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TRANSLATIONAL SOCIAL SCIENCE:

Kinship, gift exchange, and the management of diabetes

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ABSTRACT The authors examine the impact of kinship structures on the management poorly controlled type 2 diabetes.

Keywords: *kinship structure, diabetes, family*

Clinical-Social Context

Grace Thompson [pseudonym] is a 45-year-old Black woman. She has a history of childhood emotional trauma related to sexual violence from her father. Subsequently she moved across town and she is estranged from all of her biological relatives. Living alone, she raised two children, a daughter, and a transgender male to female who completed gender affirmation surgery. She is disabled and financially dependent on social services for healthcare, housing, and food stamps.

Her medical history is extraordinarily complex. She was morbidly obese with diabetes. Obesity contributed to chronic back pain. She spent several years trying to get insurance approval for reduction mammoplasty but was unsuccessful because of health insurance pre-authorization requirements. She also spent years trying to pursue gastric bypass surgery but was also unsuccessful because her health insurance introduced too many barriers to receiving care. During her monthly visits for "diet advice" she reported eating only pizza and chicken wings. When asked why those food choices continued despite the doctor's advice, she replied, "Doctor, I don't have a car. The only way I can get food is to have it delivered and the only food they deliver in my neighborhood is pizza and wings."

She had a history of bipolar I disorder and had an atypical reaction to antipsychotic medications resulting in hepatic failure and eventually hepatic cirrhosis. This was monitored for several years and stabilized. During this period, she developed lupus nephritis resulting in renal failure requiring renal replacement therapy. She's currently maintained on hemodialysis and hoping for a kidney transplant.

While on dialysis, she became unable to eat and went from being obese to being malnourished. Her doctor told her, "You deserve to be cared for and nourished," at which point her weight stabilized.

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During longitudinal care for these many complicated medical problems, she had difficulty obtaining resources such as food, housing, and transportation. Instead of treating her diabetes and obesity, we allowed her to use the family medicine office as her office because the Department of Human Services presented multiple structural barriers to accessing services. Her caseworker never answered the phone, resulting in multiple phone messages. She had excessive paperwork for everything. By using the clinic fax machine, she was able to keep a record of all communications with the Department of Human Services. Her housing was unstable, her place of residence was condemned and she was forced to find alternate housing on a budget. After all the paperwork and transportation difficulty, she found a house, but it was $4 over the Medicaid budget, and they denied her housing. During an office visit, we asked her where she was staying and she said, "my daughter and I [were] living with her auntie." We recognized that "auntie" was not a biological relative, which allowed us to explore her kinship structure further.

She continued to use the phone and fax machines in the clinic. Office space rents for $25/square foot—a resource this patient could never afford but which was a fixed cost in a medical office. We also provided her with access to a state sponsored pilot project where she could obtain fresh fruits and vegetables from a large grocery store chain. This was done when her food insecurity was recognized during a routine office visit. Like so many others, it is ironic that Ms. Thompson had obesity and was malnourished at the same time.

Statement of Social Science Concept Illustrated in the Clinical Social Context

How do kinship structures affect clinical decisions related to diabetes management?

Illustration of Translational Social Science Concept

Merriam-Webster defines the word kin as "a group of persons of common ancestry".[1] However, kinship and family structures may be much more complex upon closer inspection.

We present this case to emphasize that kinship is relevant to the management of diabetes. Ms. Grace Thompson had diabetes and the successful management of her chronic disease was impacted by kinship structures. "Auntie" provided housing when social services for housing failed. It was unrealistic to expect Ms. Thompson to follow a healthy diet when she didn't have a place to live.

Ms. Thompson came from a resource-deprived neighborhood. For the purposes of this case, we will explore an ethnography that matches Ms. Thompson's social environment and availability of resources almost perfectly. Our discussion of kinship is based on Carol Stack's book *All our kin*.[2] The author lived amongst poor urban black families in a Midwestern city and discussed kinship structures among those residing in under-resourced communities. She described these kinship structures as being shaped by necessity as a strategy to cope with poverty. She explained that welfare benefits given to mothers are the main source of income for many of these families and that they distribute resources to those in their kinship networks in times of need. It isn't uncommon for three generations of kin to be living under the same roof. Moreover, those living under the same roof are part of a kinship network but may not be biologically related, rather, they share a system of reciprocal obligation and access to resources.

In addition to sharing financial resources, these kinship networks also share social resources. For instance, children are often moved from household to household and raised by numerous individuals depending on who is available. Children may be borrowed or loaned, a phenomenon called child keeping. The author estimated that "at least one in three children have been kept by kinsmen one or two times during their childhood."[2, p. 69] The extreme level of poverty also plays a significant role in whether formal marital relationships contribute to family structure. "Women come to realize that welfare benefits and ties within kin networks provide greater security for them and their children" than resources from men.[2, p. 113] This means that the social roles of male family members are determined by markers other than marriage.

This book underpins an important point: although kinship structures and families may be very different than one expects, the economic impact of kin networks is critically important to understand how patients acquire the capital goods and services known as the Social Determinants of Health (SDoH). For this reason, it is important not to assume physicians know what a proper kinship

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structure is. In fact, the kinship/family structures in America are evolving even as we write this article. Eric Andersson writes about journalist Anderson Cooper's family arrangement: he and his ex-partner live together and co-parent his two boys, an arrangement Andersson describes as his "modern family."[3] Cooper's family is comprised of four males, in contrast to the matrilineal family structure described in *All our kin* where the financial resources and juridical decisions were made by females.

