OLDER WOMEN AND CHRONIC ILLNESS: LEARNING TO LIVE WITH DIABETES

Submitted by
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A Dissertation Submitted in Fulfilment of the Requirements for the Award of Doctor of Philosophy in Nursing

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STATEMENT OF ORIGINALITY

The thesis contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. I give consent to this copy of my thesis, when deposited in the University Library, being made available for loan and photocopying subject to the provisions of the Copyright Act 1968.

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Signature of Candidate     Date
ACKNOWLEDGEMENT

I thank the eleven women and their families who participated in this study. I am grateful for their open, genuine communication with me so soon after receiving a diabetes diagnosis. Each shared their thoughts, feelings, and experiences during a very intimate time of life. These women gave me their time, their stories and their support as we built friendships. I am deeply grateful for being allowed to research alongside them for twelve months.

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Lastly, I give loving acknowledgement to my partner Mohammad. I thank him for his patience in enduring the many days, evenings and weekends when this study was given priority. I would like to acknowledge my family in Iran as I could not visit them for three years while living and studying in Australia. However, they understood and supported me with their kind messages and telephone calls. Their encouragement helped to sustain me through the more difficult periods of researching and writing.
DEDICATION

The Address

The rider asked in the twilight "Where is the friend's house?"
Heaven paused
The passer-by bestowed the flood of light on his lips to the darkness of sands,
and pointed to a poplar and said:

"Near the tree,
Is a garden-line greener than God's dream
Where love is bluer than the feathers of honesty.
Walk to the end of the lane, which emerges from behind the adolescence,
then turn towards the flower of solitude,
two steps to the flower,
stay by the eternal mythological fountain of earth,
where a transparent fear will visit you,
in the flowing intimacy of the space you will hear a rustling sound,
you will see a child,
Who has ascended a tall plane tree to pick up chicks from the nest of light,
ask him:
Where is the friend's house?"

Sohrab Sepehri
Hasht Ketab (Eight Books), 1976, p. 23.

I dedicate this dissertation to my mother, Mehri, who patiently encouraged me to fulfil this study.
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ABSTRACT

The first line of treatment for people diagnosed with Type 2 Diabetes is a change in diet (low fat, low carbohydrates, high fibre), and an increase in exercise to promote the uptake and utilisation of carbohydrates. If the blood glucose level is not stabilised by a change in diet and exercise, then hypoglycaemic tablets may be prescribed. In many cases insulin injections may be required if blood glucose levels cannot be controlled by diet and oral medication. People receiving a diagnosis of diabetes must absorb complex information and adopt a new lifestyle almost immediately.

The purpose of this study was to explore with women, and their family members, the ways in which the women learned to live with Type 2 Diabetes. My aim was to understand what happened to the women during their first year following a diagnosis of diabetes and how it impacted on them and their family members. Using a participatory action research (PAR) methodology I also wanted to explore with them, the practical ways in which they transitioned at this time.

In this inquiry I asked eleven women recently diagnosed with diabetes what it was like for them in their first year since diagnosis. In this first year I journeyed alongside the women as they and their families learned to take the consequences of this chronic condition into their lives. The strength of this participatory action research (PAR) methodology was that I asked women to tell their own stories about learning to live with diabetes and I was able to walk alongside them for twelve months. In addition, I then brought family members into the conversation and they were able to share the impact their partner, mother, friend or spouse being newly diagnosed with diabetes had on their daily lives.

My thesis was that older women newly diagnosed with diabetes learn to take this condition into their lives when they were ready to receive information. The quality of support they received from family, friends and health care professionals and their motivation and understanding impacted on the changes in their lives. The women’s learning process in this PAR group made a theoretical contribution to our understanding of group dynamics. My part in furthering transition theory is my main theoretical contribution.
INTRODUCTION TO THE THESIS
**Introduction**

In 2002, the World Health Organisation (WHO) published an “Innovative Care for Chronic Conditions (ICCC) framework” and suggested that health professionals have a mandate to create environments to improve health care in collaboration with those living with chronic illness. The philosophy underpinning WHO is often articulated as Primary Health Care (PHC) and its four principles focus on equity and social justice in health care practice, and health promotion and working with clients and community. These principles appealed to the researcher particularly as they sanction researching with participants. In the context of this study, the WHO principles sanctioned the importance of my own beliefs and values and inspired me to research with women who were “learning to live with” a chronic condition.

Whilst there are many chronic conditions such as asthma, cancer, multiple sclerosis, cardiovascular diseases, arthritis, chronic obstructive pulmonary disease, mental ill health to name a few, this study focuses on researching with people living with diabetes. Although diabetes has been well researched over the years, particularly from a medical focus, there are, to date, few studies that explore what happens when a person is first diagnosed. It has been observed that when people are diagnosed with diabetes they must dramatically modify their everyday lives and lifestyles, but the way in which these changes take place (or may not take place) has not been researched or studied. More importantly, what can be learned from researching with people as they take the diagnosis of a chronic condition into their lives and with family members has not been researched or studied. In line with the PHC principles, an important consideration is how health care professionals might improve their practice and create environments
where newly diagnosed people can be facilitated to learn to live with a chronic illness and thrive.

Before environments in which people can thrive can be created there needs to be a greater understanding about what happens when people are first diagnosed with a chronic illness. There are several debates about the notion of ‘disease’ and ‘illness’ which also reflect the type of therapeutic relationship patients and health care professionals have developed. For example, health professionals bring expertise in general understanding of disease, its aetiology, diagnosis and prognosis, and the advice about treatment options, associated risks and probable health outcomes. Patients, however, develop expertise as they live with and experience their illness. In other words, patients are the experts in their illness. With this in mind, the focus of this inquiry was to understand the way in which mastery or becoming an expert was learned (or not) by women who were to participate in this study.

The “Participatory Action Research” (PAR) study described in this thesis captures how the researcher walked alongside participants for a year in order to explore what happened in their lives as they learned to live with diabetes, with their family and to observe changes in themselves and their immediate environments.

The participants for this study were women newly diagnosed with diabetes. In this inquiry I show how I built relationships with newly diagnosed women through one to one interviews, over time, and how I recruited family members who were willing to talk with me. I observed the ways in which the women learned to incorporate their chronic condition into their lives, the way in which their learning occurred and how they
transitioned with their condition during the first year following their diagnosis of diabetes. In discussion with each woman/family, I invited participants to share their learning in participatory action research groups facilitated by me.

It is hoped that the findings from the participatory action research groups will inform health care professionals about ways in which they can improve future services and programmes for people newly diagnosed with diabetes. Of importance is that the women were able to share ways in which health care professionals might create different learning environments in which people “learn to live with” a chronic condition and thrive.

