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Risk perception trajectory of elderly chronic disease patients in the community under COVID-19: A qualitative research

Xiaoyu Wu, BS^{a,#}, Ni Gong, PhD^{b,#}, Ya Meng, BS^a, Mengyao Zhu, BS^a, Wenjie Zou, BS^a, Yu Cheng, PhD^{c,**}, Meifen Zhang, PhD^{a,*}

^a School of Nursing, Sun Yat-sen University, Guangzhou, Guangdong 510080, China

^b School of Nursing, Ji Nan University, Guangzhou, Guangdong 510632, China

^c School of Sociology & Anthropology, Sun Yat-sen University, Guangzhou, Guangdong 510080, China



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ABSTRACT

Introduction: While traditional “non-medical” prevention and control measures have achieved remarkable results during the COVID-19 pandemic, they have generated difficult situations for older adult patients with chronic disease. The purpose of this study was to understand and identify the COVID-19 risk perception process and trajectory among older adults with chronic disease living in the community.

Material and methods: This was a qualitative research study that used in-depth semi-structured interviews to explore the experiences of 21 older adult patients with chronic disease. Data were analyzed using conventional content analysis methods.

Results: Three themes emerged: restricted travel, psychological shock and panic, and unintended consequences.

Conclusions: The perceptions of epidemic risk among older adult patients with chronic disease living in the community had varying characteristics at different stages. Correct identification of risk perception processes and trajectories will assist in formulating more scientific emergency measures in the event of future public health emergencies.

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Introduction

In December 2019, a COVID-19 outbreak began in Wuhan, Hubei Province, and subsequently spread rapidly throughout China and worldwide.¹ The global spread of COVID-19 has had a profound impact on daily life in affected populations.^{2–4} As the site of the epidemic outbreak, China quickly adopted the most comprehensive, thorough, and strict prevention and control measures in the face of this public health emergency. Traditional “non-medical” prevention and control measures, such as city closure, community isolation, and suspension of population movement, have achieved remarkable results.^{5,6}

These prevention and control measures have had notable success in preventing the virus from infecting healthy people; however, there is a specific group of people who need particular attention in this outbreak, namely, older adults with chronic diseases. With better health care and lower fertility rates, the world population is aging more

quickly than ever.⁷ According to the official website of the National Bureau of Statistics of China, by the end of 2019, the proportion of individuals > 60 years old in China reached 18.1%, and the elderly population is increasing annually.⁸ Because of the increase in the aging population, the number of patients with chronic diseases is also gradually rising. Almost half (53.2%) of adults > 60 years old in China suffer from hypertension, diabetes, and other chronic diseases.^{9,10} Although the general population is susceptible to the novel coronavirus, older adults with chronic disease are among high-risk groups and have more serious clinical manifestations and consequences following infection.^{11,12} Further, chronic diseases in older patients are characterized by prolonged illness, as well as high rates of mortality and disability,¹³ and such individuals need to attend hospital regularly for re-examination and take medicine for the rest of their lives.

For older patients with chronic diseases, these prevention and control measures place older patients with chronic disease in difficult situations. In one aspect, they are trapped in strict community isolation, routine hospital visits are suspended, and they are subject to other epidemic prevention policies.⁶ On the other hand, while they are a population at high-risk from COVID-19, they also need to leave home for medical treatment, to acquire medications, and for regular check-ups,^{11–13} representing a major conflict with epidemic prevention

* Corresponding author at: School of Nursing, Sun Yat-sen University, No. 74 Zhongshan 2nd Road, Guangzhou, Guangdong 510080, China.

**School of Sociology & Anthropology, Sun Yat-sen University, Xin gang xi Road, Guangzhou, Guangdong 510080, China

E-mail address: zhmfen@mail.sysu.edu.cn (M. Zhang).

Xiaoyu Wu AND Ni Gong should be considered joint first author.

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policies. In the face of public health emergencies, the public often evaluates the risk of unknown public health emergencies based on personal experience, and the perception of risk will affect the response behavior to public health emergencies.¹⁴ Therefore, it is an important public health issue to understand how elderly patients with chronic diseases perceive and respond to the risk of the epidemic.

