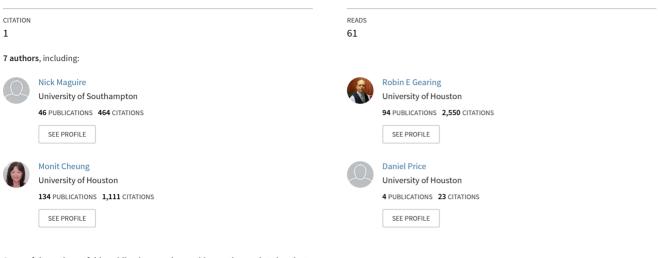
See discussions, stats, and author profiles for this publication at: https://www.researchgate.net/publication/354513706

# Community-engaged healthcare model for currently under-served individuals involved in the healthcare system

Article *in* SSM - Population Health · September 2021 DOI: 10.1016/j.ssmph.2021.100905



Some of the authors of this publication are also working on these related projects:

Homeless Youth Risk and Resilience Study (HYRRS) View project

Project

Rice Therapy (c) Monit Cheung, PhD, LCSW View project



Contents lists available at ScienceDirect

### SSM - Population Health

SSM-POPULATION HEALTH

journal homepage: www.elsevier.com/locate/ssmph

## Community-engaged healthcare model for currently under-served individuals involved in the healthcare system

S.L. Barker<sup>a,\*</sup>, N. Maguire<sup>a</sup>, R.E. Gearing<sup>b</sup>, M. Cheung<sup>b</sup>, D. Price<sup>d</sup>, S.C. Narendorf<sup>b</sup>, D.S. Buck<sup>c</sup>

<sup>a</sup> University of Southampton, School of Psychology, Building 44, University Road, Southampton, SO17 1BJ, United Kingdom

<sup>b</sup> University of Houston, Graduate College of Social Work, Houston, TX, 77204, USA

<sup>c</sup> University of Houston College of Medicine, Houston, TX, 77204, USA

<sup>d</sup> University of Houston, Honors College, Houston, TX, 77204, USA

#### ARTICLE INFO

Keywords: Community engagement Agency Power High need High cost Inclusive health

#### ABSTRACT

In the US, many people are excluded from healthcare structures and systems, due to multiple macro and micro factors. Poverty, health ecosystems, mental health, and community amenities are some of the issues confronting those who are not able to access appropriate support. This population is often referred to as 'high needs, high cost' (HNHC), a term that has been applied to refer to people who repeatedly utilize services without significant benefit (we have replaced this term with 'currently under-served'; C-US). For many traditional health solutions may not address the fundamental issues confronting their health. Community-Engaged Healthcare (CEH) is an approach that equips members of the community to levy power to advocate for their own health or social solutions, designing their own interventions to address needs with support from health providers. A realist review was conducted to identify the existing literature around CEH. This yielded ten papers that were reviewed by at least two authors and rated in terms of quality. A model describing the processes underpinning CEH was then iteratively generated, resulting in additional terms that were used in a second review of the literature. A further 16 peer-reviewed articles were identified and were independently reviewed and quality rated. These articles were used to refine further iterations of the model and included in the review where appropriate. The resulting model schematically posits a set of relational factors identified to be important in the establishment of CEH. Notably, the transfer of autonomy and power over health decision-making processes is emphasized, which will require revolutionary thinking about how healthcare is delivered for patients.

#### 1. A call for a patient engagement model

Many people with complex health and mental health needs are not served well within our current health service configuration. 'High-need, high-cost (HNHC) patients' is a term that has been used by healthcare systems for many years to describe individual consumers who have multiple chronic health conditions and functional limitations inhibiting their daily activities (Hayes et al., 2016). The high needs often result in high costs due to the way in which health care ecosystems are set up, meaning effective engagement and treatment is difficult. These people are often overwhelmed by the number of tasks to be undertaken or appointments needed as well as the complexity in choosing between competing needs to manage their health (Rifkin, 2009). This results in difficulties in acquiring essential services, and consequently they are unable to obtain timely access to community-based treatment, may experience exacerbations in their health and disease conditions, and end up seeking emergency treatment (Hamilton et al., 2016). Further, these individuals' limited ability to pay for services where universal healthcare is not available often results in additional treatment costs being born by healthcare providers, which has stimulated ideas for inter-professional teams to design a community engagement model that reduces costs and embodies 'person-centered and efficient care delivery' (Smeets, Kroese, Ruwaard, Hameleers, & Elissen, 2020).

However the term 'high needs, high cost', although commonly used, is deemed by the authors to be pejorative and unhelpful, inherently blaming people for their high needs and consequent high health costs. We propose the term 'Currently under-served individuals familiar with the healthcare system' (short-form: C-US) to replace HNHC. This

\* Corresponding author.

https://doi.org/10.1016/j.ssmph.2021.100905

Received 18 June 2021; Received in revised form 22 August 2021; Accepted 23 August 2021 Available online 10 September 2021

2352-8273/© 2021 Published by Elsevier Ltd. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).

*E-mail addresses*: S.Barker@soton.ac.uk (S.L. Barker), nm10@soton.ac.uk (N. Maguire), rgearing@uh.edu (R.E. Gearing), mcheung@uh.edu (M. Cheung), dprice2@uh.edu (D. Price), sanarendorf@uh.edu (S.C. Narendorf), dsbuck@uh.edu (D.S. Buck).

acknowledges that despite complex needs, many individuals are not served well by current configurations of healthcare services.

In the United States, 5% of the population are responsible for 50% of healthcare spending, of which 47% are C-US patients (Hayes et al., 2016). Interventions designed to address the health conditions of people with multiple needs have not demonstrated effectiveness in the longer term (Ryan, Abrams, Doty, Shah, & Schneider, 2016). Specifically, feedback on these existing treatments includes health service trends designed to treat the insured majority that tend to be system-centric, e. g., medical care that is setup for the convenience of the providers rather than the patients or care targeting a single health condition rather than the intersecting healthcare issues (Aldridge et al., 2018). Alternate treatment models for this patient population need to reduce the time patients spend seeking services to reduce costs for both patients and services (Barker, Maguire, et al., 2020; Rochon et al., 2006). Further, treatment initiation should focus on engagement and ongoing adherence to address these patients' multiple chronic diseases. C-US patients frequently lack connections to social and internal resources (often due to competing priorities) for managing these co-morbid conditions (Doupe et al., 2012).