I explored learning and transitioning in women with a diagnosis of diabetes and where they were expected to come to an immediate understanding, in lay terms, of the disease process in order to be able to understand and comprehend a large amount of unfamiliar and complex dietary information and adopt a new life style in terms of exercise and activity and routines associated with food intake and diet almost immediately. This thesis uncovers how women learn to incorporate these changes into their lives.

**My Background and Interest in the Inquiry**

My personal interest in the topic has come about as a result of personal experiences as a family member of an older woman, my mother, living with a chronic condition and my interest in diabetes. In relation to the study reported here, it is also important for me to share this information particularly as my experiences and the cultural understandings I
bring to the inquiry have no doubt influenced the way in which I have interpreted and communicated this inquiry.

I was born in 1981, in Tehran, Iran where I lived until commencing my PhD in Australia in 2007. My first language is Farsi. I have two older sisters, an older brother and one younger brother. I am the fourth child in my family. I call myself a ‘black sheep’, as I am the only one in my family who has left traditional family life in Iran. Traditional family life in Iran means following the parents’ ideas without questioning. In traditional families, children should just study what their parents like.

I have been privileged to have a good education and maybe this is why my parents consult with me often. My primary and secondary schooling was completed in Tehran. I was always a top performing student and it was my ambition to continue my education. My parents and my grandmothers encouraged me to study hard to enter university, as they did not have this opportunity.

**Educational Preparation**

My background in health and nursing education was in the tertiary sector associated with a Bachelor of Nursing from the Tehran University of Medical Sciences (TUMS). The University of Tehran has thirty eight research centres and has been ranked first in research for the past eight years in the Region by the Iranian Ministry of Education. When I entered the university my vision was to be a researcher, however, the Bachelor of Nursing in Iran did not include any research topics. Critical analysis was not part of my educational preparation. I was not asked to question, interrogate meaning, define
terms, or test assumptions, rather, the world was presented as facts and truths and one had to learn these. I decided to enrol separately in research workshops that were offered by the University’s Medical Sciences Research Centre. After completing these workshops, I started my first research project at the university and I encouraged the other nursing students to join me. I initiated a nursing students’ scientific research centre at the university’s nursing school where we ran some methodological and statistics workshops together for other nursing and medical students.

On completion of my undergraduate degree, I worked two years full time as a research assistant at the Endocrinology and Metabolism Research Centre of Tehran University of Medical Sciences. I enjoyed my job because I was involved with people diagnosed with diabetes and osteoporosis. I was able to engage with them and helped develop an exercise programme and so encourage them to change their lifestyle. It was foremost in my mind that I wanted to continue my engagement with this group of diabetic clients. I wanted to research alongside them. However, research in Iran is predominantly driven by a reductionist approach and there were few opportunities to practice participatory action research skills.

Following my experience as a research assistant, I decided to continue my nursing education at Masters Level. In Iran any kind of university study is very competitive and acceptance is gained through an entry exam, which is extremely difficult. I was one of the few young Iranian researchers granted entrance through winning in a National Scientific Festival, which is called Kharazmi and I was therefore able to enrol without doing the Masters Degree entrance exam. My Masters Education Programme was a combination of research and course work and I was the youngest student among my
Masters Degree classmates. As I had already worked as a researcher and I was familiar with doing research, I was the first to complete a research proposal. As a result of this work, I decided to continue my research with people diagnosed with diabetes.

I commenced my Masters’ research topic, in diabetes care, in 2006. My reason for focusing on this topic is that there are up to 5% (about 3 million out of 70 million Iranians) of people in Iran with diabetes. Before starting my Masters research thesis I went to an international diabetes congress in Italy in 2006 (Adili, Larijani, & Haghighatpanah, 2006). I became familiar with key authors who were running diabetes research programmes around the world, such as Funnel (2006) and Anderson (2006), with whom I talked, and they encouraged me to keep working on diabetes. I also met Dr Negin Masoudi and she introduced me to the trans-theoretical model of change by Prochaska and DiClemente (1982, 1983). She had spent a few months in Sweden and worked with Swedish academics. In Iran most of the nursing masters students used nursing theories such as Orem’s self-care model (1991) or Roy’s adaptation theory (1980), but Dr Masoudi encouraged me to engage in research using this trans-theoretical model. The next step was convincing my supervisors to allow me to use it.

In summary, the trans-theoretical model is a worldwide model of change which was introduced by Prochaska and DiClemente (1983) and describes five stages of change: pre-contemplation, contemplation, preparation, action and maintenance.

People who are not yet aware of a need to change their behaviour in any way are in the pre-contemplation phase; people who think about making changes in their behaviours are in the contemplation phase, which is followed by those who make themselves ready
to make changes in the preparation stage. Those who are in the process of making changes are in the action phase, whereas the final phase of this model relates to maintaining and sustaining lifestyle changes while the model also acknowledges that the process is not linear and there may be relapses in between any of these stages.

My Masters thesis was about applying the trans-theoretical model to physical activity on health indexes of people with Type 2 Diabetes. This study was conducted to investigate the impact of physical activity training on the participants’ health indexes (fasting blood glucose, HBA1c, body mass index, lipids of blood, pulse rate and blood pressure) in 2006-2007. This research was a quasi-experimental research study (before & after) with thirty two (32) women with Type 2 Diabetes who were members of the Iranian Diabetes Federation. The women were recruited according to the inclusion criteria by non-probability (simple) sampling. Data generation included a questionnaire, interview and observation methods before and after one and a half (1.5) and three (3) months physical activity training sessions.

The results of this study showed that some health indexes of the participants (fasting blood glucose, HBA1c, triglyceride, low density lipoprotein) were changed and improved significantly after three (3) months of the study by the McNemar’s test (Lachenbruch & Lynch, 1998) (P<0.05). This demonstrated the positive effect of doing exercises among participants. The quality of doing each exercise was tested by Wilcoxon’s test (Corder & Foreman, 2009). The women’s physical activity was improved based on the trans-theoretical model and after three (3) months, twenty-five (25) of the women were in the maintenance stage of the trans-theoretical model. This study confirmed the positive impact of physical activity training on the participants’
health indexes based on the trans-theoretical model among people with Type 2 Diabetes and recommended regular physical activity (Mohammadzadeh, Rajab, Mahmoodi, & Adili, 2008).

