

Integration of non-communicable chronic diseases (NCDs) and HIV/AIDS and mental health care through the involvement of chronically ill patients using empowerment evaluation

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Background: The emphasis in health care in South Africa is gradually shifting to acknowledge the different roles patients have regarding their own care. There is, however, very little evidence of this practice and of related practical outcomes.

Methods: In the North West province, empowerment evaluation was used as the vehicle for patient engagement in integrating and improving services for chronically ill patients, namely those with non-communicable diseases (NCDs), HIV and mental illnesses at primary health care (PHC) clinics. This research was designed as an additional intervention in an ongoing quality improvement (QI) cycle, which had started in 2007. Empowerment evaluation shares many participatory action research qualities with an emphasis on collaboration, emancipation and the creation of new knowledge but with the additional aspect of evaluating and monitoring the processes that have been co-developed.

Results: After 62 visits to 9 facilities over a year and after capturing 332 patient and health worker opinions and ideas, many interventions were implemented leading to improved flow at clinics, a heightened awareness of good services, interesting performance-measuring tools and patient/staff teams that acknowledged their symbiotic strength. Objective measurements comparing clinics that had been exposed to the Integrated Chronic Disease Model (ICDM, which is explained in the article) and those with the collaborative patient/staff groups showed no significant difference in clinical outcomes or waiting times. However, waiting time had improved across one sub-district. This may be because the ICDM clinics have been functioning for four years and the research clinics for only one year. There have also been many external influences on the project, such as a number of new doctors appointed at clinics, under the National Health Insurance pilot project, a high turnover of staff, a new chronic drug policy, stable patients being able to access their medication at external 'pick-up points' and others.

Conclusions: It was found that the potential of patients and patient–staff collaboration are being under-utilised in a resource-strained sector where the harnessing of this potential might contribute positively towards QI in health.

Keywords: chronic illness, empowerment evaluation, health systems improvement, patient involvement

Introduction

In a global move towards patient centredness and a focus on the recipients of services, there is much discussion on both the value of this client participative paradigm in terms of patient outcomes^{1,2} and the use of different research methods to evaluate it.^{3–6} Publications have shown improved patient outcomes relating to many medical conditions including chronic illness where there has been some measure of engagement of patients.^{7–10} Most of the patient involvement, however, has been at a superficial level where perceptions or measures of satisfaction alone have been used.^{11–14} There has been some exploration of the more authentic customer or client involvement in health systems, for example where patients have developed partnerships^{15–17} or collaborated closely with professionals on health matters like the design of a cancer hospital,¹⁸ the improvement of meals to the elderly,¹⁹ patient-led newspapers and brochures,^{20,21} and a mental health service focused completely on the needs of the recipients.²² These all led to unexpected outcomes that had not been foreseen by professionals and added value to patient experience.

A systematic review including only qualitative studies²³ indicated that the barriers to patient engagement in systems improvement were health staff hierarchies, different perceptions of their roles by patients and providers, and an apparent political and managerial will but an inability to put this into practice. The

enablers were that where there was ongoing support and mentoring this approach worked very well. In the papers analysed, there were many opportunities for patient involvement at different levels of complexity and unexpected innovation often occurred when patients were part of the improvement process.

South Africa is attempting through National Core Standards²⁴ and PHC Reengineering²⁵ to include patients more in their own care. However, this is still in its infancy and very little enquiry has been made regarding the influence of policy on practice. The key interventions of PHC Re-engineering are the establishment of community health worker (CHW) teams that support health at household level, district-based specialist medical teams concentrating on mother and child health, and strengthening of school health. A great deal of political pressure is being exerted to have this initiative fully implemented as soon as possible. In the same period in which the above was started, the Chronic Illness Directorate at the National Department of Health chose the research district being studied in this paper as one of three districts²⁶ in South Africa to brainstorm ideas regarding the integration of services to patients with combinations of NCDs and HIV as well as mental illness. The serendipity of these important movements dovetailing was an opportunity to explore different patient-empowering methods being used globally to maximise patient, family and community involvement.

Fetterman²⁷ developed empowerment evaluation as a method of client engagement 'to foster improvement and self-determination' (p. 89).²⁷ He drew on diverse influences ... to craft a vision of the evaluator as an agent of social change' (p. 273).²⁸ The intention was to offer disempowered clients control by involving them in decision and monitoring processes where they would previously have been excluded. This method has in particular been used in many situations to encourage reflection and awareness of the importance of evidence within client-provider collaborations.^{28–32} Thus, in an empowerment evaluation model, the relationship between the evaluator and the evaluation consumers, or the recipients of the service, is characterised as a collaborative partnership. The methodology shares the emancipatory paradigm of Participatory Action Research (PAR) but has a structured approach including a strong assessment component. It was designed with marginalised people in mind and a few key characteristics are that these clients are involved in the initial problem identification, the measurement thereof and the ongoing QI process. The detail of this approach will be discussed in the methods section.

The context for this research project is a district in the North West province, in the public sector. This district includes 5 hospitals and 39 fixed clinics (inclusive of 9 health centres). Chronic illness (including HIV and mental health) is the most common reason for patients to present at a clinic. These patients are therefore the focus of the research.

Aim

The aim of this research was to assess the value of patients with chronic illnesses taking control of their own health care in a QI on the integration of non-communicable chronic illnesses (NCDs) and chronic communicable diseases in the DKK district, through empowerment evaluation as a qualitative intervention.

