

## ORIGINAL RESEARCH

## The Impact of COVID-19 on Patients Receiving Care Coordination in Primary Care: A Qualitative Study

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**Introduction:** Care coordination addresses the needs of patients with complex chronic illness and psychosocial issues, coordinating their care and social needs. It is not known how such patients receiving these services managed during the COVID-19 pandemic. The objective of this study was to learn how the health, health care, social needs, and finances of patients receiving care coordination were affected by the disruptions caused by the COVID-19 pandemic.

**Method:** We conducted semistructured interviews with 19 patients receiving care coordination in primary care across a statewide sample about how the COVID-19 pandemic affected their life in general, including their overall health, social connections, finances and employment, and mental health. A content analysis approach was applied in the data analysis.

**Results:** We identified 4 primary themes in patient interviews including: (1) patients reported few to no impacts on their physical health status or health care services; (2) patients felt disconnected from family, friends, and community in ways that affected their mental health and wellbeing; (3) there were little to no pandemic related impacts for those on fixed incomes or government supports; and (4) care coordinators provided a significant and reliable source of help, support, and comfort.

**Conclusions:** Care coordination provided a supporting framework for the health and the health care needs of these patients, helping them navigate resources and maintain their physical health during the pandemic. Care coordinators were seen as providing needed communication, connection, and support that was especially needed during a time of social isolation and disconnection. (J Am Board Fam Med 2023;36:662–669.)

**Keywords:** Chronic Disease, COVID-19, Delivery of Health Care, Health Services, Mental Health, Pandemics, Primary Health Care, Qualitative Research

## Introduction

Care coordination services are provided in primary care to help address the biopsychosocial needs of adults with complex chronic illnesses and reduce high utilization and costs.<sup>1–3</sup> There are a variety of

approaches to care coordination, with many focusing on team-based care structures including nurses, social workers, physicians, and specialty care.<sup>4,5</sup> Care coordinators, however, are most often nurses who address the health care needs of patients while also addressing their mental and social health needs, providing services including chronic disease education and self-management, medication management, and referral for psychological and social resources.<sup>1</sup> The COVID-19 pandemic has had a significant impact on primary care, including patients receiving care coordination.<sup>6</sup> Although the

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effects of the pandemic on primary care are becoming clearer, the impacts on patient health and health care for those receiving care coordination have not previously been described.

Health care overall has experienced widespread disruption due to COVID-19 as health systems worked to contain the spread of the pandemic. This resulted in significant impacts on the delivery of health care services and patients using them.<sup>7-9</sup> Primary care, a central hub for health care delivery, was forced to limit patient visits, with many clinics transitioning in-person visits to telehealth visits when possible, delivered via video or telephone.<sup>10</sup> Overall there was a general reduction in health service availability, especially in the early stages of the pandemic as many staff were diverted to address acute COVID care needs.<sup>6,11,12</sup> This impacted all patients, with women and those with preexisting mental health conditions experiencing greater impacts.<sup>7,13</sup> How complex patients with multiple chronic conditions fared during this time and the potential impact care coordinators may have had on these patients as they continued to provide patient care is not yet clear.

The purpose of this study is to explore the experience of primary care patients receiving care coordination services for chronic health conditions starting before the pandemic. The study seeks to explore how patient's health, health care, finances, mental health, social needs, and social services were affected by pandemic-related disruptions caused by COVID-19 and whether having care coordination services helped them manage during this time.

## Methods

### *Design and Setting*

This qualitative cross-sectional study is a component of the *Minnesota Care Coordination Effectiveness Study [MNCARES]*, funded by the Patient-Centered Outcomes Research Institute. The study's goals are to examine patient-centered outcomes for high-cost, high-need adult patients who receive one of two models of care coordination in primary care in Minnesota, a nursing-medical model or a medical-social model that includes a social worker on the care coordination team. The study is being conducted at a not-for-profit research center affiliated with a large health system and involves 5 health plans, 42 health care systems, the Minnesota

Department of Health, and other community partners. For this study, we conducted interviews with patients who had started receiving care coordination before the COVID-19 pandemic about their experiences during the pandemic and the impact it had on their health and health services. Interviews were conducted from June to August 2021. The study was reviewed, approved, and monitored by the local Institutional Review Board.