Systematic and structural barriers associated with high wealth differentials provide a steep social gradient, one of the significant mechanisms of exclusion for C-US patients (Marmot, 2005). Systemic factors (such as insurance systems), and structural factors (such as access to transportation) are some of the mechanisms of exclusion. These factors systematically exclude those who have the worst problems as they also have least access to the income and power needed for treatment (Luchenski et al., 2017).

Research has identified barrier categories to accessing services across several domains, including the individual, family, clinician, agency, and environmental areas (Gearing, Schwalbe, & Short, 2012). The location and physical space where the service is offered, how it is offered, and methods of communicating interventions are factors potentially excluding people from accessing that service (Smeets et al., 2020). There are also barriers in terms of what is offered at the point of care, not least that the form of medical care offered, driven by provider incentives, may not be what the person wants.

Diagnostic services are influenced by reimbursement, availability, and provider preferences, introducing a circularity to service delivery (Leach, Wiese, Agnew, & Thakkar, 2018). Empirical support may be provided for such interventions on a population level, but very little evidence is generated for populations who are multiply excluded (Ryan et al., 2016), who likely differ in significant ways in their service needs. People with C-US remain under-served in all health contexts and this is likely not surprising given the frameworks that have been used to develop and test health system interventions.

An alternative paradigm is needed to serve high need populations given the persistence and failures of the dominant healthcare paradigm. Community-located health programs offer a model for providing health services that incorporates empowering community members as one of its goals. Developing services and programs responsive to community needs empower members of that community and can also be achieved through community health workers (CHWs) (or *promotoras* in Spanish-speaking communities). CHWs provide a liaison function with bidirectional communication, education in both directions, while ideally also addressing structural inequities and connecting with C-US patients (Story & To, 2016).

Community participation, or the assertion that people have the right to be involved in decisions that affect their lives and that this has a positive impact on health, has been advocated since the late 1980s in the Alma Alta Declaration (Rifkin, 2009). There have been increased efforts to achieve this, including the proliferation of CHWs and empowerment, but successes are found at the local levels only and do not easily scale up (Rifkin, 2009). Indeed, Rifkin (2009) argues that the dominant system needs to be challenged and to reframe our approach from examining effectiveness to understanding 'what works, for whom and why?' (p. 35).

Over the past decades, research methods have confronted similar barriers in attempts to study diverse and 'hard to reach' populations. There has been a shift in research epistemology and methods, which challenges the positivist view of science and is broadly captured under the rubric of participatory research (Wallerstein & Duran, 2010). The underlying principles posit that the community is the agent that is fundamental in determining the research agenda and power is shared in the planning, data collection, analysis, and dissemination of research (Wallerstein & Duran, 2010). These participatory methods have been increasingly popular in advancing research and science in hard to serve or underserved communities. Although community-based participatory research (CBPR) has been listed as one of the public health education areas since 1996 (Stoto, Abel, & Dievler, 1996), its popularity has exponentially grown in the past decade. However, a framework is warranted that can connect the development of community-engagement projects to the clinical and evaluative aspects of research on engagement.

A frequently missing or minimized element to engaging communities effectively, in health in general and health care systems in particular, is the identification of a framework that can accommodate and guide developing projects, evaluations, and research, as well as improve access to services. CBPR and similar models are largely for research purposes, including the community and its members is understanding problems but not providing an appropriate framework for all interventions. In these frameworks, a combined model that includes ecological and clinical aspects, as well as research outcomes would be ideal. A combined model would communicate a continuum of engagement whereby broad impacts on health, agency, and perception of power could be accommodated.

The proposed principle of co-design and delivery of health and social interventions has implications beyond health; the difficulties of changing systems that so powerfully discriminate are real and require a significant shift in where the power to change systems lies. This article presents a fundamental alternative to structuring healthcare delivery to better address social determinants in the context where health can be promoted or inhibited.

#### 1.1. Study objectives

This review articulates an approach to community engagement integrating best practices from models to guide practitioners and healthcare educators in an array of choices for partnering with communities. We have termed this approach Community-Engaged Healthcare (CEH). CEH involves collaboration and co-creation of communitylevel healthcare interventions.

The CEH concept uses individual and collective activities within the community to identify and direct interventions to improve health outcomes. It posits that the drive for community services should not only come from the existing providers of those services, but also from the communities (and therefore community members) themselves. The objectives of this study are:

- 1. Develop and present a model highlighting the 'community-engaged healthcare' concept
- 2. Cross-validate the model with current literature using realist methods
- 3. Examine how the model might work in practice, i.e., evaluating utility in the educational context

#### 2. Method

#### 2.1. Rationale for realist methods

Realist reviews are a focused method to understand how the existing literature suggests an intervention, or framework of interventions, would work in practice, and to develop a preliminary model of relevant processes and outcomes (Greenhalgh et al., 2015). Realist reviews approach the evidence base from a more focused theoretical stance; under a realist view, questions about 'what works' transform into "what is it about this program that works, for whom and under what circumstances" (Pawson & Bellamy, 2006, p. 22).

Realist reviews have the advantage of considering complex mechanisms of change in novel, underdeveloped interventions, rather than being limited to a simple understanding of the effectiveness of existing interventions. This is achieved by specific inclusion, interpretation and data extraction methods (Pawson & Bellamy, 2006). Although CEH has received empirical attention in terms of principles, no literature has yet modelled its implementation and mechanisms of effectiveness.

In this article, we use this framework and realist synthesis methods to create a middle-range or program theory explaining how CEH may be effective through examining a broad range of literature and iteratively searching for relevant resources.

#### 2.2. Initial database search

In accordance with guidelines for performing a realist review (Pawson, Greenhalgh, Harvey, & Walshe, 2005; Wong, Westhorp, Pawson, & Greenhalgh, 2013), this review began with an initial search of the literature (see Fig. 1). Search terms were synonyms of 'community'; 'healthcare'; 'complex needs'; and included multiple research designs. We searched PubMed, Academic Search Complete, PsycINFO, CINAHL, SocIndex and it was limited to articles published in 2009–2019, peer-reviewed journals, and in English (for details of initial search see additional file 1).

