

# Community Health Workers as intermediaries to improve health care accessibility:

## a realist evaluation of a pilot project

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**Community Health Workers as Intermediaries to improve Healthcare Accessibility: a realist evaluation of a pilot project.**


**Abstract**

***Background:***

To address existing barriers to healthcare access, the city of Ghent (Belgium) set up a community health worker (CHW) project, in which CHWs' main role was patient navigation: guiding patients in overcoming these barriers by contacting patients to arrange health care visits and transportation, reminding patients of appointments and assistance with insurance.

***Objectives:***

This study explored the process of this CHW-project to understand what works, for whom, to what extent, and under which conditions, in order to formulate some recommendations for future similar projects.

***Methods:***

Data were collected through 12 in-depth interviews and a group evaluation session by the steering group committee of the project. Using a qualitative approach, we aimed to unveil contextual factors and mechanisms that determine the CHW's effect on healthcare and its accessibility.

***Results:***

CHWs provide support to patients and enable more efficient care. The contribution of the CHW is based on trust and empathy bringing an extra humanitarian dimension into health care. Informality and free task interpretation play a facilitating role as these give room for spontaneity and flexibility. Role unclarity might be an inhibiting factor. This project shows a

promising role for CHWs in improving accessibility of future healthcare.

***Conclusion:***

This study clarified mechanisms and contextual factors by which CHWs can improve healthcare accessibility.

***Keywords:***

Community Health Workers, Patient Navigation, Empathy, Health Services Accessibility, Qualitative Research

***Key Messages:***

- CHWs provide support and efficient care, through trust, a sense of humanity and empathy and through their intermediary function.
- Informality facilitates this via enabling spontaneity and free task interpretation, but can hinder via role unclarity.
- Researchers and policymakers should explore the use of CHWs in primary health care.

## Introduction

The concept of community health workers (CHWs), trained lay people who share socioeconomic backgrounds with their patients, dates back to the 1970s (1,2). CHWs have proven to be highly effective in low- and middle-income countries in contributing to equity, community involvement, responding to local health needs and intersectoral collaboration (1,2). Driven by the growing burden of chronic diseases and concerns about shortage in health workforce, CHWs draw growing attention in high-income countries (HICs) to tackle inequity in healthcare access and outcomes among disadvantaged and vulnerable population groups (3). There is a growing but small body of contemporary evidence on CHWs' promising opportunities in the context of HICs (4–7). Javanparast et al. stated that a better understanding of the role of CHWs by practitioners and program managers would improve their acceptance and their inclusion in in multidisciplinary primary health care teams (1,8).

This study explored the process of a CHW-project in the city of Ghent (Belgium), in which CHWs' main role was patient navigation. Patient navigators are trained, lay healthcare workers who guide patients in overcoming barriers to healthcare access (9–13). Types of assistance vary widely, but common tasks are: contacting patients to arrange health care visits and transportation, reminding patients of appointments and assistance with insurance (9–13). Bridging gaps in service, it is considered as an evidence-based approach to address health disparities (10–13), but little is known about the underlying mechanisms (8).

This study explored the process of this CHW-project by interviewing caregivers, coordinator, CHWs and patients about what works, for whom, to what extent, and under which conditions. The results reveal contextual factors and underlying mechanisms that increase the aforementioned understanding of the role of CHWs as patient navigators.

## Methods

### *Setting and Project Characteristics*

As part of the Ghentian poverty policy, social welfare organisations and the healthcare field (including family doctors, Community-health Centres (CHCs), primary care services and hospitals) collaborated to undertake this pilot project with CHWs during one year (November 2018 - November 2019). Its main goals are: to increase healthcare accessibility, to support disadvantaged groups in healthcare utilisation, health (literacy) promotion, and to identify inequities and flag structural problems concerning healthcare accessibility. To reach these goals, key figures from local communities were trained and supported as CHWs to function as a bridge between disadvantaged groups and the healthcare system (cfr. Box 1). The emphasis during this pilot project was laid on assisting and guiding the patient through the complexity of social and healthcare services. Primary Health Care (PHC) lends itself perfectly as a platform for this patient navigation, because it is inextricably linked with social services and coordination of care is one of its key features (12). This study aims to gain insight in how implementation of CHWs in the PHC system of Ghent leads to these intended effects. Based on the evaluation of this pilot project, policy recommendations for future programs will be proposed.

