Perceived Adequacy of Tangible Support during Stay-at-Home Orders in Chicago and New York

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Abstract

Objectives: Physical distancing precautions during the COVID-19 pandemic may challenge the provision of tangible support many middle age and older adults receive in managing their health. We examined the association between unmet tangible support needs and self-management behaviors and mental health status during the stay-at-home orders in Chicago and New York. Methods: We used data from the COVID-19 & Chronic Conditions study collected between May 1st and May 22nd, 2020. A total of 801 middle age and older adults with ≥1 chronic condition in Chicago and New York City completed the telephone interview. Adequacy of tangible social support was measured using a brief, validated scale that determined whether an individual needed assistance managing his or her health, and if yes, whether this need was met. Participants reported their level of difficulty engaging in self-management behaviors using 2 discrete items; they also self-reported medication adherence using the ASK-12 medication adherence scale. Mental health status was measured using the depression and anxiety PROMIS short-form instruments. Results: Participants' mean age was 63 years; 30% identified as Black, 26% identified as Latino, and 12% identified unmet support needs. Inadequacy of tangible support was associated with greater difficulty managing one's health and accessing medications due to COVID-19, as well as poorer medication adherence, increased anxiety and depressive symptoms, and poorer overall well-being (*P*'s < .05). Conclusions: Perceived unmet support needs during stay-at-home orders were associated with greater difficulty engaging in self-management behaviors and poorer overall well-being. Two brief items quickly identified individuals with unmet support needs.

Keywords

COVID-19, social support, tangible assistance

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Introduction

Social support is an important determinant of self-management behaviors^{1,2} and health outcomes, including mortality.³ However, social support is a multidimensional construct that influences health via multiple different pathways.⁴ Due to variation in measurement, the evidence is fragmented, making it difficult to discern what dimension of social support is best for older adults with chronic conditions.^{5,6} There are 4 commonly recognized types of social support, which include (1) emotional, expressions of caring, (2) informational, the provision of information, (3) tangible, the provision of direct material aid or other concrete assistance, and (4) belonging, having others to engage with in social activities.⁴

The coronavirus disease 2019 (COVID-19) pandemic and accompanying physical distancing precautions have

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prompted renewed attention to the critical role of social support in health management. Early in the pandemic, many governors in the United States imposed stay-at-home orders to slow the transmission of COVID-19. While physical distancing restrictions are credited with reducing the spread of COVID-19, the provision of social support was vastly altered, which may have resulted in unintended consequences in self-management behaviors and health outcomes. Differing forms of social support may be disrupted in varying ways due to restrictions; for example, emotional or informational support can easily be provided via the telephone or virtual platforms. However, in the context of chronic disease self-management, tangible social support may be most impacted by COVID-19 restrictions, as this type of support provision does not readily transfer to remote formats. For example, many older adults receive regular inperson assistance in preparing healthy meals, obtaining and taking medications, bathing and personal grooming, and basic home cleaning, but necessary precautions have challenged or eliminated the provision of this assistance. The reduction in tangible support may have a detrimental impact on older adults' well-being and ability to engage in routine health management behaviors. We sought to evaluate the association between unmet tangible support needs with health management and mental health among middle age and older adults during stay-at-home orders in Chicago, Illinois and New York City, New York.

Methods

The COVID-19 & Chronic Conditions (C3) study is a longitudinal survey examining how older adults with one or more chronic conditions are responding to the pandemic, taking action to minimize infection, and continuing to self-manage their chronic conditions. The study began at the onset of the U.S. outbreak (March 13-20, 2020) in Chicago, 7,8 and expanded to New York for subsequent waves beginning in May 2020. For this analysis, we used data collected during the third wave of the survey, conducted between May 1st and May 22nd, 2020.

Sample and Procedure

The C3 sample is comprised of 801 active participants involved in one of 5 ongoing federally-funded health services research studies taking place among 6 academic internal medicine and 2 community health centers in Chicago, Illinois and New York City, New York. Each of the parent studies (a cohort study assessing cognitive aging, a cohort study assessing COPD and comorbid conditions, and 3 randomized trials testing technology-based strategies to improve medication adherence), have previously been described in detail. 9-13 While specific inclusion criteria for each parent study varied, they generally enrolled older,

English- or Spanish-speaking individuals who were diagnosed with 1 or more chronic condition.

Trained research coordinators contacted study participants whose last parent study interview was performed between January 2018 and March 2020 and invited them to participate in a brief supplemental survey about COVID-19, their health and capacity to self-manage during the pandemic. After obtaining verbal consent, the research coordinators administered the brief survey by phone and recorded participant responses using REDCap® survey software. The study was approved by the Northwestern University and Icahn School of Medicine Institutional Review Boards.

