

How to improve diabetic care in the Wesbank/ Ilingu

Lethu suburb of Malmesbury, Western Cape

by

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DECLARATION

I, DANIEL WILHELM BEUKES, declare that the contents of this thesis represent my own unaided work, and that the thesis has not previously been submitted in its entirety or in part, at any university for a degree.

Signed

Date

ABSTRACT

Introduction: Diabetes in Africa has been described as a pandemic, with the prevalence in South Africa estimated at 4.5% of the population. Despite clear national guidelines from the Society of Endocrinology, Metabolism and Diabetes of South Africa, an unpublished quality improvement cycle in 2007 has shown poor patient knowledge with associated uncontrolled glycaemic and hypertensive control in diabetic patients in a district health system. The purpose of the study was to identify possible reasons for this and to find solutions for improving diabetic care within the Wesbank/ Ilingu Lethu suburb of Malmesbury, Western Cape.

Methods: A cooperative inquiry group was established, consisting of primary health care providers at a district hospital and a primary health care clinic. The inquiry completed several cycles of action-reflection over a period of eight months, and included training in diabetic related topics and critical reflection techniques. At the end of the inquiry consensus was reached on key findings by group and learning within the group.

Findings: Consensus was expressed in two key findings. The group identified and prioritized continuity of care and diabetic education key areas where diabetic care could be improved in the research population. The first was addressed by initiating diabetic registries, establishment of a regular diabetic clinic, implementation of a diabetic schedule within the medical records and the forming of a diabetic team that could support continuity of relationships, clinical management and organisation of care between both facilities. The diabetic team involved non-governmental organizations, private health providers and the community to increase awareness and develop capacity to improve diabetic care. The other finding confirmed diabetic education as a critical area in diabetic self management. The diabetic team initiated a diabetic community forum for educational and informative group activities. There was also continued professional development with education sessions within the cooperative inquiry group themselves.

Conclusions: Improving diabetic care through continuity of care and education is well supported in known evidence based literature. The challenge is to translate/ transfer the available knowledge and render it operational and clinical in any health setting. The co-operative inquiry process was a valuable tool to identify, prioritize and addresses unique challenges for improving diabetic care in our specific context.

Introduction, background and motivation

In a recent United Nations Resolution on Diabetes: “Time to Put Words into Action”, the Global Partnership for Effective Diabetes Management urged national governments, the general population and the global diabetes community to take action and share responsibility in the fight against diabetes.¹ An estimated 285 million people, corresponding to 6.4% of the world's adult population, will live with diabetes in 2010.¹ The number is expected to grow to 438 million by 2030, corresponding to 7.8% of the adult population.² The African continent has a comparative prevalence of diabetes in relation to other continents of 3.8% and in South Africa, the World Diabetes Foundation estimates the national prevalence of diabetes (ages 20-79yrs) as 4.5% of the total population.³ There is evidence that certain provinces in South Africa (e.g. Kwazulu-Natal) may have a prevalence as high as 13-18%.⁴ The increased prevalence of diabetes in certain population groups is also well established.⁵ Mollentze and Levitt (2007) found that, in the Cape Town area, the coloured population has a prevalence of diabetes as high as 10.8%.⁶ In the Malmesbury area, where this study is situated, 70.9% of the population is Coloured and it is expected that the coloured population will increase at 3% per annum over the medium term.⁷ Diabetes was estimated to have caused 4.3% of all deaths in South Africa in 2000.⁸ Overall, about 14% of ischaemic heart disease, 12% of hypertension, 12% of renal disease, and 10% of stroke in adults of both genders were attributable to diabetes.⁸

The principal researcher identified the need for further study into chronic diabetic care, when an unpublished quality improvement audit in 2007 in the Malmesbury sub-

district of the West Coast-Winelands Region found that 50% of diabetics had poor knowledge of diabetes, 45% had uncontrolled glycaemia (random < 15mmol/l) and 45% uncontrolled blood pressure measurements of above 139/85 mmHg. These patients also had not received proper care as set out in the new revised guidelines of SEMDSA (Society for Endocrinology, Metabolism and Diabetes of South Africa).⁹ Poor follow up, poor record keeping and non adherence with medication were some of the shortcomings identified.

These findings resonate with a Cochrane systematic review that identified several barriers to improving diabetes care.¹⁰ These included a lack of acceptance of guidelines, lack of knowledge of diabetes, poor co-operation of staff members, poor documentation of care that leads to discontinuous care, the complexity of the guidelines and the lack of information needed to incorporate them into practice, non attendance and poor compliance of patients.

In response to this situation the researcher decided to explore how to improve chronic diabetic care through a participatory action research project in the form of a co-operative inquiry group (CIG). This inquiry was focused on two underlying issues. Firstly, the need to understand the obstacles and limitations in our rural community preventing the implementation of the suggested evidence based literature (SEMDSA) and secondly, the need to explore ways of overcoming these obstacles and limitations and improving the care of diabetic patients. The setting for the research project was limited to a specific demographic suburb (Wesbank/ Ilingu Lethu) in Malmesbury. Swartland hospital is a 89 bed district hospital which also supports various primary health care (PHC) clinics in its drainage area. These facilities provide health services mainly to the uninsured population in the West Coast District in the Western Cape.

The study population is situated in one of the southern suburbs of Malmesbury, Wesbank/Ilingu Lethu, where the majority population are Coloured and speak Afrikaans. Approximately 5-10% of the population is Xhosa speaking, live on the outskirts of the suburbs and also utilize these health facilities. The principal researcher is currently working as a principal medical officer at Swartland hospital with a daily outreach clinic to the Wesbank/Ilingu Lethu clinic. Due to the clinic's close proximity to the hospital, there is considerable overlap of service delivery with patients in the suburb having open and easy access to both facilities. Members of the CIG group are all actively involved in health delivery in both these facilities. There are no specific days for chronic care clinics and only the hospital is open 24 hours a day.