Carol Stack's book is an ethnography. Ethnographies combine observation within a theoretical context. The basic theoretical concept of *All our kin* is based on Marcel Mauss's *The gift*.[4] Carol Stack talked about the gift exchange as a form of trading goods and resources in a resource-deprived urban setting. "The obligation to accept is no less constraining… the obligation to reciprocate worthily is imperative."[4, pp. 52-54] The individual unable to repay the loan or reciprocate loses his rank or status.[4]

In her ethnography, Carol Stack describes a poor Black community in the Midwest called "the Flats". The housing was frequently "deteriorating" or "dilapidated". Crowding was ubiquitous and privacy impossible. Healthcare services were inadequate. Transportation was walking, riding a bicycle, or taking a cab. Structural racism in social services was described thus: "here we are where the devils is."[2, p. 20]

The ethnographer, "white Caroline," formed a close relationship with Ruby Banks [pseudonym]:[2, p. 18]

> When Ruby's youngest child was sick in the hospital, we went to visit her. The first day, the white nurse on duty stopped me—the rules stated that only close relatives could visit. Ruby, told the nurse angrily, "Caroline here is my sister, and nothing's stopping her from visiting this baby." Ruby's claim went unchallenged, and we were able to visit the baby every day.[2, p. 21]

Through this friendship, "… [the ethnographer] became another link in the systems of exchanges that were part of their existence"[2, p. 20]

> The resources possessions, and services exchanged between individuals residing in The Flats are intricately interwoven. People exchange various objects generously: new things, treasured items, furniture, cars, goods that are perishable, and services which are exchanged for childcare, residence, or shared meals... "Trading" in The Flats generally refers to any object given or service offered with the intent of obligating. An object given or traded represents a possession, a pledge, a loan, a trust, a bank account—given on the condition that something will be returned, that the giver can draw on the account, and that the initiator of the trade gains prerogatives in taking what he or she needs from the receiver. [2, p. 33-34]

Although labeled "gifts" by Marcel Mauss and "swapping" by Carol Stack, what they are really doing is exchanging capital goods. The advantage is that this ensures survival in a resource-deprived environment. The disadvantage is that no one in the social system can accumulate capital to participate in a capitalist economy.[5]

Kinship, then, is an economic system between individuals that supports the resource acquisition necessary to raise children.

New Knowledge Related to Clinical Decision Science

Kinship structures determine how patients view their world and priorities. We need to understand how our patients see the world related to chronic disease management. Grace Thomson was trying to address numerous health issues but she did not have access to stable shelter, food, or transportation, and this made communication/coordination between healthcare facilities, government agencies, and others very difficult and undoubtedly resulted in delayed and/or failed treatments.

As a physician running from room to room (at least 20 minutes behind schedule), it's easy to avoid inquiring about the diverse social structures that patients inhabit. However, if we just focus on vitals, labs, imaging, medications, and treatment plan adherence we may miss the root cause of our patients' lived experience with chronic disease—family is the setting for diabetes.[6] In our privileged experience, it may be understandable for a physician to become frustrated when step-by-step dietary directions are disregarded and clinical deterioration ensues. If physician believes the patient made a choice not to trust them and their clinical judgment or lacked the will to better themselves, they may label that non-compliance.[7] But in reality, the health outcome may have had far less to do

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with a patient's trust in their physician or personal willpower, and more to do with survival choices they were forced to make. In the light of our understanding of the patient's lived experience, we might be willing to label that adherence.

The social structures for Grace Thompson impact her health outcomes far more than the medicines that we prescribe or the lifestyle advice we give. Her irreverent family medicine doctor was heard to say, "Screw the diabetes medicines – she needs a house!"

Sometimes asking patients about their kinship structures can inform us about their current social situations and help us to develop an understanding of their priorities and challenges. In turn, this may serve to align the physician's and patient's goals. By inquiring about our patients' kinship structures, we are practicing a concept called cultural humility (opposed to cultural competence), and this represents an opportunity to build rapport.[8]

In addition to ignorance and lack of time, another reason that physicians may not be inclined to ask about kinship structures is because we feel as though we lack control over any of these social situations, and by extension lack the ability to effect any meaningful changes in our patient's lives. This isn't necessarily true. We can engage in social prescribing. "Social prescribing is a process whereby primary care patients are linked or referred to nonmedical sources of support in the community and voluntary sector."[8] Some examples of social prescribing include:

- Encouraging patients to interact socially with their neighbors to help combat loneliness/isolation
- Promoting stress reduction techniques such as box breathing, meditation, or journaling
- Educating patients about strategies of grocery shopping and cooking meals that are healthy and/or affordable
- Prescribing home exercise regimens that take into consideration the safety of their community and access to equipment
- Referring to social/community workers who can help them connect with resources including food assistance programs, therapy, access to resume building/job finding, or financial assistance programs
- Refer to educational programs relating to their ailments i.e.: diabetes, Alcoholics Anonymous, etc.
- Giving patients access to capital goods and services embedded at the clinic. Let them use the phone! Let them use the fax machine! (as demonstrated in the Clinical-Social Context)

Once physicians have a better grasp on the kinship structures of our patients, we might develop insight as to why patients were unable to adhere to their treatment plans from prior visits. Moreover, we might be able to leverage these kinship/family structures to improve health outcomes.

Although it seems counterintuitive, patients with limitations on access to social resources that comprise the SDoH can use the same strategy described by Carol Stack. Doctors can counsel patients to do favors for their kin, because that is the equivalent of money in the bank that can be swapped for services in the future when health needs occur. This is a way for patients in limited-resource situations to survive, which will naturally result in improved health outcomes.

Primary care physicians have the privilege of continuity with patients, where over time we can understand kinship structures and provide resources as necessary.

Conflict Of Interest Statement

The authors declare no conflicts of interest.

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