Objectives of the empowerment evaluation research:

- (1) to describe the processes of the QI where patients and staff are co-workers;
- (2) to describe both patient empowerment and clinical outcomes;
- (3) to measure the general integration process at the involved sites through waiting time surveys, patient satisfaction, file audits, and patient flow;
- (4) to compare the current traditional QI with the empowerment model as intervention.

Methods

Study design

Empowerment evaluation was used in communities of stable chronically ill patients in a district in the North West province.

Site of study

The research district initiated a QI regarding non-communicable diseases (NCDs), e.g. diabetes mellitus, asthma, epilepsy and hypertension in 2007 due to poor outcomes for NCDs in the district.³³ Part of the QI was to investigate the possibility of integrating care for all chronic patients, including HIV, mental illness and NCDs, as these had been managed separately, which led to many different service points and duplicated systems for one patient with compound chronic conditions. The National Department of Health (NDOH) subsequently chose this district as a pilot site in the investigation into the integration of chronic care services (ICDM). The process from the National Department was a pre-planned situational analysis for each of the nine pilot

clinics in the district, a patient satisfaction tool, a tool to audit chronic NCD files and a waiting-time survey. These steps were completed and analysed. Solutions were subsequently suggested, implemented and monitored by the department. In this process, there was no patient involvement at all and little allowance for staff inputs or innovation.

Nine other clinics in the district were selected by the researcher by convenience sampling to include clinics in each sub-district, to participate in the empowerment evaluation. The clinic staff were requested to identify active chronic patients who would be willing to be part of a patient/staff group as well as appropriate staff members.

Study population

The study population was patients with chronic illnesses in the district being managed at primary care level and this included both NCDs as in diabetes and asthma and communicable illnesses, e.g. HIV/AIDS as well as stable mentally ill patients. Staff, including the CHW teams working in these clinics, were also part of the research population.

Sampling

At each of the clinics, through the clinic staff, a cohort of patients was approached to form a team, with the researcher as 'coach'. The team was generally a manageable size ranging from 5 to 12 people.

Inclusion criteria were that patients were able to communicate in English or Afrikaans, have a stable chronic illness, i.e. a patient with hypertension, diabetes, epilepsy or HIV, accessing chronic services from the particular study clinic, a mentally ill patient able to communicate well; a staff member working with chronically ill patients at the study clinic, any members of the PHC Re-engineering outreach teams, namely team leaders (nurses) and community health workers (CHWs) attached to that clinic.

Exclusion criteria comprised unstable or very ill chronic patients.

Data collection

Data were gathered at the outset to establish the importance of measurement. Quantitative indicators from the 9 clinics were assessed by doing file audits and waiting times before embarking on the research, and this was repeated 12 months later. The occasional waiting times and patient satisfaction surveys collected by the clinics as part of routine data were also included where possible for the year of study. Audio and video recordings of the group meetings were supplemented by minutes of each meeting, physical artefacts³⁴ such as photos and the material that was created by the groups, e.g. posters, letters and registers.

Empowerment research, which is discussed below, was an intervention inserted into the already existing chronic illness QI (see Figure 1).

Empowerment research

This includes developing an open and trusting relationship with the collaborators (patients and staff) beginning with the first step of *taking stock* (understanding the situation from the patients' perspectives). Here the most important clinical activities perceived at each clinic were identified, prioritised and scored by each participant, using a 1–10 scale. A matrix was created and reflection on the scores was done as part of the empowerment exercise in creating a baseline measurement.

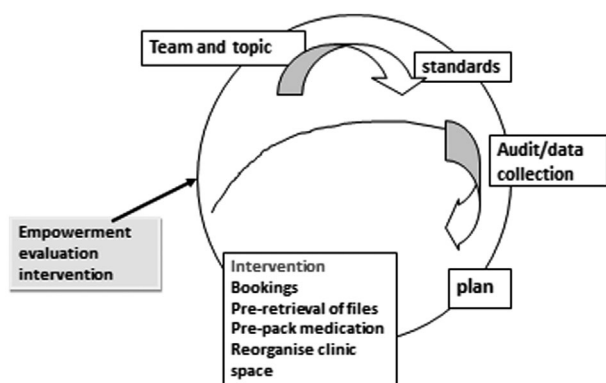


Figure 1: Empowerment evaluation project as intervention in the chronic illness QI in DKK district.

Step 2 is asking the question as to where you are and where you want to end up. This is also seen as the *vision* of the group. This was co-created at each of the nine facilities by the group at the first meeting. From this vision, action plans and *strategies* need to be encouraged and developed. Clear goals need to be documented. This is a cyclical process and re-interpretation and reflection needs to be done. All the above occurred and were documented and used as feedback at the meetings.

An important element is the ongoing collaborative creation of *an assessment to document progress*. This was encouraged from the second visit at each clinic and was discussed at each subsequent meeting, with assessment suggestions being implemented and discussed in an ongoing way. Innovations were shared amongst all the involved clinics.

Ethics

Ethical clearance was sought from the University of the Witwatersrand as well as from the relevant managers and the provincial research committee. Each participant was requested to sign a letter of consent, having been informed that there would be no identifying characteristics indicated in the research or in the feedback to any other QI task team. It was made clear that there would be no repercussions on clinical care should participants refuse to be part of the research or wish to withdraw at any time. Regular reports were given to the various managers as well as to the appropriate QI groups concerning the development of the project. All copies of video or audiotapes were secured and will be kept for five years after the research has been completed.