Aim

The aim of the study was to explore how to improve the chronic care of diabetes mellitus in the Wesbank/ Ilingu Lethu suburb of Malmesbury in the West Coast Winelands region of South Africa.

Objectives

- To explore and identify the current obstacles of chronic diabetic care in this rural health care setting.
- To explore how diabetic care can be improved through cycles of action and reflection
- To suggest recommendations to the Department of Health on how to improve chronic care of diabetes mellitus, within the district health care environment.

Study design

Systematic reviews show an increase in the use of participatory action research methodology to address the complexity of health environments, using participation, action and research to address unique problems in health care delivery.¹¹ Professional action research is a process of inquiry into the transformation of one's practice. It is the systematic, reflective study of one's actions and the effects of these actions in a workplace context. The participants evaluate and reflect on their work and try to find opportunities to improve. Action research is a way of continued learning within the work environment and researchers both act and seek to learn from the actions taken.¹² Engaging in reflective practice means developing the capacity to continuously engage in critical dialogue about ones professional activities individually and collectively. It is a reflective process in that it is constant, repetitive and continuing. Action research tends to be:^{13,14}

Cyclical- similar steps, repeated in the same sequences.

Participative- people are involved as partners (active participants) in the research process,

Qualitative- it deals more with experience, perceptions, views, behaviours and language than with numbers, although quantitative measurements are not excluded.

Reflective- critical reflection is part of the process to inform and guide new action and construct new knowledge, concepts and theory.

The co-operative inquiry group within the domain of professional action research is a specific method that can be used. John Heron and Peter Reason describe the practice of co-operative inquiry as collaboration between people who have similar concerns and interests as the researcher, which enables a process of collective reflection on action taken.¹⁵ This process assists us in understanding the world we live in, making

sense of our experience and developing new and creative ways of looking at things. It also teaches us to change things and find a way to improve life and/or work. This is research with, rather than on people.¹⁵ As the name states, in co-operative inquiry there is collaboration, so that all those involved work together as co-researchers and as co-subjects. Everyone is involved in the design and management of the unfolding inquiry. The primary procedure is to use inquiry cycles, moving several times between reflection and action. There are usually several cycles of reflection and action in this process. Its strength as a research method lies in its focus on generating solutions to practical problems and its ability to empower practitioners to engage and act on problems identified in their daily practice.¹⁶

Method

Recruiting the co-operative inquiry group members

Members of the CIG were recruited from health personnel working within the two health facilities. Two informational sessions was held in Swartland hospital and Wesbank clinic to inform all personnel at these facilities of the proposed research and provide background to the methodology used and the commitment required from anyone who wished to participate.

At the first meeting, a fellow medical officer, 4 clinical nurse practitioners, 2 health promoters and one administrative clerk committed themselves to the CIG. The non-clinical member of the group was the admission clerk at Wesbank Clinic, who was also a diabetic patient herself. First languages used by the CIG members were Afrikaans, and Xhosa. I negotiated a 10-12 month commitment with the CIG members.

Establishing the CIG

At the initial meeting ground rules for the inquiry process were agreed on, for example, it's a voluntary process, participants can refuse to engage with issues they are not interested in, confidentiality, commitment, and keeping within the suggested time limit for meetings. This was particularly important because all of the meetings were scheduled after normal working hours, due to daily work commitments.

DW, the principal researcher, provided background to the reason for focusing on chronic diabetic care within our demographic area and explained the methodology of action research, specifically concentrating on what co-operative inquiry means. Some time was given for group members to introduce themselves and present their expectations of the process. A short discussion was held about the implications of undertaking such an inquiry and that it could have a direct and personal effect upon the participants.

CIG group members were informed that important discussions and decisions would be documented and distributed to each member after each CIG meeting, all group meetings would be audiotaped so that the principal researcher could capture feedback on actions taken (what happened), individual and group reflections (new ideas, questions and concepts) and individual plans for the next period of time before the group met again. The recordings would also allow the principal researcher, who facilitated the meetings, to reflect on his facilitation skills, group dynamics and group process issues.

Individual members received personal diaries and went through a training session on how to write observational notes and narrative accounts related to chronic diabetic care in their working environment. At the end of the proposed research period each

person would be expected to give written feedback describing his or her personal journey during this period. The final meeting of the CIG would be devoted to achieving consensus on what was achieved personally, in the group and through the research process.

We concluded this introductory session with some discussion around the validity and the importance of data collection. The session included the reason for data collection and that as individuals their most important tool was a diary in which actions, experiences and initial reflections could be captured to inform the inquiry process.

Time was spent on how to keep a diary and what critical reflection entails.

Group sessions and the PAR cycles

A summary of the group sessions and PAR cycles is shown in Table 1.

Table 1: Summary of sessions and meetings held by the CIG.

Date	Type of Meeting	Description
12/07/2009	Information session	Invitation to participate in research process, explanation of research question and what co-operative inquiry is- Swartland hospital facility
17/07/2009	Information session	Invitation to participate in research process, explanation of research question and what co-operative inquiry is- Wes bank Community Health Clinic
30/07/2009	Introductory session	Presentation of research project to participants, setting ground rules, contracting, exploring participant expectations. Explanation of data capturing through personal diaries and the audio taping of each meeting.

