

Social inequality and equity in community actions for health

Edited by

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Published in

Frontiers in Public Health
Frontiers in Medicine



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ISSN 1664-8714
ISBN 978-2-83251-770-3
DOI 10.3389/978-2-83251-770-3

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Social inequality and equity in community actions for health

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Citation

Balogun, M., Banke-Thomas, A., Galvin, S., Boateng, G. O., eds. (2023). *Social inequality and equity in community actions for health*. Lausanne: Frontiers Media SA. doi: 10.3389/978-2-83251-770-3

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SPECIALTY SECTION
This article was submitted to
Life-Course Epidemiology and Social
Inequalities in Health,
a section of the journal
Frontiers in Public Health

RECEIVED 15 January 2023
ACCEPTED 27 January 2023
PUBLISHED 13 February 2023

CITATION
Balogun M, Banke-Thomas A, Galvin S and
Boateng GO (2023) Editorial: Social inequality
and equity in community actions for health.
Front. Public Health 11:1144910.
doi: 10.3389/fpubh.2023.1144910

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Editorial: Social inequality and equity in community actions for health

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KEYWORDS

social inequalities, equity, access, community action, community participation

Editorial on the Research Topic

Social inequality and equity in community actions for health

Health inequities are systematic differences in the health status of different population groups (1). These differences are widening between and within countries with such concern that the World Health Organization used World Health Day 2021 to mark health equity and commenced a year-long equity campaign to bring people together to build a fairer, healthier world (2). The causes of health inequity stem from a range of social, economic, environmental, and structural disparities that result in differences in health outcomes across populations (3). The Coronavirus Disease 2019 (COVID-19) pandemic has further illuminated and magnified health inequities in both high-, middle- and low-income countries (4, 5), reversing progress made over the last 20 years. Consequently, we launched this Research Topic on the 21st of September 2021 with the aim of cataloging articles that document health inequality and inequity globally as well as articles that address both through community action.

Of the manuscripts that were submitted, we eventually accepted and published 10 which fall into four research areas: (1) relationship between social inequality and health outcomes, (2) community actions among socially vulnerable groups, (3) role of health professionals in addressing health inequity in communities and (4) new concepts in defining health disparities.

There is a gradient between socioeconomic status and health with each level in the hierarchy generally having less morbidity and mortality. For some health conditions, however, there has been no change in health or worsening health status over time for economically disadvantaged populations (6). [Holder-Pearson and Chase](#) in their opinion article describe how certain marginalized ethnic and socioeconomic groups in New Zealand bear a disproportionately high burden of Type 2 diabetes mellitus, suffer higher financial costs of care and have lower access to life-saving treatment. Contrarily, two studies in our topic did not elicit negative health outcomes among populations with social disadvantages. First, [Chan et al.](#) in their review article show that individuals experiencing homelessness and traumatic brain injuries in studies from United States of America and Canada had rehabilitation services available to them. They recommend that existing rehabilitation for these individuals should be tailored to include screening for TBI, conducting cognitive and functional assessments and involve multidisciplinary teams. Second, [Hamilton et al.](#) in their single-center retrospective study of 73 children with medical complexities presenting with sepsis, did not find any association between social determinants of health and length of stay in the pediatric intensive care unit.

Community actions play a vital role in promoting health equity, as they occur at a level closer to individuals and can be better targeted at high-risk individuals. Each community is unique in the nature and degree of health inequities as well as the required community-based efforts (7). Mishra et al. used a participatory learning action technique to formatively assess community participation in a rural, vulnerable population in India and developed a conceptual framework for community participation while Hoffman et al. engaged community experts and organizations working in refugee, immigrant and migrant communities and explored their perspectives and roles in the COVID-19 pandemic response.

Regarding the role of health professionals in addressing health inequity in communities, Hurley-Kim et al. outline the health disparities that exist in pharmacists' practice in the United States, including communities with limited access to pharmacies (pharmacy deserts) and innovative solutions proposed by pharmacy leaders to address the disparities. Chong et al. share how community pharmacists in Malaysia manage medication wastage, returned medicines, and medicines disposal while Li et al. describe the role and challenges of village doctors in rural China during the prevention and control of the COVID-19 pandemic. These articles underscore the central role health care professionals have in addressing health inequity. Indeed, a previous study includes provider distribution according to population need and practice patterns oriented to addressing root causes of disparities as some of the critical domains to advancing health equity (8).

Two new concepts feature in the fourth area of research. The first by Dierx and Kasper details the development of a new grouping to measure socio-economic status, providing new insights into health inequalities. This is critical since advancement of health equity requires a proper assessment of differences in health and its determinants (9). Development of structured formats of measurements for different societies is deemed necessary (10). The second by Ju et al. proposes a new model for the process of rumor diffusion about COVID-19 and they recommend announcing true information publicly to instantly contain the COVID-19 rumor diffusion.

In conclusion, our Research Topic brought together multiple scientific disciplines to catalog social inequality, health inequity, community and health care professionals' actions and innovation to advance health equity. The COVID-19 pandemic has highlighted the relevance of community-based efforts to advance health equity. Most of our studies were cross-sectional; further studies that use randomized control trials and/or longitudinal data are recommended to establish causal relationships.

Author contributions

All authors listed have made a substantial, direct, and intellectual contribution to the work and approved it for publication.

Acknowledgments

We thank all the authors, reviewers, and editors that contributed to this Research Topic.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Online Rumor Diffusion Model Based on Variation and Silence Phenomenon in the Context of COVID-19

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OPEN ACCESS

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Specialty section:

This article was submitted to
Life-Course Epidemiology and Social
Inequalities in Health,
a section of the journal
Frontiers in Public Health

Received: 02 October 2021

Accepted: 27 December 2021

Published: 27 January 2022

Citation:

Ju C, Jiang Y, Bao F, Zou B and Xu C
(2022) Online Rumor Diffusion Model
Based on Variation and Silence
Phenomenon in the Context of
COVID-19.
Front. Public Health 9:788475.
doi: 10.3389/fpubh.2021.788475

In the era of mobile internet, information dissemination has made a new leap in speed and in breadth. With the outbreak of the coronavirus disease 2019 (COVID-19), the COVID-19 rumor diffusion that is not limited by time and by space often becomes extremely complex and fickle. It is also normal that a piece of unsubstantiated news about COVID-19 could develop to many versions. We focus on the stagnant role and information variants in the process of rumor diffusion about COVID-19, and through the study of variability and silence in the dissemination, which combines the effects of stagnation phenomenon and information variation on the whole communication system in the circulation of rumors about COVID-19, based on the classic rumor SIR (Susceptible Infected Recovered) model, we introduce a new concept of “variation” and “oyster”. The stability of the new model is analyzed by the mean field equation, and the threshold of COVID-19 rumor propagation is obtained later. According to the results of the simulation experiment, whether in the small world network or in the scale-free network, the increase of the immature and the silent probability of the variation can effectively reduce the speed of rumor diffusion about COVID-19 and is conducive to the dissemination of the truth in the whole population. Studies have also shown that increasing the silence rate of variation can reduce COVID-19 rumor transmission more quickly than the immunization rate. The interesting discovery is that at the same time, a higher rumor infection rate can bring more rumors about COVID-19 but does not always maintain a high number of the variation which could reduce variant tendency of rumors. The more information diffuses in the social group, the more consistent the version and content of the information will be, which proves that the more adequate each individual information is, the slower and less likely rumors about COVID-19 spread. This consequence tells us that the government needs to guide the public to the truth. Announcing the true information publicly could instantly contain the COVID-19 rumor diffusion well rather than making them hidden or voiceless.

Keywords: COVID-19 rumor diffusion, variation, oyster, infection rate, ISVOR model

INTRODUCTION

Information diffusion is a typical model of dissemination in human society. Whenever an emergency occurs, such as the occurrence of COVID-19, it is easy for rumors about COVID-19 to appear and to swirl due to asymmetric information, fuzzy facts, and subjective conjectures (1), which have numerous negative effects. With the rapid development of mobile networks and various social applications, the speed and breadth of information dissemination have changed qualitatively. This has demanded new requirements for relevant organizations to effectively guide the public opinion about COVID-19 and to reduce the harm of rumors about COVID-19.

The research on the propagation model of rumors started in the 1970s. Daley and Kendall (2) proposed a Daley-Kendall (DK) model that combines rumor diffusion with virus infection and divides the individuals into three groups: people who have not heard of the rumor, people who actively spread it, and people who help stop the rumor. As the follow-up research continued, Maki and Thompson (3), based on the DK model, assumed that when a rumor spreader contacts with another spreader, only the former spreader can be transformed into an immunizer. With the development of modern technology, scholars have started to consider the complexity of large-scale social networks. For the first time, Zanette and Damián (4) put a model of rumor propagation in a small-world network environment and obtained its threshold. Subsequently, Moreno et al. (5) replaced the environment of rumor propagation with a scale-free network, described the propagation process with an average field equation, and verified it with a random analysis and computer simulation. Pan et al. (6) studied the propagation simulation of rumors on a scale-free network with a power law distribution and variable clustering coefficients and found that increasing the variable clustering coefficient can effectively prevent the diffusion of rumors and increase the information transparency which helps to dispel rumors.

Nekovee et al. (7) combined the phenomenon that some people stop spreading on account of forgetting rumors in real life, integrated the forgetting mechanism into the classic SIR rumor model, and analyzed its threshold. On this basis, Zhao et al. (8) improved and carried out simulation experiments with LiveJournal data. It was found that the network average degree, forgetting parameters and immune parameters, had significant effects on the rumor diffusion. Later Zhao et al. (9) added the hibernator role with the forgetting and memory mechanism and proposed a new Susceptible-Infected-Hibernator-Removed (SIHR) model. Wang (10) introduced a trust mechanism and concluded that trust factors can effectively reduce the size of the final rumor diffusion and delay the process, but it will increase the threshold of propagation in the network. Wang et al. (11) divided the people into four categories based on the forgetting mechanism, and proposed SIRaRu. The Ra is used to indicate those who have heard rumors but have no interest in spreading them. The Ru stands for those people who are completely immune to rumors. It has a significant impact that the forgetting parameter can determine the final propagation threshold. Wang et al. (12) proposed a Credulous-Spreader-Rationals (CSR) model based on the increasing convenience of social networks,

which divided the nodes in the group into three categories: credulous, spreader, and rational. Huo and Huang (13) applied the idea of system dynamics to integrate the influence of popular science propaganda and media reports on the diffusion of false information, and proposed an optimal control strategy. Wang et al. (14) extended the forgetting mechanism, set the forgetting rate which could be changed over time, and proved that a larger initial forgetting rate or forgetting speed can reduce the size of the final rumor. Zhang et al. (15) constructed a net rumor diffusing model with a social strengthening mechanism and attenuation characteristics and proved that intervention in public interest can effectively curb rumor diffusion. Liu et al. (16) studied the modified Susceptible-Exposed-Infectious-Recovered (SEIR) model on a scale-free network and compared the effectiveness of the two strategies of group immunity and target immunity. Li and Ma (17) constructed a two-tier social network, which is online and offline, to describe the diffusion of public opinion. Seoyong and Sunhee (18) analyzed rumor data collected from the social survey about Fukushima nuclear accident. They think the best way to neutralize rumors is by reducing the perceived risk and negative information, and enlarging the source credibility, perceived benefit, trust, and knowledge. Zhu and Ma (19) proposed a Susceptible-Hesitated-Infected-Removed (SHIR) model with hesitant roles on heterogeneous random networks based on the individual dynamic relationship changes and subjective judgments, and people who expressed individual choices through the weight of edges. Zan (20) proposed a Double-Susceptible-Infectious-Recovered (DSIR) (Double Rumor) model, where two rumors compete with one another. The selection parameters are used to represent the attractiveness of each rumor, while the time delay parameter is used to represent the time difference between each other. Amaral and Arenzon (21) proposed a propagation model with skeptical characters and simulated the symbiosis of survivor zombies to characterize the equilibrium status of each character during the diffusion of rumors. Zhu and Wang (22) established a rumor propagation model with uncertainty based on the spatiotemporal diffusion framework. Experiments proved the uncertainty of network topology and human behavior when it reaches to the threshold and determines the density of infected connections. With the improvement of specific capabilities of society, rumors diffuse to a stable state at a faster rate. Ankur et al. (23) found that the different interests of each person are uncertain and volatile about rumor propagation. Therefore, a deterministic model and a random model were established on a homogeneous network, and a deterministic equation was introduced on the random uniform network to discuss if the noise could extend the diffusion of rumors. Liu and He (24) proposed a non-linear dynamic propagation model for information competition from the viewpoint of public opinion control. The Markov chain theory was used to analyze the node state transition matrix in the perspective of competition and verified the feasibility of competing information dissemination with the empirical analysis of hot events, which was used for comparison. Zhang et al. (25) added a communicator who will diffuse real information, combined with the effect of forgetting mechanism on propagation, and used the regeneration matrix to obtain the threshold for simulation experiments. Guo et

al. (26) designed a multi-feature diffusion model (MF-model), formulated a multi-feature rumor blocking (MFRB) problem on a multi-layer network structure, and proposed a Revised-IMM algorithm, considering the spread of rumor is determined by multiple features. Leonid (27) modified the spreader which is divided into the low rate of active spreaders and the high rate of active spreaders, and got its stability under stochastic perturbation with the method of linear matrix inequalities. Guo et al. (28) proposed an overall evaluation on benefits of influence (OEBI) problem, based on the phenomenon that a user is influenced by both our own information and the information of our rival. They proved the objective function of the OEBI problem is not monotone, not submodular, and not super modular.

However, with the continuous deepening of research on rumors, the temporary non-spreading role in the middle state also needs to be considered in the rumor propagation model, which has played a temporary buffer role in the diffusion. At the same time, the instability of the turbulent information has a strong offset property, which causes the variation of rumors in various versions. In the uninterrupted diffusion of rumors, there is a lot of chaos based on subjective emotions derived from objective factors. During the diffusion of rumors, with various mutations and distortions, there will be numerous new descriptions that are far different from the original version. Therefore, mutational rumors display different effects on rumor propagation.

In the context of the COVID-19 outbreak, and based on the classic rumor SIR model, this research combines the effects of stagnant roles and information variants in the circulation of COVID-19 rumors on the entire communication system, introduces new concepts of mutants and silent people, and proposes the ISVOR (Ignorance-Spreader-Variation-Oyster-Recovery) model. The research also calculated the corresponding average field equation, and further studied its propagation law and the influence of various parameters during the propagation. The research work has profoundly explored the theory of new rumor propagation model, and it has practical significance for the government or enterprises to effectively guide forward the public opinion of COVID-19 on the Internet.

The main contributions are summarized as follows:

- In order to accurately study the propagation of rumors during COVID-19, two novel variables called “variation” and “oyster” are introduced. Then an ISVOR model with Ignorance-Spreaders-Oyster is proposed.
- In order to find the balanced state of the rumor spreading quickly, we use the average field equation to derive the threshold value of opinion propagation.
- The findings can better help the government and relevant departments in responding to rumor control in emergencies.

PROBLEM ANALYSIS

The COVID-19 is a global health emergency that is having a profound impact on the physical and mental health of people. Take the information “Wuhan lockdown”, for example, that once

diffused online. During COVID-19, some widely circulated but unconfirmed news on social media, such as that the salt brine mouthwash and smoked vinegar could prevent viruses, and some people heard the news and went to grab these items, causing them to sell out, while those who did not grab the items felt the social inequality caused by the information asymmetry, but these unconfirmed messages were eventually confirmed as rumors by public media and experts. A study shows that, in the context of the increasingly sound development of new media functions, the elderly population is enjoying short videos spread through WeChat and Microblog, and the authenticity of which cannot be verified. These contents were often identified as rumors (12). Among those people who heard this news, some people were reflecting on the news or were waiting for the news from the official website which could be in a silent state of not spreading. After a period of silence, some silencers became immune to this rumor because of rational thinking or other reasons. Some silencers might return to the state of “diffusing rumors”. The rumor will continue to mutate under the turmoil. Previous studies have often ignored the role of “silent people” and focused on the own propagation of the communicator. Also, the rumor variation in the process and the influence of variation instability factors on the entire communication chain were neglected, as circled in **Figure 1**.

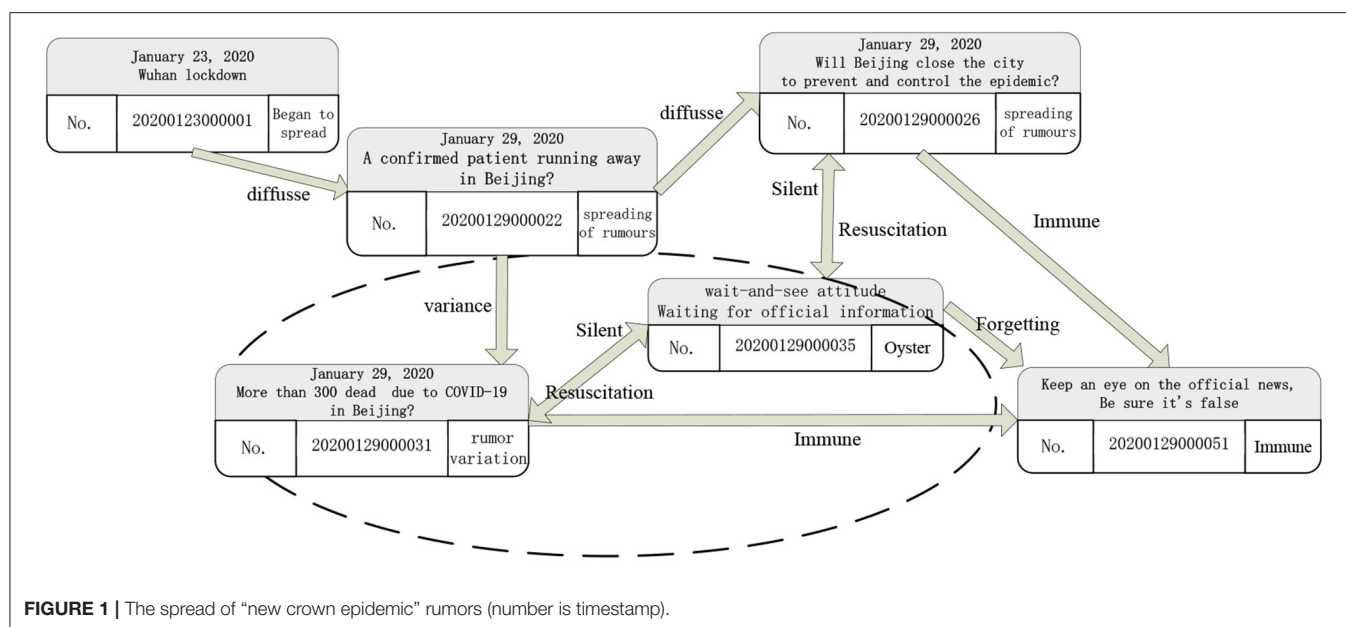
The typical instability of rumors makes it easily but incorrectly relayed. Especially in the event of sudden events to satisfy the curiosity of the public about unknown things, a variety of information, which is hard to detect, will be circulated in society, particularly on the Internet. Although the information itself is full of various uncertain factors, according to their own needs and psychological reasons (1), many people will involuntarily believe the rumors, then substitute their own subjective assumptions, amplify the empathy of the group, and continue to promote the development of rumors. In the process of online communication, frictions can occur among individuals. The trajectory of the rumors will be deflected and twisted, and the rumors will begin to mutate. At the same time, calm and rational attitudes are mixed with blind following. Disputes of different views come on stage in turn.

IMPROVED ISVOR MODEL BASED ON SIR MODEL

This paper is based on the SIR epidemic model, the ISVOR model was constructed by introducing two novel variables of “variation” and “oyster”.

SIR Model

In the 1860s, Daley and Kendal found the similarities between infectious diseases and information transmission by comparing them. They first proposed the classic DK model (2), that is, the SIR model, which is the most widely used. In this model, the population is abstractly divided into three categories: susceptible, infected, and recovered individuals, corresponding to the individuals who do not know the information, the



individuals who transmit the information and the individuals who no longer participate in the information transmission.

ISVOR Model

The ISOVR model was established based on the classical SIR rumor propagation model by introducing the novel role concepts of mutators and silencers, and the concepts of stagnant roles and information variants were proposed, which were defined as follows:

Stagnant Role

When certain nodes in the network, i.e., real people, choose to remain in a brief state of stagnation by not spreading rumors after receiving them. However, this role will change again as the rumor continues to spread, and finally remain immune to the rumor or return to the state of rumor spreading.

Information Variants

As rumors spread on the Internet, they are altered by some people, amplifying the uncertain content of the information, and adding their own distorted understanding or deliberate misinterpretation of the fabrication. The mutated rumors change the speed of their dissemination, thus, causing other actors to be affected in various ways in the process of rumor spreading.

In the following, we will define the variables of the ISVOR model:

Ignorance

People who have not yet heard rumors about COVID-19 and could easily believe the rumors about COVID-19.

Spreader

Ordinary rumor spreader, people who contacted the earliest version of the rumors about COVID-19 and believed it. Also, they would spread the rumors about COVID-19 actively.

Variation

Variable spreader, which is different from the ordinary spreader. The content or version of rumors about COVID-19 that the variable spreader carries has transformed a lot than before, the property of the message and specific information have changed, and there is a trend of continuous change.

Oyster

People who received the information about COVID-19 rumors, but stay silent, will not actively spread it, in a state of thinking or bystander.

Recovery

People who know the truth of the rumors about COVID-19 and refuse to spread the rumors about COVID-19, and can help others enter the immune state.

Forgetting

After a period of continuous silent thinking or being bystander, the oyster forgets rumors about COVID-19 or ignores rumors about COVID-19 and transforms into the recovery.

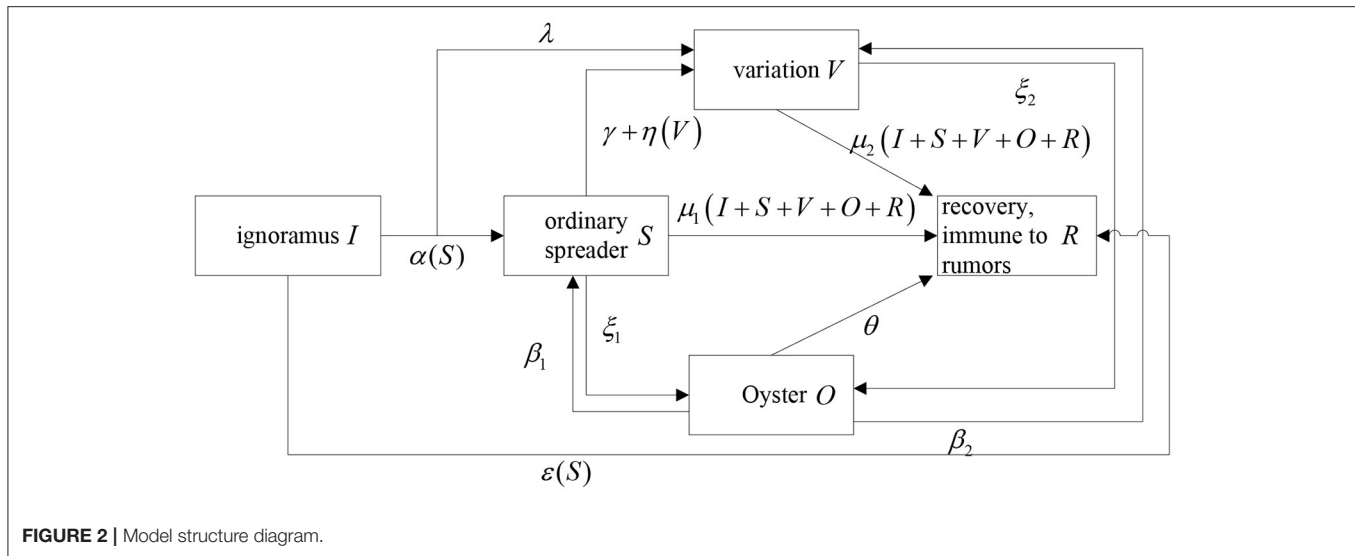
Resuscitation

After a period of continuous silent thinking or being bystander, the oyster re-enters the state of rumors about COVID-19 spreading or transforms into the variation.

Immune

Understanding the truth or refuse to spread the rumors about COVID-19, and owning the ability to help others transform into the recovery.

Assuming there is an evenly mixed social network with N vertices, vertices represent individuals in the society, while the edges represent the connection between two individuals. In this way, an undirected graph can be obtained, which is a set of all



vertices and a set of all edges. The diffusion of rumors about COVID-19 can be abstracted into the model shown in **Figure 2**.

The symbols are explained as follows:

I: ignoramus, in the state of ignorance in the information network, is easily susceptible to rumors about COVID-19; *S*: ordinary spreader, prophase rumors about COVID-19 carrier, believes and diffuses rumors about COVID-19 and can infect the ignorance; *O*: oyster, who do not spread rumors about COVID-19 due to factors such as reflection on rumors; *R*: recovery, immune to rumors about COVID-19, who does not spread rumors about COVID-19 and even spread the truth; *V*: variation, a special spreader, whose content or property mutated from some early versions comparing with ordinary spreader's rumors about COVID-19.

α : the probability of the ignorance infected by rumors about COVID-19 to become the spreader; ε : the probability of ignorance contacted with rumors about COVID-19 to become the recovery; λ : the probability of ignorance to become the variation among those who are infected.

μ_1 : the immunity probability of the spreader that becomes the recovery under the influence of other roles; γ : the probability of the spreader that spontaneously becomes the oyster; ξ_1 : the silent probability of the spreader that becomes the oyster; η : the probability of the spreader coming into contact with the variation and becoming the variation.

μ_2 : the immunity probability of the variation becoming the recovery under the influence of other roles; ξ_2 : the silent probability of the variation that becomes the oyster.

θ : the probability of the oyster to forget the rumors; β_1 : the probability of the oyster that goes back into the spreader; β_2 : the probability of the oyster that goes back into the variation.

The process of rumors about COVID-19 diffusion is as follows.

- When in contact with the spreader, the ignorance with the probability α turns into the spreader. Among them, some is transformed into the variation with the probability λ ;

- When in contact with the spreader, the ignorant is transformed into the recovery with the probability ε ;
- When in contact with other roles like the spreader, variation, oyster, and recovery, the spreader turns into the recovery with the probability μ_1 ;
- When there is no contact with the variation, the spreader turns into the variation with the probability γ ; when in contact with the variation, it turns into the variation with the probability η ;
- When in contact with others, the variation turns into the recovery with the probability μ_2 ;
- The spreader and the variation become the oyster with probability ξ_1 and ξ_2 . The oyster may forget the rumors about COVID-19 or lose interest in it then no longer spread it which becomes the recovery with the probability θ ;
- The oyster will be resuscitated as the spreader and the variation, again, with the probability of β_1 and β_2 .

The model divides all the people in the whole group into five roles. Each role has its own specific probability, which is conducive to make a concrete analysis of the situation after the COVID-19 rumor occurs in emergency circumstances.

STEADY STATE ANALYSIS OF COVID-19 RUMOR PROPAGATION

Mean field theory is to average the applied force exerted by the surrounding environment of objects (29), quantifying the information of a physical model, which is widely used in complex systems and electromagnetics. The mean field theory replaces the effect of the environment on objects with the average effect instead of the individual effects and can average the influence of other nodes in the complex network on itself.

In this model, $I(t)$, $S(t)$, $V(t)$, $O(t)$, and $R(t)$ each represents the density of the ignorance, the spreader, the variation, the oyster, and the recovery in the network at time t . We can get the average field equation of the ISVOR model in the network:

$$\left\{ \begin{array}{l} \frac{dI(t)}{dt} = -\alpha I(t)S(t) - \alpha I(t)V(t) \\ \frac{dS(t)}{dt} = -\mu I(t)S(t)(S(t) + V(t) + O(t) + R(t)) - (\xi I + \gamma)S(t) \\ \quad + \alpha I(t)S(t) + \beta I(t)O(t) - \eta I(t)V(t) \\ \frac{dV(t)}{dt} = -\mu I(t)V(t)(S(t) + V(t) + O(t) + R(t)) - \xi V(t) \\ \quad + \gamma S(t) + \alpha I(t)V(t) + \eta I(t)V(t) + \beta I(t)O(t) \\ \frac{dO(t)}{dt} = -(\beta I + \beta O)O(t) + \xi I(t)S(t) + \xi V(t) \\ \quad - \theta O(t)(S(t) + V(t) + O(t) + R(t)) \\ \frac{dR(t)}{dt} = \theta O(t) + \mu I(t)S(t)(S(t) + V(t) + O(t) + R(t)) \\ \quad + \mu I(t)V(t)(S(t) + V(t) + O(t) + R(t)) \end{array} \right.$$

Setting the left part of the equation to 0, we can formulate the non-negative equilibrium solution $E_1 = (I_1, 0, 0, 0, 1 - I_1)$, $E_2 = (0, S_2, V_2, O_2, 1 - S_2 - V_2 - O_2)$, $E_3 = (I_3, S_3, V_3, O_3, 1 - S_3 - V_3 - O_3 - I_3)$. Among those, for E_1 , when I_1 equals any non-negative real number < 1 , these equations hold obviously.

For E_2 , given that $\left\{ \begin{array}{l} S_2 > 0 \\ V_2 > 0 \\ O_2 > 0 \\ 1 - S_2 - V_2 - O_2 > 0 \end{array} \right.$, we can obtain the equation that $\mu I_1 S_1 + \mu I_2 S_2 + \theta O_2 = 0$, which is not correspond with the fact. Thus, there is no variable for E_2 .

For E_3 , given that $\left\{ \begin{array}{l} I_3 > 0 \\ S_3 > 0 \\ V_3 > 0 \\ O_3 > 0 \\ 1 - S_3 - V_3 - O_3 > 0 \end{array} \right.$, we can obtain the equation that $\alpha I_3 S_3 + -\lambda I_3 V_3 = 0$, which is not correspond with the fact either. Thus, there is no variable for E_3 .

To summarize, there is only one equilibrium solution $E_1 = (I_1, 0, 0, 0, 1 - I_1)$ ($I_1 > 0$).

Referring to Li's mathematical method (30), assuming $E^* = (I^*, S^*, V^*, O^*, R^*)$ is the solution, we can get the following:

$$\left\{ \begin{array}{l} \frac{dY(t)}{dt} = (\alpha I^* S^* + \mu I^* S^*)X(t) + (\mu I^* I^* - \mu I^* k - \xi I^* - \gamma + \alpha I^* - \eta I^* V^*)Y(t) - \\ \quad \eta I^* S^* Z(t) + \beta I^* W(t) + (\mu I^* k + \alpha I^*)X(t)Y(t) - \eta I^* Y(t)Z(t) \\ \frac{dZ(t)}{dt} = (\lambda I^* V^* + \mu I^* S^*)X(t) + (\gamma + \eta I^* V^*)Y(t) + \\ \quad (\mu I^* k - \mu I^* k - \xi I^* + \lambda I^* + \eta I^* S^*)Z(t) + \\ \quad \beta I^* W(t) + (\mu I^* k + \lambda I^*)X(t)Z(t) + \eta I^* Y(t)Z(t) \\ \frac{dW(t)}{dt} = \xi I^* Y(t) + \xi I^* Z(t) - (\beta I^* + \beta I^* + \theta)W(t) \end{array} \right.$$

We substitute the variable, then can get the Jacobian matrix of coefficient.

$$J(E^*) = \begin{pmatrix} \mu I^* k I^* - \mu I^* k - \xi I^* - \gamma + \alpha I^* & 0 & \beta I^* \\ \gamma & \mu I^* k I^* - \mu I^* k - \xi I^* + \lambda I^* & \beta I^* \\ \xi I^* & \xi I^* & \theta I^* - (\beta I^* + \beta I^* + \theta)X(t) \end{pmatrix}$$

Supposing two of the characteristic values $\chi_1 = U_1$, $\chi_2 = U_2$, then $\text{tr}(J(E^*)) = U_1 + U_2 + \theta I^* - (\beta I^* + \beta I^*)$. We can obtain $\chi_3 = \theta I^* - (\beta I^* + \beta I^*)$ and the characteristic equation equals 0.

$$\chi^3 - (U_1 + U_2 + B)\chi^2 + [(U_1 + U_2)B + U_1 U_2]\chi - U_1 U_2 B = 0$$

where $U_1 = \mu I^* k I^* - \mu I^* k - \xi I^* - \gamma + \alpha I^*$, $U_2 = \mu I^* k I^* - \mu I^* k - \xi I^* + \lambda I^*$, $B = \theta I^* - (\beta I^* + \beta I^*)$.

According to stability theory and Hurwitz theorem, if the system is in stable, we can have $\Delta_1 = -(U_1 + U_2 + B) > 0$, $\Delta_2 = -(U_1 + U_2 + B)[(U_1 + U_2)B + U_1 U_2] - U_1 U_2 B > 0$,

$\Delta_3 = -U_1 U_2 B > 0$. Additionally, we can get that $\left\{ \begin{array}{l} U_1 < 0 \\ U_2 > 0 \text{ or} \\ B > 0 \end{array} \right.$

$\left\{ \begin{array}{l} U_1 > 0 \\ U_2 < 0 \end{array} \right.$. Thus, if the system is in stable, I_1 needs to satisfy the $B > 0$

$$\left\{ \begin{array}{l} \frac{\mu I^* k + \xi I^* + \gamma}{\mu I^* k + \alpha I^*} < I_1 < \min\left(\frac{\mu I^* k + \xi I^* + \gamma}{\mu I^* k + \lambda I^*}, \frac{\beta I^* + \beta I^*}{\theta}\right) \quad \left(\frac{\mu I^* k + \xi I^* + \gamma}{\mu I^* k + \alpha I^*} < \frac{\mu I^* k + \xi I^* + \gamma}{\mu I^* k + \lambda I^*}\right) \\ \frac{\mu I^* k + \xi I^* + \gamma}{\mu I^* k + \lambda I^*} < I_1 < \min\left(\frac{\mu I^* k + \xi I^* + \gamma}{\mu I^* k + \alpha I^*}, \frac{\beta I^* + \beta I^*}{\theta}\right) \quad \left(\frac{\mu I^* k + \xi I^* + \gamma}{\mu I^* k + \alpha I^*} > \frac{\mu I^* k + \xi I^* + \gamma}{\mu I^* k + \lambda I^*}\right) \end{array} \right.$$

To sum up, when $\left\{ \begin{array}{l} \frac{\mu I^* k + \xi I^* + \gamma}{\mu I^* k + \alpha I^*} < I_1 < \min\left(\frac{\mu I^* k + \xi I^* + \gamma}{\mu I^* k + \lambda I^*}, \frac{\beta I^* + \beta I^*}{\theta}\right) \quad \left(\frac{\mu I^* k + \xi I^* + \gamma}{\mu I^* k + \alpha I^*} < \frac{\mu I^* k + \xi I^* + \gamma}{\mu I^* k + \lambda I^*}\right) \\ \frac{\mu I^* k + \xi I^* + \gamma}{\mu I^* k + \lambda I^*} < I_1 < \min\left(\frac{\mu I^* k + \xi I^* + \gamma}{\mu I^* k + \alpha I^*}, \frac{\beta I^* + \beta I^*}{\theta}\right) \quad \left(\frac{\mu I^* k + \xi I^* + \gamma}{\mu I^* k + \alpha I^*} > \frac{\mu I^* k + \xi I^* + \gamma}{\mu I^* k + \lambda I^*}\right) \end{array} \right.$, the equilibrium solution $E_1 = (I_1, 0, 0, 0, 1 - I_1)$ exists and there is a global asymptotic stability of the system. Regarding the spreading process of COVID-19 rumors shown in Figure 2, as time increases, eventually all the Ignorance, the Spreader, the Variation, the Oyster, and the Recovery will tend to stop and no longer disseminate any rumors, and, finally, the Ignorance in the system may stabilize at a certain constant value. In real life, for any propagating rumors during COVID-19, once any rumors ferment, it will have a major impact on social harmony and on the stability of lives of people. For government departments, since the beginning of the spread of rumors, they hope to effectively control all the false information and to better prevent it before it happens. In the next part of this article, we will explore the influence of various parameters of the ISVOR model on the propagation of rumors by means of numerical simulation experiments.

SIMULATION EXPERIMENT

In this section, we use the Monte Carlo method to simulate the simulation on the Matlab platform to verify the proposed model. For the real complex network environment in the diffusion of rumors about COVID-19, we choose a WS small world network as the representative of uniform network, BA scale-free network as the representative of non-uniform network, the nodes in the network represents the real individuals, and the edge represents the connection between individuals in the real network. We set the total number of individuals $N = 2000$. For the WS small world network, the probability of random reconnection $p = 0.4$, average degree $\langle k \rangle = 10$; for the BA scale-free network, average degree $\langle k \rangle = 10$ and the power law distribution $P(k) = 2m^2 k^{-3}$ where $m = 5$.

The Changes of Roles During the Diffusion of Rumors About COVID-19

Figure 3 shows the density changes of the ignorant, the spreader, the variation, the oyster, and the recovery under the WS small world and BA scale-free networks with the default parameters. As can be seen from **Figure 3**, during the course, the number of the spreader, the variation, the oyster has experienced rapid growth and then steadily reached the peak after a rapid decline process, the number of the ignorant quickly reduces at the beginning and gradually goes down to zero, the recovery rises rapidly and then stabilizes to the highest value. Due to the character of the individual, the spreader appeared before the variation and the oyster. When the rumors about COVID-19 begins to diffuse, the spreader comes to the stage in large numbers. During the individual-to-individual interaction, the information about COVID-19 rumors that carried starts to change, which led to the emergence and swift increase of the variation. When the spreader reaches the threshold, its number goes into a declining period, and people who propagate the rumor in the network will be composed of the spreader and the variation. Due to the factors such as individual thinking and environment, some of the spreader and the variation will temporarily stop diffusing, and a large number of oysters also arise at the very moment, and will occupy a large proportion.

Comparison Between SIR and ISVOR Models

The classic rumor models, SIR, SEIR (31), Twin-SIR (32), and our ISVOR, are used to analyze the spreading process of rumors about COVID-19. In the model SIR, S is considered as “susceptible” (people who have not been exposed to rumors about COVID-19), I is considered as “infective” (people who are infected with rumors about COVID-19 and can spread), R is considered as “remover” (people who are immune with rumors about COVID-19). In the SIR model, we choose α as the probability that S accepts rumors about COVID-19 and becomes I , and choose μ_1 as the probability that I changes into R . **Figure 4** shows the density changes of the SIR, SEIR, twin-SIR, and ISVOR models in the scale-free network when the total number of nodes is $N = 2000$, $\alpha = 0.5$, $\beta_1 = 0.1$, $\beta_2 = 0.1$, $\lambda = 0.2$, $\eta = 0.5$, $\xi_1 = 0.5$, $\xi_2 = 0.5$, $\gamma = 0.3$, $\theta = 0.25$, $\mu_1 = 0.5$, and $\mu_2 = 0.5$.

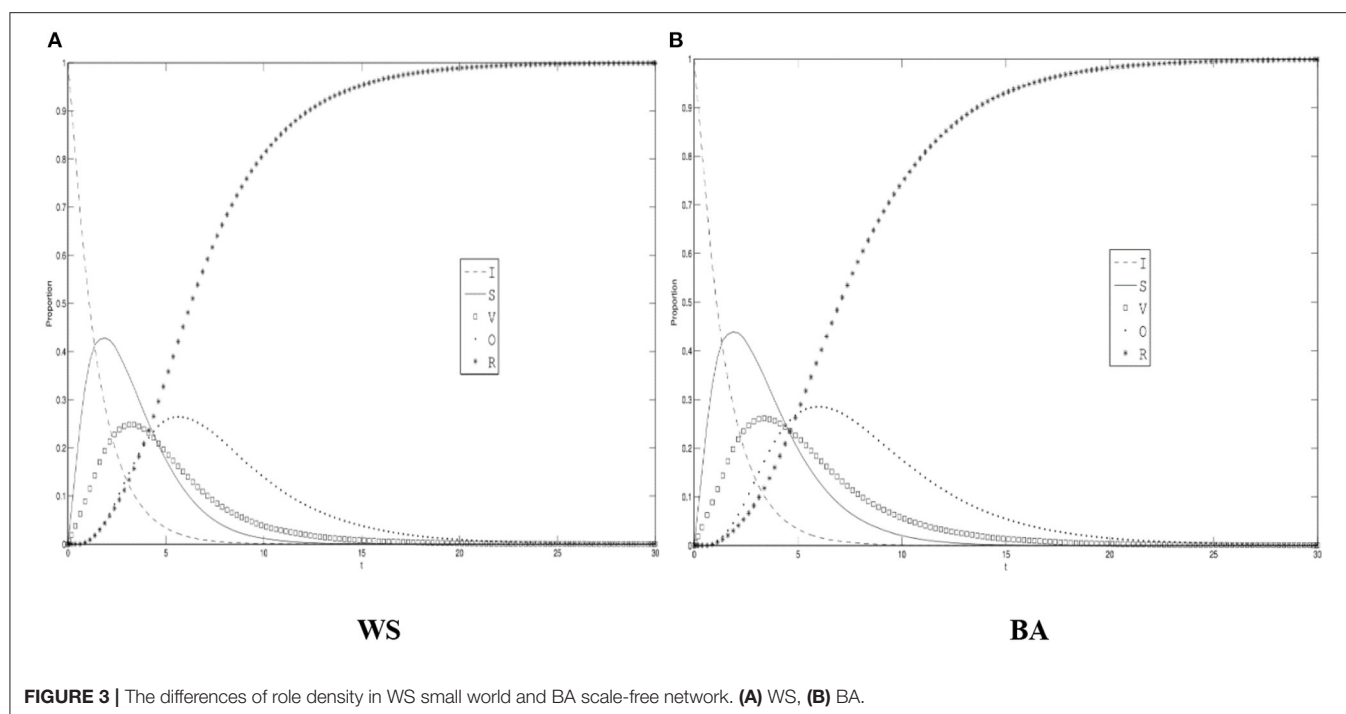
The classical SIR model has only a simple relationship from S to I or I to R . As can be seen in **Figure 4A**, the number of S decreases rapidly, and I continues to increase until it decreases after the peak. During this period, R starts to appear and continues to increase. We use the number of S and V to represent the people who diffuse rumors about COVID-19 in the network.

From the curves of the ISVOR model in **Figure 4B**, the numbers rise faster than in the SIR model, and the peak value is smaller. This is because there is variation in ISVOR. After some of the spreader become the variation which has greater infectivity, thus, accelerating the diffusion of rumors about COVID-19 in the network. At the same time, an “oyster” phenomenon occurs in the group because some people are good at thinking or there

are other factors. Some people who diffuse the rumors about COVID-19 will become buffer silencers and reduce the peak of rumor. The principle of “oyster” and “variation” in ISVOR is more complex and reasonable than the simple straight-line relationship in SIR. It is closer to reality which is more in line with the situation of “incorrectly relay an erroneous information” and “unsuspecting onlookers” in life.

The SEIR model introduces a hesitating mechanism, which takes the attractiveness and fuzziness of rumor into consideration. The Susceptible (S) refers to people who have not been infected with the disease and are, so far, healthy. The Exposed (E) is the population that is in the incubation period of this infectious disease, the Infected (I) is the population that has been diagnosed, and the Removed (R) is the population who has recovered from the rumor. As the rumor spreads from **Figure 4B**, E rises rapidly and will reach the peak firstly, and then, when most of E become infected, the Infected will reach an inflection point of growth. With external treatment and autoimmunity, the number of the E and infected people will decrease while the number of R increased. The Twin-SIR model introduces a new kind of node named “rumor dispeller” with the spreading ability. The rumor dispeller is also in the process of spreading rumor. The S_1 is the spreader, while the S_2 is the rumor dispeller. It can be seen from the **Figure 4C** that S_1 appears when the rumors begin to spread. With the appearance of S_2 , the growth of S_1 is suppressed and the growth rate decreases. The final propagation range, that is, maximum is smaller than SIR and SEIR.

Since ISVOR has a mutation phenomenon, after some of the S became V , which has greater infectivity, thus, accelerating the diffusion of rumors about COVID-19 in the network. At the same time, an “oyster” phenomenon occurs in the group because some people are good at thinking or due to some especial factors. Some people who diffuse the rumors about COVID-19 will become buffer silencers and reduce the peak of rumor. The ignorant people who affected the surrounding infected more nodes and kept rising at a higher rate. After the nodes collide and interact with each other, more and more S turn into V . The V has a more powerful infectious ability and influence effect, prompting other characters to change in the direction of variation, making the communicators start to decline after reaching the peak. At the same time, due to the individual's own immune ability, some nodes will be in a silent state, neither infected nor spreading, and becomes O . After continuous interaction, a part of the S and V enters the silent interval and turns into O with the change of state. The proportion of the O keeps a certain proportion and slowly increases until it peaks. When the truth of the rumors begins to spread, those who are immune will quickly spread across the Internet and quickly affected the transformation of the carriers of the rumors. The principle of “oyster” and “variation” in ISVOR is more complex and reasonable than the simple straight-line relationship in SIR. It is closer to reality which is more in line with the situation of “incorrectly relay an erroneous information” and “unsuspecting onlookers” in life.



The Impact of the Variation's Immune Probability on COVID-19 Rumor Diffusion

Assuming $\max\{S(t) + V(t)\}$ is the maximum value of the density of the diffuser (which is composed of the spreader and the variation) during the propagation process, that is used to express the maximum contagion capacity of COVID-19 rumors diffusion in the network.

Figures 5–7 show the density of the diffuser, the recovery, and the oyster, respectively, in the WS small world network and BA scale-free network when the variation's immune probability μ_2 will be taken as 0.1, 0.3, and 0.5, respectively. It can be seen from Figure 5 that $\max\{S(t) + V(t)\}$ has gone through a process of continuous growth and declining after reaching the peak. Also, it decreases with the increase of the variation's immune probability. When the variation has a lower immunity probability than the spreader, compared with the spreader, more variation is more likely to be in the state of diffusing rumors about COVID-19.

We can also see from Figure 5 that due to the characteristics of the BA scale-free network, the network structure is relatively "fragile" compared to the WS small world. When a hub point with a large degree is infected, it will have a greater infection ability and contagion capacity, so all the rumors about COVID-19 have higher peaks in the scale-free network. And, when μ_2 decreases, it grows more in the scale-free network.

Figure 6 shows that in two network environments, before reaching the threshold, the density of the recovery increases when μ_2 increases. No matter what kind of network it is, the densities of the recovery are the same when they reach the threshold. Therefore, even μ_2 is controlled, the threshold of their stability cannot be lowered, but the density of the recovery during the diffusion of rumors about COVID-19 can still be changed and

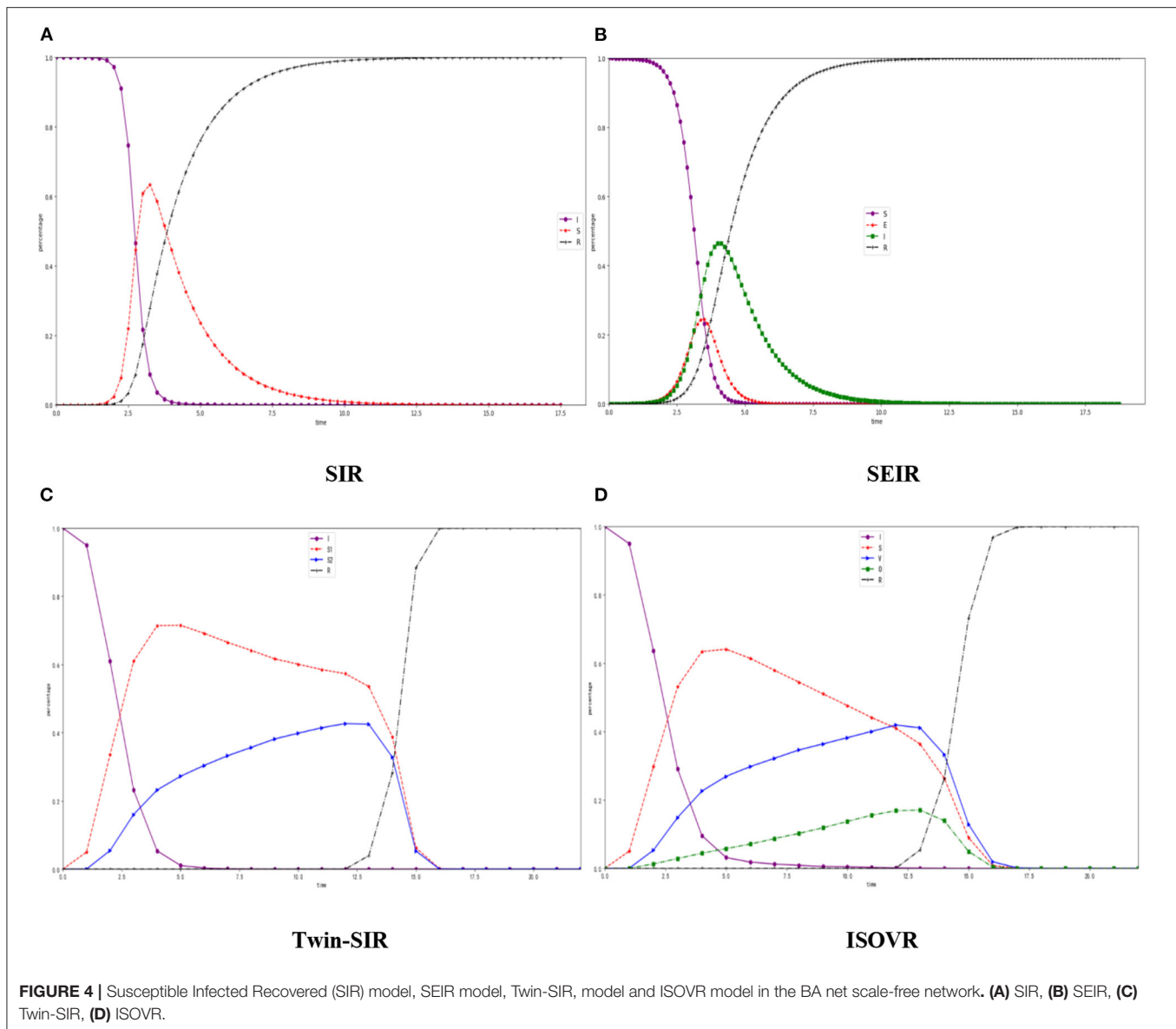
the efficiency of disproving rumors can be improved through corresponding the measures.