### *Participants and Recruitment*

A purposive sampling strategy was used to identify a diverse sample of clinics in the broader study from which potential study participants could be identified. Participating health care systems (n = 38) identified patients who had started receiving care coordination services in primary care between January 2018 and February 2019. For this study, we wanted to identify patients from clinics with factors known to be important in the delivery of care coordination services including: the care coordination model (nursing-medical model/medical-social model); clinic geography (urban/rural, defined by US Census Bureau Rural-Urban Commuting Area Codes); and health system size (large,  $\geq 10$  primary care clinics/small,  $< 10$  clinics). Using a stratified sampling strategy, we selected 12 clinics roughly fitting the 8 cells determined by these factors. A convenience sampling strategy was then used within clinics to identify patients meeting eligibility criteria. Care coordinators in the clinics were asked to identify a diverse set of 2-to-5 patients meeting the following criteria: aged 18 or older; receiving care coordination services before (at least 3 contacts) the onset of COVID-19; interested and able to complete the interview in English without proxy or legal guardian. Care coordinators invited interested participants to contact the interview team. Among 34 patients expressing interest, 26 completed study screening, 2 were ineligible, with 20 completing the study interview. An audio recording failure during one interview resulted in a final sample of 19 participants.

### *Data Collection*

Interviews were conducted by trained interviewers not known to the participants and who screened, consented, and individually interviewed patients by telephone. Patients were provided a \$35.00 gift card for their participation in study interviews. The semistructured interview-guide contained 11 questions focusing on how COVID-19 affected the patient's life in general, their overall health/

wellbeing and 2 most important health problems, social connections, finances/employment, and mental health. Detailed health information was not asked of patients because it was not the focus of the interviews. Patients were also asked about experiences with health care including health care access, experience with their care coordinator and things they wish their clinics had provided during the pandemic. Probes were used to explore participant responses in greater depth. Interviews were audio-recorded with interviewers completing detailed notes after interviews that were used in the analysis. Interviews averaged 42-minutes (Median, 39 minutes; Range 30 to 67 minutes). Interviews were professionally transcribed, deidentified, and prepared for analysis.

### Data Analysis

Interview data were analyzed using NVivo qualitative analysis software (QSR International, Version 1.6.2 for Mac) using a conventional content analysis approach.<sup>14</sup> The analysis team was composed of 5 authors (RW/LS/MJ/AB/JK) with experience in qualitative methods, care coordination, health services, and patient perspectives. The team first independently reviewed 10 interview transcripts ( $\approx 50\%$ ) identifying initial codes and categories arising in the text, then met regularly employing an iterative process to identify emergent patterns and themes in the data. Issues of reflexivity in the analysis were addressed, with team members reflecting their experience regarding the topic and its assumptions and meaning for the data.<sup>15</sup> Codes, categories, and themes were analyzed and discussed until no new themes emerged in the analysis indicating that inductive thematic saturation was reached.<sup>16</sup> Following consensus, a coding framework was developed, which was then applied to all data by one analyst [RW]. A study codebook comprising an audit trail addressing coding, analytic decisions enhanced trustworthiness and rigor in the analysis.<sup>17</sup>

### Results

Nineteen patients participated in the study, ages 43 to 93 years, with an average age of 67 years. Participants were predominately White, non-Hispanic women receiving a medical-social model of care coordination in small care systems (see Table 1). Patients reporting their 2 most important health problems cited conditions including cancer, diabetes, depression, arthritis, heart problems,

**Table 1. Characteristics of Study Participants**

Demographics	(N = 19) %/#
Age	M 67 years/Range 43 to 93 (Median 66)
Sex	
Female	68% (13)
Male	32% (6)
Ethnicity	
Hispanic or Latino	5% (1)
Not Hispanic or Latino	95% (18)
Race	
Black or African American	11% (2)
White	84% (16)
Missing	5% (1)
CC Model	
Nursing-Medical	26% (5)
Medical-Social	63% (12)
Mixed	11% (2)
Health System Size	
Larger $\geq 10$ Clinics	32% (6)
Small $< 10$ Clinics	68% (13)
Geographic Area	
Urban	58% (11)
Rural	42% (8)

Abbreviation: CC, Care Coordination.

high blood pressure, back problems, and breathing problems. Four primary themes with 3 subthemes arose in the data (see Table 2). Coded patient identifiers are listed beside quotes reflecting the presence of the themes across the full sample of interviews.