13/08/2009	Co-operative inquiry meeting	Group work on identifying problems in delivering chronic diabetic care. Reflection on causes of poor chronic care delivery. Identification of 7 core areas where chronic care can be improved. Planning action and reflecting on vision for chronic diabetic care.
03/09/2010	Co-operative inquiry meeting	Teaching on basic diabetic physiology Teaching on the key domains in the chronic care model as found in the literature. Alignment of CIG actions with known scientific literature Planning action to identify how to improve chronic care within local context.
15/10/2009	Co-operative inquiry meeting	Teaching on the diabetic foot Reflection, planning and convergence of ideas into core concepts. Using these concepts to prioritize the initiation of better diabetic care.
05/11/2010	Co-operative inquiry meeting	Teaching on diabetes and smoking Methodology review in meeting Informal discussion and reflection of personal patient interviews(diaries) Reflection, planning and convergence of ideas into core concepts. Using these concepts to prioritize the initiation of better diabetic care. <ul style="list-style-type: none"> • Development of chronic diabetic treatment schedule • Reflection on ways to improve awareness of diabetes • Asset mapping in demographic area
22/12/2009	Co-operative inquiry meeting	Teaching on motivational interviewing Informal discussion and reflection of personal

		<p>patient interviews(diaries)</p> <p>Consensus on the 7 key domains for action to be taken. Participation of whole group completing fishbone diagram</p>
26/01/2010	Co-operative inquiry meeting	<p>Reflections on actions taken.</p> <p>Planning of further action to be taken</p>
11/02/2010	Co-operative inquiry meeting and information sharing with NGO	<p>Planning questions for focused group discussion to be held</p> <p>Focused group discussion held</p> <p>Dissemination of FGD findings</p>
13/04/2010	Co-operative inquiry meeting	<p>Reflection on personal experience and evaluation of CIG process</p> <p>Workshop on reflection techniques</p>
01/05/2010	Co-operative inquiry meeting	<p>Reaching consensus on the findings of the co-operative inquiry group</p> <p>Reflection on individual experiences</p> <p>Reflection on group process</p> <p>Planning for future cycles</p>

Quality and co-operative inquiry

Quality criteria that can be used to critically appraise co-operative inquiry have been described by Mash and Meulenberg-Buskens.¹⁷ Table 2 outlines these criteria and the application thereof in the research process is discussed below:

Table 2. Quality criteria in co-operative inquiry

<p>Alignment with purpose</p>	<p>Alignment of the group members of the research both drives the process and acts as the contract between the members. Aligning oneself with a particular outcome or personal intention, rather than the purpose of the research, may lead to a lack of openness in the inquiry</p>
<p>Ownership of the inquiry process</p>	<p>Ownership of the research by members of the group is crucial to the quality of the inquiry. The initiating researcher will need to transfer power, knowledge of the research methodology, ownership of the research questions and process so that after the group is established he or she does not dominate the inquiry.</p>
<p>Development of reflectivity</p>	<p>As the members of the group are both the researchers and the researched the quality of the inquiry will depend on their ability to witness themselves. This requires a reflective stance that is characterised by heightened awareness, open mindedness, critical questioning and comment to dialogue.</p>
<p>Democratic and collaborative group dynamics and facilitation</p>	<p>The facilitator must strive for a genuine collaborative and democratic group process. The level of trust will be related to telling the truth without judgement and staying within the common purpose. Breaking this contract with each other leads to a loss of trust and commitment and the facilitator must guard against this.</p>
<p>Commitment to practical action and experience</p>	<p>The group must be committed to a balance of both action and reflection. Some groups may find it easy to take action, but difficult to pause for adequate documentation and reflection. Others might be good at planning and reflecting, but short on actually engaging with the practical action.</p>

Documentation of the process	The following three steps must be documented: The individual experience and action. The group process and dynamics. The developing reflections, research statements and conclusions. The quality of the research process is made publicly accountable through documentation as emphasised in the CRASP mode of action research.
Transferability	Transferability is another aspect of quality whereby the groups findings should be sufficiently clearly described to enable readers to understand what aspects of the inquiry can be appropriate to their own context. The reporting of this research therefore should be in its rich contextual detail.
Construction of practical knowledge	The purpose of co-operative inquiry is to construct practical knowledge through cycles of action and reflection. Therefore one way of judging the quality of the research is in the practical usefulness of this new knowledge. The way in which this consensus was constructed will also reflect on the quality of the inquiry

Alignment with purpose

Alignment with purpose implies constant assessment of the groups' activities and reflections relative to the purpose of the research and awareness of when group members are pursuing their own non-aligned personal agendas. It was clear that negative emotions regarding the health system and personal agendas could cloud the research objectives. Facilitation attempted to make people conscious of these issues as they could also impact on chronic diabetic care and to constantly remind them of the research purpose at each meeting.

Ownership of the inquiry process

The transfer of ownership of the inquiry process from the principal researcher to the group members was gradual and ongoing over all the cycles. This process came to fruition as each participant engaged with their personal journeys and documented their personal inquiry findings.

Development of reflectivity

The primary tool used in the development of reflectivity was the keeping of a personal diary, in which critical incidents from daily practice were recorded. The diary also allowed them to document what they had observed or learnt from the incident, and what they intended to do about it. Dick states that reflection after an event is helped by careful observation during the event.¹⁸ In turn, that is helped by good planning, and in particular the surfacing of assumptions, before the event. He suggests a set of questions to guide planning before the action and for review (reflection) afterwards. This helps participants to understand any assumptions that might guide their actions and identify if the outcomes support or disconfirm the assumptions made. DW made use of these questions to achieve reflectivity in the initial stages of the inquiry:¹⁸

- What do I think are the prominent features in the current management of chronic diabetic care?
- Why do I think they are prominent and what evidence do I have?
- If I am correct about my assumptions, what outcomes do I believe are desirable?
- Why do I think those outcomes are desirable in that situation?
- If I am correct about the situation and the desirability of the outcomes, what actions do I think will give me the outcomes?
- Why do I think those actions will deliver those outcomes in that situation?

