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## The use of participatory action research to design a patient-centered community health worker care transitions intervention

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### ABSTRACT

**Background:** Policymakers, patients and clinicians are increasingly eager to foster patient involvement in health care innovation. Our objective was to use participatory action research with high-risk hospitalized patients to design a post-hospital transition intervention.

**Methods:** We conducted qualitative interviews with sixty-five low-income, recently hospitalized patients exploring their perceptions of barriers to post-hospital recovery and ideas for improvement. We then used a modified grounded theory approach to design an intervention that would address each barrier using patients' suggestions.

**Results:** Five key themes were translated into design elements. First, patients wished to establish a relationship with healthcare personnel to whom they could relate. The intervention was provided by an empathic community health worker (CHW) who established rapport during hospitalization. Second, patients suggested tailoring support to their needs and goals. CHWs and patients designed individualized action plans for achieving their goals for recovery. Third, patient goals were misaligned with those of the inpatient team. CHW facilitated patient-provider discharge communication to align goals. Fourth, patients lacked post-discharge support for predominantly psychosocial or financial issues that undermined recovery. CHWs provided support tailored to patient needs. Finally, patients faced numerous barriers in obtaining post-hospital primary care. CHWs helped patients to obtain timely care with a suitable provider. **Conclusions:** Low-income hospitalized patients voiced needs and suggestions that were directly translated into the design of a scalable patient-centered CHW intervention.

**Implications:** The approach of using participatory action research to tightly mapping patient input into intervention design is rapid and systematic strategy for operationalizing patient involvement in innovation.

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### 1. Background

Increasing patient involvement in healthcare innovation has become a national priority. Yet in practice, most interventions are still designed without the input of the patients they are intended to benefit. This gap between principle and practice may be due to difficulties operationalizing the collaboration between health system leaders, researchers and patients.<sup>1</sup> These challenges are even greater with patients of low socioeconomic status (SES) due

to barriers such as low health literacy and patient mistrust of healthcare personnel and researchers.<sup>2,3</sup> As a result, innovations may not be designed for the low-SES patient, even though they may have the greatest need for novel approaches.

For example, a significant body of evidence demonstrates that low-SES patients are at high risk for poor outcomes during hospitalization and the post-hospital transition.<sup>4–13</sup> These patients are 18% more likely to report poorer quality of inpatient care,<sup>5</sup> 30% less likely to access post-hospital outpatient care<sup>8,14</sup> and face an

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elevated risk of all-cause readmission and death across a variety of diseases.<sup>9-13</sup> Over the past 5 years, improvement of the post-hospital transition has been a major policy focus,<sup>15,16</sup> sparking numerous novel interventions and redesign efforts. Unfortunately, with few exceptions,<sup>17</sup> low-SES patients have not had input into the design of these interventions, contributing to low rates of uptake<sup>18</sup> and variable success<sup>19</sup> among this high-risk population.

Participatory action research (PAR)<sup>20</sup> may be a useful strategy for operationalizing patient involvement in health care design. PAR is an approach in which researchers collaborate with stakeholders affected by a problem to generate knowledge of, and solutions to, these problems.<sup>21</sup> PAR is characterized by an iterative cycle of knowledge generation and action<sup>20,22</sup> and cooperative inquiry i.e. “research ‘with’ rather than ‘on’ people”.<sup>23,24</sup> This cooperative and iterative nature of PAR allows researchers, clinicians and patients to collaborate in designing an intervention that has already been validated by end-users. PAR may also be used to adapt and tailor an existing intervention to local needs as it is disseminated to new settings and patient groups.

In this paper, we describe the use of a qualitative PAR study with hospitalized low-SES patients to design a scalable, patient-centered community health worker (CHW) intervention called IMPaCT (Individualized Management for Patient-Centered Targets).

