity of care with the individual patients was transformative both for me and for them. It laid the foundation for meaning, healing, and safety to take place (Lynch, 2021). Lastly, this story illustrates the power of abiding, the ability to be and to stay with woundedness (Scott et al., 2008). I think this is the most powerful of these aspects because it is anathema to the existing health care paradigm, and requires a letting go of our ego as physicians. But, when we can do it, it is worth it—surrendering to abiding is transformational for the clinician and the patient. Sometimes, when we let go of the need to fix or control and allow ourselves and our patients time to be with what is, we find the spark of healing.

A Geriatric Physician Assistant Steps in **(James Bindas)**

My father, a veteran of the Korean Conflict, age 89, and my mother, age 92, lived in the same home for 60 years. They were determined to age-in-place. I lived in the same city, worked full-time, and wanted to honor their wishes. However, I was challenged trying to manage their care. In particular, the growing physical and psychosocial needs of my father.

As my father's unpaid caregiver and having worked in an administrative capacity in several healthcare organizations, I thought I knew what to expect: attendance at doctor's appointments, making sure he took the right meds at the right time, and fulfilling transportation needs. I did not realize how much more was involved, from helping to manage multiple medical conditions and multiple medications with adverse side effects. My father's growing cognitive impairment forced us to revoke driving privileges, pursue guardianship, and deal with other safety and legal issues.

My father's healthcare provider of choice was our local Veterans Affairs Medical Center (VAMC). As with most large healthcare systems, I had come to expect delays: delays in obtaining appointments, delays in accessing in receiving ancillary services and specialty care. The only thing that seemed timely, with these and other systems, were the bills. Adding in the additional complexities of a government system led me to wonder if my father would receive the timely care he needed in a coordinated fashion to have the desired effect on his wellbeing and quality of life.

I realized I was clearly in over my head.

That is until I met TW, a geriatric physician assistant associated with the VAMC, whom I found to be my father's strongest advocate.

During each clinic visit, I observed the rising number of sick patients, strained resources, and lack of support personnel. Overworked and under-supported, TW nevertheless was always pleasant, personable, and professional, despite my father's bigoted attitude and disdain at being treated by a female practitioner. TW never wavered in her focus on treating my father as a whole person, acting as a true advocate—coordinating needed specialty care even, when at my request, the care was delivered outside the VAMC system. At every visit, TW took the time to ask how my mother was doing, to ask how I was doing as a caregiver. She made me feel as though she understood what I was going through and related her own personal experience with her mother. This personal sharing anchored me as my father's condition deteriorated. She even went as far as to provide me with a mini exam (and notes to share with my personal physician) when she could tell I was struggling with some of my own chronic health issues. She was a beacon in a storm, guiding me through a process I was not yet ready to acknowledge—becoming a trusted confidant and a powerhouse of knowledge, gently "forcing" me to recognize what was becoming inevitable. What astonished me was that she did all of this while working for a largely bureaucratic organization. I expected to experience a hierarchy, with processes based on policy, procedure, and specifically defined responsibilities. What I got was a professional who was flexible, adapted her thinking, by bringing innovation and creativity into play, to meet my father's individual needs.

TW's focus was on improving the quality of care delivered. She set goals, helped develop actions for meeting those goals, and connected and collaborated with other organizations. TW provided access to care by giving me her cell phone number. She engaged my father and our family and guided us through the complex healthcare system. As an active participant in my father's care, I was involved decision making and felt free to share information, express opinions about different treatment methods, and accept TW's recommendations.

It has been just over a year since my father passed away. We had a complex relationship for most of my adult life. TW revealed life-changing insights that made my father's final journey peaceful—we were able to talk about how much we loved each other. Through her lived experience, TW provided wisdom on how to approach the ever changing physical and cognitive needs of my father—wisdom gained from her personal struggles as she cared for an aging parent, as well as caring for many patients. TW took the time to listen, to help me understand my own fears and provided me the support I needed to make some difficulty decisions. Most importantly TW reminded me that we are all human and encouraged me to talk to my father from the heart and not let my own baggage get in the way.

Taking a step back and looking at our healthcare landscape, I realized our immense population, complete with a large aging sector, is facing increasingly complex chronic diseases, comorbidities, and social determinants of health that cause healthcare delivery to look different than it did in the recent past. Healthcare professionals need to work inter-professionally, rely on the strengths of advanced practice providers, and allow those who have earned the credential to practice at the top of their license and ability. I found myself acknowledging the special skills of those who practice geriatric medicine. I also came to realize that geriatric medicine is multi-faceted due to the complexities of chronic health conditions, frailty, dementia, changing psychosocial conditions and serious illnesses that lead to frequent hospitalizations. Geriatric patients need, and deserve, clear and compassionate communication, coordination, and teamwork not only from their medical providers, but from family and other caregivers.

As I reflect on the last year of my father's life, I have come to realize that TW's actions can be part of the sustainable solution to "fix" our broken healthcare system. People feel lost in today's healthcare system. TW's approach fostered connection and shed a new light on the broken healthcare processes that stand between providers and patient care. To me, her words and actions acknowledged that being a physician assistant, obtaining the training and having the opportunity to transform her patients' lives, is a privilege. She acknowledged how much she learned from me, and from her other patients and their families, and how that made her a better person (and clinician).

My father's end of life care, and my ability to provide the support he and mother both needed, would not have had the same impact had it not been for the guidance and support of TW. Her compassion and caring are powerful tools. She touches the souls of her patients, and their families—a gift she gives to all who entrust her with their lives.

Being There (and not)
(Kurt Stange)

I cared for two eponymous retirees, Jim and Doris Bauer for many years, providing routine care (Kurt C. Stange, 2009). For Jim this consisted of managing his high blood pressure, nagging him about his cigar smoking, and caring for various musculoskeletal complaints from his work on his boats and his garden. For Doris, it included helping her to get on with walking their dog or playing bridge while she dealt with her diabetes, hypertension, hypothyroidism, and arthritis; for both, looking for teachable moments to work a little more regular physical activity into their routines, and more veggies and less animal fat and sugar and calories in their eating.

Sometimes seeing people over time, the familiarity can allow the doctor and patient to know when to let things go. Sometimes it can breed complacency. Other times, it provides a sense of when something that appears routine is not quite right and is worthy of looking into a bit more. But just as often, this duet of knowing and being known can provide hunches on both sides of when it is important to pay particular attention.

Jim had a good story about a new onset of pain in his upper back that started after overworking in the garden. But after two weeks of ice packs, daily ibuprofen and two physical therapy appointments, it was no better. When he came in for follow up, I could feel the spasm in the muscle between his spine and his shoulder blade. Jim had laid off yard work and even stopped puttering around on his beloved boat, so I knew this pain was really irritating him.

There are a lot of organs in that area—muscles, shoulder, spine, nerves, heart, lungs, and esophagus. Each organ has its own specialist who would be happy to see if their organ of interest was the culprit. But getting the answer "not my table," if I chose wrongly, didn't seem like a good option. It still looked like a muscle spasm, but something didn't seem quite right.

I gave Jim a few more stretching exercises to try, and gave Doris instructions to call to schedule Jim a CT scan of the chest and back. A week later, the radiologist paged me to say we "got our money's worth from the CT scan." I called Jim's house to ask if I could bring over the pictures after supper. I took my time walking up the front path, as Jim and Doris watched me through the screen door.

I showed Jim and Doris the cross-sectional picture on the CT scan, and pointed to a round, white blob—an enlargement of the aorta carrying blood from the heart to the body. Jim's aorta measured 7 centimeters in diameter—already larger than the usual 6-centimeter threshold for operating to prevent a catastrophic rupture.

Somehow, Jim knew to ask if there was anything else.

Yes, there is a lump on the left kidney, about 3 centimeters in diameter. This was found by accident, but most likely was a cancer of the kidney. I doubted this had anything to do with the back pain, but the kidney needed to come out. (You can live fine with just one kidney.)

Shaking, Doris asked "What do we need to do?"

"There is something more," I ventured, pointing to a poorly defined grey area. "A thickening of the esophagus, in the right location to be causing the back pain."

"What is it?" Jim asked.

"Possibly another cancer."

Now Jim sat down. Doris moved her chair close and held his calloused hand. "What do we need to do?" she asked again, but the shaking in her voice and hands had gone.

I reviewed the situation. "First, we need more information. We have found two things that could be causing the back pain. I still think the pain is from muscle spasms. But rather than being caused by overworking in the yard, the spasm may be caused by the aortic aneurysm or the esophageal thickening. We need to find out what the thickening is."

"Okay" said Jim and Doris together.

I arranged for a visit to a gastroenterologist to take a biopsy of the esophagus, and a chest surgeon for advice about the aneurysm, and coordinated with them and the physical therapist.

The biopsy showed esophageal cancer, and I arranged for an oncologist to do chemotherapy before the chest surgeon removed the tumor. Together, Jim, Doris, the chest surgeon, and I weighed the pros and cons of operating on the aneurysm and decided to hold off on an operation that could kill Jim or leave him paralyzed from disrupting the blood vessels that go to the spinal cord. After his recovery from chemotherapy and chest surgery, I arranged for Jim to see a urologist, who removed his cancerous kidney. I'd tried to get him to do it at the same time as Jim was under anesthesia for the esophageal surgery, but the surgical approaches were so different it didn't make sense.

Over the next three years, to minimize the risk of the aneurysm rupturing, I used multiple medications to lower Jim's blood pressure until he started to feel dizzy, then backed off, keeping the pressure as low as he could tolerate. Twice I hospitalized him for urgent blood pressure control when his back pain ominously returned, consulting the surgeon to confirm that an operation wasn't needed.

Sometimes, Jim had problems swallowing when the scar thickened where the surgeon hooked Jim's stomach up to the back of his throat after removing the esophagus. When this happened, I asked Jim to see the gastroenterologist for a dilation procedure. Not surprisingly, Jim had horrible acid reflux. When nothing else helped, I work with Jim's son, who lived in Canada, to get a new drug recommended by the gastroenterologist but not yet available in the U.S. It helped.

I helped Jim formulate his wishes in a living will and cared for the effect of his illness on Doris, integrating care of her anxiety and insomnia with management of her diabetes, hypertension, hypothyroidism, and arthritis. I tried to make one medication work for her anxiety, insomnia, and arthritis pain, rather than using a different medication for each, and encouraged lifestyle change over medication when possible. When Jim's blood pressure gradually increased, it served as a malleable moment to encourage positive changes in

Doris. They began daily walks, which helped their high blood pressure and arthritis, and reduced Doris' medication needs. It also gave Doris and Jim quiet moments to try to find meaning from Jim's illness and from a long life together that now seemed more finite.

Then, early one morning when I was out of the country on a research trip, Doris awakened to find Jim shuddering, then unmoving and unconscious next to her in bed. She called my house. My wife told her to call 911. Even today, I wonder if I had been there, if we would have been able to say that this is the end and avoid what followed. However, in my absence, Jim's chest was compressed, and his lungs ventilated. Because of his dire condition, the ambulance crew was required to take him to the nearest hospital where the physician covering for me was not on staff, and where Jim was not known.

After anticipating for years that an event like this would be caused by the aneurysm rupturing, a CT scan showed no leakage. The aneurysm was fine, but Jim was not. The intensive care specialist called in a neurologist who declared Jim brain dead. Surrounded by strangers, Doris and their children allowed Jim's life support to be turned off, and he died.

What Care Do Older People Need?

Geriatrician Amasa "Buzz" Ford, MD, one of the originators of the widely-used Activities of Daily Living (ADL) measure of function (Katz et al., 1963), was a big proponent of primary care. When asked about this, he said, "Older people need what family doctors do."

The stories above give a sense of what is involved in the generalist approach embodied in primary care (Gunn et al., 2008; Kurt C. Stange, 2009). It begins with a comprehensive focus on the whole person in their family and community context, then uses that broad focus to provide the majority of care, selectively involving those with narrower expertise when that is likely to be helpful, and coordinating multiple sources of care (Donaldson et al., 1996; Starfield, 1998). It is based on treating health care as a relationship (Colwill et al., 2016; Green & Puffer, 2016; Miller, 2016; Rudebeck, 2019; Scott et al., 2008; Soubhi et al., 2010), not just as a commodity (Heath, 2006; Lown, 2007; Stange, 2016; Sturmberg & Cilliers, 2009)—getting to know people over time (Bazemore et al., 2018; Ford-Gilboe et al., 2018; Olaisen et al., 2020; Team, 2017), and by being available during critical life events (Mainous et al., 2004). That knowledge of the person in context allows them to help the older person and family to prioritize the most important aspects of care, taking a life course perspective and integrating care across multiple chronic illnesses, acute concerns, preventive opportunities, mental health, and family care (Stange, 2009b). Ideally it involves communication, rather than diffusion of responsibility, among health care teams (Balasubramanian et al., 2010; Bolen & Stange, 2017; Chesluk & Holmboe, 2010; Cohen et al., 2020; Friedman, 2021; Hoff et al., 2021; Jabbarpour, 2016; Pany et al., 2021; Rodriguez et al., 2007; Sinsky et al., 2010).

What Matters in Health Care?

To try to understand what matters in health care, we went to the source, and asked hundreds of people receiving and providing care, and a smaller number (about 80) of people paying for care. We asked, “What matters? What is important in health care? How do you know good care when you see it?” Each respondent generated about a dozen ideas, and a multidisciplinary team carefully analyzed the responses to identify themes (Starfield III Summit, October 4-6, 2017). The identified attributes of what matters then were vetted and interpreted in a 2½ day workshop among 70 national and international health system leaders with diverse perspectives. In this Starfield III Summit, participants shared personal, research and policy experiences, surfacing multifaceted mechanisms by which primary care can foster personal and population health, healing, and systemic value (Starfield III Summit, October 4-6, 2017).

In analysis of responses from the surveys and of the work by the Starfield III Summit participants, we identified eleven domains of care that represent the essence of high-quality primary care, from the perspective of those receiving or providing care. We developed an 11-item patient reported measure and assessed its validity and reliability. The resulting patient reported Person-Centered Primary Care Measure (PCPCM) has been translated into 28 languages (Larry A. Green Center for the Advancement of Primary Health Care for the Public Good; Tse et al., 2020; Zyzanski et al., 2021). It is freely available (Etz et al., 2019; Larry A. Green Center for the Advancement of Primary Health Care for the Public Good), and recently was endorsed by the National Quality Forum and by the Center for Medicare and Medicaid Services for use in measuring high value primary care in quality performance programs.

The headings below identify these 11 domains, followed by the *italicized actual question* from the Person-Centered Primary Care Measure. Below each heading, we consider the role each of these interacting domains in providing integrated, personalized care for older people.

Accessibility

The practice makes it easy for me to get care.

One of the great needs of older people is to be seen at early, undifferentiated stages of illness when interventions often are most effective (Donner-Banzhoff, 2018; Lin et al., 1999). Even when the diagnosis is not readily apparent, time and therapeutic trials may be used until things become clear (Donner-Banzhoff & Hertwig, 2014; Heath, 1995).

One of the problems with the shortage of primary care in the U.S. (Cohen, 2022; Steinbrook, 2009) and the imbalance of generalist to specialist clinicians (Kindig, 1991; Starfield, 2006; Starfield, Lemke, et al., 2005), is that it often takes weeks to get an appointment, and this fundamental advantage of primary care is lost. In addition, as the Chronic Care Model gained dominance (Coleman et al., 2009; Wagner, Austin, et al., 2001; Wagner et al., 1996a, 1996b), and care became more and more organized around helping people to manage their chronic diseases (Bensken et al., 2021), the idea that primary care should be available to people during their acute illnesses has fallen by the wayside in how health care is organized, with people being told to go to urgent care or the emergency department (Bensken et al., 2021; Johansen et al., 2016).

The decisions that health care systems make regarding accessibility show the trade-offs among these 11 domains of care that matters. Often heath care systems prioritize accessibility to any clinician over continuity of care with someone who knows the patient (Day et al., 2013). Thus, even if accessibility is good according to the metrics that systems use to assess it, that accessibility means being able to see a nurse practitioner or physician assistant or urgent care physician who doesn't have the needed relationship and context to provide personalized care, and often orders additional tests that someone who knows the patient wouldn't (Kahana et al., 1997).

In the second case story, TW enhanced Mr. Bindas' access to care by being personable and professional, even when her patient was off-putting. She gave his son her mobile phone number which allowed him to get advice that averted crises, avoided unnecessary visits, and led to earlier visits when she was able to identify a problem by phone.

A Comprehensive, Whole-Person Focus

This practice is able to provide most of my care.

Primary care can take care of approximately 90% of what brings people in for health care (Stange, Zyzanski, et al., 1998). The advantage is not only efficiency, but the ability to see each part of a person's care as an aspect of a larger whole (Stange, 2002, 2010b). This enables many of the other domains of high value care described below.

As care has become more and more specialized, and as even generalists' scope of care has diminished (Jetty et al., 2019; Kraus & DuBois, 2017; Loxterkamp, 2019; Peabody et al., 2018; Russell et al., 2021), this ability to see and act on the whole has been hampered, along with the trust and relationship development engendered by beginning care with the broadest possible question – What is wrong and what can I do to help? (Jonas, 2020; Lee et al., 2019) vs. Do you have what is in my scope to treat? (Bayliss et al., 2014).

A recent study (Gray et al., 2022) found that the large majority of newly trained general internal medicine physicians are becoming hospitalists, and the majority of general internal medicine physicians who are not hospitalists see only outpatients. The ability to have a single physician who knows the patient and provides care in both the inpatient and outpatient setting is rapidly becoming a thing of the past, with obvious consequences for the efficiency and effectiveness of care (Jetty et al., 2019).

The comprehensive care provided in all three of the case stories both avoided unnecessary emergency department and specialist visits and fostered early care of serious illness. More subtly, a comprehensive scope of practice allowed the clinicians to focus on meeting the needs of the whole person, and engendered trust by being trustworthy.

Integrating Care Across Acute & Chronic Illness, Prevention, Mental Health, & Life Events

In caring for me, my doctor considers all of the factors that affect my health.

Evidence-based guidelines, on which clinicians are evaluated for their quality of care, are based on scientific evidence from clinical trials that typically exclude people with co-morbid conditions (Fortin et al., 2006). And yet, most older people, and most people coming in for primary care, are living with multiple chronic conditions (Fortin et al., 2005; Hu et al., 2022). Optimizing care for one disease at a time is one of the major reasons for older people taking many drugs, leading them to experience exponentially growing possibilities for adverse interactions, and unsustainable cost and complexity (Burt et al., 2018; Doherty et al., 2021; McCarthy et al., 2017; Muth et al., 2019; Sasseville et al., 2019; Wehling, 2011).

Primary care clinicians look for a single medication that can help with multiple diseases, and they look for behavioral and other cross-cutting therapies effective in preventing and treating multiple conditions (Sturmberg et al., 2021). They use acute illness care as an opportunity to identify teachable moments for health behavior change that prevents or treats multiple illnesses (Cohen et al., 2011; Flocke et al., 2021; Flocke et al., 2012; Flocke, Clark, et al., 2014; Flocke & Stange, 2004; Lawson & Flocke, 2009), and they are alert for the mental health and psychosocial causes of illness and opportunities for prevention (Flocke & Stange, 2004; Lawson & Flocke, 2009).

For example, we saw that Mrs. Bauer's doctor prescribed a single drug for which the main effect or side effects helped her anxiety, insomnia, diabetic neuropathy, and arthritis pain. And by encouraging Mr. and Mrs. Bauer to walk, he prescribed a behavior change that reduced both of their needs for medication, as well as having a positive social effect on their interactions. Mr. P's and Mr. Bindas' care, by considering their sometimes-challenging personalities, helped to smooth both care and care transitions that otherwise would have been fraught.

Coordinating Care in a Fragmented System

My practice coordinates the care I get from multiple places.

Being seriously ill in the current U.S. health care system can be a lonely, dangerous experience, as each specialist provides advice or treatment for their condition of interest, but no quarterback coordinates that game plan.(Haggerty et al., 2012; Kathol & Kathol, 2010;

McDonald et al., 2013; Panagioti et al., 2015; Press, 2014) Care coordination protects people from the dangers of overtreatment (Franks et al., 1992; Steel et al., 2014), iatrogenesis (Ecks, 2020), and decontextualized care (Weiner, 2004; Weiner, 2021; Weiner et al., 2010; Weiner et al., 2007).

TW coordinated complex care needs for Mr. Bindas, taking a large burden off his son, and helping him get what he needed in a complex and bureaucratic system. Mr. Bauer's doctor provided most of his care, diagnosed a complex set of new illnesses, and then got the needed specialists to provide their expertise at the moments when it could be most helpful, making the specialists more effective and protecting Mr. Bauer from the potential harms of over- or under-treatment.

Knowing the Patient as a Person

My doctor or practice know me as a person.

Being known improves diagnosis (Donner-Banzhoff, 2018; Donner-Banzhoff & Hertwig, 2014). It leads to more tailored treatment (McWhinney, 1975; Parchman et al., 2002). Being known as a person is healing in itself (Scott et al., 2008; Scott et al., 2009; Scott et al., 2017). As we increasingly conceptualize health care as a commodity, rather than as a relationship (Beach & Inui, 2006; Frankel, 2004; Safran et al., 2006), it is easy to develop systems that unintentionally make it more and more difficult to get to know people who provide the life context that is so vital for good care of older people (and all people). Being known not only optimizes care, it is vital for helping to decide when it is time to back off on health care to provide end-of-life caring (Shippee et al., 2018; Stange, 1999) .

Mr. P's care was greatly enhanced by a physician who took an interest in him as a person. This personal connection may have been healing in itself (Scott et al., 2008; Scott et al., 2009; Scott et al., 2017), and by allowing his personality, difficulty with relationships, and challenging background to be considered, enabled him to get care that otherwise would have been put off by the difficulties of others in dealing with him. Similarly, by investing in the relationship, TW was able to develop trust with a patient who tended to drive others away. For Mr. Bauer, knowledge developed over time helped his doctor to intuit that a common symptom might represent something serious, and that knowledge and the resulting trust helped him to orchestrate complicated and effective care.

Developing a Relationship through Key Life Events

My doctor and I have been through a lot together.

In a prior study, we found two pathways toward people valuing the relationship with their family physician (Mainous et al., 2004). One is simply being together over a long period of time—during care for multiple small illnesses that develop trust and a sense of being known that serve as an interest-bearing account that can be drawn upon when the chips are down. The other pathway, independent of being together for a long time, is the degree to which the family physician is available to people for critical life and health events. This doesn't necessarily require being physically present but does involve knowing about key events and being engaged in witnessing and trying to help. When both longitudinality and availability during key events are present, patients will do nearly anything to stick with their physician, and vice versa (Mainous et al., 2004; Nutting et al., 2003).

All three of the patients in the case presentations likely would have strongly endorsed this item in the PCP-CM. For Mr. P, his doctor was one of the few people with personal knowledge of his experiences in prison and the community. Mr. and Mrs. Bauer had major diagnoses, treatments contextualized understanding developed over time as a basis for developing a trusting bond, with that bond strained by a missed end-of-life event. TW made herself available for multiple medical events for the patient and his son and helped them through his ever-changing needs.

Advocacy

My doctor or practice stands up for me.

Advocacy for patients involves using the three kinds of medical power—charismatic (personal), social, and Aesculapian (based on medical knowledge) (Brody, 1992)—to work to advance the health and wellbeing of the patient (Stange, 2010a). In the commodified and fragmented U.S. health care system that is designed to maximize revenue for health care providers and systems, it is vital to have an advocate. Often this is family and friends. But having an advocate inside the system—a primary care clinician who knows the person and their needs and is willing to stand up for them—is vital.

Mr. P's doctor's advocacy went beyond his individual care to setting up health screening sessions in prison and transportation system and a dedicated clinic for people coming out of prison. Mr. P's doctor enabled him to remain in the care system by serving as an outlet for them to share their own frustrating interactions with the patient. TW advocated for Mr. Bindas in a bureaucratic system. Mr. Bauer's doctor found a way to get a helpful drug that wasn't available in the U.S. In a system in which it often feels like every care provider is just doing the minimum to get through their overwhelming number of patients, this sort of personal advocacy reduces the system's danger and patients' and families' sense of aloneness. As the primary care system increasingly is overwhelmed, their ability to swim upstream in this advocacy role is diminished.

Providing Care in a Family Context

The care I get takes into account knowledge of my family.

All of us, but particularly older people, gain or lose health in the family context. Knowing the family is vital to personalizing care for familial illness and for all the health solutions that are best if family is engaged (Medalie, 1978). This is easiest when all members of a family see the same primary care clinician, but it is a vital aspect of primary care to know the family context for each individual patient (Medalie et al., 2000; Medalie et al., 1998).

Mrs. and Mrs. Bauer had the advantage of being cared for by a physician who knew them both as patients, and who could look for cross-cutting strategies to help both of them. Even though Mr. Bindas' son wasn't explicitly her patient, TW recognized how important he was to the health of her patient, and she provided him with care and advice when needed. The family context for Mr. P's care was more subtle, with his doctor using some of her knowledge of the patient and his estranged family relationships to compensate by using some of her social capital to arrange connections for a person who tended to destroy the connections in his life.

Interestingly, in a direct observation study of 4,454 patient visits to 138 family physicians, we found that the family was discussed in approximately half of new patient visits and a quarter of visits by established patients, and the presence and involvement of family members was most common in the youngest and oldest age groups (Medalie et al., 2000; Medalie et al., 1998). In 18% of visits, care was provided to another family member than the identified patient for the visit. Half the time, that patient wasn't even present in the exam room for the visit (Flocke, Goodwin, et al., 1998; Orzano et al., 2001).

Providing Care in a Community Context

The care I get in this practice is informed by knowledge of my community.

A vital aspect of providing culturally sensitive care and for taking advantage of local resources for health is knowing a person's community context (Geiger, 2002; Gruß et al., 2020; Hughes et al., 2016; Longlett et al., 2001; Martin et al., 2004; Mullan & Epstein, 2002; Nutting, 1986; Plescia & Groblewski, 2004; Sweeney et al., 2012).

Mr. P's doctor worked to understand the unique community of the prison system, the community factors that led people to be imprisoned, and the connections necessary to re-engage in society. For marginalized groups, this sort of understanding and contextualization of care can be lifesaving. TW used her knowledge of the community of veterans' and their experiences to be open and sensitive to how this experience might affect her patient's interpersonal interactions, including those with her. The Bauer's doctor lived in the same community as they did, so had lived knowledge of the community context and provided care for the family in the home.

Goal-oriented Care

Over time, this practice helps me to meet my goals.

Goal-oriented care is focused on what is important to the patient (Mold et al., 1991). What is important changes over the life course, and so a goal-oriented approach may be particularly important for older people who may, for example, value functional or quality of life outcomes more than the biomarker and disease outcomes that often are the focus of medical care (Mold, 2017; 2020; 2022).

Mold and Green contrast goal-oriented care with the more common problem-oriented care, noting that goal-oriented care encourages patients to articulate what health means for them. It encourages dialogue and relationship development with health care providers and fosters a focus on strengths and resources (Mold et al., 1991). Reuben and Tinetti espouse three advantages of goal-oriented care that are particularly important for older patients—it tailors care to the individual rather than to the average effects that are the target of evidence-based care; it simplifies decision making for people with multiple chronic conditions by focusing on outcomes that are important to the patient, and it prompts patients to focus on what is important, and thus informs the often overlooked prioritizing function in health care (Reuben & Tinetti, 2012). Goal-oriented care may protect people from the over-treatment that is so common in the U.S. (Franks et al., 1992), particularly at the end of life (Shippee et al., 2018), but also can offer protection from undertreatment that happens when health care professionals make ageist assumptions (Henke et al., 2009; Miles, 2007; Parchman et al., 2007; Phillips et al., 2001).

TW worked with Mr. Bindas and his son to develop evolving goals as the scope of what was possible for his health changed over time. Mr. P and his doctor established a tacit goal of showing up for each other. The Bauer's doctor helped them to develop a living will and explicit end of life care preferences, which probably were helpful when his actual end of life needed to be negotiated with doctors who didn't know him.

Disease, Illness, and Prevention Management

Over time, my practice helps me to stay healthy.

Seeing the whole person over time provides multiple opportunities to prevent illness, to make subtle changes in illness management that over time can make a big difference (Freeman & McWhinney, 2016; Stewart et al., 2013). In the direct observation study of 4,454 visits to 138 family physicians, we found that preventive services were delivered during 1/3 of visits for illness (Stange, Flocke, et al., 1998). Many of these preventive services were linked to opportunities to improve care of chronic illnesses, or used an acute illness as a teachable moment for improving health behaviors (Cooper et al., 2001; Flocke, Stange, et al., 1998; Stange et al., 1994).

In all three cases, the clinicians wove prevention into the course of caring for the patients' illnesses and concerns—sometimes as explicit preventive services, more looking for teachable moments for health behavior change (Cohen et al., 2011; Flocke et al., 2021; Flocke et al., 2012; Flocke, Clark, et al., 2014; Flocke & Stange, 2004; Flocke, Step, et al., 2014; Lawson & Flocke, 2009; McBride et al., 2003).

Eleven Domains that Together Form a Complex Whole

The multiple domains of primary care work together in an integrated way enabled by a comprehensive focus on the whole person in context and investment in relationships over time (Heath, 1995; Heath et al., 2009; Heath & Sweeney, 2005; Sweeney & Heath, 2006). Different ways of knowing and doing represent trade-offs, and the right decision among competing demands and opportunities requires local knowledge on-the-ground and in-the-moment (Kringos et al., 2010; Sturmberg & Schattner, 2001).

The diverse attributes of the Person-Centered Primary Care Measure, as assessed by the patient, all factor analyze into a single factor (Etz et al., 2019)—showing that there is strong conceptual coherence to the comprehensiveness of a person-focused approach to health care (Etz et al., 2019; Ronis et al., 2020; Tse et al., 2020; Tse et al., 2021).

During the Starfield III Summit, participants struggled to fit the interrelated complexities of the generalist approach and primary care into the usual reductionist classification and measurement systems that assume that the whole is merely the sum of its parts. The complexity of primary care was well captured in stories, and participants were able to begin to identify the mechanisms by which those complex ways of knowing and doing could be described. But in trying to operationalize measurement of these ways of knowing and doing, they became quite anxious that a measure of any individual function could be misused. They emphasized that the individual facets of primary care must be understood, acted upon, and supported as a whole (Etz, 2016; Jonas, 2020; Lynch, Dowrick, et al., 2021; Lynch, van Driel, et al., 2021b; Thomas et al., 2018). This whole is much more than the sum of the parts (Stange, 2002), and efforts to measure and incentivize only the individual components risk damaging the integrative force of primary care for personalizing the care of the individual and for advancing the health of the population (Stange et al., 2014; Stange et al., 2010).

Simple Rules to Understand the Craft of Generalism & the Complementary Specialist Function

An interesting attribute of complex system (Sweeney, 2006; Sweeney & Griffiths, 2002), such as the systems required to provide integrated care for older people (Adams et al., 2002; Boult & Wieland, 2010; Buja et al., 2018; Donaldson et al., 1996; Koroukian et al., 2007), is that their emergent behavior often can be described and understood by simple rules (Institute of Medicine: Committee on Quality of Health Care in America, 2001; Plsek & Greenhalgh, 2001; Trochim et al., 2006). When we used this idea to conduct further analyses of our crowd-sourced data and the Starfield III Summit, we uncovered three simple rules that, when actualized together by patients, clinicians, and practices, and supported by systems, describe the generalist approach from which the beneficial personalized care and population health outcomes of primary care emerge (Etz et al., 2021). These analyses also reveal complementary simple rules for the more narrowly focused specialist function (Etz et al., 2021).

When clinicians act as specialists, their behavior can be explained by three simple rules that represent the dominant approach to health care organization and quality measurement (Etz et al., 2021):

1) **Identify** and classify disease for management;
2) **Interpret t**hrough specialized knowledge;
3) **Generate** and carry out a management plan.

However, when clinicians act as generalists (Kurt C. Stange, 2009), their thoughts and actions invoke three simple rules that are focused not only on single disease elements, but on the whole person (Etz et al., 2021). They consider the person in their larger context (Weiner, 2004; Weiner, 2021). They:

1) **Recognize** a broad range of problems/opportunities/capacities;
2) **Prioritize** attention and action with the intent of promoting *health, healing,* and *connection*;
3) **Personalize** care based on the particulars of the individual or family in their local context.

These rules work together to focus care on what is most important for each patient at a given time, and over time through a life course perspective.