In recent years, there have been frequent international public health emergencies, such as SARS, measles, dengue fever, and other serious infectious diseases, as well as the outbreak and epidemic of COVID-19 in 2020. Experts and scholars have gradually realized the impact of public risk perception on their response, and relevant research has gradually increased. In the face of the Zika virus outbreak in 2015, the U.S. government took timely "3C" control measures—avoiding closed spaces, crowded places, and close-contact situations—to ease public panic.¹⁵ When the Ebola epidemic broke out, the U.S. support team established the Inter-Agency Standing Committee on Crisis Intervention to create a psychological intervention support system.¹⁶ At the same time, scholars have studied the risk perception characteristics in public crisis events. Xie Xiaofei et al.¹⁷ divided the characteristic dimension of public perception of SARS risk into three dimensions: anxiety, controllability, and possibility of SARS.

Although studies on risk perception in public health events are gradually increasing, most of the previous studies focused on the characteristics of risk perception, government public opinion, and theoretical research, while studies on emergencies are relatively limited; in particular, the risk perception and response path and process are not clear. The purpose of this study was to understand and characterize the COVID-19 risk perception process and trajectory among older people with chronic disease living in the community to provide a basis for the formulation of measures in the event of future public health emergencies.

Material and methods

Design

Using a qualitative research study design, in-depth and semi-structured interviews were conducted to explore the experiences of participants. Given the limited research into the risk perception trajectory in our population of interest, we chose a thematic analysis approach to explore and understand these complex issues.¹⁸

Recruitment and sample

The setting of this study is Guangzhou, within Southern China. Older persons with chronic diseases were recruited from the local community, which had 11,975 persons aged 65 and over, accounting for 15.5% of the total community population, including a certain proportion of elderly persons living alone, on low incomes, and with disabilities. This study relied on community organizations such as community social work stations, health service centers, and neighborhood committees to recruit older adults with chronic disease by participating in their community activities and assisting social workers in case consultations. Purposive sampling was used to recruit participants. The inclusion criteria were as follows: (a) ≥ 65 years old, (b) an established diagnosis of one or more chronic diseases, and (c) ability to speak Mandarin. Exclusion criteria were as follows: (a) a medical or psychiatric diagnosis of a cognitive or psychiatric disorder, and (b) declined to participate in the study. Interviews were conducted in an independent, quiet, and safe home environment (of the interviewer) during the isolation period.

Data collection

Data were collected between October 2020–December 2020. At this stage, China had entered the period of regular management of the epidemic. The government implemented different levels of risk management in different areas, and daily life gradually resumed.¹⁹ Permission to conduct the interviews was obtained from each participant and the community health service center. The principal researcher interviewed participants, while another member of the research team provided support, including managing the recordings. Before the interview, the purpose of our study and principles of voluntary participation, confidentiality, and willingness to participate were explained to participants. Interviews were recorded and notes were made throughout after obtaining informed consent. The final interview guide included the following questions: (a) Since the outbreak of COVID-19, when did you first start to pay attention to COVID-19? By what means? (News/TV/Internet/Other People); (b) What aspects or phenomena made you realize the seriousness of the COVID-19 epidemic? (c) What measures are being taken in your community to cope with COVID-19? (d) Do the COVID-19 outbreak and quarantine measures taken by the community make any impact or inconvenience you in your life? If so, what are the main aspects of this inconvenience? Do you think this influence or inconvenience is large (in terms of its effects on your daily life and medical treatment)? Recruitment ended when no new codes emerged, indicating that saturation was achieved.

Data analysis

Interviews were audiorecorded and transcribed verbatim within 24 h. Qualitative content analysis methods were used to determine the themes and subthemes from the narratives. Analysis and code development were conducted by two researchers to ensure reliability.^{20,21}

All researchers familiarized themselves with the data and generated initial codes related to the risk-perception trajectory. Coding was data driven and independently performed by groups 1 and 2 to identify possible coding units related to risk perception trajectory in study participants. This was followed by a team discussion to compare and discuss the coding units of the group transcripts until consensus was reached. Subsequently, codes were sorted into potential themes, which were then reviewed to ensure they met internal and external heterogeneity criteria. Finally, we defined and named the themes. Saturation was deemed to have been met when no further subthemes or themes could be identified.

Results

Ultimately, 21 older adult patients with chronic disease completed the interviews. Interviews lasted between 30 and 90 min for each participant, and some interviews were conducted on two to three separate occasions. [Table 1](#) shows the sociodemographic and clinical characteristics of the participants.

After in-depth analysis and investigation, three themes emerged from the study as follows: (a) restricted travel, (b) psychological shock and panic, and (c) unintended consequences. All participants agreed with the analysis after review. Each theme is reported with examples of the original words of the participants.

Theme 1: Restricted travel

Since 2019, COVID-19 has gradually spread throughout the world. China rapidly slowed the spread of disease by adopting municipal isolation, community isolation, and suspension of traditional "medicine," along with prevention and control measures, such as migration suspension. Therefore, most regions of China were not severely

Table 1.
Demographic Characteristics Of The Participants ($n = 21$).