Limitations

Patients were expected to find it intimidating to talk freely about reasons for the problems they encounter. Language limited the most vulnerable from being included. Even when people are quite articulate in a second language, the depth of narrative might have been compromised if not expressed in the first language.

The research methodology is time consuming, relying heavily on the facilitation of processes with as little researcher influence as possible. The perceived power relationship between patients and researcher was recognised as a possible liability. Patients within the system might have been hesitant to criticise the health processes on which they were dependent. Practical difficulties had been foreseen, such as the lack of continuity of patients and unforeseen changes in staff rotations and

availability, external influences such as the unpredictability of donors, the lack of resources and financial instability in the province.

Results

Nine clinics were involved in the research to match the nine clinics that had been part of the ICDM pilot study referred to earlier. They were purposively selected by a convenience sample from the four sub-districts. Six meetings were held at each clinic with a number of smaller follow-up visits for action. In total 62 visits were done over the year.

This research was exploring empowerment of patients but was also curious about quantitative outcomes. The quantitative data will not be reported on in detail in this paper but will be mentioned briefly. A total of 3 065 files were audited and the chronic form in each file used as the basis of the audit tool. Clinical measures such as blood pressure, blood sugar, viral load and CD4 count were the indicators assessed. Waiting time and patient satisfaction data were also compared between 2014 and 2015 to try and gauge any influence the QI intervention may have had, comparing the ICDM pilot clinics and the research clinics. There was no significant difference between the improvement of clinical indicators at the ICDM pilot clinics and the research clinics. Waiting times had improved considerably in one sub-district across all the clinics, but had remained stable at all the other clinics with no differences between ICDM pilot clinics and research clinics.

Empowerment evaluation process: Vision and taking stock

Over a period of a year, 331 people contributed towards the ideas and solutions of the improvement project; 179 were patients, 72 were staff and 80 community health workers.

When taking stock or creating a baseline for the study, according to Fetterman,²⁷ 'One tool used to minimize the time associated with prioritizing activities involves voting with dots. The empowerment evaluator gives each participant five dot stickers and asks the participants to place them by the activity on which the participant wants to focus. The participant can distribute them across five different activities or place all five on one activity. Counting the dots easily identifies the top 10 activities.'

When taking stock of the services at the clinic all the participants prioritised and discussed chronic care as one of the important services, using blue stickers to develop the matrix (see Figure 2 as example from one of the clinics). Each participant was given five stickers that they could distribute amongst the services on the list, according to the importance the particular service held for them. Once the four most important services had been identified for each group, each participant would choose a score out of 10 for each of the 4 services, which would indicate their perception of its value and excellence for them, and write it down privately in order not to be influenced by others. These scores were then shared and filled in anonymously on the poster. Five facilities scored their experience of chronic care on average at more than 8 out of 10. Four facilities scored their experience of care as chronic patients between 7 and 8. The clinic perceived by health care workers to be providing excellent clinical care with dedicated attention to detail scored the lowest from patients' perspectives.

At the final visit each group was requested to repeat the matrix exercise based on the original vision which had been co-created at that facility. This will be discussed more fully at the final step of the process.

services	1	2	3	4	5	6	7	total
Papsmear and HPV (cancer prevention)	6	5	6	5	3	9	4	38/70 54.2%
Preventative services eg flu vaccine								
Tuberculosis	8	10	8	1	1	1	2	31/70 44.2%
Antenatal care	7	9	5	4	4	1	5	35/70 50%
Chronic care	9	6	7	10	8	9	8	57/70 81%
Family Planning								
Dietician								
Social worker								
psychologist								
Emergencies								
Laboratory								
Child care								

Figure 2: Example of a matrix done at one of the facilities with the blue dots indicating the priorities of the group and the totals of the four priorities indicating the satisfaction with the four most relevant services to the group.

Vision

The vision that was co-created at the first visit at all the clinics was remarkably similar with the most common needs of patients being a short waiting time, professional and friendly staff, and available and correct medication. There were different focuses at some facilities. Unfairness was a significant discourse at one clinic: 'We get up early ... others walk straight in and get their pills — they have been arranged and they go. But I come and sit for the whole day.... There will be a squealing.... And we want to avoid that...!' People felt the unfairness as well regarding their access to the doctor: 'We are blocked to see him...!' Another major issue raised at a neighbouring clinic was the dirtiness of the surroundings. This was affecting the creation of a food garden and staff's willingness to be involved in a support-group initiative. The grounds person was not taking responsibility and was in the process of being disciplined. Cleanliness was also mentioned at another clinic where it seemed to be a favourite theme; plastic toilet seats versus other kinds were debated at length as well as the presence of dirty, broken urine glasses and the toilet being used to store the spades and rakes for the garden. It was also accepted by all the patients that toilet paper could not be left in the toilets because it would be used to 'roll zolls [cigarettes]'. The reception became the central place for people from which to fetch toilet paper and hand towels.

A very positive theme at one clinic was the presence of a strong chronic support group who cleaned the clinic surroundings weekly, maintained a vegetable garden, and started an exercise group and a knitting project. The irony at this clinic was that as the group became more articulate about reasons for patient waiting times (for example tardy staff), the more they were victimised by young staff members: 'I have a problem when I check latecomers ... have a problem when I check latec ... they are even insulting me ... young people. Being insulted by kids — I am not working for X clinic — they are working for X clinic.'