It can also be seen from Figure 7 that the increasement of the oyster density in the two networks when μ_2 declines, indicating that when the variation's immune probability decreases, there are more variation in the network. Due to the silent mechanism, there will be more oyster. Therefore, the threshold of the oyster also increases when μ_2 decrease.

Combined with Figures 5–7, in the entire network environment, when the variation's immune probability drops, fewer variation will change into the state of the recovery, the number of those who became the oyster will also increase, and the growth of those who turn into the recovery also increases more slowly and relatively. Because of the influence of the probability of the spreader turning into the variation, the reduction of the variation's immune probability does not significantly promote the diffusion of rumors about COVID-19, but it can observably increase the density of the recovery. For the government, strengthening the popularization of the truth to the variation can effectively promote the increasement of the recovery and of the widespread truth, which is notably conducive to the control the COVID-19 rumor.

The Impact of the Variation's Silent Probability on Rumors About COVID-19 Diffusion

It can be seen from Figure 8 that $\max\{S(t) + V(t)\}$ has experienced the process of continuous growth and falling after reaching the peak. With the increase of the variation's silent probability, $\max\{S(t) + V(t)\}$ declines. Meanwhile the COVID-19 rumor diffuses more slowly, indicating that in the process

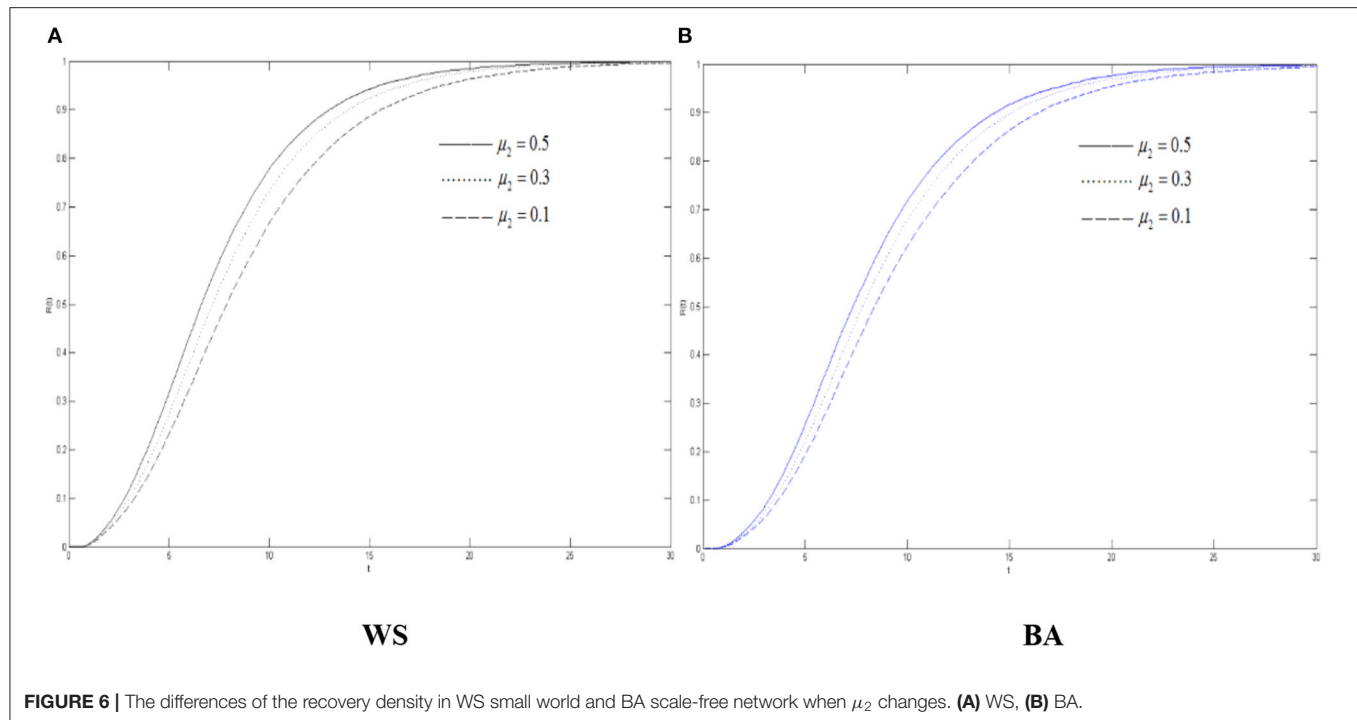
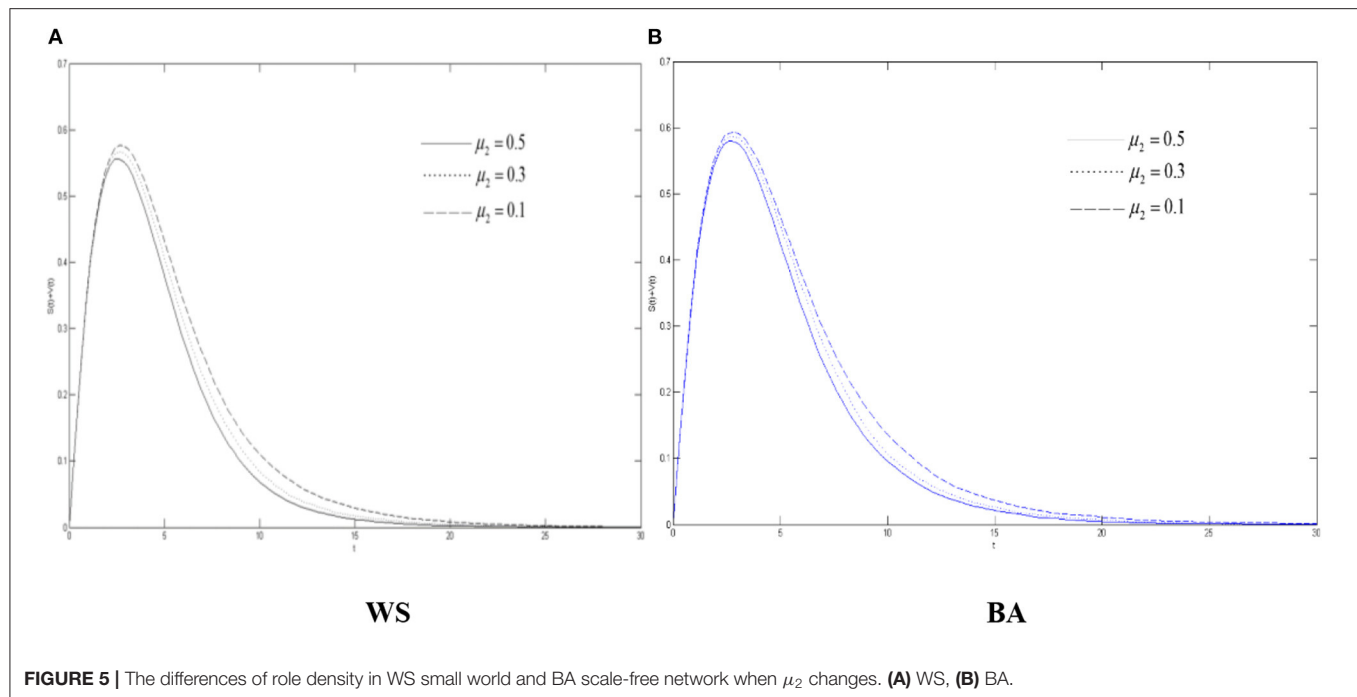


of diffusing the rumors about COVID-19, improving the ability of the community to calmly think about emergencies can well suppress the activation of the variation which could reduce the destructive effect of rumors about COVID-19. As seen from **Figures 4, 7**, compared with the variation's immune probability, the silent probability can increase the range and intensity of rumors about COVID-19 more greatly.

As can be seen from **Figure 9**, the density of the recovery $R(t)$ in the two network environments has gone through a state of increasing and then becoming stable with time. As the variation's silent probability increases, the growth of $R(t)$ becomes slower. Compared with the WS small-world network, it is growing more slowly in the BA scale-free network, which also shows that it is more difficult to refute rumors about COVID-19 in this environment. It can tell from **Figure 9** that in both networks, both densities of the oyster $O(t)$ and of the diffuser $S(t) + V(t)$

have undergone a process of continuous growth and falling after reaching the peak. As ξ_2 increases, the faster $O(t)$ rises, the greater the corresponding peak value will be.

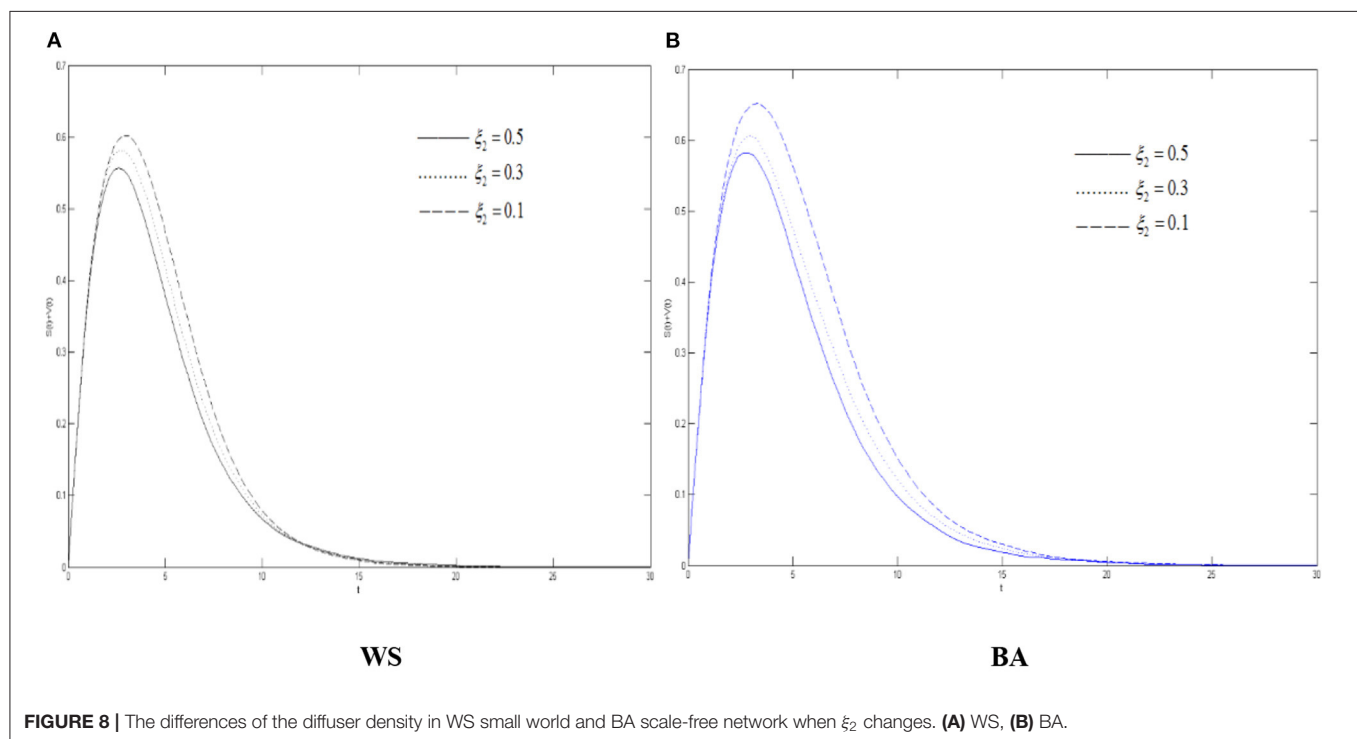
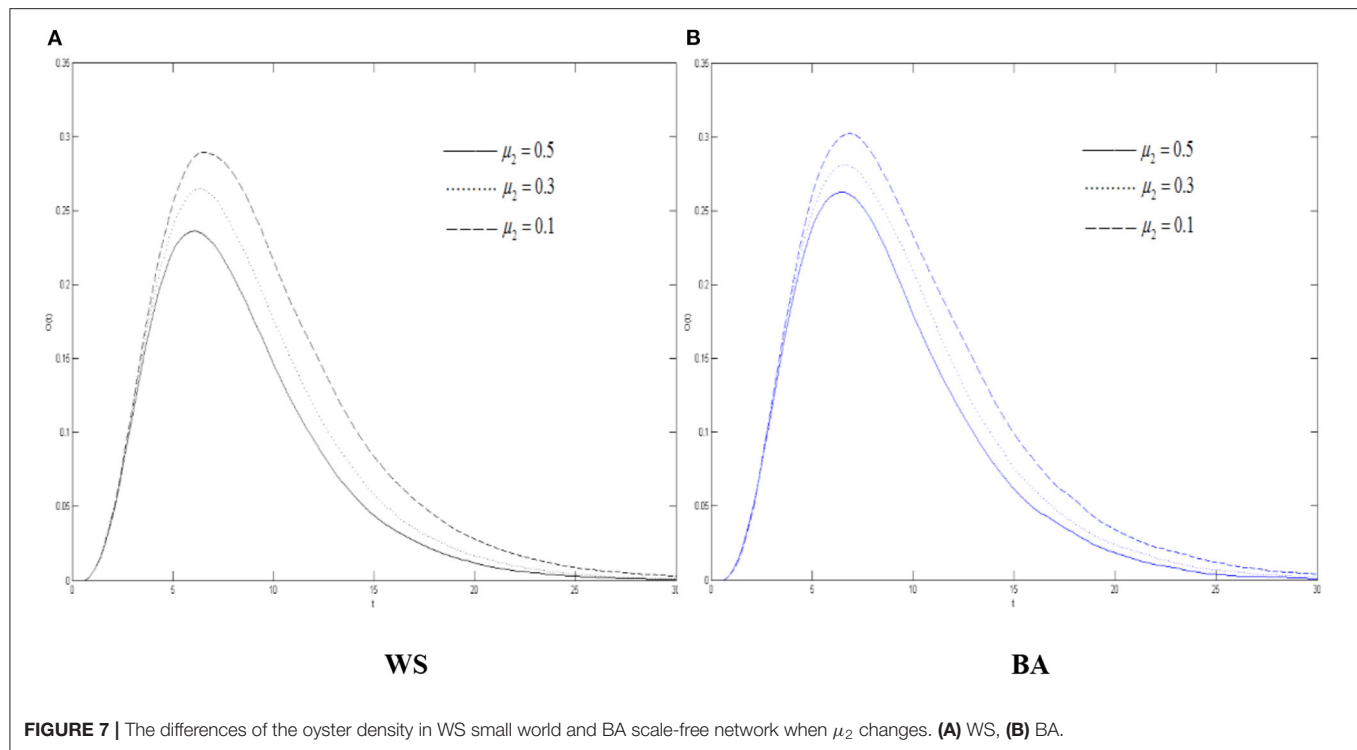
Combining **Figures 8–10**, it can be concluded that as variation's silent probability increases, more variation will become the oyster, and more diffuser in the network will tend to be "silent" and more functional as for the buffering effect of the COVID-19 rumor diffusion, more people in the group will calmly explore the truth of rumors about COVID-19, and there will be more truth carriers, thus, weakening the severity of rumors about COVID-19. For the same reason, the increasement of the silent probability of the spreaders also works to refute the rumors about COVID-19. Compared with **Figures 5–7**, it can be illustrated that if the variation's silent and immune probabilities both changed, the adjustment of the silent probability can control the diffusion of rumors about COVID-19 with a better result.



As far as it is concerned from the conclusion when rumors about COVID-19 occur, people with a higher level of elaborative faculty will be more cautious about facing the unknown public opinion. The government should also improve the education of the relevant knowledge of the crowd and improve their identification ability.

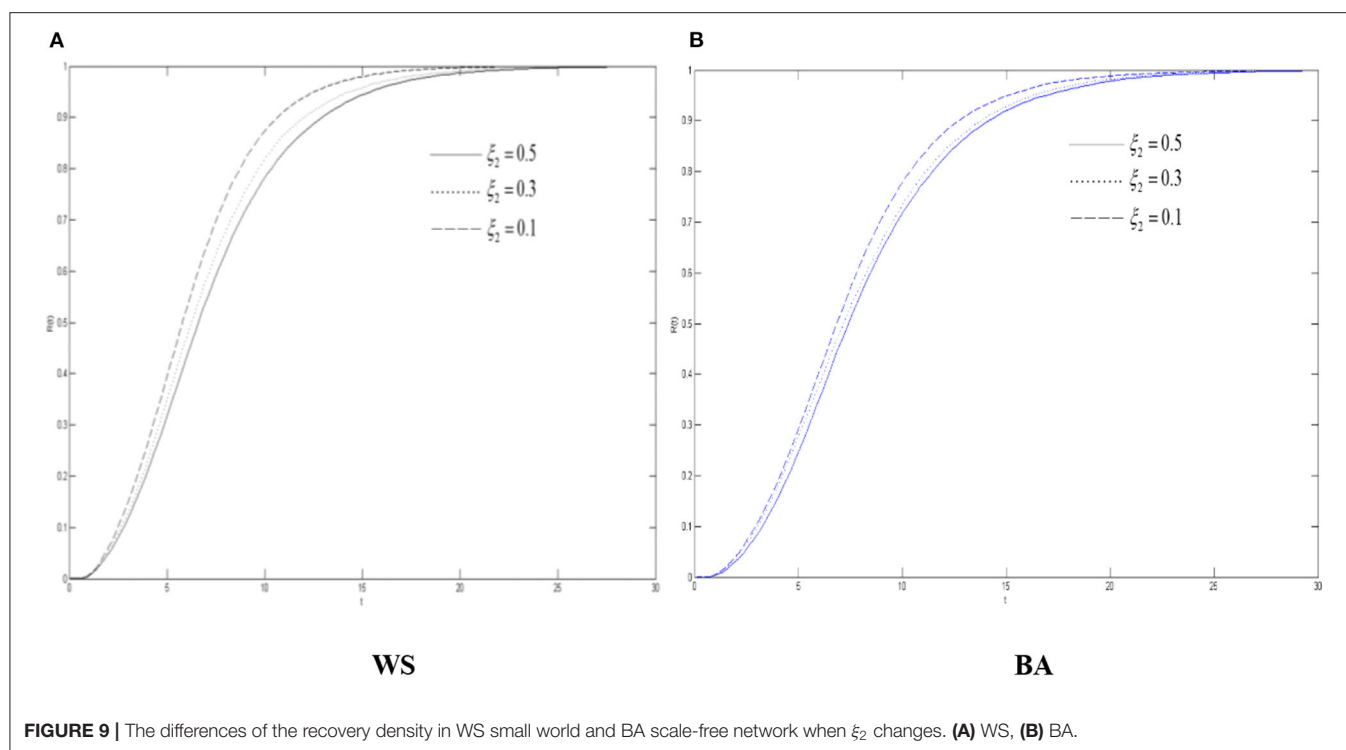
The Impact of the Spreader's Infected Probability on COVID-19 Rumor Diffusion

Figure 11 shows the changes of the density of the variation, the oyster, and the recovery in the BA scale-free network when the spreader's infected probabilities are 0.1, 0.3, and 0.5, respectively. As shown in Figure 11A, when the infected probability increases,



the density of the variation has undergone a rapid increase to the threshold, and then decreased. And, when the infected probability is higher, the density of the variation increases faster, and the peak value that is reached is also larger. It can also be

concluded from the changing curve in the figure that the initial rumors about COVID-19, with great infectivity, can quickly affect the surrounding people when diffusing in the group, making more and more groups infected with rumors about



COVID-19, which leads to a rapid increase of the variation. But, in the middle and late stages of the COVID-19 rumor propagation, the growth of the infected probability from the figure will cause the amount of the variation to fall faster after reaching the threshold, and it cannot keep the variation in a state of a large quantity. Therefore, it can be concluded that if there are more information communicators in the social group, diffusing the information versions and contents tend to be more consistent, which proves that the more sufficient each individual information is, the faster the quantity of people who spread rumors about COVID-19 drops, the less rumors about COVID-19 are likely to diffuse.

From **Figure 11B** when the infected probability increases, the density of the oyster also undergoes a process of swiftly increasing to the threshold, and then decreasing. When the infected probability is higher, the oyster density goes up faster, and the threshold reached is also larger. Combining **Figures 11A,B**, the rise of infected probability will lead to more variation and more oyster. In the middle and late stages of the COVID-19 rumor diffusion, as the quantity of all diffusers increased, the COVID-19 rumor content or version begins to stabilize, and the quantity of variation grows slowly or even decreases, but the number of the oyster did not increase accordingly. With the changes in the scale-free network of density of the recovery in **Figure 11C**, the reduced variation does not become the oyster, and, on the contrary, turn to the state of the recovery. It can be concluded that when the infected probability increases, the thresholds of the variation and the oyster will increase, but with its large quantity, it is difficult to maintain stability. Everyone will have multiple versions of the content at first, but when there is

more information about COVID-19 communicators in the social group, the version or content will quickly tend to be unanimous. The more accurate the information everyone understands, the less likely it is to diffuse rumors about COVID-19.

CONCLUSION

In view of the complex rumors about the COVID-19, we modified the traditional SIR model, and a new rumor propagation model incorporating “variation” and “oyster” is proposed. At the same time, influences of the variation and the oyster in the diffusion of rumors about COVID-19 are demonstrated, and are placed into the WS small world network and the BA scale free network for comparison. The increase of the immune and silence probability of the variation can effectively improve and reduce the density of diffusion of the propagation of truth in the group. A higher infected probability will bring more people who diffuse the rumors about COVID-19, but it will not always maintain a large quantity of the variation. The more information disseminators in the society, the more easily the version and content of the disseminated information tend to be consistent. It can prove that with more adequate information among individuals, the amount of people who diffuse the rumors about COVID-19 drops more quickly, and the chance of diffusing rumors about COVID-19 could be smaller.

First, at the beginning of the rumors about COVID-19, the information must be disclosed in a timely and effective manner. For the government, strengthening the promotion of the truth to the variation and the spreader, rather than blocking the message, can effectively increase the quantity of the recovery and

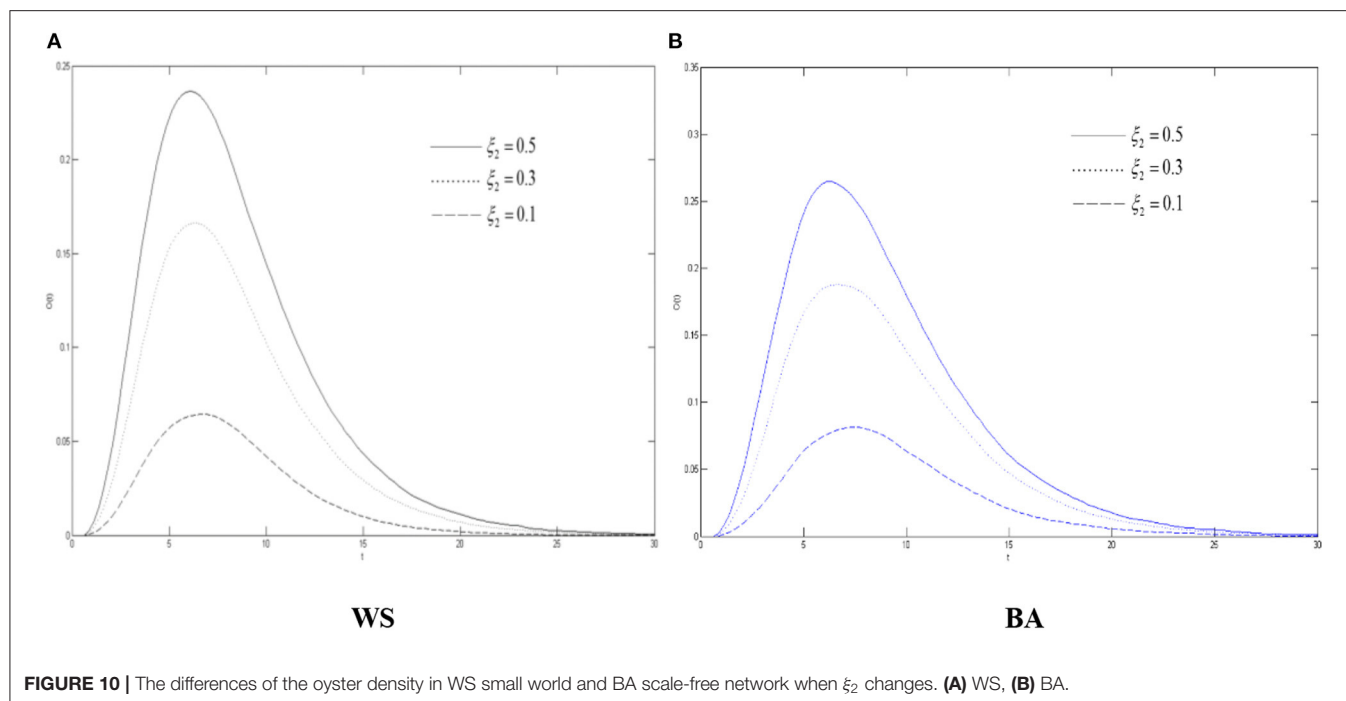


FIGURE 10 | The differences of the oyster density in WS small world and BA scale-free network when ξ_2 changes. **(A)** WS, **(B)** BA.

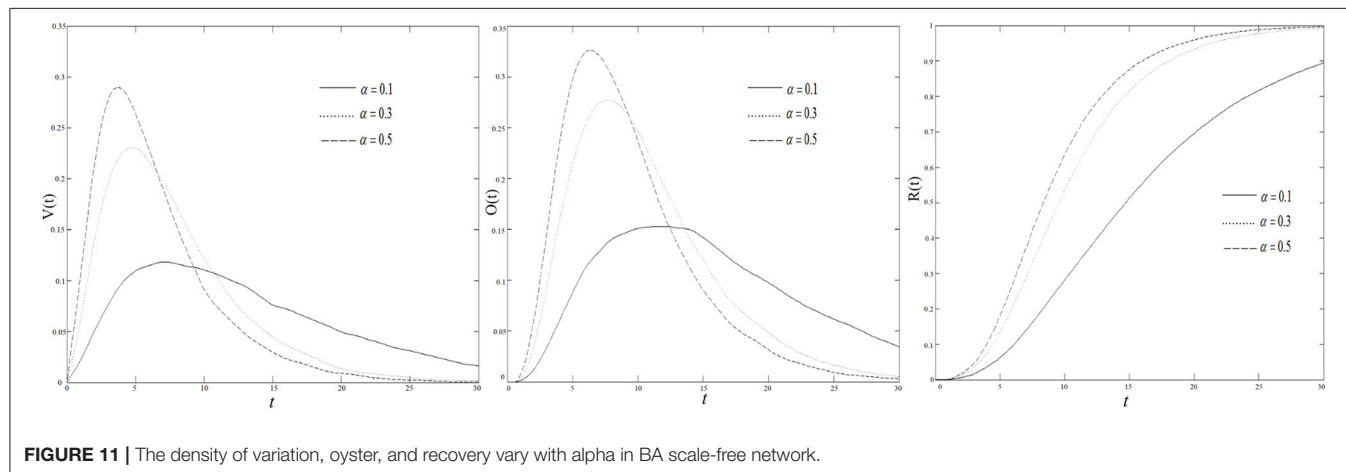


FIGURE 11 | The density of variation, oyster, and recovery vary with alpha in BA scale-free network.

the widespread dissemination of truth, which are significant and conducive to the control of rumors about COVID-19. Secondly, the oysters, which are silent and often possesses good skepticism ability, thus, availably guide the people who are captivated by the rumors about COVID-19, which will play a positive role in shaping the public opinion about COVID-19. Thirdly, compared with non-response, timely and effective interpretation can improve the ability of the group to distinguish rumors about COVID-19. In the meantime, it provides a new model for the related departments to solve the phenomenon of increasingly widespread internet COVID-19 rumors, which has certain practical guiding significance. This study about the individual's own situation is not detailed enough. The next stage will study the interaction between individuals at the micro level in the context of the spread of epidemic rumors. In the future,

the research results can be applied into various fields including personalized recommendation (33–35), anomaly detection (36, 37), sustainable tourism (38, 39), personal health (40), and so on.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

AUTHOR CONTRIBUTIONS

CJ designed the study and conceived the manuscript. FB and CX implemented the simulation experiments. YJ, FB, and BZ drafted the manuscript. CX and BZ were involved in revising the

manuscript. All authors were involved in writing the manuscript and approve of its final version.

FUNDING

This research was funded by Natural Science Foundation of Zhejiang Province (Nos. LQ20G010002 and LY20G010001),

the National Science Foundation of China (No. 71702164), the project of China (Hangzhou) Cross-border E-commerce College (No. 2021KXYJ06), the Philosophy and Social Science Foundation of Zhejiang Province (No. 21NDJC083YB), and Contemporary Business and Trade Research Center of Zhejiang Gongshang University (Nos. XT202103 and XT202105).

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Health Disparities in Pharmacy Practice Within the Community: Let's Brainstorm for Solutions

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OPEN ACCESS

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Reviewed by:

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Specialty section:

This article was submitted to
Life-Course Epidemiology and Social
Inequalities in Health,
a section of the journal
Frontiers in Public Health

Received: 03 January 2022

Accepted: 28 February 2022

Published: 08 April 2022

Citation:

Hurley-Kim K, Unonu J, Wisseh C,
Cadiz C, Knox E, Ozaki AF and Chan A
(2022) Health Disparities in Pharmacy
Practice Within the Community: Let's
Brainstorm for Solutions.
Front. Public Health 10:847696.
doi: 10.3389/fpubh.2022.847696

Health disparity is defined as a type of health difference that is closely linked with social, economic and/or environmental disadvantage. Over the past two decades, major efforts have been undertaken to mitigate health disparities and promote health equity in the United States. Within pharmacy practice, health disparities have also been identified to play a role in influencing pharmacists' practice across various clinical settings. However, well-characterized solutions to address such disparities, particularly within pharmacy practice, are lacking in the literature. Recognizing that a significant amount of work will be necessary to reduce or eliminate health disparities, the University of California, Irvine (UCI) School of Pharmacy and Pharmaceutical Sciences held a webinar in June 2021 to explore pertinent issues related to this topic. During the session, participants were given the opportunity to propose and discuss innovative solutions to overcome health disparities in pharmacy practice. The goal of this perspective article is to distill the essence of the presentations and discussions from this interactive session, and to synthesize ideas for practical solutions that can be translated to practice to address this public health problem.

Keywords: health disparities, vaccinations, pharmacy desert, pharmacy practice, pharmacists, community

INTRODUCTION

Health disparities are defined as preventable differences in health indicators and outcomes that are closely linked with racial/ethnic, social, economic, or environmental disadvantage (1). They manifest as significant discrepancies in the rate of disease prevalence, incidence, morbidity, mortality, or survival of a marginalized population when compared to the health status of the majority population (2). According to the World Health Organization (WHO), "equity is the absence of unfair, avoidable, or remediable differences among groups of people, whether those groups are defined socially, economically, demographically, geographically or by other dimensions of inequality (i.e., sex, gender, race, ethnicity, disability, or sexual orientation)." Thus, health equity would be defined as the absence of unfair and avoidable or remediable differences in health among population groups that have been defined socially, economically, demographically, or geographically (3). As health inequities are rooted in structural inequity and are systematic differences in the health status of different population groups, health equity can only be achieved when policies and practices that maintain the inequitable distribution of social, economic, and environmental determinants of health are removed and/or reimaged through an equity and

justice lens. In short, achieving health equity requires a multifaceted approach to reduce and subsequently eliminate health disparities.

Currently in pharmacy practice, there has been a growing body of literature documenting health disparities and associated social determinants of health (SDOH) common within this discipline (4). Various social determinants have been evaluated as contributing to health disparities in many healthcare settings. Within pharmacy practice, knowledge and perception of health disparities have been identified to play an important role in pharmacists' practice across various clinical settings (5). However, practical solutions to address such disparities are generally lacking in the literature.

On June 4th, 2021, the University of California, Irvine (UCI) School of Pharmacy and Pharmaceutical Sciences hosted a webinar titled "Health Disparities in Pharmacy Practice within the Community." The online event brought together pharmacy leaders from the university who were organizers of the webinar. Through inviting external guests to participate in case studies sharing and discussions, participants were given opportunities to discuss the barriers and potential driving forces behind implementing health services to overcome health disparities in the community. The goal of this article is to distill the essence of the presentations and discussions from this interactive session, and to synthesize ideas for practical solutions that can be translated to practice to address this public health problem.

Case Study 1. Identifying Pharmacy Deserts

According to the United States Department of Agriculture and Centers for Disease Control and Prevention, pharmacy deserts are communities with no pharmacy within a one-mile radius or communities with limited vehicle access and no pharmacy within a half mile radius (6). Analyses of Los Angeles County Service Planning Areas (SPAs) based on the USDA and CDC definitions revealed that 571 of 2,323 census tracts were pharmacy deserts and 1,752 were non-deserts. Further analysis with k-means clustering of SDOH population indicators, identified two distinct types of deserts, type 1 and type 2 (7). In total, there were 238 census tracts that were type 1 pharmacy deserts and 333 census tracts that were type 2 pharmacy deserts.

In comparison to type 2 desert residents, type 1 desert residents live in areas in which their SDOH indicators potentially compound the negative effects of being greater than one mile away from a pharmacy (7). Type 1 pharmacy deserts also contain a denser population, more non-Hispanic Black or Hispanic residents, more renters, more people who speak English as their second language, and more residents who might be experiencing linguistic isolation. Socially, type 1 pharmacy deserts occur in areas with less vehicle ownership, fewer health professionals to serve the community, have more residents who are living under the federal poverty level, more residents who experience crimes against property and people, and fewer residents with health insurance. For example, when compared to SPA 6 (South Los Angeles), SPA 5 (West Los Angeles) had almost 5 times as many pharmacies per 1,000 residents even though the population

per square mile of SPA 6 was 4 times more than SPA 5. This demonstrates an inequitable distribution of the SDOH within the two types of pharmacy deserts, which drives health disparities along racial, ethnic, and socioeconomic dimensions (7).

The inequitable distribution of social determinants of health in the two types of pharmacy deserts can be attributed to structural inequities which historically and at present, influence population migration in Los Angeles County. Market forces also play a role in the formation of pharmacy deserts through closures and competition for market share. There is a need for more comprehensive analyses of the implications and consequences of pharmacy deserts to population and public health. Residents in pharmacy deserts might benefit greatly from equitable, community-based interventions that can increase access to medications, pharmacy services, and pharmacists (7).

Case Study 2. Overcoming Vaccination Disparities

Los Angeles County (LAC) in California is the largest county in the United States by population, and has considerable racial, ethnic, and cultural diversity. LAC also has a relatively high rate of poverty (13.4%) with Black and Latinx residents experiencing significant socioeconomic and health-related disparities (8). During the COVID-19 pandemic, the county experienced a massive wave of disease spread beginning in October 2020 through March 2021, with more than 900,000 cases and 16,000 deaths. Consistent with preexisting health- and non-health-related disparities, the distribution of cases was highly uneven in terms of geography, socioeconomic status and race/ethnicity. Latinx and Black residents of South and Central LAC, as well as the Antelope Valley, neighborhoods with higher rates of poverty, were most heavily affected (9, 10).

From December 2020, when COVID-19 vaccines first became available, through July 2021, more than 6.3 million LAC residents received at least one dose of the vaccine. This represented >71% of those who were eligible to receive the vaccine, including nearly 90% of seniors aged 65 and older. Yet vaccinations in the groups that saw the highest rates of COVID infections lagged behind these averages; only about 56% of Latinx and about 47% of Black residents received any vaccine dose by August 1, 2021. At the time of this webinar, many neighborhoods in South LAC and the Antelope Valley had yet to achieve 60% of residents vaccinated (11).

As in many jurisdictions, pharmacists in LAC remain present along every inch of "the last mile" of vaccine distribution in pharmacies, mass vaccination campaigns, clinics, hospitals, and long-term care facilities. The depth and breadth of pharmacists' contributions make us unique among healthcare providers. Throughout, pharmacists have been involved in public health planning, vaccine communication, acquisition and storage, dose preparation, patient education, vaccine administration, management of side effects, and data reporting to governmental agencies. To help address issues of access, pharmacists have also overseen campaigns such as the mass vaccination site at Los Angeles' Dodger Stadium, where nearly a half-million doses were administered in the first half of 2021, and in community health

centers that serve as a major source of healthcare for underserved residents, including those who are undocumented. However, it is important to note that many neighborhoods and communities of color continue to experience unequal access to sources of vaccines, including pharmacies (7).

Relatively low vaccination rates and disparate access to healthcare in general in the communities hit hardest by COVID-19 highlight the glaring need to allocate additional, culturally sensitive public health efforts and resources for vaccinating in underserved areas. Moreover, research is needed to investigate the levels and causes of vaccine-related disparities, as well as to determine effective means to address them.

Case Study 3. Gaining Trust Among Underserved Patients

A patient touch point is any contact spot between a patient and a provider that can occur in any setting (such as hospital, retail, urgent care, ambulatory care clinic, COVID-19 clinic), and that can impact a patient's overall experience and satisfaction with the health care team.

A study of patient touch points published by Shadrav et al. examined the potential benefits of being in contact with patients for at least seven times out of the 12 months of the year (11). These researchers showed that all seven contacts need not be in person, but can include newsletters, phone calls, check-ins, emails, etc. The touch points were used to provide information to patients and to confirm understanding of the instructions or information provided during previous touch points. Each touch point does not have to be limited to one provider and its content can vary, including using time to share information such as general medication education. A benefit of having multiple touch points conducted by multiple providers is that other providers such as a pharmacist can play a key role in managing care without solely relying on physicians for the all touch points. For example, although a pharmacist may have seen a patient 2 or 3 weeks ago, a phone check-in can be scheduled, even when changes to therapy are not necessary. This provides an additional touch point for a patient who may otherwise not be meeting with their physician for several months, which enables a pharmacist to address various issues proactively and creates an opportunity to communicate with the physician provider when needed, and assist in adjusting an action plan prior to the next visit.

The more touch points a patient can have with the healthcare team, the more likely the patient will remain loyal to the care plan, which in turn can improve treatment adherence as well as increase patient engagement in their own health care. A more engaged patient may be more attentive during sessions with the pharmacist and thereby lead to a better understanding of discussion points during counseling. Improving the education of the patient has been linked to increased patient satisfaction which is positively associated with treatment adherence (12). When a patient is engaged, the interaction consists of more than discussing standard information, but also encompasses further assessment of the patient's situation, especially with regard to various SDOH such as financial issues or complex family issues that can hinder health management, which is particularly

important for underserved populations. In short, increasing meaningful touch points through the use of pharmacists can be seen as a potential longitudinal approach to building trust among patients, increasing patient engagement, and better creating shared care plans to address patients' specific needs.

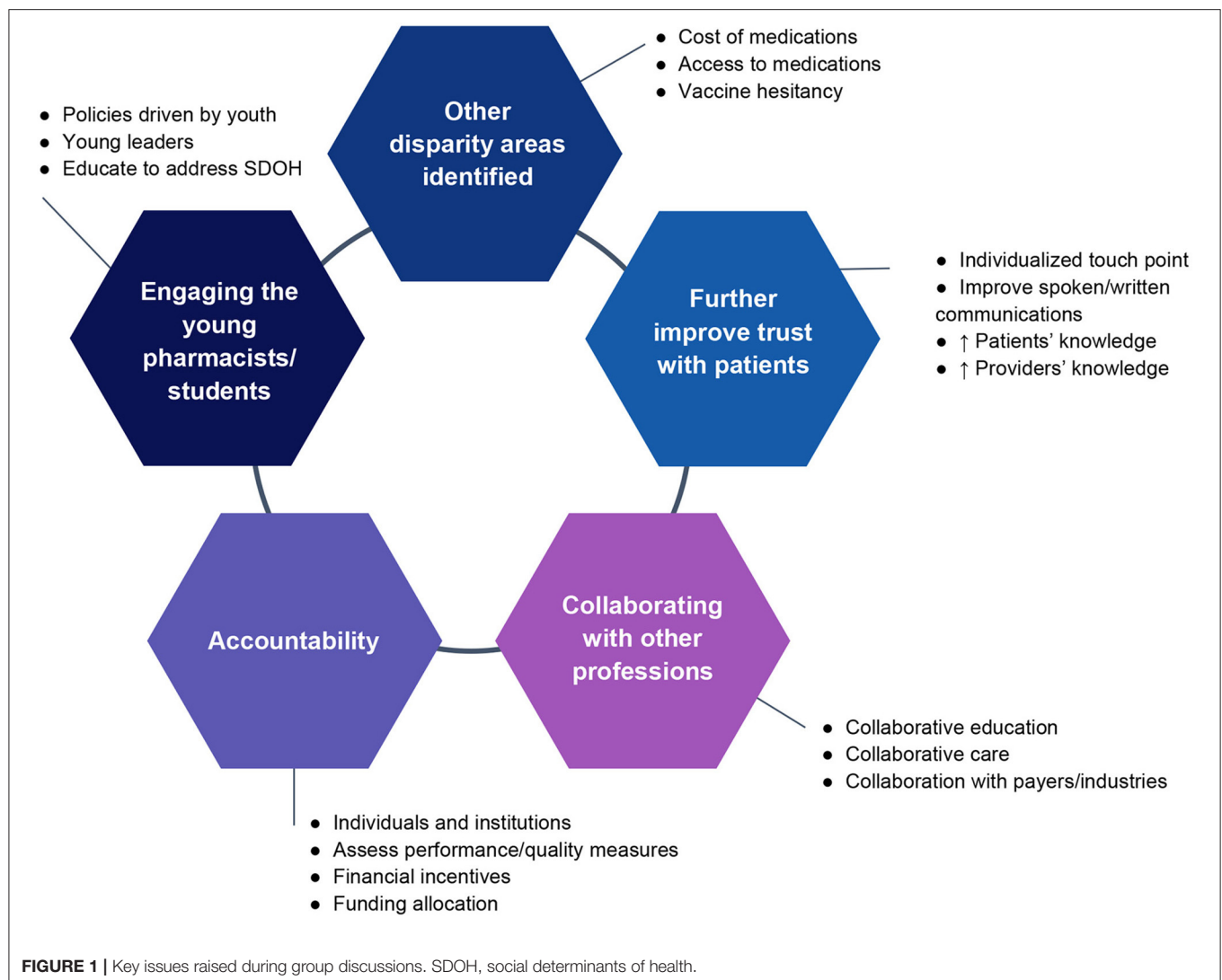
DISCUSSION OF PERTINENT ISSUES

Following the sharing of these case studies during the webinar, five pertinent issues (**Figure 1**) surfaced from participant group discussions which were related to the case studies but were not specifically discussed by the speakers, as well as new issues that were introduced by the participants.

Issue #1. Other Areas of Disparity Were Identified

The cost of medications may affect patients' selection of treatment options. Even when evidence clearly demonstrates superior clinical outcomes with certain medications, patients may inevitably choose cheaper options due to cost considerations or forgo the medication all together. Additionally, patients may compare their medication regimen with those of other patients, thus influencing their decisions about their own treatments. Other disparities can affect access to medications (e.g., access to care, lack of pharmacies in the neighborhood, poor health insurance coverage, language barriers when interpreter services are not available). Given that pharmacists are providers with a wealth of knowledge, bringing pharmaceutical care services including special follow-up or extra touch points to patients with inadequate access services may help address these aforementioned challenges. Vaccine hesitancy is a concerning example of how some of these existing disparities can amplify disparities in COVID-19 vaccine uptake. A practical step to addressing this challenge is to recognize that the onus and the burden of vaccine decision-making and uptake should not be placed solely on the patient who may have low confidence in the vaccines. It is important to understand the historical and socio-cultural context of such concerns, and be aware of vaccine hesitancy among racially, ethnically, and socioeconomically diverse populations. Providers should anticipate, acknowledge, and proactively address these concerns while building trust with the patient.

Medication out-of-pocket costs may also be a significant barrier for socioeconomically disadvantaged patients. By partnering with pharmaceutical companies, pharmacists are positioned to provide information on sponsored patient assistance programs (PAPs). Pharmaceutical Research and Manufacturers of America (PhRMA) can also partner with pharmacists to provide patient outreach and marketing on the medicine assistance tool. Such tools extend personalized resources for patients to obtain specific medications, often employing PAPs, ultimately improving patient access while enabling PhRMA to meet goals set forth in the organization's commitment to equity (13). Though some concerns exist about utilization of PAPs leading to increased high-cost medication use in order to lower out-of-pocket costs to patients (14), one



study has demonstrated that PAPs may have limited impact on prescription drug utilization (15).

Issue #2. How to Further Improve Trust With Patients

Although multiple touch points are necessary to develop a trusting relationship with patients, the means and frequency should be individualized. Sending emails or newsletters, rather than calling or visiting, might be preferable, for example when providing information regarding medications or adverse drug reactions. However, it is important to note that these communications may not be applicable to patients with poor health literacy and/or language barriers. Other strategies to improve spoken and written communications such as using tools for follow-up patients and creating educational materials are recommended by several health agencies including the Agency for Healthcare Research and Quality (16). The timing of reaching out to patients also should be tailored to individual patients. Instead of providing a large amount of information

at once, providing multiple follow-ups based on their need is critical for forming trust. Trust may affect patient behavior or decision-making especially when the situations involve stigmatized conditions or chronic disease states that require complex coordination of management. For example, patients may not trust a government-run mass vaccination clinic vs. clinics or providers with whom they have a previously established a relationship with. It requires time and effort to develop a trusting relationship with patients. Furthermore, there may be a lack of patient knowledge about the roles that pharmacists can play, which leads to the underutilization of these providers. Information on the types of services that pharmacists can provide could increase awareness of their scope of practice and should be widely disseminated to underserved communities. In some situations, it is apparent that pharmacists and other health care professionals had a poor understanding of patient care preferences, particularly for those with different ethnic or racial backgrounds or with different levels of education from their own (17, 18). Within discussions, it was observed that racial

and ethnic minority groups often lack trust in the healthcare system, stemming from patients' past experiences, especially given a long history of poor care and disregarded needs among minority individuals.

Issue #3. Collaborating With Other Professions to Create Solutions

Within the context of a discussion on structural competency, it is important to recognize how social, political, and religious factors in underserved and underrepresented populations impact health (19). One primary issue (and avenue for change) identified was education. Health educators are in a unique position to teach the next generation of health care providers, including pharmacists, beyond what is typically taught in the traditional curriculum. Although pharmacists can play an important role in reducing health disparities, they have historically done so primarily by collaborating with nurses, physicians, and other health care providers. While pharmacists should continue to advocate for collaboration (starting in the educational setting), they should also explore opportunities to expand partnerships by working with social science colleagues and other non-health sector professionals such as anthropologists, policymakers, and lawmakers. These different sector professionals can bring valuable nontraditional perspectives and distinct areas of expertise to help reduce and eliminate health disparities.

Issue #4. Accountability—How to Successfully Carry Out Proposed Solutions

In order to effectively reduce health disparities, it is important to ensure that individuals and institutions are held accountable for implementing certain changes, or most efforts will fall short. As such, financial incentives and consequences related to reimbursement or accreditation may represent potential means to building accountability. Utilization of metrics including the Healthcare Effectiveness Data and Information Set (HEDIS) or the Health Equity Summary Score (HESS) is useful as performance and quality measures (20, 21). Along this line, funding allocation is another important way to assure that changes are carried out where gaps exist. For example, while mass COVID-19 vaccination clinics did serve a certain percentage of minority groups, this was clearly insufficient. Those who are responsible for mass vaccination clinics should ensure that there is equitable vaccine distribution by prioritizing and implementing more resource-intensive services in areas known to have gaps and low vaccine access and uptake (e.g., in poverty-stricken neighborhoods and rural regions with limited access to health services). Moving forward, funding allocation decisions should be structured so that those who come from underrepresented groups provide input and have a stake in funding streams.

Issue #5. Importance of Engaging Young Pharmacists

Historically, many social movements related to racial inequities have been led by youth and young adults. For example,

much of the drive toward change to anti-racist policies in academic medicine have been driven by medical students and residents. In future efforts to create change, it will be vital to involve more members of groups early in their career trajectories. For decades, the National Pharmaceutical Association and several organizations that include serving marginalized populations as part of their mission have already done work in this area. There is an opportunity to engage young leaders in creating new initiatives and working with faculty and pharmacist champions within professional organizations that conduct outreach in the community. As part of updated standards, the Accreditation Council for Pharmacy Education (ACPE 2016) has emphasized the need for student pharmacists to recognize addressing SDOH as a way to decrease disparities and inequities in quality healthcare (22). In addition, a 2021 ACPE guidance document endorses educational content on health disparities in communities and how pharmacists can serve marginalized populations (23). A curriculum that supports these efforts can foster excitement and enthusiasm in student pharmacists. By applying these educational goals and directives to organizations that train and work with student pharmacists, change could be achieved, harnessing the voice, energy and passion of these young professionals.