### *Study Design*

Realist evaluation was used as a method to understand mechanisms, contextual factors and outcomes of the intervention. Realist evaluation studies have the purpose to identify 'what works in which circumstances and for whom?' (14,15). In this study we explore how the implementation of a CHW increases PHC accessibility in Ghent, by exploring CHWs' and patients' experiences. This approach allows the extrapolation of the results as it describes

how this particular intervention works and which are the contextual factors that facilitate or hinder outcomes.

Realist evaluation starts from an initial program theory formulated in a context-mechanism-outcome-structure (CMO). A grounded analysis (16) of the study data will lead to an adapted concluding theory (figure 1). The initial program theory was drawn from a document analysis of grey literature and input from staff members of participating organisations: 'CHWs who share similar characteristics with patients, including community of residence, culture, language and/or socioeconomic status, can increase accessibility and coordination of care, by developing a mechanism of trust between them and the population they serve.'

***Recruitment of Participants, Data Collection and Data Analysis***

We intended to unravel the underlying process in depth and from different perspectives by involving various profiles, including physicians, social workers, the coordinator, CHWs and patients. We selected participants through a purposive sampling approach. Participants were contacted and invited by the coordinator face-to-face and via e-mail. They all agreed to participate and gave informed consent. Data were collected through 12 in-depth interviews and a group evaluation session by the steering group committee. Once sufficient data were collected for in-depth analysis we stopped including new participants. From September to October 2019, six CHWs, four health professionals (three general practitioners and one social worker), one patient and one coordinator were interviewed individually (each 30-60 minutes). The script of the interviews was based on the initial program theory. The first author conducted the interviews. Field notes were taken during the interviews. The interviews were audio-recorded, de-identified and transcribed. Transcripts were imported into NVivo 11 qualitative data analysis program. The first author structured the data

following the CMO categories of the realist evaluation approach. This was extensively discussed with the supervisor, PD.

Ethics approval was obtained from the Ethics Committee of Ghent University Hospital in November 2018 (registration number: B670201837593).

## Results

### *Outcomes of the Intervention*

It was clear for every respondent that the intervention caused a better linking between and within services, thus more efficient care. Patients were guided by the CHW to the right services in case of referrals, and many found their way to primary health care or health insurance facilities with the help of the CHW.

All respondents also put forward that the CHWs provide necessary emotional and mental support to patients. Many mentioned a form of companionship or a feeling of someone 'being there'.

*According to them, I'm 'a gift sent from above'. (...) They say: 'you give us so much positive energy, you stand with us, you listen more, you don't judge'. (...) That's my goal: to motivate them again, make them believe in it… that it's worth the effort. I just want to remind them. (CHW)*

*He was my Xanax as a figure of speech. Because normally I always have my tranquilizer with me if necessary. But when he's with me, I don't need it. (patient)*

During the project, some CHWs dropped out of the project. Sometimes this was related to a prior underestimation of tasks and labour intensity, often it was due to insufficiently indicating personal limits. Respondents argued that it was important for the CHW to keep a certain amount of professional distance and to guard their personal boundaries.

*You've got to set your limits. They can really cling to you (...) Sometimes it's difficult to discern between the cry for help and the real need. Some patients' whole life stories come up. But we carry our own burden too, and then these memories start coming up. Then it can get too heavy. (CHW)*

In some cases, the CHW withdrew from the project because he or she found a job or an education, sometimes linked to the skills and knowledge they gained during the project. These inherent qualities of working with volunteers made it complicated for all actors involved to keep an overview.

CHWs and health professionals reported that CHWs empowered patients and stimulated self-management. Often it helped patients to firstly visit services accompanied by the CHW, to learn their way to and within the healthcare system, to subsequently undertake these steps autonomously.