Another clinic had 'staff attitudes' presented as a reason for patients to default on their planned visit dates. This led to a snowball effect of clerks not pre-retrieving files because patients did not arrive on correct dates. When discussing this, a nurse said 'but now we are all victims because the community is not specifying who and what...'. Patients were allegedly too scared

to complain but passively aggressively came on wrong days. Non-adherence to booked dates was the main discourse at another facility as well. Here many reasons were given by patients, e.g. social reasons like funerals out of town, babysitting and forgetting. So, although waiting time was a recurrent theme, issues emerged that were particular to and impacting on different clinics.

All the groups agreed to their vision being displayed in their clinic and assisted in translating it into local languages. Patients were involved in doing the translation at four clinics and CHWs or health promoters at the others. See Figure 3 as an example of a chronic vision poster.

Setting objectives and generating problem statements and initial solutions

This happened over three or more meetings at each facility. Each group discussed in detail possible solutions and options based on the vision that had been created. The assessment of progress, which will be discussed in more detail later and is integral to empowerment evaluation, was part of every discussion and was seen as innovation, as were a number of measurement options that were suggested and tested. Table 1 summarises in particular the innovations at each facility that emerged from the collaborative groups as well as the measuring tools or assessment options that emerged.

Commonalities that needed to be attended to at most of the clinics were waiting time, queue marshals, pre-retrieving of files on the previous day, medication being delivered at home, improved attitudes of staff, separation of chronic services, a daily doctor and support groups.

The chronic vision for XXXXX CHC

This health centre will provide quality care to chronically ill patients by

- Having a short waiting time 
- Complete, available medication 
- Separate chronic services 
- Good communication 
- Professional friendly staff and a regular doctor 
- Strictly follow the queue (excluding disabled, frail and emergency patients) 
- Patients must honour their appointments 
- Health education 
- Availability of other services eg Psychologist, dietician, (refer XX town)
- Booked patients only to:

eye nurse:	Ca SPC
social worker	Ca SPC
dentist	Ca SPC

Figure 3: The English translation of one facility's vision.

Table 1: Innovations and measurements

Clinic	Innovation	Transferred (Y/N)	Measurement
1	Queue Marshal apron/sash Fast queue poster Start support group and food garden	All clinics	
2	Vision poster with allied health workers annual contact dates inserted Numbers for acute patients to avoid unfairness Boxes for chronic files to be booked at the end of the day	Yes one other clinic One other clinic	Non-adherence to appointment survey; Questionnaire to defaulters of the day Red, yellow and green dots for satisfaction
3	Poster with tips to remind patients of their dates Poster — don't do vitals on AA patients Time-slot appointments as opposed to just a date Chairs facing different directions for different groups	Yes x 2 One One	Booking book —numbers coming on right day
4	CHW forms for AA to be taken to patients Team building for all staff Fast queue box for files at the front Time appointments Visual waiting-time data Start support group and exercises Start food garden	One	
5	Soup cooking for chronic patients/biokinetic exercises/ cleaning clinic/surrounds/knitting/flu injections Whiteboard info on the programme for the day Equipment taken home, e.g. glucometers for diabetics	One Two	Tried patient-initiated waiting time (in and out cards with times)
6	'War rooms' for reproductive health to lessen pressure on clinic Glucometers at home Identification of working patients with blue stickers on patient books Pill poster re new national drug changes Using permanent markers in different colours on seats to identify the different queues Hand paper at reception instead of towels in bathrooms	One One All	Doctors' number of unbooked patients analysed to see whether the doctor is assisting the chronic programme 'Asking patients what they think of the service' by patients and CHWs
7	CHWs doing vitals and pre retrieving files and drugs Employed patients having a specific time or day	Two	Measure the number of patients when the clinic was finished and see if this improves Also hear if people know about the dates of allied staff
8	Complaints against staff anonymously dropped into complaints box Queue marshal having a daily set welcome		Booking book for adhering to date Complaints minutes to identify if decreasing
9	Support groups devolved to wards		

In total, 37 different interventions were suggested by the collaborative groups and 23 were implemented. A number of the 23 interventions were duplicated at all 9 clinics such as the queue marshals and the pill posters. Where unusual or different thoughts emerged, ongoing sharing between groups was practised but it was relatively seldom that an idea was accepted by all. The queue marshal as an oral source of information was generally preferred to written notices, posters or boards. To this end aprons and sashes were made to identify the queue marshal (Figure 4). Different role players were identified to take on this task, e.g. a clinic committee member at four clinics and a patient at one clinic; the others were counsellors, health promoters and a peer educator. A further refinement of this role was made at a health

centre where the group crafted a daily speech including information regarding nurse availability, the complaints procedure and a hearty welcome, as well as a signposting function.

Other innovations that were co-developed and shared were a poster with practical tips on how to remember your follow-up clinic date, a poster with photos of boxes and pills explaining the changes happening nationally with changed tenders and different pills (causing a great deal of unhappiness amongst patients). Three new support groups were started as the importance of patient interaction was acknowledged. A few suggestions were not attempted, e.g. staff team building and pictorial data for illiterate patients.



Figure 4: Queue marshal (patient) with identifying apron.

External unexpected outcomes, which were direct results of the patient advocacy within the chronic groups, were the renovation of an almost impassable clinic access road, seeds and agricultural expertise being made available for gardens at four clinics, and a park home that was erected to extend the space of a small facility — but with no electricity or water — eventually being connected to these amenities. The local university also became involved with biokinetic exercises for two support groups, 50 glucometers were donated to patients who belonged to support groups and some support group activities were devolved to ‘war rooms’ (shared venues at local wards) where patients could be involved without having to move great distances.