IMPLICATIONS FOR PRACTICE

Our efforts mark the first steps in the search for solutions to reduce and eliminate health disparities in pharmacy practice. While addressing these gaps in care will not occur overnight, the pharmacy profession can begin by prioritizing several actions:

- 1) Increase and expand collaborative efforts with health and non-health professionals: The pharmacy profession needs to promote multidisciplinary care by expanding team care models to include more pharmacist-led comprehensive medication management programs within health systems and primary care settings including in federally qualified health centers and outpatient settings where pharmacists are integrated into patient-centered medical homes. To foster this type of integrated team care, continued advocacy for provider recognition and policy change in pharmacists' scope of work will be needed. For example, while strategic changes in scope of practice gains for the advanced practice pharmacist designation in several states in the United States have adopted, similar actions are still required in more states to assure that this designation can become relatively uniform nationally and benefit the quality of care for all patients. Additionally, collaboration with non-traditional partners from outside the health care team should be prioritized. The unique perspectives of these professionals, such as social science researchers, public health professionals, policy makers, and lawmakers, can offer important insights and nuanced innovations to address health disparities in pharmacy practice.

- 2) Identify resources and implement practical solutions: There is a need to identify resources to support this movement, and hold pharmacists accountable for implementing some of the more feasible solutions identified. A specific and timely example may be expansion of programs that support COVID-19 related services in independent community pharmacies. These pharmacies often serve low-income neighborhoods that are under-vaccinated, have less access to testing, and have greater health literacy needs despite initiatives to address them from corporate pharmacies and other healthcare entities. With support from governmental incentive programs, many of these pharmacies can spearhead vaccinations, testing, and patient education in these underserved areas.
- 3) Educate the next generation of pharmacists, harnessing the voice, energy, and passion of young professionals: The profession should commit to improving the education for the next generation of pharmacists, especially on the importance of mitigating and eliminating health disparities. There is an opportunity to expand and innovate education beyond didactic instruction and to incorporate student pharmacists in this process and in community endeavors that are designed to reduce health disparities.

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CONCLUSION

Emerging focus areas were identified within pharmacy practice where pharmacists can play a major role to reduce and eliminate health disparities. The issues raised such as access to pharmacies, disparities in vaccination rates, and patient trust in providers have global implications in pharmacy practice. Research studies should be conducted to address these concerns, and ultimately building an evidence base to establish on how pharmacists can play a vital role to help reduce or eliminate structural inequality in healthcare.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author/s.

AUTHOR CONTRIBUTIONS

KH-K, JU, CW, CC, EK, AFO, and AC interpreted the webinar details and drafted the commentary. All authors read and approved the final manuscript.

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Analyzing Relationships Between Economic and Neighborhood-Related Social Determinants of Health and Intensive Care Unit Length of Stay for Critically Ill Children With Medical Complexity Presenting With Severe Sepsis

OPEN ACCESS

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Specialty section:

This article was submitted to
Life-Course Epidemiology and Social
Inequalities in Health,
a section of the journal
Frontiers in Public Health

Received: 05 October 2021

Accepted: 09 March 2022

Published: 29 April 2022

Citation:

Hamilton H, West AN, Ammar N,
Chinthala L, Gunturkun F, Jones T,
Shaban-Nejad A and Shah SH (2022)
Analyzing Relationships
Between Economic and
Neighborhood-Related Social
Determinants of Health and Intensive
Care Unit Length of Stay for Critically
Ill Children With Medical Complexity
Presenting With Severe Sepsis.
Front. Public Health 10:789999.
doi: 10.3389/fpubh.2022.789999

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Objectives: Of the Social Determinants of Health (SDoH), we evaluated socioeconomic and neighborhood-related factors which may affect children with medical complexity (CMC) admitted to a Pediatric Intensive Care Unit (PICU) in Shelby County, Tennessee with severe sepsis and their association with PICU length of stay (LOS). We hypothesized that census tract-level socioeconomic and neighborhood factors were associated with prolonged PICU LOS in CMC admitted with severe sepsis in the underserved community.

Methods: This single-center retrospective observational study included CMC living in Shelby County, Tennessee admitted to the ICU with severe sepsis over an 18-month period. Severe sepsis CMC patients were identified using an existing algorithm incorporated into the electronic medical record at a freestanding children's hospital. SDoH information was collected and analyzed using patient records and publicly available census-tract level data, with ICU length of stay as the primary outcome.

Results: 83 encounters representing 73 patients were included in the analysis. The median PICU LOS was 9.04 days (IQR 3.99–20.35). The population was 53% male with a median age of 4.1 years (IQR 1.96–12.02). There were 57 Black/African American patients (68.7%) and 85.5% had public insurance. Based on census tract-level data, about half (49.4%) of the CMC severe sepsis population lived in census tracts classified as suffering from high social vulnerability. There were no statistically significant relationships between any socioeconomic and neighborhood level factors and PICU LOS.

Conclusion: Pediatric CMC severe sepsis patients admitted to the PICU do not have prolonged lengths of ICU stay related to socioeconomic and neighborhood-level SDoH at our center. A larger sample with the use of individual-level screening would need to be evaluated for associations between social determinants of health and PICU outcomes of these patients.

Keywords: health disparities, social determinants of health, children with medical complexity, severe sepsis, pediatric intensive care unit

INTRODUCTION

Children with medical complexity (CMC) are frequently described as having multiple chronic conditions, resulting in functional limitations, ongoing use of medical technology, and high resource utilization (1–3) and account for 0.4% of children in the United States (1). In addition to chronic comorbidities, CMC are disproportionately affected by acute critical illness, including severe sepsis (4). Severe sepsis can lead to increased pediatric hospitalizations (5–7), possibly further affecting this population. CMC have more admissions and greater morbidity and mortality when compared with previously healthy children (4, 8–10). Social determinants of health (SDoH) related to socioeconomic status (poverty level, household income) and neighborhood environment, including housing instability (especially household crowding), neighborhood quality, and access to food, transportation, and healthcare (11), may lead to unmet needs at home. If these SDoH are superimposed onto acute-on-chronic illness of hospitalized patients (1, 12–14), prolonged pediatric intensive care unit (PICU) care may be a result.

In the metropolitan Memphis, Tennessee and surrounding Shelby County areas, 25.3% of families live beneath the poverty line, which is twice the percentage for the state of Tennessee and 2.5 times that of the United States in general (15, 16). Due to the high percentage of poverty in these areas, we suspect that there are negative impacts on our patients from SDoH related to the economic instability and negative neighborhood attributes, which can impact healthcare delivery and overall patient outcomes. Evidence of neighborhood variation effects on negative health outcomes is consistent across the literature, despite heterogeneity of study designs, definitions, and locations (17). Health outcomes can occur on an income gradient and housing instability is associated with postponed medical care and missed medications (18, 19). Further, housing instability, food insecurity, and home health access are associated with delays in hospital discharge amongst CMC (19, 20). Infant bacterial infections and sepsis-related mortality are associated with health disparities and decreased socioeconomic and neighborhood quality (21–27).

We suspect that of all SDoH, high economic burden and neighborhood environment characteristics such as decreased housing quality, access to healthcare, food, and transportation could be key drivers of outcomes in our CMC patient population (28). As prolonged PICU length of stay (LOS) is associated with severity of illness in CMC, our study aimed to evaluate

the effect of socioeconomically and neighborhood-driven factors on PICU LOS in CMC within the underserved community of Shelby County, Tennessee admitted to the pediatric critical care complex with severe sepsis. The secondary aim was to describe the CMC population admitted with severe sepsis. The central hypothesis of this study was that census tract-level socioeconomic and neighborhood SDoH are associated with longer PICU length of stay for CMC admitted with severe sepsis.

METHODS

Study Design and Ethics

This retrospective single-center observational study was reviewed and approved by the Institutional Review Board at the University of Tennessee Health Science Center in Memphis, Tennessee.

Patient Selection

For this study, patients aged 12 months up to 18 years with clinically relevant severe sepsis (severe sepsis identified using quantifiable data based on best evidence) were identified using a severe sepsis algorithm (29) incorporated into an existing electronic medical record (EMR), Cerner® Powerchart (Cerner Corporation, North Kansas City, Missouri). This alert mechanism continuously screens EMR-based physiologic data and laboratory results, and when previously defined criteria are met for SIRS and acute organ dysfunction (30), an electronic alert was generated and sent to a critical care smartphone with information regarding the alert characteristics. The patient's bedside nurse was also alerted, prompting an assessment by the primary team and a member of the PICU staff followed by recommendations for ongoing care or new therapies. The algorithm used in our hospital has been validated with a sensitivity of 90% and specificity of 96% (31, 32).

All hospital-wide severe sepsis alerts triggered between January 2019 through June 2020 were reviewed by a critical care clinician (HH) and two critical care nursing data analysts. Patients were determined to have clinically relevant severe sepsis based on clinical criteria (30, 33) and documented infection at the time of or within 24 h of the timestamped alert. Those meeting criteria for severe sepsis were further screened for PICU admission associated with the positive severe sepsis alert. The records of patients with PICU admissions were then examined for inclusion of patients with medical complexity and exclusion of those not defined as CMC and/or not admitted to PICU.

A study-specific definition for CMC was created and included patients with at least 2 of the following: a documented chronic

disease or syndrome associated with functional limitations (for example cerebral palsy, chromosomal abnormalities, bronchopulmonary dysplasia/chronic lung disease, complex congenital heart disease), reliance on medical equipment or technology (such as gastrostomy tube, tracheostomy, home oxygen or ventilator, chronic central venous access for TPN or infusions), and/or high healthcare utilization. High utilization was defined as multiple visits to 2 or more pediatric subspecialty clinics in the 6 months prior to admission.

From this cohort, patients residing in Shelby County, Tennessee were selected for analysis based on available census tract data. Those with incomplete records were excluded from the analysis. Patients younger than 12 months were also excluded from the cohort as the electronic severe sepsis screening algorithm has not been validated for this age group. In the event of multiple admissions involving the same patient, each admission represented by a unique financial identification number (FIN) was treated as a separate encounter.

Data Sources

We collected patient-level demographic data including medical history/diagnoses, age at PICU admission, sex, race, primary address, and insurance status directly from patient records. Our severe sepsis algorithm bins patients into the following age risk categories at the time of alert- 1–5, 6–12, and 13–18 years of age (29, 33). Race categories were White, Black/African American, and Other. The “Other” category included Latin/Hispanic, Asian, and Native American. Insurance categories were public and private. Public insurance is defined here as Medicaid or similar programs. Private insurance is defined here as commercial or military insurance. We also collected information regarding LOS, the source of sepsis, and the organ dysfunction associated with the episode of severe sepsis.

Next, we mapped the addresses of the 73 unique patients into 54 unique census tracts within Shelby County, Tennessee. Data for social vulnerability, environmental health hazards, and lead exposure risk for Memphis and Shelby County, Tennessee was obtained and visualized using PolicyMap® (34–36). Overall social vulnerability index (SVI), designed for disaster and disease outbreaks and indicates the negative impact of external factors on community health typically under hazardous conditions, was used as a major indicator of economic stability and neighborhood and built environment (37, 38). Each census tract is assigned an overall vulnerability level based on four categories: socioeconomic status, household composition, race/ethnicity/language, and housing and transportation. The SVI scale ranges from 0–1, with 1 representing the highest neighborhood-level social vulnerability. SVI was pre-classified into quartiles by the CDC as extremely low, low, moderate, and high categories.

Data pertaining to several variables reflecting neighborhood-level exposures were also analyzed. The Environmental Health Hazard Index (EHHI) from the US Department of Housing and Urban Development summarizes the potential for exposure to harmful toxins at a neighborhood level (35, 39). EHHI values range from 1 to 100 representing a percentile rank nationally, and higher values are representative of lower exposure risk and

therefore better environmental quality of the neighborhood. As a surrogate of neighborhood quality, which includes increased pollutant exposure, neighborhood-level risk of lead exposure was evaluated using data from the Washington State Department of Health (40, 41). Lead exposure risk has been calculated based on the average age of buildings in a neighborhood and income-to-poverty ratio and we categorized neighborhoods as having low (bottom third), moderate (middle third), or high (top third) risk of lead exposure with 1 representing the lowest lead exposure and 10 the highest.

SDoH data corresponding to socioeconomic status (estimated median family income and percent of population below the poverty line) and household composition (percent of households headed by a single female with children) were obtained from the most recent US Census American Community Survey, 5-year estimate (42). Food access variables (distance to a farmers’ market and percentage of housing units without a vehicle and located beyond 0.5 miles from a supermarket) were obtained from the US Department of Agriculture’s food access research atlas (43). Neighborhood-level data pertaining to transportation (estimated percentage of housing units without a vehicle) and healthcare access (distance to the nearest hospital) were gathered from the University of Memphis Center for Applied Earth Science and Engineering Research (CAESER) (44).

Outcome Measures

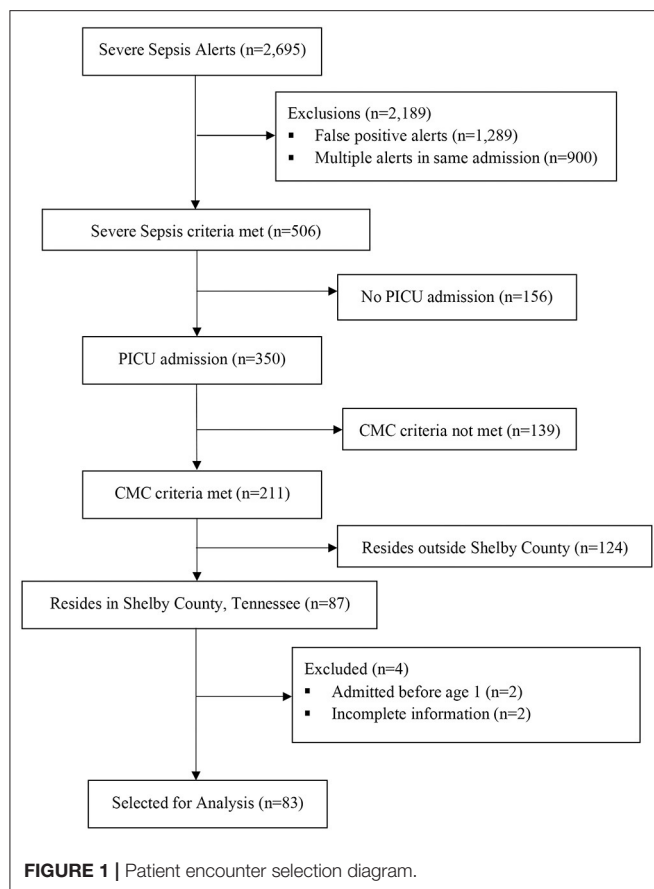
PICU LOS was identified as the primary outcome measure given that (1) high intensity therapies for this patient population occurs in the PICU and (2) our hospital discharges technology-dependent patients such as CMC directly from the PICU to home, capturing the duration of hospital stay.

Statistical Analysis

Categorical data were summarized using frequency and percentages. The primary outcome PICU LOS was defined as the date from admission to date of discharge (or date of death). Patients who were not discharged, such as those who died in the PICU, were censored (45). To account for multiple encounters and time to event analysis, mixed effects Cox regression models were used to determine association or impact of each risk factor on PICU LOS for the bivariate analyses. For the multivariable mixed effects Cox regression model, a backward model selection approach was used to retain variables with a p -value < 0.05 . A hazard ratio (HR) < 1 indicates the risk of discharge is low or longer PICU LOS. All survival analyses were implemented using the statistical software R Studio. A p -value < 0.05 was considered statistically significant.

RESULTS

Severe sepsis encounters are illustrated in **Figure 1**. Between January 1, 2019, and June 31, 2020, there were 2,695 severe sepsis alerts triggered in our hospital, 1,406 of which were determined to be true positives based on the predefined criteria. After reviewing each alert, 83 encounters representing 73 patients met inclusion criteria for the study.



CMC Patient Demographics and Severe Sepsis Characteristics

Patient demographics can be viewed in **Table 1**. The median age of patients in the study was 4.1 years (IQR 1.96–12.02). There was a slight male predominance in the group (53 vs. 47%), and the racial diversity closely approximated that of Shelby County, Tennessee (68.7% Black, 18.1% White, and 13.3% Other). Most patients (85.5%) had public insurance. The median LOS in the PICU was 9.04 days (IQR 3.99–20.35) and mortality in the study population was 7.2%.

Table 2 describes the characteristics of medical complexity and severe sepsis at the time of severe sepsis alert. The majority (59%) of CMC patients in the study had more than one chronic condition or diagnosis. The most common conditions were neuromuscular (57.8%), followed by cardiovascular, respiratory, and genetic conditions (30.1%). Technology dependence was present in 88% of the CMC included in the study, with many (44.6%) relying on multiple pieces of equipment or technology. The most frequently observed modalities were gastrostomy tube (66.3%) and tracheostomy dependence (33.7%). Regarding healthcare utilization, 80.7% of patients included in the study received care from more than 2 subspecialists in the 6 months prior to admission.

Respiratory infection (65.1%) was the most common source of sepsis, and 10.8% of patients had more than one source identified.

TABLE 1 | CMC patient demographics.

Age in years, n (%)	
1–5	46 (55.4)
6–12	15 (18.1)
13–18	22 (26.5)
Race, n (%)	
Black/African American	57 (68.7)
White	15 (18.1)
Other	11 (13.3)
Gender, n (%)	
Male	44 (53.0)
Female	39 (47.0)
Insurance status, n (%)	
Public	71 (85.5)
Private	12 (14.5)

Isolated respiratory failure was experienced by 56.6% of the study group, with an additional 36.1% of patients suffering respiratory failure along with dysfunction of another organ system (data not shown). Of the 83 encounters in the study, 3 required extracorporeal membrane oxygenation (ECMO) support, and 3 patients underwent new tracheostomy placement during the admission. As previously reported, 6 patients died.

Association of Social Determinants of Health With LOS Among Pediatric CMC Patients With Severe Sepsis

SDoH of CMC patients with severe sepsis are described in **Supplementary Table S1**. The majority of patients are exposed to high SVI and lead exposure with access to healthcare, food sources, and transportation. Households consisted of 20% with a single female parent and 2% of households were non-English speaking. In a mixed effects Cox model, (**Table 3**), associations between PICU LOS vs. demographic and SDoH variables were analyzed. High and moderate SVI groups were associated with longer PICU LOS compared to extremely low SVI although not significant (**Table 3**). Neighborhood quality was comprised of lead exposure risk and environmental health index. Patient neighborhood quality in Shelby County was classified based on a score of 38 (range 4–71) and was not significantly correlated with PICU LOS. The length of PICU stay increases as the level of lead exposure risk increases but did not reach statistical significance (**Table 3**). The length of PICU stay decreases as the environmental health index increases, but this association is not statistically significant.

Furthermore, there were no significant associations between other measures of SDoH and PICU LOS including estimated median income of a family, % population below poverty rate, estimated % housing units without vehicles, distance to the nearest hospital in miles, distance to the nearest farmer's market, estimated % of housing units without a vehicle and beyond 0.5 miles from a supermarket or grocery store, estimated % of all families that are headed by a single female with children, and estimated % of all people

TABLE 2 | CMC co-morbidities and severe sepsis characteristics.

CMC patient characteristics	<i>n</i> (%)
Peri-alert source of infection	
> 1 source	9 (10.8)
Respiratory, viral	22 (26.5)
Respiratory, bacterial	32 (38.6)
Bloodstream	6 (7.2)
Urinary tract	9 (10.8)
Other ^a	11 (13.3)
Unknown ^b	12 (14.5)
Pre-existing medical conditions	
> 1 condition	49 (59.0)
Neuromuscular	48 (57.8)
Cardiovascular	25 (30.1)
Respiratory	25 (30.1)
Gastrointestinal	7 (8.4)
Renal/genitourinary	10 (12.1)
Musculoskeletal	5 (6.0)
Oncologic	4 (4.8)
Genetic/chromosomal	25 (30.1)
Prematurity	26 (31.3)
Other (immune deficiency, transplant recipient, rheumatologic, endocrine condition)	17 (20.5)
Pre-existing technology/equipment	
> 1 dependence	37 (44.6)
Gastrostomy	55 (66.3)
Tracheostomy	28 (33.7)
VP shunt	8 (9.6)
Central venous line	7 (8.4)
Home ventilator	10 (12.1)
Home oxygen	20 (24.1)
Other (baclofen pump, vagal nerve stimulator, dialysis catheter, pacemaker)	8 (9.6)
Patients with >2 subspecialists pre-PICU admission	67 (80.7)
Present organ dysfunction at time of severe sepsis alert	
> 1 organ system	32 (38.6)
Respiratory	77 (92.8)
Cardiac	26 (31.3)
CNS	11 (13.3)
Renal	10 (12.1)
Hematologic	9 (10.8)
Hepatic	7 (8.4)
Mortality	6 (7.2)

^aOther source of infection—sources of infection not listed.

^bUnknown source of infection—based on clinical and laboratory data outside of infection source microbiology.

age 5 and older who were non-English speakers (data not shown). After following a backward model selection procedure and using $p > 0.05$ to remove non-significant variables, none of the variables remained in the mixed effects Cox multivariable model.

TABLE 3 | Results of mixed effect survival models.

	<i>n</i>	HR (95% CI)	<i>p</i> -value
Demographics			
Age, years			
1–5 (reference)	46	1	-
6–12	15	0.57 (0.25–1.28)	0.17
13–18	22	1.91 (0.98–3.72)	0.06
Sex			
Male	44	0.8 (0.5–1.26)	0.33
Female (reference)	39	1	-
Race			
Black (reference)	57	1	-
Other	26	0.93 (0.57–1.52)	0.77
Insurance			
Public (reference)	70	1	-
Other	13	1.09 (0.57–2.08)	0.79
Overall social vulnerability index (SVI)^a			
Extremely low (reference)	18	1	-
Low	6	1.89 (0.74–4.87)	0.18
Moderate	18	0.98 (0.49–1.97)	0.95
High	41	0.90 (0.51–1.60)	0.72
Risk of exposure to lead^b			
1–4	19	1	-
5–7	30	0.89 (0.46–1.72)	0.72
8–10	34	0.72 (0.38–1.39)	0.33
Environmental health index (1–100)^c	83	1.01 (1–1.03)	0.09
Socioeconomic status			
Estimated median income of a family (USD) ^d	83	1 (1–1)	0.94
% population below poverty rate	83	0.99 (0.98–1.01)	0.16

^aHigh (0.75–1.00), Moderate (0.50–0.75), Low (0.25–0.50), Extremely Low (0.00–0.25); Source: CDC (34, 37).

^bLow risk of lead exposure, 1–4; Moderate risk of lead exposure, 5–7; High risk of lead exposure, 8–10. Source: Washington State Department of Health (36, 40).

^c1–100 (Low–high index of environmental health hazard; 1–high health hazard, 100–low health hazard); Source, U.S. Dept. Housing and Urban Development (HUD) (35, 39).

^dSource, US Census ACS (2015–2019) (42).

DISCUSSION

This is the first study to evaluate the association of socioeconomic and neighborhood-related SDoH with PICU LOS in the CMC population admitted with severe sepsis. While our results supported that SDoH among CMC presenting with severe sepsis were not associated with increased PICU LOS, we demonstrate several other key points. The study population was representative of the racial diversity in Shelby County, Tennessee (15). Patient age conformed to the bimodal peak of distribution observed in pediatric severe sepsis patients (46). Lastly, the median PICU LOS for CMC patients presenting with severe sepsis was 9 days, which is higher than the average LOS compared to other studies examining trends of all PICU children admitted with severe sepsis (7). Although Black race and public insurance

are associated with PICU readmission of CMC following tracheostomy and gastrostomy tube placement (47), there was no significant difference attributable to gender, racial background, or insurance status in our study.

As childhood poverty is associated with increased PICU admission (48), SVI and specific neighborhood quality indicators (lead exposure risk and environmental health index) were the primary SDoH-related variables analyzed for association with PICU LOS. Although there were no significant associations found between socioeconomic and neighborhood factors in this study, there are trends worthy of discussion. Patients with high SVI and lower neighborhood quality were more susceptible to a longer PICU LOS than those in the other groups. This finding was not statistically significant, but larger studies with higher power might be warranted to evaluate SDoH effects on this outcome further. Other SDoH-related variables including socioeconomic status, access to transportation, healthcare, food sources, household composition, and language demonstrated no statistically significant associations with PICU LOS in our study. No significant associations between the SDoH variables and PICU LOS were found in our study population. We suspect the level of care provided at our facility mediates the impact of SDoH. Characteristics of care which could impede studying the impact of SDoH at our institution are the widespread education of severe sepsis across our institution, presence of a severe sepsis electronic alert mechanism, and rapid transfer of critically ill patients to the ICU.

There are other key factors that could not be evaluated in this study which may add a layer of complexity to SDoH of our CMC population and affect their outcomes such as PICU LOS. First, we did not consider the number of hospital readmissions as a potential outcome, which may be related to underlying abnormal or unstable functional status prior to previous PICU discharge (47, 49). Instability from a prior discharge with compounding SDoH could lead to an admission for critical illness including severe sepsis. Second, the availability of home health access or other healthcare utilization required by CMC was not considered as a risk factor. CMC often require extensive home health services involving additional economic resources which can compound pre-existing SDoH in any given home. Third, retrospective census-level data could mask individual poverty information of families with CMC and underestimate results, given that underserved children are at risk of higher PICU utilization (50). Lastly, other potential outcome measures such as mortality using the Pediatric Index of Mortality-2 (PIM-2) known to be associated with SDoH (51), severity of illness scoring measures for which we do not have sufficient data including the Pediatric Risk of Mortality Score III (PRISM III), were not evaluated in this study as some patients were not admitted to the PICU from the Emergency Department. Pediatric Logistic Organ Dysfunction-2 (PELOD-2) scores are not calculated at our hospital. Analysis of such outcome measures in association with SDoH may provide a more robust framework to further provide resources in the care of this patient population.

This study had several limitations. Sample size was limited by the incidence of severe sepsis and our strict inclusion criteria. Second, our hospital's location created some challenges for our team. Patients are referred to our center via hospitals around the Memphis metropolitan area, which includes 3 states and 9 counties, and beyond. CMC in the Memphis metropolitan area and Shelby County that died due to pediatric severe sepsis could not be accounted for in this study. Third, as community-level data is reported differently from county to county and state to state, we were limited in our ability to include more patients and to establish controls for comparison. Fourth, SDoH data was collected at a neighborhood-level, possibly limiting the ability to infer associations with individual PICU LOS. Individual screening of SDoH would provide information to better assess associations with individual PICU outcomes, including LOS. Lastly, we encountered documentation inconsistencies during our chart review process that prohibited analysis which controlled or corrected for variables such as illness severity and comorbidities that we feel would have strengthened our study.

CONCLUSION

Incorporating SDoH data into clinical and public health decision-making processes enables precision prevention, treatment, and equity (28) and improves patient safety and quality of care. This study explored associations between social vulnerability and neighborhood-level SDoH in the health outcomes of CMC admitted to the PICU with severe sepsis. Although there are no associations between SDoH and CMC with severe sepsis in our exploratory analysis, we anticipate the results of this research will be used as a platform to conduct further confirmatory studies to advocate for increased resources for care of this population and generate new hypotheses using additional data collected from multiple settings at a higher geographical resolution for in-depth investigation of associations of PICU outcomes with SDoH.

DATA AVAILABILITY STATEMENT

The data analyzed in this study is subject to the following licenses/restrictions: The dataset from the EMR contains patient identifiers and is not publicly available. However, we did use public databases to search information, cited in the article. Requests to access these datasets should be directed to sshah7@uthsc.edu.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by University of Tennessee Health Science Center. Written informed consent from the participants' legal

guardian/next of kin was not required to participate in this study in accordance with the national legislation and the institutional requirements.

AUTHOR CONTRIBUTIONS

HH, AW, and SS conceptualized the study. AS-N, NA, and LC assisted with study design. HH reviewed chart and collected data. NA, TJ, FG, and LC completed the data analysis. HH and AW wrote the manuscript with assistance from NA and TJ and it was reviewed and edited by SS and AS-N. All authors reviewed the manuscript and approved it prior to submission.

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ACKNOWLEDGMENTS

We would like to express our gratitude to Kim Giles, Charlene Summerall, Karen Brinkley, and Anna Burroughs for their assistance with reviewing sepsis alerts.

SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: <https://www.frontiersin.org/articles/10.3389/fpubh.2022.789999/full#supplementary-material>

Supplementary Table S1 | Social Determinants of Health among CMC with Severe Sepsis in Shelby County, Tennessee.

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Socio-Economic Inequity: Diabetes in New Zealand

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Keywords: diabetes, inequity, rationing of care, hardware commoditization, unaffordable care, low-cost alternatives, insulin pump (CSII)

OPEN ACCESS

Edited by:

Mobolanle Balogun,
University of Lagos, Nigeria

Reviewed by:

Carlos Miguel Rios-González,
National University of Caaguazú,
Paraguay

Babatunde Akodu,
University of Lagos, Nigeria

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Specialty section:

This article was submitted to
Family Medicine and Primary Care,
a section of the journal
Frontiers in Medicine

Received: 10 August 2021

Accepted: 19 April 2022

Published: 10 May 2022

Citation:

Holder-Pearson L and Chase JG
(2022) Socio-Economic Inequity:
Diabetes in New Zealand.
Front. Med. 9:756223.
doi: 10.3389/fmed.2022.756223

1. INTRODUCTION

New Zealand is on collision course with the iceberg of unaffordable medicine. Diabetes is one example which has seen — and is projected to see — significant growth, stressing the health system. A decreasing workforce supporting an aging population, combined with a considerable increase in the prevalence, means gold-standard care will be unobtainable except for an increasingly select few, with public resources distributed among hundreds of thousands of sufferers. There are currently an estimated 228,000 New Zealanders suffering from type-2 diabetes alone, with a projected growth of 70–90%, to approximately 400,000 people by 2,040 (1). Considering rates are higher and outcomes worse among Māori and Pasifika (1, 2), and they typically face greater socio-economic hardship (3), there is a double burden. The current healthcare system seeks intrinsic advancements—increased productivity without increased efficiency. Demographic and prevalence challenges beg for extrinsic changes: innovative disruptions to current care models, combating growing inequity of access to care and outcomes.

2. DIABETES—IS IT REALLY THAT BAD? THE HUMAN COST

Diabetes seems to have become so common, even those suffering from it claim to be of good health (4). Active management involves medication to: (a) artificially increase the sensitivity to insulin; (b) stimulate further production of insulin; and finally (c) supplement with external insulin. The aim is to lower circulating blood glucose concentrations. High blood glucose results in harm to many body structures, causing significant complications, cumulative cost, life-limiting disability (5, 6), and early death (1, 7–10).

The human cost of diabetes is paid for disproportionately by certain ethnic and socio-economic groups. In New Zealand, Māori are 2.5× more likely to have type-2 diabetes than their Pkeh counterparts, with prevalence of 7.5% compared to the national average of 4.7%. Pasifika peoples are further over-represented, with an estimated prevalence of 15.1% (1). Even given the same access to primary healthcare, there is an inequity of outcome (11), with Māori and Pasifika having a HbA1C 11–13 mmol/mol higher, after adjusting for both medical management and demographic factors (2, 12). Adjusted for ethnicity, lower household income alone is correlated with a 2× risk of diabetes mellitus (13). Trends in outcomes are also significantly worse, with the most deprived now 3× more likely to die from cardiovascular pathology than the least deprived, compared to equal risk two decades prior (11).

3. IS IT REALLY THAT BAD? THE FINANCIAL COST

While overall health spending has increased from 7.5% of GDP to 9.2% since 2000 (14), publicly-funded treatment diabetes and its complications now costs New Zealand 0.67% of GDP, and ≈10%

of the total health budget, or \$2.1B NZD per annum (1). Predictions estimate by 2,040, diabetes will cost New Zealand \$3.5 billion in 2021 dollars, equal to 16% of the current health budget.

Systemic health costs from diabetes are growing, but personal health costs are rising faster to cover the gap. Private spending accounts for approximately 20% of total health expenditure in New Zealand (15), of which 12–15% is directly an out-of-pocket expense (14). Added to explicit expenses, is considerable personal loss from lost wages due to activity-impairing complications, and lost non-salary productivity due to the inability to perform activities such as domestic cares or voluntary work (1). Lost personal wages have an estimated economic cost of \$562 m in 2020, but increase 47%–\$755 m in 2,040, and non-salary economic loss is predicted to increase from \$334 to \$506 m in the same period (1). The lost wages are accompanied by a loss of government revenue through income tax, from \$163 m in 2020 to \$221 m in 2,040. Lost tax revenue because of disability from diabetes is equal to 8% of the current governmental health expenditure on diabetes (1).

The large projected growth of financial costs of treating diabetes is driven by increasing prevalence, population growth, aging population, and higher costs per patient because of earlier diagnoses. In particular, the average lifetime cost is 13 times greater when diagnosed with type 2 diabetes at 25-years, compared to 75-years [\$565 vs. \$44 k (1)]. Previous screening trials indicated almost one in five people had pre-diabetes in 2008/2009. These trends, especially among Māori and Pasifika mean the healthcare system cannot afford to delay either actively acting to prevent type 2 diabetes, or introduce extrinsic changes to provide equitable access to more effective management.

4. THE ONLY POSITIVE THING ABOUT INEQUITY IS THE FEEDBACK LOOP

Diabetes inequities are not only worsening, but self-perpetuating. Financially, inequity is increasing due to increases in out-of-pocket spending, as shown in **Figure 1**. Accounting for private insurances and charitable spending, the most recent data from the Ministry of Health show out-of-pocket expenditure increased on average 4.3% per annum (albeit in 2012 when it was last reported). This rate compares to an average inflation rate of 2.7% (18), and an average median wage growth of 3.2% (3). To exaggerate inequity further, the mean household income of the 20th centile [P20 from Table 9.1 of (16)] has risen on average only 1.5% per annum, a cohort which Māori are 30% more likely to be in than European descendants (3). These financial impediments to healthcare are seen in the ability to access primary healthcare, something 38% of Māori report as being unable to do (19).

Forming a disproportionately high amount of the lower socio-economic cohort (3), Māori have worse diabetes outcomes compared to their pkeh counterparts (2, 20). One possible explanation is less equitable access to primary care (2), as evidenced in lower-income households having 25% fewer GP appointments relative to the portion who report being of 'poor health', than NZ average (21). Even accounting for government subsidy schemes, such as the community services card, a GP

appointment costs up to \$19.50. The average household in the lowest quintile in New Zealand has only \$230 per week disposable income after housing (3). **Visiting a general practitioner for the most vulnerable is as much, if not more, a financial decision as a healthcare one.**

Projections for out-of-pocket diabetes-related spending are expected to increase 3.0% per annum, rising almost 80% in the two decades to 2,040 (1), similar to historic median wage growth, but two times the 20th centile. As primary healthcare is expected to see the largest rises in out-of-pocket health expenditure in GP appointments and prescription co-payments (1), access to preventative healthcare becomes less equitable, impeding early intervention and compounding inequity of outcomes for healthcare. This inequity is compounded by the positive feedback loop of poor health literacy (22, 23), which furthers distrust in the profession as a whole.

Inequity of access to both care and outcomes in diabetes is a positive-feedback loop of increasing loss of equity, with resultant harm and cost, which requires extrinsic, innovative changes to current care models to break.

5. ONE SMALL DRIVER FOR BIG CHANGE

One technology which provides better control for individuals with both type-one and type-two diabetes (24, 25), but is available only to a minority of New Zealanders, is insulin pumps. Pumps in New Zealand are up to \$10,000 if self-funded, or, if stringent requirements are met, publicly funded (26). Criteria for public funding are evidence the pump will reduce HbA1C by 10 mmol/mol, or "four severe unexplained hypoglycaemic episodes" requiring medical assistance (27). If not publicly-funded, there are additional out-of-pocket costs for consumables approximately \$1,500 per year. In poorer households, these required out-of-pocket costs, compounded by poorer health literacy, are preventing equitable access to best care (28, 29).

An open-licence pump developed at the University of Canterbury in partnership with local diabetes clinicians, is currently being prototyped with a bill of materials approximately $\frac{1}{50}$ the cost of the devices currently available—the ultra-low cost insulin pump (ULCIP) with comparable performance (30). Accounting for comfortable production, support, and development overheads would enable purchase of the device at \$500 per device - enabling 14–20× the number of insulin pumps for no added investment, which would allow significant relaxation of the insulin pump eligibility criteria, thus increasing the equity of access to best care.

The flow-on benefits of widespread access to insulin pumps are such extrinsic changes required to address growing health demands. Currently, secondary care spending accounts for 57% of diabetes spending, a portion which is expected to grow (1). Widespread adoption of insulin pumps for no additional investment would see an increase in good glucose control, which subsequently reduces complication rate and severity (2, 24, 31). This reduces the number, and cost, of secondary care presentations for individuals with diabetes, allowing for further

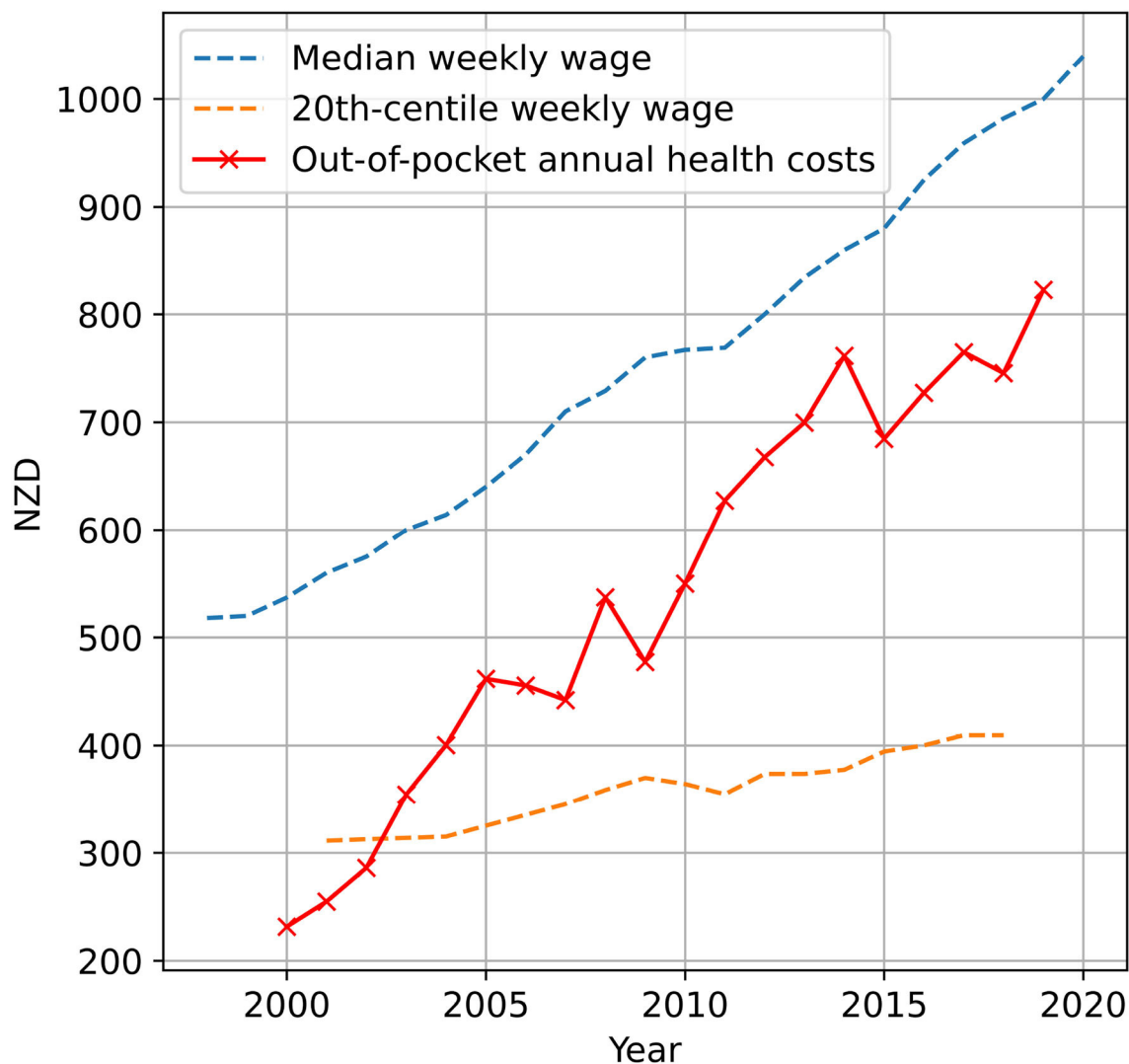


FIGURE 1 | Historic average annual out-of-pocket health expenditure per capita (14), compared to median weekly wage (16, 17), and mean of 20th-centile weekly household income (16). Out-of-pocket health expenses are exclusive of charitable and private insurance spending. Average historic annual increases are 4.3% for out-of-pocket healthcare expenditure, compared to 3.2% for median wage growth, and only 1.5% for the 20th centile.

investment in preventative medicine, increasing equitable access to better health outcomes.

6. DISCUSSION

The inequities present in healthcare in New Zealand, specifically diabetes, are worsening in light of increasing prevalence and severity of diabetes. Increases in the personal out-of-pockets costs of healthcare are the result of explicit rationing of care: an implicit redefinition of the social contract, where systemic healthcare is becoming less accessible and less thorough in its application. Māori, who have a history of underinvestment and poor engagement, continue to suffer disproportionately in a public health system considered “hostile and alienating” (32). Within diabetes specifically, inequities in outcomes have been

recognized for over two decades (2). Despite this recognition, there has been a lack of progress to address outcomes through increased access or similar schemes. This lack of progress is evident in the lack of access to specialist care (2), and thus technologies that require prescription by a specialist (33).

These results generalize broadly to other indigenous populations, where disparities of care still exist around diabetes and care in general (34–36). Equally, some European focused studies show similar results around socio-economic status (37). Hence, there are international studies showing similar trends as the New Zealand studies showing growing inequity, where this analysis provides a first overall analysis of how these outcomes translate into inequity in access to care and outcomes.

Despite the financial trends highlighted, representative of “persisting inequities ... in access and outcomes for Māori, Pacific

Island, and low-income populations” (19), comparisons between out-of-pocket expenditure and wages are lacking. This analysis links the lack of access to a fundamental cause on the part of the patient. There is academic agreement at a system level, inequities remain in the health system as a continuation of inequities generated through colonization (38), and reinforced by continued poverty, lack of access to housing, and lack of access to primary healthcare (19, 38). However, the economic and more specific reasons have not been to date explicitly analyzed.

More specifically, the reasons for the trends observed include continued underinvestment of the public health system, resulting in a larger portion of healthcare expenditure shifted to private expenditure (19). Considering the New Zealand healthcare funding policies where secondary care is fully publicly funded, but primary healthcare is not, primary healthcare has become increasingly unaffordable for those with the greatest socio-economic deprivation. This gap is particularly evident where only the wealthier 28.8% of individuals possess private healthcare insurance (19), allowing them to obtain private secondary care ahead of rationing in a system under stress.

The results of these are evident in the significantly higher rates of emergency department re-admission (39) for Māori, suggesting that where follow-up care from a primary healthcare provider may be appropriate, Māori are instead disproportionately seeking it through emergency departments. Missing primary care due to economic and availability reasons poses inequitable access to preventative care, thus patients presenting to emergency departments are also more complex, exacerbating potentially avoidable negative outcomes. Hence, there is a strong, economically-driven feedback loop where patients unable to access primary care suffer negative outcomes,

and for Māori in particular, these reasons are both socio-economic as well as ethnic in origin.

Healthcare inequities due to increased rationing of care require solutions which enable increased productivity without an increase in resources. A broadly interoperable insulin pump paired with an equally openly-accessible glucose monitor (40) would enable a low-cost, equitable artificial pancreas system (LEAPS). In addition to improved patient-led diabetes care, a LEAPS solution would also more timely and efficient clinician assistance through cloud-based processing for patient-level and system-wide analysis.

AUTHOR CONTRIBUTIONS

LH-P developed and researched the exact extent of the problems and led writing. JC provided considerable insight, context, and editing. All authors contributed to the article and approved the submitted version.

FUNDING

This work was supported by the NZ National Science Challenge 7, Science for Technology and Innovation (2019-S3-CRS).

ACKNOWLEDGMENTS

The authors wish to acknowledge Matt Payne and Francis Pooke for their hard work and Martin de Bock for his insights and patience.

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Management of Medicines Wastage, Returned Medicines and Safe Disposal in Malaysian Community Pharmacies: A Qualitative Study

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OPEN ACCESS

Edited by:

Shannon Galvin,
Northwestern University, United States

Reviewed by:

Christie Bertram,
Northwestern Memorial Hospital,
United States
Raphael Zozimus Sangede,
Muhimbili University of Health and
Allied Sciences, Tanzania

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Specialty section:

This article was submitted to
Family Medicine and Primary Care,
a section of the journal
Frontiers in Medicine

Received: 26 February 2022

Accepted: 22 April 2022

Published: 19 May 2022

Citation:

Chong KM, Rajiah K, Chong D and
Maharajan MK (2022) Management of
Medicines Wastage, Returned
Medicines and Safe Disposal in
Malaysian Community Pharmacies: A
Qualitative Study.
Front. Med. 9:884482.
doi: 10.3389/fmed.2022.884482

Introduction: In supplying medicines to patients and consumers waste can occur in prescribing, dispensing, and leftover stages. Pharmacists in community pharmacies play a crucial role in dispensing and should share information on appropriate medicines disposal with consumers. This qualitative study explored how Malaysian community pharmacists manage medication wastage, returned medicines, and medicines disposal by eliciting their opinions on medicines wastage, the challenges faced, and feasibility of medicine return and safe medicine disposal in the setting of Malaysian community pharmacy.

Methods: Telephonic interviews were conducted using a pre-validated interview guide among community pharmacists. Purposive sampling was used to ensure heterogeneity of participants in terms of gender, age, and position in the pharmacy. The interview was conducted until a point where no new information was obtained. Interview data were thematically analyzed.

Results: The analysis identified nine themes organized into four domains. The results revealed that pharmacists have positive perceptions of the safe disposal of medicines. Pharmacists mentioned that medicine returns to service in community pharmacies are not common due to a lack of facilities in the management of unwanted, expired, and returned medicines. As such pharmacists have suggested a few ways to minimize medicinal wastage.

Conclusions: Respondents aimed to minimize medicines wastage (unused medicines) in order to minimize loss of revenue. Respondents did not usually accept returned medicines due to the operational costs of safe disposal. Disposal of unused medicines was undertaken by centralizing the stocks at an organization facility before being disposed of by outsourced waste management companies.

Keywords: medicines wastage, unused medicines, expired medicines, medicines disposal, returned medicines

INTRODUCTION

Community pharmacies are the primary healthcare facilities most accessible to the public (1). The conventional roles of community pharmacists are mostly business orientated, where they focus more on prescription dispensing, selling over-the-counter drugs and running the pharmacy business (1, 2). Over time, the roles of community pharmacists have expanded to focus on quality and safe use of medicines in the primary healthcare system (2). Pharmacists involving in safe use of medication, including its storage, and disposal.

Considering the chemical and biological nature of medications, improper use and disposal of medications in community and hospital pharmacies led to economic losses and cause damage to the environment and society. This impact of medication wastage increased the awareness of potential waste minimization strategies to be implemented in community and hospital pharmacies. Medication waste can occur in the prescribing, dispensing, and leftover stages of the pharmaceutical supply chain (3). Pharmacists have the most influence while dispensing the “over-the-counter” medications. Here, one cause of medicine wastage is large manufacturers’ packs which may contain a greater quantity of the medicine than that needed for treatment (4). The direct cost of medication waste is of major concern and can jeopardize the sustainability of healthcare systems (4). In the leftover stage, non-adherence is the most common cause of medicine wastage. This happens often among elderly patients, who may have difficulty in remembering to take medicines due to the large number of different products that they are required to take each day (5). For these patients, unused or forgotten medications are often left to expire and to be disposed of as garbage or into the sewage system (6).

Management of medication wastage, medicine return, and safe medicine disposal has been a global challenge in the sustainability of healthcare systems (7). Health policymakers, pharmaceutical organizations, healthcare professionals, and the wider community, emphasize this issue due to its undeniably detrimental effects on the environment, the economy, and patient safety (7, 8).

Pharmacists play an important role in minimizing medicine wastage and educating the public in safe medicine disposal (3, 9). Education on the appropriate disposal of medications is a key intervention for all pharmacy settings. In Malaysia, public hospital pharmacists could rely on the government’s “Return Your Medicines” Program to encourage returns of unused and expired medications to minimize wastage of medicines and their inappropriate disposal (10). On the other hand, the practices of community pharmacists in the management of medication wastage, medicine returns, and safe medicine disposal have not been explored as there are no relevant governmental regulations or frameworks. The roles of community pharmacists in these practices could be enhanced and given greater emphasis, as community pharmacies are one of the most accessible health care facilities for medication-related advice. Therefore, this study aimed to explore the management of medication wastage, medicine return, and safe medicine disposal in Malaysian community pharmacies. It will be useful to understand the

common practices and methods employed by community pharmacists in these activities, along with, their opinions concerning medicine wastage issues and the challenges faced, as well as the feasibility of medicine return and safe medicine disposal in Malaysian community pharmacies; this will facilitate concrete steps to be taken to encourage standard pharmaceutical waste management in community pharmacy settings.

Ethical Considerations

The study was approved by the IMU Joint-Committee on Research and Ethics [MPP I-2020(07)].