*Sometimes you've got to push people a bit and for example say we'd meet next time at the location instead of at home. (...) "How are we going to return, what do you think?", and then she said "I'll try to do it by myself, so I can go by myself next time." (...) People want to be self-reliant. They don't just give up and leave it to someone else. (CHW)*

***The Program Mechanisms that produce Outcomes***

*Voluntary Engagement brings an extra humanitarian Dimension into Health Care*

As volunteers, the CHWs possess the time and flexibility that allows them to physically accompany a patient, and to repeat or fully spell out certain messages or explanations from caregivers, when caregivers themselves do not, because of their professional limitations and obligations. Interviewed caregivers pointed out they experienced this as a welcome and vital answer to this hiatus in care. An essential feature of this approach is the empathetic element of the listening ear. Many respondents identify this aspect of real human contact as crucial for the CHW project.

*I rather avoid the social services. It's just so bureaucratic and coercive, without any feeling. And X (*name CHW*) works with feeling, that's the big difference. Like, 'Alright, come, take a cup of coffee, and tell me.' (...) Empathy, that's what's missing (*in official services*), and that's what he* does *have. He lets me rage, he lets me cry. That humanity, that's what it's all about, and you can't find that in any official service. (...) When I passed him during his job somewhere else, he waved at me. Just that wave is enough. I can't imagine my social worker waving at me, all right! (...) I hope he always stays the same. When I would see him change… When I would see him become 'official', then the whole thing changes for me. Then I would put my guard up. (patient)*

Time, inherent to the voluntary nature of the CHW's engagement, fosters another point-of-view: a more human and practical perspective. In health care services, this sometimes gets lost or forgotten in the daily rush caused by the growing emphasis on efficiency and speed or the multitude of procedures and administrative tasks. A new external perspective can be a breath of fresh air in often complex cases. The CHWs can notice issues that accustomed caregivers don't see anymore.

*He takes his time. If it takes an hour, then it takes an hour. (...) He looks beyond your particular problem. He examines how you got into this situation and looks further, so when the problem is solved, it won't return later. (...) He accompanied me to the doctor. It's important he hears what the doctors say. Social workers are also just doing their job, but they don't accompany you. He does. And he looks at it from a different angle than mine of course… (patient)*

*CHWs develop a Bond of Trust with Patients.*

As a result of their accessible nature, CHWs promptly gain trust of patients. Trust was often mentioned as one of the key elements in the CHW-patient relationship. Respondents expressed CHWs reap trust via a sense of authenticity and recognition. Patients recognize aspects of the CHWs' background and vice versa. This familiar sense, which is fundamental to working with volunteers from the community, emerges along with a feeling of authenticity.

*I try to make them feel comfortable. They notice quickly I'm not that person that judges them, I'm not 'mister doctor' or the nurse who says 'you must do this and that'. But, what happens if they see someone similar to them, a regular person… It's easier to talk, it's remarkable. I'm also sitting literally next to that person, not creating big expectations, just, trying to be myself. (CHW)*

Respondents also noted that the feeling of safety is often crucial for trust between CHW and patient. Especially in cases where patients have some fear or suspicion towards official organizations or the health care system in general (due to financial debts, bad experiences or lack of residence permit), it's specifically key to display a clear and substantial distance between 'the system' and the CHW. In case of previous bad experiences (where patients were treated in a rude or condescending manner, or cases of racist insults) the CHW can also play a supporting role as a witness.

*They trust us because we respect their privacy. They don't have the feeling they have to pay attention to what they say because it could be used against them. Sometimes they have that feeling with people 'of the system'. (...) They say: 'Even though you don't do anything, I feel safer. I'm not alone.' (...) I've witnessed awful remarks by doctors, racist things... Normally that would make them even weaker, but now they know: 'You are a kind of witness, you are here, and you will do something about it'. (CHW)*

When patients don't have a residence permit or suffer other legal problems, anonymity and protection of privacy can also become increasingly important. Building trust can be challenging in these cases. CHWs mentioned they often need to share some of their own experiences and stories, to create an atmosphere of mutual openness and trust.

The interplay between the aspects of time and trust yields the CHW's intermediary function as a bridge between patient and caregiver. This mediator function works in both ways. CHWs help getting the message across from the caregiver to the patient, but can also clarify cultural sensitivities, necessary nuances or extra questions on behalf of the patient.