Simultaneous changes that were happening and which impacted on the project, were the chronic medication National Health Insurance (NHI) project, i.e. making drugs available at so-called ‘pick-up points’, a number of new doctors being appointed under the NHI grant and training for the CHWs on chronic care.

Iterative feedback

A formal feedback session was held at all the clinics to give feedback to staff. The responses were generally neutral or positive. At each of the six visits, feedback was given to the collaborative group regarding objectives that had been reached.

The overall flow of patients, based on Lean principles,^{35–37} which had been prescribed for the initial ICDM pilot clinics by the NDOH, had to a large extent unknowingly been replicated by patient and staff involvement in the research clinics. The vision was displayed in eight of nine clinics, queue marshals were identified at all clinics to help with the flow, and files were pre-

retrieved at five of the nine sites. CHWs were being utilised at most clinics to prepack medication while patients awaited the consultation or CHWs were being incorporated to take medication to homes. All clinics had separated their chronic patients’ space in different ways, for instance by blue stickers on a few rows of chairs for chronic patients, by positioning chairs in different directions, by laminated words stuck to chairs or by indelible ink in different colours on chairs. All chronic patient rooms were clearly demarcated and in six clinics there were designated screening areas for chronic patients. This organisational flow took a lot of perseverance to implement because stickers were removed from chairs and posters thrown away by cleaners and then the staff would simply say it did not work. The booking book was eventually functioning in all clinics but none managed to identify the attendance of patients on their correct appointment days.

Measurement

From the first meeting the concept of ongoing evaluation of a system’s improvement was discussed. Methods suggested and tried by different groups are summarised in Table 2. The most common suggestion was waiting-time surveys and patient satisfaction surveys, which are being done occasionally and superficially by facilities as part of the National Core Standards. On at least three of the five contact sessions at each group meeting, these routine data were shared with patients as an empowerment exercise. A suggestion from one facility was that a pictorial version of data should be created for the illiterate.

Other measurement attempts were a red, yellow and green sticker opinion sheet offered to patients in the waiting room, a short questionnaire for latecomers to elicit their reasons for non-adherence to dates, and measuring the numbers of people seen by the closing time on a daily basis and averaging it, to monitor non-adherent appointments by analysing the booking book and by getting qualitative feedback from patients.

The final measurement based on the objectives identified at each clinic at the first visit and displayed as the ‘chronic vision’ was done at the last visit, using the matrix. This time each point (i.e. objective) of the vision was scored out of 10 by each participant. An additional point was added asking what each person thought the contribution from the collaborative group had been to improve services at their clinic (See Table 3).

In this case, points 1 to 15 were items from the original vision that the group from this particular clinic had wanted to be implemented or improved. There was still dissatisfaction with waiting time and the availability of some allied services. Point 16 was added to assess on which scale participants perceived their involvement to have assisted in improvements. It is clear that all of these participants felt that their contributions had improved chronic services at their clinic. At this clinic all those who participated in this final exercise were patients. Generally, all the other eight facilities scored their own impact extremely positively. Waiting time, medication availability and support by allied health workers were the common problems still identified at all the clinics, with problems regarding filing or insufficient equipment being noted at a few others. Satisfaction with staff was rated low in only one clinic.

Discussion

The primary purpose of this research was to introduce the patient involvement factor into a process of integrating chronic care at clinics. In 2011 nine pilot clinics in the district had been

Table 2: Objectives related to the chronic vision implemented at each clinic

Clinic	Vision displayed	Chronic patients well separated	Queue marshal	Pre-retrieval of files	Daily doctor	Support group	Other
B	Yes	Yes — five areas	Yes	Yes	Yes	Yes	Road improved
LDS	Yes	Partly	Yes	No	Yes	No	Patient satisfaction stickers
Kh	Yes	Yes	Yes	No	Yes	No	Add chronic room
TC	Yes	Yes	Yes	Partly	Yes	Yes	Staff debriefing
L	Yes	Yes	Partly	Yes	Yes	Yes	Many activities and garden
P	No	Partly	Yes	Yes	Yes	Partly	War rooms Accessible medication
M	Yes	Yes	Yes	Yes	Yes	No	-
JBM	Yes	Yes	Yes	Yes	Yes	No	Complaints mechanism for staff attitudes
K	Yes	Partly	Yes	No	Yes	Yes	Park home water and electricity connected

involved, with the National Department of Health, in changing their systems to offer a more efficient service to patients by following certain Lean principles. These included pre-booking patients and ensuring that the expected patient load would be evenly spread across the week in order to plan staff availability on any given day. Files were also reorganised according to patients' date of birth for ease of extraction. It was intended that all the booked patients' files should be pre-retrieved the day before to prevent a bottleneck at the beginning of the day. The pre-packing of each booked patient's medication was also initially part of the pilot process. Each of the pilot clinics had to physically re-plan their patient flow for chronic patients, identifying a dedicated waiting space, a vital signs area and one or more consulting rooms specifically for chronic patients. This was to separate them from the very busy mother-and-child services and the large number of patients presenting with acute illnesses. All these interventions were intended to decrease the

unacceptably long waiting times for chronic patients. The intervention was called the Integration of Chronic Disease Management (ICDM) and involved all categories of chronically ill patients. The above plans were attempted with greater or lesser success at the nine pilot clinics, but there was no effort to involve staff in thinking creatively and no engagement with patients.