Recognizing requires foraging for salient information (Donner-Banzhoff, 2018) based on a comprehensive generalist perspective—watching for teachable moments (Heath, 1995), clues, risks and opportunities (Cohen et al., 2011; Flocke, Clark, et al., 2014; Foucault, 1975; Lawson & Flocke, 2009; Kurt C. Stange, 2009).

Prioritizing begins with the broad, inclusive generalist perspective, and then sorts, ranks, and negotiates what is most important, to identify what action has the greatest potential to advance *health, healing, and connection* (O'Connor et al., 2017; Stange, 2009; Stange, 2009b; Stange et al., 2014).

Personalizing care moves from the statistical generalities of evidence-based medicine to the nitty-gritty of this person or family in their moment, place, and context. Over time, there are many particular moments (Bazemore et al., 2018; Henbest & Stewart, 1990; Stange et al., 2014; Stange, 2009; Stewart et al., 2000; Stewart et al., 2003), and attending to these develops knowledge of the person, trust, and trustworthiness (McWhinney, 1989).

The generalist rules interact and operate in an iterative fashion (Leopold et al., 1996; Ronis et al., 2019; Scott et al., 2008; Wilson et al., 1995): 1) as new information reframes problems and opportunities; 2) as what is most important continually evolves; and 3) as hypotheses are tried out with the intent of promoting some combination of health, healing, and/or connection. The cumulative effect of actualizing these rules is an investment in a relationship bank that can be drawn upon with interest during challenging moments in the health and lives of individuals, families, and communities (Bergman et al., 2020; Stange, 2009b).

Balanced with the right mix of specialist approaches, and connected with functional social systems, the generalist approach serves as an integrating and personalizing force in systems that otherwise tend to be fragmented (Lynch, 2021; Lynch, van Driel, et al., 2021a).

Focusing comprehensively on the needs of the whole person, over time, in relationship, combined with selective use of more narrow expertise, results in care that is personalized, integrated, and prioritized (Stange, 2009b; Stange, Jaén, et al., 1998). That approach fosters healthy individuals, families, and communities, and can contribute to a more fair, effective, and sustainable health care system (Starfield, 1992; Starfield, Shi, et al., 2005).

Policy Implications for Integrated, Personalized Care for Older People

A New NASEM Report

A recent report from the National Academies of Science, Engineering and Medicine (NASEM) calls for supporting primary health care as a common good, so that it can serve as a force for integration in our currently fragmented system (National Academies of Sciences, 2021). These policy changes to support the integrating, personalizing functions of primary care that are so essential to the care of older people. They recommend a multilevel implementation strategy, and emphasize:

1) Paying for primary care teams to care for people, not doctors to deliver services;
2) Ensuring that high-quality primary care is available to every individual and family in every community;
3) Training primary care teams where people live and work;
4) Designing information technology that serves the patient, family, and interprofessional care team;
5) Ensuring that high-quality primary care is implemented in the US.

The report stresses the importance of increasing the proportion of health care spending toward primary care, and payment models that support integrated care and sustained relationships, particularly "hybrid" models that move from fee-for-service toward capitation. The report highlights the importance of relevant research, coordinated leadership, more helpful digital support, and policies that enable locally tailored care. The recommendation that the US Department of Health and Human Services establish a Secretary's Council on Primary Care to coordinate across multiple government entities, already has been implemented (Grumbach et al., 2021).

An interesting historical analysis commissioned in support of the NASEM report shows the unintended fragmenting and depersonalizing consequences of four decades of care organization improvement initiatives, and highlights the need for business models that support and promote this generalist, whole person, relational care over time, in contrast to current models that add administrative burden by carving care into billable pieces and performance of reductionist outcomes (Miller, 2021).

Another analysis commissioned for the NASEM report (Stange, 2021), and an article in a previous issue of this journal (Gullett, 2021), highlight how the pandemic has uncovered the disastrous effects of decades of disinvestment in primary care and overspending on healthcare infrastructure that fragments care, reduces its accessibility for the most vulnerable, and reduces the resilience of people and systems attempting to integrate care for whole people.

Relationship-centered Models for Organizing Care

Current U.S. health care invests in technology, bureaucracy, and commodified service delivery (Heath, 2006; Hoff, 2022; Knai et al., 2018; Lown, 2007; National Academies of Sciences, 2018; Stange, 2016; Weiner et al., 2004). In order to provide integrated, personalized care for older people, it is vital to invest in supporting relationships (Hoff, 2017; Hoff, 2019). Relationship-centered care (Beach & Inui, 2006) provides the opportunity to focus on what matters to older people (Wasson, Ho, et al., 2018; Wasson, Soloway, et al., 2018), rather than providing services for which the system can maximize payment. Relationship-centered care is a cornerstone of the healing process (Scott et al., 2008; Scott et al., 2009; Scott et al., 2017), and provides a platform to providing and coordinating needed care (Sturmberg et al., 2012). Investing in relationships, particularly for older people, generates of bank of knowledge and trust that can be drawn on with interest when the chips are down—such as a new illness, a sudden loss of function, a critical life event, or nearing the end of life (Mainous et al., 2004; Nutting et al., 2003; Olaisen et al., 2020; Stange, 2016).

People who provide primary care went into the healing professions to provide this kind of relationship-centered care (Colwill et al., 2016; Griswold, 2016; Loxterkamp, 2018). But the current fragmented system has nearly destroyed their ability to provide this kind of care (Bujold, 2015, 2017). The moral distress of seeing what kind of help could be provided, but being unable to accomplish it (Frezza Md, 2019; Heston & Pahang, 2019), has led to rampant burnout (Bodenheimer & Sinsky, 2014; Dyrbye et al., 2017; Puffer et al., 2017; Rotenstein et al., 2018; Shanafelt et al., 2012).

Current health care systems emphasize vertical integration—organizing care around disease pathways, focused in a top-down fashion on managing named disease conditions or risk factors for ill health (Orszag & Rekhi, 2020).

Vertical integration connects people with defined needs with specialized services across multiple levels of the system (Baker et al., 2014). This can be helpful for managing individual diseases that fall neatly into named categories. Vertical integration can be very helpful once problems have been characterized and is a viable way to organize multiple specialized systems around a well-defined need. But if the only integrating organization is around well-characterized problems, complex multifactorial, undifferentiated, and unexplained problems get short shrift (Sturmberg et al., 2021).

Most older people have multiple chronic and acute conditions and surrounding social and family needs that don't fit neatly into boxes that can be vertically integrated. Older people need care that also is horizontally integrated—organized around whole people with complex needs in their family and community context. Horizontal integration involves broad-based collaboration to improve overall health (De Maeseneer et al., 2008). The dynamic processes of horizontal integration require flexible systems that iteratively link on-the-ground experience with efforts to grasp the larger contexts in which they operate. Primary care for older people can serve as a force for horizontal integration that make the vertically integrated systems more efficient and effective (Stange, 2021).

Comprehensive, whole systems integration includes a balance of both vertical and horizontal integration (Thomas et al., 2008). However, in the U.S., we have conceptualized and organized primary care and public health solely as part of top-down vertically integrated systems focused on problems rather than on people and communities, resulting in diminished effectiveness (Chan, 2008; De Maeseneer et al., 2008; Lawn et al., 2008; McPake & Mensah, 2008; Miller, 2021).

Local adaptation of the generalist function to specific individuals, families and communities is also reflected in the wide adaptability of the primary care function at the sociopolitical and population level. The particular needs of older people, and the high cost of their care and the care of multiple chronic conditions, have spawned some interesting practice innovations.

"Slow medicine" (Hill, 2021; Kerrigan, 2017; Marx & Kahn, 2021) that emphasizes using time and relationship as allies (Boult & Wieland, 2010; Sturmberg & Cilliers, 2009), guided care (Aliotta et al., 2008; Boyd et al., 2007) that supports integrated care of individuals and care coordination across multiple providers and settings; and multiple innovative practice models, particularly (Casalino et al., 2016; Casalino et al., 2018) in the Medicare Advantage space, appear worthy of initial support and further evaluation (ChenMed; Howe, 2017; Oak Street Health). While not focused specifically on older people, Direct Primary Care models that involve practices with small panel sizes and low-overhead from eschewing insurance and providing inclusive primary care for a small monthly fee, are revitalizing a primary care workforce energized by the ability to spend time with patients (Brekke et al., 2021; Brusch et al., 2020; *Direct Primary Care Coalition*; DPC Alliance; Wu et al., 2010).

The specter of venture capital looking for short-term, large return on investment is a concern (Braun et al., 2021; Brown et al., 2020; Casalino, 2020; Casalino et al., 2019; La Forgia et al., 2022), as is the current zeitgeist of bureaucratic government and not-for-profit health care systems that act like for-profit entities, both requiring stifling top-down, reductionist documentation burdens that distort the whole-person focus of frontline care of older people. But if these corrupting influences can be minimized, it is promising to invest in and evaluate creative approaches to support the time and resources needed to integrate care for whole people.

In the plurality of the U.S. health care system, there will not be one way to optimally organize care for older people. In the diversity of older people, there will not be one way to optimally care for individuals in their family and community context. What is important, is to recognize that the knowledge needed to personalize and integrate care for older people lies at the very local level of the person, family, and primary care practitioners (Heath, 1995; Loxterkamp, 2001; Loxterkamp, 2016; Loxterkamp, 2018; Miller et al., 2010; Ventres et al., 2017; Ventres & Frankel, 2015). What is needed are systems that support investment in relationship at this local level.

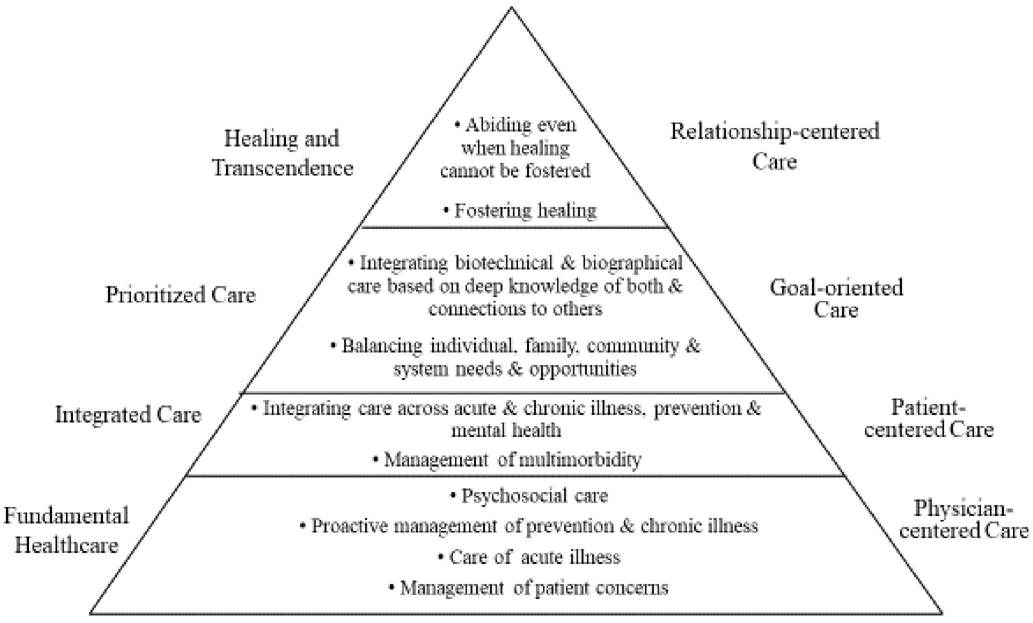
Integrating Conceptualizations, Language, and Measurement

In the current *Zeitgeist*, we conceptualize that understanding comes from focusing narrowly (Diez Roux, 2011; Lynch, Dowrick, et al., 2021; Lynch, van Driel, et al., 2021a; Martin & Félix-Bortolotti, 2010; Vogt et al., 2016). In this view, the best scientific evidence comes from experimental designs in which randomization allows us to ignore messy contextual factors (Davis & Taylor-Vaisey, 1997; Gabbay & May, 2004; Genuis, 2005; Graham et al., 2000; Grol, 1993; Hayward et al., 1995; Hrobjartsson et al., 1998; Inouye et al., 1998; James et al., 1997; Lichtenfeld, 1993; Tinetti et al., 2004; Woolf, 1990; Woolf, 1993). Quality comes from narrowly-focused specialization, assessed as the sum of adherence to one-disease-at-a-time clinical guidelines (Okeowo et al., 2018). This whole as the sum of the parts understanding works well for simple or even complicated, well-defined problems (Heath et al., 2009). But it doesn't fit with the complexity of the care of older people (Sturmberg et al., 2021). It leads to problem definitions and top-down solutions that blames the individual for systemics problems and that don't support the bottom-up solutions needed to care for older people (Love, 2012).

The results of reductionist understanding, however, is an increasingly fragmented, impersonal, expensive, and often ineffective system that doesn't work for either the providers or recipients of care (Stange, 2009a). Our resulting efforts to improve care have added administrative burdens that have become intolerable for providers and patients/families alike (Bujold, 2015, 2017; Martin, 2017; Sinsky et al., 2021).

In order to begin to develop the needed new systems, we need to broaden our understanding of health and health care as a complex system (Lynch, Dowrick, et al., 2021; Martin & Félix-Bortolotti, 2010). Such understanding helps us to understand that there are multiple levels of care (Stange, 2009b). As shown in the figure below, basic care involves the diagnosis and treatment of individual acute diseases and problems of living, management of individual chronic conditions, support of disease prevention through healthy behaviors, early detection of treatable diseases, immunizations, and preventive medications. Currently, this basic care is all our scientific evidence can inform. Basic primary care also includes care of families.

Levels of Health Care



From: Stange KC. A Science of Connectedness. Ann Fam Med. 2009;7(5):387-395.

There is a higher level of care. Integrated care raises the gaze from individual problems and opportunities to look at the large whole of the person in context. It requires iteration between the parts and the whole, between general scientific evidence and the particulars of the person, family, and community. It involves integrating care across chronic illness, acute concerns, preventive opportunities, mental health, and family care. Our current one-disease-at-a-time evidence-based clinical guidelines are blind to this integrated care. In fact, providing integrated care often flies in the face of individual disease specific guidelines, and thus integrated care is punished in quality reporting metrics and in pay-for-performance schemes that reward only compliance with disease-specific metrics.

A higher level of care still is prioritized care—focusing on what is most important in the moment, or ideally in many moments over time. Prioritized care is based on, and benefits from, knowing the person over time. It helps people and creates efficiency and effectiveness at the system level.

Prioritizing and integrating care are not supported by current information technology or reward systems, but they set up the highest level of care which involves healing and transcendence—providing cure when possible, palliation and support always, and sticking with people even when neither are possible (Jonas, 2018). Investment in the lower levels of care sets up this higher level of care which is vital near the end of life, but also for helping people with their health needs that don't fit neatly into the boxes of our currently commodified care systems.

As indicated in the figure, fundamental care often can be seen as physician-centered. Integrated care is patient-centered. Prioritized care is goal-oriented. Healing and transcendent care is relationship-centered.

Generating New Knowledge Relevant for Integrating and Personalizing Care of Whole People

A largely disease-focused National Institutes of Health (NIH) has made tremendous strides in advancing basic and disease-specific knowledge. But this siloed approach has fragmented knowledge and resulted in fragmented clinical care guidelines that fly in the face of efforts to integrate care for whole people. The National Institute on Aging has the potential to focus on the care of whole older people across the lifespan, and does so to some extent, but also is subject to the same reductionist pressures and conceptualizations that are dominant in the larger research environment. A more holistic, integrated, whole person focus is needed.

A reductionist research lens, peer review process, and funding structure limits the kind of questions that can be asked. Questions that have to do with whole people, with illnesses or preventive opportunities that transcend individual diseases, or how care can be integrated and prioritized, don't have a funding home or even a way to be seen as legitimate targets for inquiry (Miller et al., 2003). As a result, the research that we have excludes people with multiple or difficult to define conditions. It specifically excludes the contextual factors that are so important with understanding illness and health processes in older people, and the integrative solutions to advancing health (Sturmberg et al., 2021).

Integrative cross-cutting conceptualizations of health and illness are needed that take into account contextual factors across multiple levels: historic context, structural systems of bias and advantage, public policy, place, community, health care systems, family, and person, as well as the cellular and molecular levels where most research currently is focused (Balasubramanian et al., 2015; Peek et al., 2014; Stange et al., 2014; Stange & Glasgow, 2013; Tomoaia-Cotisel et al., 2013). New knowledge is needed that moves from a disease focus toward a person-driven, goal-directed emphasis (Mold et al., 1991). Non-reductionist research methods are needed that are participatory, flexible, multilevel, quantitative and qualitative, conducive to longitudinal dynamic measurement from diverse data sources, sufficiently detailed to consider what works for whom in which situation, and generative of ongoing communities of learning, living and practice. Rigorous, integrated, participatory, multimethod approaches to generate new knowledge and diverse partnerships are needed to increase the relevance of research to make health care of older people more sustainable, safe, equitable and effective, to reduce suffering, and to improve quality of life (Bayliss et al., 2014; Miller et al., 2003; Stange, 2010b; Stange et al., 2001).

Conclusion

The health and health care of older people requires contextualized knowledge, personal knowing, and systems that support horizontal as well as vertical integration. Such systems require understanding and supporting health care as a relationship. Focusing, measuring, and supporting whole-person care provides hope for integrated, personalized care of older people.

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Shaping Long-term Care for Older Adults: Exploring the Role of Geriatricians in Italy and the United States

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Abstract

Aging and the need to reconfigure the provision of long-term care for aging adults has become a pressing policy issue for many high and middle-level income countries across the world. Traditionally, research on long-term care and its organization has centered on the analysis of the triangle of state/market/family to understand its operation and distribution across social actors. To this day, however, little to no attention has been paid to the role that doctors play in these processes, notwithstanding the fact that they are a key node at the intersection of the above-mentioned institutions. This paper begins to fill this gap by exploring the role that geriatric doctors play in supporting, maintaining, reproducing, and sometimes challenging how aging and its processes are understood by society at large and how they are addressed at macro and micro-levels. The paper is based on qualitative interviews with geriatric doctors in the United States and Italy operating both in the private and public sector, on participant observations at Italian geriatric conferences, and on the analysis of email threads of the American Geriatrics Society. The analysis of the data shows that limited geriatricians' presence in both countries affects both how society at large, from individuals to institutions, understand aging and its processes and the increased need for long-term care Addressing these issues from a policy perspective has the potential to greatly improve, both from an economic and social perspective, how long-term care for aging adults is understood, organized, and delivered.

Keywords: aging Italy, aging U.S., geriatric doctors, long-term care, qualitative research

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Dar forma al cuidado a largo plazo para adultos mayores: Explorar el papel de los geriatras en Italia y los Estados Unidos

RESUMEN

El envejecimiento y la necesidad de reconfigurar la provisión de atención a largo plazo para los adultos mayores se ha convertido en un problema de política apremiante para muchos países de ingresos medios y altos en todo el mundo. Tradicionalmente, la investigación sobre los cuidados de larga duración y su organización se ha centrado en el análisis del triángulo estado/mercado/familia para comprender su funcionamiento y distribución entre los actores sociales. Sin embargo, hasta el día de hoy, se ha prestado poca o ninguna atención al papel que juegan los médicos en estos procesos, a pesar de que son un nodo clave en la intersección de las instituciones mencionadas. Este documento comienza a llenar este vacío al explorar el papel que desempeñan los médicos geriátricos en el apoyo, el mantenimiento, la reproducción y, en ocasiones, el desafío de cómo la sociedad en general entiende el envejecimiento y sus procesos y cómo se abordan a nivel macro y micro. El documento se basa en entrevistas cualitativas con médicos geriatras en los Estados Unidos e Italia que operan tanto en el sector público como en el privado, en observaciones de participantes en conferencias geriátricas italianas y en el análisis de hilos de correo electrónico de la Sociedad Estadounidense de Geriatría. El análisis de los datos muestra que la presencia limitada de geriatras en ambos países afecta tanto la forma en que la sociedad en general, desde los individuos hasta las instituciones, entiende el envejecimiento y sus procesos y la mayor necesidad de atención a largo plazo. Abordar estos problemas desde una perspectiva política tiene el potencial mejorar en gran medida, tanto desde una perspectiva económica como social, cómo se entiende, organiza y brinda la atención a largo plazo para adultos mayores.

Palabras clave: envejecimiento de Italia, envejecimiento de EE. UU., médicos geriátricos, atención a largo plazo, investigación cualitativa

为老年人制定长期护理：探究老年病学家在意大利和美国的作用

摘要

老龄化和老年人长期护理服务的重新配置需求已成为世界上许多中高收入国家所面临的紧迫政策问题。传统上，关于长期护理及其组织的研究聚焦于分析国家/市场/家庭的三角关系，以理解其在社会行动者之间的运作和分配。不过，直到今天，医生在这些过程中所发挥的作用几乎没有受到关注，尽管事实上他们是上述机构交叉点的关键节点。本文试图填补该空白，探究了老年病学医生在支持、维持、再生产以及有时挑战“社会对老龄化及其过程的理解以及如何在宏观和微观层面应对这些过程”一事中发挥的作用。本文基于对美国和意大利私营和公共部门的老年病学医生的定性访谈、意大利老年病学会议参与者的观察、以及对美国老年医学会（American Geriatrics Society）电子邮件讨论的分析。数据分析表明，这两个国家的有限老年病学家人数会影响整个社会（从个人到机构）对老龄化及其过程的理解，并影响长期护理需求的增加。从政策角度解决这些问题有可能在经济和社会方面极大地改善对老年人长期护理的理解、组织和提供方式。

关键词：意大利老龄化，美国老龄化，老年病学医生，长期护理，定性研究

Recent developments connected to the COVID 19 pandemic have directed the spotlight on a growing concern for many wealthy, post-industrial societies, namely how to provide sustainable long-term care for growing numbers of aging adults. This issue, which has been on the table for quite some time but had never reached mainstream, is now front and center of many national debates. Who should provide long-term care, how and where care is offered, in what forms it is received, and who should fund it and how are central questions that require an in-depth investigation of the issue at macro-, meso-, and micro-levels to include the perspectives of the many social actors involved in these processes and provide applicable answers. Traditionally research on the organization of long-term care has focused on the triangle involving state, families, and market to highlight different configurations among different societies (among others Ambrosini, 2016; DaRoit, 2017; Lutz, 2016; Ogawa et al., 2018; Rugolotto, 2017; Scrinzi, 2017).

Only recently have scholars begun to focus on the many intermediaries that participate in shaping, maintaining, reproducing and, sometimes, challenging the existing organizations of long-term care. These intermediaries include, among others, nurse managers (Dever, 2018), care convoys (Kemp et al., 2018) cultural mediators and local NGOs (Degiuli, 2016; Yang, 2018), and social cooperatives (DeMarchi & Sarti, 2010). At this point, however, little to no attention has been paid to the role of doctors in these processes. This paper begins to fill this gap by exploring the role that geriatric doctors play (or fail to play) in shaping long-term care at the individual, interpersonal, and structural level. Through in-depth qualitative interviews with geriatricians in Italy and the United States, participant observations at Italian geriatric conferences, and a monitoring of web-based threads of the American Geriatric Association, the paper discusses how these social actors make sense of their limited presence in the medical communities and/or healthcare settings of their respective countries and elaborates on the societal, political, and medical effects of their limited imprint. Finally, in light of these conversations, the paper lays out some policy suggestions aimed at improving the current status quo.

Background

The world of today is aging at a great speed and is still doing so almost three years into the COVID-19 pandemic. According to the United Nations, in 2020 there were an estimated 727 million people aged 65 and over worldwide—a number that is projected to more than double in the next few decades, reaching over 1.5 billion people in 2050 (UN DESA, 2020). Preliminary research suggests that while the pandemic has and will potentially affect life expectancy for years to come, it has not slowed down the graying of populations (Harper, 2021). In Italy, a country with one of the oldest populations of the world and one deeply affected by COVID 19, the population of 65 and older has grown from 22.8 in 2018 to 23.5 percent of the population in 2020, while the percentage of 80 and over, the one most affected by the pandemic, has grown from 6.9 in 2018 to 7.6 in 2020 (ISTAT 2021, 2022). In the United States, a country experiencing one of the largest losses of life expectancy connected to the pandemic (Aburto et al., 2022), population projections show that by 2050 the total number of adults 65 and older is expected to grow from 54 million to 85.7 million, while the population of 85 and older is projected to more than double, going from 6.6 million in 2019 to 14.4 million in 2040 (AoA, 2020).

Although people living longer represent one of the greatest achievements of the last century, often an extension of life expectancy does not correspond to an extension of healthy lives. Aging populations, particularly those with a high percentage of the oldest old, are often affected by chronic conditions that render them vulnerable and frequently require extended long-term care. The COVID-19 pandemic, particularly in its early stages, has made this vulnerability visible to all. Data provided by European Regional Office of the World Health Organization highlight that 95% of the deaths attributed to COVID 19 occurred in adults older than 60 and that more than 50% of all deaths were people aged 80 and over. Many of these deaths were among individuals with at least one co-morbidity, in particular cardiovascular disease/hypertension and diabetes, but also a range of other chronic underlying conditions (WHO, 2020). In addition, the pandemic and its effects have also highlighted the inefficiency and the fragility of the current organization for long-term care. Early international evidence estimates that up to 60% of total of mortality associated with COVID-19 can be traced to residents of care homes (Comas-Herrera et al., 2020), a pattern repeated in the United States where, during the pandemic, nursing homes and long-term care facilities became the epicenter of infection and death (Barnett & Graboski, 2020; Kahana, 2020, p.3).

The crisis also revealed important weaknesses in other areas of U.S. and European long-term care systems. As national borders closed, thousands of migrant care workers could not go back to their homes or were unable to return to their employers (Burtscher, 2020). Those who stayed encountered difficult conditions as many were laid off and were, at least early on, excluded by governmental programs aimed at supporting those who lost their jobs. Others, engaged in informal labor relationships received no support at all (Pasquinelli & Pozzoli, 2021). Another, albeit more invisible, group of caregivers affected by Covid-19 were family caregivers, mostly women, whose daily amount of carework skyrocketed during the lockdown, making it almost impossible to juggle the many demands placed on them from work, daily management of their families, and the care required by their elderly and disabled relatives (Ranji et al., 2021; Scarpetta et al., 2020).

Observers have pointed out the need for reform of welfare states' provisions on long-term care long before the spread of COVID-19. Demographic change, the transformation of family structures, and cuts in public spending were just some of the developments exercising pressure on long-term care systems, but the current situation has made the conversation urgent.

Historically, studies on long-term care and its organization have focused on three main social actors: the State, the market, and the family to explore the potential configurations of care provision (among others DaRoit, 2010; Ogawa et al., 2018; Osterman, 2017; Schulz, 2010; Williams, 2011). Only in recent years have scholars shifted their focus on the many intermediaries operating either as public and private actors, and sometimes as a mix of both, in long-term care. These are, among others, brokering and employment agencies (Liang, 2018), convoys of care (Kemp, 2018), cultural mediators and NGOs (Degiuli, 2016; Kemp et al., 2017), nurse managers (Dever, 2018), and social cooperatives (DeMarchi & Sarti, 2010). To this point, however, little to no attention has been paid to the role of geriatricians in these processes. I believe this gap needs to be filled because doctors, aside from playing a key role in the adaptation, maintenance, and performance of existing healthcare systems (Denis & Van Gestel, 2016, May & Finch, 2009, Waring, 2009), also have the ability to shape societal and cultural understandings of biological processes and the "best way" to address them (among others Fasih, 2020; Foucault, 1978/2009; Greco, 2020; Waitzkin, 1991).

Geriatrics is the branch of medicine that focuses on the stage of life in which biological aging, which does not necessarily reflect chronological age, becomes more advanced and progressively dominates the relationship between body and disease (Incalzi et al., 2019). Geriatric medicine also specializes in the management of multiple concurrent chronic conditions, complex health histories, fragility, and cognitive degeneration, as it aims to maintain quality of life and prevent disabilities as long as possible (Kotsani et al., 2021). In addition, geriatricians advocate for a holistic approach that goes beyond the medical, cognitive, and functional assessment of patients to include an examination of living conditions and the extent and availability of a network of care to ensure, more than life prolongation, good physical function, autonomy, well-being, social engagement, and a dignified end of life (Kotsani et al., 2021; Mishra et al., 2020; Pilotto & Polidori, 2018). As such, they appear to be, at least on paper, the ultimate authority on aging, not only from a medical perspective but also, potentially, from a social welfare one. In addition, thanks to their specific location at the intersection of state, market, and family, geriatricians have, ideally, the potential to shape aging and long-term care at different levels. They could do so as:

- **Experts** – Geriatricians have, potentially, the ability to shape societal understandings of aging and its problematics, legitimize "best practices" of long-term care, treat patients and design long-term care plans, and define/create new subjects in a clinical perspective e.g., *the frail elder* (Among others Factora & Saxena, 2021; Geddes et al., 2020; Ruggiero et al., 2007; Woo, 2018).

- **Mediators between patients and formal/informal caregivers** – Geriatricians have the opportunity to counsel patients and families in the decision process concerning long-term care and therapies, supervise the increasing delegation of medical tasks to formal and informal caregivers, and in some cases, help train informal caregivers (among others Van Eijken et al., 2008).

- **Enforcers and gatekeepers of public services/funding/programs and of private policies and requirements** – Geriatricians assess patients, categorize them, and provide and/or deny access to services, welfare programs, specialists. In the process, they implement decisions taken by healthcare administrators at different levels and policymakers (Denis & Van Gestel 2016; Sorrentino et al., 2005).

- **Challengers** – In the everyday practice of their job, in their direct relationship with patients, or in relating with institutions, geriatricians have the ability to transform, interpret, stretch, and, in some cases, even openly challenge health care policies' requirements and restrictions (Broom et al., 2014).

Understanding how geriatricians make sense of these different roles and their work, describe aging and its related issues, define best practices of care and why, and connect the macro-level demands of care management in the practice of daily care provision will provide insights into how long-term care for older adults is understood, managed, and provided in contemporary post-industrial societies and, potentially, how to improve it. In addition, a comparison of how these actors operate in two national systems with different care regimes[1] and different medical education systems will offer the opportunity to analyze and compare different healthcare models and consequentially potentially varying outcomes, as well as to assess increasing convergences linked to technology, neoliberal understandings of healthcare provision, and hierarchies of knowledge production (Beckfield et al., 2013; Cortez, 2009; Peters, 2011).

This paper focuses, specifically, on one of the latter, namely the scarcity of geriatricians in both countries. The limited presence of geriatricians is not a new phenomenon. It is an issue that has been well documented, particularly by geriatricians themselves for quite some time (see for example AGS, 2018; Fletcher, 2007; Golden et al., 2015; Incalzi, 2019; Lee & Sumaya, 2013). Some of the studies have also attempted to provide suggestions on how to improve the current situations in terms of improving recruitment and retention (among other Lester et al., 2020), while others have focused in proving the value of geriatricians in treating patients with very specific illnesses (among others Greene et al., 2022), after specific interventions (Coary et al., 2019; Friedman et al., 2008; Luo et al., 2022), in collaborations with other medical specialists (Callahan et al., 2006; Dham et al., 2017), in varying healthcare structures (among others D'Arcy et al., 2013; Forbes et al., 2018; Marsden et al., 2022) or in long-term care facilities (Achterberg et al., 2019; Crotty et al., 2004; Steves et al., 2009). Other studies have instead focused on geriatricians' contribution in treating frail patients (among others De Vincentis et al., 2021; Totten et al., 2012), developing comprehensive geriatric assessment (among others Ellis, 2011; Soobiah et al., 2017) or implementing interdisciplinary or integrated forms of medicine (among others Famadas et al., 2008; Puelle et al., 2018; Zhang et al., 2022). In addition, the majority of these studies have focused primarily on the medical and economic benefits that a greater presence of geriatricians could bring in improving outcomes, reducing mortality, reducing lengths of stays in expensive healthcare facilities, reducing hospitalizations or reducing overall costs (all the studies mentioned above). Up to this point, however, little to no attention has been paid to the social, cultural, and, potentially, political impact that a limited presence of geriatricians has on society at large and on many social dynamics connected to ageing and its progression. This paper aims to fill this gap by exploring how geriatricians themselves make sense of their relative absence among the Italian and American medical community and discuss the effects of this absence on societal understandings of aging and its processes, of long-term care provisions, of best practices of medical and social care for aging adults.