*The doctor started to act condescending, saying what I should and shouldn't do. X (*name CHW*) sat there and listened, when I exploded like a bomb. He just let me be angry and said: 'the doctor has your best interests at heart, try to understand'. Then he explained it from the doctor's point of view. (...) 'I hadn't looked at it like that yet', I said. He knows how to calm me down.(patient)*

This mediator function allows CHWs to use a broad cross-service knowledge that is experience-based or shared by the network of CHWs. It also allows CHWs to perform many practical tasks, such as managing appointments or transport and alleviating language barriers.

***Contextual Factors that support the Program Mechanisms***

Different essential elements related to informality facilitated the process. Patients and CHWs sharing the same background, as well as specific CHW attitudes (openness, patience, non-judging,...) are important conditions to create trust. The personal voluntary aspect serves spontaneity and a free interpretation of tasks for the CHW, as it supports the volunteer to authentically "just be himself" and deliver the demanded time and flexibility. Volunteers were allowed a relative amount of personal freedom in filling in the details of their CHW role. CHWs differed in ideas on responsibilities and boundaries, and hence also in performance and concrete actions. This loose interpretation requires a considerable amount of trust and support by the coordinator and a willingness of all actors to work with an unfixed and dynamic concept.

*I was sent to her (*a patient*) with a very vague request from the caregiver. I didn't know where it would lead. (...) I just let her talk for a long time, and in the end, she said she mainly needed some company. (...) Sometimes it's frustrating for some CHWs who are very 'function oriented' and think: 'What do I have to do here?'. As a CHW, sometimes you have to accept there won't always be a result, and you just have to listen. You don't always have to go with somebody from A to B, with a solution. Because sometimes there is no solution, and that's OK. (CHW)*

Due to the vulnerabilities of the target groups (limited network, financial or language barriers, motivational issues,...), the project demands some trust from caregivers towards the CHWs. Trusting the CHW is easier for caregivers (and patients) who are used to a multidisciplinary approach.

***Contextual Factors that inhibit the Program Mechanisms***

Other aspects of informality came up in interviews as inhibiting factors. Being a pilot project, working with a limited number of volunteers raises issues of capacity and continuity. Some respondents mentioned the delay between request and assignment as a reason not to call on the CHW. Informality also generated unclarity at all levels. Unclarity about the CHWs role and limitations was sometimes reported as challenging for both caregivers and patients as well as for CHWs themselves. Being unacquainted with the CHWs -as a person- makes some caregivers hesitate to make use of the project.

*We didn't know their professional experience. It's important for us to know who they are: 'Will they get along with that particular patient?' (...) Especially for patients that lack some trust and don't make it to referrals... When I had to say them 'Someone will come but I don't know who, but they will call and then meet with you'... People didn't approve. (family doctor)*

At the level of caregivers there were two additional inhibitory factors. Caregivers told they often forget about the project, as it is hard to remember all different sorts of ongoing projects and think about it mid-consultation. Some caregivers declared they don't request the CHW's help because they feel as if they would be taking over a patient's autonomy and self-reliance.

**Discussion**

Like the initial program theory proclaimed, the project made health services more accessible. CHWs helped patients to make and keep appointments. This generated more efficiency and better tuning between services. Eventually, this could create an increase of patient satisfaction and continuity, as it is known that no-shows cause disruptions in care and frustration with patient and provider (1,9–12).

Some caregivers had concerns about limiting patients' self-reliance and autonomy. However, one could argue that practical assistance or company is not hindering but stimulating self-growth of vulnerable patients. It could be a means to facilitate future decisions or actions, when otherwise these would be hampered by the demanding struggle with challenging circumstances (10,17). There's a thin line between empowering and taking over. When this balance is respected, making time and accompanying a person can mean a valuable recognition of the person's vulnerability whilst respecting the complexity in all dimensions of their multiple narratives, rather than a sole reduction of this person to his vulnerability (18,19).

Trust could indirectly benefit accessible care because of CHWs' intermediary position (18). Patients' trust in CHWs could radiate to healthcare services by virtue of the connection between healthcare service and CHW (10,18,20).