MATERIALS AND METHODS

Study Design

One-to-one telephone interviews were conducted using a pre-validated interview guide from December 2020 to June 2021. Community pharmacists were approached after their working hours, introduced to the purpose of the study, and verified for eligibility for the study; only eligible individuals were invited to participate. Eligible respondents were provided with an outline of the study objectives and informed of the time needed for the study. Only full-time, fully-registered pharmacists working in a community pharmacy were included, with the exclusion of locum community pharmacists and provisionally registered pharmacists. Participation was by voluntary written informed consent.

Interview Guide

A semi-structured interview guide was created by reviewing the literature on medicine wastage, return of medicine, and safe disposal. The guide was modified as a result of suggestions and recommendations from experts in qualitative studies. Open-ended questions were preferred to provide interviewees with a full opportunity to convey their opinions and help in obtaining a greater understanding of issues. A pilot interview was conducted with two pharmacists. The questions were rephrased based on the pilot interview. The data collected during the pilot interview were not included in the results.

Sampling Method and Sample Size

Purposive and snowball sampling was used to select participants to ensure heterogeneity of the participants’ demographic characteristics in terms of their gender, age, and position in the pharmacy. Sampling was undertaken until the saturation point. The saturation point was determined by analyzing the collected data that indicated a further collection of data may not bring any new theme. In other words, the researchers reached a point where there were no new themes are generated from the data collected (11).

Data Collection

Telephone interviews were conducted. The interview durations were between 30 to 45 min. All interviews were audio-recorded. The interview recordings were subsequently transcribed verbatim by a researcher. All transcripts were checked for accuracy by two researchers. The transcripts were subsequently

returned to the respondents for comments and corrections. The final transcripts were stored in password-protected Microsoft Office Word document.

Data Analysis

Transcribed data were coded and analyzed for emergent themes using thematic analysis, as per the approach and steps recommended by Braun and Clarke (12). The data were coded based on common themes, where the data were sorted into categories with similar trends. The codes were then labeled, and notes were written about the ideas which arise from them. The data were then grouped into themes and inductive thematic analysis was conducted as per the following steps. First, the researchers familiarized themselves with the data, then the initial codes were generated. Followed by suitable searching of themes, reviewing of themes, defining and naming themes were done. Finally, the report was produced (12). The data collection, coding, and interpretation were carried out in an iterative manner by a researcher and the resultant data were confirmed by two researchers.

Data Trustworthiness

In this study, trustworthiness was established in several phases. To reduce researcher bias, a reflective journal was used while taking field notes. To address the data transferability, respondents' characteristics were mentioned. Completeness and credibility of the content were ensured by establishing the sample size based on saturation. To give proper meaning to the text, the unit of analysis was taken as sentences instead of letters or words.

RESULTS

Eighteen eligible community pharmacists participated in this study. Most of the respondents were aged 30 years or below. Ten of the respondents were female and eight of them were male. Most respondents had at least 5 years of experience working in urban areas as pharmacists; only one respondent was from a rural setting. **Table 1** summarizes the demographic characteristics of the respondents.

The thematic analysis identified nine themes organized into four domains: (1) Perception of pharmacists regarding medicine disposal (2) Availability of medicine return service in community pharmacies (3) Management of unwanted, expired, and returned medicines (4) Minimization of medicines wastage. **Table 2** summarizes the themes and the domains.

Domain 1: Perception of Pharmacists Regarding Medicine Disposal

Theme 1: Safe Medicine Disposal Practices

All the 18 respondents agreed that safe medicine disposal is beneficial for public health and acknowledged the negative effects of improper medicine disposal on the environment and healthcare costs.

"We rarely see customers buying bulk-buying medications as they have to pay from their own pockets." R5

TABLE 1 | Demographic data of the respondents.

Characteristics	Number of respondents
Age (Years)	
18–30	10
31–40	05
41 and above	03
Gender	
Male	08
Female	10
Experience in years	
Less than a year	05
1–5	09
More than 5	04
Job description	
Pharmacist	16
Pharmacy manager	02
Pharmacy location	
Urban	17
Rural	01

"I think patients that are likely to have unused medications are those getting the medications from government hospitals, where the medications are dispensed at low prices or even free." R12

"If people do not dispose of the medicine properly, it may affect the surroundings and cause hazards." R8

Theme 2: Medication Return Program

All the 18 respondents mentioned that medication return services in their pharmacies were low and rare. They perceived that the lack of demand for such services from their customers and lack of public awareness were the main reasons for the absence of such services.

"I agree that the medicine return program is important in promoting safe medicine disposal. As far as I know, there are no formal guidelines or requirements for community pharmacies to accept medicine returns from the public. It is also the responsibility of the chain pharmacies as well. We cannot always rely on the government to execute the schemes. The companies should come forward and run these kinds of schemes at least as their CSR (Corporate Social Responsibility) activity. Hence, I don't see the need for such programs in community pharmacies exist in the first place without any formal guidelines. It is better to have a guideline first for community pharmacies" R6

I personally had never received any request from my customers to return medicines, nor questions regarding how to dispose of medicines correctly." R18

I think, perhaps it's due to the low public awareness on safe medicine disposal practices." R3

Domain 2: Availability of Medicine Return Service in Community Pharmacies

All the 18 respondents agreed that a medicine return service should be available in community pharmacies.

TABLE 2 | Identified domains and themes of the study.

S. No	Domains	Themes and sub-themes
1	Perception of pharmacists regarding medicine disposal	1. Safe medicine disposal practices 2. Medicine Return Program
2	Availability of Medicine Returns Service in Community Pharmacies	3. Driving factors toward medicine return service 3.1: Environmental impacts and pediatric poisoning 3.2: Convenient location 3.3: Promote government initiative 3.4: Support from the company 3.5: Incentives from the government 4. Detering factors toward medicine return service 4.1: Lack of guidelines 4.2: Operational costs and incineration fees
3	Management of unwanted, expired and returned medicines	5. Close-expiry medicines 6. Expired medicine stocks and medicinal wastage 7. Medicine returns from the public
4	Minimization of medicinal wastage	8. Pharmacy stocks 9. Dispensed medications

Theme 3: Driving Factors for Medicines Return Service

Fourteen respondents considered that they were ready to provide medicines return services at their pharmacies. Respondents mentioned five key driving factors.

Sub Theme 3.1: Environmental Impacts and Risk of Child Poisoning

Ten respondents considered environmental impact and the potential risks of unsafe medicine disposal as the reasons for their readiness to provide medicines return services. Respondents spoke of the risks that children might ingest unwanted medicines.

"If medicine return service is not available for the people, they will start dumping medicines in backyards" R4

"There are chances the medicine wastage becomes unsafe for the kids at home and it may affect the safety environment at home as well. Cases have been reported about children using expired or unused medicines either intentionally or unintentionally" R15

Sub Theme 3.2: Convenient Location

Twelve respondents mentioned that providing a convenient location for consumers to dispose of unwanted medicines would encourage their return. Respondents said that collaboration with non-profit organizations may help drive medicines return programs.

"I think there should be a system to collect the unused medications from the residential areas. Pharmacies are one such place" R8

The location to return the medicines should be conveniently reachable by the public. Hence unused medicine collection points

can be initiated along with the NGOs (Non-Governmental Organization)" R11

Sub Theme 3.3: Promote Government Initiative

Eight respondents wanted to stand by the government initiatives as an act of support to encourage the practices of safe medicine disposal. They feel that it is their responsibility to take forwards the government initiatives. This shows that pharmacists are key to promoting government initiatives, though there are no clear guidelines for safe medicine disposal.

"I think as a pharmacist I should stand by the government schemes and programs that promote health and well-being" R2

"I feel it's our responsibility to involve in government schemes and encourage the public to use those schemes" R11

Sub Theme 3.4: Support From the Company

Ten respondents mentioned that any medicines return service should be enforced and supported at the company level. They also mentioned that it should be seen as the companies' corporate social responsibility.

"It is the responsibility of the chain pharmacies as well. We cannot always rely on the government to execute the schemes. The companies should come forward and run these kinds of schemes at least as their CSR (Corporate Social Responsibility) activity" R6

Sub Theme 3.5: Incentives From the Government

Nine respondents wanted to receive incentives from the government for providing such a service.

"To consider providing medicine return service at the retail pharmacy, there should be some sort of help like incentives from the government, as the process can be an extra workload for the pharmacy staff and an increase in operational cost for the pharmacy." R10, R5

Theme 4: Detering Factors Toward Medicine Return Service

The reasons that the 18 respondents perceived for the lack of medicines return services in most community pharmacies are:

Sub Theme 4.1: Lack of Guidelines

Fifteen respondents mentioned that there should be definite guidelines for community pharmacies in terms of medicine return programs.

"As far as I know, there is no formal guidelines or requirements for community pharmacies to accept medicine returns from the public. It is better to have a guideline first for community pharmacies" R6

Sub Theme 4.2: Operational Costs and Incineration Fees

Nine respondents mentioned that charges for the incineration of returned medications are determined by the weight, thus collecting medications from the public in large amounts would be unfavorable to the company's operational costs, unless there are subsidies from the government and consumers are willing to bear the extra costs of the medicine return service.

"Accepting medicine returns from the public is unfavorable, as the waste management company charges the medicine waste incineration fees based on weight. The more waste there is, the more expensive the incineration fees would be." R5

Domain 3: Management of Unwanted, Expired, and Returned Medicines

Theme 5: Close-Expiry Medicines

Thirteen respondents cleared close-expiry medication stocks in their pharmacy by selling them at lower prices to consumers and private clinics, or by transferring them to other pharmacies with higher stock movement. Most of the respondents mentioned that expired medication stocks would mean a profit loss to the pharmacy and hence the number of expired stocks for any effectively managed pharmacies would be kept at a minimal level.

"Any medication waste in a community pharmacy meant revenue loss." R13

"We will try to sell the close-expiry stocks out at discounted prices to customers or transfer them to other outlets with higher stock movement to avoid profit loss." R4

"We will order according to demands and stock movements, and try to minimize inventory of slow-moving products" R17

Theme 6: Expired Medicine Stocks and Medicinal Wastage

Eleven respondents mentioned that the amount and type of the expired medications would be documented before transferring the expired medications to the headquarters or warehouse for centralized disposal and incineration by qualified waste management companies.

"For expired medications, we will record the name, type and amount of the expired stocks before sending them to the company warehouse for incineration. This is to ensure that no products are lost due to theft and for documentation purposes." R1

"If the supplier or seller of the medication accepts returns of expired stocks, we will return the stocks to them in exchange of new stocks or rebates." R9, R18

Theme 7: Medicine Returns From the Public

Sixteen respondents did not accept medicine returns from customers at their pharmacies. Some respondents suggested that customers utilize the Medication Return Program (MRP) available at government healthcare facilities, while some did not suggest any alternative safe medicine disposal methods to their consumers.

"We do have a pharmacy outlet in Bangsar that accepts medicine returns from the public. In my outlet, we would accept the returned medications and transfer them to that outlet for safe disposal." R1

"I would just tell the customers that we do not accept medicine returns. I will not tell them how to dispose of the medicines proactively unless they asked, which I would recommend them to go to any government healthcare facilities for proper disposal." R8

Domain 4: Minimization of Medicinal Wastage

Theme 8: Pharmacy Stocks

To reduce the possibility of ending up with expired medication stocks, 10 respondents reported practicing First-Expiry-First-Out (FEFO) while selling and arranging the stocks on the shelves. Periodic stock checks to check the expiry dates for different products are also conducted to minimize the amount of close-expiry medicine stocks. For expensive and rarely used medicines, pharmacists will only order the item as needed.

"When we receive new stocks, we will arrange the stocks according to the expiry dates so that the old stocks could be sold first." R8

"We perform checking of product expiry dates weekly to keep a record of the stock shelf-life and to decide which product to preferably sell first." R2

Theme 9: Dispensed Medications

To minimize the bulk-storing of medications by customers, which may lead to wastage, 12 respondents mentioned that they advise customers to frequently check the medications' expiry dates when making a purchase or for medications stored at home.

"We do ask the customers to check the expiry dates of medications which are there at their homes and advise them not to store too many medications of the same kind." R15

"We recommend customers to keep their medicines at the cool dry area in their house, and to avoid places like the car or washroom, which are not the ideal environment for medicine storage." R3

DISCUSSION

In this study, we explored the opinions of community pharmacists in the management of medication wastage, medicine return, and safe medicine disposal in Malaysia; we sought their views on the challenges involved and the feasibility of medicine return and safe disposal in a community pharmacy setting.

Respondents perceived that safe medicines disposal and medication return programs would be beneficial for their customers and the public. The main reason contributing to medicines wastage is non-adherence and poor adherence to medicine return program (4–6). The study also revealed that customers purchasing medications from community pharmacies are less likely to end up with leftover medications, because the customers had to pay out of their own pockets, unlike in most government healthcare facilities where medications are dispensed free, or at very low cost. The participants identified no specific approaches to their management of medicine returns from the public, and the methods differed from one outlet to another. Availability of the medicine return services in a pharmacy is based on whether the nearby healthcare facilities offer MRP. This concurs with a study by Smale et al. (13). Hence, in most pharmacies, pharmacists do not accept medicines returned from the public. Some pharmacists voluntarily collected

the returned medicines and sent them to nearby healthcare facilities that offer MRP or to those pharmacy outlets, especially chain pharmacies, which provide MRP services. None of the returned medications are re-dispensed, resold, or donated to non-profit organizations.

Participating community pharmacists wanted the medicine returns service to be available in their pharmacies and mentioned environmental impact and the risk of child poisoning that can occur with unused and expired medicines. A previous study in Malaysia revealed that pharmaceutical substances were the causative agents in 40.5% of cases of intentional poisoning, and 30% of cases of unintentional poisoning; 46% of the victims of unintentional poisoning cases were children aged between 1 to 9 years (14). Another study stated that the largest contributing factor in pediatric poisoning was pharmaceutical substances, accounting for 39.2 % of the reported cases (15).

Respondents mentioned that a convenient location for the public to return their medicines would be a driving factor for people to return medicines. Different countries employ various strategies to manage expired and unwanted medicine returns from the public. In the United States, the Drug Enforcement Administration (DEA) conducts National Prescription Drug Take-Back Day twice annually, where participating local law enforcement agencies, retail pharmacies, hospitals or clinics from communities nationwide set up collection points for unwanted medications for safe disposal (16). In addition, there are all-year-round medicine disposal programs and DEA-authorized collectors in many local communities that facilitate the public in the safe disposal of unwanted medications (17). Moreover, there are many DEA-authorized collection bins located in many local community pharmacies in the United States. However, in Malaysia, there are no such collection points or government authorized collectors. In Malaysia, the MRP program is known as "Return Your Medicines", which was introduced by the Pharmaceutical Services Division of the Ministry of Health Malaysia (MOH) in 2010 and allows the public to return unused medications to pharmacy counters in any government health facility for safe disposal (10); however, there is no compulsory participation in MRP for private-owned healthcare facilities and pharmacies. The present findings suggest that pharmacists would support government-led healthcare initiatives, provided they receive incentives and support either from the government or from their organizations. The study indicates that Malaysian community pharmacists are ready to take on this task with reasonable remuneration for the service. Factors that deter pharmacists from using the medicine returns service include lack of guidelines by the government and operational costs along with incineration fees. From a health economics standpoint, medicines wastage is wastage of budgetary resources and an opportunity cost. Studies in Malaysian public hospitals have shown that average monthly medicines wastage was much higher than that could have been spent per patient treatment (18, 19). Hence, operational costs for safe disposal remain a quandary during the budget allocation for any government. Though Malaysia does not have specific guidelines for medicines return, a legislative framework governs the disposal of hazardous and scheduled wastes from healthcare facilities and manufacturing

premises (20). The Environmental Quality (Scheduled Wastes) Regulations 2005 (EQSWR) applied the cradle-to-grave approach in its management principles of scheduled waste; this means that the onus is on the waste generators to manage the hazardous waste from the creation until its ultimate disposal, for example, by appointing a licensed contractor to collect the waste for disposal at scheduled incinerators or secure landfills. EQSWR regulates the generation, storage, treatment, transport, and disposal of scheduled waste, including unwanted and expired pharmaceuticals, only by industrial premises, hospitals and other healthcare institutions and facilities (20).

The management of unwanted expired and returned medicines could be achieved by effective stock control of close-expiry and expired medicine. Pharmacists tend to minimize the retention of expired medicines as this would affect the pharmacy's profit. Instead, close-expiry medications are sold at a lower price to cover costs and minimize profit loss. Expired medications are usually collected at a centralized company facility, which then is managed and incinerated by external waste management companies. There are other methods of reducing medicine wastage such as exchanging stocks with other pharmacies, medication reconciliation with customers and adjusting the quantities during dispensing, especially during the treatment initiation stage where patients are more likely to discontinue their treatment (21–24). Re-dispensing of returned medications is not practiced in Malaysia because of concerns regarding risks to patients arising from the condition of returned medications and the presence of counterfeit products (25). However, many studies support the re-use of returned unexpired medicines as a cost-effective method of minimizing medicines wastage (3).

Studies have suggested that minimizing medical wastage improves the quality of the healthcare system through better utilization of healthcare resources, allowing healthcare professionals to emphasize patient care (26–28).

RECOMMENDATIONS

In Malaysia, there is no specific directive on how members of the public should manage unwanted medicines. Doctors and pharmacists could minimize medicines wastage by avoiding overprescribing and encouraging consumers to return unwanted and expired medicines for safe disposal. Further studies are required on consumers' attitudes regarding the return of medicines and their safe disposal.

LIMITATIONS

This study has some limitations. In this study, purposive and snowball sampling techniques were used. Though these methods helped the researchers to discover the study characteristics of this population, sampling bias might have affected the study. Also, the sampling technique could have led to the chances of selection bias. This study focused on specific issues in a particular set of populations, hence caution should be made while generalizing

the research findings. In this study, the respondents are from chain pharmacies. Hence the results may not depict the scenarios of independent pharmacies.

CONCLUSIONS

This qualitative study revealed the perception of community pharmacists regarding the management of medicine wastage, medicine return, and safe disposal of medicines in Malaysia. Medication wastage due to unused medications in community pharmacies was kept minimal to reduce profit loss. Medicine returns were normally not accepted in community pharmacies due to operational costs except for a handful of pharmacies outlets that had the Medicines Return Program (MRP) supported at their organizational level. Disposal of unused medications was undertaken by centralizing the stocks at an organization facility before being disposed of by outsourced waste management companies. Pharmacists mentioned that MRP in community pharmacies would be widely used if there was increased public awareness about safe medicine disposal. Moreover, there is an increased need for such a service; implementation of the official MRP in community pharmacies would require government subsidies.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding authors.

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ETHICS STATEMENT

The studies involving human participants were reviewed and approved by International Medical University (IMU) Joint-Committee on Research and Ethics. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

KR and KC: conceptualization and data curation. KR and MM: methodology, writing—review and editing, project administration, and funding acquisition. DC: validation, resources, and visualization. KC: formal analysis, investigation, and writing—original draft preparation. KR, DC, and MM: supervision. All authors contributed to the article and approved the submitted version.

FUNDING

This research was funded by the Institute for Research, Development and Innovation (IRDI), International Medical University, Malaysia (MPP I-2020(07)).

ACKNOWLEDGMENTS

All authors acknowledge Prof. Brian Furman, University of Strathclyde, for his help in improving the use of English in the manuscript.

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Understanding Community Participation in Rural Health Care: A Participatory Learning and Action Approach

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OPEN ACCESS

Edited by:

Mobolanle Balogun,
University of Lagos, Nigeria

Reviewed by:

Ranjit Kumar Dehury,
University of Hyderabad, India
Esther Oluwale,
University of Lagos, Nigeria

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Specialty section:

This article was submitted to
Public Health Education and
Promotion,
a section of the journal
Frontiers in Public Health

Received: 23 January 2022

Accepted: 27 April 2022

Published: 06 June 2022

Citation:

Mishra A, Singh AK, Parida SP,
Pradhan SK and Nair J (2022)
Understanding Community
Participation in Rural Health Care: A
Participatory Learning and Action
Approach.
Front. Public Health 10:860792.
doi: 10.3389/fpubh.2022.860792

Community participation is one of the founding pillars of primary health care. However, due to various reasons, we are yet to achieve complete integration of this component into the health system functioning in India. The objective of our study was to do a formative assessment of community participation in a rural healthcare setting by adopting participatory learning action (PLA) technique. The study participants included frontline health workers and members from local governing institutions of rural areas. The study design is qualitative in nature with a participatory approach. A number of three PLA techniques have been used as a part of this study to recognize available resources for community participation, address its barriers and facilitators, and finally devise a time-line-based action plan. Based on the this, a conceptual framework for community participation pertaining to the rural healthcare system has been developed. This study highlights the importance of understanding the psychosocial aspects of community participation among various stakeholders involved in rural health care. Lessons learned from this PLA study will be helpful in the integration of community-based participatory approach within grassroot level healthcare planning and service delivery.

Keywords: community participation, participatory learning and action, rural health, health system, community engagement

INTRODUCTION

Community participation is a key factor that enables effective health system functioning and is the first step toward true community empowerment in health (1). This is one of the founding principles of Primary Health Care since Alma Ata declaration, 1978. This principle reflects the underlying value of social justice in improving health, especially in deprived areas, through the involvement of the community in planning and implementation of activities toward building a healthy society (2). The way public health interventions are executed through community participation is critical to achieving a sustained improvement in health outcomes within the community (3). India is a multi-cultural, multi-ethnic developing country with diversity in health issues and challenges, which requires a sustained community participatory approach toward health compared to other countries in the world. Community participation in health has been developed and evolved in the past few decades and is rightly being augmented by the health system at the policy level in India (4, 5). Institutionalized mechanisms such as Village Health Sanitation and nutrition

committees (VHNSCs), Rogi Kalyan Samiti (RKS), Panchayati Raj institutions (PRIs), Gaon Kalyan Samiti (GKS), and Self-help groups (SHGs), and so on have been the significant contributors for promoting community participation in health, especially in rural areas (6, 7). However, India is still struggling to achieve inclusive and sustained community engagement within health system due to uneven functionality and effectiveness of community participation across the country (8–10).

Planning is now considered as a “people-driven” activity, in which each level of governance has been given some degrees of self-governance and has to coordinate with each of their successive levels to implement their share of activity. This is brought the concept of micro-planning through people’s participation. The “base upwards” all-inclusive planning based on the micro-planning exercises comprising multiple stakeholders could be the key toward self-resilience and demand generation (11). Incorporation of these concepts into the research ecosystem has led to the emergence of participatory methods in community-based research.

Participatory learning action (PLA) is one of these approaches which is applauded for building local capacity to work toward a healthier community. Initially, it was known as participatory rural appraisal (PRA). due to its prominent usage in rural appraisal and resource management. But later, it was adapted for other contexts such as health care, poverty, malnutrition, governance, livelihood, and so on and formally termed as “Participatory Learning Action” (PLA) (12, 13). PLA’s main goal is to help people in communities analyze their situations rather than relying on outsiders to do so and to ensure that any learning is then translated into action. This strategy aids the primary stakeholders, who are often poor or from rural populations, in taking ownership throughout the process. It also allows the residents to discuss local-level issues, identify, prioritize issues or challenges, and develop practical action plans to address these complex situations. The use of PLA tools as a part of formative community engagement is a sustainable, low-tech, and labor-intensive technique for establishing ties between health workers and community people prior to the implementation of initiatives. The PLA has been contributing significantly to qualitative public health research, especially in the field of maternal and child health as well as nutrition (14, 15). Government of India has also recognized the role of PLA in empowering local institutions for identifying and planning for health-related problems within the community (16, 17).

There is a need for meaningful research, especially through a participatory approach to explore factors affecting community participation and achieving true community empowerment within the public healthcare delivery system. Many findings imply that applying PLA methodologies to the sensitive and understudied subject of gap identification and prioritization might yield contextual data on need assessment, mobilization, and group building experiences. Finally, participatory techniques can aid in the design of evaluations as well as the discovery of causal pathways and potential mechanisms for program change.

Research Context

Odisha, a state from eastern India, is home to more than 40% socially vulnerable population with majority of them deprived in terms of key human development matrices (18). While engaging with the community in one of the rural field practice areas of All India Institute of Medical Sciences (AIIMS), Bhubaneswar, Odisha, it was observed that there is a sense of dormancy toward community participation within the population and villagers perceived health care as the responsibility of government and frontline health workers. Community participation had been limited only to Information Education and Counseling activities, thereby limiting the creative potential of community members in planning and implementation of public health interventions at the local level. This perception has been backed by evidence from various studies in India (19–21). To further enhance the understanding in this context, this study was planned through a PLA approach while involving various stakeholders associated with rural healthcare delivery at the village level. The objective of the study was to identify and explore the contextual factors embedded in the current healthcare delivery process through community participation at the village level.

METHODOLOGY

Study Setting

The study was conducted in rural health training center, Tangi operated under the Department of Community Medicine and Family medicine, AIIMS Bhubaneswar. A total of 10 villages were selected among 143 villages from the Tangi block of Khordha district, Odisha. The criteria used for their selection were based on average infant mortality rate during the last 5 years. It was assumed that the infant mortality rate represents the challenging health scenario of these villages (22).

Study Design

The study design is qualitative type where PLA methods are being applied among a conveniently sampled group of participants (23). A qualitative design also provided deeper understanding of how PLA can empower the stakeholders involved in rural healthcare delivery system toward decision-making through community centered group activities.

Study Participants

A team of resident doctors and medical social workers visited all the selected 10 villages and held discussions with key community members (PRI and GKS members, Ex-PRI and Ex-GKS members) as well as healthcare workers from those villages. At the end, 20 participants were nominated through an agreement between our team and key community members from each village. The aim of this activity in this study was to recruit individuals who were decision-makers or opinion formers or service providers from each village. The distribution and key characteristics of study participants have been explained in **Table 1**.

A total of four types of participants were recruited based on their designation and representation in various aspects of rural health care. The ASHA represents the implementation

TABLE 1 | Characteristics of study participants ($n=20$).

S. No.	Participant	Frequency (%)
(a). Gender		
1.	Male	5 (25)
2.	Female	15 (75)
(b). Age group		
1.	<30 years	5 (25)
2.	30–60 years	13 (65)
3.	>60 years	2 (10)
(c). Educational status		
1.	Primary to Secondary level	6 (30)
2.	Higher secondary to Intermediate level	10 (50)
3.	Graduate and above	4 (40)
(d). Designation		
1.	Accredited Social Health Activist (ASHA)*	10 (50)
2.	Gaon Kalyan Samiti (GKS). member	4 (20)
3.	Panchayati Raj Institution (PRI). member	2 (10)
4.	Self Help Group (SHG). member	4 (20)

*Each team was having one ASHA.

aspect, the GKS and PRI members project the decision-making and resource utilization aspect, and finally, the SHG member represents the community engagement aspect. We have maintained homogeneity within each group as far as the educational level of participants is concerned, which balances reflexivity in qualitative methods.

Participatory Learning Action (PLA) Tools

We used three PLA tools for this study to understand the participant groups perception toward resource identification, planning, and implementation of solutions for health-related concerns through community participation. The activities were aimed to obtain knowledge of the situation—specifically, community stakeholders' experiences—in terms of perceived obstacles and enablers in the village, the status of various community resources, and preferences for aligning with a village health plans through community participation.

The PLA activity was spanned over 2 days with the first day being used for orientation of participants regarding the exercises followed by the PLA session and presentation on the second day. A total of 10 teams from 10 villages participated in the PLA session with three exercises for each team separately. The overall process has been summarized as Facilitation and Dissemination.

The three PLA tools used were as follows: H diagram, resource mapping, and now, sooner, and later (NSL). chart. All of them had been pilot tested in the community before their application in this exercise. The pilot testing was done in one village. They are explained in **Table 2**. A PLA tool guide was prepared based on validated standard methodology (24, 25).

Facilitation

Each PLA exercise was facilitated by one member (medical social worker). of the research team trained in conducting participatory

TABLE 2 | Summary and objectives of PLA techniques.

S. No.	PLA tool	Objective and implementation
1.	H-Diagram	The objective of this activity was to identify enablers and barriers toward community participation in health within their villages. Each team was instructed to list out facilitators in one arm and barriers in another arm of H-diagram in a chart paper.
2.	Resource mapping	The objective of this exercise was to identify the location and distances of available resources in the community contributing to health in their villages. Each team was instructed to plot the identified resources on village map in a chart paper based on the geographical direction and distance. They listed distance in terms of time duration (hours, minutes). and space (meters, kilometers).
3.	NSL (Now, Sooner, Later). chart	The objective was to classify the local solutions through community participation based on factors and resources identified in previous two activities. During this urgency and importance of the problems were also taken into consideration. All the teams were asked to prepare an action plan and put the solutions in three boxes, i.e., now (within 3 months), sooner (3 months to 1 year), and later (1 to 2 years)

research. Once the invited participants had gathered at the meeting hall, the facilitators welcomed them and provided all the logistics required for PLA exercises. The role of the facilitator was to communicate the instructions and guide the team without interfering in the PLA process proper. Another member was assigned for the documentation and reporting of all the activities. Each team was given 3 h each to complete the exercises. The team also prepared detailed field notes including short non-formal interviews with the key participants. So, in total, 30 PLA exercises for the selected 10 villages have been included in the study (**Figures 1–5**).

Dissemination

After the completion of the PLA exercises, each team presented and summarized key findings from PLA session and invited feedback from other participants. It was a participant-driven discussion that was documented by our reporting team for further analysis.

Data Analysis

We used the data from worksheets of PLA exercises and final dissemination in the form of open discussion among participants to construct conceptual categories which characterized major themes. A qualitative content analysis of the data was performed through deductive approach (26, 27). It was our objective that any generalized theoretical statements in the form of verbatims would be embedded in these thematic categories and subcategories. The Quirkos qualitative data analysis software was used to undertake coding, analysis, and data management for this study. The content analysis was done in the following ways. As the



FIGURE 1 | PLA activity.



FIGURE 2 | Dissemination and participant driven discussion.

first step, the data were reviewed and transcripts were re-read to identify important codes under deductive approach. Then, the patterns and possible relationships between codes were identified and organized into categories and themes. The statements in the field notes were categorized and analyzed according to the frequency in general, frequency in each field note from different facilitators and controversial discussion of the statements from participants. Typical statements were marked and used for later citation through consensus among investigators. Analysis, interpretation, and conclusions were meticulously drawn describing the study context and the attributes of the study participants.

Ethical Consideration

The written consent of the participants was taken and the study protocol was approved by Institutional Ethical Committee of AIIMS Bhubaneswar (IEC ref. no.: T/IM-NF/CM&FM21/53). In addition, permission for documentation of PLA sheets and discussions were obtained from all participants. Names of participants were excluded from the final datasets to ensure confidentiality and anonymity.

RESULTS

In this section, we present the key thematic findings from each of the three PLA techniques which were synthesized from

facilitators' notes for each team as well as from our ethnographic observation. We identified three interrelated themes, i.e., factors, resources, and action plan, based on of stakeholders' experiences and perspective on community participation. The "Factor" theme was further divided into subthemes of barriers and enablers. The categories under each theme have been explained further in the result section. Based on the final analysis results, a framework for community participation with respect to rural health care was developed (Figure 6).

The Factors

In this PLA exercise, community members across almost all villages spoke about the importance of identifying the enabler and barriers toward different aspects of health through the H-diagram.

Enablers

Many participants identified the existing social coherence in their villages as one of the significant enablers of community participation.

"In my village, there is a sense of belongingness to the society... Everybody feels to be a part of a larger family and tries to contribute in whatever way possible if needed by the village..."
(PRI member)

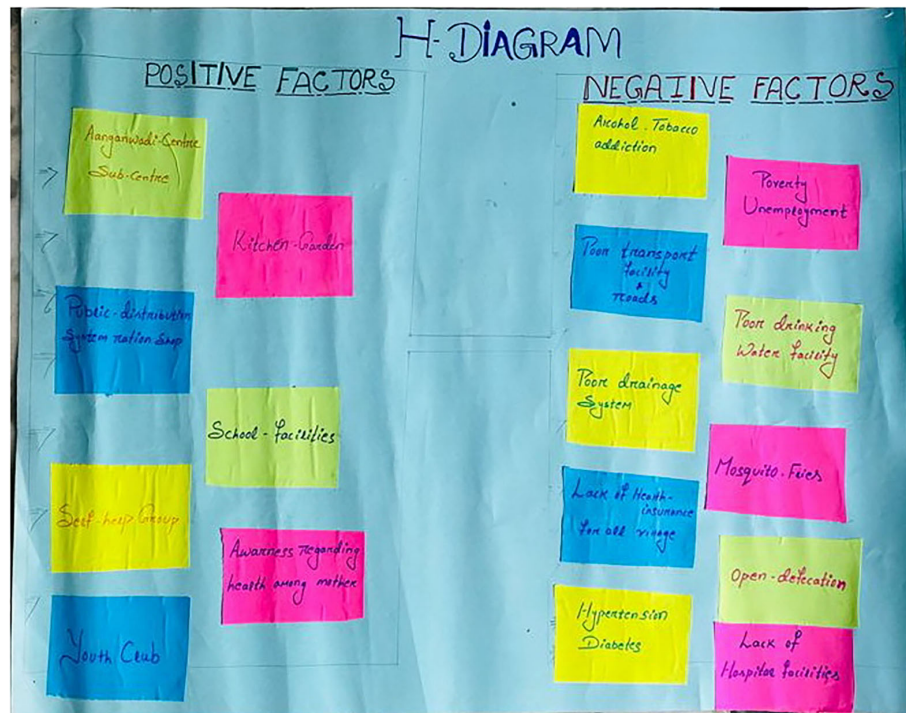


FIGURE 3 | H-diagram.



FIGURE 4 | Resource map of a village.

ପ୍ରଶ୍ନ	ଉତ୍ତର	ମନ୍ତବ୍ୟ
1. କିପରି କରାଯାଇଛି ?	1. ନାମ ନିର୍ଦ୍ଧାରଣ ସଂପର୍କୀତ	1. ମନ୍ତବ୍ୟ ମଧ୍ୟରେ ନାମ ଦେଖାଯାଇଛି ।
2. କିପରି କରାଯାଇଛି ?	2. ପୋଷ୍ଟାଲ ସଂପର୍କୀତ	2. ମନ୍ତବ୍ୟ ମଧ୍ୟରେ ନାମ ଦେଖାଯାଇଛି ।
3. କିପରି କରାଯାଇଛି ?	3. ମାଧ୍ୟମିକ ସଂପର୍କୀତ	3. ମନ୍ତବ୍ୟ ମଧ୍ୟରେ ନାମ ଦେଖାଯାଇଛି ।
4. କିପରି କରାଯାଇଛି ?	4. ମାଧ୍ୟମିକ ସଂପର୍କୀତ	4. ମନ୍ତବ୍ୟ ମଧ୍ୟରେ ନାମ ଦେଖାଯାଇଛି ।
5. କିପରି କରାଯାଇଛି ?	5. ମାଧ୍ୟମିକ ସଂପର୍କୀତ	5. ମନ୍ତବ୍ୟ ମଧ୍ୟରେ ନାମ ଦେଖାଯାଇଛି ।

FIGURE 5 | NSL Chart prepared by a team.

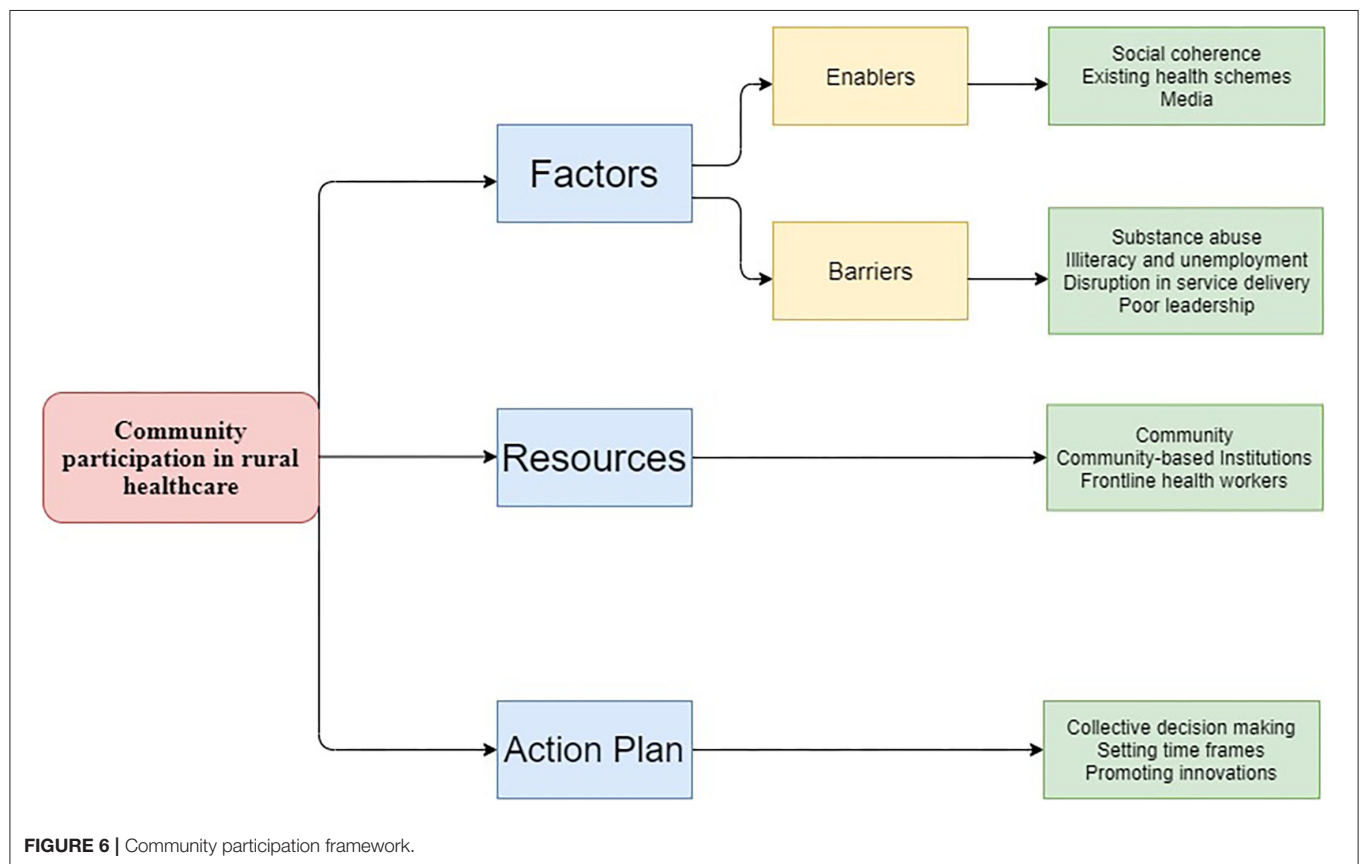


FIGURE 6 | Community participation framework.

All the stakeholders reported that schemes such as Ujjwala Yojana (free LPG gas connection), Swachh Bharat Mission (free toilet), Public Distribution System (PDS), and so on have played a significant role in maintaining the health in their community. In addition to this, these schemes have also helped to build an enabling environment for community participation at the village level either directly or indirectly. Most of the participants echoed the fact that maternal and child health care have improved significantly in their villages due to community participation in public health programs and enhanced awareness within the female community.

“When we think about delivery 8–10 years back, most of the families were preferring home deliveries and we had to counsel them to go to the hospital for institutional delivery... Now the government is providing so much financial and other types of support to pregnant mothers... So, they are opting for delivery at hospitals. Even the number of mothers participating in VHNDs has also increased.” (ASHA)

Most of the participants felt that the COVID-19 pandemic has made villagers more responsible toward disease prevention within their community. Many of them agreed that this pandemic has taught the villagers how health is a collective responsibility of everyone within their community. The local PRIs also feel more empowered due to the role played by them in managing this pandemic at the village level through community participation.

“During this pandemic, the government empowered the PRIs in many ways to deal with it... As we are staying in villages, we are more motivated to keep it safe... Villagers also supported us in this fight against COVID except for few instances when we had to take the help of law.” (PRI member)

Many participants emphasized the role of media and the internet in improving community participation in their villages as they have increased the availability of information as well as the speed of communication.

“Now-a-days health-related information are available in news media and the internet. People are getting the right information at the right time which is motivating them to take part in various community-based health-related activities” (GKS member)

Some of the stakeholders were less vocal about the enablers of community participation in their community as they were more concerned about the barriers. On the other hand, the participants also expressed a need for further improvement in some of the enabling factors of community participation highlighted by them.

Barriers

Social challenges such as illiteracy, migration, unemployment, and the lack of awareness regarding health were described as the most important barriers toward establishing health as a shared responsibility among the rural population.

“Villagers are so much entangled in the day-to-day issues that health becomes the least priority for them. Many villagers who are without

regular employment are busy in their daily struggle for income.” (PRI member)

Almost all the participants identified alcohol and other substance abuse as a significant challenge from a public health perspective in their community. They also highlighted that alcohol abuse leads to an increased incidence of other social evils such as domestic violence, sexual abuse, and so on. Problems such as substance abuse and local politics have eroded the social cohesion existing in villages. This in turn is hampering the environment for social mobilization as well as sustained collaboration required for community participation.

“As the government is providing free ration to poor villagers, they are using their income in buying alcohol... It's not like they are unaware of ill effects of alcohol... but initially, they start it due to peer pressure and later they get addicted... So many people are getting admitted in hospital due to liver problems...” (SHG member)

“No major community awareness event has ever been implemented in our village related to prevention of alcohol abuse” (ASHA)

As per some participants, disruption in service delivery has also affected the enthusiasm toward community participation among the village population. Dissatisfaction among the community regarding the quality of health care affects the motivation of villagers toward community participation. Some of the participants also highlighted that many from the rural population are depending on private health care for health services making them less enthusiastic toward community participation.

“Previously we used to have more adolescents girls coming to VHNDs as we were distributing sanitary pads at affordable costs... But since few months we are not being able to provide them... this has affected the footfall of girls in VHNDs...” (SHG member)

Among other barriers highlighted by the participants, the lack of leadership quality among PRIs and failure of government in solving some of the pre-existing problems related to basic health needs of villages have affected the involvement of villagers in community-based health events.

The Resources

All the participant groups mapped the resources playing a significant role in maintaining health in their community through a resource mapping exercise. Only three out of 10 villages had subcenter in their village and none of the villages had a primary health center. Although most of the villages had primary health centers within manageable distance, poor road connectivity was one of the important issues highlighted by the teams. Few villages were having community centers but were seldom utilized for health-related events.

“For most of the common ailments, our villagers go to the nearest Primary health centers... Due to poor road, it almost takes 1 h to reach the primary health center... On the other hand for

community-based events related to health, we either use schools or Anganwadi” (PRI member)

The most important resource for community participation in villages was the ASHAs and AWWs as agreed by most of the stakeholders, especially the PRI members and SHG members.

“In our villages, people approach ASHAs first for any health issues as they are easily approachable and they are working very hard. People trust ASHA and Anganwadi workers because they always try to create awareness about health within the community by involving villagers, especially women” (GKS member)

Most of the ASHAs and AWWs were staying in the same locality and were well engaged with the community assigned to them. In case of any community-based activity, ANM and ASHA take the lead role in community mobilization. AWW, members from PRIs and SHGs, support them in reaching to villagers and creating positive opinions regarding the event within the society. Few participants reported that now-a-days school teachers are getting involved in health-related events such as the Measles-Rubella campaign, mass drug administration, and so on in villages. However, primarily, they are involved in teaching and providing nutritious food to school children through a mid-day meal program.

“School teachers come to our village for survey and some other health-related campaigns... On the other hand, our children get mid-day meals in schools but here the school is quite far from our village... The food quality in schools can also be improved” (GKS member)

As per the participants, most of the villagers were having farming and daily labor as an occupation. But they were dependent on the public distribution system (PDS) for subsidized monthly food supply through ration cards. On the other hand, it was voiced by some members that food security is no replacement for nutrition security and kitchen gardens are trying to fill this gap to some extent. Some other resources such as drinking water supply and proper drainage were mapped by the team members but during discussion, and they expressed their dissatisfaction due to poor accessibility and maintenance. They also agreed upon the need for villagers to take the responsibility for maintaining a clean and hygienic village environment.

“Our village had drainage system for last 3 years but most of the time it remains blocked due to poor maintenance... Some villagers use this as an excuse to stay away from community-based cleanliness drives that we plan occasionally. Villagers dispose of all the wastes into drainage and nobody cares for its cleaning...” (ASHA)

Most of the stakeholders were putting the responsibility on government administration for equipping the villages with sufficient resources needed for a healthy community. Many participants agreed that community mobilization needs sustained efforts and not just resources as it has a significant role in primary health care, especially in resource-limited settings.

“The fund that we receive from government are very little to solve the problems... Crowdfunding is not an option always as there is a chance of corruption... Villagers should also be more responsible toward utilizing services. For example... Despite getting free toilets built in their backyards, people are still going for open defecation...” (PRI member)

Most of the participants were able to identify the resources and their utilities already available in their villages in improving community participation. They considered local level institutions such as AWC, subcenter, schools, and panchayat office as the essential resources promoting community participation in their villages. However, they were lacking in orientation toward a structured approach for community participation in solving local problems and utilizing available resources.

The Action Plan

All the teams were asked to prepare an action plan for community participation in their village using now, sooner, later (NSL) chart as a part of the final exercise. The participants were realistic in preparing the action plan as most of them were well aware of their limitations. The action plan was based on priority issues identified by the teams and resources available to their village. The majority of the teams planned to restart and strengthen existing activities such as adolescent health days, monthly mother's meetings, cleaning drainage, and so on within 6 months. Few SHG members suggested planning awareness campaigns within their community against issues such as alcohol abuse, early marriage, open defecation, and so on. Some even suggested innovative approaches such as creating social media groups, peer support groups among elderly patients, and increasing the number of “Swasthya Kantha” (village health awareness walls) in their villages within the next few months. Participants also planned to contribute vegetables from kitchen gardens to AWC, so that their children can get nutritious food even at AWC.

“Now-a-days every household has a mobile phone. Why can't we form what's app groups and send awareness messages through them... We can plan meetings and discussions through them!!!!...” (GKS member)

Under long-term plans, some villages proposed collaborating with local NGOs in implementing their annual action plans for their community. Crowdfunding was also discussed as an option to implement low-cost solutions through proper planning and transparency. GKS members from some teams suggested improving the coverage of beneficial health-related schemes such as Biju Swasthya Kalyan Yojana (Biju health insurance scheme) and other social benefit schemes to get more community support. The majority of the teams also pointed out that they would promote physical activity and adoption of a healthy lifestyle through community participation as a part of their action plan to tackle NCDs in their community. All the villages, especially those teams with SHG members stressed working toward improving menstrual health in their community by strengthening adolescent health services in their community.

"Our girls need to adopt better menstrual hygiene practices... I have read somewhere that the local SHGs in some of our villages are making sanitary napkins by themselves... We will also plan to do that in our village... but we need some training and funding... let's see how it proceeds..." (SHG member)

Although all the team members were very much excited in preparing an action plan for their villages, many of the interventions they identified needed infrastructural changes (e.g., building roads, hospitals, etc.). All of them agreed to highlight these needs in front of the administration more sensibly and coherently.

"Although our plans include many actions in near future... we will work more toward creating a sense of collective responsibility within community members as maintaining a healthy environment in our villages is the priority now for us..." (GKS member)

"No doubt that without government support we cannot act on our plans... But to change our community, we need to change ourselves first... We need to change our behaviors... Schemes are there... but we will work on its implementation so that more people get benefitted..." (PRI member)

Most of the participants agreed that there is already an existing system for community participation in every village. Many participants stressed the need for regular village meetings with health as a priority topic to maintain a sense of urgency among the general population. Most of the teams also echoed the fact that the PLA technique can be very much useful in planning for healthcare interventions at the village level.

DISCUSSION

For all the participants, this exercise was a novel experience as most of them were used to a reactive work culture rather than a proactive one. Our findings demonstrate that employing the PLA mode of engagement and participatory techniques can result in the meaningful association of stakeholders who came from diverse backgrounds but work toward achieving a common goal. Already, there is enough evidence existing with regard to the effectiveness of the participatory approach in bringing improvement in the health status of the community (28, 29). However, incorporating it into the routine work culture and sustaining it would be more fruitful if we are to achieve effective community empowerment.

This study reinforced the fact that frontline health workers such as ASHAs are the face of the health system within the rural community and would continue to remain the same in the future (30). Similarly, It was observed that self-help groups (SHGs). have emerged as an essential component of community participation in the healthcare delivery system due to a broad population coverage and significant social capital produced by their activities in rural areas (31). But the GKS and PRI members were much more focused on the unavailability of resources rather than utilization of the available ones. This may be associated with poor multisectoral convergence and lack of leadership quality needed for healthcare delivery at the village level (32).

Many of the participants acknowledged that major communicable diseases had been tackled successfully through community participation. This has been backed by various Indian studies done in the field of undernutrition and communicable diseases (33–35). However, all the participants took note of the emergence of newer health-related challenges such as non-communicable diseases (NCDs), the ongoing COVID-19 pandemic as a significant threat to the health of their community which is obvious due to the epidemiological transition that has been witnessed at the global level including India (36). On the other hand, it has been recognized that community participation will play an even bigger role in tackling these future challenges. But, the frontline health workers still lack clarity on the role of community participation in NCD control, probably due to poor supportive supervision and implementation issues (37).