Title and abstract screening were completed by reviewers based on methodology (e.g., excluding book reviews, literature reviews, and letters to the editor) and relevance to the topic. Each article was screened by at least two reviewers/authors at each stage of the sifting process. Any disagreements were brought to the wider research team for discussion and resolution. Through screening, we focused our review on those articles that described 'community-engaged healthcare' (CEH) research. That is, research with the community beyond community participation or 'community-based' research (e.g., collaboratively developed interventions, research questions, methods, analyses).

Subsequently, data were extracted from each article by two reviewers from the research team (see additional file 2 for data extraction). We extracted basic article information, identified any patterns, identified change mechanisms, the context of each study, any identified theoretical aspects, and outcomes reported in each article.

Quality of empirical articles was assessed using the Mixed Method Appraisal Tool (MMAT; Souto et al., 2015). The MMAT justifies how much to weigh articles when considering the impact on the developing model. However, we also used guiding principles of relevance to the research aims and methodological rigor (Wong, Westhorp, et al., 2013). When the initially assigned reviewers had discrepancies in their MMAT ratings, the research team discussed and revised their ratings. If a conflict was not resolved, the research team as a group would join the discussion until consensus was reached. MMAT/Quality assessment resulted in the exclusion of three articles, given that reviewers agreed that these articles lacked relevance to the established research aims.

The initial search identified many studies, very few of which seemed to investigate community-engaged interventions. Nevertheless, three broad categories of literature were identified: 1) community-based

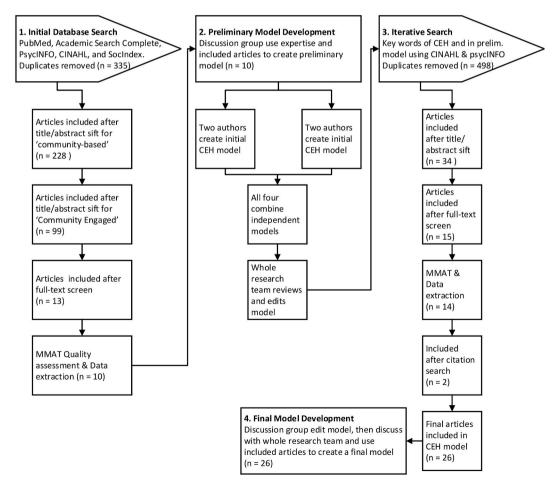


Fig. 1. RAMESES (Realist And Meta-narrative Evidence Syntheses: Evolving Standards) Search Strategy and Model Development Flow Diagram (Wong, Greenhalgh, Westhorp, Buckingham, & Pawson, 2013, p. 7).

interventions, where the health interventions were based in the community but did not have any clear elements of collaboration or cocreation; 2) community-based interventions with some elements of community engagement and collaboration; and 3) descriptions of principles of community engagement and barriers to execution. Consequently, this step required us to re-evaluate the aims of this work and use more flexible methods to further explore the role of community engagement in healthcare.

Using the identified literature and a discussion group in the research team, a preliminary model emerged. Four team members collaborated to develop a model of CEH. The discussion group worked as pairs, each developing their understanding of what CEH would look like using their expertise and informed by the existing literature from the initial search (see Fig. 1). Then the pairs compared their conceptualization, integrating them to create a preliminary 'abstracted program theory,' which was then shared with the rest of the research team and further refined (Wong, Westhorp, et al., 2013). This preliminary CEH model is presented in the results section.

#### 2.3. Second search of database

Once the preliminary model was developed and refined, we conducted a second literature search using CINAHL and PsycINFO. Using new key terms and concepts identified from the initial search and model development (see additional file 1), we searched two databases removing the limits of the initial time boundary (searching all years) and not limited to peer-reviewed journals. This search was limited by the use of English language and exact key terms identified through the selected literature in the preliminary model.

This resulted in the additional of 14 articles to our initial search results. Sifting, data extraction, and quality assessment as procedurally detailed above were again followed. A subsequent citation search was conducted on all 24 included articles, conducting a hand search for relevant articles in the reference lists and citing research. One-hundred and eighty articles were screened for relevance, resulting in another two included articles (see additional documents for details). Therefore, the final total number of included articles in this review is 26.

#### 3. Results

#### 3.1. The preliminary community-engaged healthcare model

The preliminary CEH model was developed with the literature from the initial search in addition to the discussion within the research team, drawing upon our collective knowledge and known literature that might explain elements of a CEH model (see Fig. 2). Individual and group factors dynamically interact with the local environment making it a complex system that is difficult to design (Ronzi et al., 2019). Any model attempting to describe such complex interactions will necessarily need to simplify the issues. A good model needs to be flexible enough to adequately describe the interplay of individual and group interactions, but specific enough to enable predictions about how the interventions can be effectively implemented. Upon reflection, our preliminary model did not adequately represent the tension between both imperatives.

#### 3.2. Changes to the CEH model

Data extraction and literature from the initial search revealed the preliminary model was lacking. For example, terms like 'agency' and 'power' are important underlying concepts found in our preliminary literature that needed to be further explored in a final CEH model.

Evidence was further examined for considering additional novel concepts that were not used to build the preliminary model. Extra efforts revealed literature with other inclusion criteria: keywords related to community-engaged healthcare and synonyms of concepts in the preliminary model.

After completion of the secondary literature search, data extraction, and MMAT quality assessment, the research team modified the preliminary model. Several changes were made to the model and schematic, and consideration of the literature included (shown in Fig. 3). It is important to take account of multiple factors when describing this inherently complex process.

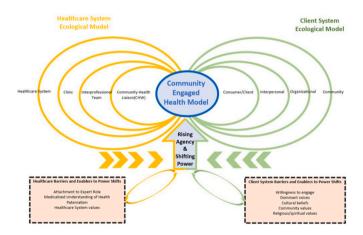


Fig. 3. Final CEH model.

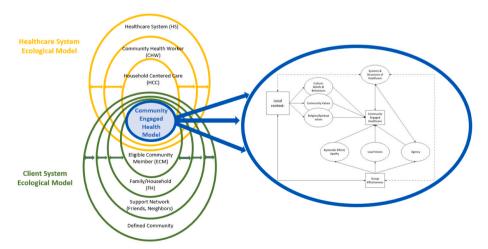


Fig. 2. The Preliminary CEH model.

The following is a summary of reflections on the process of designing and developing the model. The authors agreed that the identification of power and agency (see below), and the way in which this is shifted to the community were important steps in the process. The two epistemological approaches (broadly psychological and systems) were distinct and a discursive approach was taken to knit the diverse constructs into a fluid model which accounted for the change in ecological and individual terms.