### Theme 1: There Were Few to No Impacts on Provision of Health Services or Physical Health Status

When asked about pandemic effects on their health and difficulties getting health care or accessing clinicians and services, all participants commented on how their clinics worked hard to ensure their health care needs were met during the pandemic, with the majority noting that their health status hadn't changed significantly over that period. Many patients credited their care coordinators for this and talked about the extent to which their care coordinators and clinics went in ensuring delivery of services to them, with one patient saying, "the thing that helped was the care coordinator ... I worked so closely with my care coordinator" (P03). Other patients noted, "My clinic, is really amazing ... I got all the care that I needed one way or the other" (P13), and "if I need something, I call the

**Table 2. Overview of Qualitative Themes and Subthemes**

Theme/Subtheme	(N = 19) %/#	Thematic Description
1. Patients reported few to no impacts on their health care services or physical health status	100% (19)	Patients thought their clinics went above and beyond to support them and make sure they were getting the care they needed. Most had no significant change in their physical health status during the pandemic.
1a. Some had a dislike of the shift to virtual appointments	32% (6)	Patients felt they were not getting the same level of care as an in-person visit and they were less personal.
2. Disconnection and isolation from family friends, and community affect mental health and wellbeing	95% (18)	The impact of social distancing had a significant impact on patient's wellbeing and relationships. They felt lonely and isolated from their family, friends, and important social connections.
2a. There were pandemic related increases in anxiety and depression	63% (13)	Disconnection and isolation acted like fuel on the fire for depression and anxiety, significantly impacting those already struggling with these mental health issues.
3. There were little to no pandemic related financial impacts for those on fixed income or government support	79% (15)	The majority of patients were retired or receiving government support and their finances were not impacted by the pandemic.
3a. Financial impacts were mainly for care coordination patients still employed	32% (6)	Younger patients in care coordination who were still working experienced furloughs and job and wage losses affecting them and their families.
4. Care coordinators provided a significant and reliable source of help, support, and comfort	79% (15)	Care coordinators provided ongoing stability, kindness, and support for these patients who described them as a friend, advocate, and trusted advisor.

clinic and talk to the nurse or care coordinator, we work it all out and truthfully, I am very pleased with my medical care. I think it is some of the best I've had over my 77 years" (P15). Many patients discussed their health services in more personal ways, noting their long-standing relationship to their care coordinators, clinics, and clinicians. "It did not really affect the health care I could have because the clinic that I go to, I've been going there for a while and they know who I am" (P02), with another patient reflecting on talking with her care coordinator "It is almost like talking to a family member" (P05). This was particularly true in smaller rural clinics where many have received care from the same clinic and clinicians for much of their lives. Patients reflected on the length of their connection to their clinicians; "I've had my doctor for about 20 years" (P16); and how their clinicians "know me personally [and] were very good to me during the pandemic" (P02).

Patients also talked about the methods clinics used to provide health care during this time, "I do not know how much more they could support you. I mean, you have the phone calls. You got the video. You got people. They are really good about doing everything for you" (P10), and "My clinic was actually really good about seeing their patients . . . of course, we did most of it over the phone for a while" (P10). Another patient reflected on the new experience of using telehealth, "I

was shocked at how, almost better, telehealth is. So that is one thing that changed during COVID is my feelings about telehealth" (P13).

#### ***Subtheme 1a: Some Had a Dislike of the Shift to Virtual Appointments***

Although some patients expressed positive views of telehealth, that sentiment was not shared by all. A subtheme reflected that some patients had a dislike of the shift to virtual appointments. These patients expressed concern about the shortness of visits, "I just felt like the visit was very short . . . Oh, hi. How are doing? Well, we'll see you in 3 months" (P17). Other patients expressed concerns about the level of care during telehealth visits, "It just seemed like—I do not know how my doctor in the TV can properly evaluate me" (P03), and the loss of personal connection, "Telemedicine is great, but I do not feel like I got the same level of care doing it on the computer as I did in an in-person visit . . . not seeing her [doctor] in person, that personal connection again. There's just something missing" (P01).