Measures

Adequacy of tangible social support. Adequacy of tangible social support was measured using a validated two-item scale to identify whether an individual needed assistance managing his or her health in the past 2 months, and if this need for assistance was met. Participants were classified as (1) no perceived need for help; (2) received sufficient help (needed help, but all needs met); (3) more help needed (most needs for help met); and (4) much more help needed (only some, little, or none of needs for help met). Those who reported needing additional assistance were asked in an open-ended format to specify the additional help they needed.

Self-management behaviors. Participants reported the level of difficulty they experienced managing their health with the following 2 statements: "Managing my health has become more difficult during the coronavirus outbreak" and "Accessing and remembering to take medications has become more difficult during the coronavirus outbreak." For each statement, participants responded on a scale from 1 to 10 (with 10 being the greatest difficulty); statements were analyzed separately.

We also assessed medication adherence using the 12-item Adherence Starts with Knowledge (ASK-12) survey, a subjective assessment of general adherence behaviors and barriers to treatment adherence. Scores from the ASK-12 were summed (scores ranging from 12 to 60), with higher scores indicating greater barriers to adherence.

Mental health status. Mental health status was assessed using Patient Reported Outcomes Measurement Information Service (PROMIS) short-form instruments of depression and anxiety, which are validated and normed among the general U.S. population. ¹⁶ A raw score was calculated for each scale, then transformed into a corresponding T-score with a mean of 50 and standard deviation of 10. Higher scores indicate more symptoms.

We also assessed overall mental well-being with the World Health Organization 5 Well-Being Index (WHO-5).¹⁷ This is a 5-item, validated, unidimensional measure of an

O'Conor et al 3

individual's mental well-being. A raw score (0-25) was converted to a percentage, with a higher score indicating more positive mental well-being.

Covariates. Across all 5 studies, there was existing, uniform collection of patient demographics (age, sex, race/ethnicity), socioeconomic status (household income, employment status), and self-reported number of chronic conditions. All parent studies also included a measure of health literacy: 4 used the Newest Vital Sign (NVS)¹⁸ and 1 used the validated, single item brief health literacy screen (BHLS), which asks participants "How confident are you filling out medical forms by yourself?" Classifications for these 2 instruments highly correspond with one another, and participants were classified as having low, marginal or adequate health literacy. To ensure our measurement of tangible social support was conceptually distinct from social isolation or loneliness constructs, we controlled for self-reported levels of loneliness during the past week due to COVID-19.

Analysis

Descriptive statistics were calculated for all patient characteristics and survey responses. Associations between patient characteristics and perceived adequacy of tangible support were then examined using chi-square and t-tests, as appropriate. To examine if there was systematic bias by site we conducted stratified unadjusted multivariate analyses to examine potential differences in results by site (Chicago vs New York). As no significant differences were observed, we combined the data and adjusted for site. Next, we conducted generalized linear models predicting our outcomes of interest (self-management behaviors and mental health status) from perceived tangible social support. All models controlled for age, sex, race/ethnicity, income, number of chronic conditions, loneliness, site, interview date and parent study. We reported least squares means (LSM) and 95% confidence intervals. Statistical analyses were performed using STATA/ SE software, version 15 (College Station, TX).

Results

Among our study participants, approximately 1 in 5 participants reported needing tangible assistance during the stayathome orders in Chicago and New York City; specifically, 5% (n=42) received sufficient help, 4% (n=31) needed more help, and 8% (n=62) needed much more help. A total of 83% (n=665) of participants reported no perceived need for assistance. Needing additional tangible assistance was more common among individuals living below the poverty level or in New York City; it was also more common among those who self-identified as Black, those who had low health literacy, and those who had 3 or more chronic conditions (Table 1). Among the 93 participants who reported needing

more or much more help, the majority specified needing additional assistance with household chores or maintenance, obtaining groceries, cooking, personal care, or health management (attending medical visits, obtaining medications).

In adjusted analyses, inadequacy of tangible support was associated with greater difficulty managing one's health, and accessing medications, poorer medication adherence, more anxiety and depressive symptoms, and poorer overall well-being (Table 2).