The preliminary model, according to the team, seemed to be describing two different models with two different aims that were not integrating well. The nested ecological models seemed to be presenting a framework without accounting for psychological interplay and the breakout box was more concerned with identifying specific mechanisms and a process without accounting for the dynamic of power transitions that are in real-time and in constant flux.

There were iterative attempts to integrate the two models. One attempt brought the box to the center and collapsed the two different ecological models (the client system and the healthcare system). But this potential adaptation seemed to suggest that the process we describe was occurring at the center, the individual level, rather than a communitylevel process which we were attempting to detail.

The model was adapted when we determined that we were depicting a process that shifted power and agency from the healthcare system, which has traditionally held this power, to the community. With the concepts of power and autonomy clarified, it became clear that the model was trying to describe a dynamic process whereby CEH could be achieved, rather than just the state of CEH operating. This idea of representing power and control passing to the community from care providers is crucial, as the barriers to this then become apparent (e.g. practitioners having a vested interest in keeping healthcare in hospitals).

#### 4. The Community-Engaged Healthcare evolved model

#### 4.1. Client and healthcare systems: the ecological model

The CEH model is situated in the larger ecological model, which recognizes that an individual is influenced by and influences the larger mezzo (e.g., family, school, work) and macro (e.g., community, culture, societal policies) environmental systems situated in their environment (Amutah-Onukagha et al., 2018; Brault et al., 2018; Bronfrenbrenner, 1979; Wheeler, Roennfeldt, Slattery, Krinks, & Stewart, 2018).

Specifically, the ecological model emphasizes the complex interaction, interplay, and interdependence between the individual and their extending physical and sociocultural environmental systems (Hochman & Kernan, 2011; Krug, Mercy, Dahlberg, & Zwi, 2002). Core concepts within the ecological model facilitate the identification of intervention points for engaging and promoting health (McLeroy, Bibeau, Steckler, & Glanz, 1988). The concept of 'reciprocal causation' recognizes firstly that behavior "affects, and is affected by, multiple levels of influence; secondly, individual behavior both shapes, and is shaped by, the social environment" (Rimer & Glanz, 2005, p. 11).

Higher performing communities in Brault et al. (2018) shared similar social contexts and saw reduced emergency health service usage. Higher performing communities were those that complemented the work of health providers and were built upon strong informal support networks, underscoring the reciprocal nature between context and health outcomes.

The inclusion of the transactional model recognizes how the transaction between the client and worker, and their ecological models, interact and influence each other across time. For example, the therapeutic alliance between client and worker grows and develops iteratively, not just from one interaction, but across a multitude of interactions over time. Originally used to describe and emphasize the dynamic relationship between a child and parent across time (Sameroff & Chandler, 1975), the transactional model has been adapted for any dynamic reciprocal interchanges and context between two individuals, such as a patient and a health worker, where each has a bidirectional influence on the other (Sameroff & Mackenzie, 2003). The CEH model posits the importance of the reciprocal transaction over time. For example, Jobling et al. (2016) used information from focus groups with Aboriginal and Torres Strait Islander people in Australia to highlight the importance of developing a long-term trusting relationship with a health provider, validated in ways that respect the culture, which allowed navigating and overcoming other barriers.

Beyond describing transactions at a system and community level, it is necessary to describe factors at an individual level, including psychological factors that may be implicated in an individual's motivation to engage in positive health behaviors. Included literature suggested that lack of patient agency led to barriers in relationships between patients and health providers (Backman, Stacey, Crick, Cho-Young, & Marck, 2018; Kangovi et al., 2017; Lechner et al., 2016). Similarly, Lazarus et al. (2014) evidenced the utility of peer workers and the relationships that were built between current drug users in Ottawa, Canada, enabling trust to develop and participant buy-in to the research methodology. Another included study highlighted the value of participatory methods in developing an intervention (Poleshuck et al., 2018). These methods involve community members who provide input to demonstrate how the various CEH components impact research and intervention development.

A community is made up of individuals, and although many individuals change behaviors when acting in groups (Deutsch & Gerard, 1955), it is important to account for motivation at the individual level. Issues such as perceptions of personal agency (Deci & Ryan, 2008), bystander apathy (Latané & Darley, 1969), and dominant leadership may influence an individual's likelihood of engaging in community health delivery.

In the United Kingdom, for example, a national initiative for local groups to oversee health care delivery was met with mixed results, with leadership and engagement being cited as key factors in success (White, 2013). This is a useful lesson in the effectiveness of community interventions and the diverse factors which are implicated in their utility. At a slightly higher level, communities center on cultural, spiritual, or other values, which may inhibit or promote community engagement. Individuals form groups with norms and values, leaders, and followers-all of which moderate the ways several groups of individuals may behave as a community.

#### 4.2. Rising agency and shifting power: barriers and enablers

Brunton et al. (2017) highlight the role of power in 'community engagement' and argue that many authors do not consider the underlying tradition of the community-engagement model to which they subscribe. They argue two dominant schools of thought: utilitarian and social justice. Utilitarian models seek to involve communities to enhance the effectiveness of an intervention so that elements of the intervention are often pre-determined and not developed in collaboration with the community. In contrast, a community-driven model with a social justice focus could assert that the health need is identified by the community and then acted upon by members. Brunton et al. (2017) posit that the best method to enhance community engagement is one that shares power and is not merely focused on enhancing outcomes.

Therefore, the CEH model is likely to be most effective when there is true and meaningful co-creation. That is, health providers cede power and instead help to support the community to change their environment and health issues as they define them in ways that make sense for them.

This is further supported and extended by Howard and Howard (2000) that examines self-determination and self-reliance in a community context, with the aim of communities becoming self-sufficient. Since agency and community engagement are core to the CEH model, a novel concept that might underpin this is the bystander effect (Banyard, Weber, Grych, & Hamby, 2016). The study by Banyard et al. (2016) found bystanders would be helpful in a crisis if perceptions of informal community and social support were increased. This shows that context and perceptions of informal social support are important to an effective CEH model and underlines the interplay between social contexts, pinpointing where potential barriers may emerge.