This study highlighted many common challenges related to health faced by villages but the PLA session prompted the attendees to think on solutions with the minimal resources available to them through community participation. This may help in activating the social accountability system within their community when they start working on their action plans. Through this process, the participants acknowledged that their strategy for health education must evolve from creating health awareness to achieving health literacy. A study on the tactics and effects of integrated community case management (iCCM). program in Niger and Mozambique demonstrated that service uptake can be improved through community involvement with a significant emphasis on demand generation (38). It was also perceived by most of the participants that community participation must focus on preventive strategies in addition to curative ones. On the other hand, it was also observed in our study that there is a sense of pessimism among participants, which needs to be addressed through sustained dialogue with political as well as administrative stakeholders (39, 40).

Community participation is widely believed to be beneficial to the planning, implementation, and evaluation of health services (15). It has potential advantages and consequences for community empowerment, with regard to health care, as well as promotion of locally appropriate services to reflect community needs (41). One study from rural Mexico found that patients did not have access to complete advanced treatment prior to the launch of the Right to Health Care Initiative, a community participation activity (42). However, this study showed that many challenges to successful and sustainable community involvement still remain. Francesca and Nicholas in a similar study done in India reported how mechanisms for community participation have been hampered due to confusion between accountability and decentralization functions of grassroot level institutions (43). Committees such as VHNSC, GKS, and so on are the ultimate representative of community participation in health. But, the presence of these community-based mechanisms must be added by professionalism and teamwork attitude to bring about transformation in their functioning. Similarly, there must be clarity on the path to be followed by the stakeholders in empowering these institutions with adequate resources (44).

We conclude that the PLA activity helped augment the knowledge, capacity, and self-confidence of participants to enact village health plans through community participation in a rational and effective manner. Participants credited this transition to the intervention and to the participatory approach which involved group members in critical thinking through need assessment and active dialogue. Although community participatory approaches in health have been undermined for a large duration due to its resource-intensive and complex nature, they can be a game changer if utilized logically. Participatory learning activities can become a potent intervention for addressing health issues at the village level by helping the community in shifting away from passive to active community participation. There is a need for reinforcement of public health responses to empower local organizations at the village level to complement community-based efforts. The health system needs to focus on skill upgradation and capability reinvigoration among all stakeholders of rural health care to provide adequate leadership required for community participation. Most important of all is the development of the “spirit” of participation in the society, which needs a balanced approach involving people, policy and pragmatism.

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DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors without undue reservation upon reasonable request.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Institutional Ethical Committee, All India Institute of Medical Sciences, Bhubaeswar. The patients/participants provided their written informed consent to participate in this study. Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

AUTHOR CONTRIBUTIONS

AM, SKP, and JN did the literature search, data acquisition, data analysis, and manuscript preparation. AM, AS, SPP, SKP, and JN contributed in manuscript editing, manuscript review, concepts, design, and definition of intellectual content. All authors contributed to the article and approved the submitted version.

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Roles and Challenges for Village Doctors in COVID-19 Pandemic Prevention and Control in Rural Beijing, China: A Qualitative Study

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Specialty section:

This article was submitted to
Family Medicine and Primary Care,
a section of the journal
Frontiers in Public Health

Received: 02 March 2022

Accepted: 06 June 2022

Published: 29 June 2022

Citation:

Li J, Zhao N, Zhang H, Yang H and
Yang J (2022) Roles and Challenges
for Village Doctors in COVID-19
Pandemic Prevention and Control in
Rural Beijing, China: A Qualitative
Study.
Front. Public Health 10:888374.
doi: 10.3389/fpubh.2022.888374

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Objectives: Rural areas in China are more vulnerable to COVID-19 pandemic than urban areas, due to their far fewer health care resources. Village doctors, as rural grassroots health workers in China, have been actively engaged in the pandemic prevention and control. This study aims to describe the roles of village doctors in rural China, and the challenges they have faced during the prevention and control of the COVID-19 pandemic.

Setting: This study was conducted in three towns in Huairou District, Beijing, China.

Design: We carried out semi-structured interviews with 75 key informants. All the interviews were audio-recorded and transcribed verbatim. We employed thematic analysis to define themes and sub-themes from the qualitative data.

Results: We reported four themes. First, the village doctor guided the village committee to carry out decontamination, monitored home-isolated residents, and disseminated knowledge on prevention of the COVID-19 pandemic during the rural pandemic prevention and control. Second, they took pandemic prevention measures in village clinics, distributed pandemic prevention materials, and undertook pre-screening triage. Third, village doctors provided basic medical care, including treatment of common diseases as well as the purchase and delivery of medicines to villagers. Fourth, village doctors faced difficulties and challenges, such as inadequate medical skills, aging staff structure, and lack of pandemic prevention materials.

Conclusions: Despite many difficulties and challenges, village doctors have actively participated in rural pandemic prevention and control, and made outstanding contributions to curbing spread of COVID-19 pandemic in rural areas. Village doctors provide basic health care while participating in various non-medical tasks.

Keywords: rural area, village doctor, COVID-19, qualitative study, prevention and control of pandemics

INTRODUCTION

Since the first case of coronavirus disease 2019 (COVID-19) was detected in Wuhan, Hubei Province in December 2019, COVID-19 had spread rapidly worldwide (1), having a profound impact on daily lives. Many provinces in China have consecutively reported confirmed cases. In order to control the fast spread of COVID-19, China took the strictest, and most thorough prevention and control measures (2, 3). The Chinese government adopted such “non-medical” measures, as closing community, prohibiting social activities, and scanning “health codes”, which had proven to be significantly effective (4). In preventing and controlling COVID-19, rural areas cannot be ignored, despite its low population density, relatively fixed places for villagers’ activities and low population mobility (5). One reason is that compared with urban areas, rural public health emergency system is much weaker, definitely increasing the risk of infection for rural residents (6). Additionally, rural populations don’t have equal medical resources as those in urban areas making it more difficult to quickly detect pandemics and treat infected patients (7).

In late January 2021, there was a localized pandemic in Hebei Province, with more than 85% of infected patients coming from rural areas (8). Different from the early 2020 this time the pandemic broke out and spread widely in rural areas. As the “gatekeeper” of farmers’ health at bottom of the rural three-tier medical service network, village doctors function as an important component of the rural pandemic prevention and control team (9). Village doctors are required to provide basic medical and public health services to rural residents including health education, assistance in the implementation of infectious disease reporting and other prevention and control measures, and responding to public health emergencies. The State Council also issued a series of policies during the pandemic that specified the responsibilities of village doctors in COVID-19 prevention and control. Those responsibilities include monitoring the health status of residents in home isolation, assisting in tracking close contacts and conducting epidemiological investigations, as well as improving health management of priority populations with chronic diseases (10, 11).

Village doctors in China, on the other hand, are facing difficulties and challenges. Currently, part of village doctors are transformed from “barefoot doctors” (12). Mostly overage, less educated, less qualified and incompetent in information technology. Those features affect the quality, efficiency and accessibility of basic public health services (13–16). Therefore, it is worth studying what village doctors do, what roles they play, and what new challenges they are facing during the COVID-19 pandemic.

Previous studies have researched the roles and challenges of medical workers in the prevention and control of COVID-19 pandemic. Scholars from China, UK, Ireland, Singapore and other countries have studied the barriers and coping strategies of primary health workers in COVID-19 pandemic control (17–19). Several studies have found that medical workers face high levels of work stress and psychological pressure and lack of social support during the COVID-19 pandemic (20–23).

Previous researches have researched the impact of the COVID-19 pandemic on special populations such as pregnant women, newborns, patients with chronic diseases, and school students (24–27). There is also research on how pandemic prevention and control is carried out in rural China and the challenges faced in rural areas (28). Hsu et al. and Putzer et al. argued that rural infrastructure and health resources were inadequate to respond to public health emergencies, and that vast majority of village doctors did not have confidence in diagnosing or treating public health emergency cases (29, 30). However, there is no literature on the participation of health workers in China in pandemic prevention and control in rural areas and the difficulties they encountered in rural settings.

According to the National Bureau of Statistics, by the end of 2020, China’s rural population has reached 510 million, accounting for 36.1% of the total population. The official media reported that more than 4 million primary health workers in China have actively participated in the prevention and control of the pandemic, including 1.44 million village doctors, who play an important role in community prevention, control and screening personnel (31, 32).

Beijing has a population pattern of “big city, small rural area”. By the end of 2019, the resident population of Beijing was 21.536 million, including 2.886 million in rural areas. In the prevention and control of the COVID-19 pandemic, the prevention and control work in the capital city is vital, and making good efforts in its rural areas also can lay important foundation for the social stability in the capital city. Rural areas are the weak point of the health care system in Beijing, with relatively insufficient medical facilities and health manpower, and low awareness of disease prevention among rural residents. Remote rural areas have complex terrain, scattered dwellings and shortage of village doctors. Some mixed urban and rural areas are densely populated, highly mobile, with complex environments and insufficient quality medical resources. Hence there was greater pressure to prevent and control the COVID-19 pandemic in rural Beijing. Beijing has issued a series of documents requiring primary medical institutions to strengthen the monitoring and reporting of pandemics and to strictly manage fever and suspicious cases, as well as to strengthen rural pandemic prevention and control education and health management (33, 34).

As the first defense line of pandemic prevention and control in rural areas, village clinics and village doctors have made necessary contributions to the COVID-19 pandemic (35, 36). Hence, it is reasonable to have a comprehensive understanding of the roles of village doctors and challenges they may face in the prevention and control of COVID-19 pandemic, and offer suggestions for improving the rural public health emergency system.

MATERIALS AND METHODS

Study Design

This study adopted a qualitative research method, using semi-structured interviews to collect respondents’ views and experiences. Given the limited research related to the role of village doctors in rural pandemic prevention and control,

TABLE 1 | Selection of respondents for interviews (%).

Respondents	Town X	Town Y	Town Z	Total
Village doctors (P1–18)	8 (29.6)	5 (20.8)	5 (20.8)	18 (24.0)
Village officers (P19–33)	5 (18.5)	5 (20.8)	5 (20.8)	15 (20.0)
Residents (P34–63)	10 (37.0)	10 (41.7)	10 (41.7)	30 (40.0)
Town health center managers (P64–69)	2 (7.4)	2 (8.3)	2 (8.3)	6 (8.0)
Town government managers (P70–75)	2 (7.4)	2 (8.3)	2 (8.3)	6 (8.0)
Total	27 (100.0)	24 (100.0)	24 (100.0)	75 (100.0)

* “P” refers to participant.

we chose a thematic framework analysis approach to explore and analyze these issues (37, 38), because thematic framework analysis is particularly well suited for identifying policy- and practice-relevant findings (39). We designed a semi-structured interview based on relevant policies and several rounds of expert consultation. Specific questions were developed for different interviewees to understand the role of and problems from village doctors in pandemic prevention and control. We selected a village doctor, a village officer, a villager, a town-level community health center manager, and a town government manager for pre-interviews before the formal interviews. Major topics covered responsibilities of village doctors during the pandemic, changes in the number of patients who visited village clinics during the pandemic, the way how village doctors provided medical services during the pandemic, and difficulties encountered in providing medical care (see **Supplementary Material**).

Study Area and Recruitment

This study was carried out in three towns in Huairou District, Beijing. Huairou District is a distant suburban district located in the northeast of Beijing, with a total area of 2,122.8 square kilometers, of which the mountainous area accounts for 89%. There are 14 towns and 284 administrative villages in the region, and a resident rural population of 121,000. Huairou is the region with low incidence of COVID-19 in Beijing. Until March 1, 2021, there were only 8 confirmed cases, ranking Huairou the last fourth in terms of case numbers. Based on the three aspects of geographic location, accessibility of health services, and the number of infected cases, three towns, X, Y and Z, were selected in Huairou District. X town belongs to shallow mountainous terrain with no COVID-19 cases reported. There are 21 administrative villages, with a permanent population of 15,754, and 21 village doctors aged 59.9 years on average of whom 4 are capable of doing pharyngeal swab sampling. Y town belongs to deep mountainous terrain with no COVID-19 cases reported. There are 24 administrative villages with a permanent population of 3,560, and 20 village doctors aged 64.7 years on average. All village doctors in Y town are not capable of doing pharyngeal swab sampling or epidemiological investigation. Z town belongs to plain terrain with reported COVID-19 cases. There are 18 administrative villages with a permanent population of 18,657, and 16 village doctors aged 64.2 years on average, all of whom cannot do pharyngeal swab

sampling or epidemiological investigation. Interview sites were selected considering the village geography, size, population and distribution of village clinics. Five villages were selected in each town (2 large villages, 2 medium villages and 1 small village). Two towns government managers and two town-level health center managers were selected for each town. In each village, two villagers, a village officer and a village doctor were selected (6 village doctors in 3 villages in X town). All participants agreed to be interviewed after they understood the purpose of the study.

Data Collection

The interview data were collected from March 2021 to July 2021, when Beijing has achieved the normalization of pandemic prevention and control, and the administrative village in Huairou District has also finished its closed management. All interviews were conducted face-to-face by interviewers who had been trained for conducting qualitative research. We trained a total of 12 interviewers. With the help of the district health administration, we also conducted semi-structured interviews with the community health center managers and government managers in each town. Before interviewing, we first explained the purpose of the study, voluntary participation, and principle of confidentiality to the interviewees and obtained their written informed consent. Afterwards, the interviews were noted and audio-recorded throughout the process. Interviews lasted 40–80 min.

Data Analysis

The audio records of the interviews were transcribed verbatim and collated within 48 h. We developed a seven-stage analysis framework: (a) familiarizing with original materials; (b) identifying important themes or keywords; (c) listing original themes catalog or analytical framework; (d) coding original materials based on the theme catalog; (e) categorizing data based on themes or sub-themes; (f) summarizing or synthesizing data; (g) explaining data. Two researchers completed the previous five steps independently, and then invited several experts to compare codes, discuss existent disagreements, and finally reach consensus. At the early stages, to identify, analyze, and report the themes and subthemes from the interview data, we employed the thematic framework analysis, and developed the preliminary codebooks for data analysis based on the first three transcripts. Then we used continually reviewed transcripts to extend existing themes and identify new ones with a constant comparison method (40, 41).

RESULTS

This study employed purposive sampling of 75 participants from three towns (X, Y, Z) in Huairou District, Beijing, including 18 village doctors, 15 village officers, 30 residents, 6 town-level community health center managers, and 6 town government managers. The average age of the participants was 57 years, and the majority were female. **Tables 1, 2** present participant's basic characteristics.

After in-depth compilation and analysis of the interview data, the role played by village doctors during the pandemic

TABLE 2 | Basic sociological characteristics of respondents.

Variables	Village doctors	Village officers	Residents	Town health center managers	Town government managers	Total
Age (years) $X \pm SD$	63.11 \pm 11.79	52.93 \pm 8.78	60.38 \pm 12.40	43.8 \pm 7.19	45.83 \pm 5.56	57.19 \pm 12.35
Gender	10	7	4	2	3	26
Male						
Female	8	8	26	4	3	49
Education						
Junior high school or lower	12	2	21	0	0	35
High school	3	6	6	0	0	15
College or higher	3	7	3	6	6	25

was summarized in three themes as follows: (a) participation in pandemic prevention and control; (b) pandemic prevention in village health offices; and (c) basic medical service delivery. **Table 3** shows the themes and sub-themes. Each theme is illustrated with the original words of the participants as examples.

Theme 1: Participation in Pandemic Prevention and Control

During the COVID-19 pandemic, rural communities in China adopted social distancing and lockdown measures. Village doctors, as the only health professionals in the village, also took on different levels of pandemic prevention and control tasks. Respondents described what village doctors did during the COVID-19 pandemic from their own perspectives.

Guiding the Village Committee to Conduct Disinfection

Environmental disinfection is an important measure to kill virus and prevent and control the COVID-19 pandemic. In order to guarantee the residents' health and life safety, the village committee regularly arranged people to carry out environmental disinfection every week. Thus, the village doctor, as a professional, also became part of the sanitization team. Village doctors supervised technicians to do the environmental disinfection in the village, while in other cases technicians personally took the sanitizer devices to disinfect surroundings in the village.

"I thought the village doctor did play a big role in the pandemic prevention and control. He guided the implementation of various measures, including environmental disinfection. Just now we talked about villager autonomy. Actually there were many villages which did not allow the community health center staff to enter the village. You can only let him (village doctor) do it, as (village doctor) is also a professional. And he has prestige in the village committee, so his words are valid." (P72)

Monitoring Persons in Home Isolation

Under confined management, people who are not from the village were not allowed to enter the village. The village clinic is at the bottom of the network of rural three-tier medical services, and in this situation the role of the village doctor is

highlighted. The village doctor must not only do his original job, but also take on some of the tasks of the community health center. Medical observation and health monitoring of people in home isolation is an important task. During several outbreaks in China, such as Wuhan pandemic and Beijing Xinfadi pandemic, the government required home quarantine for people who had visited the pandemic outbreak sites. The village doctor was required to record the temperature and symptoms of the home isolates daily and report the data to the community health center.

"The community health center, the town department in charge of health and the village committee had high requirements on the village doctor, after all the village doctor was a professional. For example, the village doctor identified people in the village who have an abnormal body temperature and reported whether they are returning from outside." (P22) *"The village doctor followed up with some febrile patients who were seen in secondary and tertiary hospitals, and he may not be a suspicious subject for the COVID-19. But after he returned to the village, someone had to supervise him and take his temperature every day. At this time the community health center may arrange a follow-up visit by a village doctor."* (P67)

Disseminating Knowledge on Prevention of COVID-19 Pandemic

Based on the information provided by the community health center about the prevention and control of the pandemic, the village doctors disseminated knowledge to villagers, including knowledge on the dynamics of the COVID-19 pandemic, and personal and family protection against infectious diseases.

"There was no village doctor in our village, but a village doctor from other places drove to the village to educate us on pandemic prevention. There was no broadcast, so the village doctor could only explain to the villagers face to face; there was no village clinic to provide medical services to the villagers, and a company project department was rented as a temporary medical site." (P27)

In order to improve the ability of village doctors to deal with the COVID-19 pandemic, the community health center regularly conducted training for village doctors.

TABLE 3 | Themes for village doctors' responsibilities and challenges in the COVID-19 pandemic prevention and control.

Themes	Sub-theme	Illustrative quotes
Participation in pandemic prevention and control	Guiding the village committee to conduct disinfection	"The village should be disinfected regularly. The village doctor mixed the proportion of disinfectant water, and then the village committee assigned someone to disinfect. Because the village doctor is older, we did not call him (to disinfect)."—P32
	Monitoring persons in home isolation	"(Village doctor) monitored the situation of residents in the village at all times and reported any feverish patients to the community health center at once."—P68
Pandemic prevention measures in village clinics	Disseminating knowledge on prevention of COVID-19 pandemic	"Sometimes (village doctor) came over and broadcasted the pandemic prevention knowledge by 'loudspeaker' in the village."—P74
	Distributing village clinic pandemic prevention materials	"After March 2020, we distributed some pandemic prevention and control materials to village clinics, such as disinfectant alcohol and disinfectant solution, medical masks, etc."—P64
	Undertaking village clinic pre-screening	"When a patient came to the village clinic, he first scanned the 'health code' and then asked about his epidemiological history. The observation room was set up next door and no (patients in fever) were found. From the COVID-19 outbreak until now, not even patients with fever have been seen, and there are fewer people getting colds."—P4
Basic medical service delivery	Common diseases and chronic diseases treatment	"The village doctor used to study and take exams in the county. The medical skills are fine. Headaches and minor ailments can be diagnosed and treated."—P39
	Medicine delivery from the community health center	"There were a lot of chronic patients in the village. They need to go to the community health center to buy drugs. The village clinic did not have these drugs, and the cost could not be reimbursed. During this pandemic they all could not go out of the village, so the village doctor went to the community health center to help them get medicine."—P65
Difficulties and challenges	Lack of pandemic prevention materials	"During the pandemic, the village doctors had insufficient supplies for pandemic prevention and the budgets for supplies were inadequate. According to the requirements of pandemic prevention norms (wearing protective suit, gloves, masks and face masks and changing them once a day), it actually failed to meet such requirements."—P71
	Inadequate capacity of village doctors	"To be honest, (the village clinic) cannot provide medical treatment; now many diseases cannot be treated, and he will directly tell you to go to the community (health center)."—P57
	Overage village doctors	"Village doctors can do few work, and all other work is done by the community health center and village committee staff, because the village doctor team is aging."—P21

"The community health center conducted training for village doctors during the pandemic, on the detection and reporting of suspicious cases, epidemiological investigations, referrals, infection prevention and control, disinfection knowledge and skills, and personal protective measures." (P69)

the village clinic) I had to wear a mask, a white coat, open windows and do ventilation, and disinfect twice a day." (P15)

Theme 2: Pandemic Prevention Measures in Village Clinics

When the village was locked down, the village clinic became almost the sole medical facility for the villagers to seek medical treatment. In order to perform the "sentinel" monitoring role of the village clinic, two aspects of work need to be done.

Distributing Village Clinic Pandemic Prevention Materials

With a variety of patients seeking treatment at the village clinic, it becomes a high-risk site for COVID-19. Therefore, the village clinic has to prepare pandemic prevention and control materials and conduct environmental disinfection to ensure safety in healthcare services to the residents.

"The community health center handed out masks to us a few times, but the number was small and they told me to use them sparingly, and the alcohol and disinfectant was bought by myself." (P9) "(In

Undertaking Village Clinic Pre-screening

Pre-screening is the means for medical institutions to effectively control infectious diseases and prevent cross-infection within medical institutions. All patients who visited the village clinic must register valid identification information or scan the "health code". For patients whose diagnosis were not clear and who could not be excluded from infectious diseases, the village clinic should promptly report and take isolation measures for patients.

"The patient's temperature was taken before he enters the village clinic, and then was asked to scan the 'health code' and register, and was asked if he had been out of the village and where he had been." (P11)

Theme 3: Basic Medical Service Delivery

The village doctor is the gatekeeper of the majority farmers' health. He provides the basic medical services for farmers and alleviates the lack of healthcare and medicine in the vast rural areas of China. The village doctors are usually able to provide timely and brief treatment for common and multiple diseases. In remote rural areas, village doctors play a role that cannot be replaced by urban public hospitals.

Common Diseases and Chronic Diseases Treatment

Village doctors are the closest medical resource to the villagers. Since the rural elderly population is large and has a greater demand for medical services, village doctors provide initial treatment for common diseases and chronic diseases for villagers. Especially in villages with remote locations and inconvenient traffic, village doctors play an important role as “gatekeepers”.

“The village doctor is closer to my house, and although expenses of the medicine cannot be reimbursed at the village clinic, it takes a short time to get there by bike. At that time, I ran out of my antihypertensive drugs, so I went to him to buy some.” (P39)

Medicine Delivery From the Community Health Center

There are many patients with chronic diseases in the village, but provision of the long-term medicine of some patients was affected during the pandemic. To facilitate safe use of drugs and reduce the risk of cross-infection, the village doctor helps patients buy drugs from the community health center and delivers them to their homes.

“During the pandemic we practiced purchasing on their behalf; we took their health insurance cards and went to the community health center to prescribe drugs for them. We established a procurement team with two people. I was responsible for procurement and the other villager was managing the money. We communicate with the villagers about their demands in WeChat groups.” (P18)

Theme 4: Difficulties and Challenges

Village doctors have played a great role in pandemic prevention and control, but at the same time, they have also shown shortcomings, which brings great challenges to the construction of rural pandemic prevention and control systems.

Lack of Pandemic Prevention Materials

At the early stage of the pandemic, due to the lack of a comprehensive emergency supplies reserve system in each region, the shortage of supplies at the grassroots level was prominent. Most health professionals in rural areas only wore daily work clothes and disposable medical masks, which increased the risk of cross-infection through direct physical contact with key populations. Other materials for pandemic prevention and control were also unavailable.

“The village needs to report and isolate people with fevers, but some rural pandemic prevention materials were inadequate, such as temperature measuring instruments, which are inaccurate sometimes. The tents used at the village entrance checkpoint were not adequate, and these tents do not have a long service lifetime.” (P20)

Inadequate Capacity of Village Doctors

According to statistical data, more than half of the village doctors have been educated at junior high school level or below. There are even village doctors who are “barefoot doctors” without

professional and systematic medical training. The medical knowledge possessed by village doctors is not enough to keep up with medical developments. Outdated knowledge and lack of clinical experience make it difficult for village doctors to identify and report the COVID-19 timely.

“Because of the limited medical expertise of the village doctor, if he is allowed to practice alone in the village, and a patient infected with COVID-19 failed to report the pandemic history, then everyone is faced with the risk of being infected. The village doctor has an assisting role, responsible for taking temperature, blood pressure and organizing and coordinating. The part that requires professional knowledge will be done by the community health center doctor.” (P65)

Overage Village Doctors

The results show that the average age of village doctors has exceeded 60 years. Because of low-incomes, high medical risks, and the lack of pension security, it is difficult for rural areas to recruit young village doctors. Difficulties faced by the old village doctors in pandemic prevention and control include being unable to operate with information technology, being easily infected, and having weak awareness.

“The main difficulty is that the village doctor is too old, and they can't physically withstand the long hours of work. The youngest village doctor is 55 years old now, and the oldest is over 70. So we invite them to work here in the morning and let them rest in the afternoon.” (P66)

DISCUSSION

This study has explored the roles of and challenges faced by village doctors during the COVID-19 pandemic in rural Beijing. By reporting village doctors' contributions to the prevention and control of COVID-19 in China in the context of worldwide public health emergencies, our study enriches the international discussion of similar topics. The results of interviews showed that village doctors played multiple roles in pandemic prevention and control at the village level, both medical and non-medical. (a) “Sentinel monitors”, which means strictly practicing pre-screening triage system and timely reporting of suspicious patients such as those in fever. (b) “Message examiner”, which means examining ones returning from the medium and high risk areas, and reporting the information to superior departments in time. (c) “Educators”, which means spreading pandemic prevention and control knowledge, policies and medical guidelines to villagers via various channels. (d) “Gatekeepers”, which means providing services such as basic medical care and medicine purchase on behalf of patients in the village, delivering medicines to patients at home, as well as making health follow-ups for patients with chronic diseases. (e) “Guidance officer”, which means working as a professional to guide the implementation of health-related work for local people.

Meanwhile, the study found that village doctors are facing multiple challenges in rural COVID-19 pandemic prevention and

control efforts, including exposure to serious infection risks due to lack of pandemic prevention materials, the aging village doctor workforce, and inadequate pandemic prevention and control capacity and medical skills. In rural China, rural pandemic prevention and control teams are formed with village officers as leaders and village doctors and volunteers as auxiliaries. The team is tasked with quarantine, health education, and travel restrictions in the village, effectively reducing the spread of the pandemic in rural areas. This is consistent with other studies (42, 43).

Our study found that in the absence of available health care options, village clinics became the sole source of health care services. Village clinics are the tail end of medical service network and also the most broadly covered primary health care institutions (44). The vast majority of village doctors have been practicing for more than 10 years and have established a good doctor-patient relationship with villagers (45, 46). After the pandemic outbreak, village doctors became major forces in the prevention and control of rural pandemics by virtue of their familiarity with villagers. Village doctors do not fear hard work, no matter how much they are paid, or how high the risk is of being infected in the front line of the fight against the pandemic. Some village doctors eventually collapsed in the front line of pandemic prevention and control because of overwork. A number of studies have found that frontline health care workers are under tremendous mental stress and that some are experiencing anxiety and depression, yet without any access to psychological support (47–49). Therefore, health authorities and local governments should pay “pandemic prevention allowance” and humanistic care to village doctors for their contribution and keep them motivated to work.

The research shows that the role of village doctors in the prevention and control of the COVID-19 pandemic in rural areas is mainly evident in both “prevention” and “treatment”. “Prevention” refers to interrupting the spread of COVID-19 pandemic and early detecting suspected cases through pre-screening and triage at early stage, as well as spreading knowledge of COVID-19 prevention and disinfection. Those are also common public health measures taken in China (50, 51). “Treatment” refers to the village doctors’ providing medical services and basic public health services to patients with chronic and common diseases in the village. During lockdowns of the village, the community health center medical staff could not enter the village and villagers could not leave. Village doctors undertook basic medical and basic public health services in the village, such as following up with hypertensive and diabetic patients and fetching medicine for villagers.

Severe aging and lack of capacity are critical problems exposed by the village doctor workforce when they are involved in pandemic prevention and control. Many village doctors are transformed from “barefoot doctors” who have received less medical education, resulting in village doctors not meeting the medical needs of residents (12). The data showed that 26.8% of village doctors in China were over 60 years old in 2018, and only 5% were below 35 years old. 93.4% of village doctors are with education in secondary school (high school) or below (52). The proportion of village doctors who aged above 60 in some

towns reached 80% (36). The low capacity and overage staff pose challenges for carrying out pandemic prevention and control in three aspects. Firstly, since elderly village doctors practice irregularly, they face higher risk of being infected, and repeated contact with villagers can easily cause cross-infection. Secondly, high-intensity work can cause more physical and psychological stress for village doctors. Thirdly, village doctors do not know how to use information technology, which invariably increases workload and causes low efficiency.

In 2015, six national departments united to issue a document to train free “Tailor-made medical students for rural areas” (53). After graduation, those medical students will be assigned to the town-level community health center or village clinic to practice for a certain number of years. The government hopes to supplement the number of young village doctors and improve the service quality of primary care institutions in this way. In order to achieve the Healthy China and Rural Revitalization Strategy, the Chinese government is formulating policies to strengthen the construction of primary health care service system and talent pool to facilitate the development of village doctors’ team. The outbreak of COVID-19 has shown the shortcomings of rural areas in pandemic prevention and control, and also highlighting the role of village doctors. Therefore, it has accelerated the formulation and improvement of related policies from various aspects.

A study has shown a COVID-19 knowledge gap among different populations, with education level and internet media use two main influential factors (54). This is also true for village doctors and villagers. Village doctors are not informed about the prevention and control protocols and infection characteristics of the COVID-19 in time, which is harmful to early detection of infectious diseases and thus may result in missing of the best period of pandemic prevention and control. Thus, the health department should promptly train village doctors on infectious disease prevention related laws, emergency plans, infection symptoms, etc. A good command of knowledge on the COVID-19 can guarantee that village doctor raises villagers’ awareness of pandemic prevention by health education and follow-up visits.

During the pandemic, the rural areas have not yet established comprehensive emergency supply reserve system, and there is an extreme shortage of pandemic prevention and control supplies. Village doctors were in direct and close contact with key populations while only wearing ordinary white coats and disposable masks, which greatly increased the risk of cross-infection. Thus, the government like the Emergency Management Bureau should optimize the medical emergency material supply system so as to promptly equip village doctors with emergency materials. Meanwhile, it is recommended to strengthen the deployment of materials for primary health care institutions. The needs of primary health care institutions should not be ignored in material allocations.

Strengths and Limitations

Village doctors are an important force in the prevention and control of COVID-19 pandemic in rural China, but the role of and the challenges encountered by village doctors in the prevention and control of COVID-19 pandemic have not been

sufficiently and effectively explored. We also provided suggestion for enhancing roles of village doctors in the prevention and control of COVID-19 pandemic in rural areas in order to improve the public health emergency system in rural China. Meanwhile, the experiences from China's rural areas in pandemic prevention and control can provide a reference for rural areas in other countries. This study has several limitations. First, we recruited interviewers from only one district in Beijing, and the responsibilities of village doctors may vary among districts. Second, the pandemic was already under control when we interviewed, so the results may have recall bias. Third, because of the strict pandemic prevention and control in some pandemic outbreak areas, we were not able to interview the relevant personnel to fully understand the role of village doctors in the pandemic outbreak areas.

CONCLUSIONS

We interviewed five groups of participants in Huairou District, Beijing, to understand the contribution of village doctors when the strict COVID-19 quarantine measures were implemented, and analyzed the difficulties and challenges they have faced in pandemic prevention and control. Village doctors played the role of educators, messengers, monitors, gatekeepers, and instructors in pandemic prevention and control. Their work included guiding the disinfection, providing basic health care, monitoring the temperature of people isolated at home, screening the information of people returning to the village, and educating on the prevention of infectious diseases. They do their best to use their expertise to contain the spread of COVID-19 in rural areas. But the fragile public health system in rural areas is highly vulnerable to public health emergencies. Lack of rural pandemic prevention materials, low medical level of village doctors and aging staff structure have also become the weaknesses of rural pandemic prevention and control. The outbreak of the COVID-19 pandemic should prompt the government to invest in more skilled manpower, material and financial resources in the rural health care system, especially in village clinics and village doctors. In preparation for any public health emergencies at any time, great efforts should be made to upgrade medical equipment in village clinics and to improve pension security and salaries for village doctors to attract more young talents to work as village doctors.

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DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by the Ethics Committee of Capital Medical University (Z2022SY021). The participants signed an informed consent form for their participation in this study. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

JL and JY conceived and designed of the study, and contributed to the revision of the manuscript. NZ, HY, and HZ collated the database. NZ and JL performed the data analysis. JL wrote the first draft of the manuscript. All authors contributed to the interview data collection. All authors contributed to reviewing and proofreading the manuscript and approved the submitted version.

FUNDING

This work was supported by the Capital Health Management and Policy Research Base, China (2021JD06), and the Beijing Social Science Foundation (20JCB004), and the Beijing Education Commission (SZ201910025008).

ACKNOWLEDGMENTS

We thank all the participants, experts, and researchers who participated in this study. We also appreciate Tao Xin and Guo Jing from the Department of Applied Linguistics, School of Medical Humanities, Capital Medical University, for the language editing assistance.

SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: <https://www.frontiersin.org/articles/10.3389/fpubh.2022.888374/full#supplementary-material>

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OPEN ACCESS

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SPECIALTY SECTION

This article was submitted to
Life-Course Epidemiology and Social
Inequalities in Health,
a section of the journal
Frontiers in Public Health

RECEIVED 21 March 2022

ACCEPTED 22 August 2022

PUBLISHED 21 September 2022

CITATION

Hoffman SJ, Garcia Y,
Altamirano-Crosby J, Ortega SM, Yu K,
Abudiab SM, de Acosta D,
Fredkove WM, Karim S, Mann E,
Thomas CM, Yun K and
Dawson-Hahn EE (2022) "How can
you advocate for something that is
nonexistent?" (CM16-17) Power of
community in a pandemic and the
evolution of community-led response
within a COVID-19 CICT and testing
context.
Front. Public Health 10:901230.
doi: 10.3389/fpubh.2022.901230

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"How can you advocate for something that is nonexistent?" (CM16-17) Power of community in a pandemic and the evolution of community-led response within a COVID-19 CICT and testing context

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Formal and informal bilingual/bicultural organizations and networks form the backbone of support for refugee, immigrant, and migrant (RIM) communities in the United States. They are pivotal in mitigating barriers and inequities in social and structural determinants of health. These organizations and networks are situated within the communities they serve, and often are established and run by members of a community, to serve the community. In the United States, the COVID-19 pandemic surfaced and widened existing health inequities for some racial and ethnic communities. Our primary objectives were to: (1) describe the processes that underpinned the pivotal role of immigrant-serving community structures in developing and implementing culturally sustaining programming in the context of pandemic response, and (2) amplify the voices of community experts, as they shared experiences and perspectives around these humanistic and community-centered approaches. We applied a community case study approach to a national sample of RIM-serving community structures representing broad country/region-of-origin, cultural, and linguistic identities. Community engagement strategies utilized in the project period included engaging community partners to identify and facilitate connections, and consult on analysis and dissemination. The project team conducted 20 in-depth, semi-structured interviews with a purposive

sample of community experts/community organizations. Sampling strategy was further informed by immigrant identity (i.e., characterization of status) and geography (i.e., United States Department of Health & Human Services, Office of Intergovernmental and External Affairs Regions). Through thematic analysis, results identified key contextual, process-, and impact-oriented themes inherent to community-led COVID-19 responses, that were situated within and around the public and health system response to the pandemic. As public health and health systems scrambled to address acute and unprecedented barriers to access, distribution of COVID-19-related health resources and services, and disparate health outcomes, community structures diligently and intentionally reimagined and reconceptualized their response to COVID-19, frequently in the setting of scarce resources. The grassroots response evolved as a counter-narrative to top-down equity processes, historically defined by systems and applied to the community.

KEYWORDS

refugee, immigrant, migrant, COVID-19, community, public health

Introduction

This qualitative community case study is focused on the pivotal role of community experts and immigrant-serving community-based organizations in innovating and implementing culturally responsive programming in the context of a public health COVID-19 pandemic response. We leverage the platform of the Centers for Disease Control and Prevention (CDC) funded National Resource Center for Refugee Immigrant and Migrants (NRC-RIM) project to amplify the voices of individuals and organizations who created a roadmap for community-led pandemic response.

Central to our inquiry is the disproportionate impacts of the COVID-19 pandemic on migrant, immigrant, and refugee communities. In the United States, immigration status is an important social determinant of health (1). The COVID-19 pandemic has surfaced, or made visible, and perpetuated health inequities experienced by immigrant communities (2, 3). This is particularly the case in the setting of systemic inequity and the compounding effects of chronic stress and trauma (4). Immigrant populations are underrepresented in disaggregated results of studies examining the impact of the COVID-19 pandemic on priority populations (5–7). In a state-level analysis, Black and Latinx communities experienced statistically significant increases in COVID-19 case rates in the first 5 months of the pandemic, where factors such as “foreign-born noncitizen status,” employment type, and key structural inequities explained the disproportionate impacts observed (8). A health system analysis reported that COVID-19 test positivity rates among non-English language speakers were more than four times the test positivity observed among English language speakers in the sample (9). Underrepresented communities, in

particular African American and Latinx communities in the United States, have endured the greatest burden of the pandemic (10). Explanations for the disproportionate impact of the pandemic on communities of color and immigrant communities are expansive and complicated, emphasizing multifactorial and intersectional origins (11).

Partnering with immigrant communities to understand their perspectives and leadership is critical to addressing the health inequities that COVID-19 has caused. This case study is intended to highlight and amplify the perspectives of a diverse sample of community experts based on immigrant communities. Our primary objective was to describe processes that underpinned the pivotal role of immigrant-serving community structures in developing and implementing culturally responsive programming in the context of pandemic response.

Methods

The parent project is a qualitative initiative situated within the National Resource Center for Refugees, Immigrants and Migrants (NRC-RIM) project based at the University of Minnesota. Key objectives of the parent project were to: (1) explore the perspectives of public health and health system practitioners and community experts on perceived and/or experienced facilitators and barriers of the COVID-19 response in immigrant communities; and (2) inform the development of best and promising practices for case investigations and contact tracing within immigrant communities. In this report, we focus on the subset of the data collected through interviews with refugee, immigrant, and migrant- (subsequently referenced as

“immigrant” in this report) serving community experts and key representatives from community organizations (subsequently referenced as “CE/CO” or “interviewee” in this report). We applied a community case study approach to a national sample of immigrant-serving community structures representing broad country/region-of-origin, cultural, and linguistic identities.

Community consultation

Two community-based consultants were consulted to guide the interpretation of data, analytic decisions, manuscript development, and dissemination. Both identified as members of immigrant communities and held leadership positions in established and active immigrant-serving organizations.

Ethical considerations

The quality improvement initiative protocol was reviewed and determined not human subjects research by the University of Minnesota and exempt by the University of Washington Institutional Review Boards.

Interview guide

A semi-structured interview guide was developed by members of the qualitative team and key project stakeholders. The guide was used across data sets in the parent study and was iteratively adapted in the community to reflect ways that CE/CO was engaging with Case Investigation and Contact Tracing (CICT), or the tracking of infection source and spread within networks, and vaccination.

Sample

The target sample was 20 community experts and/or representatives of immigrant-serving community-based organizations. Through a mix of self-referral and targeted purposive sampling via the networks of the study team (including the NRC-RIM Community Leadership Board), 40 stakeholders representing diverse geographies and backgrounds were invited to participate. Among those contacted for interviews, 19 declined, did not respond, or it was mutually determined that the contact did not meet inclusion criteria. A single organization provided written resources to the team. We framed our sampling strategy to prioritize communities who, to the best of our knowledge, were among the most heavily affected by the pandemic. Potential interviewees were screened and included if they: (1) identified as a member of a refugee, immigrant, or migrant community; and (2)

were engaged in the COVID-19 response with immigrant communities. Representation across the 10 US Department of Health & Human Services (HHS), Office of Intergovernmental and External Affairs Regions was prioritized. We categorized organizations as “refugee, immigrant, migrant-specific” if the organization as a whole or the community expert representing the organization self-reported a specific focus on RIM communities. Interviewees received a \$40 gift card upon the completion of the interview.

Procedures

Interviews with CE/COs were conducted from December 2020 to April 2021 via the Zoom platform with members of the qualitative team. Following the completion of a demographic survey, interviewers reviewed the project objectives and procedures with the interviewees and obtained permission to audio record. Semi-structured interviews lasted 60 min and were professionally transcribed. Transcripts were uploaded into a secure file-sharing platform hosted by the University of Minnesota. The interviewer then completed a rapid interview summary based on the transcript for review and discussion by the full qualitative team. All interviews were conducted in the English language. In one case, a group interview included two interviewees; otherwise, interviews were conducted with a single interviewee.

Analysis

Demographic data were collected and stored using University of Washington REDCap electronic data capture tools (12, 13). Transcripts were uploaded and coded using Dedoose software (14). Initially, a two-member coding team independently double coded five transcripts. Of those five, two were reconciled line by line with a focus on code development. Subsequently, three transcripts were reconciled holistically with a focus on codebook refinement. Deductive codes were established *a priori* in the initial waves of data collection with health system providers and public health officials. Subsequently, inductive codes unique to the CE/CO data set were identified through open coding. Upon the completion of the initial transcripts and preliminary codebook, a single study team member coded the remaining 14 transcripts over a 25-week period (January 2021–July 2021). One transcript was deemed not relevant to the interview set and was transcribed but not coded. Members of the coding team met weekly to review and reconcile the codebook. The full qualitative team met weekly with the coding team and supported key decision points in codebook development.

Thematic analysis (15) functioned as the analytic foundation. Two members of the study team led the analysis. Initially, analysts re-read all interview transcripts. Independently, the analysts organized parent and child codes into themes with a focus on prevalence and keyness to guide decision-making. Analysts met weekly to reconcile code organization and theme identification. Themes were then preliminarily defined and an initial conceptual diagram was drafted to visualize the relationships between themes. Excerpts within each theme were then re-reviewed to establish alignment and consistency within the themes. A multi-layered analytic and methodologic memoing strategy was a prominent analytic tool. Theme names and definitions and the conceptual diagram were finalized. Key excerpts representing each theme were identified and extracted, co-occurring codes were examined for analytic relevance. References in excerpts to specific countries and ethnic groups were deidentified. This decision was made in consultation with community-based manuscript consultants as the study team weighed the balance between acknowledging and preserving unique cultural experiences in the COVID-19 pandemic with privacy and possible potentiation of stigma and harm.

Findings

Table 1 describes the demographic characteristics of the interviewees. Interviews geographically represented all HHS regions except region 7, there was no representation in this interview set from Iowa, Kansas, Missouri, or Nebraska. A wide range of ethnoracial groups was represented and populations of focus included refugee, immigrant, and migrant communities. The roles interviewees held within their organizations or coalitions were diverse.

Findings are organized by the five themes: understanding context, orientation, relationality, presence, and impact (Figure 1). Themes represent prominent characteristics of a culturally responsive and impactful, community-led pandemic response identified by CE/COs.

Understanding context

CE/COs provided rich and meaningful descriptions of community membership, perspectives on community-level pandemic impact, COVID-19 pandemic response, and community attitudes and perceptions. In essence, CE/COs described how they understood community context and thus explained the framework through which they approached and supported the community.

TABLE 1 Demographic characteristics of community expert/community organization (CE/CO) participants.

Characteristics	CE/CO numbers
Total number of interviewees*	22
Location, by HHS region	
1 or 2	3
3 or 4	6
5 or 6	1
7 or 8	1
9 or 10	8
Organizational level	
Local (City/County)	16
State	1
Regional	0
Southern border/state community	2
Organizational type	
Non profit	11
Community based organization	2
Community health/advocacy organization	4
Informal [#]	2
Refugee immigrant migrant (RIM)-specific organization**	19
Populations served***	
Refugees	9
Migrant workers	8
Other immigrants	7
Interview completed after first COVID vaccine Emergency Use Authorization (EUA)****	10

*Many organizations requested group interviews with 2 or more staff members.

**We categorized organizations as "refugee, immigrant, migrant-specific" if the organization as a whole or the operational unit within the organization (e.g., a state refugee health program within a Department of Public Health) focuses specifically on RIM communities.

***Many organizations work with more than one population.

****December 11, 2020.

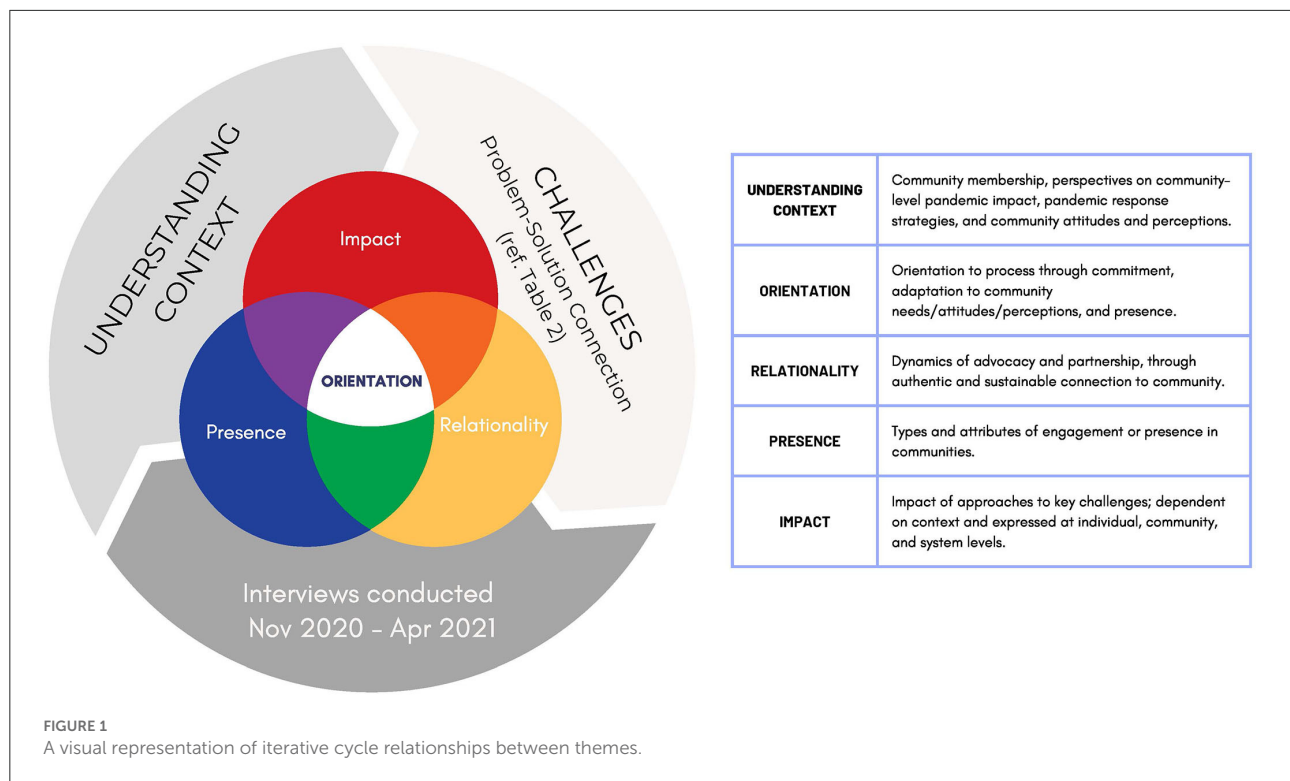
[#]Informal organization type characterized informants that did not report a formal nonprofit designation and/or self-identified as being not affiliated with an existing entity.

Community-level pandemic impact

CE/COs described existing systemic inequities that were heightened in the pandemic.

...most of the time we really are invisible to the systems. Like when we're identified as you're either [deidentified] or you're [deidentified], but the whole identity of our communities is erased, as when they label us as those two major groups, not necessarily capturing the diversity within the community, that we're a multi-ethnic and multi-lingual nation. (CM19-21)

Isolation and the economic impact of the pandemic on immigrant communities were prominent in statements.



...People who are non-white...it has affected them more than it has affected people who are from a white background. For my community specifically, the loss of jobs. A lot of people have lost their jobs and it really had a ripple effect because they lost their jobs, they were behind on rent, didn't have enough money to buy food, so they relied a lot on food pantries or churches or mosques that offered free food, or the schools that delivered or that offered free lunches for the kids because of home schooling. ...We're a very communal people. We like to connect, hang out and eat together, pray together, go to naming ceremonies when somebody has a child or when somebody passes away or when somebody is getting married. Those social events were gatherings that had some sort of mental effect, right, creating stress and depression, because you're not connecting with your people like that. You have to be in quarantine. (CM08)

Underlying these statements was a dual role many CE/COs held as individual members of the community experiencing the challenges of the pandemic and essential community support.

COVID-19 pandemic response

CE/COs outlined three iterative phases of community capacity building for pandemic response: (1) functional, (2) operational, and (3) structural. The *functional* phase

acknowledged a realization of/preparation for/movement toward activities or positions that were not yet actualized due to insufficient resources. At the point where resources were available, the *operational* phase was how those functional adaptations were put into practice/operationalized in a more systematic and supported way. Operationalizing also moved the practices/programs along the continuum of being available to the community. The *structural* phase represented the framework of response that became embedded within the organization structure and/or layered in a web of response strategies unique to the community.