Methods

The project, designed according to the tenets of qualitative epistemology and grounded theory (Glaser & Strauss, 1967/1999) follows an inductive approach, is and is currently on-going. This paper is based on 30 semi-structured interviews with geriatric doctors both in Italy and the United States recruited through snowball sampling in the public and private sector collected between 2019 and 2022. The interview schedules were designed as semi-structured and included open-ended questions designed to cover all the following areas of inquiry:

- *Patients:* demographics, changes, relationships
- *Caregivers:* family/nonfamily; formal/informal, demographics, relationships
- *Structures and Organizations:* transformations, current organization, difficulties, tensions
- *Problematics inherent to long-term care*: funding, availability, future
- *Personal insights/beliefs on aging, long-term care, and its management*

In addition to the interviews, the project included a smaller component of participant observation at regional and national conferences of geriatric doctors in Italy and monitored the message boards, chats, and announcements of the American Geriatrics Society.[2] As of this writing, I have interviewed 18 geriatricians in Italy, of whom ten operate in Piemonte, one in Liguria, three in Lazio, one in the Marche, one in Puglia, one in Calabria, and one in Campania. Six of them work in large hospitals, two work in post-acute structures, two visit patients privately, five work in public ambulatory settings, and two work in nursing homes. One additional interviewee, instead, works for a regional branch of the national healthcare system (ASL) tasked to assess geriatric patients who formally request economic support from the region. Finally, I attended two geriatric conferences, a regional one in Turin and a national one in Rome, and attended three workshops on long-term care organized by the Observatory on Long-term Care organized by the Bocconi University. In the United States I have interviewed 12 geriatricians: six in New York city, four in New Jersey, one in Georgia, and one in Pennsylvania. Six of them work in major research hospitals, two work in nursing homes, three provide ambulatory care, and one worked two part-time jobs: one at an independent living facility and the other for a company providing geriatric house calls. In addition, to compensate for pandemic restrictions which made participant observation impossible, I monitored the weekly emails issued to members by the American Geriatrics Society and the web-based discussion threads of its members during 2019-2020 and 2022.[3]

The paper is based predominantly on the interviews, while participant observations and the monitoring of the announcements, discussion threads, and emails were used as background information to better understand the different national context in which the two groups of geriatricians operate. Due to the restrictions connected to COVID-19, the majority of the interviews (22 out of 30) were conducted either via Zoom or via phone, recorded (26 out of 30), and then transcribed. In four cases, the interviews were not recorded because the interviewees did not agree to it. In those cases, I asked them to go slow and repeat their points multiple times to capture full quotes and write extensive notes. All the interviews were then coded and analyzed in two cycles (Saldaña, 2012). First, the data was coded manually through a process defined as "open coding" (Charmaz, 2008), which consists of reading the interviews line by line to produce a first level of analysis. At a later stage, categories and patterns that emerged in the first coding were analyzed with the help of ATLAS.ti, a qualitative software that allowed for a more sophisticated grouping of the data according not only to words and categories, but also geographical location, which allowed for a more nuanced theoretical coding of the material.

Findings

Indirect Influence: Absence Rather than Presence

In both Italy and the United States, the first fact that becomes immediately apparent is that the number of geriatricians is quite low, and this comes in stark contrast with the demographic characteristics of the populations and potential need. In Italy, according to ISTAT, in 2017 there were 4,249 doctors with a specialization in geriatrics, of whom 2,167 work in the North, 775 in the Center, 899 in the South, and 408 in the Islands. However, according to both SIGG and SIGOT[1] Italian geriatric associations, in 2019, only 2,500 of these doctors currently worked in this capacity (SIGG 2019, personal conversation). The future does not look better. In 2017-18 there were only 164 students specializing in geriatrics (compared with 396 future pediatricians) against an estimated need of 450 a year (Incalzi, 2019). A similar pattern exists in the United States. According to the American Geriatrics Association, as of 2018 there were only 7,298 certified geriatricians practicing in the United States—a fraction of the estimated need of 20,053 (American Geriatrics Society 2019). Here too the gap will not be easily filled if we consider that of the 153 geriatric fellowship programs for the

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[1] SIGG stands for Società Italiana di Gerontologia e Geriatria, while SIGOT stands for Società Italiana Geriatria Ospedali e Territorio.

2022 appointment year, only 57 were filled (NRMP 2018).

The reasons behind the low numbers vary between the two countries and, while an in-depth analysis of them goes beyond the scope of this paper, three explanations recur among the interviewees independently of national context. One is that geriatricians' wages are perceived to be lower than those of other specialists, partly because older adults require more time than younger patients for their visits. Second, the amount of emotional labor required to care and support aging adults, and sometimes their families, is considered too high and too time-consuming when compared to other branches of family medicine or other specializations. Third, geriatricians see themselves as having low status both among the medical community at large and among healthcare and hospital administrators. While all elements are important and require further analysis, the third is particularly relevant for the specifics of this paper because, according to a majority of the interviewees, their low status among the medical community, and, consequently, their limited political power directly affect their ability to promote a more nuanced understanding of aging and its processes. This has negative implications for society both at the individual and at the structural level, but also directly affects geriatricians' ability to influence the organization of long-term care. Dr. R, a male geriatrician practicing in Rome, Italy, explains:

> To this day, acute care still appears to be a more valued asset than chronic care. This does not make sense at all if we consider that most people, particularly in countries with aging populations, are affected by one or more chronic conditions. Nevertheless, hospital administrators prefer to invest in flashy departments like cardiology than in post-acute structures for the elders. Therefore, in the last ten years, geriatric departments across the country have been dismantled or fused with other departments. This applies to us as well. A cardiologist or a neurologist has more value and, consequently, more political power than a geriatrician. What we do is still highly devalued and, honestly, poorly understood.

Dr. J, a female geriatrician working in New York City, echoes this sentiment:

> I tell people a sort of an anecdote. I graduated from medical school in 1983, so I've been a geriatrician for 30 years if you start with the end of my training and my first job after [my] fellowship. When I was a resident and I went [inaudible] with one of the program directors, he said, "Don't go into geriatrics. It's for losers." And that was the general gist. You went to geriatrics because you couldn't do anything else. Now it's changing, but we still spend a lot of time justifying our existence.

Both doctors highlight a very interesting contradiction in contemporary post-industrial societies with aging populations: to this day acute care continues to be valued more by the medical community, health care administrators, and politicians, than the management of chronic illnesses and long-term care. This is particularly interesting when we consider that in both Europe and the United States, chronic illnesses are considered one of the biggest challenges of contemporary healthcare systems (Nolte et al., 2014; Raghupathi & Raghupathi, 2018). In addition, the quotes highlight why it is so difficult to recruit geriatricians in both contexts, given the low interest demonstrated by colleagues and health administrators in supporting geriatricians in their work together with the low value, both political and economic, that is placed in caring for older adults. Finally, both quotes illustrate how ageism and its negative dimensions, far from being limited to its direct subjects, spills over to encompass professionals involved in the care of elderly populations (Ayalon, 2020; Ball 2018; King, Roberts, & Bowers, 2013).

According to geriatricians, these practices, and the cultural and ideological discourses that support them, make it very difficult to garner the necessary strength to call societal and political attention to aging and the growing need for long term care. In addition, they hinder geriatricians' ability to promote open conversations about biological aging, the variety of patterns it may follow, the changes it can bring, and the potential ways to address them. In the next sections I will discuss three specific areas that, according to geriatricians, are particularly affected by their absence: these are education, evaluation, and treatment.

Understanding Aging and Its Processes

When asked to discuss the potential downside of having small numbers of geriatricians in the context of growing numbers of ageing adults, respondents in both countries pointed to a lack of attention and a failure to acknowledge the reality of ageing and its needs at the structural level, coupled with a lack of accurate information and understanding of the process itself. Dr. C., a U.S. geriatrician operating in New York City, explains:

> The medical community has failed to communicate to society the reality of aging and what that entails. It has failed to communicate how important it is to prepare for it in terms of economic resources certainly but also in terms of thinking about what one would want for him/herself. We have started to do that for advanced care directives, but we do not have that for long-term care, we haven't really told people to prepare for it. So, these problems tend to sneak up on families.

A similar preoccupation, albeit presented in different terms, emerges in the words of Dr. P., an Italian geriatrician practicing in Rome. He states:

> The fact that there are so few of us means that only a few aging

> adults have the chance to meet us early on … For the most part, until there is bigger problem, they keep going to their GPs. This is great, but it does not help them to understand that at 75, while you may still feel healthy and young, you are entering a different stage of the life cycle, one that may require a different approach and, in time, some changes, not only from a medical perspective … In other words, it allows for a collective denial of what is going to come.

Independent of national context, geriatricians discuss how to this day institutions fail to fully acknowledge ageing and the overall graying of the population as a central aspect of contemporary society. Denying these realities does not permit the medical community to shift its attention to where is needed, namely in the management of chronic disease, potential physical and cognitive deterioration, and the varying care needs that these developments may generate. In addition, these doctors point out some of the consequences that this approach generates both at individual and the structural level. At the individual level these processes fail to promote a full acknowledgement of the reality of aging in all its complexity and variation, including the potential physical and cognitive deterioration that accompany it. This failure, in turn, neglects to produce an individual reflection on how to address these declines not only in terms of wish and desires, as pointed out by Dr. C., but also in terms of care needs, potential care burden, and economic preparedness. On the contrary, coupled with the culturally and economically enforced requirement to remain *young* typical of wealthy, post-industrial society, these same processes promote a collective desire to deny this stage of the life cycle or avoid it as long as possible. Dr. M., a geriatrician working in the Italian region of Campania, elucidates:

> In the current moment, our society sees aging as a loss of value, as negative. It is a stage of human life that needs to be postponed or hidden. We have heard it every day, read it every day during the pandemic: “It is only old people who die” as if their life had less value than that of others. This is wrong because it is more than ageist, it openly suggests that older people are second class citizens who have less value. In this context who would want to see or define themselves as old? Who would want to acknowledge this reality?

The fear of being understood or seen as *old* became even more prominent during the COVID-19 pandemic when being labelled as *old* not only meant a loss of value and respect, but also, potentially, the difference between life and death. As witnessed during the COVID-19 pandemic, aging adults, and particularly the oldest old among them,[4] were approached predominantly through the lens of chronological age and not, as geriatricians would argue, through a multi-level assessment of comorbidities and functional abilities

(Cesari & Proietti, 2020). This means that often the oldest old end up being considered expendable in terms of resources, funding, and efforts, even when their physical and mental conditions are better than those of much younger patients. Dr. L., a geriatrician practicing in New Jersey, explains:

> I took care of a guy who into his early 90s his love was hiking in the Swiss Alps, and every summer he spent a month hiking in the Alps … Here was a person who was traveling, was physically robust, and for that kind of person I'm much more willing to be aggressive, because their functional status, and their disease burden is so low my gut is telling me that they have – with exception of dying of a stroke or a heart attack […] still have more years left to live that are probably good. As opposed to somebody with the six diseases and 12 medicines. So, it's not age alone, no. It's really – it's their level of frailty/co-morbidity.

This misunderstanding of aging and its dynamics became so dangerous that the American Geriatric Society felt compelled in 2020 to produce a position statement aimed at "stakeholders including hospitals, health systems, and policymakers about ethical considerations to consider when developing strategies for allocating scarce resources during an emergency involving older adults" (Farrell et al., 2020, p. 1137). The goal was to replace arbitrary notions on advanced age with a scientific review of existing literature conducted in collaboration with interprofessional experts in the fields of ethics, laws, medicine, and nursing.

A limited understanding of the aging process also affects how individuals, and their families respond to the increased need for care often associated with longer life expectancy. Dr. T, a female geriatrician working in Turin, Italy, elucidates:

> The lack of understanding of how aging progresses is a problem, a problem that is reflected also in the ways in which families manage care provision. The common misconceptions I deal with are … I would say, three: one, that the process of body/mind deterioration [determined by aging] is a progressive development that does not end or resolves itself quickly; two, that it may take only one small medical event to transform a perfectly functioning older adult into a fully dependent person; three, that caring for an aging adult is not like caring for a child. The families I work with often hire a home-care assistant in the same way in which they hire a baby-sitter. They hire somebody only to get over a small hurdle, something that will get better in time, but it is not like that. It can be for some time, but at any moment things can escalate or they can degenerate in patterns that are not necessarily linear.

The result is that often individuals and their families face the growing need for long-term care as a short-term crisis instead of an enduring event often requiring increasing levels of intervention. This means that families tend to respond to the growing need for long-term care in a private, individual manner, as quickly as possible, and, often, particularly in Italy where market options are limited, through cost containing options found predominantly in the informal labor market (Degiuli, 2016). This is, once again, problematic at different levels. At the individual level, urgency defeats quality, and care plans, instead of being assessed professionally with the well-being of the aging adult in mind, end up being devised predominantly based on family needs and capabilities. At the structural level, urgency and need fail to produce a collective reflection on ageing that would generate societal demands and require or, at least, encourage politicians, healthcare administrators, and policymakers to address long-term care and its provision in a more systematic manner. Dr. M., an Italian geriatrician operating in a hospital in the vicinity of Turin, explains:

> There is a sort of blindness from the part of the administrators and politicians insofar they do not see how important it is for contemporary societies to keep the aging population healthy and able. They think it is a waste of time to spend money and resources on the oldest adult because they will end up dying. They do not understand that supporting them allows to support the entire network involved in the care of that adult. It is a valuable expense because it relieves the load on families, on personal and homecare aids, and this is a serious problem. To this day spending money on things that shine and look good like a reanimation unit, an expensive cancer medication, is still considered a priority.

This "blindness" is perilous because it prevents a full understanding of the impact that long-term care management and provision has, not only on the social actors directly involved, but also on large swaths of the population directly and indirectly related to them. Care and its provision are, in fact, social and collective processes that affect and shape relationships at multiple levels and areas of social life: at the micro-, meso-, and macro-level, and across institutions, from family to work, from immigration to global/national politics. And while these ideas have gained some traction at the policy level in terms of childcare, little to no conversation on this has been generated for aging and long-term care.

Assessing Patients, Managing Care, and Defining Goals

The limited availability of geriatricians also means that the American and Italian health care systems lack specialists capable of accurately assessing the needs of a complex population, or the ability to respond to it in a nuanced and effective manner. To this day aging adults, and particularly the oldest old among them,[5] continue to be understood and addressed predominantly through the lens of chronological age, an approach that geriatricians consider simplistic and dangerous at the same time. Dr. F, a geriatrician operating at a nursing home in New Jersey, explains:

> Labelling the population only in terms of chronological age is inaccurate because it lumps together older adults who display enormous variation in terms of cognitive and physical abilities. If we look at the numbers this way, the problem of aging becomes daunting, and no one wants to deal with it. The reality is much different.

In place of using chronological age, geriatricians argue for a multi-dimensional and multidisciplinary assessment of aging designed to evaluate functional ability, physical health, cognition, and mental health as well as socioenvironmental circumstances. Dr. Z., a male geriatrician practicing in Turin, Italy, explains:

> Geriatricians are trained to see their patients in their globality. We assess physical function, the composition of the family in which the patient lives, the relationships that go on between the patient and his wife, the patient and his daughter…we need to use psychology to fully understand the patient.[…] Sometimes they hide.[…] One needs to spend some time with them to fully understand what is happening in their lives—the stressors[…]Everything matters from a medical point of view.[…] If he comes with a swollen knee, I can't just look at his knee.[…] I need to assess his diet—if he eats or not. I need to assess if he is still able to move if his living conditions allow him to go out or not. I need to make sure that there is no underlying depression. Older adults are complicated because they are often subject to multiple pathologies at the same time, and it is crucial to understand what is causing what.

This approach, which differs from that of general practitioners and other specialists, is crucial according to the interiewees because it allows them to obtain a full picture of the current conditions of the patient—physical, mental, but also social—as well as an assessment of all possible interactions capable of increasing patients' fragility[6] in the future. This, in turn, allows them to provide patients and their care networks with an overview of their current care needs together with a tentative prediction for future ones. Finally, this comprehensive and dynamic view of a patient overall status in the present and the future also allow geriatricians to help patients and their networks evaluate the pros and cons of different care options. Dr. L, a New York geriatrician operating predominantly in an outpatient clinic elaborates:

> I think one of our roles as a geriatrician is a capacity assessment.

> Do [patients] have the insight, the capability to decide what care would be most safe for themselves? For the most part, they don't for a variety of reasons. This is part of – I think as a geriatrician, this is what we do all the time, making a mental status evaluations or gait problems, looking at complex evaluations and finding clues.

In addition, geriatricians' multi-dimensional evaluations help to fully highlight, for individuals but also for stakeholders and policymakers, how important it is to bridge medical and social needs. Dr. E, a female geriatrician working in Atlanta, Georgia, explains:

> Taking care of aging adults in a sensible manner requires thinking not only about medical issues, but also social issues … but also about very practical things like transportation or company. As they say here, to take care of them properly 'requires a village.' We should think about the problem from different angles and come up with multidisciplinary, multilevel solutions.

Conducting evaluations on a wide scale, and using a standardized format across states and/or regions would also help to address the issue at the structural level. Dr. G., a geriatrician operating in Rome and head of an important Italian NGO concerned with the well-being of the aging population, explains:

> If we could generate a standardized multi-dimensional evaluation widely adopted not only by geriatricians, but by all medical structures and professionals who treat aging adults, we would be able to collect data useful for many, for healthcare administrators and professionals, politicians, and policymakers who would gain a full view of the existing needs of the population, needs that are both medical and social and that are often hidden and addressed at a great cost, both economically and emotionally, by individual families.

According to the majority of geriatricians interviewed for this project, bringing to light the full extent of the existing need for long-term care would be beneficial at all levels: at the individual level, it would help individuals and their families feel less isolated, allow for a freer exchange of information among different members of the care network, and generate collective conversations about aging that could possibly produce collective demands. At the policy level, it would provide stakeholders with statistical evidence of the complexity, extent, and magnitude of the issue which possibly would prompt action, while at the same time offering a roadmap of where to intervene first, in what ways, and with what tools.

Lastly, according to the interviewees, low numbers of geriatricians and a limited understanding of geriatric principles also affect the quality of medical care that patients receive. This too has great consequences: at the individual level, it affects the quality of life of the individual, at the interpersonal level, it impacts the relationships with both formal and informal caregivers, and at the structural level, poor medical care has the potential to exacerbate costly problems such as repeat visits, unnecessary testing, stressful and often damaging ER visits, and/or hospitalizations. Interviewees argue that a lack of specialized care is particularly problematic because it generates two somewhat contradictory outcomes. On one hand, when older adults continue to see their regular GPs instead of switching to a geriatrician they are subjected to the same protocols and requirements applied to the general population. This means that often when a medical problem emerges, GPs assess the problem and direct patients to different specialists for each of their ailments. The result is that older patients can end up with extensive and complex medication regimens that, over time, may lead to overmedication, overtreatment, or negative interactions. As in the case of ageism, this issue had been addressed as early as 2013 by the American Geriatric Society in collaboration with the American Board of Internal Medicine through an awareness campaign[7] and through other publications (including AGS 2019), as well as by the Italian Geriatric and Gerontological Association through presentations at national and regional congresses (among others Ferrara, 2018). Nevertheless, this issue continues to be a concern. Dr. F., a geriatrician working in Pennsylvania, elucidates:

> This is something that we as geriatricians see often and try to focus on, it's called polypharmacy and it is a real issue. Many of the people we see have, over the years, had several health issues and seen several specialists, and you know, they come in with a laundry list of drugs and we take a close look at them because these drugs when not carefully managed in terms of interactions and benefit can cause more harm than good. We do have a digital system in place to catch the bigger issues, but they do not always catch all the potential side effects or risk of adverse effects specific to the older populations … like increasing dizziness and therefore the risk of falls or other things like cognitive issues … for example in the general population we worry above all about strokes or heart attack, but for seniors the risk of falling and breaking their hip and/or hitting their head and dying are very real and, somewhat, underestimated.

On the other hand, because of their age, some of the health and/or behavioral problems created by overmedication and/or negative interactions, instead of being thoroughly investigated and addressed, tend to remain unidentified and often ascribed simply to the condition of "being old." Dr. P, a female geriatrician working in a small town in the region of Piedmont, Italy, explains:

> Just to give you an example […] I have a patient who has dementia—a frontal-temporal dementia characterized by behavioral

> disinhibition and apathy. He says inappropriate things; he has no self-restraint—is agitated and often confused. His wife died four months ago, and she was his caregiver [...] He was a writer, a truly brilliant person, who had had a bad case of polio when was young and was in constant pain [...] Chronic pain as you know is a big problem in older adults, and because of that he was followed by an anesthesiologist to control it. This specialist had given him two medications—very effective—but that, in elderly patients, can cause agitation and confusion. His GPs did not know that, or had not been paying close attention, in any case he didn't catch it. Three months ago, the patient fell in his house, and he broke his leg. He was recovered in the ER and then was brought up to our [post-acute] department. At the beginning he was considered capricious—truly unbearable—and nobody wanted to work with him. He was intolerable with his family and with the physiotherapist assigned to him. They all thought that his behavior was connected to his age. Truthfully, it was a terrible combination ... frontal-temporal dementia stimulated by the medications given to reduce the pain—a perfect storm. I said, 'No, let's not give up on him.' I called my colleague and asked to revise the protocol. A week later his daughter called me saying 'What did you do? My father is more present, he wants to work, he asked for his computer, he doesn't call me every five minutes.' And I answered: 'What happened is simply that we tried to understand your father.'

As the quote indicates, a greater ability to understand older adults in all their complexity and with an eye to their individual histories, skills, and needs, coupled with expert knowledge helps to improve not only the quality of life of older adults themselves, but also that of the entire formal and informal care network surrounding them. This has an enormous positive effect for relationships, working conditions, care burden, and overall well-being of all subjects involved. Finally, doctors interviewed for this project point out that greater access to geriatricians or other personnel trained in geriatric principles would allow an approach to aging and its management less focused on discipline-specific guidelines aimed at extending life, and more on patients' goals. Dr. V., a geriatrician working in New York City, explains:

> As geriatricians we look primarily at the patient's goals. I think that one of the main things that we do is to understand how patients' goals fit into what treatments are available. So I think, sometimes, people have—there's a problem and people look for a treatment per se, but they don't really look at what the goals of the patients are. Will it really benefit someone as they're older? And

> one kind of example is that let's say you are age 40 or 50 and have diabetes. In this case the goal is really to be tighter and stricter in monitoring the sugars and make sure that distributors are low because we need to make sure that you arrive at 60s or 70s in good conditions. But [once] you are in your 80s and 90s we can become more liberal in monitoring your sugars. I think we're coming at it at a holistic approach. We're saying, "Well, okay, well, you don't treat an 80 or 90-year old with a diabetes the same as you treat a 40 or 50-year-old." We question and think about those things and do not prescribe aggressive treatment for someone when that can actually harm them.

The thinking of geriatricians aims at placing aging adults at the center of medicine and not as an afterthought. While this is crucial to increase the overall quality of their living and to help society at large to understand the different needs of biological aging, it would also help managing and reducing the cost of care in a way that would benefit individuals but also institutional actors.

Conclusions

The interviews with American and Italian geriatricians bring to the fore patterns and contradictions underlying the ways in which these two post-industrial societies, very different in their configurations of welfare and healthcare systems, approach the graying of the population and the increasing need for long-term care. The geriatricians interviewed for this project demonstrate that the actual process of ageing and its many complex and varying dimensions continue to be poorly understood by the stakeholders involved in its management. These stakeholders include hospital and healthcare administrators, the medical community, politicians, policymakers, as well as society at large. In practice, this means that to this day governments, healthcare systems, and the medical community not only have failed to fully acknowledge the extent of this new reality and to provide a systematic approach to the demands that aging generates, but, through their inaction, have supported a negative and stigmatizing understanding of it. In turn, this has promoted and continues to promote a devaluation of all the subjects involved, from aging adults to the people who care for them both formally and informally. This devaluation has also meant that despite the growing numbers of aging adults and a shift from acute medicine to chronic medicine, the attention of hospital and healthcare administrators and policy makers has not followed. To this day both Italy and the United States do not have enough specialized doctors to care for their growing ageing populations, and geriatricians' work and value for society continues to be poorly understood.

According to geriatricians' own assessments, this approach, or the lack of a systematic approach, to the growing numbers of aging adults and their needs has created multiple problems both at the individual and structural level. To this day aging and its development, which may vary greatly from individual to individual and does not necessarily follow chronological age, continues to be only arbitrarily understood as are the potential physical and cognitive degenerations that the process carries with it. Because of these failures and oversights very little has been done both at the institutional and individual level to prepare for it. At the structural level little has been done in terms of allocating funds to support the population in need of long-term care or in designing and providing services and support. At the individual level, a stigmatization of old age has generated a collective denial that often brings individuals and their families to acknowledge its reality only through a crisis, with little preparation in terms of both care decisions and economic planning. To address these societal, political, and economic issues, it is essential to implement changes at all levels of society and revalue how we understand the aging population and the impact that caring for them has on society at large. In addition, it is crucial to combat ageism at all levels to remove the stigma attached to this stage of the life cycle. It is essential not only to ensure more respect and dignity for the growing numbers of aging adults, but also for those who care for them in different functions: from geriatricians to caregivers, from nurses to homecare aids.

To achieve these changes, policymakers and stakeholders should implement educational campaigns, training programs, and policies aimed directly at the medical community and at society at large. First and foremost, it is essential both in Italy and the United States to address the acute shortage of geriatricians and geriatric healthcare professionals at all levels. This should be done through programs aimed at reducing the costs of education, through economic incentives for students' committing to the specialization, as well as through a valorization of the profession and its goals. Secondarily, it is crucial to develop and promote at the state/regional[8] levels geriatric training for all healthcare providers to ensure an optimization in terms of quality, costs, and caregiver burdens. Third, national Geriatric Scientific Associations in both countries should, in collaboration with other associations such as the American Board of Internal Medicine in the United States or the Ordine dei Medici Chirurghi e degli Odontoiatri in Italy, develop a geriatric multi-dimensional evaluation to be adopted by all medical institutions providing care to aging adults to gather federal/national data on existing social and medical needs of aging adults. Data gathered from the evaluations would help to understand the areas of the needs and potential investment in both medical and social areas. Fourth, geriatricians and geriatrics health professionals should be allocated funding by federal/national governments to develop an educational campaign aimed at informing society at large on aging and its processes and on the need to prepare emotionally, strategically, and economically for this specific stage of the life cycle. Fifth, states/regions should fund, design, and implement campaigns aimed at all ages to combat negative and arbitrary understandings of ageing. These programs should be implemented at all educational levels, in all workplaces, and in public spaces such as, for example, libraries. Taken together these campaigns, programs, and policies will help reframe our current understanding of aging and provide stakeholders and society at large with the understanding and support it needs to address the graying of the population in an equitable and caring manner.

Limitations

Despite the significant contribution that this study makes both in filling a gap in the existing literature and in providing policy suggestions it has some limitations. The size of the sample does not allow for empirical generalizations applicable to the entire category of doctors both in Italy and the United States. In addition, the sample does not capture the range of diversity in terms of age, gender, and race/ethnicity of the target population or correctly reflects their distribution in geographical terms. Similarly, the snowball sampling adopted for the study may have potentially attracted respondents who share a similar understanding of geriatric medicine and its application. Finally, the differences in national contexts between the United States and Italy have been sketched more than fully detailed. However, it is important to keep in mind that this study does not intend to be conclusive. On the contrary, its main goal is to provide a starting point for new research including, but not limited to, ageism in the medical community, understanding of ageing and its processes among the general population, individual and family planning for ageing and long-term care, and comparative analysis of long-term care provision and organization in different countries.

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Endnotes

1 The Italian system is characterized by universal healthcare, relatively generous public pensions, mandated familial involvement, low public investment in long-term care (1.3% of the GDP), and an underdeveloped formal market of care (European Commission 2018) while the American is characterized by an insurance-based health care system, a mixed (public/private) pension system, limited welfare provisions for long-term care, voluntary familial involvement, and a highly developed formal market of care.

2 Unfortunately, the pandemic limited my ability to attend geriatric conferences in the United States. It is for this reason that I decided to include web-based material to the data collection.

3 I chose this approach because in the past two years access to scientific conferences was difficult due to the restrictions connected to Covid 19.

4 As Kahana pointed out in the first issue of this journal and my own personal experience in Italy, aging adults were often treated as expendable in the early phases of the COVID-19 pandemic when medical resources were limited independently from their levels of frailty. For specifics see the studies of Britain (Merrick, 2020) and Italy (Cesari & Proietti, 2020), for benefits, instead, of being co-treated by geriatricians see Piers et al. 2021

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6 The literature discussing frailty and fragility in relationship to ageing is a burgeoning one. I am mentioning it here only in passing because this is how the respondents chose to discuss it. While frailty and fragility were widely discussed in the literature and the conferences I attended, the interviewees did not go into the specific of it during the data collection.

7 Since 2012, the American Geriatrics Society (AGS) has also been collaborating with the American Board of Internal Medicine (ABIM) Foundation, joining its "Choosing Wisely" campaign. The campaign aims to engage healthcare organizations and professionals, individuals, and family caregivers in discussions related to the safety and appropriateness of medical tests, medications, and procedures. Geriatricians collaborated to the campaign by generating two lists titled: Five Things Healthcare Providers and Patient Should Question. The first was published in 2013 and the second in 2014. They are available at: https://www.healthinaging.org/tools-and-tips/tip-sheet-ten-things-physicians-and-patients-should-question.

8 I use this language because in the United States some programs are federal and other are state-based, similarly in Italy some programs are nationally based, but others are regional.

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"Here it was waiting for me:" Diabetes Diagnosis Pathways and Implications for Health Policy

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ABSTRACT

Diabetes in older adults is a growing public health concern with nearly 30% of Americans 65 and older having diabetes. This includes 2.6 million older adults with undiagnosed diabetes who are at high risk of microvascular and cardiovascular complications (Centers for Disease Control and Prevention, 2022). The majority of cases are Type-2 diabetes. The past decade has witnessed an expansion in screening recommendations in an effort to reduce rates of undiagnosed older adults. Drawing on the sociology of diagnosis, we suggest further attention to the social factors that shape the diagnosis process is needed. We examine the diabetes diagnosis process from the perspective of older adults with type 2 diabetes. The data derive from diabetes illness narrative interviews with non-Hispanic White and African American older adult men and women (age ≥50) with type 2 diabetes (N=83). Our thematic analysis reveals four pathways to diagnosis: 1. Annual wellness exam, 2. Workplace screening, 3. Community-based opportunities, and 4. Health event or alarm. Diabetes' early symptoms are often normalized within daily life, with health insurance gaps, providers' dismissal of symptoms, and nonprescription medications reinforcing efforts to address initial symptoms within the home. Wellness visits, as well as worksite and community-based screening, critically intercede in the unfolding of symptoms. In contrast, diagnosis in connection with a health event or alarm carries an additional toll on social and emotional well-being. These findings have implications for national screening policies and local diabetes control efforts.

Keywords: health disparities, older adults, urban population, diabetes screening

"Aquí me estaba esperando eso:" Vías de diagnóstico de diabetes e implicaciones para la política de salud

RESUMEN

La diabetes en los adultos mayores es un problema de salud pública cada vez mayor, ya que casi el 30 % de los estadounidenses mayores de 65 años tienen diabetes. Esto incluye a 2,6 millones de adultos mayores con diabetes no diagnosticada que tienen un alto riesgo de complicaciones microvasculares y cardiovasculares (Centros para el Control y la Prevención de Enfermedades, 2022). La mayoría de los casos son diabetes tipo 2. La última década ha sido testigo de una expansión en las recomendaciones de detección en un esfuerzo por reducir las tasas de adultos mayores no diagnosticados. Basándonos en la sociología del diagnóstico, sugerimos que se necesita más atención a los factores sociales que dan forma al proceso de diagnóstico. Examinamos el proceso de diagnóstico de la diabetes desde la perspectiva de los adultos mayores con diabetes tipo 2. Los datos se derivan de entrevistas narrativas de la enfermedad de la diabetes con hombres y mujeres adultos mayores blancos no hispanos y afroamericanos (edad ≥50) con diabetes tipo 2 (N = 83). Nuestro análisis temático revela cuatro caminos hacia el diagnóstico: 1. Examen anual de bienestar, 2. Evaluación en el lugar de trabajo, 3. Oportunidades basadas en la comunidad y 4. Evento o alarma de salud. Los primeros síntomas de la diabetes a menudo se normalizan dentro de la vida diaria, con brechas en el seguro médico, desestimación de los síntomas por parte de los proveedores y medicamentos sin receta que refuerzan los esfuerzos para abordar los síntomas iniciales dentro del hogar. Las visitas de bienestar, así como las evaluaciones en el lugar de trabajo y en la comunidad, intervienen de manera crítica en el desarrollo de los síntomas. Por el contrario, el diagnóstico en relación con un evento o alarma de salud conlleva un costo adicional en el bienestar social y emocional. Estos hallazgos tienen implicaciones para las políticas nacionales de detección y los esfuerzos locales de control de la diabetes.