Evidence shows the consideration needed for cultural and/or religious groups – health providers need to consider the context of the community they are serving and engage in discourse to overcome barriers presented by the dominant approach to the health system (Adjei et al., 2013; Anderson, Calvillo, & Fongwa, 2007; Krause & Hayward, 2013; Kwon et al., 2017).

As the CEH model gets more detailed, it is useful to consider the roles of health providers and community leaders needed in effective CEH, e. g., community members, community leaders, CHWs, Health care workers (nurses, community mental health, physicians), researchers, commissioners, and politicians (Kudless & White, 2007; Maguire et al., 2019; Rodriguez, Bowie, Frattaroli, & Gielen, 2009; Story & To, 2016).

Shea et al. (2017) developed a tool for community-engaged dissemination and implementation research, highlighting some novel concepts for the CEH model. By examining the role of a researcher within a participatory research setting, we can draw upon these aspects to understand how a health provider may need to consider the community and ways to share/redistribute power in a CEH setting. Specifically, this highlights the importance of introspection and openness, identifying existing strengths, engaging and adapting to the community's attitudes, and understanding of prior experience with health providers and its systems. In effect through co-development and co-creation with the community and its leader, CEH will be feasible.

#### 4.3. Culture shifting

Any community-engaged health model needs to account for the shift in power from the medical establishment within the community being served. This is no less than a revolutionary step, as medicine and medical services have set themselves up as the agents of change related to health. The CEH proposition is that the agents of change are members of the community themselves, engaging medicine only when they deem it necessary. This process towards sharing of power by the healthcare ecosystem and the resulting empowerment of the community is a central element of CEH.

The CEH model highlights areas of power and agency addressing system failures by encouraging collaboration and communication between services and community (Nunes & Lotta, 2019). By moving towards co-creation, the current system can make changes to address systemic failures. The most frequently reviewed concept for use in the CEH model is about a patient's engagement and ongoing involvement in the decision-making process. This element enhances the feasibility of moving from the current medical model to CEH because it incorporates the users' perspective and empowers patients to become informed users, rather than focusing on service utilization or other statistical metrics.

In addition, the priorities of the patients may not necessarily align with the priorities of the healthcare provider/clinician or system. Sathanapally et al. (2020) found that clinician and patient agreement on the priorities of treatment was patchy and low. In such a power relationship, the patients' agency is lowered and might lead to disengagement. In a context where collaboration is valued, these types of discrepancies would be infrequent and resolved through dialogue valuing differing perspectives.

#### 5. Discussion

This review synthesized evidence to define a Community-Engaged Healthcare (CEH) model outlining how health providers might shift power and position the community for improving the health of C-US patients. The initial search resulted in 10 articles describing engaging with the community beyond basic community participation. Following the realist methods, we created a preliminary model of CEH and refined it through discussions and evidence. A second literature search was subsequently conducted, using key terms that were noted to be missing from the first search, which resulted in an additional 14 articles. The final model was adapted to reflect changes through synthesis and a final citation search was conducted, including two more articles. Therefore, the total number of articles included in this review is 26.

The final evolved model of this realist review shows how CEH is nested within ecological systems that are shifting power and agency from the healthcare system to clients, recognizing potential barriers and enablers.

#### 5.1. Centralization and decentralization

Traditional healthcare involves a set of implicit assumptions about where care is provided (e.g., provided via clinics or hospitals), who is the most important person in the transaction and therefore around whom the services are configured (the healthcare professional), and how and what form of intervention is warranted (something medical at the level of the individual patient). For some medical needs (e.g., acute illness or pathology) there may be a very good rationale for this, but where community health is concerned, we may question these assumptions. Thus, traditional medical care may be seen to be highly centralized, with resources organized around the care provider. While there are efficiencies in this on behalf of the health system (in terms of serving a large population e.g., travel time, built environment, reduction of service duplication, resource management, etc.), there are inherent inefficiencies for dealing with chronic and socially determined health issues. The CEH model proposes organizing care around the patient and health system rather than only the health system or clinician; however, it must include all aspects to ensure co-production. Methods must integrate patients' beliefs and preferences about their health in the interventions and lead the discussion. These kinds of methods are not new; indeed, manufacturing has made use of such methods. In this way, some of the factors in healthcare provision may address social determinants of health

#### 5.2. Co-creation

Co-creation is a key concept underlying the CEH model. This review suggests that meaningful participation in co-creation will result in a realigning and shift of power. Indeed, barriers to CEH such as attachment to expert role and healthcare system values on the part of the provider are inherently challenged by co-creation. These roles can be seen as barriers in excluding certain groups from leadership, for example those experiencing homelessness; we have found these social barriers can be overcome if structures are in place to accommodate variation in experience, education, and training (Buck et al., 2004). Co-creation, shared decision making, (a communication strategy used to identify patient preferences, values, and goals for treatment; Drake et al., 2009), and reframing healthcare issues through a community lens (rather than a medicalized understanding of health) will increase participation through better engagement and incorporating community values (Maguire et al., 2019). Broadly, co-creation is the mechanism of change that will result in the outcome of shifts in power and agency key to CEH success.

Some evidence suggests that CHWs might be predisposed to a CEH model, as there has been development of relationships and distribution/ shifting of power between care providers and CHWs. CHWs are generally people with lived experience in a health system and/or particular issues that influence health (such as mental or physical health, addiction, or homelessness; Barker, Maguire, et al., 2020). Involving service recipients into the delivery of that intervention requires a certain level of reflection and openness to feedback by everyone involved in the organization. CHWs can help a healthcare service with co-production, by engaging people at all levels of service delivery and being willing to reflect and change when necessary. Nevertheless, the expertise of the CHW must be uplifted and recognized through the power they are given to shape clinical team decisions and through adequate compensation that recognizes the importance of their role. The mere presence of CHWs on a team does not ensure the application of a CEH approach.

#### 5.3. Service recommendations

To challenge traditional status quo power structures, healthcare systems could consider the different types/roles of power. The core power constructs include the following:

- Person-power: Each involved agency must engage a liaison (person or team) in Interagency and multidisciplinary collaboration with a local hospital/clinic/community health unit;
- Agency-power: A part of the mission in each health team/agency must include a language related to community engagement development or commitment;
- Knowledge/expertise-power: Research and practice ideas are integrated to enhance patient engagement for effective treatment; and
- Policy-power: State or local government must adhere to a policy that provides preventive measures/services for the healthcare system informed by the priorities of consumer communities.