Variable	Category	<i>n</i>	%
Gender	Male	13	61.9
	Female	8	38.1
Age (years)	65 ^a 70	4	19.1
	70 ^a 75	7	33.3
	75 ^a 80	7	33.3
	80 ^a	3	14.3
Marital status	Marriage	16	76.2
	Widowed	4	19.1
	Divorced	1	4.7
Education	High school	11	52.4
	College	8	38.1
	Other	2	9.5
Type of chronic diseases	Hypertension	3	14.3
	Diabetes	2	9.5
	Stroke	1	4.7
	Cancer	5	23.9
	Heart disease	1	4.7
	Contains two or more of the above	9	42.9

affected; however, for a large number of ordinary residents, daily life was effectively suspended, and public life was greatly limited at different levels.

During the most severe stage of the epidemic in China (from February to March, 2020), to prevent the spread of the disease as quickly as possible, all major cities in China adopted relatively strict stay-at-home orders.²² For example, the community strictly implemented grid management and dragnet screening. Strict management of community travel was also adopted, such as limiting travel by each family to 2–3 times per week. Community members needed to apply for entry cards to enter and exit, and daily travel became difficult. Business shutdowns and lockdowns became a way of life for almost everybody.

For older adults living in the community, the limitation of public space became the main interruption to their daily lives. When we asked participants what impact COVID-19 had on them and their families, they said:

“I used to do some volunteer work and organize some community activities, and I needed to get out and exercise every day. My wife and I travel a lot every year. We don’t really spend much time at home all year round. But during the epidemic, I couldn’t go anywhere.” (P1)

In addition to the reduced range of activities, the impact of restricted travel was also reflected in inconvenience to activities of general life.

“I used to go shopping with my wife every morning. But at the height of the epidemic, we couldn’t get out and it was hard to get food. All we did was eat what we had stored and we were very frugal.” (P4)

Community control of travel not only limited the amount older adults could go out but also prevented their children and other relatives from visiting.

“I live with a carer and my son lives with his ex-wife. My son used to visit me in my neighborhood every week and accompany me to

dinner. But during the worst of the epidemic, there were community rules against going in and out, so even when my son and I were in the same city, we couldn’t see each other.” (P5)

Theme 2: Psychological shock and panic

At the beginning of the epidemic, because of the lack of information about the virus and with the increasing number of confirmed and suspected cases and deaths, coupled with the transmission of false information about the epidemic, psychological panic spread among the public. Because older adults with chronic diseases are at high risk of COVID-19, fear of infection was their most prominent psychological experience.

“During the outbreak, when I heard someone nearby coughing or having a fever, I would get so nervous that I would lock my door and not go out, in case someone new infected me.” (P8)

“I get scared when I see the news on TV. Especially when I saw the increase in the number of cases reported on the news every day, I was afraid that I would get infected and then be sent to the hospital to be quarantined, because I heard that after being sent to be quarantined, I could not come out.” (P11)

At the beginning of the epidemic, the virus was unknown; therefore, the only way to reduce the incidence of infection was to cut off the viral transmission route. As a result, masks were in short supply and many older people made great efforts to find a way to buy them.

“It was on the news that you had to wear a mask. At that time, the drugstores nearby were very expensive and it was very difficult to get one. I told my son to go around trying to get a mask. I don’t go out, but I feel a little more at ease.” (P15)

In the face of emergencies, people experiencing different degrees of anxiety, despair, helplessness, and other psychological reactions may react further to take part in looting and other irrational behavior. With the development of the epidemic, a certain drug was constantly publicized as having a miraculous effect against COVID-19, leading to fighting among the public for the drug.

“I watched the news every day reporting the statistics on the development of the epidemic, and I was afraid I was infected. Later, I heard that Shuanghuanglian is useful. Although I know it may not be scientific, I would rather believe it than not believe it. So I also asked someone to buy it.” (P9)

Theme 3: Unintended consequences

Due to the rapid spread of the disease, daily travel was restricted to slow disease spread and became difficult, especially to high-risk places such as hospitals. For older chronically ill people living in the community, the risks associated with the outbreak went beyond the risk of viral infection. Although older adults with chronic disease are at high risk from COVID-19 infection, they still need to go out for medical treatment and regular check-ups. In the early days of strictly remaining at home, travel restrictions became a problem for many patients with chronic diseases.