Palabras clave: disparidades en salud, adultos mayores, población urbana, tamizaje de diabetes

“它在这里等着我” 糖尿病诊断途径和对卫生政策的影响

摘要

老年人患糖尿病是一个日益严重的公共卫生问题，近30%的65岁及以上的美国人患有糖尿病。这包括260万未确诊糖尿病的老年人，他们极易患微血管和心血管并发症（美国疾病控制与预防中心，2022年）。大多数病例是2型糖尿病。过去十年见证了筛查建议的扩大，以期降低未确诊老年人的比例。基于诊断社会学，我们建议进一步关注影响诊断过程的社会因素。我们从患有2型糖尿病的老年人的角度分析糖尿

病的诊断过程。数据来自一系列糖尿病叙事访谈，访谈对象为患有2型糖尿病的非西班牙裔白人和非裔老年男性和女性（年龄≥50岁）（N=83）。我们的主题分析揭示了四种诊断途径：1. 年度健康检查，2. 工作场所筛查，3. 基于社区的机会，以及4. 健康事件或警报。糖尿病的早期症状通常在日常生活中被正常化，这归因于医疗保险缺口、医疗提供者对症状的忽视、以及一系列促进在家解决初始症状的非处方药。健康访问以及基于工作场所和社区的筛查对症状的出现起到关键的干预作用。相比之下，与健康事件或警报相关的诊断会对社交健康和情绪健康造成额外的影响。这些发现对全国筛查政策和地方糖尿病控制工作具有启示。

关键词：健康差异，老年人，城市人口，糖尿病筛查

Introduction

Reducing the morbidity and mortality burden of diabetes is a U.S. public health priority (Diabetes - Healthy People 2030 | health.gov). However, approximately 8.5 million adults in the U.S. have undiagnosed diabetes, 2.6 million of whom are age 65 and older (Centers for Disease Control and Prevention, 2022). The majority of cases represent type 2 diabetes (hereafter diabetes), the focus of this paper. The past decade has witnessed an expansion in screening recommendations in an effort to reduce these numbers (Davidson et al., 2021). Others note the need to enhance treatment support following diagnosis, particularly for those with the greatest risk of complications (Gregg & Moin, 2021). Calls also exist to address variables such as education regarding the condition's early, indistinct symptomatology (O'Connor et al., 2006). We examine the diabetes diagnosis process from the perspective of older adults (age ≥50) with diabetes. Building on the sociology of diagnosis (Brown, 1990; Jutel & Nettleton, 2011), we argue discussions of diabetes screening policies need to recognize diagnosis as a social process that is deeply informed by the resources and relationships within which older adults are embedded. Efforts to reduce the number of undiagnosed must address the extensive social barriers to early diagnosis.

The Impact of Diabetes

Diabetes is the eighth leading cause of mortality in the United States (Ahmad & Anderson, 2021). The number of severe complications like end stage kidney disease have steadily risen over the past decade (Ríos Burrows et al., 2022). Considerable racial and ethnic disparities exist in rates of diabetes and diabetes complications (Centers for Disease Control and Prevention, 2022). For example, African American men and women have double the risk of death from diabetes than non-Hispanic Whites (Office of Minority Health, 2021). African American adults additionally tend to experience diabetes at younger ages than non-Hispanic White adults (Lee et al., 2019) and lower rates of screening (Casagrande et al., 2014).

Although considerable variability exists in the progression of diabetes (Yudkin & Montori, 2014), older adults in general carry an increased risk of complications (Caspersen et al., 2012), including macrovascular disease and death (Meneilly & Tessier, 2001; Zoungas et al., 2014). Hypoglycemia is an additional threat among older adults, depending on their underlying health status (Abdelhafiz et al., 2015; Bruce et al., 2018; Strain et al., 2018).

The financial burden of diabetes is high. Medical and nonmedical costs for diagnosed diabetes totaled over $327.2 billion in 2017; costs for undiagnosed diabetes totaled $31.7 billion (Dall et al., 2019).

Undiagnosed Diabetes and Older Adults

Improving rates of undiagnosed diabetes is important to efforts to reduce the disease's impact among older adults. Microvascular damage, including retinopathy, initiates early in the disease process, often prior to diagnosis (Harris et al., 1992; Kirthi et al., 2021).

Diabetes' diagnosis is associated with clinically significant reductions in risk factors for diabetes complications, including improvements in blood pressure, aspirin use, and weight loss within the first year of diagnosis (O'Connor et al., 2006). Diagnosis also correlates with modest increases in physical activity (Schneider et al., 2013). Early glycemic control additionally may have a "legacy effect" that reduces complications (Holman et al., 2008; Khunti et al., 2018; Laiteerapong et al., 2018). However, tight glycemic control over time is not without risk (Reaven et al., 2019), with older adults at particular risk of overtreatment (Bruce et al., 2018).

Diabetes diagnosis is hindered by the condition's subtle early symptoms. Common initial signs, such as increased thirst, frequent urination, unexplained weight loss, and fatigue can take months to recognize (Singh et al., 1992). Older adults at times experience additional nonspecific symptoms, such as confusion, or have an absence of symptoms, e.g., thirst can be suppressed with age (Meneilly & Tessier, 2001). Diagnosis is often then "serendipitous," i.e., dependent upon patients identifying concerning signs or receiving care for other conditions (Koopman et al., 2004). Diagnosis is more likely to occur in the context of acute care than in a preventive care visit (O'Connor et al., 2006).

Much of the policy focus regarding diabetes diagnosis has centered on diagnostic criteria, risk factors supporting screening, and the cost-benefit of screening approaches (American Diabetes Association Professional Practice Committee, 2021). Simulation research in the U.S., for example, suggests initiating regular screening between the ages of 30 to 45 can cost-effectively improve quality-adjusted life-years (Kahn et al., 2010). Other note the cost-savings to health systems through diabetes screening (Chatterjee et al., 2010). Population-based screening trials elsewhere, however, found screening of persons at high risk of diabetes does not reduce mortality (Simmons et al., 2012). Identifying a “moderate net benefit” based on systematic review of the literature, the U.S. Preventive Services Task Force suggests lowering screening initiation in primary care from age 40 to 35 for adults meeting criteria for overweight or obesity based on BMI and who have no symptoms of diabetes (Davidson et al., 2021). Missing from these analyses, however, is discussion of the way diagnosis occurs in the lives of older adults, that is, how do older adults encounter diabetes screenings that result in diagnosis; how might policy address the challenges surrounding diagnosis that are encountered in U.S. urban contexts?

Sociology of Diagnosis and the Diabetes Context

Efforts to improve diabetes diagnosis need to more fully recognize that disease diagnosis is an intensely social process, with social conditions shaping not only disease risk, but the construction and assignment of disease categories (Brown et al., 2011; Jutel & Nettleton, 2011). Diagnosis is racialized (Carter, 2021) and entails providers dissecting complex human experience “into bytes and bits of ‘evidence’” (Smith-Morris, 2015, p. 3).

In the case of diabetes, the disease has long been associated with “lifestyle,” a term that connotes the failings of the individual (Carruth & Mendenhall, 2019). Yet, public policy (Carney, 2015; Gálvez, 2018) and systemic racism (Hill-Briggs et al., 2021) critically shape the epidemic across settings. Within U.S. cities, inequities in the built environment, working conditions, and health care access, among other factors, heavily contribute to racial, ethnic, and socioeconomic variation in diabetes (Hill-Briggs et al., 2021). Where and how diabetes screening occurs (Vasquez, 2021) as well as diagnostic criteria (Bunkley, 2021; Hunt et al., 2021) additionally can reflect political and private interests.

This paper seeks to extend these discussions by examining how diabetes diagnosis unfolds for older adults in the urban U.S. context. We take a qualitative approach to identify how diagnosis is situated in everyday life, exploring older adults’ perceptions of their diagnosis. Participants’ discussions provide important insights for both public policy and clinical providers.

Data and Methods

Data Collection

Data for this analysis are drawn from The Subjective Experience of Diabetes Study, a National Institute on Aging-funded study of African American and non-Hispanic White older adults’ (age≥50) experiences with diabetes (N=83). Utilizing a modification of the McGill Illness Narrative Interview

(Groleau et al., 2006), ethnographically-oriented interviewers asked participants to share the story of their diabetes, including the context of the diagnosis and diabetes' management in daily life. The prompt to initiate the interview involved an open-ended statement, "please tell me about your diabetes." The participant was encouraged to begin as they saw fit. With a narrative approach, the participant then guides the discussion, elaborating on elements of the illness and life context that are of personal importance (Chase, 2003). Any descriptions of their disease status, e.g., blood glucose levels, represents their self-report. Participants can emphasize areas of relief or accomplishment as well as misgivings. The illness narrative thus is a window into how illness unfolds and is experienced by an individual within the broader social context (Acuff & Paulus, 2016; Phoenix et al., 2010). The ability to reflect on the meaning of a story as it is told greatly enhances the analysis and interpretation (Chase, 2003). We focus here on participants' discussions of how they came to be diagnosed with diabetes. The study received institutional review board approval from the University of Maryland, Baltimore County. All names used here are pseudonyms. Unique personal details, including distinct illnesses, also are masked.

Interviews were conducted by three qualitatively trained, non-clinician women, matched by race when possible to facilitate rapport. Interviewers met participants in their preferred location, with most participants inviting the interviewer to their home. Meeting in the participant's home stimulated storytelling and introductions to family and friends. Interviewers completed the consent process in-person, prior to the start of the interview. Interviews were audio-recorded and averaged 100 minutes in length. Participants received a US$50 honorarium.

Data Coding

Following each interview, interviewers wrote fieldnotes to capture details of the participant's home, neighborhood, and interactions. Interviews were transcribed verbatim by professional transcribers. The original paired coding process through which data were coded is described elsewhere (Chard et al., 2017). Briefly, the research team reviewed a selection of transcripts (n=8) line-by-line to identify an initial set of inductive codes. Team members then reviewed additional transcripts in order to identify additional codes and test the codebook. This process continued until pattern saturation was reached (n=20) (Saldana, 2016). Rotating teams coded transcripts line by line via qualitative data management software. Throughout our coding and analysis processes discrepancies between team members were resolved through discussion by the entire team; these discussions at times involved returning to the original audio recording. Our process of rotating, dual coding and team discussion was aimed at reducing bias and strengthening validity (Bernard & Ryan, 2010). Demographic data were analyzed using a statistical software package.

Study Sample and Setting

The Subjective Experiences of Diabetes project sample was recruited from a longitudinal study of health disparities in Baltimore city (Evans et al., 2010). We employed a purposive sampling frame designed to fill race and gender inclusion criteria for male and female, African American and non-Hispanic White adults age ≥50. We selected age 50 and above as our inclusion criteria in order to include persons from across stages of later life. A clinical diabetes diagnosis (e.g., blood glucose >7 mmol/L, fasting) was an additional criterion for inclusion; major cognitive impairment was an exclusion criterion. We recruited through this epidemiological project in order to identify participants who were community-living older adults with confirmed diabetes. We then engaged with participants as non-clinicians, as well as independent from the project through which they were recruited, in order to hear the details of diabetes that the participants themselves felt were important.

The study focuses on African American and non-Hispanic White adults because of the city's long history of systemic racism towards African American residents. Decades of redlining and deindustrialization in Baltimore, for example, have led to large racial and socioeconomic inequities in the distribution of amenities and disamenities (Grove et al., 2018). Wide racial and economic disparities exist in the experience of violence, heart disease and diabetes (Baltimore City Health Department, 2017); 26% of residents at the lowest income level reporting unmet medical needs over the previous year (Spencer et al., 2011). Community health assessments also have found a high sense of social isolation among persons living below the poverty line (Baltimore City Health Department, 2017). At the same time, the city is home to strong neighborhood-based civic and religious organizations, activists, and business owners, many of whom devote significant time to the community.

Thematic Analysis

The thematic analysis discussed here involved co-authors SC, LG, and LH engaging in independent close reading of the transcript data coded for diagnosis. The diagnosis code captured participants' discussions of how they came to know they had diabetes, from first indications of sickness through the formal diagnosis and next steps. This close reading also included examining the diagnosis discussions within the broader transcript to identify what brings persons into contact with an opportunity for diagnosis and the experiences following the diagnosis. The first two authors reviewed and reconciled the coding notes on the diagnosis process through a side-by-side comparison and discussion. They then identified patterns or groupings within their coded material that represented major themes (Roulston, 2010). As a validity check, co-authors engaged in additional review of interviews and fieldnotes to identify confirming and disconfirming evidence (Bernard & Ryan, 2010). The co-authors, who represent persons who identify as African American Women (N=2), White women (N=4), and as a White man (N=1) approached each step of the analysis with concern for positionality.

Through this thematic analysis we identified four pathways to diagnosis among participants: 1. Annual wellness exam, 2. Workplace screening, 3. Community-based opportunities, and 4. Health event or alarm. In the sections below we examine the diagnosis experience within each path. We then turn to the barriers and prompts leading to the diagnosis. These include how early symptoms are interpreted, the availability of nonprescription medications, health insurance, and the intervention of family and friends. Within each section, quotations from participants' narratives were selected to provide cogent illustrations of the findings.

Results

Demographic data are provided in Table 1. No significant difference exists in income by race or gender. Fifty-four participants (65%) were born in the city. The remainder had lived there for over 10 years, with a mean of 51 years (SD=17).

Table 1: Demographic Characteristics[a]

Characteristics	**Frequency (%)**	**Mean (SD)**
Gender		
Male	35 (42.2)	
Female	48 (57.8)	
Race		
African American	41 (49.4)	
Non-Hispanic White	42 (50.6)	
Age		
African American		61.5(5.6)
Non-Hispanic White		60.9 (6.3)
Education[b]		
<High school	26 (32)	
High school diploma/GED	36 (44)	
Some college	14 (17)	
College degree	5 (6)	
MA degree	1 (1)	
Monthly household income (U.S. dollars)		
African American		1804 (1451)
Non-Hispanic White		2563 (2179)

[a] N=83

[b] N=82; missing=1

Pathways to Diagnosis

Seventy-five participants (90.4%) offered descriptions of their diagnosis process over the course of their diabetes narrative. Eight participants (9.6%) did not elaborate when probed regarding how they became diagnosed; they noted simply the year they became diagnosed or precipitating events such as an injury, but not the diabetes diagnosis.

Focusing on the 75 participants who described becoming diagnosed, their discussions revealed four major pathways to a diabetes diagnosis (Table 2). For 47 participants (62.7%), diagnosis occurs in connection with a health event or the experience of alarming symptoms, e.g., loss of consciousness while driving or sudden, extreme polyuria. Less than a quarter indicated their diagnosis occurred through annual preventive care exams or in connection with worksite testing. Ten (13.3%) reported being diagnosed through the original community-based epidemiological study from which the sample was drawn. Little gender or racial variation existed in participants' reports of their diagnosis path, except for diagnosis through the community-based study. Six of the 10 participants who were diagnosed through the community opportunity were African American women. The sections below examine each of these paths in more detail.

Table 2: Pathways to Diabetes Diagnosis (N=75)

Diagnosis Path	**N (%)**
Annual wellness exam	13 (17.3)
Workplace screening	5 (6.7)
Community-based opportunities (e.g., research participation)	10 (13.3)
Health event or alarm prompt health care seeking	47 (62.7)

Annual Wellness Exams: "Blessing" Diagnoses

Only thirteen participants (17.3%) were diagnosed with diabetes as part of a wellness visit with a primary care provider, i.e., during a "checkup" or "annual." James, a 64-year-old African American man reported that his doctor had been "telling me for years that I was on the borderline. And then one day she says to me, I'm going to put you on the pills." He further noted, "if someone hadn't told me that I had it, I would never have known it." Although James speculates that he may still be "borderline," he indicated that he takes his medication because of the trust he and his provider have established over the years. Receiving the diagnosis led him to take a diabetes education class and he has become very conscientious about his approach to meals.

In the case of Linda, a 61-year-old African American woman who described being tested as part of her annual gynecological exam, the diagnosis "was a blessing," because it identified what was "coming about." She noted that her urine had become sticky, and she was using the bathroom "a lot." That she "loved water," however, also explained her bathroom use. She further elaborated that because she was not experiencing what she believed to be the central markers of diabetes, fainting or feeling sick, she did not perceive the need to consult a doctor. Linda reported her annual exam revealed an elevated blood glucose that was considered serious. She described many side effects from her initial prescriptions, which has led to ongoing discussions with her provider regarding her treatment plan.

Both James and Linda reveal the negotiations that surround a diabetes diagnosis. For James, it is whether he has diabetes; for Linda, it is the treatment plan. This discussion, including their ability to directly question their provider, is facilitated by their ongoing relationship. Such exchanges in turn, particularly in the case of James, further affirms the relationship.

Workplace Screening: "My Sugar Is All Right"

Workplace testing took the form of informal, voluntary testing opportunities and required employer screenings. Both similarly alerted participants to the presence of diabetes prior to a state of alarm. Graham, a 72-year-old African American man, recalled after his diagnosis that he had been experiencing mild urinary urgency, but had not acted. His job duties require a yearly physical, at which point his diabetes was identified and he followed up with his doctor. For Graham, as well as others, work orients life; Graham identified features of work as leading to both his diabetes and its diagnosis.

Joyce, a 61-year-old African American woman, found she had elevated blood glucose when colleagues in her clinical work setting were practicing testing one afternoon. Having just eaten candy, she initially dismissed the results that were in the 300s, thinking "Oh, my sugar is all right." Her coworkers insisted she see her doctor, "I did go and here it [diabetes] was waiting for me."

Across her interview, Joyce reveals that she is very mindful of how she uses her time. Joyce likely would not have consulted a doctor without the urging of her coworkers following the blood glucose test. Joyce explained her approach to provider visits:

> If I got a problem, then I go back. If I, if everything is OK, I'm fine, don't bother me, I ain't going to bother you. You take care of the people that you got to take care of that need your help, I'm OK right now … I have not been, ever been a person that stayed in the doctor's office all the time. Even when I was coming up, my mother didn't go, ever went.

Consistent with her stance that there are situations that require help, Joyce did seek diabetes education following her diagnosis. Having previously worked with patients who experienced amputation due to diabetes, she explained, "I just made my mind up, I'm not going to do that, I'm not going there…" She noted that her doctor had complimented her efforts, telling her she "took control of her own diabetes from day one." Joyce also began sharing with coworkers information she learned about diabetes.

Work screening cut through norms to keep working and minimize symptoms. Both Graham and Joyce are fortunate to have workplaces that supported their follow up and the diagnosis did not impact their livelihood. For Joyce, having a supportive workplace also meant reciprocal information exchanges among coworkers.

Community-based Opportunities: "I Wouldn't Go to the Doctor"

Community-based opportunities for testing, which in this context was offered by the neighborhood-focused research study from which participants were recruited, identified diabetes in ten (13.3%) of participants. Participants' experiences suggest local, accessible testing was particularly vital for very active participants, those who were not well connected to providers, and participants who have found their providers unresponsive to their self-report. African American women credited the community-based screening with identifying their diabetes more than any of the other subgroups in the sample.

Sarah, a 62-year-old African American woman, for example, had multiple symptoms that she did not associate with diabetes. She explained, "I was experiencing every symptom that one could have with diabetes, but I was in total denial … I had tingling fingers, my vision was blurred. I was seeing spots..." Though familiar with the symptoms of diabetes through her professional education, she did not make a connection with her own body, "I'm thinking, that can't possibly be me." Sarah's hemoglobin A1c test (HbA1c) result, conducted through the community research project, was exceptionally high. She admitted that after receiving the recommendation to go to her doctor, "I still didn't go right away." Sarah works full time and belongs to many community organizations, which keep her very busy. When she did call and explained her test results, she received a same day appointment.

Mary, a 65-year-old African American woman, similarly noted that prior to receiving her diagnosis she occasionally had felt dizzy when sitting. At the time, she was not under the care of a provider and struggled with depression. Although she spent much of her life providing care to loved ones, it was difficult for her to give attention to herself. She said, "I was the kind of person where if I really wasn't, wasn't sick, sick, sick, I wouldn't go to the doctor." She indicated that when she had blood drawn as part of the community research project, the project informed her she should seek follow up care for diabetes. This prompted Mary to identify a regular care provider and, "from there I've been trying to do what I need–trying to sort of do what I need to do." This included taking a nutrition class and other wellness seminars that her new provider recommended. She described,

"…that's how I kind of learned about what you need to do and what not do, but at the same time I still don't understand a lot…"

Encouragement regarding follow-up care and having documented test results from the community study were important for participants whose providers were not responsive to self-report of poor health. Jean, a 57-year-old White woman with limited resources, was frustrated with her primary care doctor "because they don't take care of you well, I believe." She described trying to find answers to why she was "feeling bad," asking for further follow-up, and being dismissed. Put off by her provider, Jean brought the emergency department staff her "paperwork" from the community research study. They noted the blood glucose finding indicative of diabetes and provided Jean with her sought-after explanation for feeling ill. She subsequently switched her primary care provider, a move made feasible after she obtained insurance with more expansive coverage through the health insurance marketplace.

Health Event or Alarm: "I Passed Out One Time"

While primary care wellness visits and community-based testing represent pivotal pathways to a diabetes diagnosis, most participants (62.7%) were diagnosed after experiencing a health event or alarming symptoms, including episodes of hypo- or hyperglycemia. For these participants, a diabetes diagnosis often arrived with the additional disruption of a hospital stay and a multitude of diagnoses.

William, a 59-year-old African American man, for example, struck by the intensity of his need to urinate at night, "put a five-gallon bucket by me, by my bed just to see, just because I was curious, and I filled the bucket up within three hours." Feeling increasingly ill over the course of the evening, William went to the emergency department. He recalled being told his blood glucose level was in the 600s and that "if I would have stayed home just one or two more hours, I would have died." William remained in the hospital for two weeks.

Rodney, a 69-year-old African American man, similarly described a health scare that prompted his diagnosis,

> I had lost a whole lotta weight. Matter of fact, I passed out one time. I didn't know what was wrong with me ... My car, I'm thinking it was a joke … I parked, and I started my car up and I couldn't stop it and I'm looking straight ahead, and I saw it [another car] and I had run into this car. I couldn't stop it [my car] at all.

Rodney then gave his car to a relative, remarking "I had just got it and [it was] brand new … I was scared to drive because I said I don't want to kill nobody and I don't want to kill myself." The toll of these health crises thus is both emotional and instrumental, involving the processing of the potential for harm and the loss of the car.

When diabetes is diagnosed as part of an assemblage of health conditions, patients are often very unwell. Jane, a 62-year-old White woman described, "My body crashed when I was 51. I mean literally crashed. I was sick. Everything started going wrong. I was diagnosed with diabetes, and thyroid and arthritis and COPD and you know." Jane had to confront multiple serious conditions within a very short time frame. For Benny, a 69-year-old White male, "pins and needles" and blurry vision resulted in a visit to the emergency department. He was admitted to the hospital and diagnosed with severe carotid artery disease. He vividly remembered the doctor's offhand comment regarding diabetes:

> "We're going to let your primary care doctor handle your diabetes if he wants to put you on medicine or not, we don't know what he wants to do." I said, "Diabetes! I don't have no diabetes." "Yes, you do."

Benny described his embarrassment at the time: "I had soda sitting there. Well, I didn't know I had it [diabetes]!" As with Jane, Benny had to grapple with news of multiple conditions and feelings as if somehow, he was supposed to have known.

Barriers and Prompts to Seek Clinical Care

Throughout participants' diagnosis narratives, but particularly within discussions of health care crises, participants reflected on the reasons for not consulting a health care provider as symptoms were emerging and the prompts that led to a provider. Their explanations for not pursuing clinical care included how changes in their body were interpreted, the availability of numerous non-prescription medications, and health care insurance coverage. The prompts that led to a clinical encounter included obtaining insurance and the intervention of family and friends.

Interpreting symptoms: "It didn't seem abnormal." In describing the illness episodes that led to their diabetes diagnosis, participants suggested that early markers of diabetes were not necessarily missed or ignored. Rather, they were readily explained and resolved using cues from daily life. For example, when participants experienced persistent and excessive thirst, they justified the symptom as normal for a particular season (summertime calls for increased water). In addition, water consumption or a preference for sweet beverages are markers of identity, a habit that represents who one is, as Linda noted with her love of water.

Darrell, a 57-year-old African American man whose work took him outside frequently, attributed his water consumption and bathroom trips to the city's hot weather:

> [A]t that time it didn't seem abnormal because it was in the summer and I was keeping myself hydrated. So, I was thinking along the lines that the more water I put in, the more water had to come out, so I kinda dismissed the fact that there could be a possibility of something being wrong medically.

Darrell noted that shortly after he became cognizant of his heavy water consumption, he "was driving and out of the clear blue, my vision became blurred." He pulled the car to the side and a friend drove him to his primary care provider who conducted a urine test:

> [T]he urine stick was so high that she [the doctor] couldn't get a reading so she suggested that I shut this [the test] down and go immediately to the hospital and when I went to the hospital, they further did more extensive tests like drawing blood and things of that nature and at that time they discovered that I had diabetes.

Increased thirst and frequent urination were incorporated in the rituals of daily life for Matthew, a 63-year-old White male. Matthew described how his habit of consuming sweet beverages intensified silently:

> I'd get home from work or be doing something, and I'd sit there, and I'd load the sugar up on Kool-Aid or, or anything, my coffee had like four teaspoons of sugar in the morning and I didn't realize it. And I kept drinking, drinking, drinking, I couldn't satisfy myself.

Only after visiting the emergency department due to difficulty breathing and severe weakness one evening did he learn he had diabetes. He was hospitalized for two days. Reflecting, Matthew lamented, "I didn't know no better." He elaborated, "I never thought to get tested with diabetic [sic]." A Vietnam veteran who receives his health care through the Department of Veteran Affairs, he asserted that his doctors also did not consider diabetes,

> [E]very time you go you get a blood test and all at the doctors, you know, it's just so simple to do. They check your blood pressure. They test your urine, you know. They take your stool samples and send 'em in but they don't check your blood, your blood sugar. That's crazy. [chuckle] ... you know they [people] got it and they totally don't realize they got it. I never would if I never thought I had it. Never would have thought that, man.

Participants across the study find ready means to account for diabetes' signals. Matthew then suggests it is the provider who needs to provide timely guidance because simply, people "don't realize they got it."

Nonprescription medications: "I … bought all kinds of stuff." The availability of over-the-counter medications also informs home treatment. For example, the common response of women participants experiencing vaginal itching was to obtain commercial products for vaginal irritation and yeast infections. As Evelyn, a 58-year-old African American woman described, "I went to a Walmart and bought all kinds of stuff, Rite Aid, still wouldn't stop itching. Still wouldn't stop itching. Did all I could. All night long, it itch, itch, itch, itch, itch." For Loretta, a 57-year-old

African-American woman, dry mouth and nausea similarly were problematic for months. Along with drinking water "constantly," she turned to a relatively expensive dry mouth rinse at the recommendation of her primary care provider. Describing how she learned that her symptoms were diabetes after visiting the emergency department for unexplained vomiting, she exclaimed:

> And I say well, God, I say you mean, I mean all this time, I mean, I've been feeling nauseous and my mouth being dry and everything because it went on for maybe like four months before I started throwing up ... And when I finally went to the emergency room, that's what they told me. Because my primary care doctor could never tell me why I was feeling, you know, nauseous and my mouth was being dry, you know, until I went to the emergency room and they told me that's what it was, I was a diabetic.

It is striking that Loretta's primary care doctor did not identify her diabetes given her strong family history of the disease that included both parents, a grandparent, and several siblings. Loretta herself even anticipated "eventually that I would probably get it because it runs in my family."

Early symptoms, thus, at times are visible and are readily, but inaccurately, explained by context. Participants respond in ways that are familiar and consistent with their understanding of themselves -a love of water, a response to heat, and the promise of over-the-counter medications to discreetly resolve a vexing irritation.

"The insurance don't kick in 'til June." While health insurance coverage is an established correlate of diabetes management (Lee et al., 2019), our findings additionally highlight how health insurance coverage shapes decisions to consult a provider for preventive or acute care and the level suffering prior to diagnosis. Regarding office visits, obtaining insurance that covers routine office visits is an impetus for scheduling a wellness examination that then reveals diabetes. One female participant described her thought process after her health insurance coverage expanded: "I figured I should get to the doctor … I went because I had the insurance and I said it's time to go and just get checked and stuff." The wellness visit identified her diabetes.

Gaps in health insurance in turn can extend participants' experience of troubling symptoms. May, a 65-year-old White woman, lost her health insurance after being forced out of her retail clerk position. In the gap between the job loss and her eligibility for Medicare, she developed a severe bladder infection. She described:

> I didn't go to the doctor for it and it kept getting worse and worse and [friend] was here then and he kept, I wasn't eating or eat very little and then he said to me, the way I looked and everything, he said, 'you got to go to the doctors.' And I [said] 'no, I'm not

> going. The insurance don't kick in 'til June.' So soon as the insurance kicked in, and I was feeling so bad, I said to [friend], 'come on, take me over to the hospital.'

During May's weeklong hospitalization, she was diagnosed with diabetes and started on insulin. May directly related her reliance on insulin with her lack of insurance. She described, "I mean if I had insurance I would have went to the doctors and they probably would have found this [diabetes] out and I probably wouldn't be on insulin today. I'd probably just be on the metformin." May further noted that she still is paying off the money owed for the hospitalization.

Friends and family: offering alerts and intervention. For participants whose symptoms continue, friends and family play a central role in sounding alarm. Above, May's friend urged her to consult a provider and brought her to the hospital as soon as she consented. Similarly, Evelyn, also above, vividly recalled how she "kept using the bathroom and diarrhea and feet got cold … and I got so stumbling and weak," at one point cutting her hand in a fall. It was Evelyn's significant other who contacted her doctor, telling Evelyn, "You're not eating and you're using a lot of water, drinking a lot of water, drinking a lot of fluids but you're not eating nothing.""

Chuck, a 66-year-old white male, said he was fortunate to have completed contract work for a physician who he was able to telephone for guidance as he was increasingly not feeling well:

> I called him up. I said I don't really feel great. I don't know what's going on … I feel like I can't get enough to drink and constantly have to go to the bathroom and I feel kinda tired. I said I hope not I said but I think I might have diabetes.

Chuck described his friend's response:

> [H]e [the doctor] says, 'come on over, I'll work you in, just come over ... I'll send you down to the lab to get some lab work done, but I'm going to test your blood right here.' My God, it was, phew, super high.

Chuck was started on "pills and with an evening injection." Although very much alarmed at the time of his diagnosis, he credits his friend's quick intervention with limiting the overall impact of diabetes on his life.

Discussion

Consistent with prior research, our examination of the diabetes diagnosis process found that diabetes is not commonly diagnosed through wellness visits with primary care providers (O'Connor et al., 2006; Peel et al., 2004). Rather, diabetes diagnosis more often occurs in the context of distressing symptoms, which may involve terrifying experiences of sudden blurred vision or loss of consciousness while driving, emergency visits to the doctor, or extended hospitalization.

The identification of diabetes within other health events results in little time for detailed answers to questions and limits the development of a multi-dimensional treatment plan. Among participants in this study and elsewhere, this lack of information at diagnosis contributes to feelings of distress (Peel et al., 2004). Participants further expressed chagrin that crises and hospitalization led to the prescription of insulin. In addition to concerns regarding the use of needles (Wallace et al., 2017), insulin carries a heavy stigma (Della et al., 2016). While further research is needed to fully evaluate how the diagnosis context shapes treatment plans, participants' narratives suggest a threefold effect of diagnosis in the context of complications: the loss of autonomy in treatment decision-making, treatment plans forefront pharmaceutical intervention, and diabetes carries an additional taint of fear and distress.

The unfolding of diabetes within an episode of hyper- or hypoglycemia or with an assemblage of secondary conditions also extracts a toll on patients' social well-being. Participants like Rodney suddenly find themselves unable to drive. In the absence of safe, accessible public transportation, no longer driving means staying home and increased isolation. Rodney describes his decreased involvement with previous hobbies after transferring his car to a relative. He also is not able to provide rides to others, his means of social connection and sense of purpose. Thus, diagnoses that occur after the onset of complications can carry additional hidden costs, particularly damaging independence and quality of life.