**PhD Scholarship at University of Newcastle, Australia**

Upon receipt of a tuition fee and living cost scholarships funded by the University of Newcastle, School of Nursing and Midwifery, I arrived in Australia from Iran in 2007. Although I had travelled extensively around the world I had not lived in an English speaking country before. I was required to complete the University English Language Intensive Courses for Overseas Students (ELICOS) for ten weeks as part of my study. I satisfied the English language requirement to commence this PhD inquiry in October 2007.

As I was familiar with Professor Tina Koch’s work on chronic illness experience and had read her participatory action research (PAR) book and papers (Koch, 1993, 1994, 1996, 1998, 2003; Koch & Harrington, 1998; Koch, Jenkin, & Kralik, 2004; Koch & Kralik, 2001, 2006; Koch, Kralik & Sonnack, 1999a; Koch, Kralik & Taylor, 1999b; Koch, Mann, Kralik, & Van Loon, 2005; Koch, Selim, & Kralik, 2002), I was pleased that both my interests, a participatory action research methodology and researching with people who live with diabetes, could be accommodated, when she agreed to be my supervisor. As most people with mature onset diabetes (Type 2 Diabetes) happen to be older people, Professor Isabel Higgins, who holds the Chair in Older Person Nursing, became my other supervisor and she is now the primary supervisor after Professor Koch retired. Professor Higgins had worked collaboratively with Professor Koch in a
participatory action research project. I understood that learning about participatory action research required an apprenticeship and I was pleased to have these mentors.

My supervisors and I talked about having access to a group of people with diabetes with whom I could research. As I had worked with older women in my Masters study, I was interested to work with the same group of people in Australia. Eventually we negotiated access to the Newcastle region’s health service as this area had a large cohort of older people with diabetes. Researching with people from a different cultural background was to be challenging. We agreed that I research with women as they would be more comfortable to talk about the different aspects of their chronic condition, such as sexuality, with a same-gender researcher and later with a group of other women, through the PAR group meetings. I needed to be mindful of ways I could build relationships with older Australian women, given that I was younger, Iranian and possibly held very different views: an outsider researcher. I would need to learn to relate in different ways to those to which I am accustomed, given language and cultural differences. There were many observations in my first few months in Newcastle.

I noticed that Australian people appreciate dessert after their meals or sugary snacks in between meals. This is not a common practice in my country. Perhaps this lifestyle behaviour is related to a higher incidence of diabetes in Australia. In other words lifestyle such as the food choices is one of the contributors in becoming a diabetic. In contrast, Iranian people prefer to eat homemade food, such as vegetables, stews and eat less carbohydrate-based snacks and foods.
Interestingly, during the first days of my arrival in Australia my contact with neighbours assumed that Iran was a poor developing country. These people were surprised when I showed them the pictures of Iran and extremely modern cities as they seemed to have had a concept that Iran was a third world, developing nation. Later my research participants asked me about my culture and I recall that they did not believe that Iran has wonderful buildings and is a hub of fashion design.

My Mother’s Illness

As discussed previously, my research interests are in diabetes, lifestyle change and participatory action research. I am also interested in researching alongside people with a chronic condition as this draws upon my personal experience with my mother who was diagnosed with Chronic Cardiac Failure (CCF), while I was still nursing in Iran. Even though I was able to support and advise her, I realised that she struggled to integrate the information that she had been given by the health professionals at the hospital clinic she attended and it is now well understood, and the focus of much clinician education, that people who are diagnosed with a serious disease retain very little of the information given during their consultation with specialist medical personnel (Glanz, Rimer, & Viswanath, 2008). I remember that it had a profound impact on our family and my mother’s sense of who she was in relation to her household, her sense of value, worth and importance.

When I was young my mother was diagnosed with a Mitral Valve Prolapse (MVP). As a result, she was on a low salt and low fat diet and Mum was also worried about developing diabetes, she also cut down her carbohydrate and sugar intake, as well. Mum
was responsible for the kitchen and cooking. Her diet did not have a negative effect on our family, as everybody was interested in a healthy diet and we easily adjusted to the lower salt and sugar in our diet. Nobody complained about changing their diet, except my younger brother who did not like it, so Mum sometimes cooked two versions of the same dish with different flavours to ensure everybody in the family was happy.

Mum’s chronic condition adjustment was not just about food. Her identity was wrapped up in the cooking and provision of “food”: food, diet and the role of housekeeper, were also significant factors in the adaptation to a diagnosis of her chronic condition, I was to discover. After about twenty years, my mother’s situation worsened and she needed open heart surgery. There was no choice but to accept surgery to survive and after a couple of months she decided to go with the open heart operation. We passed a worrying time with the best cardiac surgeon in Iran. Mum was hospitalised for ten days after the surgery and as my older sisters were married and I was living with my parents, I took on the responsibility of looking after our home and, of course, Mum as well. This was a difficult time for me because I was studying most of the time and I did not know how to cook or even use the washing machine! Everything at home was new for me and it gave me a fresh appreciation of how much Mum worked at home. When she was discharged from the hospital she was not as active as before; she could not take a shower or walk independently, however we worked together as a family and I played a key role in helping her to return to her previous life. For example, Mum was depressed after surgery because of her restricted activity; she cried often. In order to help her, I drove her and two of her close friends to different parks around Tehran. I made sandwiches and shared their company. Gradually Mum returned to independent
mobility, even driving. Through this experience as a family member I became familiar with what it means to live with a chronic illness.

**Shifting to Participatory Action Research**

In Iran I worked in a research unit that excelled in quantitative research. My previous work and my Masters degree were quantitative. I had to make a shift in thinking from quantitative research to qualitative research when I made the decision that participatory action research was the most suitable way to proceed with my inquiry. That meant I had to test my assumptions unpinning research approaches. I was familiar with the scientific approach. In quantitative research the process of measurement involves deciding what to measure, how to measure it and determining the reliability and validity of the instrument. I use the terms 'scientific method', 'scientific approach', 'positivistic approaches' and 'quantitative methods' interchangeably. They refer to a general orientation to research that implies the world can only be known if observable entities and regularities may be demonstrated and general laws verified through their measurement and verification. It relies on the positivist assumption that an objective reality exists: objectivity is the key term. The notion of value neutrality is accepted as critical in carrying out quantitative research. My challenge was to think differently about research and to learn about the orientation to qualitative research. I understand that qualitative research is an umbrella term for a wide variety of methodologies. The point is that I failed to realise the enormity of the shift I would need to make in order to understand participatory action research. When reflecting on my journey I often find myself shifting from one way of thinking about research to another. I have learned that selection of a methodology
depends on the research question you want answered. I will continue to explore the assumptions underpinning participatory action research in chapter four.