Disruption of medical supplies

Taking regular medication is the norm for people with chronic diseases; however, during the outbreak, travel restrictions prevented them from obtaining a continued supply of medicines. One of our interviewees was a cancer patient, and the decline in physical function caused by cancer treatment made her particularly careful to avoid disease risk.

"I've been on medication ever since I got cancer. I never stopped, but when the epidemic was serious, I stopped for a period of time, because at that time, I was afraid to go to the hospital to get medicine, because my immunity is poor. What if I go out and get infected with coronavirus?" (P14)

Understanding the risk posed by the novel coronavirus made her feel afraid to go to the hospital, which led to an interruption in her treatment. In addition to personal psychological reasons, treatment interruptions also occurred because of hospital treatment policies during the epidemic. We also interviewed a patient who had suffered a stroke, for which he needed to take anticoagulant drugs regularly for a long period of time; however, the epidemic outbreak resulted in his having to stop taking the drugs for a period.

"I have to take aspirin every day, but I have to adjust it so I can take it for half a month at a time. When the epidemic was serious, I ran out of medicine and wanted to go to the hospital to get medicine, but I couldn't, because the hospital only provided a fever clinic at that time, so I didn't take medicine during that period. I was afraid of causing a blood clot if I didn't take the medicine, but there was nothing I could do." (P20)

Delay in treatment

In addition to those with chronic disease who regularly needed to buy medicine, there were also older adults who needed to see a doctor because of acute diseases during the epidemic.

"During the outbreak, the hospital would not admit patients except for fever clinics. I had shingles at that time and my hand was very painful, so I couldn't see a doctor. I had to take painkillers every day to relieve the symptoms. When I saw the doctor later, the doctor said it was a minor problem, but it was delayed, so the treatment effect was not good, and there were sequelae." (P7)

Among the older adults with chronic disease, there was a specific group of patients with cancer. The aggressive nature of the malignancies and the need to treat them led to even greater challenges for this group during the outbreak.

One of our interviewees was a patient who was diagnosed with rectal cancer in April 2020. The clinically recommended protocol was five cycles of chemotherapy; however, due to epidemic prevention and control measures, he did not receive treatment quickly and smoothly.

"The procedures in big hospitals during the epidemic were very strict. I waited a while before I could start chemotherapy. I was worried every day that my disease would progress because it was a malignant tumor and if left untreated it would kill me." (P15)

Discussion

Perceived risk of disease is directly related to the protective actions taken by the individual. The perceptions of individuals of different risks from the outside world also have different characteristics at different periods and stages.²³ As described in this study, the perception of epidemic risk among older patients with chronic disease living in the community had different characteristics during different stages of the outbreak. In the early stage of the epidemic, faced with an outbreak of an unknown virus, blocking the transmission route became the most important prevention and control method,²⁴ with travel restriction the main prevention and control measure. Sensitive groups could intuitively feel the huge changes occurring in the external environment and influencing their familiar daily life; however,

the specific impact of such changes on daily life has yet to be subject to clear reflection. At this stage, individuals adopt a relatively calm, "wait-and-see" attitude. In contrast, in the middle stage of the epidemic, with comprehensive coverage in various media, negative information was communicated to the study participants. Faced with this sudden information explosion, the interviewees gradually realized the potential risk, and panic, fear, worry, and other negative emotions, gradually emerged. However, it is precisely because of the instantaneous information overload that older patients with chronic diseases in particular initially found it difficult to respond appropriately, as making specific plans related to the disease in advance became more challenging, and their attention was more strongly influenced by developments in the epidemic. With the spread of the virus, a genuine crisis related to the daily lives of older adult patients with chronic diseases appears as a result of tougher lockdown and preventive measures and medicine shortages. For older adult patients with chronic diseases, there is an irreconcilable contradiction between not being able to go out and the need to go out regularly to buy medicine and the need for medical care visits, which leads to the dilemma of treatment delay and drug interruption. Therefore, this stage mainly manifested as a response to dramatic changes in the external environment and familiar rules governing the operation of daily life, and it was difficult to make accurate and timely responses to these risks over a short period of time; that is, it is only when the real dangers in daily life collided with the external world that older adults, a specific group of people with chronic diseases, genuinely perceived the occurrence of risk.