Functional phase

The functional phase described the adaptation that was necessary for CE/COs to be responsive to community needs, particularly as the public health system became overwhelmed. Interviewees described the effectiveness of the CE/CO role as a conduit of information, resources, and connection.

We basically created another organization within the organization, just to respond to the COVID pandemic. We started with popup food pantries and now we actually are a formal food pantry, one of the largest in the city serving 11,000 people per week. That is with pickup, drive through and home delivery food. Then we also have promotores

de salud, health promoters disseminating PPE and testing education and now vaccination education. We also supported with unemployment application assistance, so triaging and making sure that people were applying for unemployment and supporting that process...(CM23)

Interviews reflected the shifting context of the pandemic. Early on, when testing, treatment, and a fundamental understanding of the virus itself were significantly deficient, fear was prevalent among community members.

So, I feel that it's been in different stages. In March, when we, as employees, were sent home, we stopped everything that we were doing and started focusing on first learning what COVID was. Because, as everybody else we had no idea. A lot of people were scared, and you can imagine that extra layer of fear in our community, because they're only fearful of getting in trouble here or driving and the police catching me without a driver's license. All that, to then all these shutdowns that happened and people having to go to work and all these things that they were saying, "If we catch you driving after this time..." So, it really affected a lot of people not being able to work and having to stay home, not making money to feed their families or pay bills. So, right after we learned [what] COVID was, it wasn't even the fear of getting infected, it was more of—how do I pay my bills? How do I see my family?—that was there, right? So, after that fear kinda, it was like, "Well, this is just something else we've got to work with." (CM01)

This statement highlighted the depth of understanding CE/COs had about the concerns that were circulating in communities. The interviewee referenced privilege in the ability to choose to work remotely; whereas that choice may not have been accessible to individuals choosing to work due to personal or economic circumstances

Operational phase

The operational phase described how available services and resources were put into action and/or made accessible to the community, e.g., testing, CICT, linguistic services, and education outreach. Where *function* was to understand what the community needed, and when and how to meet that need, *operation* was to set resources in motion. Interviewees described ways that the *functional phase* often guided or preceded the *operational phase*, because there were delays in capacity and resources. The availability of linguistic resources and services underpinned this phase. Interviewees reflected on how language access drove widening health inequities.

We continued to do education and outreach and we developed materials in Indigenous languages. There's often the belief that you can just write the language, which is true, but more for the academic kind of world and for people that have

access to that, but most of our community doesn't know how to read and write in [deidentified]. So we worked on a lot of audios, with different organizations, with the state, among ourselves to get the message across and have our staff either send it through our community or have those one-on-one conversations with them as well. That's some of the outreach and education we have done. (CM19-CM21)

CE/COs described a process-oriented approach to developing effective health communication that was essential for key elements of pandemic response (e.g., CICT, testing, outreach, and concurrent service provision) to be understood, initiated, and sustained.

You can say in English, "you need to get tested, because you can save lives." That is core and English-speaking folks that have access to information can be like, yeah, it saves lives. But for working-class Indigenous folks, it's like, I don't have health insurance. Is this going to be free? The message needs to be about access and about it is free. You can do that, but at the same time, for it to be adequate, doing a testing site at 9 AM, it's not going to work for people that now are considered essential and have to work. (CM19-21)

Interviewees emphasized that language, not just words but also timing, meaning, and delivery, informed effective health communication.

Structural phase

The structural phase of pandemic response was realized when an approach became embedded within the organizational structure and/or layered in a web of response strategies unique to the community. A CE/CO described the evolution of the response and ultimately the layering of services and outreach that were part of service provision.

At first two, three people that went out in the fields, getting up at 7 in the morning to take PPE, to make sure that people got the information they need. It was at first two staff members. Then they noticed everyone was going to be fine. "We can go and be OK," so then more of our staff kept joining. In [deidentified] we were able to go to the fields and visit the workers to ensure that they got not just the PPE, but they had the information they need, the more up-to-date information on COVID development... Then from there we worked with the county health department to get a contract to do not only education and outreach but contact tracing, that we were offering that language access support at the testing sites and were promoting that. We were ensuring that our community also got quarantine support, so if they needed it, they could go through the county – we had some funds from the county

– or individually [deidentified] got funding through different foundations to ensure that people got economic support and that was part of our response. (CM19-CM21)

CE/COs evolved with the pandemic response: anticipating needs, bundling response strategies, and ultimately embedding these in programming. The functional-operational-structural capacity cycle was part of a responsive, community-centered, and nimble approach to challenges faced by immigrant communities.

Community attitudes and perceptions

CE/CO awareness of the circulating attitudes and perceptions about COVID-19 within the community guided and facilitated the translation of community voices into action steps. CE/COs described how fear and sense of responsibility drove the actions of community members. Fear was expressed in relation to concerns about livelihood; protection and care of family; isolation resulting from the closing of places of worship and loss of cultural gathering traditions; and reflections on the disproportionate impact of COVID-19 including economic inequity and misinformation.

Folks don't have health insurance. There was fear at the beginning of the pandemic; there were bills coming back to people who had gotten tested. In communities like ours, [when] something good happens, everyone in town will know what's going on. But if something bad happens, word gets out even faster, what goes wrong. That has been, even until now a barrier. It's not been accurate information. (CM19-21)

An interviewee compared observations from previous work in lead poisoning prevention with immigrant families, to observations of current fear-driven responses of families.

I was working within public health with some other organization...this organization was never able-able to communicate this message properly on behalf of public health...they didn't know culture, how they behaved, why they behaved. As soon as we got that contract from them I literally told them that, hey, this is a population that – these are people that literally they are my family, my friends, I go to their houses and let me do this. I don't want to do it because of the \$50,000 grant but because this an urgent public health issue in our community. We strategized, we sent for our community, we brought our elder, we brought our religious scholars...and we talked with people and they're afraid. The main reason that they don't take their kids to get tested was

that they thought that the Childcare Protective Services would come take your kid because you put them in that situation that they have a high level of lead. So they hid. (CM05)

In contrast to threads of fear were narratives of humanity and resilience, where community supported community and emphasized the protection of one another. Interviewees shared observations of informal contact tracing, where individuals who tested positive would self-notify families and friends they had been in contact with. One interviewee (CM09) emphasized that it was not mistrust in the government or health system driving these actions, but rather a conscientiousness around the safety of contacts and preventing broader community exposure. An interviewee described dynamics in younger immigrant communities that promoted a sense of responsibility and giving back.

The immigrant population of [deidentified] is very young, in their 20s and 30s, and a lot of the young individuals that come in, they're coming to make money to send back to their countries. They form families, they start having babies, so it's a very young, new, open generation that not only is here to work and make money to send back to their countries, but they also want to build their own American Dream, right?...The biggest thing that I've noticed with our [deidentified] population is that they are wanting to give back to the community. So, these 14 individuals that I'm telling you that I have as community health workers or promotores, the majority of them, we helped them some way, somehow, and they've wanted, they've been wanting to give back, so they volunteer their time to help us. (CM01)

CE/COs reflected on how a shared value of looking out for one another guided community action during the pandemic.

I think it's important to know that our community, they're resilient. They take care of each other. They really try to take care of each other, and when the system falls, we all help each other, all try to, you know, "Hey, this person has Covid-19, so let's all go take some food," or something. We all try to help each other that way. We're extended families, relatives that, it doesn't matter if my grandmother and my great-grandmother, they're first cousins or something; we're a close bond, you know...we don't believe in leaving somebody alone only. In deaths or anything like that, we're always there. (CM15)

Community context influenced CE/CO approaches during COVID-19 through an understanding of the history of the communities served, how community attitudes and perceptions evolved across the trajectory of the pandemic, and ways

organizations themselves pivoted to reflect the community-expressed needs.

Orientation

The CE/CO orientation to *process*, emphasizing intention and how activities were approached, was characterized by commitment, adaptation to community needs/attitudes/perceptions, and presence. One interviewee stated... *we are still here... we are like essential workers serving essential workers* (CM16-17). Generational and sociopolitical orientations were important factors informing tailored and targeted processes.

Generational orientation

CE/COs acknowledged the strengths and challenges unique to generations, important interactions between generations in the community, and ways that CE/COs integrated this understanding into their work.

Understand that it takes time for people sometimes to adapt to this new world, new culture, and being patient with us. Some people, they expect us to come here, within a few months, a year or so, just be on point and know everything, know where to go for things, and sometimes that's not the case, especially when you're dealing with elderly people. Young people, they're OK because they can adapt faster. They go to school; they interact with others, but elderly people or sick people don't have the ability to connect how young people connect, social media and stuff like that, and are more closed off, introverted and don't really communicate with others unless it's people from the same community. (CM08)

Isolation and a lack of cultural connection were well-documented challenges during the pandemic among immigrant communities, where cultural traditions and rituals often centered around community gatherings. In many spaces, social media served an essential role, not only in the dissemination of information, but in re-establishing the connection. Interviewees noted that access to technology was a barrier among older members of communities. Young people in communities functioned as a bridge, helping the older generation to access information related to COVID-19 and other pandemic resources (e.g., testing, vaccination), as well as maintaining a connection with culture and community. Said another way, *There is a reliance on the younger generation to see things on social media and share with families* (CM23). Generation-related observations informed the work of organizations to foster connection.

One interviewee described a balance between the process of doing CICT effectively and efficiency in the context of generational considerations.

But then for the older generation, elders, it [case investigation] can take up to an hour because, like I said, they like to tell you their stories and how they're feeling. You just have to be willing to be on the phone with them, just to listen to them so they're opening up to you. That's how you gain their trust, too, if you're not rushing them. Like I said, you have to have that sincere tone when you're talking to them. (CM22)

The ability to understand generational perspectives and integrate this into an approach to CICT required a deeper understanding of lived experience. Trust was fostered at the intersection of process and intentionality.

Sociopolitical orientation

Circumstances related to economics, politics, and gender that were inherent to the migration experience in the United States informed CE/CO approaches. CE/COs were not themselves political entities. But interviewees described the need to respond to the highly politicized nature of the pandemic response through programmatic shifts in service delivery in order to mitigate sensitivities around immigration status and documentation. Sociopolitical context was one of the areas where perspectives of public health and perspectives of CE/COs were most discordant. Concerns about how immigration status influenced access were made implicit and explicit by interviewees. These concerns were referenced or alluded to in discussions around testing access and other COVID-19 services, housing, eligibility for stimulus payments, and other forms of economic support. CE/COs were involved in and supported individuals who were weighing difficult decisions around public health guidance and sustaining their families.

When we decided to do this testing, it was anonymous and taking all barriers from the people, that we were not going to be asking for insurance, we were not going to be asking for employers; all we were asking was, if you're interested and you want to take it, just give us a contact number, your phone number, where we would send you the results. (CM16-17)

CE/COs were constantly adapting activities and priorities based on how identities and lived experiences were discussed, measured in data (being seen and being counted), and acknowledged as critical to health justice. For example, the importance of acknowledging multilingual community members and language justice, a framework emphasizing the complex role of language in equity.

Service delivery models promoting access

CE/COs adopted approaches that allowed rapid and nimble pivots in service delivery. These service delivery models, organizational partnerships, and coalition-building activities supported CE/CO ability to serve communities despite the variable availability of resources and support. At times CE/COs learned and innovated independently from public health and health systems during the pandemic, using existing knowledge to adapt efficient, culturally rooted systems of service delivery. Most notably, interviewees described robust community health worker (CHW) implementation models and the impact of those services.

...CHWs would get those names and reach out to those individuals that tested positive. There's a section with a question that asks what language do you prefer, so all the [deidentified]-speaking community members are picked up by the other CBO that is working with the [deidentified] community. I feel like this COVID Equity Project has been really helpful, geared toward the community members. (CM22)

CE/COs highlighted intentional approaches to CHW training and professional development, specifically, where communication, sincerity, patience, and trust building formed the foundation of the interactions with community members. CHWs identified and met generational needs related to communication platform, time allocated and spent with older members of the community, and the various ways the “need to feel heard” was manifested across age groups. CE/COs described a perceived underutilization of CHWs by the public health system—particularly in circumstances where CHWs could have quickly pivoted to meet an unaddressed need.

I think just having the right staff trained for the communities that they will be working with is really helpful. Like I said, they know the communities, they have the language, they know how to speak to the communities to have them have that trust. And just to be able to listen to them when you speak to them, because maybe they don't get a lot of phone calls. “We just want to call and listen to you, your stories,” especially from the elders. They're lonely, so if people don't call and talk to them... They've gone through so much in life, running away from the [deidentified] War and the transformation from the refugee camps to the United States. They've just gone through so much, so I think just having the right team and have them trained and to have them listen to them, it would really open up more conversations with community members, so that they have trust in the organization that you're working with. And then if you're offering resources, offering other things for them, make sure

to follow up. Don't just leave and say maybe they got the resources; maybe they didn't. Make sure to follow up with them, so that they continue to have the trust in you. (CM22)

Relationality

CE/COs pursued authentic and sustainable connection to the community and reflected on the relationships between local public health, the CE/CO, and community. Dynamics of advocacy and partnership were complex. The characteristics of these relationships either widened gaps or challenges or helped to bridge gaps. Despite good intentions, a lack of clarity and/or inconsistent actions and messaging ultimately undermined efforts and the formation of trust. Dependability was important.

...I get calls from people that tested positive and public health has not reached out to them, and then I get calls from people, “They said they would call me back, and they have not. They took our list of what we've really needed, and we've not gotten nothing,” those kinds of things. And because I am a cultural navigator with public health, I ask them, “How can we help? Because people are calling us. How can we help?” We understand there's a pandemic and they're so overwhelmed with everything, but utilize us as people that are directly in contact with the community. But there's all kinds of bureaucratic stuff. (CM08)

Interviewees described how consistency and authenticity fostered trusting relationships.

We have gone to knock on doors. We knock on doors, especially where we know our community concentrates, so we have specific neighborhoods that we go and do some door knocking. We do calls, so we call the lists of contacts that we have. We also go to little stores, especially in the rural areas in the different counties in the [deidentified]. We go in and do a table at one of the community stores or laundromats. We go and talk to the community where we know they're still going, not to pass out information at events, but just to have those conversations as people are coming to those places. (CM19-21)

Relationality was achieved through deep connection and knowledge of community, consistency, and presence. As CE/COs reflected on the characteristics of authentic relationships, they shared the value of trusted messengers, for example, community leaders, as information pathways.

It's easier to believe the community leader than the CDC... So if the CDC or public health is contacting this guy or the leader about it and talk to him. There's a lot of things, culture,

society, religion... But if the community leader can talk to them, it's easier to believe him than the others [public health]. If they believe and trust him, they'd be like, "I can go ahead and do that." (CM26)

CE/COs also described community leaders as trusted messengers through mutuality and partnership.

... Going into those communities, because you have to show up, too. Not everything can be done online, so you have to be present in those communities and connecting with those leaders in those communities to be able to have that partnership with them. They are trusted community members, so they can relay the message to the larger group. What else? Trust... You have to be present. I'm sorry, but we don't see people. People don't come to us. They don't come to our communities and talk to us, share those resources. They may post it on their website or go to a community event in another area, not where my people live, so they don't know about those things. Yeah, being present, coming into our communities and connecting with those religious leaders or ethnic leaders. (CM08)

Schools were also perceived as important trusted messengers. Interviewees acknowledged that existing relationships between schools and public health, the consistency of school messaging, and the qualities of the relationship between schools and families facilitated the transfer of information about COVID-19 within the community.

... People are receiving dependable information. They receive a message or text message about the schools linked with the COVID-19, so that's really important and families are always participating in the schools' Zoom meetings... the school system is really good because they can reach each family because they have their system. When they [schools] receive any of this from the health department, they put their own information on top of that and send that to all families. They [schools] have interpreters and translate all those materials into the languages that people speak in the community and send it to them. So every family, if they have kids enrolled in school, they receive updated information every day. (CM09)

Social media functioned as an essential platform for connection with and within immigrant communities. Social media was prominent in statements describing means to connect systems or institutions and community. CE/COs acknowledged the importance of social media for information, the potential for misinformation, and therefore, the need to balance this with communication approaches that promote mutual understanding.

Key components of communication for multilingual communities include language access and language justice.

Interviewees reflected that even before the pandemic, language access and language justice presented significant, systemic barriers to accessing information and reinforced the invisibility of immigrant communities within systems.

We see our communities really being left behind and not their different needs being addressed. Many of our community members don't know how to read and write. Many of them may only speak or feel more comfortable with their native language and the information around COVID has only been in the major languages, so in Spanish or English. It's always assumed to do COVID testing and even the COVID vaccine has been, register to take a test. To do that you need to have an email; you need to be able to navigate the Internet. So it's always assumed that people, one, know how to read and write, two, that they know how to use the Internet, and three, that they even have access to Internet to do it and that they know how to use it and navigate those sites. There's a lot of those assumptions and I don't think it's only true for [deidentified] communities, but many other immigrants or refugees that don't speak English and they don't have access. (CM19-21)

Limited language access impacted each step necessary to get tested or vaccinated and reinforced the disproportionate impact of COVID-19 on immigrant communities. Further, when CE/COs found a lack of emphasis on language access, language justice, and trust, they observed hesitancy to disclose personal information about COVID-19 and the perpetuation of stigma about COVID-19.

But it feels like if you don't have those relationships or if people didn't know how you were using these numbers, "why am I telling you?" There was that hesitancy to disclose who you were close to. Again, it goes back to how it's messaged and who calls. There needs to be enough awareness of why am I providing this number for you to call, and the stigma around having COVID. (CM19-21)

Relationality in terms of community connection and trust is related closely to presence or engagement within the community.

Presence

CE/COs explained the types of engagement or presence they pursued or observed in the pandemic response. These included: authentic presence, conditional presence, and lack of presence. CE/COs described the attributes of these presence "types" and how community members felt the presence. The presence was a key component of how CE/COs supported the process of CICT rather than seeking transactional information or service transfer. Interviewees reflected on

attributes of presence, like frequency, consistency, and visibility. They expanded on the role of trusted messengers and described developing and sustaining connections through presence.

In describing authentic presence, CE/COs emphasized supporting the process and relationship building rather than information transfer. They reflected on the role of listening, an approach that facilitated mutuality in identifying and working toward solutions in and with communities. At the core of authentic presence, interviewees described that their presence in the community was because they were the community (CM16-17). CE/COs also explained observations that contrasted how they perceived or experienced authentic presence. One interviewee reflected on their participation in a government task force noting, "...They're there, but at the same time it feels like they're not (CM20). Authentic presence was often equated to sustained physical presence.

Interviewees communicated frustration when presence felt lacking or conditional in comparison to the engagement of CE/COs at the frontline work of the pandemic.

Come often – the frequency. Don't just do one event and be gone. You know what I mean? Because it's the pandemic and you're just doing pandemic-related stuff and we won't see you again until 10 years from now, 20 years from now when there's another pandemic. Be present, be consistent with the community. Don't just do drop-ins. (CM08)

Presence included visibility and accessibility. The presence of individuals who were not trusted partners, and a demonstrated lack of understanding of how particular partners may be perceived as unsafe, undermined trust.

We were not involved at all, but they hired this ex-military group to do kind of like the security. Imagine, when you're working with an immigrant/non-documented community, how would that look to you, and the food was not culturally appropriate... I have requested whether they have evaluated the process and it's just gone into a black hole, my request. (CM23)

This interviewee described an effort by a local jurisdiction and health system to provide housing for individuals isolated after a positive COVID-19 diagnosis. The CE/CO was not involved in the setup and was critical of decisions they felt perpetuated tension and hesitancy in the community, i.e., the ex-military group as security, specifically because of the prevalence and sociopolitical context of irregular migration in the community. The interviewee went on to say, "...They actually left. They [the jurisdiction] put them [community members] in and they left the next day. (CM23)

Genuine connections fostered mutual partnerships through physical presence and consistency. CE/COs acknowledged

circumstances where partner groups appeared motivated by image or reputation in the media or in the community. This conditional presence was detrimental to trust-building and collaboration.

I made phone calls to the [deidentified] and they said, "No, we don't have the capacity to go there." I was really disappointed, and then when they noticed, because it was in the newspaper... they called me back and they said, "We think that we are going to be able to do that... So you have to push the people, right, in order to react." (CM25)

The disproportionate distribution of resources for COVID-19 among BIPOC and immigrant communities emphasized the need for equity focused and culturally responsive service provision at the center of the pandemic response. CE/COs described employee safety, equipment provision to frontline workers, and access to medical care as inequitable components of the pandemic response, which later included CICT, testing, and vaccination.

Again, people think about, when they put public health measures and all that, they don't think about our population. They think about the general, again, white-collar population with that, "Okay, you can do this, you can do that. Oh, use your hand sanitizer, your Lysol." Sometimes you don't have money to buy food. Are you going to spend \$4, \$5, \$10 that they were spending on Lysol? They're not. So a lot of the public health messages are not realistic, are not sensitive to the real needs of the people that are most hit. And that's what we saw. That's what we did. That's what we responded. (CM16-17)

The inequitable distribution of resources to address the pandemic included limited funding and a lack of an advocacy platform.

It's so frustrating because we all know what our community is needing, so we all put our money from our own pockets into a thing to make a basket to take. There's funding out there. You hear about all this funding and then, "Why can't they help our organization to help our people?" (CM15)

Impact

CE/COs summarized approaches to key challenges, broadly categorized as related to access, isolation, mental health, and fear. The impact of these approaches on key challenges was dependent on context and reached across individual, community, and system levels. Interviewees described the strengths-focused CE/CO solutions to the identified challenges. Solutions included ensuring multilingual language access and

multilingual messaging; leveraging or empowering student groups and professionals; providing technology support to elderly and/or low literacy communities in innovative spaces and identifying artistic outlets.

CE/COs described the position of women in communities facilitating impact. Women were pivotal in families and communities as disseminators of knowledge and awareness.

...When you educate those women within our communities, we're able to talk to our spouses, our brothers, our sisters, our daughters, our little kids and share that information with them when you're talking about health. And I'm thinking the whole spectrum, from diabetes, blood pressure, all the illnesses, so educating women specifically on health matters, it helps the whole family; it helps the whole community. (CM08)

In addition to outreach efforts focused on women, CE/COs described targeted outreach toward youth. Youth were perceived as being highly skilled in technology and social media. Leveraging this skill set was a means to equitable distribution of resources in the community. In contrast, when skill sets were felt to be ineffectively utilized CE/COs felt a sense of lessened impact.

...I get calls from people that tested positive and public health has not reached out to them, and then I get calls from people, "They said they would call me back, and they have not. They took our list of what we've really needed, and we've not gotten nothing," those kinds of things. And because I am a cultural navigator with public health, I ask them, "How can we help? Because people are calling us. How can we help?" We understand there's a pandemic and they're so overwhelmed with everything, but utilize us as people that are directly in contact with the community. (CM15)

CE/COs envisioned how their impact could have been optimized had they been successful in establishing engagement with collaborating systems.

"Okay, so if you need to, you can use us and let us get the training for HIPAA, because we're there and we can help you." It's not like we're just saying that; we can help you, because we're connected with our community. And so if we want to even help lessen the burden or the work... you know what I mean?...If that's all we need to do, then let us do it. Let us get the training, and let's get whatever needs to be done so we can help you, so this virus, this pandemic and the spread, it helps that, if we could do that. Those are the things that we are really trying to figure out what to do. But there's so much... bureaucratic stuff, policies. (CM15)

Despite this, CE/COs amplified voices that were impacted, silenced, excluded, or targeted. They listened to what

communities identified they needed during the pandemic. As they had always done, CE/COs continued to provide space for perspectives to be shared and for relationships and trust to develop. Cultural humility was fundamental in this work.

I recommend to every one of you that you find your cultural mentor. My husband is...my cultural mentor as his own culture...So that's the beauty of that, when you realize your capabilities and your willingness. It's like, OK, I'm capable in that, but I'm color blind in this. You have to be honest. (CM25)

Cultural concordance was foundational to impactful collaborations.

And the organization hires individuals from the community to help our own community. We train them, we build their capacity, so we build capacity, among the community and in general in the population that we serve, to help themselves. We believe that's where our, in our mission, it's self-sustainability. We believe that the type of individuals and culture that we are, the ways that we are, we take pride in having our own sustaining system, no matter what that is. But we take pride in helping our own, helping ourselves. And contrary to what many believe, that we just come to this country to ask for services, it is the contrary. We come here to work, we come here to find ways to help ourselves, and we are willing to do the hardest jobs that a lot of people are not willing to endure. And that is the population I represent and how we serve them. (CM16-17)

Table 2 shows examples of challenges presented to CE/COs at individual, community, and system levels and ways CE/COs generated impact through presence, relationality, and orientation. Embedded are NRC-RIM toolkits and promising practices that offer strategies for public health jurisdictions pursuing a comprehensive partnership with communities to optimize capacity in emergency public health response.

Discussion

This community case study described the prominent characteristics of impactful community-led COVID-19 response strategies implemented in partnership with immigrant communities in the United States. CE/COs emphasized understanding context and a culturally responsive, process-oriented approach to a community-led COVID-19 response. The actions, processes, and outcomes CE/COs described were not necessarily new, meaning they had cycled before or were cycling currently in other contexts. A key difference in the context of the COVID-19 pandemic was that the health inequities targeted by actions, processes, and outcomes had not previously posed as acute or widespread a risk to human health.

TABLE 2 Individual/community/system level challenges and problem-solution connection strategies with embedded NRC-RIM toolkit and promising practice starting points for public health jurisdictions focused on building capacity.

Individual challenge & problem-solution

That person called me crying. What will happen with my child?...If my child falls sick or if I myself fall sick, what will happen?...[I said] It doesn't mean that you're going to die, but it doesn't also mean you can neglect it. You need to take it seriously, but don't cry. It will be fixed. Then she said, "oh, this gives me peace of mind."...She started calling friends..."I am in quarantine. I was in touch with you. Please be careful." (CM10-CM13)

Challenge-solution integration	Challenge: Fear of COVID-19 resulting from lack of or misinformation Solution: Access to trusted community leader
Operating theme	Relationality
Toolkit for public health	Communications
Promising practice	Cultural Navigators to Liaise Between Communities and Public Health

Community challenge and problem-solution

When there's a funeral a lot of people would participate. And just having them not being able to do that, it was very traumatizing. They gather at the mosque or pray. They wash the body. I remember calling family members. [Family would ask] What do we have to do? Where do we go to do that? How does it work with covid when they have to cover the body with plastic? It was a very difficult moment for many of us. (CM18)

Challenge-solution integration	Challenge: Loss of cultural connection Solution: Culturally situated information pathway
Operating theme	Presence
Toolkit for public health	Community Engagement Toolkit
Promising practice	COVID-19 Community Coordinators

System challenge and problem-solution

[The doctors] were not able to talk to the families because of the language barrier; they were not able to talk with them because of the time restraints... This is completely new to everybody. A lot of people who were admitted into the hospital... listed me as a spokesperson or the person to contact, so I was able to help them try to communicate between the hospital and the patients. (CM14)

Challenge-solution integration	Challenge: Healthcare system capacity Solution: Culturally responsive, linguistically concordant liaison
Operating theme	Orientation
Toolkit for public health	Community Health Workers - Toolkit
Promising practice	Community Health Workers - Case Examples

CE/COs diligently and intentionally reimaged and recontextualized the public health response to COVID-19 in immigrant communities, frequently in the setting of scarce resources, as the pandemic circumstances evolved. CE/COs demonstrated sustained presence and support in communities, while educating, advocating, and promoting access to public health services, testing, and vaccination in culturally responsive ways. An orientation to the process was foundational to the ways that community organizations approached their work within the context of the COVID-19 pandemic, in contrast to the outcomes-oriented focus of public health and health systems. This orientation was evident in how generational differences and family dynamics were integrated into testing and CICT and how COVID-19 services were tailored around

employment. Identifying and building on community strengths was prioritized over compliance. Establishing a deep sense of community context facilitated communication and the ability to rapidly adjust to meet emerging needs.

Results were aligned with the expansive evidence supporting the role of community-based organizations in sustaining community health and wellbeing. While actions, processes, and outcomes associated with the community-led COVID-19 pandemic response were predominantly in circulation at the onset of the pandemic, important innovation happened within those cycles. These innovations offered new insights into the translation of advocacy into health outcomes. For example, an organization supporting a diverse network of Indigenous farmworkers described the operationalization of

the language justice framework, as a practice [(16), S. M. Ortega, personal communication, March 1, 2022]. Through language-inclusive resources and services and rights-oriented outreach, the organization promoted the sustainability of an essential workforce through capacity building, representation, and resilience. CE/COs also recognized the critical role of culturally and linguistically concordant staff in order to build trust and prevent erosion of trust, and deliver services in an equitable manner, advocating for the integration of cultural mentorship into reflective and authentic work with diverse immigrant communities [(17), J. Altamirano-Crosby, personal communication, March 1, 2022]. Broadly, CHW service delivery emphasizes health promotion and community wellbeing and is accessible, particularly where issues of equitable access and complex system navigation are problems. CHW models support capacity building in health promotion among priority communities (18–21). CHWs were leveraged extensively by CE/COs to create and implement culturally responsive COVID-19 programming in the communities where they lived and worked.

CE/COs evolved foundational practices in community-public health partnership building. Health communication cycles are dependent on the presence of credible sources or “trusted messengers” (22, 23). CE/COs described the roles of religious leaders and schools in communication and messaging as more active and bidirectional. Faith and education institutions were serving mediating roles in communication. Not only were the institutions facilitating the transmission of credible information but they were also influencing the underlying relationship between the senders and receivers of information (24). Additionally, these roles represented an important counterbalance to the prevalence of misinformation on social media (25). It is essential that public health fosters relationships with these channels in addition to wider dissemination strategies, in the interest of accurate and efficient communication dissemination. Community partnership is a well-established standard in public health preparedness. CE/COs expanded on this through descriptions of the impact of sustained physical presence in the community. For example, CE/COs promoted representation as they were physically and visibly present at COVID-19 testing and vaccination sites, sometimes getting tested or vaccinated. They described fielding phone calls and questions from community members, emphasizing the role of accessibility in presence. These approaches complemented the position of public health in relationship building and partnership.

Limitations included the role of selection bias in determining our final sample. Though our sampling frame was broad, the reach of our networks (including members of the project Community Leadership Board) may have been a limiting factor in the project team’s ability to engage key groups. Engagement was more limited in HHS Regions 5–8. Interviews were conducted via the Zoom platform,

which could have potentially been prohibitive for certain individuals/communities depending on broadband access, and were conducted solely in the English language. Interviews were conducted at one point in time. While this design served the objectives of this project phase, it is likely that key iterations and evolutions of the roles of immigrant-serving community structures in developing and implementing culturally sustaining programming in the context of a pandemic response were not elucidated. While we attempted to gain the perspective of multiple forms of community engagement, it was not possible to capture all. Limitations were mitigated by facets of the method and procedures that established trustworthiness and authenticity (26, 27), and the informants’ fundamentally important positions, perspectives, and lived experiences.

Conclusion

...It’s kind of sad that because of the pandemic we’re finally getting noticed, you know what I mean? Like we’re getting the help that the community needs, and it’s sad that it took a pandemic to finally hear our words, hear our needs. (CM15)

Interviewees defined equity as the co-creation of comprehensive and holistic pandemic response services rooted in language and culture. CE/COs explained that an equitable system honors and acknowledges the unique circumstances under which decisions to migrate were made as well as the ongoing impacts of those decisions on health. The breadth of the work and observations described in the interviews are captured in the excerpt that opens the paper, *How can you advocate for something that is nonexistent?* (CM16–17). Through a critical examination of systemic barriers and the elevation of partnerships between communities and systems that support the visibility of immigrant communities, we broaden the capacity of pandemic response. Findings inform the next steps in the application of best and promising practices that address health inequities among refugee, immigrant, and migrant communities in the United States.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The initiative was determined not human subjects research by the University of Minnesota and exempt by the

University of Washington Institutional Review Boards. Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.

Author contributions

SH and YG led analysis and manuscript development. JA-C and SO provided consultation on the interpretation of results and manuscript development. KiY contributed to manuscript sections. SA, DA, WF, SK, EM, and CT contributed to analytic direction and manuscript revision. KaY and ED-H contributed to conception and design of the study. All authors read and approved the submitted version.

Funding

This work was performed under the National Resource Center for Refugees, Immigrants, and Migrants (NRC-RIM) which was funded by the US Centers for Disease Control and Prevention and the International Organization for Migration (award number CK000495-03-00/ES1874).

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Acknowledgments

We thank the interviewees who shared their time in an unprecedented and unrelenting phase of the pandemic to offer lived experiences as community members and expertise as essential community supports.

Conflict of interest

Author JA-C was employed by WAGRO Foundation.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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SPECIALTY SECTION

This article was submitted to
Life-Course Epidemiology and Social
Inequalities in Health,
a section of the journal
Frontiers in Public Health

RECEIVED 05 January 2022

ACCEPTED 06 September 2022

PUBLISHED 17 October 2022

CITATION

Dierx JAJ and Kasper HDP (2022) The
magnitude and importance of
perceived health dimensions define
effective tailor-made
health-promoting interventions per
targeted socioeconomic group.
Front. Public Health 10:849013.
doi: 10.3389/fpubh.2022.849013

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The magnitude and importance of perceived health dimensions define effective tailor-made health-promoting interventions per targeted socioeconomic group

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Recent insights and developments on health and society urge a critical look at the positive relationship between socioeconomic status (SES) and health. We challenge the notions that it is sufficient to distinguish only between two groups of SES (low and high) and that only overall health is taken into account. A new grouping of SES was developed based on both income and education, resulting in six SES groups. Health was defined in terms of a new positive health concept, operationalized into six health dimensions generating a measure of total general health (TGH). Next, six socioeconomic and demographic determinants of health were included. Linear regression, *T*-tests and one-way ANOVA were applied to investigate the relationships in a Dutch sample. A subjective way to measure health was applied: self-rated health (SRH). As a result, four out of six dimensions of health determined TGH: bodily functions, daily functioning, quality of life, and social and societal participation. Three out of six socioeconomic and demographic determinants impacted TGH: housing situation, age, and difficulties meeting financial obligations. While this is the general picture for the entire sample, there were interesting similarities and differences between the six SES groups. The similarities lie in the positive impact of the evaluation of bodily functions and daily functioning on TGH in all SES groups. The other dimensions affected TGH in some groups, and some dimensions only in one SES group. None of the socioeconomic and demographic determinants affected TGH in all SES groups. New insights on health inequalities are provided. It is concluded, first that the well-known positive relationship between SES and health is confirmed in this study. Second, further refining the health concept into six dimensions provides more detailed insights on which dimensions impact health the most. The subjective approach applied offers more refined information to better understand which health issues really matter to people. This yields new insights to develop tailor-made interventions aimed at increasing healthy behaviour in specific societal groups.

KEYWORDS

positive health, socioeconomic status, self-rated health, subjective approach, Netherlands, tailored interventions

Introduction

The impact of people's socioeconomic status (SES) on health has been studied extensively (1–3). An elaborate literature review by Petrovic et al. (3) shows that such studies differ in four aspects. First, outcome parameters range from biological indicators (4–6) to health behaviour parameters (7–9), morbidities like cardiovascular disease and diabetes (10–14) and all-cause mortality (8, 9, 15). Second, SES is constituted in a non-uniform way with most studies using gross household income, parental education and employment (or occupation) as SES parameters (4, 9, 13, 15, 16). Third, in almost all studies the effect of each SES parameter on the outcome parameter is studied separately, where some dichotomise the multilevel SES parameters into high and low SES (17). Only a few create an overall SES parameter based on income, education and/or employment (or occupation) (9, 18, 19). Fourth, studies differ in measured objective parameters of health and SES vs. subjective or self-rated health (5-level score, range poor-to-good) and SES (9, 17–20). In this study we investigate a multidimensional view on both SES and self-rated health (SRH) by distinguishing six groups of SES and six dimensions of health next to Total General Health (TGH) to gain more refined insights into the complex relationship between SES and health. Our study is unique in three ways. We:

- Construct a SES variable based on the respondents' individual combined score on their household income as well as their highest educational level;
- Apply a six-dimensional health concept based on the presence of people's health instead of their absence of health as measured by illness or disease in terms of mortality of morbidity;
- Use people's self-rated (subjective) health instead of objective indicators of health.

SES is an undisputedly major factor influencing TGH and health behaviour. Simply stated, it can be concluded that a positive relationship exists between SES and health (1, 3, 10, 19, 21–23). The socioeconomic determinants of TGH as mentioned and described in the model of Lalonde (24) have been studied elaborately (2, 21, 25–29). The complexity of the relationships between socioeconomic determinants of health has been conceptualised in the rainbow model of Whitehead and Dahlgren (30). This model, implicitly or explicitly, includes age, gender, marital status, household size and employment as socioeconomic determinants of health and depicts the interactions between them at the level of individual lifestyle,

social and community network, and general socioeconomic, cultural and environmental conditions. The rainbow model is still the most abundant and complete to date. Many studies describe the socioeconomic health disparities between people with low and high SES scores. Since synonyms like “health inequity” and “health inequalities” are used in the literature for the term “health disparities,” it is important that we use “health inequalities,” following the approach of McCartney et al. (31) (see Socioeconomic determinants of health section).

In light of recent insights and developments on health and society, a critical look at the way SES and health are defined and/or operationalized is needed to expand understanding of their relationships and of interventions to increase healthy behaviour and reduce health inequalities. We will reveal that distinguishing more SES groups on an aggregated level based on education and income and that applying the concept of positive health and its six dimensions will provide these better and more refined insights. This study therefore addresses the following three research questions:

1. What health dimensions determine the perception of TGH?
2. What socioeconomic and demographic variables determine the perception of TGH?
3. To what extent do these relationships differ between various groups of SES distinguishing six instead of two groups of high and low SES?

The implications of the results on future research and on possible health-promoting interventions toward diminishing socioeconomic health inequality are discussed. The empirical study was conducted in the Netherlands.

Socioeconomic determinants of health

In their overview article, McCartney et al. (31) define health inequalities as “...the systematic, avoidable and unfair differences in health outcomes that can be observed between populations, between social groups within the same population or as a gradient across a population ranked by social position...” We will focus on such systematic and avoidable differences in health outcomes.

In the Netherlands, people from low SES groups report on average living 18 more years with illness and dying 7 years earlier than people from high SES groups (32). There are multiple factors that account for this inequality. In terms of behaviour, people from low SES groups tend to participate more often in risky health behaviours such as smoking, higher fat and lower fruit and vegetable consumption, low physical activity and higher alcohol consumption more often (3, 33–36). This tends to be more pronounced in men than in women, leading ultimately to men reporting lower self-rated health (33, 34) and suffering significantly more from chronic diseases (35). Premature deaths in non-married persons tend to be higher than in married

Abbreviations: SD, standard deviation; SES, socioeconomic status; SRH, self-rated health; TGH, total general health; WHO, World Health Organization.

persons (21). Another common factor is unemployment or poor job satisfaction having detrimental effects on health (36–38). Household size has likewise been shown to impact health (39–44). These studies refer to long-term detrimental effects of family SES on health, in the sense of low family income and parents as well as grandparents belonging to low SES groups (44–46). In larger families, mothers tend to stay at home caring for children, so these families have lower income than families where the mother is employed (41–43, 45, 46). By contrast, obesity in siblings living in larger households appears to be less common and is dependent on order of birth, as younger siblings tend to show higher odds of becoming obese (40, 42). Hence these studies suggest a socially hereditary component of SES with family size too as a possible determinant for poor health. Whether and how people can escape from such a socially inherited inequality cage or will remain unhealthy from one generation to the next is a point of discussion, as these inequalities persist for many years and even tend to increase despite interventions to change such situations (44). Crises like the recession of the early 2000s and the current COVID-19 pandemic might even enhance existing inequalities (43, 47, 48). Petrovic et al. (3) (p. 23) show that “socially disadvantaged individuals tend to adhere more to health detrimental behaviors either due to material and financial constraints, perceptions of fewer benefits of health behaviours for longevity, a lack of knowledge of their detrimental effect, difficulties to take up health promoting messages as well as more pessimistic attitudes about life. Often, the deprived neighbourhoods where they live offer little opportunities for a healthy life.” These health inequalities based on socioeconomic and demographic variables as well as on behaviour seem to be systematic, and whether they can be avoided or changed by specific single health or lifestyle interventions remains debatable. A more multidisciplinary approach is advocated to develop effective interventions (49).

Socioeconomic status: The concept and its operationalization

The concept of socioeconomic status usually refers to the description of groups of people and the differences in relation to their social class and financial situation. As reviewed by Petrovic et al. (3), SES is operationalised by the determinants of education and income. Two approaches can be distinguished: one applying only one of these two determinants, another a combination of the two. In the latter approach researchers form two groups of people according to their SES by distinguishing between people with low education and low income (= low SES) vs. those with high education and high income (= high SES) (18, 33, 50). We suggest that the relationship between income and education may not be that straightforward at the

individual or group level. More recently, Hoes et al. (51) used nine levels of education which were transformed into three levels in the analysis: low, intermediate and high. They also categorised net household income per month into three levels: low, intermediate and high. Separate analyses were performed for the three educational groups as well as for the three income groups. For both income and education, Hoes et al. (51) compared respondents from the high group to those from the low group, and respondents from the intermediate group with those from the low group. However, either no comparison was made between respondents with high income but a low education (or vice versa) or it was not taken into account. In their California Health Interview Survey, Meyer et al. (19) (p 1735) take a next step in developing their SES variable based on respondents' actual level of education and income. They describe their procedure to develop a composite index of SES: “Individuals reported on their education by selecting 1 of 11 options ranging from having no formal education to having a PhD or equivalent. We computed income by dividing total household income by the number of adults residing in the household. We then standardized this value and averaged it with a standardized version of the education variable to create a composite index of SES.” In our study, we operationalised SES more or less similarly by combining the 7-level education variable with a 7-level income variable.

As suggested by Flinterman et al. (52), several participants had low education but were successful high-income entrepreneurs. On the other hand, several participants with high education ended up earning low incomes due to unemployment or negative life events such as divorce or illness. Clearly more combinations of income and education exist than merely the two of low income/low education vs. high income/high education. Recent studies also report the COVID-19 pandemic affecting the often-highly-educated and mid-to-high-income self-employed, rendering them low-income (43, 47, 48). This shows that income can fluctuate during life and is not a fixed given (47). Hence where the traditional and often continuous or dichotomised classification probably discloses the general effects of SES on health, a classification into more SES groups as a combined measure based on the SES determinants of education and income might shed additional and more detailed light on the way SES impacts health. We propose distinguishing six groups of various combinations of income and education.

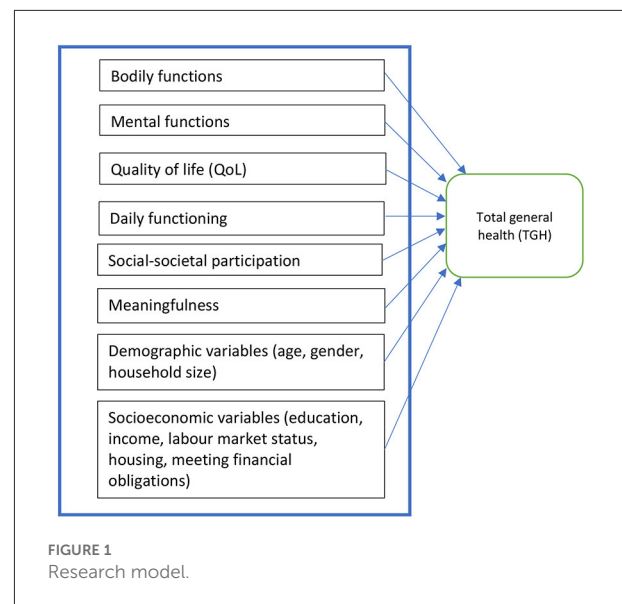
Health: The concept and its operationalisation

In 1948, the WHO defined health as “A state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity” (53). Since then, thanks to developments in society, medicine, science, public health

and technology, people's views on health have changed. This has already been elaborately described by others, and several attempts have been made to update this definition to one more suitable to the times (31, 54–57). The main discourse is about including parameters other than health, doing more justice to the individual perception of health, the impact of the physical environment on health, and the fact that “health” is not static but rather dynamic. Elaborating on the original WHO definition adhering to Nordenfelt's conception of health (55, 56) Bircher defined health as “a dynamic state of wellbeing characterized by a physical, mental and social potential, which satisfies the demands of a life commensurate with age, culture, and personal responsibility. If the potential is insufficient to satisfy these demands the state is disease”.

When evaluating this definition we believe it holds an objective professionals' perspective, which is often deficit-based as medical professionals tend to focus is on “what (potential) is lacking” and strive for maximum achievable outcome. Huber et al. (58) took all of this into account and proposed a more “positive” definition of health, with health as “...the ability to adapt and self-manage, in the face of social, physical and emotional challenges.” Such an approach, also criticised for being too general and hence not specific enough (59), holds a subjective patient-centred perspective and is asset-based, focusing on meaningful possibilities striving for optimal outcome. In this respect, the term “assets” can be defined as “any factor (or resource) which enhances the ability of individuals, groups, communities, populations, social systems and/or institutions to maintain and sustain health and wellbeing and to help to reduce health inequities” (60). We would like to emphasise that this positive approach to health focuses on the potential people have instead of what they lack. In light of equality, this means that everyone should be able to have equal opportunity and access to these assets, as they are at the core of the capability approach (54, 61–63).

Huber subsequently operationalised this definition with the concept of positive health, this time adding the three dimensions of meaningfulness, quality of life and daily functioning to bodily functions, mental functions, and social and societal participation (the equivalent of the three WHO dimensions of health) (64). The positive health approach relies on people's own perceived (subjective) evaluation of their health instead of on the professional's (more objective) judgement of a patient's health. In investigating the perceived health of a population, this concept of positive health appears to have added value (65). Traditionally, studies on health tend to use quantitative and rather objective measures, like blood pressure, weight, body mass index and specific diseases (4–6, 12, 13, 23). From the literature on consumer behaviour it is well-documented that not only objective information affects people's behaviour but that behaviour is much more affected by the way people perceive those issues subjectively (66, 67). For



example, whether they perceive their illness as serious or whether they perceive their smoking habit as pleasant can determine behaviour to a larger extent than mere factual information on, e.g., the dangers of smoking. In line with this way of thinking, we will apply a subjective approach toward evaluating participants' own health instead of objective factual judgements made by professionals. In line with recent findings (20, 68), we argue that interventions based on such a subjective approach of self-rated health (SRH) might be more effective than interventions based on an objective, professional judgement-based approach. Here using the positive health concept offers the opportunity to focus the interventions on people's own judgement of their health potential (what they can do) instead of their perceived shortcomings (what they cannot do).

Methods

Research model

The research model as shown in Figure 1 was used to answer the three research questions. We studied whether and how the six dimensions of the positive health concept and several socioeconomic and demographic variables like age, gender, educational level, labour market status, income, household size and housing situation determined perceived TGH in the average Dutch population. We also included the way people perceive their income situation (ability to meet financial obligations) instead of only looking at the amount of gross household income as an explanatory variable in our models.

Research population and data collection

In the fall of 2016 an online questionnaire was sent to all internet panel participants of RMI, a Dutch commercial market research company. This panel consists of 30,000 respondents aged 18 years and older, and is a representative sample of age, gender and urban-rural population. The respondents are members of the RMI Internet panel and participated in the study voluntarily. At the start of this Internet panel years ago, RMI obtained informed consent from all panel members agreeing to participate in this study panel. To encourage people to participate in studies, respondents receive a small fee of €1 for every completed questionnaire.

The 32-item Positive Health questionnaire as developed and kindly made available by Dr Huber (64) was used with some slight adaptations. Other topics were added to measure socioeconomic and demographic status. The final version consisted of 20 questions and 45 items. Participants were asked to assess their total perceived health and their perceived health on each of the six dimensions of the positive health concept after scoring the 32 items of the positive health scale from 1 (poor) to 5 (excellent). In this way all respondents evaluated their health on the same topics, avoiding different interpretations of health (69). The research design opted for analysing the dataset with regression analysis.

Data collection was terminated after a representative sample of 1,000 participants had responded. This number was decided upon because it allows for breaking down into several subgroups if necessary. For instance, if it were interesting to define four or six SES groups, group sizes would still be sufficient for adequate statistical analysis. Ideally, for regression analyses to be performed the number of respondents should be at least the quadrate of the number of independent variables, so with 12 independent variables the number of respondents in a group should ideally be at least $12 \times 12 = 144$. Since regression analysis is a very robust technique, a lower number of respondents should still allow for proper analysis.

After checking the response for missing data on the SES items income and education, a total of 772 respondents were included in the statistical analysis. Only on educational level did the sample appear not to be representative of the Dutch population. Educational level was slightly higher in the sample compared to the average Dutch population and was corrected for during statistical analysis of the results.

Ethics

Since participants in this study did not undergo any physical examination and bodily fluids or other medical data were not collected, the Medical Research Involving Human Subjects Act does not apply to the current study. Although this approval does not appear to be mandatory, the Ethics Committee of the

Silverbrains Board approved the research design and protocols for the data collection and analysis. The study was conducted in accordance with the rules and guidelines of the Dutch Expertise Center for Marketing Insights, Research and Analytics (MOA) and the Association for Policy Research (VBO), which are in line with the rules and guidelines of the European Society for Opinion and Marketing Research (ESOMAR).

Statistical analysis

Data of the 772 respondents were analysed using IBM SPSS Statistics 26. Spearman correlations and linear regression analysis were performed, determining the direct relationships and relative contributions of the health determinants as well as the socioeconomic and demographic determinants to perceived TGH. Linear regression is a commonly used statistical technique and a justified way to analyse these relationships (69). *T*-tests and one-way ANOVA were used to test for statistical differences between the SES groups.