**Values, Interests, Assumptions and Principles**

I recognise that a researcher’s values and interests influence the direction of one’s inquiry therefore it is important to state at the outset my beliefs, positions, values and interests.

My values are respecting people and letting them talk about their concerns and interests. I respect diversity of opinion, even when some ideas are different to mine. I do not like to judge people. I believe that people make their own decisions about their lives. In my professional life as a nurse I have not forced a client to follow what I say, although I remember when I was working as a diabetes nurse educator in Iran, people wanted me to make decisions for them. I resisted. Instead I let them know about the different aspects of their treatments so they could make the final decision.

I value working *with* people. I like helping people. My friends call me a caring and understanding person. Maybe this is one of the reasons that I chose nursing as my profession. It gives me the scope to help people until they can help themselves.

I value social justice; I do not like racial, ethnic or social discrimination among people and I remember that I was criticised by one of my colleagues when I was working at the Endocrinology and Metabolism Research Centre in Iran, who held that some people did not deserve treatment because they had not complied with their medication regimen. I
disagreed with her because I believe that everybody deserves treatment regardless of their behaviour, class and/or education.

I come to this inquiry with a basic set of beliefs to let people have a voice and set their own agenda which I will attempt to outline as follows; I was always ‘superior’ or an expert in relation to my participants in my previous research studies. This time, however, I wanted to research alongside the participants and acknowledge them as co-researchers. They would be able to say what they wanted, validate the data generation and have their own voice heard and acknowledged. I believe that my inquiry should be of practical use for the participants and that they should feel that they belonged in the research process and it to them.

The principles selected to guide this inquiry are my belief in democratic principles - social justice, social equity, freedom of speech and human rights – hence my participative world view. These principles embrace a democratic, collaborative approach to research that equitably involves all persons (facilitators/researchers and participants) in the research process. In principle, I recognise the unique strength that each person brings to the inquiry, I insist that voices are heard and I attempt to break down the distinction between facilitator/researcher and participants. When researching alongside people collaboratively, I work toward building sustainable relationships, I recognise a group as a community and I build on strengths and resources within that community. As a facilitator/researcher I sought to help this community to work together to improve their lives (reform). These principles are appealing to me, particularly as they sanction research with participants and in this inquiry, and particularly allow me to
research with participants who are in the process of “learning to live with” a chronic condition.

As discussed previously, I was more familiar with a non-participatory action research approach. But I was convinced that researching with the women would allow me a far richer understanding of the process of learning. I also assume that, whereas numbers and statistics are “safe” and “acceptable”, listening to and exploring stories is exciting work and that it may be challenging at times.

With my experiences, interests, beliefs and values in mind I wanted to understand how women and their families learn to live with, and adjust to chronic illness conditions. My premise for doing this is that by understanding how people and families adjust to chronic conditions, I may be able to make a meaningful contribution to the lives of others by sharing this knowledge with people in this situation in the future and with the health professionals who play a key role during the illness transition process.

**Purpose of the Study**

The purpose of this study is to explore with women, and their family members, the ways in which the women learned to live with Type 2 Diabetes. My aim is to understand what happens to the women during their first year following a diagnosis of diabetes and how it impacts on them and their family members. Using a participatory action research (PAR) methodology, I also wanted to explore with them, the practical ways in which they transitioned at this time. I reasoned that as women are learning to live with diabetes, it is possible that the lifestyle changes they are encouraged to make will have
an impact on their families. Ultimately, I was interested to know what practical suggestions women might have for this transitional period and what, if any, suggestions they would make for health care professionals about educational programmes and/or support services for people with diabetes. I used PAR methodology because it aligned with my core values and interests previously described above. As it is important to know how people who are newly diagnosed with diabetes learn to live with their condition and make changes in their lives, I was interested to follow the women’s learning process over twelve months.

Research Question

The research question for the study is:

**How do older women, who are newly diagnosed with diabetes, learn to accommodate and live with their condition during the first year post diagnosis?**

Related researcher questions are:

1. What happens in the lives of older women and what are their learning processes in the first year post diagnosis?
2. What happens within the women’s families as a consequence of being diagnosed with diabetes?
3. In terms of sharing learning to live with diabetes, what are possible reform strategies suggested by participatory action research group participants that could inform the practice of health care professionals?
Overall Aims

The aims of the study are;

- explore with women, and their family members, ways in which the women learn to live with Type 2 Diabetes, how it impacts them and
- explore possible reform strategies

My Objectives in Relation to the Inquiry are as Follows:

1. In the first phase of this participatory action research process, to engage with women (and then their families) in ongoing interviews and conversations to ‘look and think’ about what is happening in their lives and explore individual and family members’ learning processes since the woman’s diagnosis with diabetes.

2. Using the ‘look, think and act’ participatory action research process, to concurrently analyse ongoing interviews with the women and conversations with their families, and provide feedback on actions and document progress (or otherwise).

3. To track ‘learning events’, in each woman’s life trajectory since diabetes was diagnosed, (achieved through sustained involvement with the family), that is, tracking points in her day to day life where she has learned a new strategy, or had an experience which she remembers, associated with a change in her attitude to her diabetes.

4. To invite women and their families to join a participatory action research group, and in collaboration with this group explore possible reform strategies that the
participants may suggest in health promotion activities and service delivery. This group will run concurrently to the individual interviews with women and/or family conversations.

5. Share suggested reform strategies with health care professionals. In the effort to create environments in which people can thrive, consider ways in which these findings can be shared with the participants, families and the medical staff who deliver care.

I understand the sequence of ontology and epistemology leading to methodology: the ontological question: 'What is there that can be known?'; the epistemological question: 'What is the relationship of the knower to the known?'; and the methodological question 'How do we go about finding out?' (Guba & Lincoln, 1989).

My ontological position was to discover how older women who are newly diagnosed with diabetes learn to live with their chronic condition: What is it like being diagnosed with diabetes? My epistemological position was to investigate, by listening to the women and the families’ stories, how they learn to live with diabetes during their first year following diagnosis. In addressing this stance, I accepted that people create their own knowledge and that I should trust the women and their family for this knowledge. The women’s stories were not to be judged by me. I incorporated excerpts from my reflective journal and note my observations while in the field, through the individual and PAR group meetings. The women and their families were to be encouraged to validate their own stories until they were satisfied. This pointed to a participatory action research methodology approach which is consistent with my values, interest, ontological and epistemological stance.
In the participatory action research (PAR) framework proposed here, I as the researcher walked alongside participants for one year, (the longitudinal arm of the inquiry), as they accommodated their changed life circumstances. I explored what happened in their lives in the context of their family and observed the changes that occurred? I observed how the women learned and accommodated their diabetes during the first year. I also observed and explored what changes occurred within their families as a result of their wife’s or mother’s diagnosis. Finally, I recorded and monitored the reform strategies that they introduced into their lives.