Schon's view on the reflective practitioner and Brockbank and McGill's five dimensions of reflection were used as a guide to evaluate the group's process.^{19,20} A questionnaire focussed the group's final evaluation on the research process, group

dynamics and its impact on personal learning (Table 3).²¹ Another technique used for reflection was free-drawing which allowed learning that had remained unrecognised or unconscious before to be expressed.²²

Table 3 Questions to evaluate our learning/experience.

- | |
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| <ol style="list-style-type: none">1. What have I gained or learnt from the CIG group or done differently as a result of the group:<ul style="list-style-type: none">• For myself?• For my work in relation to:• My personal work practice?• My colleagues and staff?2. What have I gained/learnt in terms of my understanding of the process of the CIG group that I have applied in my work?3. What have we gained as a group?4. How can we improve the operation of the group to make it more effective?5. How do we wish to utilize the set in the next year and/or6. Where do we go from here?7. What issues do I wish to bring to the group that I think is important to me and my work?8. How might we link up, and to what purpose, with the other staff members in the work environment who have experience in action learning9. Are there any implications for the department as a result of the operation of the CIG group?10. Any other issues that you wish to raise or mention? |
|--|

Democratic and collaborative group dynamics and facilitation

All members were given the opportunity to share their experiences with the group in each meeting. One of the ground rules stated that everyone should be able to discuss their feelings and perspectives in the group and others should not interfere during this statement process. DW and a fellow group member FC had a short discussion after each meeting evaluating dynamics and member participation in the session.

Commitment to practical action and experience

Members were invited and encouraged to provide feedback on their actions and experiences at each meeting. Actions to be taken were explicitly planned and documented at the end of each meeting. Many of the suggested actions remained theoretical, but reflections on shared experiences led to a change in behaviour and action in all of the participants. Their personal experiences changed from negative attitudes and disinterest in diabetes to ones of empathy, understanding and commitment to find solutions to the diabetic problems in our specific rural context. Practical solutions involved the implementation of diabetic registers, involvement in a diabetic audit and the development of a diabetic chronic care schedule.

Documentation of the process

DW attended a workshop on participatory research and the importance of record keeping. Each member was encouraged to record their experiences in narrative form using writing as a means of capturing experiences, personal observations and reactions. All group meetings were recorded and DW made a reflective summary that was circulated to the participants for discussion and further reflection at the next meeting.

Transferability of findings

The setting and findings of the CIG group are reported in this paper and readers are encouraged to apply the findings where relevant to their own context. The setting of this study is thought to be similar to many other public, primary care and rural settings in others parts of the Western Cape and South Africa.

Construction of practical knowledge

DW was aware of the constant learning that took place during this process and spent the last two meetings on collating practical knowledge learnt through the individual members and the group as a whole. All members were asked to complete a questionnaire indicating what was learnt during the research process on a personal level but also through the group dynamics and the group as a whole. The final construction of the group's learning was presented to the members for confirmation and validation at the final meeting.

Findings

Identifying the issues

At the first CIG meeting participants discussed two questions and had to recommend areas to focus on, or tasks to improve diabetic care. The questions were:

“What was your worst diabetic consultation/ interaction with patients, and why?”

“What was your best diabetic consultation/ interaction with patients, and why?”

In answering the first question it became clear that most of the people expressed a feeling of frustration and hopelessness within their day to day interaction with diabetics. There were 2 underlying causes identified, the one cause related to patient load and time constraints, and the other was the poor self-management of patients suffering from diabetes. The view was quite negative and the group's attitude was echoed in a member stating:

“I want to really sit and understand the patient's view, and I know it is wrong, but I have only 2-5 minutes to see the patient, and another forty patients are

waiting outside my door to be seen, so I just write up the medication and let the patient go”

Another doctor commented:

“The lady has been a diabetic for 15 years and says to my face she does not want any referral to a dietician because she cannot afford ‘those’ (referring to diabetic food) special food. It is too expensive any way!”

Other negative consultations identified issues of not having decent infrastructure and materials in the rural clinics, shortage of personnel and a general poor knowledge of diabetes by both staff and patients.

Addressing the second question only reiterated the negative sentiment with members identifying good consultations as those where patients had good control, effective support and successful and appropriate referral of patients to tertiary institutions and positive feedback from patients about the role the health providers played in their well-being. A pressing question emerged in the group with all members wondering why some patients with the same circumstances and quality of life managed their diabetes better than others. This was an unexpected confirmation of the research question’s relevancy in our specific rural context and indicated the CIG group taking ownership and aligning themselves with the main research question surprisingly early in the research process.

DW also provided the group with evidence based literature that stated the improvement of chronic diabetic care requires attention to 6 critical areas.²³

Self-Management: Self-management refers to the patient having a central role in determining and collaborating with their care. This relies on patients developing

personal health literacy, believing in the importance of self-care and developing self-efficacy or confidence in their ability to make a difference.

Decision Support: The treatment needs to be based on evidence which is provided in a user-friendly format that supports decision making at the point of care.

Clinical Information Systems: A disease register is a necessity when planning for resources, conducting audit or recalling patients. Informational continuity in the medical record is also important.

Delivery System Design: The delivery of patient care requires not only determining what care is needed, but clarifying responsibility for different roles and tasks between the members of the chronic care team (e.g. nurses, doctors, pharmacist, and health promoter). Teamwork is important and involves specific attention to continuity of patient care within the team. Reducing waiting times and having appointment and recall systems to ensure follow up is also important.

Quality assurance: The effort to improve diabetic care should be woven into the fabric of the organization and aligned with a quality improvement system.

Community-based services: Facility-based services should engage with community organizations that can support or expand the health system's care for diabetics. These services may support adherence, enhance self-care and promote healthy lifestyle.