Offering the assistance of a CHW to a patient, demands a minimum base of trust between caregiver and patient. Further, CHWs try to develop a real connection when patients experience fear or suspicion towards services. This indicates the issue is often more delicate than 'trust or mistrust' (18). It's about a (cultural or social) gap and incomprehension

between patient and caregiver, that's left unbridged primarily because of caregivers' time constraints (21).

Frequently, CHWs and patients share a similar background, which benefits mutual recognition and can aid communication in case of cultural or language barriers (10,18,20,22). However, these issues of interpreting and cultural sensitivity did not play a central role in the mechanisms behind this project. Again and again the sentiment emerged that it is -above all- a matter of time and empathy. So beside sharing very specific qualities, it's paramount to explicitly share a very common one: a sense of humanity (18,23). These findings reveal a delicate known flaw in our healthcare system: a scarcity of compassion, often due to lack of time and an increasing workload (23). CHWs bring real contact back into care. Our findings confirm that patient-provider cultural concordance is not necessarily associated with compassion (23,24). Even when cultural differences were acknowledged as barriers, these can nonetheless be mitigated by compassionate care by a caregiver genuinely seeking to understand these differences (23,24).

CHWs' attitudes draw upon two known facilitators of compassionate care: personal values/beliefs and personal experiences of suffering. These enable them to relate to patient's suffering and to understand the impact compassion has in relieving it (18,23,25).

This genuine sense of shared humanity surfaces smoothly in an informal context. It doesn't really matter how or where exactly CHW and patient meet. The only crucial thing is that the CHW can feel at ease to be himself/herself.

To create this authentic informality, CHWs must have some personal freedom in their tasks and limitations. This interpretation differs between volunteers, depending on experience, background and personal characteristics. To aptly match every demand with a

corresponding CHW, a large pool of volunteers will be necessary.

Different personal interpretations also create unclarity about their role and tasks. The associated uncertainty was unpleasant for some caregivers. On the other hand, it could also be a strength not everything is completely fixed in advance. It can allow the CHW to grow during this dynamic project, as this can establish a creative personalized approach (7). To cultivate caregivers' trust towards CHWs and to help caregivers remember about the project, caregivers have to know them or at least be able to put a human face on the CHW. This underscores the importance of real face-to-face contact engaging all levels of this project.

Informality is also related to a clear distance from the official healthcare system. 'Not being part of the system' can also foster trust by a feeling of safety (12,18). To preserve this *unofficial* position, CHWs best remain volunteers as such. Being clear to patients about their volunteering status, CHWs can also set proper expectations of their role and commitment. Working with volunteers means a relatively quick turnover in workforce, which could impact continuity and calls for continuous or repeated training of CHWs.

**Recommendations for future Programs**

Being a pilot project, the CHW-project operated mainly by caregivers' requests. Ultimately, it's meant to evolve towards a proactive approach. CHWs will have to become a known and trusted figure in their community, so they can guide people to services preventively. In the future, CHWs could try to activate or finetune behavioural pathways of a social network (support, influence, engagement, access to resources) (7,26). There are harmful associations with social networks for socioeconomically disadvantaged subgroups related to social exclusion, inequality and *network homophily* (26–29). To mitigate these associations, CHWs

will have to foster ‘a balanced presence of bonding, bridging and linking social capital’ (7,26–28). Achieving this balance requires a degree of formality, a necessary minimum of coordination and connection with ‘the official system’, and proper selection and training of CHWs.

The CHW-intervention should be designed as an enrichment of, rather than a substitute for, responsibilities of the regular healthcare system. It cannot act as a ‘band-aid solution’ that averts attention away from the need for system-level adjustments to enhance care-coordination (11,30). With their external perspective, CHWs could play a significant role in signalling structural deficits in healthcare accessibility. This signalling function should be further explored in future projects.

In Ghent, a multitude of parallel navigation projects exists. The development of a central point of entry or a single umbrella term could further embed the CHW in the future local healthcare system, and raise familiarity in a complex landscape.

**Project Limitations and Challenges**

Time and manpower remain delicate issues, as the project was very short in time and started off with some delay. Continuity with (a limited number of) volunteers is a challenge, as we discussed.

A relative unfamiliarity to caregivers -inherent to a pilot project- caused a slow start in submitted requests.

The project-based nature generated uncertainty about the future for CHWs and the coordinator.