#### ***Theme 2: Disconnection and Isolation from Family, Friends, and Community Affected Mental Health and Wellbeing***

Although health care and physical health status were described as relatively stable, that was not the case for mental health and wellbeing. The isolation



and disconnection from family, friends, and community caused by the pandemic had significant impacts on patient wellbeing. Participants talked about the impact of social distancing saying, “We could text each other, but we could not go to each other’s homes . . . it affected my relationship with my kids” (P04), and “You could not shake hands. You could not give people hugs. You had to sit 6-feet away, and you had to keep your distance” (P06). The lack of physical touch came up often in interviews, especially for patients living alone, “But the thing that affected me the most was I am a hugger, and I could not give hugs anymore” (P02), and “If you are a family and you are confined, you can still hug each other. But when you live alone, there’s no one there” (P08). The overall impact on most of these patients’ wellbeing was feelings of isolation and loneliness, “[you] have to stay [by] yourself, there is nowhere to go. It isolates you from being around other people. And it just makes you kind of miserable” (P12), and “Loneliness gets in there . . . just being isolated does make you feel different” (P15).

#### ***Subtheme 2a: There Were Pandemic Related Increases in Anxiety and Depression***

For a subset of patients, the isolation and disconnection experienced exacerbated ongoing mental health issues, particularly for those with anxiety and depression. As one patient reflected on their experience, “people that have mental illness really suffered” (P01). Patients talked about the ongoing impact on their mental health noting, “It is a strain on mental health” (P09) and “It affected outlook, my depression was worse during that time” (P02). Mental health issues for some were also layered on chronic conditions with known mental health effects, “I have depression with my [medical condition] to begin with, and so it just kind of fueled the fire” (P11), and “Problems . . . led to my being hospitalized for depression at the end of 2020. But I think COVID just sort of added. I think it just adds a level of anxiety and fear” (P13). Fear and anxiety regarding COVID was a prevalent theme for many, with one patient noting, “I think I was just more anxious” (P17).

#### ***Theme 3: There Were Little to No Pandemic Related Financial Impacts for Those on Fixed Income or Government Support***

Although there were large financial impacts for many during the pandemic, most of these patients

reported experiencing few financial setbacks largely as the result of being retired and receiving social security or being disabled and receiving disability payments. Patients noted, “because we’re both retired, those things are already pretty much set up, so do not have to worry about going to a job or that sort of thing” (P15), and “Yeah, my SSI and my Veterans come right on schedule” (P11). For some patients, the infusion of federal and state money actually provided unexpected support during this time, “I am on disability . . . the stimulus money and that helped pay the bills, and then with the energy assistance programs, they raised their amounts, too, so that helped a lot” (P14), and “I never had too much, but thank God for the county. The county has supplied me with food supplies almost twice as much as I was getting” (P04).

#### ***Subtheme 3a: Financial Impacts Were Mainly for Care Coordination Patients Still Employed***

Although patients reporting financial stability were mostly older adults with chronic conditions and/or disabilities, that was not the case for all patients. There was a smaller group of younger patients still in the workforce. This group experienced significant financial impacts, from loss of work hours to furloughs and job loss. Addressing the loss of work hours, one patient stated, “Our hours were [cut]—because I work at a food restaurant, so when we were not as busy, my hours were cut at work . . . and it was a little tight some months financially” (P02). Being furloughed from employment was experienced by several of these patients, “I was working at a job, and then they had to close because of COVID. And then when they were able to reopen, it was just in a very limited capacity. And so, I was put on temporary furlough, and then that actually turned into a permanent furlough” (P06), and “I did get furloughed off my job for 3 and a half months . . . I was on unemployment” (P17).

#### ***Theme 4: Care Coordinators Provided a Significant and Reliable Source of Help, Support, and Comfort***

When asked about the help their care coordinators provided them, many patients reflected at length on the importance of that relationship in their lives and to their overall health and wellbeing. They said that their interactions with their care coordinator provided a constant source of help, support, and comfort, “She’s awesome, and she’s a really, really, good nurse. And she’s good at her job, and she knows her stuff” (P02), and “She’s very good . . . [I

was very impressed with her. She's very good at what she does. Super professional" (P03). Many also reflected on the importance of their ongoing interactions with their care coordinator, "I realized how important my interactions with [care coordinator] are" (P01), and "The idea of just being able to talk to her or that she was there ... it made me comfortable with the situation" (P16), and "[care coordinator] has been very helpful for me at a point that she has been my voice... she's very helpful" (P04). Patients also spoke about their personal relationship with their care coordinators, "She's just been there like a shoulder to cry on. She's just always been there" (P17), and "Oh, just her friendliness. She's a kind person" (P18), and "Like I said, she's the nicest person I ever met. She cares" (P12). Care coordinators for these patients clearly provided a significant source of support and tended to be viewed as trusted advisors, advocates, and a friend who listened.