In contrast, although few participants report being diagnosed as part of a wellness visit, participants' narratives reveal such visits provide time to process the diagnosis and examine how nutrition and physical activity can facilitate blood glucose control. Certainly not all participants diagnosed through routine screening follow the recommendations of their providers, but screening can lead to greater discussion and reflection. Within such conversations patients interpret the meaning of a diagnosis (Ledford et al., 2020). The case of Joyce, and others in the study, provides further support for the argument that in the diagnosis process patients, as well as providers, articulate their values and negotiate their relationship (Jutel & Nettleton, 2011).

Worksite screening and community encounters with testing, which in this context came in the form of a traveling, neighborhood-based research study, also represent key sites of diabetes diagnosis. Given the unresolved ethical issues surrounding workplace health promotion (Kuhn et al., 2020), particularly for older workers (Robroek et al., 2012), we are not advocating for expanding worksite screening. We suggest further research is needed to identify how employer-based diabetes screening shapes the worksite and the experience of diabetes.

The opportunity for screening near home or at work, outside of a clinical office visit, however, does importantly address gaps in care for participants across socioeconomic statuses. These findings are consistent with studies of community interventions (e.g., Marshall et al., 2013). That African-American women disproportionately indicated their diabetes was identified through the community study further suggests community-based screening may be a valuable means to reach minority women (Berkley-Patton et al., 2020). Participants' narratives further reveal community-based screening serves as an independent arbiter. For participants who are uncertain of the significance of their physical experience or need a justification to visit a provider, community screening substantiates the need for care.

The findings additionally speak to the interplay between insurance access and diabetes, supporting quantitative data indicating health insurance coverage improves diagnosis rates (Baicker et al., 2013). The absence of health insurance played a direct role in participants' analysis of their symptoms and the decision to delay a provider visit. Those who fell into insurance gaps while waiting for Medicare experienced extensive suffering. In contrast, gaining access to benefit plans that promote wellness visits helps initiate care, particularly among those who must rationalize an office visit.

Participants' diagnosis narratives reveal that daily life frequently provides an explanation for common harbingers of diabetes, such as increased thirst. "Normal" shifts across seasons and phases of life, with cultural schemas shaping symptom interpretations (Metta et al., 2015). The urge for water or a sweet beverage can reflect simply who one is. In addition, the proliferation of non-prescription medications, such as for dry mouth or vaginal itching, reinforces the sense that conditions are appropriately managed in the home. Recognizing how diabetes' symptoms are understood within context reveals not widespread denial, but rather rational self-interpretation and codes of self-reliance. Looking back, participants note not just how polydipsia and polyuria are incorporated into work and home life, but also times that their providers have missed these signals. As Koopman et al. (2004) argue, clinicians need to be alert to these explanatory models (Kleinman, 1980). Self-descriptions that reflect local codes as well as individual experiences and expectations may lack uniformity and not align with physician's expectations (Smith-Morris, 2015).

The findings also add to understanding of the role of family and friends in diabetes care seeking. Much evidence exists regarding the influence of social networks on diabetes risk and disease management (Schram et al., 2021). Participants' experiences further suggest family and friends have timely insights on behavior and are important advocates for diagnosis. These results underscore the dangers of social isolation and add further support to efforts to expand the venues for health discourse (Palmer et al., 2021).

Policy Implications

Participants' narratives of their diagnosis experience have several policy implications. Much of the current discussion of diabetes diagnosis focuses on the targets for screening in primary care settings. Consistent with earlier research (O'Connor et al., 2006), our findings indicate that diabetes among urban older adults is not commonly diagnosed through routine screening within primary care settings. Although this study was not designed to assess physician screening rates within primary care, participants' discussions reveal gaps in their primary care. For patients such as Loretta, who meets many of the criteria for diabetes screening, her physician neglects to evaluate for diabetes; she ultimately is diagnosed in the emergency department as her condition grows steadily worse. These findings mirror data elsewhere that city residents, particularly minority and low-income residents, have insufficient access to quality care (Turpin et al., 2021), and the high reliance on hospital-based care (Mahmoudi et al., 2020). The challenge of primary care access among urban populations, many of whom are at high risk of diabetes, needs to be more directly addressed in the development of national recommendations for diabetes screening.

These findings also offer an alternative perspective on national recommendations that "community screening outside a health care setting is generally not recommended because people with positive tests may not seek, or have access to, appropriate follow-up testing and care" (American Diabetes Association Professional Practice Committee, 2021, p. S26). The recommendation offers tentative support for community screening with "adequate" referral. We found that having test results from a community screening led participants to follow up care. In the case of Sarah, the call to her provider likely would not have occurred in the absence of the results. Similarly, persons without a provider were motivated to find a primary care provider. We also note the value of community screenings for those, like Jean, similar to Loretta, whose physicians are unresponsive to their symptom report. In other words, it is precisely because older adults in urban neighborhoods are at high risk of suffering silently from diabetes, may have considerable work or other demands on their time, and/or do not have adequate primary care that community-based interventions are needed. We agree that referrals are important, but the value of targeted community outreach itself needs to be more firmly recognized.

This is not an argument for mass screening, which has mixed evidence in terms of effectiveness (Kahn et al., 2010; Simmons et al., 2012), and risks detracting from social programs addressing underlying social inequities (Vasquez, 2021). We also recognize the serious risks of over diagnosis as well as pharmaceuticalization (Hunt et al., 2021; Yudkin & Montori, 2014). Our aim is to highlight the diagnosis gaps for older adults in urban communities for whom diabetes is unfolding. Participants' narratives offer the intriguing proposition that specific outreach might reduce the occurrence of diagnosis through crisis and support older adults' treatment autonomy.

Finally, lack of insurance powerfully shaped how participants assessed their symptoms and the pursuit of care. The findings add qualitative support to arguments that insurance coverage enhances diabetes diagnosis and shapes treatment (Baicker et al., 2013). Participants' experiences also underscore the risks to the estimated eight percent of adults with undiagnosed diabetes who are not yet eligible for Medicare and who did not gain health insurance under the Affordable Care Act (Myerson et al., 2019).

Limitations

While the study's sample includes older adults who have had a wide range of work and life experiences, only 20 (24%) reported attending any years of college, with just six reporting a bachelor's degree or beyond. This college attendance rate is not unexpected for this age cohort (Administration on Aging, 2021). However, the findings might not reflect the experiences of those with higher education. In addition, with our focus on city-dwellers, we do not capture the diagnosis process of rural older adults. At the same time, many of the experiences described are like those of more rural populations (Della et al., 2016; Lobo et al., 2018). Our data also are grounded in participants' illness narratives. While the accuracy of memory may pose some concern, the goal in examining narrative is not quantitative detail. Rather, the focus is how persons make sense of their experience (Kleinman, 1989; Shapiro, 2011). Thus, while we are reliant on participants' self-report of their clinical encounters, we note narrative approaches help uncover the experiences that are most important to the person (Chase, 2003). Finally, each member of the research team participated in the research process from unique social positions, which often varied from that of the participant in terms of race, gender, and/or socioeconomic history. We acknowledge our inability to eliminate bias; we sought to reduce the impact of social position on our analysis through discussions of the lenses we used to interpret the data, continually referring back to original transcripts, and providing each other with alternative viewpoints.

Conclusion

Older adults' narratives of their diabetes diagnosis reveal that diabetes' early symptoms are often normalized within daily life. Providers' dismissal of symptoms and the availability of nonprescription medications reinforce home treatment. Gaps in insurance access also delay diagnosis. Diagnosis delays that lead to a health crisis compound the toll of diabetes.

In contrast, wellness visits that include diabetes screening, as well as worksite and community-based screening, critically intercede in the unfolding of symptoms. These diagnosis paths also represent important opportunities for older adults to articulate their values with respect to treatment.

The prevalence of undiagnosed diabetes in the U.S. remains a public health challenge. National recommendations and local diabetes control efforts need to consider how diabetes unfolds in the lives of older adults, from those who are isolated and suffering at home to those who are employed and active members of the community. A specific focus on reducing the number of older adults diagnosed through a medical crisis holds promise in shaping their relationship with diabetes and their quality of life.

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Trust Between Physicians and Family Caregivers: Qualitative Insights from Three Family-Centered Academic Medical Centers

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Abstract

Family caregivers increasingly support health care tasks but are not meaningfully integrated into the health care setting in consistent or standard way. Previous literature has established the importance of trust in patient-clinician relationships; yet, little is known about family caregiver-clinician trust, and further, how and when to integrate family caregivers into health care teams so they can better support their relative. This study examined a) how physicians assess and perceive trust with family caregivers, b) the role of culture in trust dynamics, and c) facilitators and barriers to integrating caregivers into health care teams. We conducted twenty qualitative interviews with physicians in geriatrics (n=9) and oncology/hematology (n=11) between January–March 2021. Physicians assess caregivers' competence, reliability/dependability, and fidelity. They assess caregivers' engagement (e.g., asking questions, verbal and non-verbal cues) to determine whether caregivers trust them. Physicians in our study trust other physicians more than caregivers in certain situations (e.g., for objective information, data) while they trust caregivers more than other physicians for information that requires familiarity and time with the patient (e.g., observations in the home environment). When supporting patients from diverse cultural backgrounds, physicians often rely upon caregivers to provide contextual information about relevant cultural norms. Inte-

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grating caregivers into the care team early—when the patient-caregiver relationship is strong—can be critical to providing effective patient care. Technology can facilitate the trust-building process to further support caregiver integration. Building trust-driven partnerships between physicians and family caregivers could be critical for effective communication of important information to support patient care. Guidelines and policies related to telehealth, discussions between physicians and caregivers, tools to screen caregivers for skills and caregiver burden, and reimbursements for partnering with caregivers are important priorities for supporting caregivers and patient care.

Keywords: family caregiving, geriatrics, oncology, trust

Confianza entre médicos y cuidadores familiares: conocimientos cualitativos de tres centros médicos académicos centrados en la familia

Resumen

Los cuidadores familiares apoyan cada vez más las tareas de atención de la salud, pero no están integrados de manera significativa en el entorno de atención de la salud de manera uniforme o estándar. La literatura previa ha establecido la importancia de la confianza en las relaciones médico-paciente; sin embargo, se sabe poco sobre la confianza entre el cuidador familiar y el médico y, además, sobre cómo y cuándo integrar a los cuidadores familiares en los equipos de atención médica para que puedan apoyar mejor a su familiar. Este estudio examinó a) cómo los médicos evalúan y perciben la confianza con los cuidadores familiares, b) el papel de la cultura en la dinámica de la confianza, yc) los facilitadores y las barreras para integrar a los cuidadores en los equipos de atención médica. Realizamos veinte entrevistas cualitativas con médicos en geriatría (n=9) y oncología/hematología (n=11) entre enero y marzo de 2021. Los médicos evalúan la competencia, confiabilidad/confianza y fidelidad de los cuidadores. Evalúan el compromiso de los cuidadores (p. ej., hacer preguntas, señales verbales y no verbales) para determinar si los cuidadores confían en ellos. Los médicos de nuestro estudio confían más en otros médicos que en los cuidadores en ciertas situaciones (p. ej., para obtener información objetiva, datos), mientras que confían más en los cuidadores que en otros médicos para obtener información que requiera familiaridad y tiempo con el paciente (p. ej., observaciones en el entorno del hogar). Al apoyar a pacientes de diversos orígenes culturales, los médicos a menudo confían en los cuidadores para que proporcionen información contextual sobre las normas culturales relevantes. La integración temprana de los cuidadores en el equipo de atención, cuando la relación entre el paciente y el cuidador es sólida, puede ser fundamental para brindar una atención eficaz al paciente. La tecnología puede facilitar el proceso de creación de confianza para apoyar aún más la integración del cuidador. La creación de asociaciones impulsadas por la confianza entre médicos y cuidadores familiares podría ser fundamental para la comunicación eficaz de información importante para apoyar la atención del paciente. Las pautas y políticas relacionadas con la telesalud, las discusiones entre médicos y cuidadores, las herramientas para evaluar las habilidades y la carga del cuidador y los reembolsos por asociarse con los cuidadores son prioridades importantes para apoyar a los cuidadores y la atención del paciente.

Palabras clave: cuidado familiar, geriatría, oncología, confianza

医生和家庭护理人员之间的信任：来自三个以家庭为中心的学术医疗中心的定性见解

摘要

家庭护理人员越来越多地支持医疗保健任务，但并未以一致或标准的方式有意义地融入医疗保健环境。以往研究已经确立了信任在医患关系中的重要性；不过，研究不足的是，家庭护理人员与临床医生之间的信任，以及如何与何时将家庭护理人员融入医疗团队，以便其更好地支持他们的亲属。本研究分析了a）医生如何评估和感知其与家庭护理人员的信任，b）文化在信任动态中的作用，以及c）将家庭护理人员融入医疗团队一事的促进因素和障碍。我们在2021年1月至3月期间对老年病学（n=9）和肿瘤学/血液学（n=11）的医生进行了20次定性访谈。医生评估了家庭护理人员的能力、可靠性和忠诚度。他们评估了护理人员的参与度（例如提问、口头和非口头提示），以确定护理人员是否信任他们。本研究中的医生在某些情况下（例如：客观信息和数据方面）更信任其他医生而不是护理人员，但当其获取需要熟悉病人和花时间与病人接触才能获得的信息时（例如：在家庭环境中的观察），其更信任护理人员而不是其他医生。在为来自不同文化背景的患者提供支持时，医生通常依靠护理人

员提供有关相关文化规范的背景信息。当患者与护理人员的关系牢固时，及早将护理人员融入护理团队对于提供有效的患者护理而言至关重要。技术能促进信任建立的过程，以进一步支持护理人员的融入。在医生和家庭护理人员之间建立信任驱动的伙伴关系，对于有效传播重要信息以支持患者护理一事至关重要。与远程医疗相关的指南和政策、医生和护理人员之间的讨论、用于筛选护理人员技能和负担的工具、以及与护理人员合作的报销，是支持护理人员和患者护理一事的重要优先事项。

关键词：家庭护理，老年病学，肿瘤学，信任

Introduction

Family caregivers (i.e., a spouse/partner, adult child, grandchild) assisting an adult 50 and older supplement formal care from the U.S. healthcare system with 75% of caregivers being responsible for coordinating care and managing medications (AARP & National Alliance for Caregiving, 2020; Wolff et al., 2020). Recent initiatives seek to integrate family caregivers (from hereon, caregivers) into health care teams and the healthcare system broadly (Fortinsky, 2021; Gaugler, 2021; Wolff & Roter, 2011). These initiatives include developing digital health technologies, supportive services for caregivers, funding for care coordinators to liaise with caregivers, clinician-caregiver communication training, and provider incentives (e.g., to physicians for recording caregiver information in the electronic health record, or to healthcare systems for actively involving caregivers) (Friedman & Tong, 2020; National Alliance for Caregiving, 2021; Riffin et al., 2020; Wittenberg-Lyles et al., 2013; Wolff et al., 2017). Despite these efforts to involve caregivers as members of the "team," little is known about the relationship between physicians and caregivers. For instance, they may rely on one another for important information for patient care in the health care setting or in the home. Yet the relationship dynamics between caregivers and physicians—and circumstances under which they may partner effectively—have been understudied (Hoff & Collinson, 2017). In particular, while family caregivers' trust in health professionals has been studied in contexts such as nursing homes, home health, and dementia care (Rogers et al., 2021; Russell et al., 2021; Watkins et al., 2012), examination of physician trust in family caregivers is limited.

One element fundamental to relationships in healthcare is trust, where someone (a trustor) is willing to be vulnerable to another person (a trustee) to perform a specific task (Blendon et al., 2014; Hall et al., 2001, 2002; Mechanic, 1996; Meyer et al., 2007; Rajesh et al., 2003; Stepanikova et al., 2006). Considerable literature has examined trust dynamics in relationships between clinicians and patients and between clinicians and other clinicians (Campos-Castillo & Anthony, 2019; Raj et al., 2018, 2019; Street et al., 2009; Thom et al., 2011). Studies suggest that trust in these relationships is based on multiple dimensions or characteristics such as competence (i.e., skills and training), integrity (i.e., honesty), prior experience, and/or reputation. For instance, a physician might trust a patient to follow clinical recommendations or to be honest about concerns; a patient may trust a clinician to act in the patient's best interest, or to have the skills and competence necessary to provide effective care. Yet little is known about how these dimensions apply to the specific context of clinician trust with caregivers (Fortinsky, 2021). For example, a clinician might trust a caregiver to help their relative follow clinical advice. In turn, a caregiver may trust a physician to make good treatment decisions for their relative. The dynamics of trust between physicians and caregivers could also influence the relationship between physicians and patients. For example, if a caregiver does not trust a physician, they might suggest that their relative enrolls in care with a new physician. If a physician does not trust a caregiver, they may not invite the caregiver to participate in clinical visits. This lack of trust, in turn, may present a barrier to effectively and meaningfully involving and integrating the caregiver into the care team.

Understanding trust dynamics between clinicians and caregivers is essential for identifying ways to strengthen medical training in order to ensure that clinicians are well-equipped to develop and maintain trusting relationships with patients and their caregivers. It is also critical for creating effective legislation to support integration of caregivers into the care team, as well as for developing policies within organizations to incentivize and encourage caregiver engagement. Understanding facilitators and barriers to caregiver integration could serve as additional opportunities for trust-building between physicians and caregivers. Furthermore, given the impact of cultural distance between patients and physicians on quality of those relationships, it is important to understand the potential role of culture on the trust dynamics between physicians and caregivers, who may serve as navigators or liaisons between patients and physicians (Raj, Zhou, et al., 2021; Somnath, 2006; Sullivan, 2020).

The objectives of the current study were to examine (a) how physicians assess whether they can trust a caregiver and perceive or determine whether a caregiver trusts them, (b) the role of culture in trust-building, particularly in terms of the patient/caregiver's cultural background or racial/ethnic identity; and (c) physicians' perceived barriers and facilitators to caregivers' integration into the health care team.

Methods

Study Design

We conducted semi-structured qualitative interviews with physicians at three academic medical centers from January–March 2021 to understand how they assess and perceive trust with caregivers, understand the role of culture in trust dynamics, and identify perceived barriers and facilitators to caregivers' integration into the healthcare system. The study was given permission with exemption by the University of Illinois at Urbana-Champaign Institutional Review Board.

Identification of Participating Institutions

Given our interest in trust-building between physicians and caregivers, we employed a site selection that drew upon exemplar hospitals from the Institute for Patient- and Family-Centered Care (IPFCC) (IPFCC, 2021). The IPFCC, headquartered in McLean, VA, and sponsored by healthcare systems and hospitals across North America, aims to strengthen partnerships between patients, families, and healthcare professionals to improve quality and safety. Specifically, one of the IPFCC's best practices involves changing the concept of families as "visitors" to families as "partners." Accordingly, they have developed a list of fifteen hospitals and/or healthcare systems in the U.S. and Canada that meet at least 15 of 20 criteria regarding (a) hospital leadership's advocacy for family-centered care and family participation; (b) written policies encouraging family input and participation; and (c) materials for patients based on patient and family feedback that reflect family participation policies (IPFCC, 2021).

We selected three large, geographically diverse U.S. academic medical centers from this list as physicians in academic centers may be more likely to have research or training responsibilities that may influence the types of experiences they have with caregivers or want to model for their trainees in clinical care or clinical research in the context of a broader approach towards improving patient outcomes (IPFCC & Vizient, 2021; Washington, 2018; Yaffe, 2008).

Participants

We recruited participants between January and February 2021 through individual emails to physicians listed on institution websites as specializing in geriatric medicine, medical oncology and/or hematology anticipating that these represent specialty care for which patients may be more likely to require support from family caregivers (Bevans & Stemberg, 2012; Kent et al., 2016; Raj, 2020; Wolff & Spillman, 2014). We expected that clinicians in these specialties might be familiar with the challenges associated with trust dynamics with caregivers and might have considered the facilitators and barriers to their integration in health care teams more extensively. We expected that findings from participants in this study could be valuable for developing specific recommendations for other medical institutions.

The individualized email, which included the study goal (i.e., wanting to learn more about how clinicians identify and build trust with family caregivers of adult patients), was sent to 166 physicians across the three institutions over a period of one week. To limit our sample to physicians supporting adult patients, we did not email any physicians who were listed in pediatric hematology/oncology. After one round of emails, we recruited 13 participants who completed the interview. Although we had reached saturation in that no new themes were emerging within or across institutions and we were observing consistency in emergent themes, we continued to recruit participants by sending a second email to non-respondents and recruited seven additional participants in order to ensure further consistency. Among physicians who were not enrolled, other than non-response, the most common reason for not participating was limited availability due to COVID-19 patient care responsibilities followed by duties that involved limited clinical care.

Procedures

One of the authors conducted all interviews via videoconferencing (Zoom) while the other observed. We used an interview guide adapted from previous work on physician trust (Raj et al., 2019). Interviews were 30-40 minutes and followed a semi-structured interview protocol. We asked participants four main questions: (1) How do you assess whether you can trust family caregivers?; (2) How do you determine whether caregivers trust you?; (3) How does culture (of the patient and/or caregiver, in terms of their cultural background) play a role in your trust-building practices with caregivers?; and (4) What are the facilitators and barriers associated with integrating caregivers into health care teams? Upon hearing the first few participants comparing trust with caregivers with trust with other physicians, we asked all subsequent participants to compare trust dynamics with caregivers with trust dynamics with other physicians (i.e., Who do you trust more: a family caregiver or another physician, and why?).

Analysis

All interviews were audio-recorded and transcribed professionally through human transcription by the audio-to-text transcription service, Rev. Then we conducted a thematic analysis, an approach through which researchers can identify, analyze, and interpret patterns emerging from qualitative data (Boyatzis, 1998; Mays et al., 2005)they are under increasing pressure to adopt a more systematic approach to the utilization of the complex evidence base. Decision-makers must address complicated questions about the nature and significance of the problem to be addressed; the nature of proposed interventions; their differential impact; cost-effectiveness; acceptability and so on. This means that Cochrane-style reviews alone are not sufficient. Rather, they require access to syntheses of high-quality evidence that include research and non-research sources, and both qualitative and quantitative research findings. There is no single, agreed framework for synthesizing such diverse forms of evidence and many of the approaches potentially applicable to such an endeavour were devised for either qualitative or quantitative synthesis and/or for analysing primary data. This paper describes the key stages in reviewing and synthesizing qualitative and quantitative evidence for decision-making and looks at various strategies that could offer a way forward. We identify four basic approaches: narrative (including traditional 'literature reviews' and more methodologically explicit approaches such as 'thematic analysis', 'narrative synthesis', 'realist synthesis' and 'meta-narrative mapping'. We developed our initial codebook using a deductive approach based on previous studies on physician trust (Wilk & Platt, 2016; Wu et al., 2022). We identified five dimensions of trust that are observed in dynamics between both physicians and other clinicians and physicians and patients: *competence* (the ability to perform a task successfully or with skill), *reliability/dependability* (carrying out tasks as expected or in a timely manner, exhibiting consistent quality), *confidence* (a judgment that someone will meet another's expectations), *integrity* (honesty and professional behavior), and *fidelity* (acting in the best interest of others) (Hall et al., 2001; Moskowitz et al., 2011; Raj et al., 2019; Thom et al., 2011; Wilk & Platt, 2016). Then, we reviewed transcripts and used an inductive approach to generate new preliminary codes to reflect participant interviews. We used the final set of codes as our codebook. Using this codebook, both members of the study team independently coded all transcripts. Since we initially used a deductive approach, any codes from previous work on physician trust that did not emerge from our interviews were removed from the codebook. The study team met every two weeks to discuss codes and resolve any discrepancies through discussion. During this process, we iteratively identified and modified subthemes by combining or separating them as needed (Figure 1). We used Microsoft Word for coding and qualitative analysis.

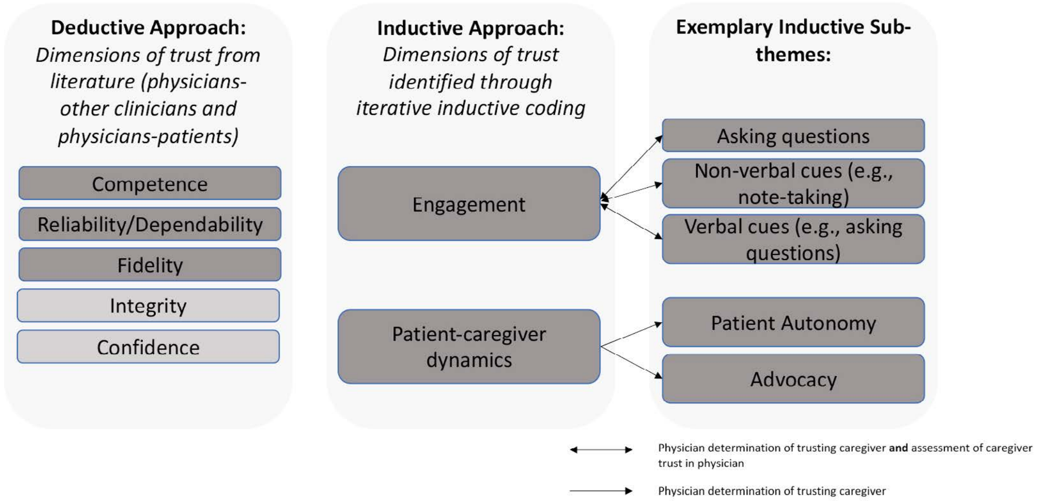

Figure 1. Deductive and inductive coding approach (n=20)

Results

Twenty physicians from three U.S. academic medical institutions participated in the interview. At Institution 1 (Midwest), three geriatricians and four oncologists participated. In Institution 2 (West coast), four geriatricians and three oncologists participated; and in Institution 3 (South), two geriatricians and four oncologists participated (Table 1).

Table 1. Characteristics of Study Sample

	Institution 1	**Institution 2**	**Institution 3**
Total participants	7	7	6
Female	4	3	2
Region	Midwest	West	South
Average years since graduating medical school	23.1	30.3	16.5

Participants discussed how they assess whether they can trust caregivers, how they perceive or determine whether caregivers trust them, and the role of culture in trust-building with caregivers. In addition, they described facilitators and challenges to integrating caregivers within care teams.

Assessing trust in family caregivers

Participants discussed multiple dimensions of trust that have been identified in the literature including the caregiver's: a) competence; b) fidelity; and c) reliability/dependability.

Participants assessed caregivers' *competence*, or their skill and ability to carry out a particular task (Raj et al., 2019), including their insight and responsiveness to their care recipient's needs. This included decisions made during the visit as well as outside of the health care setting. For instance, one participant explained:

> You're starting to get a sense in the first couple of weeks … Are you really going to be able to have this caregiver control meds, for example, because if patients have a lot of nausea meds, are they going to get confused, is it going to be a real issue? – P20

In addition, they assess caregivers' *fidelity*, meaning whether they are acting in the best interest of the patient (i.e., the care recipient) (Wilk & Platt, 2016). Participants discussed that in some circumstances caregivers might demonstrate fidelity by advocating for the patient or making decisions that align with the patients' preferences. However, in other cases, caregivers might demonstrate fidelity by urging the patient to consider the physician's advice if it is in the patient's best interest, even if the patient has a different preference that could lead to an adverse outcome. Participants also reported being attuned to the caregiver's kindness towards the patient, the patient's autonomy in decision-making in the presence of the caregiver, the patient's verbal and nonverbal cues, and the extent to which the caregiver respected the patient's preferences and opinions:

> If the decision that the caregiver is expressing is in alignment with what either the patient has previously expressed as their preference, or is in alignment with what the physician is saying is in the best interest of the patient, then I think ... that to me is evidence that the caregiver has the patient's best interest at heart. Yeah, I think it does speak to trust in that person. – P6

Another illustrated:

> Some of that is nonverbal. They [the patient] looks at their caregiver, they have body language that suggests that their caregiver is an important part of that conversation. They sometimes explicitly tell you, 'I want my husband to be here.' But if you have a sense of people, you can see when you actually should be screening for domestic abuse, for example, and those are situations in which I'm very conscious of limiting my information to those people so that the patient remains in power to be able to guide how much information they want. – P12

Participants discussed that they assess whether a caregiver is *reliable/dependable* in doing certain tasks for their relative in order to assess whether they can trust them (Raj et al., 2018). For instance, they evaluate whether a caregiver will follow through with a particular task (e.g., changing their care recipient's diet) or is engaged in their relative's care (e.g., accompanying the patient to the visit, taking notes, eye contact, body language). One participant explained:

> Are they punctual? And are they coming to an appointment? That is certainly a very strong clue if they don't come. Or do they call in and let you know, "I will be late?" All those little things, I think, you can compose into an overall assessment. – P11

Participants were also attuned to caregivers' engagement as a signal of their reliability/dependability. They explained that caregivers' attention and participation in the conversation could signal whether they could be counted on to follow through with instructions or recommendations, and to ask questions during instances of uncertainty:

> I ask them, "Do you have any questions, now that we talked to the patient?" Most supportive [caregivers], are actually the ones who come up with questions and take the stress off the patient's hands … But if they're disinterested … if they just have not said a single word during the encounter, doesn't tell me that they're a particularly significant part of the patient's circle of dependence. – P14

Assessing Caregiver Trust in Physicians

Participants recognized that they could not be certain whether a caregiver trusts them but used signals to try to determine caregivers' trust in them. These signals included the patient and caregiver returning for subsequent visits and verbal (e.g., expressing gratitude) and non-verbal cues (e.g., body language). Another signal included whether caregivers ask questions and the manner in which they ask questions. For instance, a caregiver asking many questions about a treatment or recommendation in a manner that indicated their wanting to know more, signaled to participants that the caregiver trusted them:

> I have another patient who he's very anti-vaccine, very anti-mask for COVID, and they wear masks in the clinic, but they think it's a joke ... But they really want to know my opinion, and they engage with me and like, "Well, what do you think?" And then they sit, and they listen. And they're like, "Okay, okay." And so, even as frustrating as those conversations are, if they didn't trust me, or they thought I was going to chastise them or something, they probably wouldn't bring it up in the first place ... Those are the patients I know that trust me. – P5

In contrast, however, participants also illustrated instances where they felt a lack of trust based on how caregivers asked questions and then would persist in opposing the response or recommendation provided by the physician:

> If they do not trust me as a physician, they ask questions, which are contrary to what I offer them. So if I'm suggesting option A, then they would be focused on option B and, not to have a discussion, but to have an antagonizing wheel. – P10

Though participants identified ways that they assess whether they can trust caregivers and perceived whether they are trusted by caregivers based on specific signals, culture emerged across interviews as an important theme in trust dynamics between physicians and caregivers.

Role of Culture

Participants explained several strategies for building trust with caregivers including considerations for trust-building with culturally diverse patients and their caregivers. First, participants emphasized that trust likely means the same thing across cultures, and yet the process for building and establishing trust may be different. Participants in two institutions (west coast and Midwest) discussed the cultural aspect of trust-building primarily in terms of navigating language and ethnic differences while participants in the southern institution primarily discussed racial, religious and socioeconomic diversity and its impact on trust-building. Participants, accordingly, had varied approaches to building trust with caregivers and navigating the cultural context of their patients and caregivers. For some, building trust with a caregiver involved learning about cultures of predominant patient communities in their own time or by asking colleagues or social workers for support.

Participants also learn about their patient's culture directly from patients and caregiver(s). This included norms around the health care visit, for instance, in cultures where caregivers are expected to relay important health information to the patient on behalf of the physician, or in other cultures where medical decisions are made at the family level rather than by the patient independently:

> I think you have to understand those cultural differences and you have to make sure that they know that you care about those cultural elements … In some cultures, when you talk to someone, you have to look at them in the eyes. In some other tribes, they take it as an insult. So, you have to ask explicitly, 'Is there any particular elements that I need to know about?' – P9

Another explained:

> My view is first of all, to really listen to where they come from … not geographically necessarily, but where is their cultural home and what are their spiritual needs? And what is the structure within a family? Is it a strongly patriarchal structure, or is it a more balanced, or is the mother or grandmother still the person … one has to listen and sort of really feel your way into it. – P11

Participants discussed that building trust with caregivers requires recognizing cultural differences and identifying ways to align practices with patients' and caregivers' norms and preferences. These actions were seen as fundamental to developing a strong and sustainable relationship with caregivers and maintaining their engagement in their relative's health care.