Discussion

Our study examined associations between unmet tangible support needs, and self-management and mental health among older adults with chronic medical conditions in Chicago, Illinois and New York City, New York during the initial stages of the COVID-19 pandemic. We administered our survey during the first 3 weeks of May 2020, when stay-at-home orders were in effect in both states. In Illinois, this order lasted from March 21, 2020 to May 29, 2020, and all non-essential businesses were closed and non-essential gatherings of any size were prohibited. Similar restrictions closed non-essential businesses statewide and prohibited non-essential gatherings in New York from March 22, 2020 through June 8, 2020. Given the heightened uncertainty and concern surrounding COVID-19 during this time, many residents in these cities readily complied with these orders.²¹

Considering adherence with stay-at-home restrictions, we observed relatively low levels of unmet tangible support needs during the beginning of the COVID-19 pandemic. Indeed, the majority of our sample endorsed either no need or a sufficiently met need for assistance with daily chores and activities, including personal care and health self-management. This finding may be due to the somewhat older age of our sample. In 1 study of adults living in Canada and the U.S, older age predicted more support provision and receipt due to COVID-19; however this was primarily related to emotional support rather than tangible support.²² Our results underscore the resiliency and creativity that many older individuals have demonstrated during this crisis, and suggests they were able to identify ways to maintain connections and continue to receive any necessary assistance.

However, among those who did report unmet tangible support needs, they also reported worse overall mental health and greater difficulty engaging in self-management behaviors. While there has been substantial commentary on the impact of social distancing on the overall well-being of older adults, and several empirical studies have examined the impact of physical distancing precautions on social isolation and loneliness, ²³⁻²⁵ relatively little research has examined how levels of social support may influence unmet health and self-care needs during the COVID-19 pandemic. During San Francisco's shelter-in-place orders from April thru June 2020, Kotwal et al²⁶ found that participants who

Table 1. Sample Characteristics by Perceived Adequacy of Tangible Support.

		Perceiv	ed adequacy of tangible s	ocial support	
Variable	Overall (N=801)	No perceived need (n=665)	Received sufficient help (n=42)	More help needed (n=31)	Much more help needed (n = 62)
Age, Mean (SD)	63.2 (10.8)	63.0 (11.0)	60.7 (8.8)	67.4 (10.8)	64.3 (10.0)
Female, %	61.8	60.9	61.9	71.0	67.7
Race, %					
Latino	26.2	23.7	55.3	29.0	33.9
White	39.6	43.5	13.2	41.9	14.5
Black	30.2	28.9	23.7	29.0	48.4
Other	3.9	4.0	7.9	0.0	3.2
Educational attainment, %					
HS graduate or less	30.8	29.3	48.8	25.8	38.7
Some college	26.6	25.2	31.7	32.3	35.5
College graduate	42.6	45.6	19.5	41.9	25.8
Below Poverty Level, %	35.6	32.5	61.9	41.9	48.4
Interview site, %					
Site I	75.0	77.7	61.9	61.3	61.3
Site 2	25.0	22.3	38.1	38.7	38.7
Health literacy, %					
Low	23.2	21.9	31.7	19.4	33.9
Marginal	23.4	22.4	31.7	35.5	22.6
Adequate	53.4	55.7	36.6	45.2	43.6
# Chronic conditions, %					
I	17.4	17.3	28.6	3.2	17.7
2	13.9	15.0	0.0	16.1	9.7
3 or more	68.8	67.7	71.4	80.7	72.6
Felt lonely due to COVID in	the past week, %				
Never	53.8	55.5	50.0	38.7	46.8
Some of the time	32.2	32.2	26.2	38.7	32.3
Most of the time	9.4	8.7	11.9	16.1	11.3
All of the time	4.6	3.6	11.9	6.5	9.7

^{*}Bolded results significant at P < .05 level.

were socially isolated reported greater difficulty finding help with bathing, meal preparation, grocery shopping and accessing transportation. Our study adds to this important and growing body of literature by examining a unique dimension of social relationships in the context of COVID-19: the adequacy of tangible social support. Our study is the first, to our knowledge, to assess the health implications of unmet tangible support needs among a high-risk population during the COVID-19 pandemic. Understandably, much attention and energy has been directed toward the containment of COVID-19;27 but beyond concerns surrounding COVID-19 infection and treatment, the management of other health conditions, as well as overall medical and behavioral health needs do not disappear. This study supports the need for clinicians and public health officials to consider both availability and adequacy of tangible social supports in promoting adequate health and well-being among older adults throughout the ongoing COVID-19

crisis. Furthermore, this study suggests that clinicians may need to consider the mental and physical impacts that reduced tangible support during the stay-at-home orders had on older adults with multiple chronic conditions. Future research should continue to examine the potential impact of a sustained reduction in tangible support on older adults' health and well-being.