In Europe and the USA successful collaborations between staff and clients have been formed focusing on common areas of interest.^{16,38,39} The difference in these papers was that most of them were funded and their innovations were not limited by money or other resources. It was made clear in the current research to all the groups that there would be no money in the project unless local donors could be accessed. It was encouraging to see how most ideas could be implemented with few extra resources. At the outset of this research it was also not entirely clear who should be involved. The large number of patient

Table 3: An example of the final assessment of their vision/objectives by one clinic

Team Members	A	B	C	D	E	F	G	H	I	Total	Percentage (%)
Identified space for chronic patients	5	4	4	6	9	10	9	8	8	63	70.0
Waiting time	4	3	3	5	6	8	6	7	9	51	56.6
Communication	2	4	6	10	10	10	-	10	6	68	75.5
Patients supplied with own equipment	10	10	10	10	10	10	-	10	6	76	95.0
Support group/garden	10	10	10	10	10	10	10	8	10	88	97.7
Available medication	10	10	10	8	9	8	9	10	5	79	87.7
Staff – Professional, efficient	7	5	8	7	10	10	9	8	7	71	78.8
Equipment available at clinic	10	10	10	10	10	10	9	8	6	83	92.2
Dentist availability	0	0	0	0	0	0	0	0	5	5	5.5
Dietician availability	3	3	2	0	0	0	-	2	-	10	11.0
Psychologist availability	0	0	0	0	0	0	0	0	0	0	0
Daily doctor	10	10	10	0	10	9	9	7	-	65	81.2
Eye nurse	0	0	0	0	0	0	0	0	0	0	0
Cleanliness	10	10	10	10	8	10	10	10	10	88	97.7
Health education	10	10	10	10	10	10	10	10	10	90	100
Own contribution	10	10	20	10	10	10	10	10	10	100	112!

contributions as well as the proxy voices of the CHWs that were recorded and used indicate that it is possible to involve patients in PHC. The relevance of doing so and the actual positive outcomes are further areas of interest.

Empowerment evaluation

This method has been both acclaimed and criticised.^{40–43} The methodology encourages active participation in problem identification and collaborative solutions as in PAR but adds the challenge of alerting the groups to the importance of data and monitoring processes. In a review of the method,²⁸ Miller studied 47 case examples of empowerment evaluation and found that it depended on the researchers' approach as to whether the principles of empowerment evaluation were successfully adhered to or not. He identified 'Socratic,' structured guidance and participatory approaches, which will not be discussed at length here. The Socratic approach, however, showed evidence of adherence to 7 out of the 10 principles on average, whereas the other 2 approaches each yielded 4 out of 10. These principles⁴⁴ relate to community ownership, inclusion, democratic participation, community knowledge, evidence-based information and accountability, and outcomes that would be expected are improvement, changing organisational culture, fair allocation of resources (social justice) and capacity building regarding data use. In the current research, democratic participation, community knowledge, inclusion, improvement and capacity building were strong elements at all the facilities. The others were partly accommodated, i.e. evidence-based decisions were made based on Lean principles but these were not necessarily spelt out to the participants. Resource allocation is usually an external process, which was, however, in some cases influenced by group advocacy, for example, the case of the road being fixed and the park home being completed.

Relevance and added value

Patients and staff in collaboration discovered things that neither had known about. Information was shared concerning the drug policy on pick-up points for chronic clients, which encouraged a number of patients to ask to be registered. On the other hand staff gained honest opinions regarding how colleagues were speaking on cell phones during consultations or were ignoring patients' greetings. At one clinic the clinic committee member stood on the corner and monitored all latecomers, which led to internal problems with staff but these have subsequently been dealt with. A tardy groundsperson was disciplined and left the service. These are a mixture of practical and experiential outcomes.

Empowerment of clients is an outcome that is difficult to measure but where there has been much anecdotal evidence of value in a wide range of settings, e.g. cancer care, dermatology, women's groups, general practice and others.^{45–49} The final point in the matrix was an attempt to assess self-perceived involvement and the effect the collaborative groups had had, as a proxy for empowerment. The clinic with the strongest patient group, which has made a difference by its involvement in the support group, cleaning the surroundings, keeping the staff on their toes etc., scored its contribution as an average of 100%. The two clinics with the poorest continuity and patient involvement scored averages of 63.3% and 60%. This suggests that even though this may be a very subjective, experiential measure of empowerment and involvement there is some congruency with the reality.

There was innovation and energy, which kept the momentum for change going in all the groups. This was developmental and

collaborative, as one person would begin with a fairly rough idea that would be refined by others in the group. Thus the innovations emerged from the interactions between staff and patients. This supports what was found in a systematic review regarding patient engagement in QI, i.e. that where patients are involved, and with support and mentoring, unexpected solutions emerge.²³ It has also been found by a study that 'The[ir] empirical data revealed that the users produced more original ideas than the company's professional service developers' (p. 55).⁵⁰ The newly created and contextual knowledge is also known as 'emergent'⁵¹ knowledge, which not only empowers the group but more accurately addresses the real concerns and needs of patients.

The 'chronic vision' as unifying/measuring device

As the project developed, it became clear that the initial exercise of creating a vision at each point had also been a useful way of developing an objective, measurable thread including baseline objectives that could be measured at the end of the process. The vision was a visual reminder at each meeting of what the ideal situation would be for chronically ill patients at clinics. It also reflects quite closely a sophisticated principle being used in the UK to address quality improvement and safety issues, namely the 'Almost Always'⁵² principle whereby validated tools are used to construct and measure the things that matter most to patients in certain contexts. Waiting time and access, friendly staff and medication form a strong core to this approach, as did the 'chronic vision' in the research clinics.