Integrating Caregivers into the Care Team

Participants discussed multiple facilitators and barriers associated with integrating caregivers into the health care team as a way towards maintaining relationships that could promote effective patient care. They explained that early conversations with patients about caregivers could facilitate effective integration. These conversations would ideally occur in the first visit, and would involve setting expectations about caregivers' involvement, evaluating caregivers' competence, reliability, and fidelity, assessing family dynamics, and becoming familiar with the family and home context. For instance, one participant illustrated that conversations with patients about who they consider a "caregiver" is relatively common among physicians who frequently work with caregivers:

> I think that's probably the one thing that is relatively standardized with practices and groups of doctors that often work with

> caregivers, that you start off with the patient about what they're willing to and who they would like to include within that circle of caregivers or family members that are involved within their care. – P16

Participants were also optimistic about the possibility of digital health technology, and specifically, telehealth (i.e., the delivery of health care and information via telecommunications such as videoconferencing and electronic transmission) facilitating the integration of caregivers (NEJM Catalyst, 2018). Telehealth emerged as a particularly promising way for participants to connect with caregivers during COVID-19 that they believed would continue to be useful beyond the pandemic. Participants described that assessing whether they can trust a caregiver may be slightly more difficult via telehealth because it is more difficult to observe signals such as engagement or patient-caregiver dynamics; however, they viewed caregivers' presence on telehealth visits as an indication of their engagement and dependability.

And yet, participants also recognized barriers to caregivers' integration in the health care team. The most commonly reported barrier was risky dynamics between the patient and caregiver, for instance in an abusive relationship or in a relationship with power asymmetries:

> I think the drawback is when the caregivers try to take over the meeting … or if they have some other agenda [like] they want the person to go to a nursing home or turn over their finances to someone … So that's where we do the divided appointments." – P7

In other cases, patients may not want caregiver involvement, for instance, if patients want to remain independent and having a caregiver present reinforces their perception of "being a burden" or "being dependent."

Despite these barriers, participants in our study expressed that their specialties often warranted integrating caregivers and sometimes involved finding creative solutions (such as using FaceTime) to engage caregivers, especially when caregivers cannot always be physically present during an appointment.

Comparing Trust-Building with Caregivers Versus with Other Physicians

When asked who they were more likely to trust, participants were often visibly surprised by our question, but were also very thoughtful and candid in their responses. Some participants expressed more trust in caregivers, given their familiarity with the patient:

> It's better to hear from the patient and their family member. Because what my colleague or my doctor would tell me, I don't think that it's going to be any different than how I'm going to approach it. But if I talk to the caregiver, I get a different perspective. For example, nausea,

> symptom burden, or fatigue, the referring physician will tell me, 'He doesn't have a lot of fatigue, he's doing fine.' But then when you talk to the caregiver, they tell us that 'He's doing very bad, he's not able to walk.' So, I would trust the family member more in that situation. – P10

Others discussed that certain situations or types of information warrant greater trust in caregivers versus other physicians:

> As far as objective information, data are concerned, I think I would definitely lean towards the physician. But when it comes to assessing sort of the whole environment, all the other contributing factors to a patient's condition, it is, I think, definitely a family member who is in a better position and generally, able to provide more detail that may be helpful that the physician, even though he or she may have seen the patient a couple of times, may not even be aware of. – P11

Discussion

In this study, we conducted qualitative interviews with twenty physicians across three institutions to understand how they assess trust with caregivers, the role of culture in trust-building processes, and to examine the facilitators and barriers to formally integrating caregivers into health care teams. To our knowledge, this is the first study to examine trust dynamics between physicians and caregivers, who are often responsible for communicating with care providers and accompanying patients, but are rarely integrated into health care teams in a formal or standardized way (Iott et al., 2020; Wolff et al., 2012). Here, we focused on physicians from geriatrics and oncology, anticipating that the duration and intensity of the physician-patient relationship could yield insights into trust-building in a context where it may be especially valuable.

We found that, consistent with prior literature, physicians identify a caregiver as being trustworthy when they demonstrate reliability/dependability, competence, and fidelity (Corazzini, 1977; Moskowitz et al., 2011; Raj et al., 2019; Thom et al., 2011; Wilk & Platt, 2016). These traits indicate to physicians that the caregiver's involvement will be beneficial to the overall care of their patient. In addition, physicians also observe dynamics between the patient and their caregiver to evaluate the quality of support provided in the relationship. Physicians perceive or determine whether a caregiver trusts them by evaluating the level and nature of their engagement during health care visits—a pattern that is easier to detect in-person but can be enabled through technology. Although we explicitly asked participants to reflect on these trust dynamics with caregivers for the purpose of the interview, responses indicated that in many instances, they deliberately assess these signals of trust with caregivers (e.g., verbal cues, engagement) either during the visit or after, and particularly in circumstances where caregiver engagement could be problematic for the patient's wellbeing.

We also found that culture plays an important role in trust-building and maintenance between physicians and caregivers. Trust building varies across cultures due to different social norms and distinctions between personal and professional relationships (Doney et al., 1998). Often, physicians spend time learning about cultural nuances from their patients and their families, and on their own time (e.g., through reading articles). They discussed that this enables them to effectively build and maintain trustful relationships with patients and their caregivers. They also perceived that demonstrating an interest and commitment to culturally sensitive care also facilitated caregivers' meaningful involvement in their relative's care. In fact, participants in our study were enthusiastic about integrating caregivers into care teams in the geriatrics and oncology contexts. They considered caregiver involvement to typically be beneficial, especially when initiated early on in the relationship and in circumstances of positive patient-caregiver dynamics; and trust may facilitate this integration of caregivers. It is notable that participants in our study expressed that they may trust physicians more for some types of information or tasks while trusting caregivers more for other information or tasks. This suggests that caregivers may, indeed, be a critical component of the health care team and that their integration—when built on trusting relationships with physicians—can contribute greatly to patient care. As suggested in previous literature, technology offers particular utility in facilitating caregiver integration but is largely dependent on caregivers' access to and comfort with the technology, and patients' preferences for their caregivers' involvement (Wolff et al., 2016, 2017; Wolff et al., 2016).

Implications for Policy and Practice

Findings from our study suggest a critical role of trust—and the role of physicians and the care team—to integrate caregivers into health care teams so they can support their relative(s) in and out of the health care setting. This may involve a formal discussion to assess caregiver competency, reliability/dependability, fidelity, and dynamics with the patient. For instance, during an initial consultation or at a time in the process that seems most appropriate based on the caregiver's readiness, physicians or social workers could assess caregivers' understanding of their relative's health conditions and care needs, along with their plans for following recommendations in the home. This would provide an additional opportunity for physicians and caregivers to build trust with one another and an opportunity to screen for threatening (e.g., abusive) patient-caregiver dynamics. There could be opportunities for developing formal procedures by which designated caregivers could indicate their understanding of medical tasks and responsibilities (e.g., medication management) in the home (e.g., skills training videos followed by discussions or certifications).

While some policies (e.g., the Caregiver Advise, Record, Enable Act) requires hospitals to ask patients if they have a caregiver and contact that designated caregiver with discharge information, these policies have not been implemented across all states and evaluating the implementation and effectiveness of the policy has demonstrated challenging (Coleman, 2016; Mason, 2017). One possibility would be to develop standardized language in consent documents for patients in both inpatient and outpatient settings such that patients can designate a caregiver, the extent of information they wish to be shared with the caregiver, and preferred modes of communication between caregivers and clinicians. This would provide the patient with a sense of autonomy over their health information and will equip healthcare providers with a better, more formal understanding of their patient's preferences regarding their caregiving circumstances.

Integrating caregivers into health care teams also requires system-level efforts to invite and recognize caregivers as a key part of care teams—that they are not just visitors, but active partners in patient care (IPFCC, 2021). In fact, physicians in our study distinguished that the types of trust they experience with other physicians are often different from the types of trust they experience with caregivers; and these different aspects of trust complement each other, leading to the communication of different—but equally critical—pieces of information. This may require formalizing a process by which clinicians can designate a caregiver as being involved in a patient's care, and even the types of support they provide. This process would be distinct from patient consent documents, but would require a standard conversation with patients and their caregivers. Information distinguishing patients who should be consulted individually versus those to be consulted with their caregiver could inform efficient visits that mitigate the risk of engaging caregivers who may not have the patient's best interest at heart. This could be especially important given persisting issues of fragmented care within the health care system, particularly for older adults who may see multiple specialists for distinct health conditions and associated needs. For these patients, standard language in their health record could be conveyed to different clinicians involved in a patient's care such that all clinicians would be attuned to the patient's circumstances and dynamics with their caregiver.

Achieving this level of integration will also require that health care organizations recognize and emphasize the relationship between caregiver integration and quality of care. Identifying the related structure, process, or outcome quality measures will require further study, and policymakers will need to develop procedures for reimbursing high performing clinicians and health care systems (i.e., specifically in terms of their engagement with caregivers) (National Alliance for Caregiving, 2021; Phongtankuel et al., 2020). This will also require institutional encouragement of greater collaboration between physicians and other professionals such as social workers, medical interpreters, patient navigators, and community health workers, all of whom could facilitate important discussions with caregivers and contribute to the building of trust between systems, providers, caregivers, and patients. One promising first step could be for healthcare systems to create a field in the electronic health record to designate a caregiver (National Alliance for Caregiving, 2021).

Technology-Facilitated Caregiver Integration

While participants in our study discussed the value of telehealth in engaging caregivers during visits, they did not discuss a standard protocol for doing so; it is possible that participants in our study were more likely to invite a caregiver to participate in the telehealth visit. However, studies with caregivers suggest that may not be common practice—or at least, consistent—to invite and facilitate caregivers to participate in telehealth (Raj et al., 2020). Further research is needed to understand the potential for developing caregiver-facing portals with patients' consent that could enable better exchange of information between caregivers and physicians. While studies have examined the use of tools within the health care visit itself, trust extends outside of the doctor's office—it is critical to ensure continuity of care not only for patients, but also for their caregivers (Wolff et al., 2017). Such a portal could have limited information as designated and consented to by patients (e.g., medication management instructions) and culturally tailored information (e.g., dietary information) (Raj, Zhou, et al., 2021). This additional channel of communication could help caregivers become part of important conversations between health care team members (including physicians, nurses, social workers, and other professionals) and contribute meaningful information while also obtaining information necessary to help them support their relative. Policies such as the Health Insurance Portability and Accountability Act (HIPAA) could be modified to account for the growing and critical role of caregivers beyond circumstances where caregivers are considered surrogate decision-makers for patients (Latulipe et al., 2018).

Indeed, additional designations and discussions can take time, and health literacy presents a barrier to caregivers' engagement in the healthcare system that has been especially emphasized in the context of cancer caregiving (Fields et al., 2018; Wittenberg et al., 2017). However, physicians in our study indicated that dedicating time to trust-building supported sustainable relationships and engagement from patients and caregivers. In contrast, they saw time constraints as barriers to trust building with implications for continuity of care and patient follow up. This investment could be especially valuable in relationships with patients and caregivers from diverse cultures who may already experience mistrust in the healthcare system (Nong et al., 2020). Caregivers of these patients may even have an important role in facilitating patient trust in physicians, and in turn, physicians may act as a critical broker of trust with the system (Platt et al., 2019) store and transfer information across boundaries of health care, public health and research. Health information brokers such as health care providers, public health departments and university researchers function as "access points" to manage relationships between the public and the health system. The relationship between the public and health information brokers is influenced by trust; and this relationship may predict the trust that the public has in the health system as a whole, which has implications for public trust in the system, and consequently, legitimacy of involved institutions, under circumstances of health information data sharing in the future. This paper aims to discuss these issues. Design/methodology/approach In this study, the authors aimed to examine characteristics of trustors (i.e. the public. Future research should examine the nuances of trust-building in relationships between culturally diverse physicians and culturally diverse caregivers. Fostering relationships with caregivers can also facilitate caregivers' and patients' comfort with asking questions to clinicians and advocating for their needs. This discomfort might be especially salient for caregivers who are unfamiliar with the U.S. health system or have experienced discrimination or other forms of exclusion within the system (e.g., language barriers) (Shim, 2010).

Additionally, addressing the physical, mental and employment burdens associated with caregiving remains an issue to be addressed through policy (Adelman et al., 2014; Kim et al., 2012). Participants expressed that caregivers who are reliable/dependable in coming to appointments and follow recommendations may be assessed as being more trustworthy than caregivers who appear disinterested or disengaged. While our participants emphasized nonverbal cues (e.g., texting during an appointment versus notetaking), caregiver engagement may be limited by the extensive and time-consuming responsibilities that caregivers uphold. For example, caregivers with the dual pressures of employment and caregiving responsibilities may face time and financial constraints in attending health care visits (Feinberg, 2016). Policies enabling the passage of information to trusted and designated caregivers may be particularly valuable in these cases, where having more information about their relative's health care needs may help caregivers perform various tasks. Professionals such as social workers may be especially relevant to facilitating this process of information provision to caregivers. Further, financial support for caregivers may help alleviate some of the financial burden associated with caregiving, such as through Medicaid waiver programs (Kaye & Teshale, 2020).

Implications for Medical Training

Our study also informs several recommendations for medical training. As we learned from several participants, while physicians are taught to build relationships with physicians, the process of building relationships with caregivers is primarily learned through experience in certain specialty contexts. Given our aging population and the increasing role of caregivers in health care across specialties (Ortman et al., 2014; Wolff et al., 2012; Wolff et al., 2020), the likelihood of interacting with caregivers will continue to grow. Although participants in our study primarily related the COVID-19 pandemic to the subsequent potential for using technology to facilitate integration with caregivers, the pandemic has also likely increased the likelihood of caregiver involvement across various clinical domains (e.g., due to long COVID) (Olsen, 2021).

Participants in our study were relatively experienced, having an average of 16 to 30 years of experience in the profession. Future research could examine how physicians who are newer to the profession approach family engagement and could also evaluate how medical training has evolved over time to incorporate lessons about family caregiver engagement, particularly to assess whether this form of training has grown alongside the increasing global emphasis on supporting family caregivers. Medical programs may consider incorporating lessons on trust-building with patients and caregivers throughout training. This may require further research to identify the specific roles and responsibilities of caregivers within a health care team and recognizing the value that caregivers can provide in patient care. For instance, as we found in our study, caregivers may be critical to patients enrolling and continuing their care, but they may also be invaluable sources of information about patient behaviors, concerns, preferences, and needs in their place of residence—where they likely spend the majority of their time. Health care and caregiver organizations along with programs such as Medicaid could expand opportunities for training caregivers in health care tasks ranging from observing patient progress to managing medication side effects (Coleman, 2016; Raj & Singer, 2021; Teshale et al., 2020). Support from these entities could assist clinicians so that they can immediately involve caregivers without taking time from consultations to train caregivers.

Involving caregivers early on could be beneficial, not only in the geriatrics and oncology contexts, but also in other domains such as primary care as well as other specialties such as nephrology and endocrinology. For instance, if a primary care physician is aware of an individual who may serve as a caregiver in the future, their engagement from an early stage could be beneficial both to the caregiver as well as to the patient later on in their life (Raj et al., 2021). The relationship between primary care physicians and patients is distinct in that it could be built over decades, and a patient who did not initially require support may eventually receive support from a caregiver. This may present an interesting scenario where physician-patient trust could be well-established but building physician-caregiver trust may require effort. Future research should seek the perspectives of patients, caregivers and physicians to better understand their preferences for caregiver involvement in health care teams in addition to concerns about training and health literacy and their perspectives on the boundaries of formal and informal health care work across different clinical contexts. Research should also solicit the perspectives of family caregivers, and specifically, how they determine trust in physicians and other health care professionals who are caring for their relative(s), as well as how this influences their subsequent involvement and decision-making in health care related responsibilities.

Limitations

Our study has some limitations. Although we conducted all interviews via videoconferencing to build rapport with participants, it is possible that some participants were less forthcoming about their experiences or perspectives than they would have been in person. Our use of the IPFCC list of exemplary hospitals to select participating institutions may not be inclusive of hospitals and systems that use other approaches to engage with caregivers and does not account for biases or limitations in how organizations are selected as exemplars. We also selected larger institutions from which we recruited participants; it is possible that smaller institutions or clinics may build trust with caregivers and integrate them in other informal ways because of long-term and even multi-generational relationships with family members. The perspectives of these types of institutions should be sought in the future as well.

Conclusion

Involving caregivers in health care teams has the potential to improve patient care, facilitate physician decision-making, and support caregivers. Integrating caregivers in a more standardized way requires fostering sustainable relationships between caregivers and physicians. Medical training has an important role in formalizing, standardizing, and even redefining the role that caregivers have in health care teams in order to facilitate their involvement and potentially improve patient care. Building trust-driven relationships with caregivers may represent a promising first step to effectively integrating caregivers.

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Ethical Approval

This study was granted permission with exemption by the University of Illinois at Urbana Champaign Institutional Review Board on January 12, 2021 (protocol #21563).

Disclaimers

None.

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Role of Medical Insurance in Reducing Place-based Health Disparities: Functional Disability in Rural Appalachia

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ABSTRACT

Rural Appalachia, including the entire state of West Virginia, is characterized by high health disparities. Such place-based health disparities contribute to disability across the lifespan and may exacerbate morbidity and disability in late life. Thus, examinations of the contributors to morbidity and disability at mid-and late-life are needed to inform policies and programs.

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Using the most recent data from the Centers for Disease Control and Prevention's (CDC) Behavioral Risk Factor Surveillance System (BRFSS), we examine some of the social determinants of health (e.g., age, gender, education, income) as predictors of access to health care and functional ability among 4,867 adults living in West Virginia. Access to health care was indexed by three variables, including whether one had financial barriers to medical care, the number of personal medical care professionals one saw, and the recency of wellness exams. Functional ability was indexed using items assessing difficulty with dressing, climbing stairs, and doing errands. The model fit the data well for the entire sample, X^2 (DF = 29, N = 4867) = 411.30, $p < .001$, CFI = .94, RMSEA = .052. Post hoc models with the age groups fit well, although some differences in specific paths emerged. Our results suggest that policies and programs that increase medical access for current middle-aged and older adults might decrease functional ability. Moreover, as the younger adults age into midlife, they enter with lower economic and educational resources, further exacerbating their lack of access to health care and increasing disability in future generations of West Virginians.

Keywords: rural, health disparities, policy, Medicaid, aging, older adults

Rol del seguro médico en la reducción de las disparidades de salud basadas en el lugar: Discapacidad funcional en los Apalaches rurales

RESUMEN

Los Apalaches rurales, incluido todo el estado de Virginia Occidental, se caracterizan por grandes disparidades en la salud. Tales disparidades de salud basadas en el lugar contribuyen a la discapacidad a lo largo de la vida y pueden exacerbar la morbilidad y la discapacidad en la vejez. Por lo tanto, se necesitan exámenes de los factores que contribuyen a la morbilidad y la discapacidad en la mediana edad y en la vejez para informar las políticas y los programas.

Utilizando los datos más recientes del Sistema de Vigilancia de Factores de Riesgo Conductual (BRFSS) de los Centros para el Control y la Prevención de Enfermedades (CDC), examinamos algunos de los determinantes sociales de la salud (p. ej., edad, género, educación, ingresos) como predictores del acceso a atención médica y capacidad funcional entre 4,867 adultos que viven en West Virginia. El acceso a la atención médica se indexó según tres variables, incluido si uno tenía barreras financieras para la atención médica, la cantidad de profesionales de atención médica personal que uno vio y la actualidad de los exámenes de bienestar. La capacidad funcional se indexó mediante ítems que evaluaban la dificultad para vestirse, subir escaleras y hacer recados. El modelo se ajustó bien a los datos de toda la muestra, X2 (DF = 29, N = 4867) = 411,30, p < 0,001, CFI = 0,94, RMSEA = 0,052. Los modelos post hoc con los grupos de edad encajan bien, aunque surgieron algunas diferencias en caminos específicos. Nuestros resultados sugieren que las políticas y los programas que aumentan el acceso médico para los adultos mayores y de mediana edad actuales podrían disminuir la capacidad funcional. Además, a medida que los adultos más jóvenes llegan a la mediana edad, ingresan con menores recursos económicos y educativos, lo que exacerba aún más su falta de acceso a la atención médica y aumenta la discapacidad en las generaciones futuras de habitantes de Virginia Occidental.

Palabras clave: rural, disparidades de salud, política, Medicaid, envejecimiento, adultos mayores

医疗保险在减少基于地点的健康差异一事中的作用：阿巴拉契亚农村地区的功能性障碍

摘要

阿巴拉契亚农村地区（包括整个西弗吉尼亚州）的健康差异巨大。这种基于地点的健康差异对整个生命周期的残疾情况作贡献，并可能加剧晚年的发病率和残疾。因此，需要对导致中年和晚年发病率和残疾的因素进行分析，以便为政策和计划提供信息。

通过使用美国疾病控制和预防中心（CDC）行为风险因素监测系统（BRFSS）的最新数据，我们分析了一些健康的社会决定因素（例如年龄、性别、教育、收入），将其作为西弗吉尼亚州 4,867 名成年人在医疗保健和功能性能力的获取方面的预测物。医疗保健的可及性由三个变量来衡量，包括个体是否在医疗保健方面面临经济障碍、个体拜访的个人医疗保健专业人员的数量、以及近期健康检查的时间。功能性能力

指标包括评估穿衣、爬楼梯和办事方面遭遇的困难。模型适合整个样本数据，X2（DF = 29，N = 4867）= 411.30，p < .001，CFI = .94，RMSEA = .052。年龄组的事后模型是适宜的，尽管在特定路径中出现了一些差异。我们的结果表明，那些增加当前中老年人医疗获取的政策和计划可能会降低功能性能力。此外，随着年轻人进入中年，他们的经济资源和教育资源较低，这进一步加剧了其缺乏医疗保健获取的情况，同时增加了西弗吉尼亚未来几代人的残疾情况。

关键词：农村，健康差异，政策，医疗补助，老龄化，老年人

Health disparities are those preventable differences in health care access and health outcomes that result from social, economic, and geographic factors (Duran & Perez-Stable, 2019). Duran and Perez-Stable (2019) of the National Institute on Minority Health and Health Disparities point out that in order to advance to the next level of research and policy, the field requires greater clarification of the definition of health disparity, a broader examination of minoritized groups experiencing health disparities beyond racial and ethnic identity, and a broader lens to focus on potential mechanisms of disparity beyond the descriptive trends related to demographic social determinants of health (e.g., age, race, sex, income). They suggest that including an examination of place-based health disparities and a search for modifiable mechanisms within those local contexts are the next stage in health disparities research. Thus, the goal of the next wave of health disparity research should be to focus on the interactions of age-based and place-based factors in order to identify potential interventions and policies to move toward health equity (Wasserman et al., 2019).

As research about health disparities advances, there is an increased interest in examining place-based health disparities (Allen & Roberto, 2014). The construct of place-based health disparities incorporates a variety of influences unique to a particular region or geographic location, such as local value systems, access to medical care, and other resources (Savla et al., 2018). Thus, studies that include within-region examinations may be critical for understanding how best to serve such populations. In the current study, we focus on health disparities with West Virginia. In addition to challenges inherent to most residents of Appalachia in general, West Virginia poses unique health care challenges. West Virginians have been disadvantaged by changes in natural resource-extractive technologies and the decreasing employment opportunities associated with those industry changes (Latimer & Oberholser, 2005). These changes have had repercussions across the life span, ranging from impacts on the availability of medical services, general health status, and the influx of prescription opioids, which have devasted many rural and West Virginian families and communities (Patrick et al., 2021; Stoltman et al., 2022; Warfield et al., 2019). Thus, it is important to examine health policies affecting older adults, midlife adults who are aging into late life with chronic health conditions, and younger adults who may be struggling with the direct and indirect effects of substance abuse and other diseases of despair (Case & Deaton, 2016).

As the only state contained entirely within Appalachia, West Virginia serves as an important reference point regarding health disparities for the region and the nation. When compared with their rural and nonrural peers, adults in West Virginia are older and face higher morbidity (Pollard & Jacobsen, 2021). This poor health is observed in West Virginians reporting more total unhealthy days per month, more physically unhealthy days per month, and more emotionally unhealthy days per month relative to the rest of the United States (Givens et al., 2019; Patrick et al., 2021).

Frameworks for Studying Health Disparities across the Life Span

Recent discourse has focused on race-related health disparities and who is best-positioned to conduct such work (e.g., Jordan, Brown, and Schrager, 2021; McFarling, 2021). For decades, social gerontologists have been interested in this work and its related constructs across the lifespan, such as Cumulative Dis/Advantage (Dannefer, 2020), multiple jeopardy (e.g., Ferraro, 1987; Ferraro & Farmer, 1996), resilience (Infurna, 2021), and Social Determinants of Health (e.g., Ehrlich, 2020). A benefit to linking the current focus on health disparities to the well-established social gerontology, epidemiology, and life span literatures is that there are useful frameworks and identified potential mechanisms available from these areas that can inform current work in reducing health disparities (Dannefer, 2020). For example, the gerontological literature has developed several testable models in which early disadvantage may accumulate across other developmental periods (e.g., Glymour et al., 2009). These frameworks fit well with social epidemiology models linking acute and chronic stress to wellbeing and functioning (Bagby et al., 2019; Nusslock & Miller, 2016; Wasserman et al., 2021).

It is likely that there are insights to be gained from the disablement process literature, as well. The disablement process was well-described by Verbrugge and Jette (1994) and Lawrence and Jette (1996). Disablement can be viewed as a multistage process in which one may move from disease to impairment to functional limitation to disability. This is important because these functional limitations begin to accumulate at midlife and are a main driving force for the progressive spiral into the disability process (Verbrugge & Jette, 1994). Specific socio-demographic characteristics (e.g., older age, female sex, less education) are associated with more functional limitations. With nearly three decades of empirical support, this model continues to be robust in current gerontological studies (Espinoza et al., 2018). The idea of accumulating risk factors over time is a critical consideration, although health disparity researchers are only beginning to incorporate developmental time into studies of racism and health inequities (e.g., Gee et al., 2019).

As highlighted by leading scholars (e.g., Duran & Perez-Stable, 2019; Lynn & Franco, 2020), other aspects of health disparities also require examination, including those health disparities related to rurality (Hash et al., 2015; Patrick et al., 2020). Relative to their peers in other geographic areas, rural adults experience higher comorbidities and earlier mortality (Savla et al., 2022). Access to health care providers is challenging in rural areas, as many rural areas are considered to be medically under-served and the travel to health care providers is made more difficult by distance from urban centers, poor transportation infrastructure, and even weather-related challenges that may make roads impassable (Hash et al., 2015; Lam, Broderick, and Toor, 2018; Savla et al., 2022).

Although social determinants of health (SDOH) are larger constructs than demographic indicators, SDOH are often related to such demographics and their intersections (ODPHP, 2021; Williams & Mattos, 2021). For example, SDOH often include constructs such as food insecurity, neighborhood violence, various forms of discrimination, education, poverty, and challenging early life experiences (ODHP, 2021). These contextual factors may lead to health disparities among groups, interfering with one's access to medical care. Moreover, these SDOH may exert direct and indirect effects on one's health and functional ability. Each of these may also be associated with age, race, sex, education, and income.

Cultural Contexts of Appalachia and West Virginia

Adults residing in rural Appalachia experience place-based health disparities (Allen & Roberto, 2014; Krout & Hash, 2015; Weaver et al., 2018). That is, multiple factors interact in ways that challenge the economic, physical, and emotional well-being of residents of Appalachia. Among these challenges are limited economic opportunities, educational disadvantages, few medical resources, a rugged geography which creates travel difficulties, and uneven policies (Patrick et al., 2021).

Appalachia is a 420-county region in the eastern United States which includes all of West Virginia and parts of twelve other states (Appalachian Regional Commission [ARC], 2018). Early attention on the health disparities in this region can be traced to the efforts of the labor union movement to end unsafe and exploitative mining practices in the early 1900s (Blizzard, 2010) and to Eleanor Roosevelt and her contributions to the New Deal in the 1930s and her emphasis on decreasing poverty (Arthurdale Heritage Foundation, 2022). Research into these poverty- and occupational-related health disparities was often guided by frameworks of "double or multiple jeopardy," in which the cumulative disadvantages of aging, rurality, and employment status interacted to negatively affect health and economic well-being (Patrick et al., 2017). Current investigations rely on a more nuanced view, incorporating both historical and contextual backgrounds. In addition to negative stereotypes, older Appalachians have been disadvantaged by changes in natural resource-extractive technologies and the decreasing employment opportunities associated with those industry changes (Latimer & Oberholser, 2005).

As the only state contained entirely within Appalachia, West Virginia serves as an important reference point regarding health disparities for the region and the nation. When compared with their rural and nonrural peers, adults in West Virginia are older and face higher morbidity (Pollard & Jacobsen, 2021). This poor health is observed in West Virginians reporting more total unhealthy days per month, more physically unhealthy days per month, and more emotionally unhealthy days per month relative to the rest of the United States (Givens et al., 2019; Patrick et al., 2021).

Policy issues may further exacerbate health disparities in West Virginia

As noted by the ODPHP (2021) and Palmer et al. (2021), access to medical care and interactions with health care providers are important SDOH and contribute to health disparities. Each is influenced by the social and legislative policies at the local, state, regional and national level (Appelbaum et al., 2020; Gaynor, 2020). Although federal policies are meant to be "place-neutral" (Rhubart et al., 2021, p. 24), local contexts matter. One specific policy that may differentially influence health care access and health disparities within rural areas is Medicaid. In 2014, states were able to expand Medicaid coverage, although not all states in the United States did so. In fact, many rural states did not expand coverage (Rhubart et al., 2021). However, West Virginia was among the rural states that did expand coverage to include low-income individuals and families without children. In January 2021, more than one-third of West Virginia residents, more than one-half million people, were covered by Medicaid (Rogombe, 2021). Although this policy change reduced the costs of medical care for many younger and middle-aged people (APHA, 2021), the state of West Virginia continues to be medically underserved in terms of having an insufficient number of health care providers. Moreover, the state Medicaid program is likely to become insolvent by 2025 (Rogombe, 2021).

The issue of whether state-wide programs can continue to support residents' access to medical services is critical. For example, Jackson and Engelman (2021) used data from the Health and Retirement Study (HRS) to examine trajectories of functional disability across periods of the life span. They found that those who had experienced fewer economic and social advantages (i.e., education, income, stable employment) often entered midlife with more functional impairment. For adults moving from midlife to late life, those with impairments were more likely to experience mortality, whereas those who entered late life with fewer economic disadvantages began to experience accumulating disability. Race and gender correlated with earlier disadvantage and midlife functional impairment. Similarly, Bolkan et al. (2022) reported on the associations among SDOH and access to care among older adults in Washington state. They note that rurality was associated with decreased access and financial resources were associated with increased access. Although among their sample, age, race education and sex did not uniquely contribute to the equation, these SDOH may exert differential influences among other subgroups within the United States, including those in rural Appalachia. Thus, the purpose of the current study is to examine the links among some of the known SDOH (i.e., age, sex, income, education), including access to care to the experience of functional impairment, which is exacerbated within a rural environment such as West Virginia.

Methods

Data Source

In order to examine the contributions of demographic SDOH to the relation between access to medical care and functional impairment, we used the 2020 Behavioral Risk Factor Surveillance System (BRFSS) from the Centers for Disease Control and Prevention (CDC) for the state of West Virginia. These data represent the most current data available, until the 2021 files become available in the Fall 2022. For the fifty states, a disproportionate stratified sample (DSS) frame is used to identify landlines. In 2011, the BRFSS started using data from cell phone holders, as well as from available landlines. The CDC (2020) reports using sampling frames that are commercially available to pull phone numbers at random from banks of 1,000 numbers. In years past, criticisms were levied against these data because they are collected via telephone, with arguments that phone ownership represented a sampling confound. However, recent evidence from the Federal-State Joint Board on Universal Service (2020) shows that in 2019, 98.5% of West Virginia adults had either landline, cell service, or both. Other criticisms have focuses on the length of the interview and the potential problems of respondent fatigue, However, the core interview requires approximately 17 minutes to complete; optional modules add five to ten minutes to the interview time (CDC, 2020). Thus, despite these limitations, an attraction of the BRFSS is that is includes a large number of West Virginia residents.