## Discussion

We sought to understand the impact the pandemic had on the health and health care of patients with multiple chronic conditions receiving care coordination in primary care and whether it may have helped these patients manage during this time. We found that patients thought the pandemic had little impact on their health care, with many crediting their care coordinator for this. Some patients liked the shift to virtual visits in primary care, whereas others did not, perceiving them as too short and lacking personal connection. The support of care coordinators was also perceived as providing a strong point of connection and contact for patients to their clinics and clinicians. Patient wellbeing, however, was significantly affected by pandemic driven social isolation taking a significant toll, especially on those living alone or already struggling with mental health issues. The lack of human touch like hugging was one thing many reflected on. Financially there was little change for retired seniors and those receiving disability, with impacts mainly described by younger patients still in the workforce. Care coordination overall was perceived by these patients as providing a strong foundation of support, acting as a protective factor during this time. Patients viewed their care coordinators as trusted advisors, advocates, and a friend who listened. This ongoing source of connection and communication

provided the support and comfort many of these patients needed, helping them weather the challenges of the pandemic related to their health and wellbeing.

The COVID-19 pandemic created significant medical and social disruptions in health, health care, and the social/emotional lives of people.<sup>6,7,11</sup> A scoping review of changes to health care during the pandemic found in general a reduction in use of services, as well as new barriers and exacerbation of existing barriers in access to health care. This was certainly true in primary care with a decrease in the number of patient visits and a shift to telehealth services still being felt.<sup>12,18</sup> These care coordination patients however, continued receiving health services supported by their care coordinators, who used phone/virtual visits to assess patient needs and provide support and connection on an ongoing basis. As a result, they felt their health remained stable during the pandemic with most saying that they received the services that they needed during this time. Although some of these patients did not like the shift to virtual visits, all commented on the importance of their ongoing contact with their care coordinators whether it was virtual or in-person.

This ongoing coordinator contact was particularly important from an interactional social context, given the loss of social connection so many felt in their lives due to social distancing. This was especially true for patients with preexisting mental health conditions for whom the pandemic had significant effects including increased depression and anxiety.<sup>13,19,20</sup> In discussing the disruptions caused by COVID-19, Long et al.<sup>21</sup> noted the importance of social relationships in various domains of life and how they are key to both health and resilience for people. For many of these patients, their care coordinator was the ongoing stable point of contact that connected them not only to health care, but to social and psychological resources when needed. This ongoing connection with someone they trusted to act as an advocate/advisor helped many navigate the challenges that arose with social isolation.<sup>13</sup> The importance of establishing a trusting relationship in care coordination is known to facilitate a patient's trust in health systems and their clinicians; it also can facilitate patient engagement, an important factor in treatment adherence when working with patients with multiple chronic conditions.<sup>22</sup> It is additionally worth noting that care coordination provides support not only for patients,

but most often as a team model of care also provides support for clinicians. Okunogbe et al.<sup>23</sup> found that care coordination can be a valuable tool to decrease the stress clinicians experience in navigating and managing the many needs of their complex patients.

There are limitations to the study. It is exploratory with a small sample size. Care coordinators also identified potential interviewees introducing the potential for bias in the sample. Participants were also asked to reflect on the prior 2 years for their experiences during the pandemic, introducing the possibility of errors in memory or recall. Patients in the study were also mostly White and female, reflecting the population of the state and their experiences would differ from a minority groups. It should be noted however, that these patients were representative of both urban and rural areas and came from a variety of types of health care systems across an entire state, although the sample skewed toward the medical-social model of care coordination.

In exploring the health and health care of patients receiving care coordination during the COVID-19 pandemic, we found overall that it acted as a protective factor for these patients, connecting them to their clinics and clinicians, assisting them in maintaining their health during this challenging time. Care coordinators were also seen as trusted advisors, advocates, and emotional support during this time when patient wellbeing was significantly challenged. Care coordination is crucial for patients with complex health needs, keeping them stable and out of hospitals and emergency rooms overflowing with pandemic related cases. Many questions have been raised over the years about the value and importance of care coordination services for patients in primary care. This study provides the view of patients on this and with a singular voice they find care coordination services are valuable for their overall health and wellbeing.

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To see this article online, please go to: <http://jabfm.org/content/36/4/662.full>.

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