## 2. Methods

This study developed from a collaborative group of the co-authors which included researchers, health system leaders and representatives from community-based organizations in low-SES neighborhoods within West/Southwest Philadelphia. This study team identified a key issue that was of interest to all three stakeholders: the gaps in care that low-SES patients experienced after being discharged from the hospital. The team was interested in designing an intervention to address this issue and ultimately testing the intervention using a randomized controlled trial (RCT). Some team members hypothesized – based on prior studies suggesting that community health workers (CHWs) were effective in engaging and supporting low-SES patients<sup>25</sup> – that a CHW intervention might be effective. However, the team was uncertain about the specifics of such an intervention, or even if the CHW model would be acceptable for their patient population. The team was elected to conduct a qualitative PAR study in order to engage high-risk patients and understand their needs and preferences. As a first step, the principal author hired a community member who shared life circumstance with low-SES patients, to become a part of the study team and to conduct all PAR interviews. The community member was chosen from a pool of fifteen applicants for the position of “community-based interviewer” for her innate listening skills, experience with community outreach and interest in ethnography. She was trained in qualitative interviewing technique by the University of Pennsylvania Mixed Methods Research Laboratory. Members of the study team communicated as needed over the course of the study.

Our qualitative methods have been described in detail previously.<sup>26,27</sup> Briefly, we conducted in-depth semi-structured interviews with 65 recently hospitalized low-SES individuals to explore perceptions of hospitalization and discharge, barriers to recovery, and ideas for improving the post-hospital transition.

We used a modified grounded theory<sup>28</sup> approach for analysis: the study team developed a coding structure including major ideas that emerged from the data, as well as a priori codes for barriers to recovery and ideas for improvement. Two trained research assistants used NVivo 10.0 (a qualitative data analysis software) to code the transcribed data.

Using the constant comparison method, the study team analyzed transcripts synchronously with data collection, continuously refining and adapting the interview guide based on participant responses. For instance, if several participants suggested that the hospital provide post-discharge support, this would be added to the interview guide as a prompt for subsequent interviews: “people we talked to have suggested that the hospital provide some support after hospitalization – what do you think about this?” This iterative process was used to develop, refine and test increasingly specific ideas for a post-hospital transition intervention.

After completing data collection and analysis, we performed a three-step mapping process (Fig. 1, Appendix A) to translate results into the design for an intervention. First, the study team created a list of key interview themes summarizing barriers that patients faced and their suggestions for improvement. Next, the first author and community member used logical problem-solving to design an intervention step that addressed each barrier using patients' suggestions. They then listed the traits and skills required of the workforce performing each intervention step. The resulting map was then presented to study team members for member checking and validation.

We used the map to build on existing care delivery models<sup>29,30</sup> in the design of the intervention model. Specifically, we used the “Intervention” column of the map as the basis for intervention protocols and CHW manuals. We used the “Traits” column as the basis of CHW recruitment and hiring guidelines. Finally, we built on established CHW trainings<sup>31</sup> to design a course that would teach CHWs the skills in the “Skills” column.

This study was approved by the university Institutional Review Board.

## 3. Results

The study team made initial design decisions based on the three overarching themes that emerged from interviews. First, participants frequently described a sense of disconnect from traditional healthcare personnel and wished for support from someone to whom they could relate. This confirmed the team's hypothesis that the intervention should employ CHWs who were capable of providing marginalized patients with empathic support. Second, patients felt that they were being “set up to fail” when the team set discharge goals that were confusing, in conflict with patients' own goals or unrealistic given financial constraints and lack of social support.<sup>27</sup> The team decided to base the intervention around helping patients to achieve goals that patients considered meaningful and achievable. Third, patients experienced so many barriers in obtaining post-hospital primary care that they preferred to return to the emergency room once they fell ill again.<sup>26</sup> Therefore, the team decided that the endpoint of the intervention should be to help patients obtain care with a suitable PCP.

After establishing these general principles, we began the mapping process to flesh out the details. We grouped qualitative interview nodes into major themes and tightly mapped each theme to suitable intervention steps and workforce requirements (Fig. 1, Appendix A).

### 3.1. Establishing a relationship

Patients wished to have a relationship with a support person to whom they could relate: “I need to share with somebody that can share with me, like I been there, I know where you're at.” Patients suggested that such a relationship be established “before they leave the hospital to build trust” in a safe environment. Participants described traits of a support person that would facilitate a

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