Further, we posit that a healthcare service co-creation must have the following components:

- 1) Basic principles of service delivery, design, and outcome measures;
- 2) A plan to empower patients to participate in service planning;
- 3) Patient-centered services (with patients being the first to identify medical problems before detailed examination); and
- 4) Clear roles and responsibilities for service providers and patients/ community members after coordinated efforts are called for to ensure participation from all members along with the separate activities of research, clinical provision, community intervention.

#### 5.4. Implications

The Community-Engaged Healthcare (CEH) model challenges us to modify the way we work to engage <u>with</u> C-US patients. Healthcare development requires a major shift to practices shaped by the community, based on its values and goals which may be at odds with current healthcare values. This is a call to providers to integrate major CEH concepts to improve service delivery, leadership, and governance. Further, this review suggests that research should champion participatory methods and include measurements of CEH in the interventions being evaluated. Indeed, research benefits from the input of participants in CBPR models, and this should be assessed in the evaluation of interventions.

Legislators may need to consider focused funding on a CEH culture shift, for projects and standards resulting in increased community involvement challenging power structures, and ensuring the most marginalized are supported.

#### 5.5. Strengths and limitations

The main limitation of this review is that it required a significant level of abstraction and interpretation by the research team and arguably would be interpreted differently by a different group of researchers. To mitigate this limitation, we attempted to be as explicit as possible in describing the methods and encourage readers to access our additional materials to assess the progression of the synthesis. Included studies have different strengths and limitations but their quality assessment scores were not excluded. Overall, quality appraisal ratings were moderate to high. The majority of the included studies were qualitative (n = 11). In contrast, a strength of the methods deployed in the study includes multiple reviewers for each article, ensuring agreement on the relevance

of each article and the unique contribution to the overall CEH model.

This model presents a novel understanding of the multiple levels of intervention needed to engage with a community to increase efficiency and effectiveness in health service deliveries. Rigorous methods produced the CEH model and can guide a research platform to understand how to expand essential concepts for developing community engagement interventions. Future research should focus on evidencing and clarifying concepts in the model by conducting qualitative studies to test the shared power assertions. Subsequent research could explore how to test CEH models in practice and identify key components for exemplars to inform best practice.

#### 6. Conclusion

It is challenging to engage currently under served (C-US) patients in healthcare decisions. C-US patients have remained an underserved population frequently lacking services beyond expensive and episodic emergency and hospital care that fail to address underlying illness and barriers. Current medical approaches effective with many patients are ineffective in treating the C-US population who live in marginalized conditions. The CEH Model offers a powerful new tool, an approach to engage C-US patients. Specifically, the CEH illuminates the powerful relationship between agency and shifting power to patients for greater engagement. It acknowledges the great gap in power in all aspects of the lives of many excluded populations. Understanding the methods by which these changes manifest is essential to engaged health. Community engagement, as presented in this conceptual framework, is defined as a shared power process focusing on social, economic, and respective service deliveries that patients inform and lead before the treatment team plans and co-creates an effective treatment plan with them.

#### Ethical statement

This manuscript is a realist review of literature around community engaged health, building to a proposed model describing processes that may enable such an approach. As such it did not involve any new data being gathered, and therefore no participants provided data. As such, it did not require ethical review or consideration by any institution.

#### **Financial interest**

All authors declare that there are no financial interests in the manuscript. No funding was sought or obtained for preparation of the manuscript.

#### Declaration of competing interest

All authors declare that they have no competing interests in the manuscript.

#### References

- Adjei, P., Akpalu, A., Laryea, R., Nkromah, K., Sottie, C., Ohene, S., et al. (2013). Beliefs on epilepsy in Northern Ghana. *Epilepsy and Behavior*, 29(2), 316–321. https://doi. org/10.1016/j.yebeh.2013.07.034
- Aldridge, R. W., Story, A., Hwang, S. W., Nordentoft, M., Luchenski, S. A., Hartwell, G., ... Hayward, A. C. (2018). Morbidity and mortality in homeless individuals, prisoners, sex workers, and individuals with substance use disorders in high-income countries: A systematic review and meta-analysis. *The Lancet, 391*(10117), 241–250. https://doi.org/10.1016/s0140-6736(17)31869-x
- Amutah-Onukagha, N., Mahadevan, M., Opara, I., Rodriguez, M., Trusdell, M., & Kelly, J. (2018). Project thanks: Examining HIV/AIDS-Related barriers and facilitators to care in African American women: A community perspective. *AIDS Patient Care and STDs*, 32(4), 119–128. https://doi.org/10.1089/apc.2017.0215
- Anderson, N. L. R., Calvillo, E. R., & Fongwa, M. N. (2007). Community-based approaches to strengthen cultural competency in nursing education and practice. *Journal of Transcultural Nursing*, 18(1, Suppl), 498–59S. https://doi.org/10.1177/ 1043659606295567
- Backman, C., Stacey, D., Crick, M., Cho-Young, D., & Marck, P. B. (2018). Use of participatory visual narrative methods to explore older adults' experiences of

#### S.L. Barker et al.

managing multiple chronic conditions during care transitions. BMC Health Services Research, 18(1), 482.