It was important that the participants took the ownership of the research through the whole inquiry and that participants’ voices were represented. I have therefore ensured that all of the women’s and their families’ voices are included in the text and faithfully reported in this thesis.

**Overview of the Thesis**

**In chapter one** I outline the context of the research setting for this inquiry. Three types of contexts are covered in this chapter: local, national and global. I have elected to explain these contexts, starting from the actual setting of this inquiry and then putting it in the bigger pictures of the national and then the international frames in order to give a sense of what happens when a person is diagnosed with diabetes and the service they can expect to receive, the programmes one can expect to find, and the international frameworks that give shape to chronic illness programmes. As an outsider researcher it was important to understand these contexts.
Chapter two constitutes a review of the current literature on the topic of chronic condition and diabetes research, relating to the proposed inquiry. Although I will be building my research on Kralik’s transition thesis (2000), the questions, which I kept in the forefront of my mind as I read, are:

- What are the distinguishing features of a chronic condition and the ways in which people are able to accommodate the experience of a chronic condition in their lives?
- How do people learn to live with a chronic condition?
- What is the lived experience of a chronic condition such as Type 2 Diabetes?
- What are the debates surrounding chronic conditions?
- What are the findings from studies that have explored the way in which people learn to live with and accommodate chronic disease and their illness experience?
- What does learning and education, in this context, actually mean?
- What are the distinctions in the ways in which men and women learn to accommodate a chronic disease, and how do they experience this in their lives?
- Are there any studies that focus specifically on women living with diabetes?
- Is there any research work around tracking women with newly diagnosed diabetes, and researching alongside them longitudinally?
- Can I deduce from this literature review that the research I plan has not been attempted elsewhere/ or if it has, how does my proposed study build on previous work or differ from it, and what may my study contribute?’

Chapter three traces the history and beliefs, philosophy and guiding principles of Participatory Action Research. I provide the rationale for the selection and appeal of Koch and Kralik’s (2006) PAR approach and feminist inquiry, PAR and the role of the
facilitator, storytelling and theory building and research rigour and, finally, quality in this PAR inquiry.

**Chapter four** outlines the aims and objectives of this inquiry and the research process. I expand on the setting for this inquiry and describe how I gained access, including the recruitment process. I introduce the participants (eleven women and their family members), the data generation strategies, including interviews, group meetings and the role of my own reflective journal in that generation process and the processes for analysis. How rigour and quality were attempted in this inquiry is also outlined.

**Chapter five** is about storytelling (one-to-one interviews) with eleven women and their families’ feedback and construction of a storyline. My reflections are included as well as a short discussion about commonalities of experiences.

**Chapter six** describes the PAR process as I researched alongside eleven women in a group, guided by the principles of participatory action research and following the cyclical processes of ‘looking, thinking, and acting’ as an iterative process. I describe the preparation involved for each meeting, the agreed norms for the group meetings, PAR group processes and my role as facilitator. My reflections about the PAR process are incorporated throughout the text. Most importantly I draw close attention to the way in which this PAR group functioned and explore the notion of group dynamics as it relates to PAR. I discuss the PAR group meetings’ findings and the other literatures.

**Chapter seven** answers the research question: *How do older women, who are newly diagnosed with diabetes, learn to live with their condition during the first year post*
**diagnosis?** I systematically show the ways in which I have met the objectives. The chapter also comprises the study’s limitations and a review of the implications of the inquiry for health care delivery for people with diabetes, nursing practice, education, research, practice and management. Recommendations and further research are also suggested.

**Conclusion**

In this introduction to the thesis, I provided personal background information so that the cultural understandings I bring to the inquiry are transparent to the reader. As I believe values and interests guide an inquiry, these understandings may unwittingly influence the way in which I interpret and communicate this inquiry. Cultural values I hold dear are my appreciation of family life and the support family members give each other. I have experienced firsthand what it is like when a member of the family has a chronic condition and the impact this has on the entire family. This is also the reason why I wanted to research alongside women newly diagnosed with diabetes and their families.

Mundane insights about food were shared as food shopping, preparation and its delivery to the table was inevitably my Iranian mother’s role and finding myself having to take over this role made me realise how much I had taken for granted in everyday life. In relation to this study, I suspected that women newly diagnosed with diabetes would have to change their life style and that this would impact on their families as well. The first line of treatment for people diagnosed with mature onset diabetes is a change in diet (low fat, low carbohydrates, high fibre). Given the need for a changed diet, I expected that the family would also need to comprehend a large amount of unfamiliar
and complex dietary information and routines associated with food intake and diet almost immediately. The findings from this study show this to be true.

In the following chapter I set the stage for the study by describing relevant background and contextual issues.
CHAPTER ONE

CONTEXT: SETTING THE STAGE FOR THIS INQUIRY
Introduction

In this chapter I describe the contexts and setting for the study. In order to contextualise the study I discuss the three contexts for chronic disease management, namely local, national and international by highlighting the main issues and concerns.

The local context and setting for the inquiry comprised a diabetes centre situated in a regional city Newcastle, within the Hunter and New England Local Health Network (previously known as the Hunter and New England Area Health Service) in New South Wales, Australia hereafter known as HNELHN (NSW). Secondly, in an effort to contextualise this study in a national sense, the Council of Australian Governments (COAG) and the growth of “chronic condition” programmes available around Australia will be discussed. Thirdly, I will highlight and critique the debates around chronic diseases as discussed by the World Health Organisation; describe relevant current health statistics, the perceived global epidemic and the WHO chronic disease framework. I will describe major chronic disease programmes influenced by the World Health Organisation framework.
The Local Context

As stated above, the local setting for the study was a diabetes centre situated in Newcastle, NSW, Australia. One of the reasons this local area was selected for my inquiry was because of its high rate of Type 2 Diabetes. As well, the local health service was supportive of the study, open to the idea of health reform and they were willing to help by facilitating the recruitment of potential participants. Newcastle is a beautiful coastal city north of Sydney, at the mouth of the Hunter River.
The Newcastle metropolitan area is the second most populated area in New South Wales, with a population of 500,000. It is the main city within the Hunter Region, a major coal mining and wine producing area, and currently the largest coal-exporting harbor in the world. In 2009, the two largest single employers in Newcastle were the HNELHN Service and the University of Newcastle (Australian History, 2010). Despite its apparent wealth, the Hunter Valley also has a high unemployment, domestic violence and alcohol addiction rates and poor school attendance rates. This demographic information may be of relevance in the high incidence of Type 2 Diabetes in the HNELHN (NSW).