Sample

A total of 5,880 West Virginian adults completed portions of the BRFSS in 2020. Our analyses are based on a subset of 5,172 adults who provided complete data on the variables of interest. Between 1.8% and 17.2% of responses were missing for the following: age (17.2% missing), sex (17.2% missing), education (17.2% missing), income (1.8% missing), three indictors of medical access (15% to 17.1% missing), and three items related to functional ability (15.3% to 15.6% missing). Persons excluded from the current analyses were more likely to be women, report lower incomes, report fewer years of education, and report more difficulty with each of the three activity of daily living items. Missingness was not equally distributed across age groups, with 13.6% of the younger adults missing a value on a variable of interest, 13.6% of middle-aged adults missing a value on a variable of interest, and 20.5% of the older adults missing a value of interest. Thus, our sample may under-estimate the effects of low resources on the link between difficulty with medical access and functional ability. Descriptive statistics for the analytic sample are shown in Table 1.

Table 1. Sample descriptive statistics (N = 4,867)

	Category/Coding	N/%	Mean	SD
Age		4,867	56.61	16.1
Younger	1	1,162	33.26	7.3
Middle-aged	2	1,882	55.69	5.8
Older	3	1,823	72.44	5.1
Sex			1.55	0.50
Male	1	2,201 (45.2%)		
Female	2	2,666 (54.8%)		
Education			4.78	1.0
Less than 12 years	1, 2, and 3	8.3%		
12 years/GED	4	34.3%		
Some college	5	26.6%		
4+ years College	6	30.6%		
Income			5.67	2.1
< $20,000	1, 2, and 3	17.5%		
$20,001 - $25,000	4	9.9%		
$25,001 - $35,000	5	13.8%		
$35,001 – $50,000	6	17.5%		
$50,001 - $75,000	7	15.2%		
$75,001+	8	26.0%		

(table cont'd.)

	Category/Coding	N/%	Mean	SD
Number Providers				
0		12.3%		
1-only		82.1%		
2 or more		5.6%		
Check-Up				
Within past year	1	86%		
1 to 2 years	2	6.4%		
2 to 5 years	3	3.5%		
More than 5 /never	4	4.1%		
Financial access	0 difficulty, 1 ease		0.96	0.2
Functional Ability				
Walking			1.78	0.4
Difficulty	1	21.9%		
No Difficulty	2	78.1%		
Dressing			1.95	0.2
Difficulty	1	5.5%		
No Difficulty	2	94.5%		
Errands Alone			1.89	0.3
Difficulty	1	11.0%		
No Difficulty	2	89.0%		

As shown in Table 1, of the 4,867 adults included in the current analyses, most (94.5%) identified as White Non-Hispanic, matching the demographics in the state. Mean age was 56.6 years (SD = 16.1), although about 24% were ages 18 to 44 years, 38.7% were ages 45 to 64 years, and 37.5% were age 65 years or older. Men represented 45.2% of the sample. Most (91.6%) respondents had at least at high school equivalent education, with 34.3% reporting a high school diploma/GED as their highest education, 26.6% had between 1 and 3 years of college, 30.6% had earned a 4-year college degree or higher. Average annual income ranged between $25,000 to $35,000, although 27.4% reported incomes lower than $25,000 per year and 26% reported annual incomes in excess of $75,000.

Measures

Medical Access

Medical Access was assessed via the three indicators available in the BRFSS data set. In terms of the number of health care professionals with which one interacted, most adults (82.1%) reported having a single medical professional; 5.6% had multiple health professionals and 12.3% reported having zero regular health care professionals with whom they interacted. Similarly, the majority (86%) had visited a health care provider for a wellness check within the past year, with 6.4% visiting within the past 1 to 2 years, 3.5% within the past 2 to 5 years, 3.9% reporting more than 5 years, and 0.2% reporting never having a routine wellness exam outside of an injury or illness. Our third index of medical access was a composite formed from two dichotomous items determining whether adults had a health insurance plan (94.3% affirmative) and whether they had ever foregone medical care due to high cost (90.7% had not done so). We combined these items to form an index of whether adults were able to receive care when they needed to do so, with 96% reporting the ability to receive when needed and 4% reporting difficulty.

Functional Ability

The BRFSS includes only three indictors of functional ability. Although most adults reported few problems, approximately 21.9% reported difficulty walking or climbing stairs, 5.5% reported difficulty with dressing or bathing, and 11% reported difficulty doing errands alone.

Analytical Approach

We tested the analytic version of the model shown in Figure 1 using AMOS v. 28.0.0. Based on the correlations shown in Table 2, we imposed a covariance between education and income. We used maximum likelihood procedures to simultaneously estimate all paths of the model. All analyses were calculated using covariance matrices. Because minor differences between the tested model and the underlying model often result in statistically significant chi square values in large samples (Byrne, 2010), we used additional indexes to assess the fit of the model to the data. We relied upon the comparative fit index (CFI), for which values greater than .90 suggest an acceptable fit, with values greater than .95 being preferred. We also examined the Tucker-Lewis Index (TLI), for which values greater than .90 indicated acceptable fit. We also used the root mean square error of approximation (RMSEA) for which values less than .08 are considered to be acceptable (Byrne, 2010). In addition, we examined each path in the model and evaluated its standardized beta using the critical ratio (CR). CRs >1.96 are significant at the $p < .05$ level. We also intended to examine model fit within each age group using a multigroup analysis procedure.

Results

Model Testing in the Entire Sample

Results of our analyses suggest an acceptable fit of the model to the data, X^2

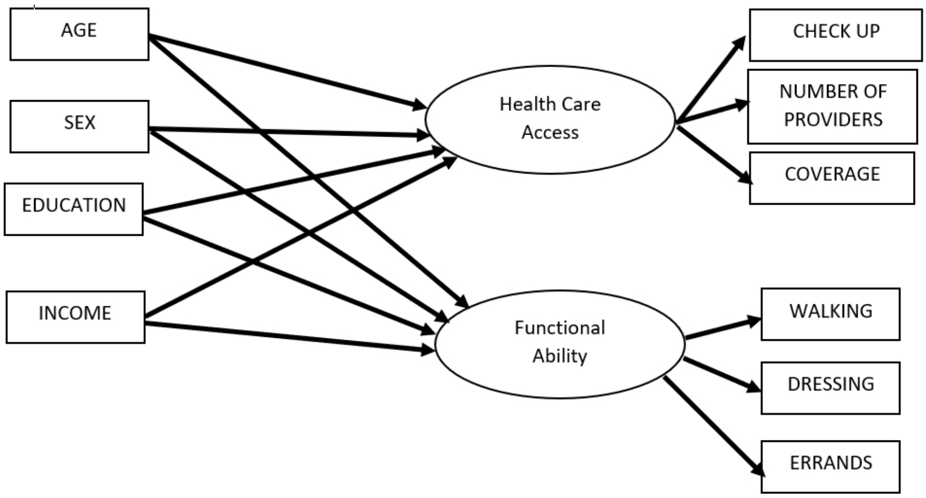

Figure 1: Conceptual Model Linking SDOH to Access and Functional Disability

(DF = 29; N = 4867) = 411.30, $p < .001$; CFI = .937; TLI = .880; RMSEA = .052. As shown in the upper portion of Table 3, the measurement model fit well. The percentage of variance accounted for (R^2 Access = .164; R^2 Function = .223) was low but non-trivial. The structural paths are presented in the lower portion of Table 3. In terms of the demographic SDOH that were associated with medical access, female sex ($\beta = .13$), older age ($\beta = .37$), and higher income ($\beta = .072$) were significant. The path between the two indicators of health disparity, Access and Functional Ability, was significant ($\beta = -.157$, $p < .001$), with those reporting more ease of access also reporting lower functional ability. Regarding the SDOH that were significantly associated with better functional ability, only younger age ($\beta = -.13$) and higher income ($\beta = .40$) reached significance. Of note, the indirect effects of SDOH on functional ability through access were very small, ranging from 0 to -.06 (age).

As shown in the lower portion of Table 3, not all of the individual hypothesized regression paths reached significance. Education, which was significantly correlated with income, was not directly linked to medical access ($\beta = .03$) or with functional ability ($\beta = .034$). Sex was also not directly associated with medical access ($\beta = -.13$). Because we had planned to examine the model based on age, we decided to forego model modifications that would drop non-significant paths, in favor of testing this model across the three age groups. However, we were especially interested in the path from medical access to functional ability, so we ran a sensitivity analysis in which the directional path was reversed between these two constructs. In that model, the path from functional ability to medical access was not significant.

Table 2. Spearman correlations (N = 4,867)

	AGE	Sex	Income	Education	Number of Providers	Recency of Check-Up	Financial barriers	Walking	Dressing	Errands alone
Age (continuous)	--									
SEX	.018	--								
INCOME	-.124**	-.091**	--							
EDUCATION	-.075**	.038**	.446**	--						
Number Providers	.245**	.076**	.018	.025	--					
Check-Up	-.230**	-.084**	-.018	-.001	-.416**	--				
Financial barriers	.121**	.053**	.062**	.070**	.167**	-.151**	--			
WALKING	-.239**	-.044**	.292**	.174**	-.140**	.117**	-.047**	--		
DRESSING	-.080**	-.002	.189**	.084**	-.066**	.041**	-.007	.395**	--	
ERRANDS ALONE	-.082**	-.084**	.290**	.128**	-.069**	.044**	-.018	.410**	.432**	--
Mean (SD)	56.61 (16.1)	54.8	5.67 (2.1)	4.78 (1.0)	0.90 (0.4)	1.25 (0.7)	0.96 (0.2)	1.78 (0.4)	1.95 (0.2)	1.89 (0.3)

Table 3: Results of Model Testing for Entire Sample (N=4,867)

			β	Estimate	S.E.	C.R.	P
Measurement Model							
No. Providers	<---	Access	.687	1.0			
Check-Up	<---	Access	-.609	-1.500	.076	-19.75	***
Financial Barrier	<---	Access	-.274	.187	.014	13.32	***
Walking	<---	Functional Ability	.664	1.000			
Dressing	<---	Function Ability	.595	.493	.017	28.22	***
Errands	<---	Functional Ability	.653	.744	.026	28.98	***
Path Model							
Access	<---	Education	.031	.009	.005	1.59	.112
Access	<---	Age	.373	.007	.000	19.55	***
Access	<---	Income	.072	.010	.003	3.69	***
Access	<---	Sex	.128	.074	.010	7.27	***
Functional Ability	<---	Sex	-.013	-.007	.009	-.79	.429
Functional Ability	<---	Education	.034	.009	.005	1.86	.063
Functional Ability	<---	Age	-.134	-.002	.000	-7.21	***
Function Ability	<---	Income	.400	.053	.003	20.39	***
Functional Ability	<---	Access	-.165	-.157	.023	-6.73	***
Income	←>	Education	.442	.938	.033	28.17	***
X^2 (DF = 29, N = 4867) = 411.30, p < .001; CFI = .937; TLI = .880; RMSEA = .052. R^2 Access = .164; R^2 Function = .223							

Table 4: Post hoc Multigroup Model testing for Younger Adults (N = 1162)

			β	Estimate	S.E.	C.R.	P
Measurement Model							
No. Providers	<---	Access	.766	1.0			
Check-Up	<---	Access	-.557	-1.36	.182	-7.43	***
Financial Barriers	<---	Access	.247	.167	.031	5.46	***
Walking	<---	Functional Ability	.686	1.000			
Dressing	<---	Functional Ability	.702	.530	.046	11.51	***
Errands	<---	Functional Ability	.436	.743	.069	10.69	***
Path Model							
Access	<---	Sex	.227	.172	.027	6.29	***
Access	<---	Education	.106	.041	.015	2.75	.006
Access	<---	Income	.095	.041	.015	2.75	.006
Functional Ability	<---	Sex	.016	.005	.011	.43	.664
Functional Ability	<---	Education	-.003	.000	.006	-.08	.937
Functional Ability	<---	Income	.288	.021	.003	7.11	***
Functional Ability	<---	Access	-.144	-.057	.019	- 3.00	.003
Income	←>	Education	.410	.834	.065	12.92	***
R^2 Access = .08; R^2 Function = .09							

Note: *** p < .001

Post hoc Multigroup: Midlife Adults (N = 1,882)

			β	Estimate	S.E.	C.R.	P
Measurement Model							
No.Providers	<---	Access	.638	1.0			
Check-Up	<---	Access	-.674	-1.86	.214	-8.68	***
Financial Barriers	<---	Access	.272	.241	.031	7.81	***
Walking	<---	Functional Ability	.690	1.000			

(table cont'd.)

			β	Estimate	S.E.	C.R.	P
Measurement Model							
Errands	<---	Functional Ability	.700	.761	.036	20.97	***
Path Model							
Access	<---	Sex	.105	.054	.015	3.51	***
Access	<---	Education	.009	.004	.015	.27	.784
Access	<---	Income	.068	.008	.004	2.06	.039
Functional Ability	<---	Sex	-.021	-.013	.015	-.86	.389
Functional Ability	<---	Education	.022	.006	.008	.819	.413
Functional Ability	<---	Income	.487	.066	.004	16.00	***
Functional Ability	<---	Access	-.192	-.223	.040	-5.61	***
Income	←>	Education	.436	.969	.056	17.35	***
R^2 Access = .015; R^2 Function = .274							

Note: *** p < .001

Post hoc Multigroup: Older Adults (N = 1823)

			β	Estimate	S.E.	C.R.	P
Measurement Model							
No. Providers	<---	Access	.426	1.0			
Check-Up	<---	Access	-.602	-1.94	.528	-3.67	***
Financial Barriers	<---	Access	.150	.098	.026	-3.83	.***
Walking	<---	Functional Ability	.570	1.000			
Dressing	<---	Functional Ability	.573	.529	.034	15.54	***
Errands	<---	Functional Ability	.717	.916	.059	15.43	***
Path Model							
Access	<---	Sex	.111	.033	.021	2.71	.007
Access	<---	Education	.029	.004	.006	.737	.461
Access	<---	Income	.062	.005	.003	1.50	.135
Functional Ability	<---	Sex	-.036	-.019	.015	-1.29	.199
Functional Ability	<---	Education	.026	.006	.008	.846	.398

(table cont'd.)

			β	Estimate	S.E.	C.R.	P
Path Model							
Functional Ability	<---	Income	.341	.047	.005	9.87	***
Functional Ability	<---	Access	-.098	-.175	.077	- 2.27	.023
Income	←>	Education	.465	.943	.052	18.01	***
R^2 Access = .02; R^2 Function = .13							

Multigroup Model Testing

In order to conduct our multigroup analysis, we removed the continuous variable of age from the model. We then constructed a three-level categorical age variable that included 1,162 younger adults (ages 18 to 44 years), 1,882 middle-aged adults (ages 45 to 64 years), and 1,823 older adults (ages 65 to 80+ years). We chose these groupings because they loosely align with other categories of younger, middle-aged, and older adults (e.g., Patrick et al., 2020), because the Medicaid expansion especially benefitted working-age adults (APHA, 2021), and because it resulted in approximately equal sized groups which facilitated the multi-group analysis (Byrne, 2010). The model fit the data well, X^2 (DF = 66) = 363.08, p < .001; CFI = .942; TLI = .881; RMSEA = .030. Regression paths for each age group are shown individually in Tables 4 (younger adults), 5 (middle-aged adults) and 6 (older adults).

Younger Adults

As shown in the upper portion of Table 4, the measurement model fit well for the younger adults. The path between the two indicators of health disparity, Access and Functional Ability, was significant (β = -.144, p = .003). The percentage of variance accounted for (R^2 Access = .08; R^2 Function = .09) was low. Among the younger adults, all three demographic SDOH were associated with access to medical care. Access was less difficult for women (β = .23, p < .001), those with higher income (β = .10, p < .02), and those with more education (β = .11, p < .01). In addition to access, the only demographic SDOH significantly associated with better functional ability was higher income (β= .29, p < .001).

Middle-Aged Adults

As shown in the upper portion of Table 5, the measurement model fit well for the middle-aged adults. The percentage of variance accounted for was low for Access (R^2 = .02), but moderate for functional ability (R^2 = .27). Among the middle-aged adults, female sex (β = .11, p < .001) and higher income (β = .07, p < .05) were associated with access to medical care. The path between the two indicators of health disparity, Access and Functional Ability, was significant (β = -.19, p < .001). In addition to access, the only demographic SDOH significantly associated with better functional ability was higher income (β= .49, $p < .001$).

Older Adults

Table 6 provides the estimates for the measurement model, which fit well for the older adults. Individual regression paths are also presented. The percentage of variance accounted for was low for Access ($R^2 = .02$) and low for functional ability ($R^2 = .13$). Among the older adults, female sex (β = .11, $p = .002$) was associated with better access to medical care. The path between the two indicators of health disparity, Access and Functional Ability, was significant (β = -.10, $p < .05$). In addition to access, higher income (β= .34, $p < .001$) was the only demographic SDOH associated with better functional ability.

Discussion

As the global population ages, rural areas are also experiencing an increase in the number and proportion of older residents. The effects of age-associated functional impairments and other challenges may be especially difficult in resource-poor areas such as Appalachia (Allen & Roberto, 2014; Patrick et al., 2021; Weaver et al., 2018). Thus, it is important to examine modifiable SDOH that may support or hinder wellbeing.

According to foundational work in the field (e.g., Lawrence & Jette, 1996; Verbrugge & Jette, 1994), the progression from functional impairment to disability may be related to age, sex, income, education and rurality. One mechanism that may disrupt the progression to disability is access to medical care. As Wasserman et al. (2019) highlight, there are many factors within the health care system that may contribute to health disparities, including patient-provider communication, payment systems, and practitioner biases and stereotypes. However, policies that enable access to medical care, such as Medicaid, may also influence the association with functional ability. Expanding medical access may be an important avenue to reducing the effects of SDOH for most Americans but may be critical for adults in rural areas.

Rural areas are often characterized by lower income and lower education compared with non-rural areas (Hash et al., 2015), which may influence residents' interactions with the health care system. For adults living in rural Appalachia, who experience increased functional limitations relative to others, medical access is often difficult and may be fraught by stereotypes and inadequate payer systems (Patrick et al., 2020; Savla et al., 2022). When the Medicaid expansion became possible under the Affordable Care Act, 38 states and the District of Columbia enacted such expansion (Rhubart et al., 2021). Of the 12 states not expanding Medicaid coverage, half were included in the Appalachia region (i.e., North Carolina, South Carolina, Tennessee, Mississippi, Alabama, and Georgia). However, West Virginia was among the six states within Appalachia that did expand eligibility, along with Kentucky, Pennsylvania, Virginia, New York, and Ohio (Rogombe, 2021). Thus, in keeping with the idea that all policies are ultimately enacted at the state level (Applebaum et al., 2020; Bolkan et al., 2022), we sought to examine the associations across demographic SDOH, difficulty accessing medical care, and functional ability with an age-diverse group of West Virginians.

Using data from the CDC's 2020 BRFSS, we focused exclusively on residents of West Virginia. The BRFSS is the nation's largest telephone-based health surveillance survey (CDC, 2020). These data are used by legislators and policymakers to assess the health of residents within specific states. West Virginia is one such state (CDC, 2020). We chose to analyze data from the BRFSS because data from more than 5,800 West Virginians are collected annually and the state often opts to include optional modules on issues of interest to gerontological researchers and service-providers, such as asthma, cognitive decline, and family caregiving. It is important to note, however, that pragmatic decisions related to conducting a large annual surveillance study limit the selection of variables and their measurement properties. For example, although data are collected across all 55 counties in West Virginia and across the calendar year, data from small counties may be anonymized such that age, gender, and other demographics which could potentially identify a person are omitted from the public data files. Thus, missingness on these key variables may potentially influence the magnitude of effects. Even with the weakness to the BRFSS data for our purposes, however, we view these analyses as a starting point for more nuanced studies in the future.

Results of our initial structural equation model examined the influences of age, sex, income, and education on ease of accessing medical care. We also examined whether these four demographic SDOH and medical access influenced functional ability. Within the age-diverse sample, our model fit the data well. Younger age, lower income, and male sex were associated with more difficulty accessing medical care. Reports of relatively greater ease accessing care were associated with lower functional ability. Although these data can not address the reasons for this counter-intuitive finding directly, we believe that it is related to the notion that increased access results in better identification of disability. In contrast, among the demographic SDOH, only income directly related to functional ability. We interpret this as an indication that the expanded coverage through Medicaid and other programs is likely reaching the intended recipients.

Moreover, expanding medical access may act as an equalizer across the age groups. For example, older West Virginians, especially women, often have less education and less income than their younger counterparts. Although such SDOH may influence access to medical care and functional ability among others, only income was directly associated with functional ability among the older adults. However, younger adults' access was multiply influenced by sex, income and education.

For middle-aged adults, only sex and income predicted access to care. We take this finding as a warning sign for our Legislature, who often does not plan on increases in medical costs or eligibility for Medicaid and other programs when planning the next fiscal year's budget (Rogombe, 2021). The population of West Virginia is among the oldest in the nation (CDC, 2022) and is continuing to increase in median age (Rogombe, 2021). The need is likely to expand among younger and middle-aged adults, as well. That is, the economy in West Virginia is changing rapidly, and unemployment and under-employment is high. Affording higher education may continue to be unattainable for many younger West Virginians.

Policy Recommendations for West Virginia

Given the changing economic landscape, the need for expanded coverage is likely to continue. We propose three broad areas for policymakers to consider: the changing demographics within the state, physical and financial barriers to medical access, and the need to include prevention in medical coverage.

Legislators must focus on the changing demographics, but also on the changing health status of residents. For example, family and health demands on workers are also changing as a function of complications from opioid treatment and reproductive health within the state (e.g., Patrick et al., 2021; Stoltman et al., 2022). Such state-wide issues must be considered as part of the context in which allocation of funds are made.

For an area such as West Virginia, rugged terrain creates geographic barriers to medical access, which could be addressed in expanded programs. Residents of rural areas often live further from hospitals than their urban or suburban peers (Lam et al., 2018). But distance is not the only metric that acts as a barrier to access. Travel times are longer on rural roads and the driving may be more challenging, especially for adults with mobility difficulties (Hash et al., 2015; Patrick et al., 2020). Although financial and physical barriers to medical access may exacerbate morbidity and functional disability, adults must be aware of services to use them (Bolkan et al., 2022). This may be one of those areas in which local stakeholders are able to facilitate and promote the use of medical services within their local communities.

A third priority should be to expand coverage to include prevention, not just treatment. Although Medicaid and other payer systems have frequently focused on a treatment model, rather than prevention, as much as 40% of health and wellbeing may be related to individual behaviors (APHA, 2021).

At its current funding in the state, West Virginia's Medicaid program is expected to be insolvent by 2025 (Rogombe, 2021). It is urgent that state leaders consider the next steps for West Virginia and other rural and Appalachian states. Evidence supports the cost-effectiveness of general Medicaid coverage over merely providing supplements (Rhubart et al., 2021), but Legislatures must allocate those funds. The repercussion of not planning beyond the next few budget cycles is that more working-aged adults, who form the tax base of the state, will enter mid- and late life with lower functional ability and increasing disability.

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Patient-Provider Relationships in an All-Inclusive Specialized Geriatric Program: A Longitudinal Qualitative Study among Older Foreign-Born Latinos with Multimorbidities

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Abstract

Objective: The quality of patient-provider relationships (PPR) is directly related to delivering patient-centered care and improved healthcare outcomes (e.g., adherence to medical treatments) and differs across types of patients to the point of health disparities. PPRs are further complicated when factoring in multiple chronic health conditions, language barriers, and limited time. This qualitative longitudinal study explored the perceived acquiring of high-quality PPR among older foreign-born Latinos over time. **Methods:** We recruited 13 patients with multi-morbidities from nine Program of All-Inclusive Care for the Elderly (PACE) centers. Researchers conducted three rounds of in-depth interviews in Spanish (N=39 interviews) over 13 months. The first interviews were conducted face-to-face and lasted one hour on average. The second and third were conducted over the phone and ranged from 60 to 90 minutes. Data were analyzed using line-by-line *in vivo* coding, identifying

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categories, and themes. **Results:** Patients reported their perceived PPR as a continuum across time, establishing three hypothesized hierarchical developmental levels to the PPR: the good doctor, the doctor of trust, and the advocate. The layers of levels built upon each other. The first level, the good doctor, was the most superficial as it focused on the physicians' technical expertise. The second level, the doctor of trust demonstrated trustworthy characteristics over time. The third level, the advocate, embodied all that a person of trust was plus an additional advocacy dimension. **Conclusion:** Unique study characteristics allowed for an exploration of PPRs. Findings elucidate factors (e.g., expertise, trust, advocacy) that contribute to the development of strong PPRs. To enhance PPRs, strategies should be considered to develop trust and advocate for patients' needs.

Keywords: closed system, Latino, aging, trust, qualitative research, semi-structured interview, longitudinal studies, continuity of care

Relaciones paciente-proveedor en un programa geriátrico especializado con todo incluido: un estudio cualitativo longitudinal entre personas mayores nacidas en Latinoamérica y con multimorbilidades

RESUMEN

Objetivo: La calidad de las relaciones paciente-proveedor (PPR) está directamente relacionada con la prestación de atención centrada en el paciente y la mejora de los resultados de la atención médica (p. ej., cumplimiento de los tratamientos médicos) y difiere entre los tipos de pacientes hasta el punto de las disparidades en la salud. Los PPR se complican aún más cuando se tienen en cuenta múltiples condiciones de salud crónicas, barreras del idioma y tiempo limitado. Este estudio longitudinal cualitativo exploró la adquisición percibida de PPR de alta calidad entre latinos mayores nacidos en el extranjero a lo largo del tiempo. **Métodos:** Reclutamos a 13 pacientes con multimorbilidades de nueve centros del Programa de atención integral para ancianos (PACE). Los investigadores realizaron tres rondas de entrevistas en profundidad en español (N=39 entrevistas) durante 13 meses. Las primeras entrevistas se realizaron cara a cara y duraron una hora en promedio. El segundo y el tercero se realizaron por teléfono y duraron entre 60 y 90 minutos. Los datos se analizaron usando codificación in vivo línea por línea, identificando categorías y temas. Resultados: Los pacientes informaron su PPR percibido como un continuo a lo largo del tiempo, estableciendo tres niveles de desarrollo jerárquicos hipotéticos para el PPR: el buen médico, el médico de confianza y el defensor. Las capas de niveles construidos unos sobre otros. El primer nivel, el buen médico, era el más superficial ya que se centraba en la experiencia técnica de los médicos. El segundo nivel, el médico de confianza demostró características de confianza a lo largo del tiempo. El tercer nivel, el defensor, encarnaba todo lo que una persona de confianza era más una dimensión adicional de defensa. **Conclusión:** Las características únicas del estudio permitieron una exploración de los PPR. Los hallazgos aclaran los factores (p. ej., experiencia, confianza, promoción) que contribuyen al desarrollo de PPR sólidos. Para mejorar los PPR, se deben considerar estrategias para desarrollar la confianza y defender las necesidades de los pacientes.

Palabras clave: sistema cerrado, latino, envejecimiento, confianza, investigación cualitativa, entrevista semiestructurada, estudios longitudinales, continuidad del cuidado

老年人全面护理计划中的医患关系：关于外国出生的、患有多种疾病的老年拉美裔人的纵向定性研究

摘要

目的：患者-医疗提供者关系（PPR）的质量与提供以患者为中心的护理和改善医疗结果（例如，药物治疗依从性）直接相关，并且会因不同患者类型而出现健康差异。当考虑到多种慢性病状况、语言障碍和有限的时间时，PPR变得更加复杂。本文采取定性纵向研究，探究了外国出生的老年拉美裔人对获取高质量PPR的感知随时间推移发生的变化。方法：我们从9个老年人全面护理计划（PACE）中心招募了13名患有多种疾病的患者。研究人员在13个月内用西班牙语进行了三轮深度访谈（N=39）。第一轮访谈是面对面进行的，平均持续一个小时。第二轮和第三轮访谈是通过电话进行的，时间从60分钟到90分钟不等。使用逐行内部编码（in vivo coding）、识别类别和主题，从而进行数据分析。结果：患者将其对PPR的感知报告为具有时间跨度的连续体，为PPR建立了三个假设的阶层式发展层面：好医生、可信赖的医生和

倡导者。各层面彼此依赖。第一个层面（好医生）是最表面的，因为它侧重于医生的技术专长。第二个层面（可信赖的医生）随时间推移表现出值得信赖的特征。第三个层面（倡导者）体现了可信赖的人，再加上额外的倡导维度。结论：独特的研究特征允许探究PPR。研究发现阐明了一系列有助于发展稳固的PPR的因素（例如，专业知识、信任、倡导）。为加强PPR，应考虑相关策略来建立信任和倡导患者需求。

关键词：封闭系统，拉丁裔，老龄化，信任，定性研究，半结构化访谈，纵向研究，护理的连续性

Introduction

An important part of quality health care rests with the patient-provider relationship (PPR), but the current fragmented healthcare system in the U.S. threatens its nature and effectiveness. Four foundational elements compose an optimum PPR including trust, knowledge, regard, and loyalty, and factors affecting the PPR may exist with either the doctor, patient, both, and/or the healthcare system (Chipidza et al., 2015). What each wants in the PPR may not agree or overlap. For example, Berger et al. (2020) found that physicians ranked fairness, reliability, devotion, and serviceability in their technical expertise and skills high, but gave lower scores for warmth and sociability. In contrast, patients highly value interpersonal skills including caring, empathy, and appreciation (Egman-Levitan et al., 2021). While these values hold true for all patients, older patients with multimorbidities often have more medical visits to ensure appropriate management. As such, these values become even more important, but the fragmented medical social services system increases the risk for poor PPR. More specifically, the long-term care system’s interface with medical services contains gaps such that patients and their care partners may even act as knowledge brokers (Wust et al., 2022). Experiences within such a fragmented system especially for older adults include a lack of continuity of care, poor communication between providers, medical mistakes, no integration between medical and social services, access issues due to different funding streams, and a general disincentive to build relationships with patients from lack of primary care (Clarfield et al., 2001).

Some long-term care models exist that reduce fragmentation, so in such settings the encounters may include extended time with their clinician so that providers can go into more depth with managing their chronic health issues. Among older adults with multiple chronic conditions, availability and continuity emerged as important domains of health and social care management (Meranius et al., 2017). The Program for All Inclusive Care (PACE) represents one such model that offers both availability and continuity of health and social care management for older adults who otherwise would need institutionalization (Clarfield et al., 2001). However, PACE eligibility includes low-income older adults who are duals: Medicare and Medicaid, even though not all have to be duals. Vulnerable subgroups of PACE recipients include ethnic minorities such as older foreign-born Latinos, who face increased risk of disability relative to other ethnic groups (National PACE Association, 2022; Usher et al., 2021).

Research exploring patient provider relationships among older foreign-born Latinos are scant (Alegría et al., 2009; González et al., 2010). In general, patient-provider relationships impact patient outcomes and patient satisfaction, but for ethno-racial minorities may be more complicated given potential language and cultural barriers. However, changes in the delivery of health care such as systemic forces due to managed care policies, the fragmentation of the medical system (e.g., waiting time, access to consultants, ability to contact physicians, time spent with physicians), and policies aimed at standardizing care and controlling costs have impaired the PPR leading to unsubstantial care and patient dissatisfaction. These components may interfere with optimal relationship development (Friedenberg, 2003). Furthermore, no studies have longitudinally explored processes contributing to the development of PPR among foreign-born Latinos, despite their increased risk for disability. These gaps obscure the development of culturally-tailored and patient-centered care among a population that is the largest ethnic minority group in the U.S., an aging population, and a group facing high risk and rising rates of multimorbidities (Quiñones et al., 2019). To address this gap and to inform culturally-tailored recommendations for patient-centered care, this study explored the perceived acquiring of high-quality PPRs among foreign-born older Latinos participating in an all-inclusive specialized program, PACE, aimed at controlling patients' costs and enhancing access to care. As such, PACE supplements older foreign-Latinos' social support for their multimorbidities with non-kin, professional relationships in a context with a lower risk for health disparities.

Social Convoys and Healthcare Disparities

A quality PPR can provide an important part of foreign-born Latino older adults' support system as they manage their chronic conditions in a community setting. One way to conceptualize the PPR exists with it being part of a larger social system composed of kin and non-kin. This social system forms a convoy around the older adult across the life course that fluctuates over time (Antonucci et al., 2013), but foreign-born Latino older adults may experience "broken convoys" from later life migration (Maleku et al., 2022). For these older adults, they needed more kin when they immigrated to the U.S., but after living here they also need non-kin such as PPR to help them manage their worsening chronic health conditions (Goldman, 2016).