- Banyard, V., Weber, M. C., Grych, J., & Hamby, S. (2016). Where are the helpful bystanders? Ecological niche and victims' perceptions of bystander intervention. *Journal of Community Psychology*, 44(2), 214–231. https://doi.org/10.1002/ jcop.21760
- Barker, S. L., Bishop, F. L., Bodley Scott, E., Stopa, L.l., & Maguire, N. (2020). Developing a model of change mechanisms within intentional unidirectional peer support (IUPS). European Journal of Homelessness \_, ume(2\_). 14.
- Barker, S. L., Maguire, N. J., Das, S., Bryant, V., Mahata, K., & Buck, D. S. (2020). Valuesbased interventions in patient engagement for those with complex needs. *Population Health Management*, 23(2), 140–145. https://doi.org/10.1089/pop.2019.0084
- Brault, M. A., Brewster, A. L., Bradley, E. H., Keene, D., Tan, A. X., & Curry, L. A. (2018). Links between social environment and health care utilization and costs. *Journal of Gerontological Social Work*, 61(2), 203–220. https://doi.org/10.1080/ 01634372.2018.1433737
- Bronfrenbrenner, U. (1979). The ecology of human development. Cambridge: Harvard Press.
- Brunton, G., Thomas, J., O'Mara-Eves, A., Jamal, F., Oliver, S., & Kavanagh, J. (2017). Narratives of community engagement: A systematic review-derived conceptual framework for public health interventions. *BMC Public Health*, 17(1), 1–15.
- Buck, D. S., Rochon, D., Davidson, H., & McCurdy, S. (2004). Involving homeless persons in the leadership of a health care organization. *Qualitative Health Research*, 14(4), 513–525.
- Deci, E. L., & Ryan, R. M. (2008). Self-determination theory: A macrotheory of human motivation, development, and health. *Canadian Psychology/Psychologie canadienne*, 49(3), 182.
- Deutsch, M., & Gerard, H. B. (1955). A study of normative and informational social influences upon individual judgment. *Journal of Abnormal and Social Psychology*, 51 (3), 629.
- Doupe, M. B., Palatnick, W., Day, S., Chateau, D., Soodeen, R. A., Burchill, C., et al. (2012). Frequent users of emergency departments: Developing standard definitions and defining prominent risk factors. *Annals of Emergency Medicine*, 60(1), 24–32. https://doi.org/10.1016/j.annemergmed.2011.11.036
- Drake, R. E., Wilkniss, S. M., Frounfelker, R. L., Whitley, R., Zipple, A. M., McHugo, G. J., et al. (2009). Public-academic partnerships: The thresholds-dartmouth partnership and research on shared decision making. *Psychiatric Services*, 60(2), 142–144.
- Gearing, R. E., Schwalbe, C. S., & Short, K. D. (2012). Adolescent adherence to psychosocial treatment: Mental health clinicians' perspectives on barriers and promoters. *Psychotherapy Research*, 22(3), 317–326. https://doi.org/10.1080/ 10503307.2011.653996
- Greenhalgh, T., Wong, G., Jagosh, J., Greenhalgh, J., Manzano, A., Westhorp, G., et al. (2015). Protocol-the RAMESES II study: Developing guidance and reporting standards for realist evaluation. *British Medical Journal*, 5(8), Article e008567. https://doi.org/10.1136/bmjopen-2015-008567
- Hamilton, J. E., Desai, P. V., Hoot, N. R., Gearing, R. E., Jeong, S., Meyer, T. D., ... Begley, C. E. (2016). Factors associated with the likelihood of hospitalization following emergency department visits for behavioral health conditions. Academic Emergency Medicine, 23(11), 1257–1266. https://doi.org/10.1111/acem.13044
- Hayes, S. L., Salzberg, C. A., McCarthy, D., Radley, D. C., Abrams, M. K., Shah, T., et al. (2016). High-need, high-cost patients: Who are they and how do they use health care? A population-based comparison of demographics, health care use, and expenditures. *Issue Brief (Commonw Fund)*, 26, 1–14.
- Hochman, S., & Kernan, W. (2011). A social-ecological model for addressing stress on the college campus. Retrieved from http://health.columbia.edu/files/healthservices/ali ce SocEcoStress ACHA 2010.pdf.
- Howard, D. C., & Howard, P. A. (2000). Towards sustainability of human services: Assessing community self-determination and self-reliance. *Canadian Journal of Program Evaluation*, 15(1), 25.
- Jobling, K., Lau, P., Kerr, D., Higgins, R. O., Worcester, M. U., Angus, L., ... Murphy, B. M. (2016). Bundap Marram Durn Durn: Engagement with Aboriginal women experiencing comorbid chronic physical and mental health conditions. *Australian & New Zealand Journal of Public Health*, 40(S1), S30–S35.
- Kangovi, S., Mitra, N., Smith, R. A., Kulkarni, R., Turr, L., Huo, H., ... Long, J. A. (2017). Decision-making and goal-setting in chronic disease management: Baseline findings of a randomized controlled trial. *Patient Education and Counseling*, 100(3), 449–455.
- Krause, N., & Hayward, R. D. (2013). Measuring communities of faith: A preliminary investigation. Journal of Religion, Spirituality and Aging, 25(3), 258–276. https://doi. org/10.1080/15528030.2013.767767
- Krug, E. G., Mercy, J. A., Dahlberg, L. L., & Zwi, A. B. (2002). The world report on violence and health. *Lancet*, 360(9339), 1083–1088. https://doi.org/10.1016/ s0140-6736(02)11133-0
- Kudless, M. W., & White, J. H. (2007). Competencies and roles of community mental health nurses. Journal of Psychosocial Nursing and Mental Health Services, 45(5), 36–44.
- Kwon, S. C., Patel, S., Choy, C., Zanowiak, J., Rideout, C., Yi, S., ... Islam, N. S. (2017). Implementing health promotion activities using community-engaged approaches in Asian American faith-based organizations in New York City and New Jersey. *Translational Behavioral Medicine*, 7(3), 444–466. https://doi.org/10.1007/s13142-017-0506-0

Latané, B., & Darley, J. M. (1969). Bystander" apathy. *American Scientist*, *57*(2), 244–268. Lazarus, L., Shaw, A., LeBlanc, S., Martin, A., Marshall, Z., Weersink, K., ...

Tyndall, M. W. (2014). Establishing a community-based participatory research partnership among people who use drugs in Ottawa: The PROUD cohort study. *Harm Reduction Journal*, *11*(1), 1–8.