From July to August the CIG group met twice and identified and established certain areas where change could improve diabetic care. The group evaluated and deliberated on these issues and concluded that the two main areas where action could ameliorate our diabetic care were related to continuity of care and education of patients and health care providers. All the other issues identified could be addressed within these two main areas. It was decided that action should be focussed at the following issues:

- Continuity of care (which included),
 - Improving medical record keeping
 - Improving diabetic care process within busy clinics
 - Improving support and referral pathways for the rehabilitation of diabetics with target organ involvement
 - Procurement of a facility for diabetic education within the community
 - Establishment of a dedicated, focused diabetic team
- Education of patients and personnel

The group had a real grip on the content of issues but struggled to identify how to change and improve the status quo.

From September to February the group convened a further six times. During this time the group were immersed in reflecting on their experience of diabetic care, making sense of the chronic care model²⁰, and exploring key issues identified.

Exploring the Key issues

The CIG's actions and reflections in relation to each key issue are summarized in the sections below.

Continuity of care

The medical record keeping on diabetic patient was very poor. Many of the patients only had “chronic files” that were issued on filling of prescriptions every six months. The extent of diabetes in the study population was unknown except for these chronic files. Record keeping and the importance of diabetic disease registers are important for statistical reasons and provide valuable information necessary to strategically plan and manage change in any organization. Clinical information systems are critical for improved diabetic care and relates to informational continuity of care²⁰

The nursing members of the CIG group identified another obstacle in continuity of care relating to the high patient loads that need to be seen during normal working hours. In both facilities nursing practitioners are expected to see in excess of 50 patients a day due to staff shortages. These consultations include keeping statistics, answering telephones and dispensing medicine, which leaves patient consultations only lasting between 3-6 minutes. This left many very exhausted, emotionally drained with very little work satisfaction at the end of the day.

The responsibilities of the nursing staff also included regular rotation between departments for those in the hospital and rotation through different outreach clinics in the community health centre. This impacted negatively on the patient-provider continuity of care, with patients not properly managed in the consultation but also having to see another health provider at every visit.

DW and FC highlighted the current guidelines for improved diabetic care for the South African context as presented by the Society for Endocrinology, Diabetes and Metabolism of South Africa. The challenge facing the CIG group was the implementation of these guidelines within the busy daily clinics. In order to find solutions, CIG members identified unique dynamics that exist within rural health. They acknowledged the unfortunate fact that chronic patients are those patients that save time because they usually do not have acute problems and only attend to have their chronic prescriptions filled.

The diabetic patient's visit was a chronic visit and health providers in our facilities did not fully comply with the basic guidelines for chronic diabetic care. The only physical measurements that were done were blood pressure and random blood glucose. The

CIG group brainstormed for ideas that would allow different health care personnel to have a focused, standardized method of complying with the chronic care needs of the diabetic patients and adherence to current guidelines. The CIG group agreed that time constraints within the actual consultation prevented any meaningful education and lifestyle promotion, since we could not begin to understand the patient's perspective and needs in 3-6 minutes per patient, and this activity had to be provided in another setting. A solution to this situation should provide a high turnover clinic, with effective and efficient use of limited time and human resources, whilst adhering to national guidelines on chronic diabetic care.

Through the CIG process, members initiated several actions to change the current working practice within the clinics. The actions were aimed at addressing actual problems, effectively becoming change agents within their daily practice.

These included:

- In both facilities a diabetic disease register was initiated, capturing basic personal information on each diabetic, including addresses, contact details and diabetic history.
- The realization that the CIG group itself became a diabetic team. Members shared an increased awareness, were focused on a specific topic and engaged in activities that improved continuity of diabetic care from a patient-provider point of view
- Development of a chronic diabetic schedule within the medical records capturing all proposed investigations and examinations within one record. This schedule would guide any health provider through each consultation and establish regular four monthly follow up evaluations.

- Establishing a routine weekly diabetic clinic ensuring regular follow up visits irrespective of health status. The focus was improving diabetic care before end-organ complication and effectively re-established good preventative medicine at a primary care level.

The group realized the best intervention was to help diabetics prevent end-organ complications through good glycaemic and blood pressure control and having structures in place that could identify these problems at an early or latent stage. It was decided this issue would be best addressed once the improvement of basic preventative diabetic care has been achieved. Supporting diabetics already suffering from end-organ complications required good referral pathways to tertiary institutions, an effective, responsive inter-facility transport system and good communication and collaboration between medical personnel. The group initiated talks with tertiary institutions for outreach clinics to support patients locally. It would save travelling costs and reduce the load of referrals to tertiary institutions. These outpatients' clinics are extremely busy and waiting lists can be up to 4-6 months. The group identified 2 main areas where it could improve support, namely retinal screening for retinopathy (ophthalmology) and foot care (podiatrists). Patient in need of specialist ophthalmological evaluation and management had to attend Tygerberg hospital (Level 3-tertiary) since there are no Level 2 support for this specialty. There are no podiatry services within the state health system and all podiatrists are in private practice. There was a need for increased capacity in transferring patients to specialist clinics. At the writing of this paper booking appointments for patients on inter-facility busses were fully booked for up to 2 months which meant any newly referred patient often could not access specialist clinics.

The CIG group discussed the need for a proper facility where diabetic related health promotion and educational activities could be presented to the community. It was important that the community has easy access to the facility and it must be available after hours. The local library was identified as an ideal location because it was easy accessible, open after hours, could accommodate quite a large group of people and had all the necessary amenities.

Education on diabetes (health personnel and patients)

One of the greatest motivations for our inquiry into chronic diabetic care was a quality improvement audit done in 2007 at Swartland hospital. The audit indicated the diabetic patients had very little understanding of diabetes, and its management. The CIG group realized we needed a better understanding of the diabetic patient within their context and embarked on a focused group interview with 10 diabetic patients from the local population. Ethical permission was granted by the University of Stellenbosch and permission was obtained for each participant. The session was digitally recorded and transcribed by DW. An informal discussion was focused around two key areas:

‘What it means to have diabetes?’ and ‘What was the impact of the disease on them personally and within the community?’ Two thirds indicated it meant they had to watch what they eat. Only one member knew it had something to do with insulin and it became evident that there was little factual knowledge and understanding of diabetes. The patients’ attitudes and perceptions of the disease were overshadowed by negativity. Their experiences with health care delivery were identified as the main problem. A picture of indifferent, over-worked and frustrated doctors and nurses was painted. One patient elaborated on the insensitivity experienced at one of the clinics saying:

“The sister yelled at me because my sugar is high and said my legs were going to fall off... I was so frightened I did not want to go back to the clinic.”