Clarification of roles

It is evident that professional nurses cannot be involved directly in service change due to their high clinical workload. In all the groups, specific people emerged as champions and leaders. These ranged from categories of staff such as health promoters and counsellors in the clinics, to strong support from the PHC re-engineering teams as well as patients. This alerts one to the unseen potential within the health system. Non-professionals were generally very keen to assist and the willingness and openness to take on new challenges was inspiring.

Looking at the quantitative clinical outcomes, there were no significant differences between the ICDM pilot clinics and the research clinics. One could argue that the research clinics had implemented the ICDM process through patient-staff collaboration within one year with comparable results to the original ICDM pilot clinics, which had had ongoing National support from the inception of the pilot in 2011 and over a number of years to arrive at their outcomes. It has been found in QI research that indicators for objective change are very difficult to measure as these projects are usually complex.⁵³ In an insightful discussion on the importance of clinical outcomes in chronic patients and what determines these, Hershberger⁵⁴ says: 'Because so many variables beyond physician control (health system control) affect patient outcomes, relying solely on outcome data (or proxies for outcomes) to determine physician (health system) effectiveness may be both inaccurate and unjustified.' In contrast, Alexander⁵³ decries the lack of consistent data to bolster claims of success in QI, which leaves one with a dilemma.

Conclusion

The way in which current QI is practised in primary care in developing countries is not well documented; and, it is therefore difficult to know whether an inclusive approach is acknowledged and practised whereby the patient is an integral part of the

process. One of the dilemmas of QI research is the quantitative measurability of outcomes within a very complex cycle of change.

It was found in this study that the empowerment of collaborative patient–provider teams may not make a significant difference in quantifiable terms but in terms of innovative measures to improve the ‘experience’ of being a patient at the clinic and in change management there is evidence of innovation and improvement.

The enormous untapped potential of patients passively entering and leaving health facilities on a daily basis needs to be recognised as a resource. Using a structured method like empowerment evaluation, which has its roots in emancipation and self-development, is a potential practical intervention in any QI process in a PHC setting.