The HNELHN provides care for approximately 840,000 people and covers a geographical area of over 130,000 square kilometres, employing approximately 14,500 health care professional and administrative staff. This region provides health services to 12% of the New South Wales population and 20% of the State's Indigenous population. It is now the largest health network in the state (HNELHN Service report, 2010).

This network spans thirty two local government areas with the head office in Newcastle and a regional office in Tamworth. This region in New South Wales Health is distinctive because it is the only Health Network with a major metropolitan centre (Newcastle/Lake Macquarie: pop: 500,000) combined with a mix of several large regional centres and many smaller rural and remote communities within its borders (HNELHN Service report, 2010).
Living with a chronic condition has a significant impact on early death, increase in disability and reduction in quality of life. It is not only the person diagnosed with a chronic disease whose life is affected; it also affects the family members and social network (Koch, Jenkin, & Kralik, 2004). The HNELHN, consistent with the national health plan (Australian Institute of Health and Welfare, 2010), has developed its own chronic disease services plan. The aim of the plan is to focus on prevention of chronic diseases (Australian Institute of Health and Welfare, 2010).

Local Chronic Disease Services Plan

This Chronic Disease Services Plan is based on the patients' needs. Many health care professionals contributed to designing the plan. In the following I outline this plan.


The New South Wales Chronic Disease Strategic Framework is about providing support strategies and elements of service delivery, for best practice relating to the care of people with chronic diseases in New South Wales. The HNELHN Service and the New South Wales Health Department outline principles for managing chronic conditions (Australian Institute of Health and Welfare, 2006).
The first principle is to adopt a population health approach and to reduce health disadvantage. Equity has been considered to include all populations, regardless of their social, economic, cultural, educational and racial backgrounds, holding that everyone ought to receive the same chronic condition service facilities (HNELHN Chronic Disease Services Plan, 2010).

The second principle of the chronic condition framework is that of prioritising health promotion and prevention. All people at risk of a disease should be encouraged to prevent the onset of that disease. Health promotion such as informing people about chronic disease and encouraging them to visit their general practitioner for screening is consistent with creating a supportive environment for people with disease, or at risk of that disease. In promoting health there is an increase in the community’s capacity to look after the sick and to make connections between people and the health services. In accordance with the principles of preventative medicine, it is important that the risk factors for chronic diseases, such as smoking, obesity, alcohol dependence, chronic high distress levels and inadequate physical activity are monitored and people encouraged to change their behaviour (HNELHN Chronic Disease Services Plan, 2010).

The third principle speaks to the need for “person-centred care” which planners believe optimises self-management of any chronic condition; that is, that any person with a chronic condition should be considered as an individual where the needs of the person - psychological, spiritual and medical - are all taken into consideration through involving the person wherever possible in all stages of his/her treatment provided by health care professionals. It is argued that people with chronic conditions can remain empowered and, if given appropriate support and information, are capable of retaining control over
their lives and thus to optimise the quality of that life (HNELHN Service Chronic Disease Services Plan, 2010).

The fourth principle of the Chronic Disease Services Plan is concerned with effective care for people living with a chronic disease, maintaining that if such care is delivered it is more likely to improve their quality of life, reduce hospitalisation, maintain optimum physical and mental capacity (within the bounds of the disease), and maintain their work and social activities (HNELHN Service Chronic Disease Services Plan, 2010).

The fifth principle of the Chronic Disease Services Plan is to facilitate coordinated and integrated multi-disciplinary care across services, settings and health care sectors. According to the plan, people with a chronic condition need individualised support from the health services, family and carers. It is desirable that these multiple care approaches be flexible to make connection between the directly affected people, family members and health care professionals and systems to work together to manage the condition (HNELHN Service Chronic Disease Services Plan, 2010).

The sixth principle in the plan regards the ability to achieve significant and sustainable change for people affected by a chronic disease, in order to self-manage, as far as possible their care and symptomatology, maximise their QOL and minimise potential complications resulting from the disease. For achieving this goal, there are different chronic illness plans and support groups in the community and people are encouraged to join them. For example, there are such plans as an asthma self-management plan, an arthritis self-management plan, and a Type 2 Diabetes self-management plan (described
later in this chapter). In fact, every chronic condition has standard care plans available to general practitioners ‘on a specific website’ (see, appendix A). According to the plan, if this principle is followed, health care professionals are “primed” to assist individuals toward achieving these aims (HNELHN Service Chronic Disease Services Plan, 2010). Finally the plan supports a principle that requires monitoring the progress of any implemented chronic disease plan, monitoring and reporting outcomes and adjusting where required (HNELHN Service Chronic Disease Services Plan, 2010).

According to the HNELHN Service report 2008, 7% of the HNELHN Service population has Diabetes or high blood glucose. In this group 19.3% have Type 1 Diabetes, 80.3% have Type 2 Diabetes and 0.4% have Gestational Diabetes Mellitus (GDM). More than 60% of people with Type 2 Diabetes are women over fifty-five years of age (HNELHN Service Diabetes Services Plan, 2009).

With these population health statistics in mind, the HNELHN Service has developed a plan for prevention and managing diabetes with the focus of this on the education of people who are at risk of the complications of diabetes (HNELHN Service Diabetes Services Plan, 2008).

**Local Diabetes Services**

In response to the increasing prevalence of diabetes within the HNELHN region, several Diabetes Services developed a Network - wide five year plan (2008 to 2012). The scope of the diabetes plan is to support the adults diagnosed with the disease in their chronic
condition self-management. The plan aims to facilitate access to the diabetes services across the HNELHN Service area especially for people with diabetes complications. The plan increases health promotion and early diabetes detection and treatment and also identifies the strategies to ensure an adequate and skilled workforce (HNELHN Diabetes Services Plan, 2008).

As discussed earlier in this section, the HNELHN Service is working with different external parties such as Diabetes Australia-New South Wales, a non-profit organisation, which works with Diabetes health care professionals, educators, researchers and health care providers to decrease the impact of diabetes in Australia through community education and the prevention, detection, management and support of people with diabetes and their families. This organisation is supported by the community and the government and funded research (Diabetes Australia Research Trust [DART]), education and the ‘kids’ camp’, and advocating for people with diabetes in relation to government decision making (Diabetes Australia Report, 2010).