I realized my own frustration and feeling of helplessness when an elderly lady, being a diabetic for 20 years just shrugged at my concern for her health and poor dietary choices. She bluntly stated:

“I have no intention to change my diet. I cannot find or afford the diabetic food I am supposed to eat. Anyway my family doesn’t like the tasteless food I have to eat and it is difficult to cook two different meals each time.”

Another expressed the same sentiment:

“I cannot eat diabetic food because it is very expensive... now I only eat boiled cabbage and chicken without the skin... my whole family eats nice food and I have to cook other food.”

This statement echoed the negative sentiment of patients and made me realize the real difficulties diabetic patients have, not only in their community but also from their families. Dietary misconceptions and myths surrounding diabetes were confirmed with statements like:

“I cannot eat any spices on my food; I can feel it affects my sugar.”

“I drink bitter herbs when I have too much dessert on a Sunday; it does wonders for my diabetes”

Lack of support at diagnosis, not understanding the disease and frustrations with long waiting times were also mentioned. One diabetic patient expressed her feeling of isolation stating:

“The sister only told me my sugar is O.K. and gave me my medicine, she didn’t even touch me!”

“I see all the HIV people, they get examined and their bloods are being taken. The sister do nothing for me, they only test my sugar and tell me to come back if I don’t feel well.”

Another mentioned:

“I came very early and sat there the whole day, I was very tired. I had so many questions but when my sister called me I said nothing because I was tired and worried my lift was going to leave me, and then I have to hike to home...”

Language barriers further broke down any effective consultations since no official translators are employed in the facilities researched. The common use of other patients and administrative personnel for translating had major implications on ethical grounds in terms of confidentiality.

On a personal level DW was reflecting his impact on diabetic patients, because his assumptions of their basic knowledge were most probably unrealistic. He realized his consultations in the last ten years were ineffective and he contemplated his real contribution to his diabetic patient’s chronic care and support when they did not understand basic concepts like insulin, glucose and the pancreas.

A decision by the CIG group was that the main focus of our planning and actions should be the promotion of a healthy lifestyle (diet and exercise) and support through regular scheduled follow up consultations. There were various suggestions by the CIG group for educating patients which included production of a local information video, role-play educational sessions and marketing and supporting diabetic related activities, like fun-walks and participation in the annual World Diabetes Day each

November. This could provide valuable opportunity to increase awareness and improve support within the local community for diabetes.

The procurement of the library in the community provided an easy accessible venue for the initiation of diabetic educational sessions. The CIG group decided to begin a diabetic forum in the community at the library on a fortnightly basis. This would serve as an opportunity to provide diabetics with education and information related to diabetes. In collaboration with a private pharmaceutical company educational material was provided. This material (Conversation Maps for group diabetic education) enabled a teaching process that relied on patient participation and discussion around topics relevant to the patients themselves. The educational content focussed on basic concepts of glucose, insulin, and the complications of diabetes in the long term. CIG members attending these sessions only had to facilitate these discussion session providing actual knowledge as required by the patients. The main themes discussed focused on “living with diabetes” and “how diabetes works”. These forum meetings engaged CIG member on a deeper level, creating awareness on the emotional impact diabetes has on patients, their families and the community. The forum provided a non-threatening and informal atmosphere drawing forth emotional responses from patients with feelings of hopelessness and anger:

“I was wondering what I did wrong and why this happened to me.”

“I was very upset and didn’t want to believe what the doctor said. I was sure it would get better, but it didn’t.”

Participants shared their pain and sorrow describing their personal journeys with each other. There were emotional times when patients with debilitating complications (stroke, amputations, and blindness) discussed their loss of privacy and the burden they are to the local community. The group members found this informal interaction

with their patients very rewarding. They realized optimal care and support includes a responsibility to treat diabetic patients as a whole. Understanding patients' deepest fears and basic needs places a responsibility on health providers if we aim to treat our diabetic patients holistically.

CIG members found this informal interaction with their patients very rewarding. It also addressed certain needs for the health providers themselves. Firstly, it contributed to revision on basic diabetic physiology and pathology. It provide new evidence based information on improving diabetic care and keep them informed of any community needs and opportunities that had to be addressed. It assisted CIG members acquiring new skills in group facilitation and the management of group dynamics within such discussion forums. It indirectly increased the health provider's capacity to become better educators. This patient interaction evoked positive responses from CIG members with one stating:

“What a brilliant, eye-opening experience. I have learnt such a lot and realize how poor my understanding of diabetes was. I was ashamed at how little I actually knew about diabetes? “

This response also indicated a need from CIG members themselves for further professional learning. One member confessed her motivation for joining the CIG process was for improving her personal need for professional development:

“I have to confess my intentions were selfish. I wanted to know more about diabetes myself. I realized my diabetic patients did not receive the best care possible, but there are so much other things to do? I just not wanted them to complain so because I did not know what to say to them, so I handed their medication as fast as possibly can and let them go.”

Group members decided to start each CIG meeting with a short educational session and during 10 months covered topics such as diabetic physiology and pathology; the diabetic foot; smoking and diabetes; and motivational interviewing.

From January to March the group met another two times. By this time the group had gone through various cycles of action and reflection. CIG members became change agents by adhering to the national guidelines for chronic diabetic care. They were much more aware and emotionally present when in consultation with diabetics.