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References

- Greenfield S, Kaplan S, Ware JE. Expanding patient involvement in care. *Ann Intern Med.* 1985;102:520–8.
- Brody DS, Miller SM, Lerman CE, et al. Patient perception of involvement in medical care. *J Gen Int Med.* 1989;4:506–11.
- Greenhalgh T, Heath I. Measuring quality in the therapeutic relationship. Part 1: ‘Hard’ approaches (surveys and interaction assessment). *Qual Saf Health Care.* 2010;19:475–8.
- Chisolm A, Askham J. What do you think of your doctor? A review of questionnaires for gathering patients’ feedback on their doctor. Oxford: Picker Institute Europe; 2006.
- Roberts C, Sarangi S. Theme-oriented discourse analysis of medical encounters. *Med Educ.* 2005;39:632–40.
- Greenhalgh T, Heath I. Measuring quality in the therapeutic relationship Part 2: subjective approaches. *Qual Saf Health Care.* 2010;19:479–83.
- Arnetz JE, Almin I, Bergström K, et al. Active patient involvement in the establishment of physical therapy goals: effects on treatment outcome and quality of care. *Adv Physiotherapy.* 2004; 6:50–69
- Chen EH, Thom DH, Hessler DM, et al. Using the Teamlet Model to Improve Chronic Care in an Academic Primary Care Practice. *J Gen Intern Med* 2010;25(Suppl 4):610–4.
- Bodenheimer T, Wagner EH, Grumbach K. Improving primary care for patients with chronic illness. *JAMA.* 2002;288:1775–9.
- Bawden R, Lindsay E. Patient Empowerment: a general practice perspective. *Br J Community Nur.* 2007;12:528–30.
- Wensing M, Elwyn G. Improving the quality of health care: methods for incorporating patients’ views in health care. *BMJ.* 2003;326(7394):877–9.
- Barr J, Giannotti TE, Sofaer S, et al. Using public reports of patient satisfaction for hospital quality improvement. *HSR.* 2006;41(3):663–82.
- Trigg L. Patients’ opinions of health care providers for supporting choice and quality improvement. *J H S R & Policy.* 2011;16(2):102–7.
- Raleigh VS, Hussey D, Seccombe I, et al. Do associations between staff and inpatient feedback have the potential for improving patient experience? An analysis of surveys in NHS acute trusts in England. *Qual Saf Health Care.* 2009;18:347–54.
- Ponte PR, Conlin G, Conway JB, et al. Making patient-centered care come alive. *JONA.* 2003;33(2):82–90.
- Grogan A, Coughlan M, O’Mahoney B, et al. The development of a patient partnership programme and its impact on quality improvements in a comprehensive haemophilia care service. *Haemophilia.* 2012;18:875–80.
- Airey R, Farrar D, Wilkinson K, et al. Improving the quality of maternity service provision. *Br J Midwifery.* 2009;17(3):182–5.
- Richardson A, Sitzia J, Cotterell P. ‘Working the system’: Achieving change through partnership working: an evaluation of cancer partnership groups. *Health Expectations.* 2005;8:210–20.
- Zeitz K, Kitson A, Gibb H, et al. Working together to improve the care of older people: a new framework for collaboration. *J Adv Nurs.* 2011;67(1):43–55.
- Truman C, Raine P. Experience and meaning of user involvement: some explorations from a community mental health project. *Health Soc Care Comm.* 2002;10(3):136–43.
- Sullins CD. Adapting the empowerment evaluation model: a mental health drop-in center case. *American J Eval.* 2003;24(3):387–98.
- Williams P. Learning to collaborate: lessons in effective partnership. *Working in Health and Social Care.* NLIH Wales. 2007; p. 1–40.
- Van Deventer C, Mclnerney P, Cook R Patients’ involvement in improvement initiatives: a qualitative systematic review. *JBI Database System Rev Implement Rep.* 2015:1–68. Unpublished: awaiting review.
- Department of Health, South Africa. Towards quality care for patients: core standards for health establishments in South Africa. 2011. p. 1–47.
- Naledi T, Barron P, Schneider H. Primary health care in SA since 1994 and implications of the new vision for PHC re-engineering. In: Padarath A, English R, editors. *South African Health Review* 2011. Durban: Health Systems Trust; 2011. p. 17–28
- Mahomed O, Asmall S. ICDM final quality improvement report Dr Kenneth Kaunda District, North West Province. Unpublished report. Report. 2011. p 1–70.
- Fetterman DM. Empowerment evaluation: building communities of practice and a culture of learning. *Am J Community Psychol.* 2002;30(1):88–102.
- Miller RL, Campbell R. Taking stock of empowerment evaluation: an empirical review. *Am J Eval.* 2006;27:296–319.
- Schnoes CJ, Murphy-Berman V, Chambers JM. Empowerment evaluation applied: experiences, analysis, and recommendations from a case study. *Am J Eval.* 2002;21(1):53–64.
- Barrington G V. Empowerment goes large scale: the Canada prenatal nutrition experience. *Can J Prog Eval.* 1999; (Special Issue):179–92.
- Campbell R, Dorey H, Naegeli M, et al. An empowerment evaluation model for sexual assault programs: empirical evidence of effectiveness. *Am J Community Psychol.* 2004;34(3–4):251–62.
- Sharma A, Suarez-Balcazar Y, Baetke M. Empowerment evaluation of a youth leadership training program. *J Prev Interv Community.* 2003;26(2):89–103.
- Van Deventer C, Couper I, Sondzaba N. Chronic patient care at North West province clinics. *Afr J Prim Health Care Fam Med.* 2009; 1(1), Article No: 8:5 p.
- Lin M, Hughes B, Katica M, et al. (2011). Service design and change of systems: human-centered approaches to implementing and spreading service design. *Int J Design.* 5(2): 73–86. 33(11):585–95.
- Thompson DN, Wolf GA, Spear SJ. Driving improvement in patient care. *JONA.* 2003;33(11):585–95.
- Herring L. Lean experience in primary care. *Q Primary Care* 2009;17:271–5.
- Pocha C. Lean six sigma in health care and the challenge of implementation of six sigma methodologies at a veterans affairs medical center. *Q Manage Health Care.* 2010;19(4):312–8.
- Angstman KB, Bender RO, Bruce SM. Patient advisory groups in practice improvement. *J Ambul Care Manage.* 2009;32(4):328–32.
- Jones SP, Auton MF, Burton CR, et al. Engaging service users in the development of stroke services: an action research study. *J Clin Nurs.* 2008;17:1270–9.
- Patton MQ. Toward distinguishing empowerment evaluation and placing it in a larger context: take two. *Am J Eval.* 2005;26(3):408–14.
- Smith NL. Empowerment evaluation as evaluation ideology. *Am J Eval.* 2007;28:169–78.
- Stufflebeam DL. Empowerment evaluation, objectivist evaluation, and evaluation standards: where the future of evaluation should not go and where it needs to go. *Am J Eval.* 1994;15:321–38.
- Scriven M. Empowerment evaluation examined. *Am J Eval.* 1997;18:165–175.

44. Wandersman A, Snell-Johns J, Lentz BE, et al. The principles of empowerment evaluation. In: Fetterman D, Wandersman A, editors. Empowerment evaluation principles in practice. New York, NY: Guilford; 2005. p. 27-41.
45. Wrixon S. Time to address a dependency culture. *Pract Nursing*. 2010;21(1):8-10.
46. Moumjid N, Morelle M, Carre`re M, et al. Elaborating patient information with patients themselves: lessons from a cancer treatment focus group. *Health Expect*. 6:128-39.
47. Alexander IM, . Emancipatory actions displayed by multi-ethnic women: 'regaining control of my health care'. *J Am Acad Nurse Pract*. 2010;22:602-11.
48. Barrie J. Patient empowerment and choice in chronic pain management. *Nurs Stand*. 2011;25(31):38-41.
49. Hoch HE, Busse KL, Dellavalle RP. Consumer empowerment in dermatology. *Dermatol Clin*. 2009;27(2):177-83.
50. Kristensson P, Magnusson PR, Matthing J. Users as a hidden resource for creativity: findings from an experimental study on user involvement. *Creat Innovat Manag*. 2002;11(1):55-61.
51. Fehrsen S. Person and population based care needs a clinical method fit for purpose. Presentation 18th Family Practitioner Conference, Durban. 2015, July.
52. De Wet C. Clinical governance. Presentation 18th Family Practitioner Conference, Durban. 2015, July.
53. Alexander JA, Hearld LR. Review: what can we learn from quality improvement research?: a critical review of research methods. *Med Care Res Rev*. 2009;66:235-71.
54. Hershberger PJ, Bricker DA. Who determines physician effectiveness? *JAMA*. 2014;312(24):2613-4.

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