The linear regression had TGH as the dependent variable to be explained by several independent variables. In the first regression for the whole sample these independent variables were the six dimensions of health as well as the SES position and the six socioeconomic and demographic variables.

$$\text{TGH} = \alpha + \beta_1 \text{ Bodily functions} + \beta_2 \text{ Daily functioning} + \beta_3 \text{ Quality of life} + \beta_4 \text{ Social and societal participation} + \beta_5 \text{ Mental functions and perception} + \beta_6 \text{ Meaningfulness} + \beta_7 \text{ SES} + \beta_8 \text{ Home ownership} + \beta_9 \text{ Age} + \beta_{10} \text{ Difficulties in meeting financial obligations} + \beta_{11} \text{ Household size} + \beta_{12} \text{ Labour market status} + \beta_{13} \text{ Gender} + \varepsilon.$$

Basically, in the regression equation α represents the “constant,” β represents the regression coefficient whose magnitude/size can be considered as an indicator of how important that particular variable is in explaining the dependent variable TGH, and ε represents the error term in such equations.

In the second instance we ran the regression again for the whole sample but without the SES variable, which turned out to be non-significant, rendering twelve independent variables explaining TGH. That model was also run for each subgroup of SES distinguished in our further analyses.

The evaluation of TGH and each health dimension was given on a five-point Likert scale ranging from 1 = poor to 2 = moderate, 3 = reasonable, 4 = good and 5 = excellent. Home ownership is a dummy variable where 1 = home ownership and 2 = rented home. Age is the actual biological age. Difficulties in meeting financial obligations was measured on a five-point Likert scale ranging from 1 = a lot of difficulties to 2 = difficulties, 3 = some difficulties, 4 = hardly any difficulties and 5 = no difficulties at all. Household size was measured as the total number of persons in the household. Labour market status was measured *via* various positions in the labour market (see Table 2); in the regression it is a dummy variable of not

having a job (=1) or having a job (=2). Individual SES scores were determined on the basis of respondents' highest achieved educational level (7 levels) and gross household income (7 levels). The procedure to calculate these individual SES scores was as follows:

Individual respondents' SES scores were calculated based on their answers to the two questions on their highest achieved educational level and gross household income (both variables were measured by ticking the appropriate answer on a seven-point scale; see also Table 1). The composite score was calculated *via* the factor analysis module in SPSS to create a new variable for the individual's SES score. In this calculation the mean score of the newly calculated SES variable of all respondents was set at zero, resulting in respondents with an individual SES score below zero while others had an individual SES score above zero (see Figure 2). Figure 2 shows that more groups of respondents can be distinguished than just the two with SES scores below or above zero. In forming these groups, we considered the distances between individual SES scores (e.g., when a "big break" occurred) and the number of respondents in each SES group, as this number should facilitate our regression analysis (meeting the rule that the number of respondents should be larger than the squared number of independent variables in our regression equations).

The distinction between the low and high SES groups in the two-SES groups situation was based on whether the individual SES score was lower or higher than zero. This resulted in 369 respondents in the low SES group and 403 respondents in the high SES group. In the six-SES groups situation the cut-off points were defined as follows (see also Figure 2):

- *SES score -2.41 to -1.13 SES very low
- *SES score -0.77 to -0.71 SES low
- *SES score -0.695 to -0.25 SES mid-low
- *SES score -0.05 to 0.153 SES mid-high
- *SES score 0.48 – 1.00 SES high
- *SES score 1.35 – 2.66 SES very high.

The six-SES groups situation relates to the two-SES groups situation in a rather simple way: the three groups with the lowest SES scores in the six-group situation belong to the low SES situation, whereas the three groups with the highest SES scores in the six-group situation belong to the high SES situation (Figure 3).

Results

Research population

Respondents' average age was almost 49 years (range 18–93). The sample consisted of 48% women and 52% men; 45% had vocational education, 7% secondary education and 48% university education as highest educational level (see Tables 1, 2). Table 1 reveals that the relationship between

education and income is not linear, given the combinations of low income/high education and high income/low education as suggested by Flinterman et al. (52).

General overview of the results on health

As illustrated in the model in Figure 3, the analysis was done at three different levels: (1) all respondents, (2) two SES groups, and (3) six SES groups. We will follow the structure of this model when presenting our results.

In general, all respondents perceived their TGH as quite good: more than two-thirds (67.5%) evaluated their TGH as good and/or excellent, in the two-SES groups situation 57.2% for the low SES group and 77.0% for the high SES group. This TGH score was constantly increasing in the six-SES groups situation: from 49.9% in the very low group *via* 58.8% (low), 64.7% (mid-low), 69.8% (mid-high) and 73.2% (high) to 90.3% in the very high group.

When distinguishing between SES groups, average TGH and mean of all the dimensions of health were perceived as better with increasing SES scores while standard deviations decreased (see Table 3). This smaller standard deviation implies that people within a higher SES group have a more common perception of their health and are a rather homogeneous group in this respect. There was quite some heterogeneity in the perceived health of lower SES participants, as SDs within each of the lower SES groups were quite large.

Analysing the evaluations of TGH in the different SES groups, Figure 4 summarises the results for the mean TGH scores per SES group. The inequality in the evaluation of TGH is clear. In the two-SES groups situation, TGH was significantly lower in the low SES group than in the high SES group. To increase readability of the results, in this section we will report only the findings that were significant.

In the six-SES groups situation, self-evaluation of health shows a gradient in the pattern of better health with increasing SES. TGH of the four lowest SES groups was the same, yet significantly lower than that of the two highest SES groups. This implies the possible gradual yet critical turning point at which a higher SES has a significant impact on (better) TGH. That turning point did not lie exactly between the low and high SES groups (in the two-SES groups situation), but is part of the (dichotomous) high SES group.

A similar gradient was found for each of the six health dimensions (Figure 5; Table 3). These evaluations were significantly higher in the two highest SES groups than in the four lower SES groups. In all dimensions, the lowest SES group and the highest SES group scored significantly lowest and highest, respectively.

Considering the socioeconomic and demographic determinants associated with TGH, respondents in higher SES groups were significantly more likely to own a house,

TABLE 1 Sample and SES groups' composition based on education and income.

	Total sample	Two SES groups		Six SES groups					
		Low SES	High SES	Very low SES	Low SES	Mid-low SES	Mid-high SES	High SES	Very high SES
Highest educational level achieved ^a									
No education/elementary/basic dutch (for foreigners)	1.0%	2.1%	–	5.0%	–	–	–	–	–
Primary/basic preparatory vocational/lower vocational	5.8%	12.0%	–	24.0%	–	5.9%	–	–	–
General preparatory vocational ^b /lower secondary or lower college-preparatory/special preparatory	9.7%	20.1%	–	26.1%	29.0%	7.3%	0.1%	0.1%	–
Higher vocational or old vocational classification	27.7%	49.3%	7.9%	44.8%	61.0%	46.8%	26.3%	3.2%	–
Upper secondary or upper college-preparatory	7.4%	3.5%	10.9%	–	10.0%	3.4%	13.3%	14.9%	1.4%
University-level up to bachelor's equivalent	35.4%	13.0%	56.0%	–	–	36.6%	51.0%	64.4%	44.8%
Master's or doctoral/post-graduate	13.1%	–	25.1%	–	–	–	9.3%	17.4%	53.8%
Gross household income per year									
<€25,000	22.9%	45.3%	2.2%	72.5%	10.0%	36.6%	9.3%	–	–
Between €25,001 and 35,000	20.1%	23.9%	16.7%	20.8%	61.0%	3.4%	51.0%	9.0%	–
Between €35,001 and 50,000	24.4%	26.0%	22.8%	6.6%	29.0%	46.8%	13.3%	39.6%	–
Between €50,001 and 70,000	19.8%	4.1%	34.2%	–	–	11.5%	26.3%	42.3%	26.1%
Between €70,001 and 100,000	9.8%	0.6%	18.3%	–	–	1.7%	0.1%	8.9%	52.2%
Between €100,001 and 250,000	2.9%	–	5.5%	–	–	–	–	0.1%	20.4%
More than €250,000	0.2%	–	0.4%	–	–	–	–	–	1.3%
Number of respondents (= 100%)	772	369	403	153	85	131	96	200	107

General descriptives of the respondents' highest educational level and gross household income per year as categorized to the different SES groups classifications. ^aIn the Netherlands, secondary education is subdivided into multiple programmes that are oriented toward the needs of the student and include vocational variants. ^bCorresponds with C-level GCSEs in the UK and 10th grade in the US.

TABLE 2 Sample and SES groups' socioeconomic and demographic descriptives.

	Total sample	Two SES groups ²		Six SES groups ³					
		Low SES	High SES	Very low SES (a)	Low SES (b)	Mid-low SES (c)	Mid-high SES (d)	High SES (e)	Very high SES (f)
Type of housing/dwelling									
Home owner	62.2%	43.8% [‡]	79.0%	30.1% ^{bcdef}	55.6% ^{aef}	52.1% ^{aef}	56.8% ^{aef}	81.9% ^{abcd}	93.5% ^{abcd}
Home renter	37.8%	56.2% [‡]	21.0%	69.9%	44.4%	47.9%	43.2%	18.1%	6.5%
Age									
Mean age in years	48.9	51.5 [‡]	46.5	55.3 ^{cdef}	54.3 ^{cdef}	45.1 ^{ab}	46.5 ^{ab}	46.1 ^{ab}	47.2 ^{ab}
Has difficulties meeting financial obligations									
Mean score ⁴	3.74	3.34 [‡]	4.11	3.19 ^{cdef}	3.31 ^{def}	3.54 ^{aef}	3.83 ^{abf}	4.08 ^{abcf}	4.40 ^{abcde}
Household size									
Total number of people in household (mean)	2.33	2.16 [‡]	2.49	1.68 ^{cdef}	2.07 ^c	2.77 ^{ab}	2.33 ^a	2.54 ^a	2.53 ^a
Labour market status ¹									
Has a paid job	52.0%	36.4% [‡]	66.3%	24.4% ^{cdef}	38.4% ^{ef}	49.0% ^{aef}	57.1% ^a	66.2% ^{abc}	74.7% ^{abc}
Retired	18.9%	23.1%	15.0%	33.7%	26.2%	8.8%	20.8%	14.0%	11.7%
Unable to work, incapacitated or chronically ill	10.8%	17.0%	5.1%	21.0%	14.5%	14.0%	9.1%	5.9%	0.1%
Unemployed	6.8%	9.8%	4.1%	13.7%	7.6%	6.7%	4.3%	4.1%	3.9%
Homemaker	4.5%	6.7%	2.6%	4.2%	9.5%	7.6%	3.0%	3.0%	1.5%
Has education and does not work	2.7%	2.6%	2.8%	0.8%	0.1%	6.3%	4.4%	2.8%	1.2%
Miscellaneous	4.3%	4.4%	4.1%	2.2%	3.5%	7.6%	1.3%	4.0%	6.9%
Gender									
Male	52.3%	43.7% [‡]	60.1%	39.6% ^{ef}	38.0% ^{ef}	52.1% ^f	49.3% ^f	58.3% ^{ab}	73.2% ^{abcd}
Female	47.7%	56.3% [‡]	39.9%	60.4%	62.0%	47.9%	50.7%	41.7%	26.8%
Number of respondents (= 100%)	772	369	403	153	85	131	96	200	107

General descriptives of the respondents' type of housing, age, difficulty in meeting their financial obligations and household size as categorized to the different SES groups classifications. ¹In the Regression Analysis This Variable Was Transformed Into a Dummy Factor (Having a Paid job or not). Statistical Differences Only Relate to This Dummy Factor. ²In the Columns of the two SES Groups, Statistical Significance Is Based on *T*-Tests With $\dagger p = 0.000$. ³In the Columns of the six SES Groups the Superscripts ^{a,b,c,d,e,f} Refer to the Statistically Significant Differences ($p < 0.05$) Between the Value in one SES Group and the Values in any of the Other five SES Groups. Statistical Differences Are Based on one-Way ANOVA. ⁴A Higher Mean Score Means Fewer Difficulties Meeting Financial Obligations.

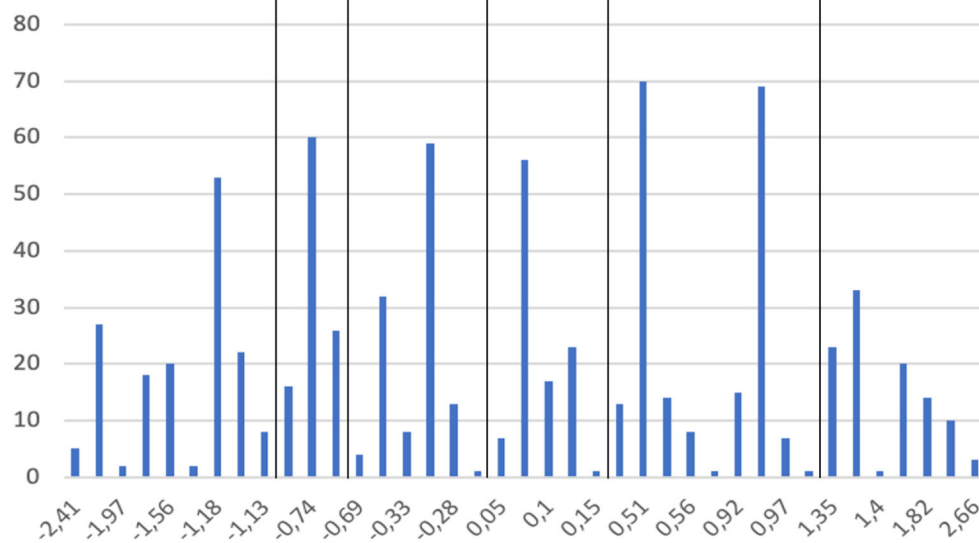


FIGURE 2
Distribution of individual SES scores.

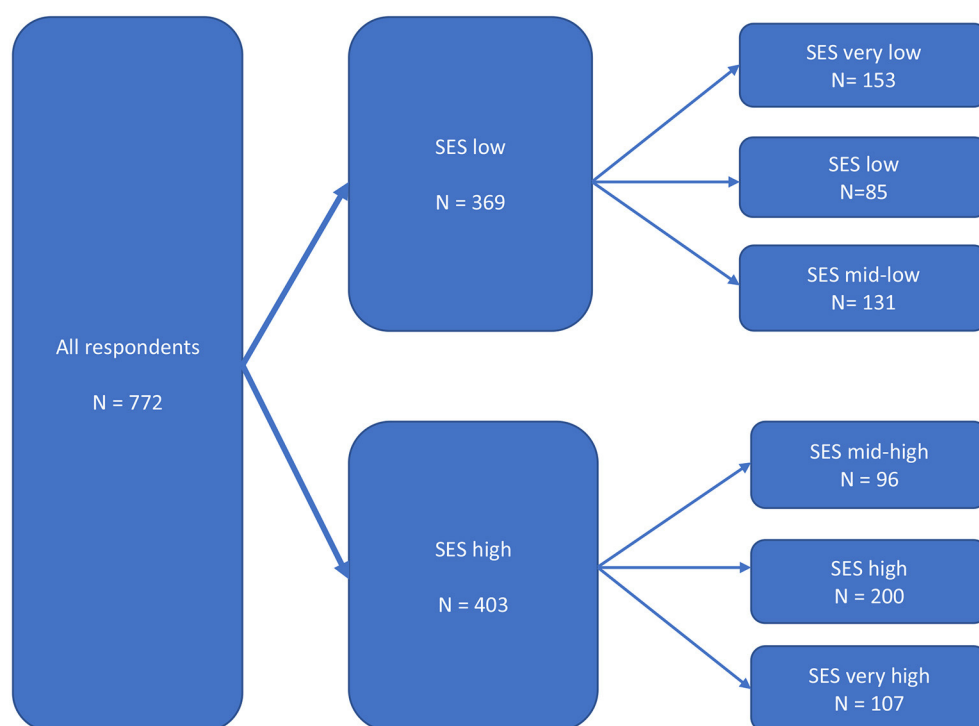


FIGURE 3
Structure of the empirical analysis.

be employed, have larger households, and have less trouble meeting financial obligations (Table 3). Gender was almost equally distributed among total respondents

but showed a gradient of more males with increasing SES. When distinguishing between both two-SES and six-SES groups, gender distribution shifted toward significantly

TABLE 3 Evaluation of health and its dimensions in total group, two and six SES groups.

	Two SES groups ¹						Six SES groups ²											
	Total sample		Low SES		High SES		Very low SES (a)		Low SES (b)		Mid-low SES (c)		Mid-high SES (d)		High SES (e)		Very high SES (f)	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Total general health	3.64	0.88	3.41 [‡]	0.97	3.86	0.73	3.34 ^{ef}	0.95	3.47 ^{ef}	0.93	3.45 ^{ef}	1.01	3.59 ^f	0.79	3.83 ^{abcf}	0.72	4.15 ^{abcde}	0.57
Bodily functions	3.58	1.00	3.32 [‡]	1.08	3.81	0.87	3.20 ^{def}	1.11	3.45 ^f	1.02	3.38 ^{ef}	1.07	3.64 ^{af}	0.87	3.72 ^{acf}	0.90	4.11 ^{abcde}	0.76
Daily functioning	3.89	0.88	3.67 [‡]	0.97	4.09	0.73	3.62 ^{ef}	1.01	3.65 ^{ef}	0.94	3.75 ^{ef}	0.95	3.81 ^f	0.75	4.07 ^{abcf}	0.74	4.39 ^{abcde}	0.58
Quality of life	3.75	0.82	3.56 [‡]	0.92	3.92	0.67	3.49 ^{ef}	0.86	3.64 ^f	0.90	3.59 ^{ef}	0.99	3.70 ^f	0.62	3.89 ^{acf}	0.69	4.18 ^{abcde}	0.60
Social and societal participation	3.60	0.86	3.45 [‡]	0.92	3.75	0.78	3.39 ^{ef}	0.90	3.48 ^f	0.88	3.49 ^f	0.96	3.61 ^f	0.67	3.66 ^{af}	0.86	4.05 ^{abcde}	0.59
Mental functions and perception	3.86	0.93	3.67 [‡]	1.05	4.03	0.76	3.58 ^{ef}	1.09	3.81 ^f	0.80	3.69 ^{ef}	1.14	3.74 ^f	0.84	4.01 ^{ac}	0.77	4.31 ^{abcd}	0.55
Meaningfulness	3.49	0.54	3.36 [‡]	1.01	3.61	0.85	3.35 ^f	1.05	3.40 ^f	0.96	3.34 ^f	1.02	3.40 ^f	0.89	3.57	0.85	3.86 ^{abcd}	0.75
Number of respondents	772		369		403		153		85		131		96		200		107	

Self Rating of total general health and the six health dimensions by respondents as categorized to the different SES-groups. ¹In the Columns of the two SES Groups, Statistical Significance Is Based on T-Tests With $p < 0.001$; ²In the Columns of the six SES Groups the Superscripts a, b, c, d, e and f Refer to the Statistically Significant Differences ($p < 0.05$) Between the Value in one SES Group and the Values in any of the Other five SES Groups. Statistical Differences Are Based on one-Way ANOVA.

higher numbers of males. Age seemed to decrease with increasing SES. The mid-high SES group resembled the three lower SES groups more than the two higher SES groups.

Results on the relationship between SES and health

When performing a single regression on the impact of the SES score on TGH for all 772 respondents, 10.1% of the variance in TGH was explained by the SES score (standardised $\beta = 0.320$; $R^2 = 0.101$, $p = 0.000$). This shows that the higher the SES score, the higher the TGH is evaluated, and illustrates that the well-known positive impact of SES on health is also present in our data. Given this 10.1% explained variance, other variables could be added to increase it. To this end, in a multiple regression analysis we included the six health determinants, the six socioeconomic and demographic determinants from our model, and participants' individual SES scores. This model is statistically significant (adjusted $R^2 = 0.777$, $p = 0.000$; see first column in Table 4). However, SES does not have an impact on the evaluation of TGH in this multiple regression (standardised $\beta = -0.025$, $p = 0.244$).

The disappearing impact of SES might be due to the fact that the influence of SES on the perception of TGH is "taken over" by other variables in the model. However, SES may still affect TGH one way or another given the significant simple regression's output. As a next step in our analysis, we therefore focus on the possible relationships between the six health determinants together with the six socioeconomic and demographic determinants in explaining TGH in the entire sample as well as within a specific SES group. We performed multiple linear regression analyses both for the traditional two-SES groups and for each of the newly developed six-SES groups. The results of our analyses are presented in detail below.

Factors determining all respondents' evaluation of TGH

When analysing the data of all respondents without the SES variable, the perception of TGH was explained by four of the six health determinants and by three of the six socioeconomic and demographic determinants (second column in Table 4). Here a higher score on perceived TGH could be largely explained by a higher score on the evaluation of bodily function and daily functioning, followed by a higher score on evaluation of quality of life. Additionally, but to a lesser extent, people reporting owning a house, people scoring higher on social and

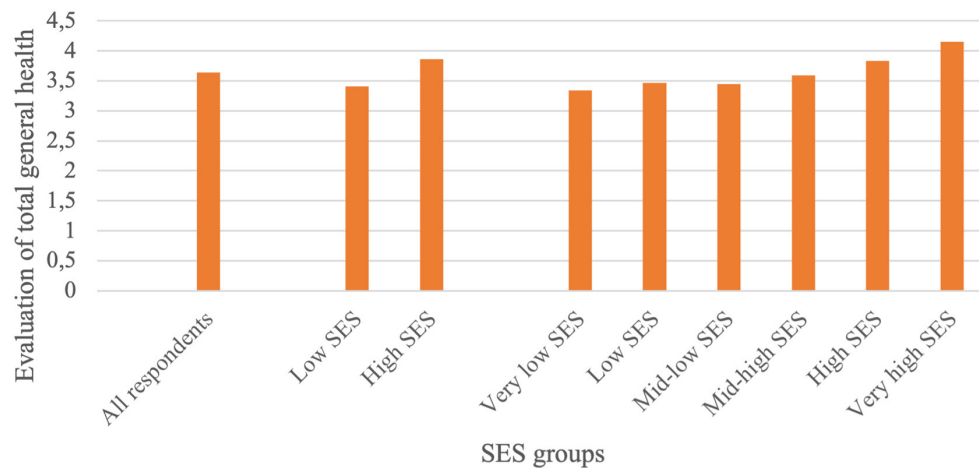


FIGURE 4
Mean scores of the evaluation of TGH.

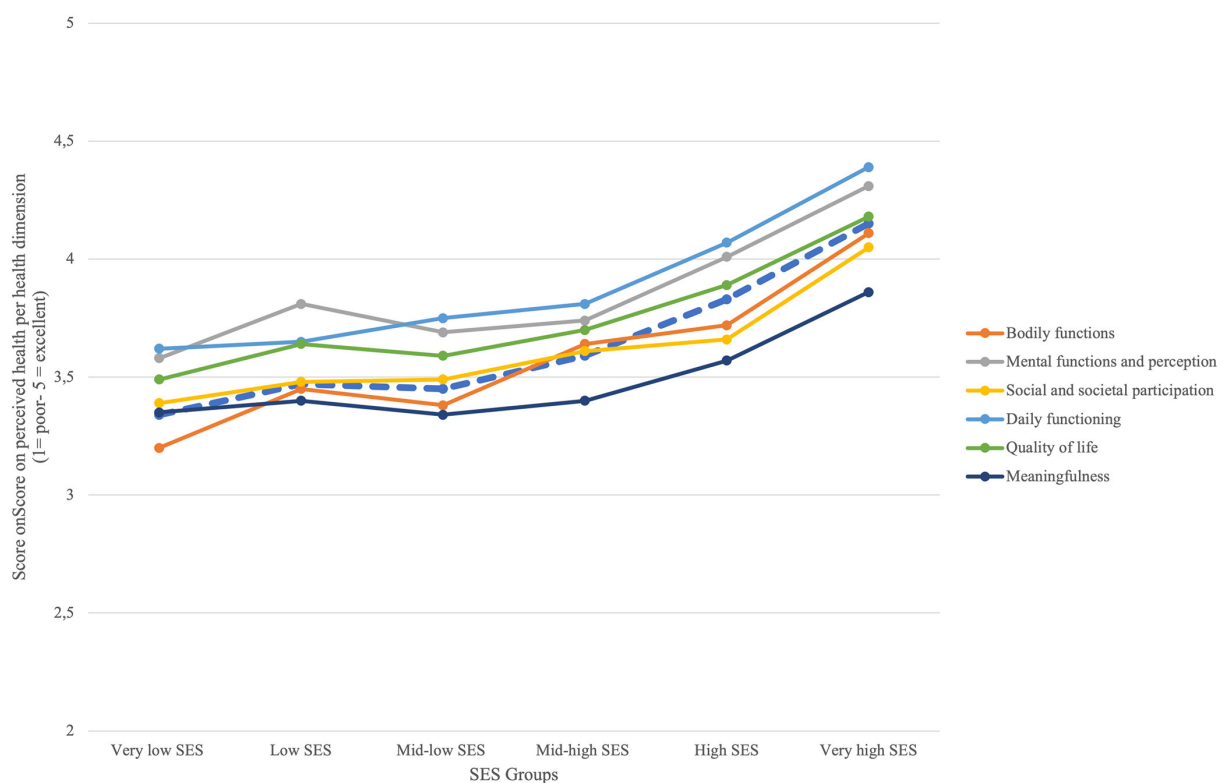


FIGURE 5
Score on perceived health per health dimension.

societal participation, younger people, and those with no or fewer difficulties meeting financial obligations scored higher on their perceived TGH. Perceived TGH was however not influenced by evaluation of the other two health dimensions of

meaningfulness and mental function, or by the socioeconomic and demographic variables of gender, household size and labour market status because no significant standardised β 's were found.

Factors determining the evaluation of TGH by distinguishing between two groups of SES

When distinguishing between two groups of SES, multiple regression analyses of both SES groups (Table 4) show that scores on bodily functions, daily functioning and quality of life have a large positive impact on perceived TGH in both SES groups. However, given the size of the standardised β 's the positive impact of each of these three health determinants differs: the positive impact of bodily functions was larger in the high SES group, while that of daily functioning and quality of life was larger in the low SES group. In both SES groups home owners perceived better TGH than renters, while the impact of the housing situation was larger in the low SES than in the high SES group.

The low and high SES groups differ on the impact of the health dimensions of mental functions and social-societal participation and the socio-demographic variables of gender, age and labour market status. These two health dimensions impacted TGH positively only in the high SES group. Also, in the high SES group only, women perceived better TGH than men, whereas age only impacted perceived TGH in the low SES group, showing decreasing health with increasing age. Lastly, having a job increased perceived health in the low SES group but decreased it in the high SES group. The health determinant of meaningfulness and the socioeconomic and demographic determinants of household size and difficulties meeting financial obligations did not impact the perception of TGH in either of these two SES groups.

In sum, with respect to the health dimensions determining the evaluation of TGH by distinguishing between two groups of SES, both SES groups show similarities as well as differences. In both groups TGH was largely and positively affected by three health dimensions: bodily functions, daily functioning and quality of life. TGH was positively affected by evaluation of social-societal participation and mental function only in the highest SES group. In both SES groups home owners perceived better health than renters. Having a job, on the other hand, impacted TGH positively in the low SES groups but negatively in the high SES group.

Factors determining the evaluation of TGH by distinguishing between six groups of SES

In all six SES groups the health dimensions of bodily functions and daily functioning contributed positively to perceived TGH. The perception of the quality-of-life dimension impacted TGH in four out of six SES groups—not in the low SES and not in the very high SES group. The size of the standardised β however reveals that this impact differs per SES

group. In the very low SES group, perceived quality of life had the biggest impact on TGH from two perspectives: compared to all other significant impacts in this SES group and compared to the significance of this quality-of-life dimension in all other SES groups. The dimension of mental functioning contributed positively only to the very high SES group's TGH. Evaluation of the meaningfulness dimension impacted on perceived TGH only in the very low SES group: respondents scoring higher in meaningfulness perceived lower TGH. The dimension of social and societal participation explained only perceived TGH in the high SES group.

None of the socioeconomic and demographic determinants impacted TGH in all six SES groups. Home ownership contributed positively to perceived TGH in the two lowest SES groups and the high SES group. The younger people are and the smaller the households, the better they perceived their TGH in the very low and the high SES groups, whereas the opposite was found in the very high SES group. Only the mid-low and the mid-high SES groups perceived that TGH was affected positively by having fewer difficulties meeting financial obligations. However, having a paid job contributed positively to perceived TGH in the mid-low SES group but negatively in the mid-high SES group. Lastly, women perceived better TGH only in the low SES and mid-high SES groups but not in the other SES groups.

In sum, these results show that different health dimensions and different socioeconomic and demographic dimensions determine the perception of TGH differently per SES group when distinguishing between six groups of SES. All six SES groups had two health dimensions (out of the six) in common that positively determined their TGH: bodily functions and daily functioning. None of the six socioeconomic and demographic variables included in this study impacted TGH in all SES groups—some variables impacted TGH positively in one SES group and negatively in another: for instance, having a paid job had a positive effect on TGH in the mid-low SES group but a negative effect in the mid-high group.

Discussion

This paper focused on three research questions, all related to the complex relationship between socioeconomic status and perceived total general health. Most respondents perceived their health quite positively: a little more than two-thirds evaluated their TGH as good and/or excellent. The lower standard deviation in TGH scores of respondents within a higher SES group shows a more common perception of their health; they are quite a homogeneous group in this respect. By contrast, there was a wide difference in perception of TGH between respondents within the lower SES groups, as shown by their higher standard deviation. In general, respondents in higher SES groups apparently not only perceived better TGH but also shared a more common evaluation of their health.

TABLE 4 Multiple regression analyses explaining total general health.

Evaluation of	Total sample		Two groups		Six groups					
	Total incl. SES variable	Total excl. SES variable	Low SES	High SES	Very low SES	Low SES	Mid-low SES	Mid-high SES	High SES	Very high SES
Bodily functions	0.382 (0.000)	0.380 (0.000)	0.333 (0.000)	0.458 (0.000)	0.261 (0.001)	0.489 (0.001)	0.378 (0.000)	0.273 (0.000)	0.490 (0.000)	0.401 (0.000)
Daily functioning	0.292 (0.000)	0.289 (0.000)	0.352 (0.000)	0.219 (0.000)	0.330 (0.000)	0.432 (0.000)	0.367 (0.000)	0.307 (0.000)	0.151 (0.004)	0.521 (0.000)
Quality of life	0.261 (0.000)	0.263 (0.000)	0.300 (0.000)	0.182 (0.000)	0.383 (0.000)	0.126 (0.153)	0.219 (0.000)	0.370 (0.000)	0.211 (0.000)	−0.102 (0.177)
Social and societal participation	0.065 (0.007)	0.066 (0.006)	0.032 (0.343)	0.092 (0.008)	0.013 (0.814)	−0.010 (0.868)	0.078 (0.198)	−0.115 (0.061)	0.162 (0.002)	0.094 (0.169)
Mental functions and perception	−0.024 (0.334)	−0.025 (0.322)	−0.064 (0.080)	0.110 (0.002)	−0.091 (0.152)	0.020 (0.737)	−0.079 (0.198)	0.076 (0.221)	0.077 (0.151)	0.198 (0.002)
Meaningfulness	−0.021 (0.292)	−0.022 (0.270)	−0.042 (0.124)	−0.014 (0.639)	−0.151 (0.004)	−0.076 (0.197)	0.009 (0.825)	−0.052 (0.266)	−0.022 (0.609)	0.051 (0.429)
Socioeconomic determinants										
SES	−0.025 (0.244)									
Home ownership or renting ^a	−0.084 (0.000)	−0.077 (0.000)	−0.112 (0.000)	−0.059 (0.024)	−0.216 (0.000)	−0.112 (0.039)	−0.076 (0.068)	0.039 (0.388)	−0.098 (0.009)	0.001 (0.982)
Age	−0.058 (0.005)	−0.055 (0.007)	−0.082 (0.006)	−0.010 (0.732)	−0.129 (0.012)	−0.032 (0.618)	−0.036 (0.426)	−0.045 (0.342)	−0.090 (0.032)	0.197 (0.003)
Difficulties meeting financial obligations	0.052 (0.011)	0.045 (0.021)	0.053 (0.056)	0.019 (0.478)	0.031 (0.537)	0.081 (0.099)	0.095 (0.034)	0.130 (0.005)	−0.008 (0.827)	−0.075 (0.190)
Household size	−0.018 (0.321)	−0.021 (0.260)	−0.033 (0.230)	−0.008 (0.747)	−0.106 (0.018)	0.039 (0.437)	0.034 (0.426)	0.006 (0.906)	−0.087 (0.016)	0.174 (0.004)
Labour market status: employed or not ^b	−0.012 (0.555)	−0.015 (0.446)	−0.080 (0.005)	0.083 (0.003)	−0.043 (0.413)	−0.086 (0.151)	−0.089 (0.026)	0.218 (0.000)	0.049 (0.209)	0.044 (0.508)
Gender	0.002 (0.902)	0.005 (0.795)	−0.026 (0.305)	0.067 (0.012)	−0.045 (0.348)	0.159 (0.005)	−0.051 (0.172)	0.100 (0.027)	0.041 (0.295)	−0.009 (0.869)
Adjusted R^2	0.777	0.776	0.785	0.758	0.726	0.852	0.856	0.868	0.763	0.730
Significance of the model	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000
F-value	207.282	224.337	22.718	13.511	34.573	41.449	65.389	53.012	54.442	24.887
Degrees of freedom	13	12	12	12	12		12	12		12

Data in the table represent regression coefficients of six health dimensions and the sociodemographic determinants explaining self-rated total general health. Significance level in parentheses and values are in bold. ^a A Minus Sign Means a Negative Impact on TGH of Renting a House (vs, a Positive Impact of on TGH of Owning a House). ^b A Minus Sign Means a Negative Impact on TGH of not Having a job (vs, a Positive Impact of on TGH of Having a job).

Answering the research questions

The first research question was about which health dimensions in life determine the perception of TGH. Using the concept of positive health, it appears that four out of the six dimensions impact the evaluation of TGH. The evaluation of bodily functions, daily functioning, quality of life, and social and societal participation had a positive impact on the evaluation of TGH, and these are also the most important health dimensions when determining TGH.

All SES groups had in common the positive impact of bodily functions and daily functioning on their TGH. However, the magnitude of the impact of these two dimensions as well as of the other two dimensions (as measured *via* the standardised β 's in our regressions) differed per SES group. The impact of the two health dimensions on mental functioning and meaningfulness seemed to be rather small and only present in a few SES groups. This is in line with findings of Stronks et al. (70) showing in a concept map where, regardless of educational level, on the one hand aspects like "absence of disease and functioning" and "health-related behaviours" and on the other hand aspects like "social life" and "attitude toward life" were perceived as important characteristics of health.

Evaluation of the other two dimensions (mental functions and meaningfulness) did not impact all respondents' TGH. It could be argued that people may not be fully aware of the possible impact of these two dimensions on perceived TGH as separate dimensions. This interpretation is in line with Vogel et al. (71) observing that mental health and meaningfulness have a close connection influencing self-reported health (SRH) and consequently are undistinguishable by people. Another interpretation could be that people only become aware of the importance of these dimensions in specific situations. This means more aware of the dimension meaningfulness when perceiving illness, as is the case only in the very low SES group where meaningfulness negatively impacts on TGH. However, more research on this specific topic is needed, given the inconclusive results in this respect. For, in the literature on the topic of SES and health in relation to meaningfulness there are no consistent findings with replicated outcomes. To illustrate, Joan and Reutter (72) showed that increasing income increases SRH in Canadian women with the sense of coherence (consisting of meaningfulness, comprehensibility and manageability) as intervening variable. Vogel et al. (71) found that meaningful activities increased SRH in incarcerated older men and Steptoe and Fancourt (73) report that SRH is an important factor for living a meaningful life whereas the reverse relationship is not that clear. The different indicators used for meaningfulness and evaluating TGH could explain these different outcomes. Standardising of methods and approaches would benefit gaining more insight in the impact of meaningfulness on TGH.

Concerning the dimension mental functions and perceptions impacting TGH only in the very high SES

group might imply that a certain level of education and income is needed for this impact to occur. This would be in line with findings of Kim and Cho (74) that especially high SES are burdened with work-life conflict decreasing mental health. These people do realize the importance of mental functions and perceptions once they have demanding high income positions; they then do realize that there is more in life than only a high income earning job. Furthermore, on the positive side, higher SES groups have been shown to report better mental health (75).

The second research question was about which socioeconomic and demographic variables determine the perception of TGH. It turned out that type of housing, age, and difficulties meeting financial obligations impacted on all respondents' perceived TGH, which proportionately worsens with increasing home renting, age, and difficulties meeting financial obligations. Gender, household size and labour market status (= having a job or not) did not impact all respondents' TGH.

These determinants of perceived TGH are in line with earlier findings on determinants of objective health. First, it is established that objective health decreases and use of healthcare increases with age (76, 77). Second, it is widely known that housing conditions are a determinant of health. People living in substandard, often rented housing in deprived neighbourhoods have more impaired health than home owners in affluent neighbourhoods (1, 30, 78). Meyer et al. (19) (pp1734) formulated in the abstract their results in a somewhat broader context of the impact of the deprived neighbourhood instead of the bad housing situation: "Low SES was associated with greater neighborhood safety concerns, which were negatively associated with physical activity, which was then negatively related to mental health and SRH." Third, having trouble meeting financial obligations is at the core of socioeconomic inequality in both objective and self-rated health (29, 79, 80).

Concerning gender differences in health, the present study shows no differences in perceived TGH between men and women. However, since men tend to show more risky health behaviour and are more predisposed to suffer significantly more from chronic diseases than women (21, 35), they might have been expected to perceive lower TGH than women. As we did not check for risky behaviour or chronic diseases, it is impossible to directly relate these findings to our results on perceived TGH. It might be speculated that good TGH can be perceived despite having a chronic disease, since other dimensions of health like daily functioning or quality of life might compensate for the impaired bodily function caused by the disease. It might also be that people accept their situation and adapt to it as is illustrated by the observation that older people compare their own decreased health with age peers who have even worse health. Concerning risky behaviour, it might be speculated that men do not perceive their behaviour as risky but more as a socially subjective norm which therefore does not influence their perception of TGH.

The determinant of household size not affecting perceived health confirms the results of a study suggesting a more social, hereditary component of SES negatively impacting health rather than family size (39). However, effect of family size on objective or self-rated health is inconclusive. Some studies find positive effects of larger families because of mothers staying at home to care for the children and hence exerting more parental control (42) and reduced obesity in families with more siblings (40). Others report negative effects of family size on health, as larger families show increased household chaos, which causes maternal stress (41, 43), plus overcrowding in early life leads to increased risk of multimorbidity in midlife (44).

Lastly, the determinant of labour market status might have been expected to affect perceived TGH, as unemployment or poor job satisfaction have detrimental effects on health (36–38). Our findings do not corroborate this expectation. However, being unemployed in general means less income and thus a higher likelihood of having difficulties meeting financial obligations. Hence a possible explanation for perceived TGH being unaffected by the determinant of labour market status is that the determinant of having trouble meeting financial obligations is compensating for that. Besides, having a job is not a guarantee for health as such, but adequate payment for a job is (1, 22).

The third research question was about the extent to which the relationships between TGH, health determinants, and socioeconomic and demographic determinants differ between various groups of SES, distinguishing six instead of the traditional two groups of high and low SES. Since discussing all the findings would complicate the readability, we will focus on only the significant findings. Our six-SES groups approach provided more detailed information than the traditional two-SES groups approach. It also produced more refined information on the similarities and differences between the SES groups. Similarities between all six groups could be found for impact of two health determinants of perceived TGH—bodily functions and daily functioning. The mean perceived TGH score did not differ between the four lowest SES groups, while these differed significantly from the mean perceived TGH score in the two highest SES groups. None of the socioeconomic and demographic determinants impacted perceived TGH in all the SES groups. The impact of all these health, socioeconomic and demographic determinants was contingent upon the specific SES group. There were different *gestalts* of the health dimensions and the socioeconomic and demographic variables, suggesting that health was perceived differently by each SES group. These findings on subjective SRH evaluation are in line with existing literature on inequality of health defined by professionals in terms of the more objective health indicators: health is evaluated better as people's SES is higher (80, 81). In terms of the methodology applied, the finding that our subjective approach leads to a conclusion similar to the professionals' opinion used thus far is new to the existing literature. This corroborates the findings of Stronks et al. (70) which show differences between

three levels of educational groups by conceptualising health using concept maps.

In general, it is important to emphasise that the six-SES groups approach shows there is a gradient instead of a linear pattern in the magnitude of perceived TGH and its six health determinants across the six SES groups. The four lower SES groups (very low, low, mid-low and mid-high) did not differ from each other on perceived TGH score or the score on its six health determinants. However, all of these scores were significantly higher in the two highest SES groups (high and very high) than in the other four SES groups.

A similar three-step gradient seems to be present in the scores on the significant socioeconomic and demographic determinants in the six SES groups, as these determinants impacted perceived TGH the most in the very low SES group, less in the following three SES groups (low, mid-low, mid-high), and little in the high and very high SES groups.

The gradient instead of linear trend in the relationship between SES and health inequality has been reported in several studies (29, 31, 79, 82). By dichotomising SES at a median cut-off point or studying SES determinants separately, possible socioeconomic effects on perceived health might have been obscured. More SES groups than only two should be distinguished, also in order to develop more effective interventions to improve people's health.

The results of our study on the determinants of perceived TGH as a measure of SRH are not only in line with the existing literature, they also add to it on three accounts. First, perceived TGH and hence SRH were operationalised by elaborately scoring on 32 items corresponding not only to the physical and psychological dimensions but also to the social-societal, quality of life, meaningfulness and daily functioning dimensions, adding new items to the scales as used in the SHQOL and SF12 questionnaires (29, 68, 78, 83, 84).

Second, we calculated a six-level SES score based on a newly created individual SES score *via* factor analysis of gross household income and education instead of using a dichotomised SES score of high and low. In this way we corrected for the possibility that during the life course income can rise or fall regardless of educational level. As has been shown, detrimental life events like divorce or unemployment due to crises like the recession of the early 2000 s or the current COVID-19 pandemic (47, 48, 85) can cause serious losses of income for both the higher and the lower educated. It is even speculated that the impact of these losses in income affect the total wellbeing of the low SES groups more than that of the high SES groups (47, 48). In addition, the impact of meaningfulness on TGH in the very low SES group was obscured when only distinguishing two SES groups. Therefore, in future studies distinguishing between more than 2 groups is recommended.

Third, we evidenced a non-linear gradient in SES impacting perceived TGH and its six health determinants. With regard to possible health-promoting interventions to improve health or TGH and reduce the socioeconomic gap in health, our findings

support the suggestion made by Stronks et al. (70) (pp. 8) that “the way health is conceptualized, challenges the legitimacy of policies that are based on a notion of health that resonates the conceptions that are valued in higher socioeconomic groups...” Translated from policies to health-promoting interventions, this means that health-promoting interventions should be tailored to the way health is perceived and valued by the target population. More specifically, such customisation should be oriented toward the importance and magnitude of the six health dimensions perceived by the specific SES group being targeted. This topic, which refers to a typical marketing approach, will be elaborated upon below.

Implications of the significant relationships between TGH and the six health determinants in the six SES groups

From marketing literature, it is known that the combination of mean scores and importance is critical in making decisions and setting priorities about which changes should be made in marketing strategies, for instance to better meet customer needs (86). In this analogy, combining the *significant impact* of the evaluation of each of the six health dimensions on TGH in each SES group from Table 4 (importance scores based on standardised β 's) with how high or low the evaluations are in each of the six SES groups from Table 3 (mean scores) yields the basis for setting priorities in potential interventions (Figure 6). For, priorities can be based on the notion that the highest priorities for interventions should be directed to those health dimensions that are considered as important but have a low evaluation score. Health dimensions with a high evaluation score and a high importance score should remain at that level and do not need interventions to improve this situation. It remains to be seen whether interventions are needed for those health dimensions that have a low importance score when financial means are scarce.

Health inequality is shown by the positioning of the very high SES group in the upper right corner of the graph. The other SES groups are positioned at lower spots in the graph, moving in roughly descending order to the lower left of the graph with the very low SES group. Some remarkable patterns do stand out. First, the importance score for evaluating the significant health dimensions in the mid-high and high SES groups is rather low (i.e., placed more to the left of the graph) compared to the scores in the other lower SES groups. This indicates that health on these determinants is perceived the same but rated as more important by the lower SES groups. Health-improving interventions aimed at daily functioning would therefore be more effective in the lowest three groups, whereas interventions aimed at bodily functions would yield a higher effect in the low and high SES groups.

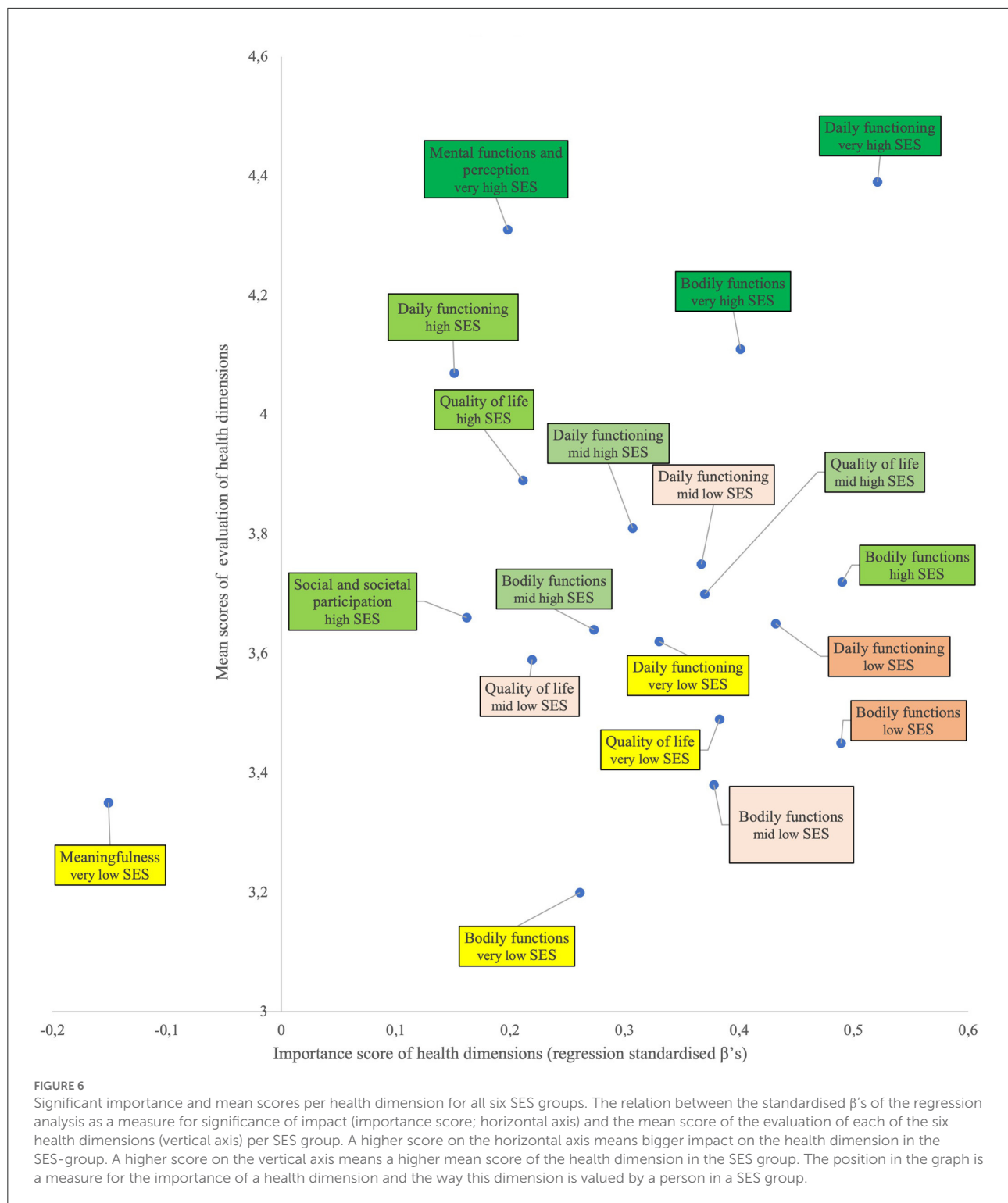
Second, other significant dimensions are placed more to the upper-left portion of the graph, indicating a smaller

importance but still a rather high score on the evaluation itself. Determinants in this part are perceived as good-very good and of low/lower importance, meaning that interventions aimed at improving these determinants will have little to no effect in these SES groups.

Third, the middle portion of the graph shows a scattered pattern for the very low, low, mid-low and mid-high SES groups (it has been shown that these four—lower—SES groups are quite similar and differ significantly from the two higher SES groups). This indicates that perceived TGH was determined by different gestalts of the evaluation of the health dimensions and their importance to respondents from these four SES groups. These gestalts were different from those in the two higher SES groups. When aiming to reduce socioeconomic differences, mixed interventions targeting the determinants of bodily functions, daily functioning and quality of life would be indicated. The higher health-promoting effectiveness of implementing an intervention mix has been shown in a study stimulating physical activity in prevocational secondary education (87).

Lastly, meaningfulness in the very low SES group was the only dimension with a negative impact on TGH, while the importance score was the lowest of all evaluations. As mentioned previously, this might suggest that people become aware of the psychological dimension of meaningfulness only when TGH is perceived as low, as was the case in the very low SES group. Further research is needed to gain more insight into this determinant affecting perceived TGH in the very low SES group.