As of April 2021, COVID-19 metrics are improving. Compared to the initial months of the pandemic, testing and treatments for COVID-19 are more widely available, and vaccine distribution is increasing. Cases of COVID-19 infection, hospitalizations, and mortality have decreased substantially from the third surge over the fall and winter of 2020. As such, many stay-at-home orders have ended or relaxed considerably. However, with the emergence of new COVID-19 variants, there is a real possibility that cases may increase yet again. Some level of social distancing precautions will likely be necessary for the foreseeable

Table 2. Adjusted Associations between Perceived Adequacy of Tangible Support and Self-Management Behaviors and Mental Health Status.

	Difficulty managing health	Difficulty with medications	Medication adherence	Anxiety symptoms	Depression symptoms	Overall well-being
Variable	LSM (95% CI)	LSM (95% CI)	LSM (95% CI)	LSM (95% CI)	LSM (95% CI)	LSM (95% CI)
Social support No perceived help needed ^a Received sufficient help More help needed Much more help needed	4.38 (3.81, 4.95) 4.78 (3.64, 5.91) 5.63 (4.37, 6.89)* 6.62 (5.66, 7.58)‡	3.03 (2.58, 3.48) 3.01 (2.05, 3.97) 2.92 (1.87, 3.98) 4.69 (3.90, 5.49)‡	20.7 (19.8, 21.6) 20.5 (18.8, 22.2) 22.1 (20.2, 24.0) 22.9 (21.5, 24.4) [‡]	54.4 (53.1, 55.8) 56.9 (54.0, 59.8) 58.9 (55.8, 62.1) [†] 59.5 (57.1, 61.8) [‡]	53.2 (52.0, 54.5) 54.6 (52.1, 57.1) 58.1 (55.3, 61.0) [‡] 59.4 (57.3, 61.5) [‡]	52.6 (48.1, 57.1) 52.4 (44.0, 60.8) 46.2 (36.8, 55.6) 41.6 (34.3, 48.9) [‡]

aldentified as the reference group. + Models were adjusted for age, gender, race, poverty, chronic condition, site, health literacy, lonely, date of interview, and study number. *P < .05. †P < .01. †P < .001.

future, and many people depending on in-person assistance will continue to remain affected by these public health restrictions. As the COVID-19 pandemic continues to progress, it is therefore critical that clinicians, public health professionals and policy makers identify ways to ensure the safety of those both providing and receiving needed assistance.

Our findings should be recognized in the context of several limitations. First, this survey was conducted among research participants enrolled in ongoing NIH-funded research studies in 2 large U.S. cities. Thus, these findings may have limited generalizability, especially for younger adults, those in rural areas, and those without underlying health conditions. However, our study samples purposefully include men and women who are socioeconomically and racial/ethnically diverse, and at increased risk from COVID-19 due to age and underlying conditions. To the former, this diversity of our sample is a strength as it helps to further expand on the experiences of a racially and ethnic diverse adults managing one or more chronic conditions during the COVID-19 pandemic. Understanding the impact on Black and Latino populations is critical, as these populations have been disproportionally impacted by complications from COVID-19.28 Additionally, all interviews were conducted by telephone for the safety and well-being of all participants and research coordinators, and as a result research participants were unable to visually observe all response options; however research coordinators repeated any questions and response options, as necessary. Lastly, we relied on participant self-report for our primary measures, which is subject to recall bias; however we limited the recall period to the previous 2 months in order to minimize this bias.

In conclusion, perceived unmet tangible support needs during stay-at-home orders were associated with greater difficulty engaging in self-management behaviors and poorer overall well-being. Physical distancing precautions may have unintended consequences on individuals' overall health, and our findings underscore the importance of health care clinicians and public health officials considering both the availability and adequacy of tangible support during the COVID-19 pandemic. Two brief items were able to quickly identify individuals requiring additional assistance in managing aspects of health and daily self-care. Use of these or similar items may be useful tools for clinical practices or social service agencies in screening for unmet tangible support needs. Health system and public health responses should also include increased consideration of how to enhance availability and access to sources of tangible social support among vulnerable individuals during the COVID-19 pandemic. Lastly, clinicians may need to consider the mental and physical impacts that reduced tangible support during the stay-at-home orders had on older adults with multiple chronic conditions.

Declaration of Conflicting Interests

The author(s) declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: Dr. Bailey reports grants from the NIH during the conduct of the study; grants from Merck, the NIH, and Eli Lilly outside the submitted work; grants and personal fees from the Gordon and Betty Moore Foundation outside the submitted work; and personal fees from Sanofi, Pfizer, and Luto outside the submitted work. Dr. Wolf reports grants from the NIH during the conduct of the study; grants from Merck, the Gordon and Betty Moore Foundation, the NIH, and Eli Lilly outside the submitted work; and personal fees from Sanofi, Pfizer, and Luto outside the submitted work. All other authors report no conflicts of interest.

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O'Conor et al 7

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