Embedded within their need for a quality PPR are risks for not only poor PPR but also less access and higher costs in accessing the health care system depending on their citizenship status (Ornelas et al., 2020). Even with citizenship, foreign-born Latino older adults face an increased risk for health disparities or issues plaguing their interaction with the healthcare system that extend beyond basic difference in utilization. Disparities stem from structural and interpersonal barriers that hinder the optimal access and quality relative to those without such disparities. Structural disparities may arise when foreign-born Latino older adults lack health care insurance, accessible locations for healthcare, transportation, and the like (Maleku et al., 2022). Interpersonal disparities may occur even when a foreign-born Latino older adult have a PPR, if the provider communicates or behaves in a discriminative manner during interactions (Berger et al., 2020; Ornelas et al., 2020). More specifically, a poor PPR may occur when a provider does not make sure to understand the needs of the patient by not asking, asking for too much, not listening, or failing to take the time (Lyles et al., 2016; Maleku et al., 2022).

If many of these factors contributing to health disparities were removed, one could better understand the characteristics of PPR in vulnerable groups of older adults. By selecting patients from the PACE program, this study minimizes these factors and allows a more focused examination of the PPR from the older foreign-born Latinos themselves. Moreover, this study explored their perceptions over time to better understand the evolution of the PPR. The main research question is: How do older foreign-born Latinos perceive their PPR over time?

Methods

This longitudinal qualitative study used a convenience sample from nine Program of All-Inclusive Care for the Elderly (PACE) centers in Southern California. The longitudinal nature of the study design allowed investigators to follow people and observe their evolving stories, attitudes around communication, and relationship development. Investigators were able to study facets of the PPR not always observed in community-dwelling foreign-born Latino elders managing multimorbidities. These patients were hyper-exposed to biomedicine and had increased opportunities to interact with medical practitioners, thereby giving investigators an insight look to gain a deeper understanding of the contextual factors surrounding communication (e.g., power imbalances and culturally appropriate interactions).

This study was approved by the UCLA Office of the Human Research Protection Program (IRB # 15-000208).

Program of All-Inclusive Care for the Elderly (PACE)

PACE is a Medicare and Medicaid managed-care program for adults over 55 years old. The program uses an interdisciplinary team approach to provide patients with medical, social, nutritional, and rehabilitative services. The care is comprehensive and integrated, including pharmacological and non-pharmacological treatments and interventions (e.g., referral to specialists, physical and occupational therapists, and alternative treatments such as acupuncture and massage therapy), screening, prevention, diagnostic tests, follow-up, and advanced care illness preparation. Prospective patients must have met nursing home ***care*** eligibility criteria to enroll. The advanced care program uses a social worker and adult day health care center model (California Department of Health Care Services, 2022).

According to the National PACE Association, the typical PACE participant is similar to the average nursing home resident—an 80-year-old female with eight medical conditions and limitations of three activities of daily living. The goal of PACE is to maintain frail adults outside of long-term institutions and allow them to remain to live safely in their communities.

Recruitment, Data Collection, and Analysis

Investigators were blinded from initial participant selection. PACE site coordinators announced study details to patients and provided investigators with contact information for clinic patients who expressed interest. Participants were not compensated for their time; therefore, investigators ensured participants understood they had a right to decline participation without repercussion to their medical services. If the participant consented to be interviewed, the location and time of interview were negotiated, and interviews were scheduled. Thirteen foreign-born older adults over the age of 65 with multimorbidities were identified.

Semi-structured in-depth interviews took place in patients' homes and at the medical facilities. An interview guide was developed to direct discussion and provide probes when necessary (Bernard, 2006). The interview covered topics around medical decisions, their communication, and relationship with providers. Investigators focused on one or two chronic conditions that were being managed and asked their experiences in speaking to their doctor about that condition. In addition, investigators used questions from the AHRQ Consumer Assessment of Healthcare Providers and Systems (CAHPS) Adult Supplemental to help initiate conversations around decision making and elaborate on communication process. Investigators asked participants to share about the most impactful clinicians' modes of communication, characteristics, and overall and examples of how communication processes occur.

Three rounds of in-depth qualitative interviews were conducted with each participant over a 9-month period (range of elapsed time between interviews was 6 to 12 weeks). The first round of interviews (T1) were conducted face-to face and lasted approximately one hour. Subsequent interviews Time 2 (T2) and Time 3 (T3) were conducted over the phone and ranged between 30 to 90 minutes. All interviews were conducted in Spanish and audio recorded by investigator with an emic perspective (RLB). Approximately three months transpired between interview rounds (T1, T2, and T3).

Investigators transcribed audio files verbatim in Spanish (original language) to prevent loss of concepts in translation. We analyzed three interviews for each of the 13 participants, 39 original transcripts and their respective interview process documentation (e.g., written and oral interview summaries) using Dedoose version 7.1.3, a web application for managing and analyzing qualitative data (Lieber, 2015).

An inductive approach was used to analyze interview data and summaries to deconstruct explicit reality and reconstruct implicit reality (Bernard, 2006; Corbin & Strauss, 2014; Creswell & Poth, 2016; Miles & Huberman, 1994). Drawing from grounded theory (Glaser & Strauss, 1967) and constructivist grounded theory principles (Charmaz, 2006), we used an iterative process of adding and updating codes so there was a blurring between steps (Figure 1). We used five transcripts using a line-by-line technique to develop an initial set of *in-vivo* codes. These codes captured a specific act, feeling, or response from the respondents in their own words. After completing the initial set of codes, line-by-line codes were grouped into broader categories, then into higher-level coding schemes by grouping them into themes, and eventually into domains. In the results sections, excerpts were translated from Spanish to English.

Results

Patient Characteristics

Table 1 illustrates participants descriptors. Most participants were monolingual Spanish-speakers (77%) and female (77%). Although a few were bilingual (23%) and spoke English as their second language, they preferred to speak Spanish with their providers. They felt more comfortable managing the nuances of Spanish language over English. Over half of the participants were born in Mexico (54%), while the remaining were from Central and South America. On average, participants were 75 years of age and had four years of education. Just over three quarters were unmarried, with the highest percentage being widowed at baseline, a percentage that only increased for subsequent interviews. The number of comorbidities per participants ranged between seven to 13 chronic conditions. Finally, under one quarter lived alone at baseline.

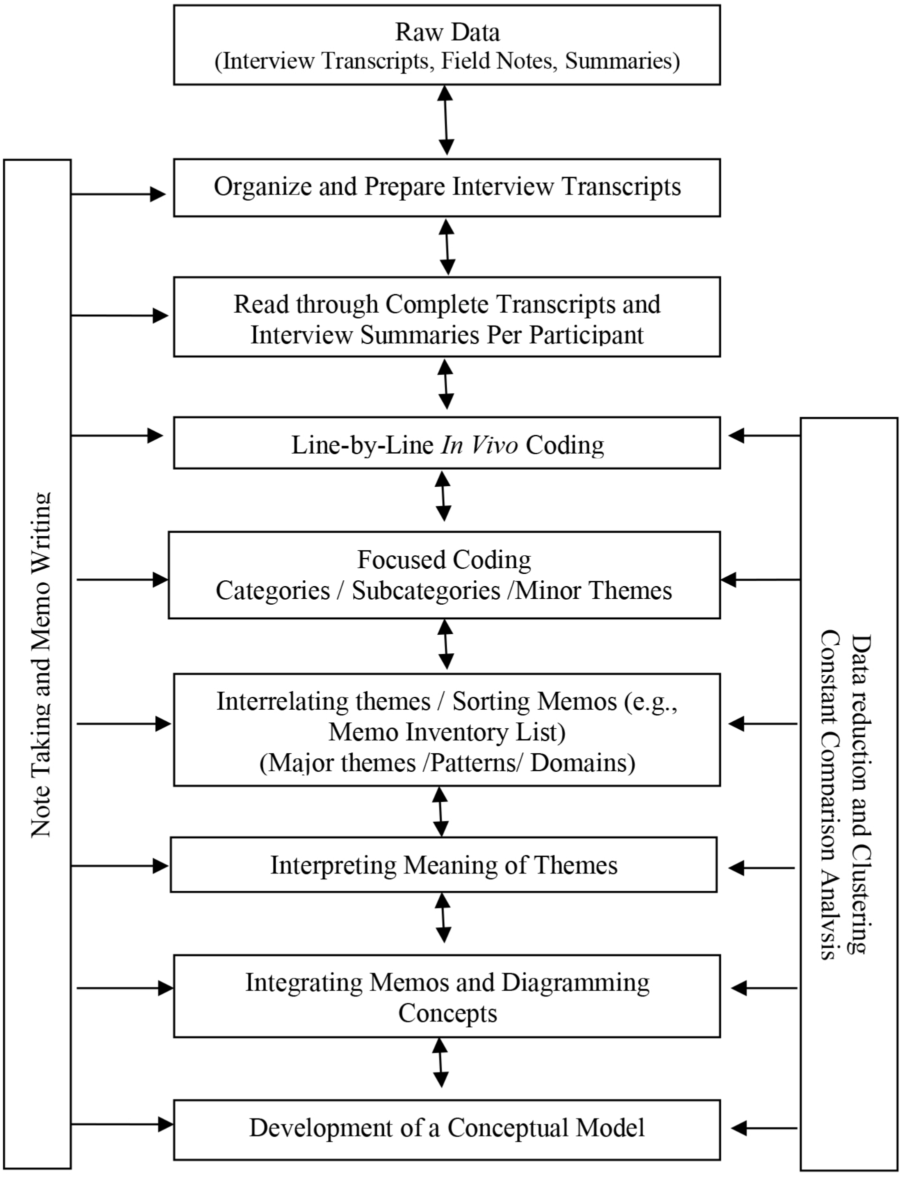

Figure 1: **Visual Representation on the Overview of the Data Analysis**
Schematic diagram outlining simplified analytic steps.

Table 1

*Patients Demographics from PACE (*n=13*)*

	Frequency (%) or *M* (range)
Age	75 years *(65-85)*
Gender	
Male	3 (23%)
Female	10 (77%)
Ethnicity	
Central /South American	6 (46%)
Mexican	7 (54%)
Marital Status @ T1[a]	
Married	3 (23%)
Widowed	7 (54%)
Separated/Divorced	3 (23%)
Living Arrangements	
Alone	3 (23%)
Family	10 (77%)
Language	
Spanish	10 (77%)
Bilingual	3 (23%)
Years in the United States	21 years *(3-52)*
Education	4.5 years *(0-16)*

Note. M = mean.

[a] T1 refers to interview at Time 1. Marital status changed between some of the participants in subsequent interviews with death of partner.

Patient-Provider Relationship Patterns

Findings identified relationship patterns between older Latino adults and providers participating in the Programs of All-Inclusive Care for the Elderly (PACE), a capitated Medicaid and Medicare program that provides comprehensive services. For the patients, barriers to accessing care (e.g., costs, transportation, language) were eliminated. Studying patient experience and their perceived relationship without interference from the business of practicing medicine allowed researchers to observe relationship patterns develop over time. Three positive relationship patterns (the good doctor, a person of trust, the advocate) are presented here and hypothesized to positively grow and build upon each other. These patterns were described as patients perceived level of trust in their practitioners improved.

The Good Doctor / "El Buen Doctor." In probing to seek what patients deemed were desirable provider characteristics, patients saturated the concept of "the good doctor." Respondents shared their belief that doctors have the basic technical information and capability to make an accurate diagnosis. These were doctors who primarily performed their skill competently by correctly diagnosing and prescribing accurate medications to eradicate or ameliorate the problem. Lucia spoke about still being in the process of evaluating her current clinician to see if he might be considered a good doctor. She needed to wait and see if he was able to correctly diagnose and provide her with the accurate medication to eliminate her ailment. The patient expected an accurate diagnosis irrespective on the amount of detail about their ailments she provided to the practitioner. Similarly, Alma received a cancer diagnosis that went undetected by two physicians before a "good doctor" diagnosed her and started her on a proper treatment regimen.

A Good Doctor Finds the Disease. "This doctor is the one who is treating me, but he was not able to diagnose me…until I went with doctor P. He did diagnose me and started me on treatment…Good doctor…The other two were not as good, as doctor P because they did not find the disease" (Female – Time 3).

A good doctor was willing to look at all possibilities and run a battery of tests to identify the problem to offer an effective solution. When Francisco was recuperating from prostate cancer surgery, he had bladder complications. His specialist prescribed medications, but his symptoms went unmanaged, severely impacting his quality of life. He went to Mexico and consulted with a doctor to obtain a second opinion. The doctor in Mexico embodied how a *buen doctor* was expected to behave.

"I went to Mexico to see a doctor, and **he told me the truth** of what was happening with my bladder. He told me my bladder was fine; it just needed more time to recuperate. He said 'I am going to prescribe this medicine and you take it for about 2-3 years. And don't stop doing the exercises. That medicine that you have is the wrong medication because that is for a prostate and you no longer have a prostate.' He then did an ultrasound and he told me 'all that medicine you have instead of curing you is producing more liquid.'" (Male-Time 3).

Francisco's incontinence did not immediately disappear. As his doctor had explained, Francisco's bladder needed time to heal. The physician from Mexico had discovered the problem, and Francisco's symptoms improved. The physician in Mexico was categorized as a good doctor because he had run the adequate number of tests needed and identified the problem, explained the facts to Francisco and delivered a treatment regimen that improved the patient's symptoms, which meant Francisco was on the road to a speedier recovery. In addition, the doctor in Mexico looked out for Francisco's future well-being by providing the patient with the required paperwork to take to his primary care provider in the United States to continue the treatment regimen he had started in Mexico. A good doctor identifies the disease and **tells you the truth**; they also listen to your preferences and either refer you to another good doctor or give recommendations.

Claudia previously spoke about not trusting U.S. doctors to perform complicated and risky procedures, such as back surgeries. She expressed her desire to seek care in her home country, and her doctor provided her with the tools to seek specific specialists needed for her back pain. Bertha sums it all, "that the [doctor] talk to me, that they tell me the truth" (Female, Time 1).

A Person of Trust / "Una Persona de Confianza." Participants spoke about ideally wanting to have a doctor that embodied characteristics of a person of trust (*una persona de confianza)*. A provider who is deemed to be a person of trust (*una persona de confianza*) is a clinician who embodies truth-telling, irrespective of what mainstream America perceives as informed decision-making. The characteristics repeatedly used to describe trust-worthy individuals personified benevolent qualities (e.g., kind, always smiling, open and sincere *amable, risueña, abierta, sincera*). Another common phrase used to refer to the concept of a person of trust is a person with heart (*una persona de corazón*). In this phase, the doctor's heart is deemed to be in the right place, with the patient and not their pocket, therefore trust is placed in the doctor's hands. A clinician who embodies the characteristics of a person of trust speaks from the heart (*habla con el corazón*), and thus sincere care is transmitted and felt by the patients. *Una persona de confianza* (a person of trust) is willing to make their opinion clear to the patient with what they think is the best method or strategy. The provider must go out on a limb stating their preferences, personal ideas and opinions about what they foresee to be the best treatment by clarifying the decision-making process.

Tells me the Truth. "A person of trust that could tell me the truth...for example, if there was a solution that they would tell me 'Francisco' it's all right. Having that confidence to give us that encouragement, right? That they tell me, you know what is good…that they do not put in doubt, but if they do make you doubt that they say 'think about it.' I would still appreciate it, right?" (Male – Time 3).

A person of trust understands how these patients view truth-telling. Francisco wanted someone to tell him the truth, which meant providing a word of encouragement when the course of action was clear to the provider and not adding doubt to an already difficult decision. However, if doubt was in order, it meant making it clear that the course of action would need to be thought out by the patient. Unfortunately, few of the patients had ever experienced a doctor in the United States as a person of trust. Most have described this kind of relationship with physicians as they had long-standing relationships in their home countries. The relationships crossed over from a mere professional relationship filled with one-way technical information to a two-way process where there was a prominently perceived level of trust.

My Favorite Provider Someone Like Me "To have a favorite provider, it would have to be me…it's that I would need a person of trust…and well right now I don't have one" (Male – Time 3).

The concept of truth-telling is crucial because it has the power to build up a relationship or destroy what little if any trust was already established. If the doctor provides the patient with information, and that information turns out to be incorrect, the patient is often left feeling as if they have been lied to. Francisco, for example, was told by his physician that he would fully recuperate from the prostate surgery side-effects in seven years. He believed that timing, and seven years later he is still suffering from the side-effects and left feeling disheartened.

> "[The urine] is what has bothered me the most since I had surgery…They have already checked me, all of the specialists, and well they say I am fine. [But the urine comes] Yes and I am still leaking, right? Yeah, but it's already a lot of time…So, the doctors say that I should have already recuperated 100 percent" (Male – Time 3).

Value and Perception of Truth-Telling. An important feature that builds a patients' trust is the concept of truth-telling. Older foreign-born Latinos do not equate truth telling as mainstream America views informed decision-making. Truth-telling is not "informed decision-making." Truth-telling is being able to appropriately tell the patient what they are to expect and to go out in a limb to share their private opinions as to what treatment they feel will be the best for the patient. Truth telling is not informing patients of all available treatment options and describing the benefits and consequences of each. The expert's function is to provide clarity; it is not to muddy a decision by introducing doubt. Older adult Latinos did not expect the doctor to share information that did not pertain specifically to their circumstances. The "expert" who cares about his patients must be willing to display what they deem are the good, bad, and ugly things for patients to consider. This means only displaying those cards on the table that pertain to the patient's unique situation. Participants did not want the physician to lay out all the cards on the table, particularly if they were not viewed as viable treatment options by the physician. The good doctor is supposed to know the trajectory and course of the patients' condition, have expected timelines, and know the patient's preferences as to what issues must be brought up to the patient and family and which ones can be left unspoken.

Patients do not expect clinicians to know everything, but they do expect the doctor to be skilled and understand the basics of science which are informed from their schooling and from their firsthand experiences in working with other patients with similar conditions.

Tell Me what I Should Do. "A sincere person that tells me exactly what is best for me. Like when we are going to die and we say, 'Doctor how many days do I have left?' No, well I can't tell you [laugh], right? What I want is that he puts the cards on the table. Seeing my health, my way of living and all of that, that he tells me exactly what I can do. That he explains it to me" (Female – Time 3).

Respondents respected clinicians who provided information benefiting the patients' wellbeing. Participants would have the physician answer, "Please put yourself in my shoes and tell me what you would do if you were in my position?" Then explain why you think this is the best treatment option for me. Bertha summed up "that the [doctor] talk to me, that they tell me the truth" (Female – Time 1).

The Advocate. The advocate embodies the features of a person of trust and more. Similarly, to the person of trust, an advocate goes out on a limb to state their opinion and support the patient's positive health and well-being. Based on the clinicians' expertise and knowledge of the patient, the clinician actively aimed to prevent undesired health consequences (e.g., side-effects from radiation, cancer diagnosis). Unlike a person of trust who speaks honestly and broaches situations as they arise, an advocate sees a potential problem likely to happen and takes action to prevent it from occurring. The advocate can play a persuasive role in the patient's decision-making process. Usually at this level of the relationship, the patient and physician share values and belief systems. This gentleman, for instance, has a provider that shares many cultural perspectives. They both share the value of limited use of drugs and increased use of natural medications.

Discouraged me from Having Additional Tests. "He [My doctor] prevented me from going to take a cardiology test. He told me, 'Francisco don't go! Don't go to the cardiologist!' They were going to do a nuclear test where they give you a lot of liquids. They had already done it one time. He told me 'Don't go, look they give you a lot of liquids. See, your heart is fine so you don't need it. The only thing is that your heart is a little big, that's it. Look' he said, 'it seems to me that it being a little big could be due to inflammation.' He said, 'it gets a little large when one suffers a stroke or when one is really stressed, but I recommend you do not do the exam.' I didn't go!" (Male – Time 1).

At this level of the relationship, there is a significant degree of trust that has been established between the patient and the provider. The patients' confidence in their physicians' recommendations weighs heavily on the patients' medical decisions. Putting your trust in something means you are relinquishing some of your control over the situation (e.g., stop getting information and go forward based on what the physician has said). The physician has established a great influential power. Some of the patient-clinician relationships reported within GraciaMed PACE evolved from a professional realm, where the value of respect (*respecto*) for those in positions of power was reported to a relationship within the realm of friendship and family-like. This transition manifested in the way the participants spoke about their medical practitioners. In the Spanish language there are two forms of speech, a formal and informal. Cultural norms and rules guide the usage of these forms of speech in addressing others, especially those who are deemed to be respected such as those in positions of power (e.g., elders, physicians). In the first level of relationship development of the good doctor (*el buen doctor*), the patient often speaks about the physician in a formal sense. As the patient acquired a higher level of trust, and the perception that the clinician opened the opportunity for more emotional and social types of engagement, the dynamics between the two people were leveled, and the forms of speech intermixed between formal "*usted*" and informal "*tu*" both meaning (you) in English. The formality remained because a physician is someone to be respected, but the number of times less respectful forms of speech were included increased. A more familiar way of addressing each other (e.g., first person) was reported in patients who had established relationships with the medical practitioner in the realm of a person of trust (*persona de confianza*) or an advocate.

In sum, the patient-practitioner relationship has the potential to flourish into a true partnership where open and honest conversations are had and the spirit of delivering patient-centered care is embodied.

Discussion

Prior research underscores the critical role of the patient-provider relationship (PPR) for patient outcomes and satisfaction (Drossman et al., 2021; Huang et al., 2020). Relational trust is key to developing high-quality genuine relationships between patients and providers, and vital for effectively managing chronic comorbidities. As older foreign-born Latino adults have high rates of multiple chronic comorbidities, poor day-to-day functioning, and high rates of mortality (Fortin et al., 2004; Marengoni et al., 2011; Ryan et al., 2015), management of multimorbidities is a public health priority among this population. As management of multimorbidities necessitates ongoing attention, requiring numerous medical encounters, investigating PPRs between foreign-born older Latinos and their providers is critical to address health disparities among this growing segment of the U.S. population. Yet a shortage of qualitative longitudinal research exists exploring PPRs among older foreign-born Latinos. Therefore, this qualitative longitudinal study aimed to explore the perceived acquiring of high-quality PPRs among older foreign-born Latinos.

Consistent with prior research, this study found that perceived relational continuity was a valued commodity in delivering healthcare and maintaining a positive patient experience for patients with multimorbidities (Murphy & Salisbury, 2020). Participants from this study perceived the PPR as a continuum across time, establishing three developmental stages in the PPR. The first stage established the concept of *el buen doctor* (a good doctor). Among the Latino medical community, the idea of a good doctor is a familiar concept. An editorial piece titled *Ser Un Buen Medico* (Being a Good Doctor) was delivered to graduating medical students and surgeons in December of 2008 in Colombia. It embodies what a future practicing physician aspires of their future relationships with their patients:

> *To those who patients call 'good doctor:' one of those aspects, and maybe the most important one, is trust, which is built from scientific competence, truthfulness, integrity, respect, and good relations with patients and colleagues* (Gómez, 2009, p. 10).

The foundation of an effective patient-clinician relationship falls upon trust, which is built on mutual respect and empathy. All other characteristics, such as respect, integrity, and good relations, are value-driven characteristics with unspoken culturally relevant dynamics most likely to be met by a person with an emic perspective. The quote embodies aspects of the findings regarding relationship development. What participants may be identifying as skillset may be the manifestation of the different paradigms and values between providers practicing in the U.S. and those in Latin America. However, additional research to identify what drives the idea needs further investigation.

Furthermore, participants emphasized that a good doctor listens to their patients' medical concerns and treatment preferences. When participants were not satisfied or felt their concerns went unheard, they would seek a second medical opinion. These findings diverge from prior research that suggests that Latinos do not want to engage in medical decision-making (Levinson et al., 2005). In other words, our sample of foreign-born Latinos with multimorbidities were active participants in their health care and the decision-making process.

During the second stage of relationship development, the patients perceived the clinician to be a person of trust. Trust was already established and strengthened as the clinician demonstrated trustworthy characteristics over time. The clinician embodied truth-telling, irrespective of the status quo. The features repeatedly used to describe trust-worthy individuals personified benevolent qualities (e.g., kind, always smiling, open and sincere *amable, risueña, abierta, sincera*). These findings are consistent with prior research that documents Latino patients valuing warm personal relationships with their providers (American Medical Association, 1994; Alegria et al., 2009).

The last stage embodied the characteristics of a person of trust plus an advocacy component: doctors who advocated for the patient's well-being and were willing to express their opinion, occasionally sticking their necks out for their patients. This finding extends prior research on PPRs among foreign-born Latinos in the U.S. Prior research in this area typically assesses confusion, frustration, and perception of poor quality of care, language concordance, and health care discrimination (Gonzalez et al., 2010; Lopez-Cevallos & Harvey, 2016). However, findings from this study underscore the importance of advocacy in fostering a strong PPR and sense of trust with foreign-born Latino patients.

Patients reported relational trust as the key to developing high-quality genuine relationships that increased their satisfaction with their receipt of care, health outcomes, and quality of life. This kind of relationship is satisfying to patients and protective against burnout and improvement to practitioners' mental health and well-being (Hojat et al., 2011; Huang et al., 2020). However, the deterioration of the patient-provider relationship is a problem for the patients' health outcomes and providers' mental health and well-being. The COVID-19 pandemic has increased the percentage of burnout to an unprecedented threat to doctors' physical and psychological health (Chatterjee et al., 2020). Before the pandemic, it was estimated that 46% of the U.S. physician workforce suffered burnout (Bansal et al., 2020; Nanda et al., 2017). Innovative solutions that reduce the pressure to see more patients in less time and to reduce administrative tasks and increase opportunities to organically engage the patients in listening sessions within the medical encounter are critically needed. The patient-clinical relationship must be redefined and operationalized to include new relational dynamics introduced by innovations in care delivery (e.g., telehealth).

When older foreign-born Latinos describe their PPR over time, one can understand that the PPR is not an incident but, rather, part of their lifestyles and management of multimorbidies. As such, PPR compose part of their social convoy in addition to spouses, children, and other family. Their social convoys represent especially important aspects of their social support network, because of their increased risk for broken convoys following migration to the U.S. (Lerman Ginzburg et al., 2021).

Policy Recommendations

The number of foreign-born Latino elders experiencing multimorbidities is expected to grow and is projected to increase the healthcare costs associated with its management. The costs associated with managing multimorbidities are generally higher for people with multimorbidities compared to the general population (Quiñones, 2019). Multiple chronic conditions pose many challenges, one being how to provide patient-centered care in the context of competitive health care priorities and increasing complexity. The findings contribute to practice-based conversations around the implementation of specialized models of geriatric care, particularly hard-to-reach vulnerable geriatric populations, such as predominantly monolingual foreign-born Latino elders.

The PACE Model of Care was a unique setting for this research project. The programmatic features/characteristics allowed the observation of patient provider relationship (PPR) development under the best of controlled circumstances for older adults foreign-born Latinos. Although the participants in this study were all foreign-born, the issues around access to care due to immigration status were not a factor. The participants were dual-eligible for Medicare and Medi-Cal and met nursing-homebound eligibility requirements upon arrival at the center. Again, the participant eligibility and the capitated feature of the program helped control costs. The issues around language barriers were also not a factor, since the number of PACE staff and professionals were ethnoculturally concurrent with the center patients. During the study, only the primary care providers and some nurses were non-Spanish speakers; most spoke the language and cultural nuances around communication were understood.

Because these were PACE participants, researchers recorded the development of PPRs Automatically, the program removed the challenges often observed in other disparity studies (e.g., access, cost, quality of healthcare delivery, and transportation). Under these optimal conditions, our study found that high quality PPR is attainable. Therefore, we recommend the following PACE Care Model modifications to expand findings to minimize health care disparities among older adults of color. First, increase the number of states to expand PACE programs to more medically underserved areas (MUA) and medically underserved populations (MUPs). PACE programs deliver Medical and Medicaid services. The National PACE Association estimated that over 1.2 million of the Medicaid beneficiaries who could benefit from PACE failed to have access to a PACE program. The greatest barrier to this service is accessibility (Kaye, 2019). Secondly, increase the number of Federally Qualified Health Centers (FQHCs) and FQHC look-alikes serving MUA or MUP's to incorporate a PACE program. Although PACE is a fundamentally different payment model with different delivery of care, FQHCs are well-positioned to take on the opportunity to incorporate PACE program. Finally, broaden the eligibility criteria to include non-nursing home bound and community-bound / home-bound people having trouble managing multiple chronic conditions.

In addition, we recommend training to replicate similar findings in traditional models of care with non-inclusive, non-capitated, and non-comprehensive components that serve aging adults. One is to train and hire case workers specializing in aging, immigrants, and Latino culture and language to advocate and oversee the healthcare coordination needs of each adult. Second, to incorporate additional training for physicians in relationship building for patients who are older and whose language of preference is other than English.

Incorporating even some of these recommendations would increase the likelihood of replicating similar results in other communities where ethnic enclaves predominate. Doing so would allow for the development of better quality PPR by controlling documented barriers to access to health care and increase the equity that predominates in the social determinant of health literature (Hall et al., 2015). We advocate for healthcare models and environments that support equitable outcomes, and minimize adverse health effects and increase access to comprehensive services to promote health and reduce health care disparities.

Limitations

Findings from this study should be considered in light of several limitations. First, participants for this study are foreign-born Latinos with multimorbidities who participated in PACE in Los Angeles County in Southern California. Given the regional nature of our study, the PPR development experiences may be unique to individuals who are foreign-born Latinos, living in Los Angeles County, and involved in PACE centers that share predominant ethnocultural concordance with providers and staff. Therefore, future research should assess PPR development in different settings, as the transferability of these findings to other populations may be limited. Second, this qualitative study sought to identify the uniqueness of PPR development among foreign-born Latinos in Los Angeles County and, therefore, not a nationally representative sample. Future research should seek to use quantitative study designs to assess whether these patterns differ among foreign-born Latinos in distinct areas of the U.S. Finally, our study was comprised of dual-eligible foreign-born Latinos with multimorbidities from Mexico and Central America. As prior research documents differences in patient-provider communication between foreign-born and U.S.-born Latinos (Alegria et al., 2009), future research should qualitatively assess PPR development among U.S.-born Latinos. Furthermore, given the heterogeneity of the Latinx population, future research should assess whether these patterns vary by time in the U.S. and by gender.

Contributions

Despite the aforementioned limitations, this study makes several contributions to the PPR literature. First, prior studies did not longitudinally explore processes contributing to developing of PPRs among foreign-born Latinos. This gap in the research literature obscures the development of culturally tailored and patient-centered care among a population that is the largest ethnic minority group in the U.S., an aging population, and a group facing high rates of multimorbidities. To address this gap and to inform culturally-tailored recommendations for patient-centered care, this study explored the perceived acquiring of high-quality PPRs among foreign-born older Latinos participating in an all-inclusive specialized program aimed at controlling patients' costs and enhancing access to care. Second, the longitudinal nature of the study design allowed investigators to follow foreign-born Latinos over time and to observe their evolving stories, attitudes around communication, and relationship development. Relatedly, because the PACE model controls patients' medical costs and increases opportunity for interactions with medical professionals, investigators were able to study facets of the PPR that are seldomly observed among community-dwelling foreign-born Latino elders managing multimorbidities. The unique study characteristics allowed for an exploration of PPRs among an understudied population: foreign-born Latinos. Findings elucidate factors (e.g., expertise, trust, advocacy) that contribute to the development of strong PPRs. As prior research documents differences in patient-provider communication between foreign-born and U.S.-born Latinos (Alegria et al., 2009), this study was able to capture PPR development over time among foreign-born Latinos specifically. Finally, although prior research has used data from a nationally-representative sample of foreign-born Latinos to assess patient-provider communication (Gonzalez et al., 2010), we extend this body of work to capture *how* PPRs develop over time among a sample of foreign-born Latinos with multimorbidities.

Conclusion

Findings from this study underscore how relationships within the healthcare system and continuity of care are valued commodities for patients. Patients want to feel genuinely cared for by their providers. Value-based care with coordination and continuation are ideal for developing relationships. Fragmented care does not work for managing multiple conditions when the broker to the patient's care is the patient. The PACE model has been shown to increase those characteristics of relationship development between patients and providers. Efforts should be made to incentivize initiatives to achieve relational continuity between providers and patients within a modern healthcare system. To address the high burden of multimorbidities among older foreign-born Latinos, continuity of care and development of PPRs (especially trust) should be a priority. To enhance PPRs among older foreign-born Latinos with multimorbidities, providers should consider strategies to develop trust and advocate for patients' needs.

Authorship Contribution Statements

Rosana Bravo: Conceptualization, methodology, investigation, analysis, and writing. **Ángela Gutiérrez:** Writing, reviewing, and editing. **Lené Levy-Storms:** Writing, reviewing and editing. All authors approved the final version.

Declaration of Competing Interest

The authors declare no conflict of interest.

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