In summary, in all six-SES groups situations investigated the evaluation of daily functioning and bodily functions had a very large and positive impact on the evaluation of TGH. Given their high-importance score, these dimensions are the ones most determining equality or inequality in health. Also, quality of life often plays an important role. It appears that the evaluation of some health dimensions (i.e., mental functions and meaningfulness) did not have an impact on TGH in this sample. It may be that participants did not (yet) realise that these dimensions are also relevant in determining TGH or only start realising their importance when they are/become ill. This study shows that different SES groups perceive different health determinants as important to their health, so there is no one-size-fits-all intervention. This could be the starting point for two approaches: to raise awareness in the SES groups of the importance of the other determinants participants do not (yet) perceive as important, and to implement health-promoting interventions matching the perceptions of the SES group. From a salutogenic and capability perspective, the latter might be preferred because first these approaches are focused on stimulating people to use their health assets; in salutogenesis these are referred to as general and specific resistance resources (88, 89) and in capability terms these are related to conversion factors (90). Second, they have the capability aspects of autonomy and freedom to participate (54, 62, 63) instead of implementing general tailored interventions



from a professional's perspective based on top-down analysis of determinants.

The marketing discipline would suggest applying the concept of market segmentation when health-promoting

interventions should be SES-group specific. Market segmentation aims to develop several market segments when the total market or population is not homogeneous. Each market segment is supposed to consist of people who are similar

to each other in terms of particular needs or problems; they are also supposed to react in a similar way to marketing stimuli, like a particular message or health intervention. That will maximise the effectiveness of the investment. Each segment is homogeneous in itself while there is great heterogeneity between the various segments. It is critical to have an understanding of the behaviour of the people in a particular segment, e.g., an SES group: what do they deem relevant and important (a graph like Figure 6 may be very helpful here), how will they respond to certain interventions, etc. In this way it is not a one-size-fits-all approach which would be implemented but a tailor-made, specific market segment approach.

Possible limitations and critical reflections

Whereas, our study adds to current conceptions of health and its socioeconomic determinants, especially the importance of discriminating between more than two levels of SES, some critical reflections are in place.

First, as mentioned, there was a slight overrepresentation of higher-educated respondents in the whole sample, which might have affected analysis and results. We were aware of this possible bias and corrected for it by calculating SES scores using a factor analysis diluting this relative educational disbalance. It is therefore unlikely for this disbalance to have affected the analysis and results to any considerable extent.

Second, in our study the group of people with perceived poor health is not that large. A study including only persons with perceived poor health might provide new insights into the importance of the mental functioning and meaningfulness determinants of health for this group of people. It may be that people do not realise how important these two determinants are for their health as long as they feel healthy.

Third, when forming SES groups using factor analysis the number of respondents differed per SES group, and especially the low and mid-high SES groups have fewer respondents than the rest. Although the rule that the number of respondents should be larger than the squared number of independent variables in our regression equations was not met, we do not consider that as a serious flaw given the robustness of the statistical technique of regression analysis. Still, a larger number of respondents in some SES groups would have been preferred.

Fourth, comparing the two-SES groups approach with the six-SES groups approach reveals that the traditional dichotomy is too simple and may lead to ineffective interventions. The six-SES groups approach reveals that the high SES group from the dichotomy contains a subgroup (mid-high) that highly resembles all three SES groups from the traditional low SES group (and these four SES groups could be regarded as one group) but differs significantly from the other two high SES groups. It would however be incorrect to conclude from this that only three new groups of SES should be distinguished when

developing interventions (the four lower groups, the high group and the very high group), as the *importance* of the determinants of TGH differs for each of the six SES groups. Since interventions should be focused on the determinants deemed important, we suggest fine-tuning the interventions to as many specific SES groups as narrowly defined as possible to achieve maximum effectiveness. In all six-SES groups interventions may relate to features of bodily functions and daily functioning being important in all groups. Quality-of-life issues are important in four of the six groups, and meaningfulness as well as mental functions in two specific groups. The impact of having a job is important in two groups: the very low (positive impact) and the mid-high (negative impact) groups. These refined insights could only be obtained by applying the concept of positive health in this study on the impact of SES on health and by challenging the traditional notion of a dichotomy in SES groups.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

It was judged that approval of a medical ethics committee was not mandatory for this research because participants did not undergo physical examination nor were bodily fluids or other medical data collected. Therefore, the Medical Research Involving Human Subjects Act does not apply to the current study. The Board of Silverbrains approved the research design and protocols for the data collection and analysis. The research was carried out in accordance with the rules and guidelines of the Dutch Market Research Organization (MOA) and the Dutch Policy Research Association (VBO) which are in line with the rules and guidelines of the European Association of Market Research (ESOMAR). The respondents voluntarily participated in the study; they are members of the RMI Internet panel. When RMI started their Internet panel years ago, all respondents agreed to participate in this panel study and written informed consent was obtained from all panel members (they all are 18 years or older). To encourage people to participate in studies, respondents receive a small fee of one euro for every completed questionnaire.

Author contributions

HK applied his expertise in marketing research, especially on the socioeconomic, demographic determinants of health, developed the questionnaire, collected the data, prepared the figures, and performed regression analysis. JD is an expert in health determinants, the concept of positive health, including theories on health inequalities, and added one-way ANOVA

analysis. Both authors wrote and reviewed the manuscript. All authors contributed to the article and approved the submitted version.

Acknowledgments

The authors thank Dr M. Huber for making the Positive Health questionnaire available.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships

that could be construed as a potential conflict of interest.

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SPECIALTY SECTION

This article was submitted to
Family Medicine and Primary Care,
a section of the journal
Frontiers in Medicine

RECEIVED 09 April 2022

ACCEPTED 24 October 2022

PUBLISHED 11 November 2022

CITATION

Chan V, Estrella MJ, Baddeliyanage R,
Shah R, Babineau J and Colantonio A
(2022) Rehabilitation among
individuals experiencing homelessness
and traumatic brain injury: A scoping
review. *Front. Med.* 9:916602.
doi: 10.3389/fmed.2022.916602

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Rehabilitation among individuals experiencing homelessness and traumatic brain injury: A scoping review

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Traumatic brain injury (TBI) is disproportionately prevalent among individuals experiencing homelessness. While rehabilitation is critical to facilitating recovery after TBI, there is currently limited information on the extent to which rehabilitation is provided to individuals experiencing homelessness and TBI. If unaddressed, this knowledge gap can perpetuate TBI-related challenges and contribute to a repetitive cycle of TBI and homelessness. This scoping review explored the extent to which rehabilitation, including the types of rehabilitation interventions, are available to, or used by, individuals experiencing homelessness and TBI. A systematic search of electronic databases (MEDLINE, Embase, Cochrane CENTRAL Register of Clinical Trials, CINAHL, APA PsycINFO, Applied Social Sciences Index and Abstracts, and Proquest Nursing and Allied Health) was conducted to identify peer-reviewed articles that met predetermined eligibility criteria. Gray literature and reference lists of eligible articles were also searched for relevant content. A descriptive numerical summary of extracted data was conducted, and qualitative analytic techniques were applied to analyze the data. Fifteen peer-reviewed articles and three gray literature reports were included, describing interventions for individuals experiencing homelessness and TBI ($N = 4$), rehabilitation for individuals experiencing homelessness without specific inclusion criteria for TBI ($N = 11$), and rehabilitation interventions that included individuals experiencing homelessness and TBI, without specific inclusion criteria for experiences of homelessness or TBI ($N = 3$). This review demonstrates that rehabilitation programs or interventions for this population already exist, and those that are focused on individuals experiencing homelessness are already serving individuals with TBI. Findings highlight opportunities to adapt existing rehabilitation for individuals who experience homelessness and TBI through screening for TBI, conducting cognitive and functional assessments, and tailoring interventions with multidisciplinary teams.

Education and training for healthcare professionals working with individuals experiencing homelessness and TBI should be explored, including structured education and training, collaboration with a multidisciplinary team, and co-development of educational materials with service users. Research that considers the rehabilitation needs of diverse individuals experiencing homelessness and TBI is urgently needed.

KEYWORDS

rehabilitation, occupational therapy, homeless persons, brain injuries, cognitive impairment, public health, diversity

Introduction

Homelessness is a serious public health concern facing modern society. An estimated 580,466 individuals in the United States experienced homelessness in 2020 (1) and based on the most recent reported national Point-in-Time count, an average of at least 235,000 individuals in Canada are experiencing homelessness in every year (2). Globally, one in five individuals experience housing insecurity (3). Homelessness arises from a complex interplay of structural and individual factors, and is associated with a broad range of health conditions (4, 5) such as infections (e.g., tuberculosis and HIV), cardiovascular and respiratory conditions, and psychiatric and substance use disorders (SUD) (6, 7). Together, these factors lead to substantially high rates of premature mortality compared to the general population (6, 7). Cognitive and functional impairments are also prevalent (8, 9), and recent evidence has identified traumatic brain injury (TBI) as a determinant of cognitive and neurological disability in the homeless population (10, 11).

TBI, defined as “an alteration in brain function or other evidence of brain pathology caused by an external force” (12), is a leading cause of death and disability worldwide that is under-recognized (13), highly prevalent, and can cause life-long debilitating challenges among individuals experiencing homelessness (14–16). A recent systematic review estimated that the lifetime prevalence of TBI of any severity was 53.1% among homeless and vulnerably housed persons (17). While there is no causal link, the relationship between TBI and homelessness is considered bidirectional, wherein experiencing homelessness could increase an individual’s vulnerability to TBI and having a TBI could increase the risk for experiencing homelessness (10, 17). TBI is associated with poorer self-reported physical and mental health and suicidality, challenges in memory, greater use of health services, involvement in the criminal justice system (15, 18), and a longer duration of homelessness and housing instability (15). The challenges associated with TBI are exacerbated by individual and structural factors and intersecting social inequities that without intervention could intensify and lead to a repetitive cycle of TBI,

homelessness, and significant health-related costs (4, 10, 16, 18, 19).

Rehabilitation, defined as “a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment,” (20) is considered a critical component of TBI management (21, 22). In the context of TBI, rehabilitation ranges from early clinical management that focuses on immediate treatment needs post-injury, to ongoing therapeutic and pharmacological interventions that target long-term functional and cognitive impairments (23, 24). Such rehabilitation interventions have demonstrated positive effects in addressing TBI sequelae, promoting functional recovery, and improving quality of life (23, 25, 26) and are well-documented in evidence-based clinical practice guidelines that guide TBI care (27). However, despite recent guidelines and reviews on TBI rehabilitation (24, 27–29) or homelessness (15, 30–32), to the best of our knowledge, no review to date has focused on rehabilitation for individuals experiencing homelessness and TBI.

This scoping review responds to this gap by exploring the extent to which rehabilitation, including the types of rehabilitation interventions, are available to, or used by, individuals experiencing homelessness and TBI. This review also explicitly charts and summarizes evidence on age, sex, gender, ethnicity, race, and other identities and experiences, as individuals experiencing homelessness also experience health disparities that are shaped by their intersecting identities (33). The results of this scoping review inform (a) opportunities to adapt existing rehabilitation for individuals who experience homelessness and TBI, (b) considerations for education and training on TBI, and (c) recommendations for future research. Overall, this scoping review provides the foundation for advancing rehabilitation for individuals experiencing homelessness and TBI.

Methods and analysis

This scoping review was guided by methodology frameworks from Arksey and O’Malley (34) and Levac et al. (35)

and the reporting of this scoping review follows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) (36). The protocol for this scoping review is published in the journal *BMJ Open* (37) and is summarized below.

Stage 1: Identifying the research question

The research question this scoping review answered was “To what extent is rehabilitation, including the types of rehabilitation interventions, available to, or used by, individuals experiencing homelessness and TBI?” The definitions of rehabilitation and homelessness that were used to guide the scoping review is presented in [Table 1](#).

Stage 2: Identifying the relevant studies

The search strategy was developed in collaboration with an Information Specialist (JB) and was conducted in the following databases: MEDLINE ALL (Ovid), Embase and Embase Classic (Ovid), Cochrane CENTRAL Register of Clinical Trials (Ovid), CINAHL (EBSCO), APA PsycINFO (Ovid), Applied Social Sciences Index and Abstracts (Proquest), and Nursing and Allied Health (Proquest). The search strategy was first conducted in April 2021 and updated in March 2022 with no changes to the strategy. Three concepts—(A) homelessness, (B) rehabilitation, and (C) TBI or cognitive impairment—were used to develop the search strategy of (A + B) OR (A + C). In addition to searching databases, reference lists of included articles were also searched. Gray literature, defined in this review as reports from relevant brain injury, housing, or rehabilitation organizations, were searched for relevant content in between May 2021 and September 2021. Specifically, they were searched by entering keywords for concepts A, B, and C in the search bar. Websites without a search bar were manually reviewed for relevant gray literature reports. No limits on language or dates were placed on the search. [Supplementary File 1](#) presents the search strategy for databases and websites of brain injury, housing, and rehabilitation organizations that were searched for gray literature.

Stage 3: Study selection

Eligible studies were peer-reviewed primary research articles or gray literature that met the following criteria: (1) describe and/or document rehabilitation interventions or describe and/or document services provided by healthcare providers or professional disciplines, as defined in [Table 1](#); (2) focus on individuals who are experiencing homelessness

at the time of the research study, as defined in [Table 1](#); and (3) include individuals with TBI. The following articles were excluded: (1) dissertations, conference proceedings, and articles that are narrative, commentaries or describe a theory of framework without reporting primary research findings and (2) articles that include the broader brain-injured population without specific mention of TBI (e.g., individuals with acquired brain injury, cognitive impairment).

EndNote X8.2 was used for reference management (39) and Covidence was used for de-duplication and study selection (40). Two reviewers (RB and RS for the search conducted in April 2021 and VC and MJE for the search updated in March 2022) independently screened all articles based on the above pre-determined eligibility criteria. At the title and abstract screen, scoping, and systematic reviews that met the above eligibility criteria and articles that did not explicitly mention TBI were also included for full-text review. Non-English language abstracts were assessed using the published English abstract. A pilot screen of 20 titles and abstracts was conducted until a minimum 80% agreement was achieved between the two reviewers. The resulting agreement at the title and abstract screen was 85.2% (RB and RS) and 97.6% (VC and MJE) for English language articles and 89.7% (RB and RS) and 80.0% (VC and MJE) for non-English language articles. Discrepancies were resolved by consensus or consultation with a third reviewer (VC or MJE).

At the full-text screen, two reviewers (RB and RS for the search conducted in April 2021 and VC and MJE for the search updated in March 2022) independently screened all articles based on the above eligibility criteria. For scoping and systematic reviews identified in the title and abstract screen, the primary research articles included in the reviews were extracted and screened according to the above eligibility criteria. Non-English language articles were translated to English language using Google Translate (41) and/or DeepL Translate (42). A pilot screen of 10% of eligible full-text articles was conducted until a minimum of 80% agreement was achieved between the two reviewers. The resulting agreement at the full-text screen was 97.6% (RB and RS; VC and MJE) for English language articles and 89.7% (RB and RS) and 100% (VC and MJE) for non-English language articles. Discrepancies were resolved by consensus or consultation with a third reviewer (VC or MJE).

Stage 4: Charting the data

The charting table was completed independently by one reviewer (RB or VC) and peer-reviewed by two reviewers (RS and/or VC). The resulting charting table is presented in [Supplementary File 2](#) and was used to inform Stage 5 of the scoping review. Discrepancies in charting the data were resolved by consensus or consultation with a third reviewer (VC or MJE).

TABLE 1 Definitions of rehabilitation and homelessness.

Concept	Definitions
Rehabilitation	<p>World Health Organization—"A set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment" (20)</p> <p>Healthcare providers/professional disciplines identified in TBI evidence-based clinical practice guidelines for TBI rehabilitation (27, 29):</p> <ul style="list-style-type: none"> • Neuropsychologist • Nurse • Nutritionist • Occupational therapist • Physiatrist • Physician • Physiotherapist • Psychologist with expertise in behavioral therapy • Psychometrist • Rehabilitation support personnel • Social worker • Speech-language pathologist • Therapeutic recreationist
Homelessness	<p>Canadian Observatory of Homelessness' typology of homelessness that encompasses the following physical living situations at the time of the research study (38):</p> <ul style="list-style-type: none"> • Unsheltered—individuals who lack housing and are not accessing shelters • Emergency sheltered—individuals who cannot secure permanent housing and are accessing shelters or other system supports • Provisionally accommodated—individuals without permanent shelter and are accessing accommodations that offer no prospect of permanent

Stage 5: Collating, summarizing, and reporting the results

Three distinct steps, as outlined by Levac's et al. methodology framework (35), were followed: (1) analyzing the data, (2) reporting the results, and (3) applying meaning to the results. To analyze the data, a descriptive numerical summary of the data extracted and presented in the charting table was compiled and qualitative content analytic techniques were applied to allow for the quantification of data in themes or category development. The results were reported in relation to the research question, using findings from the data analyses. To apply meaning to the results, implications for (a) opportunities to adapt existing rehabilitation for individuals who experience homelessness and TBI, (b) considerations for education and training on TBI, and (c) recommendations for future research were considered.

Quality appraisal, although not specified in the methodology frameworks, was conducted by one reviewer (VC) and peer-reviewed by a second reviewer (RS). The Study Quality Assessment Tools designed by methodologists from the Research Triangle Institute International and the National Heart, Lung, and Blood Institute of the National Institutes of Health and the Critical Appraisal Skills Programme (43) were used to inform the internal validity of a variety of study designs.

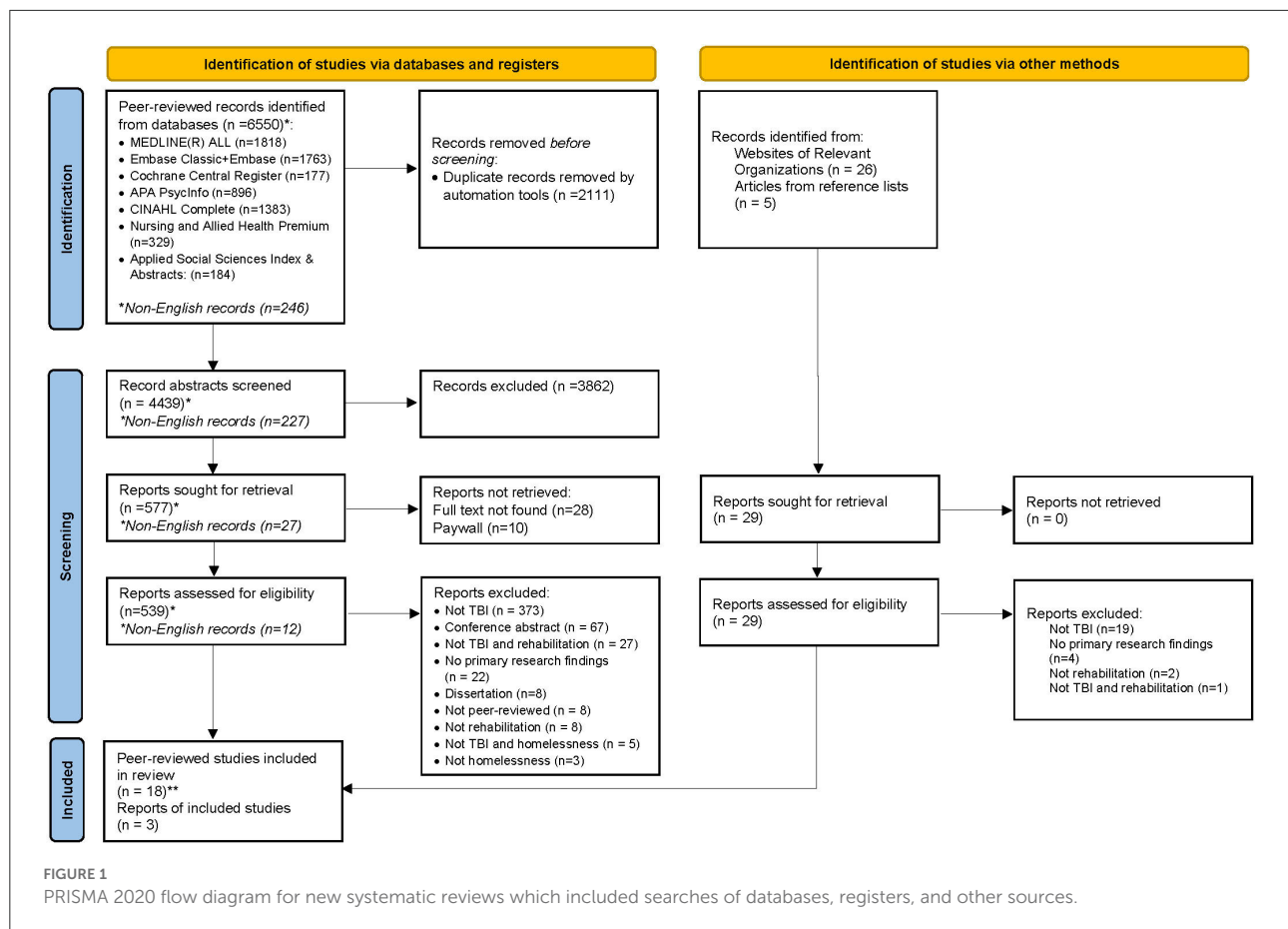
No articles were eliminated based on the quality assessment; however, findings were used to inform the process of applying meaning to the study and to identify opportunities to advance research on rehabilitation among individuals experiencing homelessness and TBI.

Stage 6: Consultation

Preliminary findings from Stage 5 were shared with the Program Advisory Committee (PAC) of the Traumatic Brain Injury in Underserved Populations Research Program (44). This PAC consists of service providers across brain injury, disability, housing, criminal justice, and violence against women sectors. Specifically, preliminary findings were presented at a PAC meeting and PAC members' feedback were incorporated in the discussion of this review.

Results

A total of 6,550 citations were identified from databases through the search strategy. After duplicates were removed, 4,439 titles and abstracts (227 non-English language) were



screened, of which 577 (27 non-English language) met eligibility for full-text review. Of these articles, 532 were excluded based on the pre-determined eligibility criteria, resulting in 15 primary research articles included in this synthesis. Gray literature search identified an additional 3 reports. Figure 1 presents the PRISMA flow diagram for the search and screening.

All the articles identified through the search described research conducted in the United States ($N = 10$, 55.6%) (45–54) or Canada ($N = 8$, 44.4%) (55–62). Four articles (22.2%) described interventions for individuals experiencing homelessness and TBI (46, 51, 57, 59). The remaining articles described rehabilitation interventions for individuals experiencing homelessness without specific inclusion criteria for TBI ($N = 11$, 61.1%) (45, 49, 50, 52, 54–56, 58, 60–62) or rehabilitation interventions that included individuals experiencing homelessness and TBI, without specific inclusion criteria for experiences of homelessness or TBI ($N = 3$, 16.7%) (47, 48, 53). None of the rehabilitation programs or interventions were based at an inpatient or outpatient rehabilitation setting; 17 of 18 articles described community-based rehabilitation that were offered through community organization healthcare clinics (45, 47–62) or mobile clinic

(54), while one article described a medical respite program that provided care to individuals onsite (46).

Males or men comprised the majority of the study sample in 11 articles, ranging from 52 to 90% (45, 48, 52, 54–62), and one article included only women in their sample (47). Except for case studies ($N = 2$) (46, 53), none of the studies stratified the findings by sex or gender. In articles that did not explicitly focus on individuals experiencing both homelessness and TBI, the proportion of individuals with TBI ranged from 2.4 to 84% and the proportion of individuals experiencing homelessness ranged from 1.2 to 100%. The majority of articles did not define how TBI was ascertained, with the exception of three articles that screened for self-reported TBI using the Ohio State University Traumatic Brain Injury Identification Method (OSU-TBI-ID) (46, 51, 57) and one article through face-to-face interviews (59). None of the articles reported injury severity.

Fourteen articles defined homelessness as part of their inclusion criteria, description of the study sample, or study setting [“absolutely or precariously housed” (55, 56, 58, 59), “experiencing homelessness” (45), “doubling up—friends and family” (62), “shelter, unsheltered, doubled-up” (54) “residing in homeless shelter or on the street” (47, 48, 51), “scattered site apartments” (45), “respite program” (46), “transitional housing”

(62) or participants were referred to as “homeless individuals” (49, 50, 52, 53, 57)]. Six articles reported participants intersected with the justice system [i.e., “ever been to jail” (45), “ever been to prison” (45), “arrested in the past” (58), “arrests in the past 6 months” (56), “times in jail/prison” (49), “had prior justice involvement” (60, 61)], with prevalence ranging from 16 to 80% (45, 49, 56, 58, 60, 61). Table 2 presents key study characteristics, Supplementary File 2 presents the charting table, and Supplementary File 3 presents the quality appraisal of included articles.

Qualitative content analysis of the three categories of articles

Findings from the three categories of rehabilitation articles identified in this scoping review are described below. Within each of the study categories, rehabilitation in the form of multidisciplinary care and specialized care were identified. For this review, multidisciplinary care refers to articles describing rehabilitation provided by more than one type of healthcare provider/professional discipline, whereas specialized care refers to articles describing rehabilitation provided by a specific healthcare provider/professional discipline.

Rehabilitation program and interventions for individuals experiencing homelessness and TBI (N = 4)

All four articles reported rehabilitation within a multidisciplinary care context, with services accessible through a multidisciplinary team of professionals and/or a case manager. Brocht et al. described a shelter-based respite program that offered access to healthcare professionals (i.e., on-site occupational therapists (OTs), social workers, registered nurses, and community health workers) (46). They detailed the roles of different healthcare professionals that contributed to the creation of a TBI-focused program. Social workers or OTs screened for TBI using the OSU-TBI-ID. Following TBI screening, OTs assessed both the cognitive and functional abilities of clients in their living environment through standardized cognitive assessment tools and functional evaluations. OTs then educated respite staff regarding TBI-related functional limitations and behaviors and collaborated with them regarding concrete strategies to manage such limitations and behaviors (e.g., external cueing strategies and environmental modifications). Other members of the respite centre’s multidisciplinary team reinforced OTs’ recommendations while performing specialized roles. Social workers supported discharge planning, case management, and provided psychotherapy evaluation, brief intervention, and linkage to housing. Registered nurses provided health education, coordinated specialty follow-up, and interpreted information

from medical provider to patients. Community health workers implemented treatment plans developed by the OTs and provided supports to patients, both direct (e.g., transportation, paperwork) and relational (e.g., maintaining positive recovery environment, developing rapport with patients). Synovec and Berry described a study on screening and provider training at a healthcare clinic (51). Comprehensive care in terms of services, such as medical, mental health, case management, occupational therapy, dental services, and supportive housing were provided. While the roles of each healthcare provider were not delineated in this study, the importance of TBI screening and strategies to address TBI-related limitations were emphasized.

Two articles described assertive community treatment (ACT) as an intervention (57, 59); however, one was specifically delivered in the context of a Housing First (HF) randomized trial and approach that also offered intensive case management (ICM), including ethnoracial-specific ICM services for racialized individuals as an option, alongside ACT (59). No information was reported regarding the healthcare professionals’ roles; however, case managers were noted to have an integral role in the care and coordination of clients (57, 59). Other members of the rehabilitation team included psychiatrists and peer support workers or peer support specialists (57, 59).

All four articles integrated TBI care in their programs or interventions through TBI screening (46, 51, 57, 59) and/or tailoring interventions to accommodate for TBI impairments that are often cognitive in nature (46, 51, 57). Face-to-face interviews were conducted (59) or the OSU-TBI-ID (46, 51, 57) were administered by trained healthcare professionals, including case managers from varying disciplinary backgrounds, OTs, and social workers, to screen for TBI. In two studies, screening for TBI was followed by functional assessments through standardized assessments or observation, to understand how cognitive limitations interfere with an individual’s ability to engage in activities (46, 51). All four articles highlighted the importance of TBI screening and/or identifying TBI-related impairments that impact daily functioning to develop strategies that accommodate such impairments (46, 51, 57, 59).

Three of the four articles described strategies for tailoring interventions to accommodate TBI-related impairments, including strategies related to the treatment session (51, 57) or the treatment environment (46). Intervention-related strategies included setting short-term, specific, measurable, achievable, realistic, and time-limited (SMART) goals (51), having shorter sessions over a longer period of time and/or booster sessions, providing patients with frequent reminders, written treatment plans and short verbal summaries using lay language, short schedules, one-on-one communication in a quiet environment, and establishing a routine (57). Environmental-related strategies included modifications to tailor the physical environment specifically for patients with TBI and involved implementing organizational aids such as calendars, program schedules, and white boards with reminders

TABLE 2 Study characteristics and description of rehabilitation.

Study characteristics	N
Country of study	
United States (45–54)	10
Canada (55–62)	8
Study design^a	
Controlled interventions (55, 56, 58–61)	6
Observational cohort/cross-sectional (48, 49, 51–54, 57, 62)	8
Case studies/series (46, 53)	2
Before-After no control groups (45, 47)	2
Qualitative (50)	2
Age eligibility for rehabilitation program/intervention	
Adults (≥ 18 years) (51, 52, 54–56, 58–61)	9
Adults only (18–65 years) (48)	1
Not reported ^b (45–47, 49, 50, 53, 57, 62)	8
Sex/Gender	
Data stratified by sex or gender ^c (46, 53)	2
Females/women only (47)	1
Authors' reference to sex and gender:	
a) Sex: Males/females (49, 54)	2
b) Gender: Men/women (59)	1
c) Gender: Males/females (45, 48, 55, 56, 58, 60–62)	8
d) No reference to sex or gender but used the terms males/females (52, 53, 57)	3
e) No reference to sex or gender but used the terms men/women (47)	1
f) Not reported (46, 50, 51)	3
Description of rehabilitation program/intervention	
Target population	
Individuals experiencing homelessness and TBI (46, 51, 57, 59)	4
Individuals experiencing homelessness without specific inclusion criteria for TBI (45, 49, 50, 52, 54–56, 58, 60–62)	11
Rehabilitation without specific inclusion criteria for experiences of homelessness or TBI (47, 48, 53)	3
Location of rehabilitation program/intervention	
Community-Based rehabilitation offered through:	
a) Community organizations (45, 47–49, 53, 55–62)	13
b) Healthcare clinics (50–52)	3
c) Mobile clinic (54)	1
Medical respite program (onsite care) (46)	1

TBI, Traumatic brain injury.

^aOne article described an observational cohort/cross sectional and case study and one report described an observational cohort/cross sectional and qualitative study.

^bWhile the age eligibility of the rehabilitation program or intervention was not reported, the average age and/or age range was reported in these articles.

^cAll case studies.

(46). One study that focused on provider training categorized such strategies into external or internal strategies (51). Examples of external strategies included structuring intervention sessions

and health professionals supporting patients in applying strategies discussed during the session. Examples of internal strategies included stress management and self-soothing strategies to accommodate for deficits related to attention, self-awareness, and self-management (51).

Rehabilitation interventions for individuals experiencing homelessness without specific inclusion criteria for TBI (N = 11)

All eight articles and three gray literature reports described rehabilitation within a multidisciplinary care context. They all focused on individuals experiencing homelessness (45, 49, 50, 52, 54–56, 58, 60–62). TBI was not an inclusion criterion for these studies but up to 80% reported their participants had a history of TBI. However, no information regarding screening was provided. Seven of these articles utilized a HF approach (45, 55, 56, 58, 60–62), a recovery-oriented approach that involves immediate provision of housing without pre-conditions followed by necessary services and supports (55, 59). These studies employed either ACT or ICM interventions, which involved multidisciplinary teams of nurses, psychiatrists, social workers, rehabilitation workers, recreation therapists, nutritionists, substance abuse workers, and peer support workers, or case managers that facilitated access to services, to deliver community-based supports that were tailored toward individual need and level of disability. One article utilized harm-reduction and peer-support approaches alongside HF (45). Two studies focused on individuals with SUD who were experiencing homelessness. The first study utilized an integrated treatment approach for individuals with SUD and severe mental illness. Treatment was administered by senior clinicians and involved case management, an evidence-based SUD group intervention, contingency management to reduce substance use, and relapse prevention interventions (49). The second study described a mobile health outreach program for individuals experiencing homelessness in response to the opioid overdose crisis (54). The program involved a mobile unit consisting of addiction medicine clinicians, public health advocates, and harm reduction specialists who delivered primary care, addiction treatment, and harm reduction services to four locations on the same day at the same time each week. The remaining studies in this category described an occupational therapy intervention at an integrated healthcare site or Federally Qualified Health Centers (FQHC) that provided comprehensive services for individuals experiencing homelessness (50, 52). Occupational therapy services included an evaluation, individualized intervention focusing on client-identified goals and occupational performance, and consultation (e.g., discussion and treatment planning with another provider and evaluation of environments). Other services that were part of the FQHC were described briefly as encompassing medical care, chronic disease management, counseling for mental health

and addiction, case management, and supportive housing, and included physicians, nurses, case managers, and social workers.

Interventions in this category did not detail strategies for tailoring interventions for TBI-related impairments. It is worth noting, however, that the studies on the occupational therapy intervention referred to TBI as a complex medical condition and specifically reported that TBI, a history of head trauma, or medical conditions that affected cognition constituted most referrals for an occupational therapy evaluation (50, 52). Providers in the FQHC also noted the value of occupational therapy in providing an in-depth understanding of cognitive challenges and their impact on an individual's daily life activities and subsequently determining necessary supports (50).

Rehabilitation service use without specific inclusion criteria for experiences of homelessness or TBI (N = 3)

A key distinction between studies in this category (47, 48, 53) and those identified in the first two categories is that experiences of homelessness and/or TBI were not inclusion criteria for participating in the research study. These specialized programs included a vocational rehabilitation program (48), an emergency services outreach program (53), and an occupational therapy intervention for women experiencing homelessness and/or domestic violence (47). The vocational rehabilitation program aimed to transition and integrate individuals from five different settings into community living; one of the settings was homeless shelters, of whom 1.1% of individuals experienced TBI (48). The emergency services outreach program utilized outreach and ICM services to engage frequent users of emergency services, of whom 88% were individuals who are homeless and have chronic mental illness and SUD; and 16.6% had a history of TBI. Services were provided exclusively by a case manager who directly interacted with frequent users of emergency services to provide tailored treatment plans and support in accessing relevant resources (53). The occupational therapy intervention for women experiencing homelessness and/or domestic violence was designed to address possible cognitive impairment sustained from domestic violence, of which 50% of women were experiencing homelessness, 19% self-reported sustaining a TBI from domestic violence, and 62% had some form of cognitive impairment documented in their chart (47). This intervention involved OTs addressing a broad range of participant-identified needs including safety planning, drug and alcohol awareness, safe sex practices, assertiveness training, anger and stress management, vocational and educational skill training, money management, housing support, leisure exploration, and health maintenance in a not-for-profit community organization. This article was the only one of the three that reported on strategies to address possible TBI or cognitive impairments and incorporated key attributes of TBI-related rehabilitation, such as the length of time needed for

change and the non-linearity of the recovery process (47). None of the articles conducted or reported on TBI screening.

Discussion

This scoping review explored the extent to which rehabilitation, including the types of rehabilitation interventions, is available to, or used by, individuals experiencing homelessness and TBI. A systematic search identified four articles focused specifically on rehabilitation for individuals experiencing homelessness and TBI (46, 51, 57, 59), 11 articles on individuals experiencing homelessness (45, 49, 50, 52, 54–56, 58, 60–62), and the remainder on general use of rehabilitation services (47, 48, 53). A broad range of multidisciplinary and specialized rehabilitation programs and/or interventions were provided by OTs, social workers, case managers, psychiatrists, registered nurses, physicians, addiction medicine and primary care clinicians, harm reduction specialists, community health workers, public health advocates, peer support specialists, and/or peer-support workers. This scoping review demonstrates that rehabilitation programs or interventions for individuals experiencing homelessness and TBI already exist. Furthermore, rehabilitation focused on individuals experiencing homelessness are already serving individuals with TBI. However, interventions described by these articles did not consider TBI in the program or intervention despite the high proportion of participants with TBI (up to 80%) (45, 47–50, 52–56, 58, 60–62). Only five articles integrated TBI in their rehabilitation programs or interventions by explicitly screening for TBI and/or including intervention- or environment-related accommodations for TBI-related impairments (46, 47, 51, 57, 59). Below, we discuss key findings in relation to (a) opportunities to adapt existing rehabilitation for individuals who experience homelessness and TBI, (b) considerations for education and training on TBI, and (c) recommendations for future research.

Opportunities to adapt existing rehabilitation for individuals who experience homelessness and TBI

Findings from this scoping review highlight opportunities to adapt existing rehabilitation programs and services through (a) screening for TBI, (b) conducting cognitive and functional assessments, and (c) tailoring interventions with multidisciplinary teams. Screening for TBI was highlighted as a critical first step in identifying clients with TBI so that interventions can be tailored to address TBI-related impairments (46, 51, 57). This finding on the importance of screening is not unique to this review, as prior research has noted that screening for TBI facilitates the identification of

and access to appropriate services and supports to individuals who need them (63). Clinical interviews and self-reports of TBI identified through validated screening tools are considered the gold standard for identifying lifetime history of exposure to TBI (64), and are also found to be beneficial in identifying a history of TBI in community samples and among underserved populations (63, 65). However, a key finding from this review is the potential benefit of conducting cognitive and functional assessments following screening for TBI. Doing so provided an opportunity to not only identify cognitive limitations associated with TBI but to also gain an in-depth understanding of how such limitations impact an individual's functional abilities as well as priority areas for treatment (46, 47, 50–52). Specifically, these assessments allowed for targeted intervention (46, 47, 51, 57) and environment-related accommodations (46) that account for TBI-related challenges such as difficulties with recall, organization, problem solving, and frustration tolerance (46) and the possible implications of these limitations on treatment (e.g., longer duration of treatment and smaller gains and non-linear trajectory of recovery) (47). The value of accommodations for TBI has been recognized outside of articles included in this review (66, 67). Importantly, it holds the potential to better support individuals with TBI to maintain stable housing, as the provision of housing without addressing TBI-related challenges may put these individuals at continued risk of experiencing homelessness (67).

Equally important is the beneficial role of a multidisciplinary team in delivering the above-mentioned rehabilitation adaptations. Notably, almost all the articles that described adaptations were provided within a multidisciplinary context consisting of OTs, social workers, case managers, psychiatrists, registered nurses, clinicians, physicians, rehabilitation workers, recreation therapists, nutritionists, substance abuse workers, community health workers, peer support specialists, and/or peer-support workers (46, 47, 51, 57, 59). We acknowledge that we are unable to comment on the effectiveness of the multidisciplinary rehabilitation programs or interventions identified in this review due to potential biases identified during the quality appraisal, including but not limited to selection, reporting, and publication bias. However, multidisciplinary rehabilitation has been demonstrated to result in improved outcomes post-TBI and cost-related savings for the individuals and society (68–71). As such, utilizing multidisciplinary teams to screen for TBI, conduct functional and cognitive assessments, and adapt programs and/or interventions to accommodate TBI-related impairments should be explored and its impact on outcomes assessed. Research into barriers and facilitators for multidisciplinary rehabilitation, particularly those offered in the community setting, for individuals experiencing homelessness and TBI is also encouraged to inform opportunities to utilize multidisciplinary rehabilitation in this setting. In particular, the introduction of multidisciplinary teams that can provide accommodations for TBI may be beneficial in supporting

individuals with TBI who are already receiving rehabilitation for homelessness.

Considerations for education and training on TBI

Education and training for healthcare professionals working with individuals experiencing homelessness and TBI should be further examined and include structured education and training sessions, collaboration with a multidisciplinary team, and co-development of educational materials with service users. First, the need for education and training in working with individuals with a history of TBI has been explicitly noted in three articles in this review, with healthcare providers highlighting the value of receiving structured training on screening and functional assessments for TBI, as well as training related to the development of concrete strategies to address the needs of those with TBI (46, 51, 57). This is because individuals with TBI were often viewed as complex and referred to other healthcare professionals such as OTs (50, 52) or discharged early due to aggressive behaviors (57). Clinicians were not aware of the impact of TBI history on rehabilitation (57) and noted the value of having another healthcare professional such as an OT providing an in-depth assessment of cognitive and functional limitations associated with TBI (46, 50). The view that TBI is a complex condition, and the need for, and importance of, formal TBI education and training has been identified in research outside of those included in this review. For example, a qualitative study sought the perspectives of housing services providers in Canada and identified attitudes around TBI that affected service delivery (72). Specifically, providers referred to TBI as an unknown and reported lacking TBI knowledge and expertise or needing to go “above and beyond” their role to support individuals with TBI in finding and maintaining housing (72).

Multidisciplinary teams may also facilitate opportunities for education on TBI. Alongside the call for formal education and training, housing service providers have also reported benefitting from partnerships and collaborations with healthcare professionals who had knowledge and expertise in working with individuals with TBI (72). This is particularly important given the intersecting challenges faced by individuals experiencing homelessness and TBI reported in articles included in this scoping review, including but not limited to criminal justice involvement (45, 49, 56, 58, 60, 61) domestic violence (47), and comorbid mental health and substance use (MHSU) challenges (45, 47–61). In fact, a systematic review on integrated care for individuals with TBI and MHSU found that multidisciplinary teams, or informal meetings and discussions between different healthcare disciplines, may offer opportunities for education. This was acknowledged to be important, as the lack of experience with TBI and MHSU was a noted barrier to diagnosis,

contributing to delayed treatment (73). Thus, opportunities for formal and informal education and training on TBI, screening, assessments, and adapted interventions should be explored.

Co-developing education materials on TBI with service users and service providers should be considered, including screening, assessments, and adapted interventions. For example, research to explore and develop screening protocols for TBI should be conducted. While screening tools for TBI exist (e.g., OSU-TBI-ID that were also used in articles identified in this review), there is limited research on the feasibility and validity of using these screening tools for individuals experiencing homelessness (63, 74–76). Importantly, while screening and/or a diagnosis of a TBI may provide opportunities to adapt interventions to accommodate for TBI-related impairments, it is acknowledged that a TBI diagnosis may also be a barrier to other treatments, particularly those for MHSU, as interventions may have exclusion criteria based on a history of TBI or cognitive impairment (77). This finding is particularly important for individuals experiencing homelessness, given the prevalence of comorbid MHSU (45, 47–61) and intersecting experiences and challenges (45, 49, 56, 58, 60, 61). As such, collaborative research that engages individuals with lived experience of TBI and homelessness on the advantages and disadvantages of screening for TBI should be conducted to inform considerations when implementing screening and to mitigate unintended consequences of TBI screening.

Opportunities for future research

Research that considers the rehabilitation needs of diverse individuals experiencing homelessness and TBI is urgently needed. None of the articles identified in this review utilized an intersectional lens or considered intersecting identities in their rehabilitation programs/interventions; only a few articles reported on a HF approach that utilized ethnoracial ICM, anti-oppression approaches (58, 59), and HF programs that developed Aboriginal activities (e.g., healing circles and annual pow-wow) and support activities for gender diverse individuals (62). We acknowledge that the lack of articles may be reflective of our search strategy, as we did not explicitly include search terms related to intersecting identities. However, the intersectionality of sex, gender, race, ethnicity, disability, and other social identities leads to unique health experiences that cannot be addressed by looking at a single facet of identity. It is also noteworthy that, of the articles that reported age eligibility for their programs or interventions, none included youths in their eligibility criteria. As such, rehabilitation programs and interventions that consider diverse experiences of individuals experiencing homelessness and TBI across the age continuum must be available to address health equity and universal access to quality healthcare (78). Research that examines equity considerations in clinical practice guidelines (CPG) for TBI and

homelessness are also encouraged. This is particularly important because CPGs are “statements that include recommendations intended to optimize patient care” (79) and used to reduce inappropriate variations in practice and enhance safety and quality of healthcare (79). However, it has been highlighted that most studies included in CPGs for TBI are population-based and do not consider the diversity of patients with TBI and, as a result, promotes a one-size-fits all approach to care (80). As such, healthcare providers using CPGs should be aware that existing recommendations may not take into account unique healthcare needs and challenges experienced by individuals experiencing homelessness and TBI. Systematic reviews of existing CPGs for TBI and homelessness to assess the extent to which evidence about homelessness and TBI is integrated in these CPGs hold the potential to provide an evidence-based foundation to advance equity considerations in CPGs.

Strengths and limitations

We acknowledge the following limitations. First, only published peer-reviewed articles or gray literature were identified; this may result in the omission of rehabilitation programs or interventions that were never formally reported or presented. However, we aimed to minimize publication bias by consulting with our PAC and searching for gray literature to capture non-peer-reviewed reports that may describe services offered by community-based organizations serving individuals experiencing homelessness and/or TBI. We also aimed to minimize language bias by including non-English language peer-reviewed articles in our search. Second, this scoping review only included articles that focused on individuals who were experiencing homelessness at the time of the research study; this excludes individuals at risk of homelessness, defined as individuals who are “not homeless, but current economic and/or housing situation is precarious or does not meet public health and safety standards” (38). We acknowledge that homelessness is a fluid experience and that homeless and vulnerably housed individuals may experience similar unmet healthcare needs. However, research articles focused on individuals experiencing homelessness may describe a different rehabilitation experience than articles that focus on individuals at risk of homelessness. Thus, we believe this exclusion was appropriate and aligns with the overall scope of this review. Future reviews on rehabilitation focused on specific populations at risk of homelessness, as well as individuals with lived experience of homelessness and are now in permanent housing, are encouraged. Third, we acknowledge that the inclusion of a quality appraisal is not consistent with scoping review methodologies outlined in this review (34, 35); no articles were eliminated as a result of the quality appraisals and results were used to inform the discussion of our findings. We recognize potential biases in the articles included in this scoping review

and acknowledge we are unable to evaluate the impact of the rehabilitation programs or interventions. Finally, while we did not restrict our search by geography, only studies conducted in the United States or Canada were identified and/or met inclusion criteria to be included in this review; thus, findings may not be generalizable to other countries or health systems due to differences in culture, resources, and social behaviors.

A major strength of our scoping review is that it was guided by scoping review methodology frameworks to address methodological rigor, which has been highlighted as a limitation of existing scoping reviews on rehabilitation (81). Furthermore, as part of Stage 6, feedback from stakeholders of our scoping review were received and integrated in the interpretation of findings from this review. The charting of the data also explicitly identified intersecting sex, gender, social identities and vulnerabilities, including intersections with the criminal justice system, which is common among individuals experiencing homelessness and TBI (82). Finally, our search strategy was purposely broad, to identify articles that explore the concepts of homelessness and rehabilitation, or homelessness and TBI. In addition, the title and abstract screen included articles that explored the broader brain-injured population without specific mention of TBI. The inclusion of these articles at the title and abstract screen reduced the risk of omitting relevant articles.

Conclusion

To the best of our knowledge, this is the first scoping review that explored the extent to which rehabilitation, including the types of rehabilitation interventions, are available to or used by, individuals experiencing homelessness and TBI. Rehabilitation programs or interventions for this population already exist, and those that are focused on individuals experiencing homelessness are already serving individuals with TBI. Opportunities to introduce multidisciplinary teams that screen for TBI, assess functioning and cognition of individuals, and tailor programs and/or interventions to accommodate TBI-related impairments should be explored to maximize the benefit of rehabilitation for this population. In particular, the introduction of accommodations for TBI holds the potential to better support individuals with TBI who are already receiving rehabilitation for homelessness. Similarly, opportunities for formal and informal education and training on TBI, screening, assessments, and treatments should be considered. These include research with service users and providers to co-develop education materials to better equip service providers with appropriate tools and knowledge to support individuals experiencing homelessness and TBI. Finally, research engaging individuals with lived experience of homelessness and TBI are urgently needed to inform considerations when developing and implementing TBI screening protocols and to better understand the rehabilitation needs of diverse

individuals. An examination of equity considerations in existing CPGs for TBI is also encouraged to provide an evidence-based foundation to advance equity considerations in rehabilitation care for individuals experiencing homelessness and TBI.

Author contributions

VC and AC conceptualized this scoping review. VC, MJE, and JB developed the search strategy. VC and MJE formulated the design. VC, MJE, RB, and RS screened the articles, charted the data, and/or completed the quality appraisal of the included articles. VC, MJE, and RB completed the analyses for this review and drafted the manuscript. All authors critically reviewed the manuscript and approved the final manuscript.

Funding

This study was supported by the Canada Research Chairs Program (Grant # N/A) and the Ontario Ministry of Health and Long-Term Care, Grant #725A.

Acknowledgments

We would like to acknowledge the Program Advisory Committee (PAC) of the Traumatic Brain Injury in Underserved Populations Research Program for their feedback on this scoping review. Members of the PAC include: Michelle McDonald, Brain Injury Canada; Alice Bellavance, Brain Injury Services of Northern Ontario (BISNO); Melissa Vigar, Brain Injury Society of Toronto; Veronica Pepper, HNHB ABI Network; Reza Ahmadi, John Howard Society of Ontario; Ruth Wilcock, Ontario Brain Injury Association; Probation Officers Association of Ontario (POAO); Silvia Samsa, SAVIS of Halton; Tori Dach, The Cridge Center for the Family; Geoff Sing, The Cridge Center for the Family; and Women's Shelters Canada.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Supplementary material

The Supplementary Material for this article can be found online at: <https://www.frontiersin.org/articles/10.3389/fmed.2022.916602/full#supplementary-material>

SUPPLEMENTARY FILE 1
Search strategy.

SUPPLEMENTARY FILE 2
Charting table.

SUPPLEMENTARY FILE 3
Quality appraisal.

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