## Limitations

Although the sample size was limited, this study displayed mechanisms and conditions relevant for future projects in similar settings. Being a realist evaluation, it does not preclude other potential explanations, so our understanding remains partial and provisional. By focusing on specific circumstances, realist evaluations are not interested in (and indeed, not useful for) black-or-white or universal predictions. To improve our understanding of the mechanisms presented, a mixed methods approach would be suitable.

## Conclusion

Implementing CHWs as patient navigators provided support to patients and enabled more efficient care. Main mechanisms leading to these outcomes were identified as trust and a sense of empathy, bringing humanity back into care. Informality in all its facets played a facilitating role as it made room for spontaneity and free task interpretation, but was also related to inhibiting factors like role unclarity. This project shows a promising role for CHWs in improving accessibility of future healthcare.

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Box 1 :

**Box 1: tasks of CHWs**

18 CHWs were recruited from the target populations and received a short training of 4 weeks. During the project, they were supported by a coordinator and took part on monthly intervision sessions. Social and healthcare workers could ask a CHW to help a patient navigate the system, using an online platform, connecting with the coordinator.

CHWs were not expected to take over tasks from healthcare professionals. Deployment of a CHW was meant to be supportive and additional.

Tasks of a CHW included:

- accompanying patients to social and healthcare services
- helping patients bridging hospitalization and discharge
- administration: assisting in arranging insurance, making appointments, creating clarity in the healthcare landscape
- reminding patients to appointments
- interpreting
- assessing patients' comprehension of received information
- escorting and comforting patients, providing a framework and continuity
- signalling structural problems regarding healthcare accessibility

Figure 1:

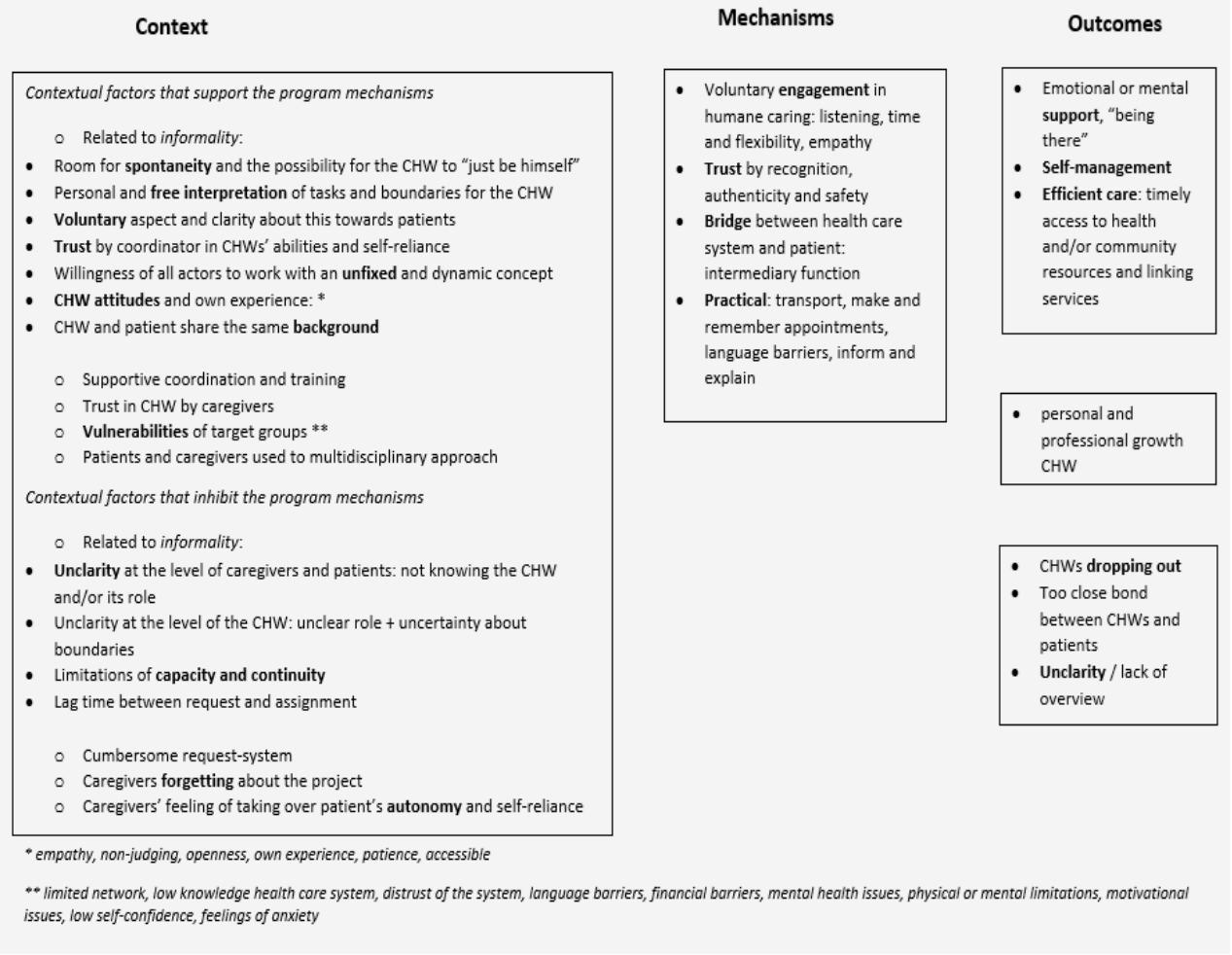



**Figure 1.** The program mechanisms in the CHW-project and the contextual factors that enhance and counteract these mechanisms. Program mechanisms explain how a program works and how the outcomes are produced.

Appendix 1:

**TOPIC LIST INTERVIEWS**

**In-depth interview: Community Health Workers**

| *Topic* | *Examples* |
|---|---|
| **General** | What does this project mean to you? What was your role in the project? |
| **Trust and connection** | How does it work? How is it organized? |
| | For whom and when does it work? Can you give an example? |
| | What does it imply? What are the effects? |
| **Accessibility of care** | How was this achieved? |
| | Was this always achieved and if not, why and when? Can you give an example? |
| **Role and boundaries** | Was it clear for you? When was it less clear? |
| | Were there difficult moments personally? Can you give an example? |
| **Other outcomes** | What makes a succeeded intervention, for you? Can you give an example? |
| | Can you give an example of an intervention that did not succeed? Why was that? |

**In-depth interview: Health professionals**

| *Topic* | *Examples* |
|---|---|
| **General** | What does this project mean to you? What was your role in the project? |
| **Accessibility of care** | Was this achieved and how? |
| | Was this always achieved for everybody and if not, why and when? Can you give an example? |
| **Trust and connection** | How does it work? |
| | For whom and in which situation does this work? When does it not? |
| | Does it have other or unexpected effects? Can you give an example? |
| **Implementation** | How was it organized? |
| | Which organizational aspects impacted the functioning of the project and how? |
| | Were there barriers for you to make use of the project? Can you give an example? |
| | If you could change anything about the project, what would it be? |

**In-depth interview: patient**

| *Topic* | *Examples* |
|---|---|
| **General** | What were your experiences with the project? |
| | What does it mean for you? Can you give an example? |
| **Accessibility of care** | What were the consequences of the project for you? |
| | How come it worked or didn't work with you? |
| **Trust and connection** | How and why did it work? |
| | How did the project make you feel? |

| | |
|---|---|
| | What consequences does this have? Can you give an example? |
| **Shared background** | How does it influence trust? Can you give an example? |
| | What else influences trust? |
| | What does it imply? |

**In-depth interview: Coordinator**

| ***Topic*** | ***Examples*** |
|---|---|
| **General** | What were your role and experiences with project? |
| **Accessibility of care** | How and why does it work? |
| | Were there times it didn't work and if not, why? Can you give an example? |
| | Were there other or unexpected effects of the project? |
| | What makes a succeeded intervention? Can you give an example of an intervention that didn't succeed? |
| **Trust and connection** | How is this created? |
| | Is this the same for every intervention or are there differences? Can you give an example? |
| | What does this mean? Does it have other effects? |
| **Implementation** | How was this organized? |
| | Were there organisational difficulties? Can you give an example? |
| **Role and boundaries** | Was it clear for you? When was it less clear? |