The other external party with whom the HNELHN is working is the National Diabetes Services Scheme, which was established in 1987. The aims of this scheme are to provide insulin syringes, pumps and diagnostic devices for people with diabetes. The Heart Foundation, another organisation which collaborates with the HNELHN, is represented through Hunter Diabetes Services (HADS) and provides information for the public and health care professionals regarding the secondary risk of coronary disease. The close collaboration of the Heart Foundation with the HNELHN Diabetes Services is related to the ‘Heart Moves’ exercise programme for people with diabetes (National Diabetes Services Scheme Report, 2010).
The HNELHN provides education programmes for people diagnosed with Type 2 Diabetes, recognising that one of the key aspects of management is self-management. The training programme includes content such as “What is pre Type 2 Diabetes and Diabetes”. It also includes an insulin education programme (IEP), which involves training people in using insulin and the signs of hypoglycaemia.

The diabetes class also includes an individualised diabetes self-management programme focused on intensive insulin therapy for the patient. I explain the diabetes self-management education programme below:

**Diabetes Self-Management Programme**

As the women in this study preferred to call this programme the ‘diabetes educational classes’ or ‘diabetes classes’, I use these terms throughout the entire thesis. Seven Diabetes Nurse Educators and seven Dietitians run the diabetes educational classes: the programme consists of three classes about diabetes, designed for those who are newly diagnosed and are free to all NHELHN Service users. There are five main centres, Newcastle, Wallsend, Maitland, Toronto and Cessnock, which provide the classes (Diabetes Self-Management Education programme Facilitators’ Manual, 2005).

According to the HNELHN Service report, 1,966 people diagnosed with Type 2 Diabetes attended diabetes classes in 2005; of this number, 904 people were newly diagnosed with Type 2 Diabetes (HNELHN Service Report, 2005).
At the start of this inquiry I sat in on the diabetes classes in order to gain an understanding of the content and focus of the self-management programme. The content of these classes was as follows: (For further information about these classes see appendix B). As noted above, these classes aim to help people with diabetes increase their knowledge, skills and motivation to self-manage. The content emphasises that people with Type 2 Diabetes need to do exercise, change their diet, take their medications and monitor their blood glucose levels (Diabetes Self-Management Education Programme Facilitators’ Manual, 2005). The programme consists of three classes about diabetes designed for those who are newly diagnosed. The classes are provided free to HNELHN users and are organised and provided by a Diabetes Nurse Educator and a Dietitian. All of the three educational classes follow the same format (Diabetes Self-Management Education Programme Facilitators’ Manual, 2005). The diabetes self management programme offered by HNELHN is directly linked to the Australian Government’s Better Health Initiative (ABHI) to address the emerging crisis in chronic conditions outlined in the following section.

The National Australian Context

Before explaining the national context of chronic disease, a brief overview of the Australian Health Care System is needed. According to the International Profiles of Health Systems (2010), Australia achieves universal coverage through Medicare, a tax-funded public insurance programme that covers most medical care, including medical, surgical and hospital services and prescription drugs. Most health services are financed and regulated by the federal government, although the states and territories have responsibility for public hospital care. Besides Medicare, roughly half of the Australian
population receives additional coverage through private insurance, which the government subsidises and which covers such services as dental care and private hospitals.

Whilst the life expectancy of an Australian in 2010 was 79 years for males and 84 years for females (Australia’s Health, 2010), the prevalence of chronic diseases is increasing, largely attributed to lifestyle factors such as stress, smoking, physical inactivity and excessive alcohol intake. According to the Australian Bureau of Statistics in (2007-2008), the prevalence of chronic diseases is reported by way of the incidence of cancer (2%), diabetes (4%), asthma (10%), chronic mental and behavioural conditions (11%), arthritis (15%) and circulatory diseases such as high blood pressure (16%). Furthermore, with the increase in the proportion of the aged in the population of Australia, there is a concomitant increase in the incidence of diseases characteristic of old age, such as Type 2 Diabetes. Of concern is that most of the Australian Health System focuses on the provision of acute care, with little focus on the need for chronic disease self-management programmes (Battersby, Lawn, & Pols, 2010).

In 2006, the Council of Australian Governments (COAG) established the Australian Better Health Initiative (ABHI) to address the emerging crisis in chronic conditions. A core element of the initiative is the education of the future and current Australian workforce in self-management support. The Flinders Human Behaviour and Health Research Unit was contracted to provide an Australian curriculum for self-management support for all undergraduate and professional entry courses across Australia such as nursing, medical professions and allied health. They provide a two-day workshop
addressing patient-centred chronic condition self-management for the health care professionals from around the world (Battersby, 2006).

Because of the forecasts for chronic diseases and the associated need for improved health care through prevention and self-management programmes, the Australian Federal, State and Territory Governments have shifted their focus onto chronic disease care through the National Chronic Disease Strategy, associated with the National Service Framework and Blue Print for Chronic diseases Surveillance (Australian Government Department of Health and Aging, 2010). In instigating the Australian Better Health Initiative (ABHI), the COAG National Reform Agenda recognises chronic disease self-management (CDSM) as an important strategy in decreasing the impact of these diseases (Australia’s Health, 2010).

The National Chronic Disease Strategy (NCDS) provides a national framework for the prevention and treatment of chronic diseases, including asthma, cancer, Type 2 Diabetes, heart, stroke and vascular conditions, osteoarthritis, rheumatoid arthritis and osteoporosis (National Chronic Disease Strategy, 2005).

The first part of this plan involves the Chronic Disease Surveillance (CDS) network, which establishes the national network for collecting, analysing and monitoring the data relating to chronic diseases and associated determinants. The second entails reporting on existing data which means disseminating the data through publication. The third plan is to prioritise national chronic condition policies and finally to focus on capacity building and bringing all surveillance to current national standards. These frameworks emphasise health promotion, prevention and monitoring the risk factors for chronic diseases,
supporting multidisciplinary care, promoting self-management in health systems, improving quality of care and particularly improving access by Aboriginal and Torres Strait Islander people to chronic disease prevention and care services (CDS, 2010).

The other way of monitoring Type 2 Diabetes prevalence in Australia is through the National Diabetes Services Scheme (NDSS) data (National Diabetes Strategy, 2010). The Institute of Obesity, Nutrition and Exercise work together with the COAG committee to decrease the prevalence of Type 2 Diabetes (COAG, 2010).

As one of the diseases with the highest rate of diagnosis in Australia is Type 2 Diabetes and it is the nub of my thesis, I discuss this in the following section.