Shared knowledge and focused consultations helped with identification of underlying diabetic related complications and early referral to doctors for optimum management..

There was the identification of community resources that could assist in the management and especially the education of patients. Diabetic awareness gained momentum when collaboration and cooperation was improved between governmental and non-governmental organizations. The home based care initiative, run by an independent provider; Sinitemba was identified as an asset that was to some extent already involved in life style education in general. We invited Sinetemba to collaborate and coordinate their activities in the future ensuring focus on the educational needs but also support to each other in the promotion of healthy lifestyles. They have educational sessions but on lifestyle changes and family planning. There was no specific education for diabetic patients and discussions are underway to initiate chronic care clinics on specific days that would make educational activities much more appropriate.

Consolidating the learning

The last two meetings occurred in April and May. As the CIG group's learning cycle neared completion, individual members reviewed the entire process that the group

went through over the 8 month period. They were given a questionnaire to assist in a critical reflective process their evaluation of the process and their learning.

The final meetings tied together the conceptual learning that took place. On a personal level all the CIG members agreed that, a new personal awareness had taken place.

Members realized that diabetic patients experience enormous obstacles in managing their disease. These included misconceptions of their disease and diet, inadequate information at the time of diagnosis and negative attitudes from health care workers.

Evaluating the difficulties diabetics faced it became clear that at the centre of these obstacles lay a basic need for education, compassion and support. One member stated:

“Before we started this group, I did my work on a faceless community, now I ‘see’ my diabetic patients and try to understand their needs. It has really given me back my empathy for diabetic patients”

“I have become more aware of the plight of diabetics and how we have neglected them. It is important to try and understand diabetics and their circumstances more”

CIG members acknowledged the importance of mutual respect and understanding between team members. This awareness also extended to appreciation of the other group members, with participants identifying the value of other team members and acknowledging their inputs in daily practice. The CIG group provided a kind of sanctuary where all the members had the opportunity to unload frustrations in an honest and open way and to realize that colleagues faced similar frustrations. We recognized fellow team members’ skills and functions within the health delivery system, leading to better understanding and collaboration to find, and implement solutions that will improve patient care and personal job satisfaction. Some of the

responses highlighted the understanding that whatever we tried had to be sustainable and ensure continuity of care:

“We have come to understand one another better and have collaboration due to regular participation in the CIG group meetings.”

“I have seen the value of incorporating inputs from other healthcare professionals into daily practice”

“The involvement of the whole team (CIG) as problem solvers means that during the implementation phase there will be better cooperation. It will not end up as a one man show that will dissipate when you withdraw”

Contemplating the research process members unconsciously identified the underlying principles of good teamwork. Some statements made were:

“It is important to recognize common priorities in the group and to work towards achievable goals. This cyclical process seemed silly initially but it really changed my diabetic care since the introduction”

“Re-evaluating what we did, incorporating everyone’s view and being patient to give the process a chance to disseminate longstanding organizational problems, was an eye-opener”

“It was such a non-threatening way of bringing different role players together and sharing ideas in a non-judgemental way. I am going to use this process on other chronic care problems I face in my facility”

Discussion

The CIG group, through a participatory process identified continuity of care and diabetic education as the two key areas for the improvement of diabetic care in Wesbank/ Ilingu Lethu. The actions taken in the research supports health care provider-related and health systems based interventions. The CIG group, through a participatory process identified continuity of care and diabetic education as the two

key areas for the improvement of diabetic care in Wesbank/ Ilingu Lethu. The actions taken in the research supports health care provider-related and health systems based interventions.

Quality improvement of diabetic care attempts to implement the latest evidence and treatment advances within health services so that the target population will benefit. In general, the quality of diabetes care remains suboptimal worldwide regardless of the country's level of development, health care system, or population characteristics.²⁴

Two important activities are needed to improve the level of care such that it will achieve better outcomes. First, research efforts are needed to translate clinical and public health interventions into those that can be delivered uniformly in typical clinical settings²⁵ These include patient-centred interventions such as diabetes self-management education delivered in clinical or community settings²⁶⁻²⁹, multifaceted health care provider- or health system-based interventions to improve process of care and in some cases outcomes of care^{27,28}, and community-based interventions.²⁶

Second, the assessment of progress using standardized evidence-based performance measures, such as the DQIP (Diabetes Quality Improvement Project), is needed. DQIP was developed in the United States of America in to provide a standard set of quality performance measures designed for universal use among health care delivery.³⁰

Feeding this information back to the health care systems, providers, and patients facilitates the identification of both successes and failures. The ultimate goal is that these assessments will further enhance uptake of research into practice and lead to improved diabetes care and clinical outcomes.

Continuity of care

Current evidence supports the importance of continuity of care in the management of diabetes, resulting in better glycaemic control among people with diabetes,^{31,32} and improved quality of life in Type 2 diabetes and³³. The CIG actions taken included the *Establishment of diabetic disease register*. - Creation of a disease registry is crucial in the management of a population of patients with chronic illness.³⁴ This collates with one of the critical areas for improved diabetic care (clinical information systems) stating the importance of registries for statistical reasons, but also in the strategic planning and management of diabetes. It actually also plays an important role in the informational continuity of care.²⁰

Development of a standardized diabetic schedule in the medical records ensures the commitment and capturing of essential data and coordinates the delivery of interventions, key examinations and self management support activities of diabetic patients.²⁰ The implementation of this tool ensures improvement in process of diabetic care committing the health provider to execute his/her duties within the diabetic consultation as prescribed in national guidelines.