- Leach, M. J., Wiese, M., Agnew, T., & Thakkar, M. (2018). Health consumer and health provider preferences for an integrative healthcare service delivery model: A national cross-sectional study. *International Journal of Clinical Practice*, 72(6), Article e13204. https://doi.org/10.1111/ijcp.13204
- Lechner, S., Herzog, W., Boehlen, F., Maatouk, I., Saum, K.-U., Brenner, H., et al. (2016). Control preferences in treatment decisions among older adults—results of a large population-based study. *Journal of Psychosomatic Research*, 86, 28–33.
- Luchenski, S., Maguire, N., Aldridge, R. W., Hayward, A., Story, A., Perri, P., ... Hewett, N. (2017). What works in inclusion health: Overview of effective interventions for marginalised and excluded populations. *The Lancet*. https://doi. org/10.1016/S0140-6736(17)31959-1
- Maguire, K., Garside, R., Poland, J., Fleming, L. E., Alcock, I., Taylor, T., ... Wheeler, B. W. (2019). Public involvement in research about environmental change and health: A case study. *Health*, 23(2), 215–233. https://doi.org/10.1177/ 1363459318809405
- Marmot, M. (2005). Social determinants of health inequalities. Lancet, 365(9464), 1099–1104. https://doi.org/10.1016/s0140-6736(05)71146-6
- McLeroy, K. R., Bibeau, D., Steckler, A., & Glanz, K. (1988). An ecological perspective on health promotion programs. *Health Education Quarterly*, 15(4), 351–377. https://doi. org/10.1177/109019818801500401
- Nunes, J., & Lotta, G. (2019). Discretion, power and the reproduction of inequality in health policy implementation: Practices, discursive styles and classifications of Brazil's community health workers. Social Science & Medicine, 242. https://doi.org/ 10.1016/j.socscimed.2019.112551
- Pawson, R., & Bellamy, J. (2006). Realist synthesis: An explanatory focus for systematic review. Moving Beyond Effectiveness in Evidence Synthesis, 83.
- Pawson, R., Greenhalgh, T., Harvey, G., & Walshe, K. (2005). Realist review–a new method of systematic review designed for complex policy interventions. *Journal of Health Services Research and Policy*, 10(1), 21–34.
- Poleshuck, E., Mazzotta, C., Resch, K., Rogachefsky, A., Bellenger, K., Raimondi, C., ... Cerulli, C. (2018). Development of an innovative treatment paradigm for intimate partner violence victims with depression and pain using community-based participatory research. *Journal of Interpersonal Violence*, 33(17), 2704–2724.
- Rifkin, S. B. (2009). Lessons from community participation in health programmes: A review of the post alma-ata experience. *International Health*, 1(1), 31–36.
- Rimer, B. K., & Glanz, K. (2005). Theory at a glance: A guide for health promotion practice: US Department of health and human services. National Institutes of Health.
- Rochon, D., Buck, D. S., Mahata, K., & Turley, J. P. (2006). The evolution of goalnegotiated care. In HIC 2006 and HINZ 2006: Proceedings (Vol. 90).
- Rodriguez, E. M., Bowie, J. V., Frattaroli, S., & Gielen, A. (2009). A qualitative exploration of the community partner experience in a faith-based breast cancer educational intervention. *Health Education Research*, 24(5), 760–771. https://doi. org/10.1093/her/cyp010
- Ronzi, S., Puzzolo, E., Hyseni, L., Higgerson, J., Stanistreet, D., Hugo, M. N. B., ... Pope, D. (2019). Using photovoice methods as a community-based participatory research tool to advance uptake of clean cooking and improve health: The LPG adoption in Cameroon evaluation studies. *Social Science & Medicine*, 228, 30–40. https://doi.org/10.1016/j.socscimed.2019.02.044
- Ryan, J., Abrams, M. K., Doty, M. M., Shah, T., & Schneider, E. C. (2016). How high-need patients experience health care in the United States. Findings from the 2016 commonwealth fund survey of high-need patients. *Issue Brief (Commonw Fund)*, 43, 1–20.
- Sameroff, & Chandler, M. J. (1975). Reproductive risk and the continuum of caretaking causality. Review of Child Development Research, 4, 197–244.
- Sameroff, & Mackenzie, M. (2003). Research strategies for capturing transactional models of development: The limits of the possible. *Development and Psychopathology*, 15(3), 613–640. https://doi.org/10.1017/s0954579403000312
- Sathanapally, H., Sidhu, M., Fahami, R., Gillies, C., Kadam, U., Davies, M. J., ... Seidu, S. (2020). Priorities of patients with multimorbidity and of clinicians regarding treatment and health outcomes: A systematic mixed studies review. *BMJ Open*, 10 (2). https://doi.org/10.1136/bmjopen-2019-033445
- Shea, C. M., Young, T. L., Powell, B. J., Rohweder, C., Enga, Z. K., Scott, J. E., ... Corbie-Smith, G. (2017). Researcher readiness for participating in community-engaged dissemination and implementation research: A conceptual framework of core competencies. *Translational Behavioral Medicine*, 7(3), 393–404. https://doi.org/ 10.1007/s13142-017-0486-0
- Smeets, R. G. M., Kroese, M., Ruwaard, D., Hameleers, N., & Elissen, A. M. J. (2020). Person-centred and efficient care delivery for high-need, high-cost patients: Primary care professionals' experiences. *BMC Family Practice*, 21(1), 106. https://doi.org/ 10.1186/s12875-020-01172-3
- Souto, R. Q., Khanassov, V., Hong, Q. N., Bush, P. L., Vedel, I., & Pluye, P. (2015). Systematic mixed studies reviews: Updating results on the reliability and efficiency of the mixed methods appraisal tool. *International Journal of Nursing Studies*, 52(1), 500–501. https://doi.org/10.1016/j.ijnurstu.2014.08.010
- Story, L., & To, Y. M. (2016). Evaluating community health advisor (CHA) core competencies: The CHA core competency retrospective pretest/posttest (CCCRP). *Journal of Transcultural Nursing*, 27(3), 218–225. https://doi.org/10.1177/ 1043659614559308
- Stoto, M., Abel, C., & Dievler, A. (Eds.). (1996). Healthy communities: New partnerships for the future of public health. Washington DC: The National Academies Press.
- Wallerstein, N., & Duran, B. (2010). Community-based participatory research contributions to intervention research: The intersection of science and practice to improve health equity. *American Journal of Public Health*, 100(Suppl 1), S40–S46. https://doi.org/10.2105/ajph.2009.184036
- Wheeler, A. J., Roennfeldt, H., Slattery, M., Krinks, R., & Stewart, V. (2018). Codesigned recommendations for increasing engagement in structured physical activity for

people with serious mental health problems in Australia. Health and Social Care in the

Community, 26(6), 860–870. https://doi.org/10.1111/hsc.12597
White, C. (2013). Healthwatch must prove its worth to survive in testing times. BMJ British Medical Journal, 346.

Wong, G., Greenhalgh, T., Westhorp, G., Buckingham, J., & Pawson, R. (2013). RAMESES publication standards: Realist syntheses. *BMC Medicine*, *11*(1), 1.
Wong, G., Westhorp, G., Pawson, R., & Greenhalgh, J. (2013). Realist synthesis: RAMESES training materials. Retrieved from http://www.ramesesproject.org.