By analyzing and summarizing our results, we found that the perception of risk by older adult patients with chronic diseases living in the community was not sudden or instantaneous. Risk perception is a process in which individuals directly evaluate and judge risk events by subjective intuition, and this process is affected by the characteristics of risk events, individual characteristics, and their interaction.²⁵ In the early stage of the epidemic, because of lack of knowledge about the virus and poor understanding of how the epidemic would actually develop, our study participants did not perceive the level of risk posed by the epidemic quickly. At this stage, the state could advocate only non-pharmaceutical public health interventions, such as hand hygiene, wearing masks, and maintaining social distance.²⁴ With travel limitations, the lifestyle of older adults with chronic diseases changed, becoming contrary to their accustomed daily life. Out of their comfort zone, life changes to which they were unaccustomed were primary prompts to an initial perception of the risks posed by the epidemic.

The rapid spread of the epidemic led governments and organizations to take what were considered promising and unprecedented response measures (e.g., sanitation, blockades, school closures, travel restrictions, information dissemination).²⁶ To manage the increasing number of infected patients, many routine health care services were delayed, while others were revolutionized by the introduction of technology and changes in working patterns.^{27,28} Such strict control measures also led to some unintended consequences and outcomes. Although traditional "non-medical" prevention and control measures, such as city closures, community isolation, and suspension of population movement, had remarkable success and avoided viral infection of healthy people to a great extent, the relatively strict quarantine measures also impeded access to medical treatment and check-ups for a large group of older adults with chronic diseases. From one perspective, these people were trapped by strict community isolation, hospital suspensions, and other prevention policies, unable to go out, and found it difficult to obtain the medicines they needed. From another point of view, although older adults with chronic disease are at high risk of COVID-19 infection, they still need to go out regularly for medical treatment and hospital follow-up.^{9,10} "Unforeseen outcomes" of social actions are consequences that social

actors have neither deliberately created nor anticipated, and these “consequences” are opposed to the original intention of the social actions.²⁹ Unforeseen consequences can be far-reaching, affecting all groups of the population (e.g., service providers, community members, vulnerable groups) and all sectors of society (e.g., health, education, environment, economy, law).³⁰ Large-scale implementation of multi-mode infection prevention and control strategies has achieved epidemic control, and the infection rates of other infectious diseases have remained stable, or even decreased, because of good adherence to use of personal protective equipment and hand hygiene.³¹ However, in this study, we describe how excessively strict prevention and control measures also resulted in interruptions to medication supply and delayed medical treatment for older patients with chronic disease. Therefore, in the event of future public health emergencies, governments should also pay attention to the particularities and needs of different groups when formulating emergency management measures, with the aim of reducing adverse and unintended outcomes.

In addition, we found that the perception of risk among older patients with chronic disease living in the community was not an interlocking chain reaction but rather a risk superposition effect. Of our three outcome themes, travel restrictions were the first to be perceived as a risk by this group of patients. Hence, based on travel restrictions, with the increasing number of confirmed cases and research on COVID-19, the outbreak entered a specific phase. In this stage, news and media communication gradually become the main source for their perception of risk. The COVID-19 pandemic has undoubtedly created a general climate of anxiety, fear, uncertainty, and insecurity,³² and the risk of a second or third pandemic wave could also create fear, uncertainty, and anxiety among people around the globe.³³ COVID-19 can influence the psychology and behavior of populations,³⁴ such as the irrational crowd looting behavior to obtain Shuanghuanglian oral liquid, caused by panic.³⁵ Further, for older adult patients with chronic disease living in the community, risk perception of the epidemic is not limited to such phenomena. Over time, some unavoidable problems emerged one by one. Insufficient stock of medicines coupled with an inability to go out to buy medicines, and needing to access hospitals for medical treatment because acute or chronic disease while the medical services were closed, became their main sources of risk at this stage. Therefore, an exploration of the trajectory of risk perception can also guide the need for sufficient understanding of the mechanisms underlying risk perception in the future to control the effects of each contributory factor.

Limitations

This study has some limitations. First, we recruited only older people with chronic diseases from one community in a southern Chinese city. Similarities in the lifestyles, customs, and culture of participants meant that the essence of their stories was also very alike. Second, through this study, we identified how grasping the boundary between strict prevention and control measures and daily life is an issue that policy makers need to pay attention to. Sample size limitations may also lead to biased results. Therefore, future studies with larger sample sizes are needed.

Conclusion

In summary, older adult patients with chronic disease living in the community had varying characteristic perceptions of epidemic risk at different stages in the COVID-19 outbreak, and this group of patients has specific features. When facing public health emergencies, policy makers need to consider the needs of both the majority of the general population and those of particular groups. Correct identification of the risk perception process and trajectory in older adult patients with chronic diseases will assist in the formulation of more complete

and scientific emergency measures in the event of future public health emergencies.

Declaration of Competing Interest

All authors have no competing interests to declare.

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