Forming of a diabetic team (CIG group) Effective communication between professionals and services and with patients provides essential cross boundary and team continuity.³¹ It also underpins the value of delivery system design within the chronic care model.²⁰ Delivery system design emphasizes that the delivery of patient care requires not only determining what care is needed, but clarifying responsibility for different roles and tasks between the members of the chronic care team (e.g. nurses, doctors, pharmacist, and health promoter). Teamwork also involves specific attention to continuity of patient care within the team. The CIG group's inquiry involved each member having the same role (same role inquiry)¹⁵, researching aspects to improve diabetic care within their practise. This CIG group consisted of co-

inquirers in different facilities which improved communication and collaboration between both facilities. The initiation of a specific diabetic clinic supports the evidence of health-based intervention to improve quality of diabetic care, guaranteeing regular review with an appointment system that provides a recall system to ensure follow up.²⁰

Improving support and referral pathways for rehabilitation of diabetic patients.

Continuity of care also encompasses support to those diabetic patients already suffering from debilitating complications. The CIG group was not able to find any tangible solutions for the capacity problems at tertiary referral centres and the delay in accessing those institutions because of a lack of state transport facilities. They were however in consultation with relevant state departments in a bid to alleviate the current obstacles.

Diabetic education

The second major finding indicated in the CIG process was *improving chronic diabetic care through patient education*. Self management as a critical area of chronic diabetic care relies on patients having health literacy that enables them to take ownership and understand the disease holistically. It informs and empowers them to self manage their illness.²⁶ Despite all the advances in diabetes treatment, education remains the cornerstone of diabetes self-management. It is of critical importance and should be considered an integral part of diabetes prevention and care. Self management education training is important since people with diabetes and their families provide 95% of their care themselves.² Without appropriate education people cannot make the complex daily medical decisions required for good health, quality of life and survival. Diabetes self-management education is the essential foundation for

patient empowerment and is necessary for patients to effectively manage diabetes and make decisions.³⁶ The reality of poor diabetic knowledge was all too obvious in the focused group discussion held with patients in the research population. Barriers to education within the research echoes what the IDF recognised in many other countries: There are too many patients for the number of health professionals who have specific training and the lack of access to education programmes for patients and health professionals.²

The CIG process established an opportunity to train health personnel (CIG) on a regular basis and implement a community diabetic forum with diabetic educational sessions on a fortnightly basis. In order to improve the capacity of educational activities, members of the CIG group in collaboration with a private pharmaceutical company established a patient centred educational programme. The interactive diabetic self-management education tools provided a participatory educational teaching process where people with diabetes were educated on understanding their condition, protecting themselves from harm and making lifestyle changes to optimize their health.³⁵ It supports further evidence for the chronic care model confirming the central role the diabetic patient plays in his/her diabetes management.²⁰

The research process found that a focus on education necessitated *continued professional training and development in diabetes*. The organization of care is relevant because as health care providers this is the domain where leadership and innovation can improve diabetic care.³⁷ We can impact and become change agents merely by understanding the context of our environment, be aware of limitations and make optimal use of available resources.

Another activity that improves quality of care relates to community based interventions. Among studies reporting results among adults, most reported

improvements in intervention groups relates to the improvement of knowledge or adoption of regular physical activity.³⁵ In order to improve chronic diabetic care the CIG group engaged with role players outside the public health system. This included collaboration with a non-governmental social organization (Sinetemba) in the promotion of healthy lifestyles and diabetic education. Community based interventions supporting continuity of care and improving quality of diabetic care are therefore mostly directed at education within the community. Data on glycemetic control provide sufficient evidence that self-management education is effective in community gathering places.³⁵

Limitations and strengths of the study

The strength of the research was intrinsic to the methodological process of action and reflection. As mentioned previously it finds solutions for practical problems through a process of participation where all key players are acknowledged and given a voice in decision making. It confirms the purpose of this process especially in the educational and health environments that are often complex and very difficult to manage.²⁹

The strength of this process also lies in its ability to act as a change agent. In order to change one needs to be responsive and the CIG group improved their attitudes, knowledge and perceptions from the first introductory meeting. In order to validate and replicate our findings the group went through various cycles to prove adequate iteration.

Generalisability of findings is one of the weaknesses of this process since the process and findings are very contextual. However the learning may well be transferable to and relevant to other rural or public sector health institutions struggling with their diabetic care. The value of this research also lies within the methodology process that

was followed to achieve change and not just the abstract conceptualisation of what was learnt. It is an enabling process especially for smaller health care institutions that facilitates optimal diabetic care. Another limitation relates to the difficulties experienced in providing protective time within normal working hours to conduct meetings. As a result not everybody could attend all of the meetings all the time.

Conclusion

The lessons learnt through this research process have contributed to change in chronic health care delivery for diabetic patients within Wesbank/Ilingu Lethu. It has highlighted the value of action research in identifying obstacles and limitations within our specific environment. It has shown the benefit of a cooperative process, critical reflection on relevant problems and identification of possible solutions. Its efficacy for change relates to the process, changing how things are done while doing it. It is adaptable, flexible and reactive to any new problems that might be identified during the process. It provides an opportunity and research strategy to engage in what is known as translation research.³⁸ This research aimed to translate available knowledge on health care and render it operational in clinical and practical health practice.

In conclusion the following recommendations can be made for improving diabetic care in the Wesbank/ Ilingu Lethu suburb of Malmesbury in the West Coast Winelands region of South Africa:

- Prioritizing the implementation of diabetic registries in all district clinics
- Institute standardized medical record schedules to improve compliance to national diabetic guidelines. This will provide the necessary data for future planning and effective allocation of resources for chronic diabetic care

- Providing training to support the community-orientated and patient-orientated education of people with diabetes
- Using the action research and the inquiry process to find ways of improving care in all chronic diseases.
- Address the severe lack of transport to tertiary institutions
- Train health professionals to become diabetic educators and appoint such individuals as part of the diabetic team.
 - Provide protected time for training of personnel.
- Quality improvement cycles can stimulate change and should be embraced at a local level

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