**Type 2 Diabetes**

The prevalence of Type 2 Diabetes is increasing and is one of the leading causes of co-morbidity and mortality. According to the Australian Institute of Health and Welfare (2008) it is estimated that 4% of Australian people were diagnosed with Type 2 Diabetes in 2008. Type 2 Diabetes is responsible for 3% of deaths and for 5.5% of the burden of disease in Australia.

The focus of the Australian Diabetes Strategy (2010) is on prevention and treatment of diabetes. The mission of this strategy is improving the general level of health in Australia by reducing the personal and public burden of this chronic disease. This strategy’s principles include: effective service delivery for people with Type 2 Diabetes to reduce the rate of mortality, improving the skilled workforce to focus on prevention,
early detection and management of diabetes, providing information systems for managing Type 2 Diabetes and its complications. The goals of this strategy include: improving the capacity of the health system, preventing diabetes, improving the quality of life and reducing morbidity, achieving long term plans for mothers with diabetes and their children and advancing knowledge about all types of diabetes. In addition, there is a National Service Framework for Diabetes (NSFD) (National Diabetes Framework, 2010).

This framework helps people with diabetes and their families to manage their condition. It has five priorities: the people with diabetes and their families; the needs of people with diabetes; the requirements for making changes; improving care and national actions for making changes in diabetes management. For achieving this goal it is important that people with diabetes and the health care systems collaborate with each other very closely. It is also important for people who are at risk of developing Type 2 Diabetes to make changes in their lifestyles by such means as increasing physical activity, a focus on healthy diets, reducing stress and giving up smoking (National Diabetes Strategy, 2010).

In 2010 the Prevention of Diabetes programme was designed by the COAG to prevent or delay the onset of diabetes (COAG, 2010). This Australian Federal Government programme enables people who are in their forties, who are at risk of Type 2 Diabetes, to receive lifestyle advice from their general practitioners. The Australian Federal Government has also funded campaigns to encourage the change to a healthy lifestyle to prevent the onset of diabetes or encourage people with diabetes to manage their condition (National Diabetes Framework, 2010). For example, the Government
subsidises diabetes medications and also funds the National Centre for monitoring diabetes within the Australian Institute of Health and Welfare (AIHW) and the National Diabetes Registry, an AIHW managed database that collects information about people who use insulin, for managing their Diabetes.

Diabetes Australia is another important organisation that helps people with diabetes. The help provided ranges from providing educational classes, books, magazines, blood glucose meters, needles, strips for assessing blood glucose levels and diabetes foods. They also publish a colourful and appealing magazine, containing personal anecdotes for people with Diabetes, coupled with tips for successful self management (Diabetes Australia, 2010).

**The Global Context**

As I mentioned earlier in this chapter, diabetes is a chronic disease not restricted to Australia; it is with this in mind that I discuss the global public health issues associated with diabetes.

According to the WHO, in 2010 the major chronic diseases in the world currently are: cardiovascular disease, cancers, diabetes and chronic respiratory conditions. It is estimated that 35 million deaths each year are related to chronic disease, however, up to 80% of cardiac conditions, stroke and diabetes and more than 33% of cancers could be prevented by reducing non-salutogenic lifestyles. When talking about unhealthy lifestyle factors they refer to: tobacco consumption, unhealthy diet with too much
saturated fat and refined carbohydrates, a sedentary lifestyle and alcohol consumption (WHO, 2010).

The death rate resulting from a chronic condition is predicted to increase to 17% over the next ten years. The highest mortality rates relate to the African region (27%), followed by the Eastern Mediterranean region (25%) (Yach, Leeder, Bell, Kistnasamy, 2005). The WHO has therefore devised an action plan (2008-2013) for a global strategy for the prevention and control of non-communicable conditions or chronic diseases. The overall aims of this action plan are: mapping the epidemiological, social, economic, behavioural and political aspects of the chronic conditions, reducing the individual exposure to chronic condition risk factors such as poverty, pollution and tobacco consumption and strengthening the health care for people with a chronic condition. The foundation of this action plan is the global strategy for the prevention and control of chronic conditions in order to reduce premature mortality and improve quality of life (WHO, 2010).

This plan was made based on the World Health Organisation Framework Convention on Tobacco Control and the Global Strategy on Diet, Physical Activity and Health (WHO, 2008). In addition, the plan focuses on the harmful effects of alcohol consumption; a plan also guided by the Medium-term Strategic Plan 2008-2013 and the Eleventh General Programme of Work, to prevent chronic conditions. This action plan has six objectives, which give details of the domestic, national and international actions and indicators of performance. The first objective is to raise chronic disease as a priority globally and nationally and to integrate prevention and control of such conditions into policies across all government departments. International public health advocacy groups
must be aware of the relationship between chronic conditions and global social and economic development. In addition, the people suffering from chronic conditions are often those also blighted by poverty (WHO, 2010).

There are some actions which are proposed for the local health care providers. These actions include: access and monitor the public health burden of chronic diseases, especially for poor populations, incorporate to prevent and control the chronic conditions, adopt approaches to involve all of the government departments and implement programmes for prevention of chronic conditions among the whole population, particularly for low income people. There are also actions for the WHO such as: raise the priority of chronic disease prevention agenda for national and international leaders, work closely with countries to make policies for chronic conditions and disease management and considering poverty, help countries to make policies for determining the risk factors. WHO should also support policy coherence and making connections between the findings of the Commission on Social Determinants of Health and the prevention and control of chronic disease conditions (WHO Action Plan, 2008).

The second objective is to establish and strengthen national policies and plans for the prevention and control of chronic conditions. These policies consider gender, ethnic and socioeconomic factors in each country. The proposed actions for the local health systems include: develop and implement a comprehensive policy, planning, guiding, monitoring and evaluating the national policy, assessing the policies problems and reviewing the evidence-based legislations. Proposed actions in WHO include: reviewing the international experience in prevention and control of chronic conditions,
recommending successful approaches in prevention of chronic condition based on the country’s experience and providing guidelines for the development of the national policy framework for reduction of risk factors and supporting individual countries, also using the existing strategies such as World Health Organisation Framework on Tobacco Control, The Global Strategy on Diet, Physical Activity and Health, The Global Strategy for Infant and Young Child Feeding and other relevant strategies for reducing the risk factors of chronic condition and supporting the regional and global community-based programmes (WHO Action Plan, 2008).

The third objective is to improve interventions to reduce the main shared modifiable risk factors for chronic conditions: tobacco use, unhealthy diets, physical inactivity, poverty, pollution and harmful use of alcohol. The proposed actions for the local health systems are controlling tobacco by implementing prevention policy, warning people about the side effects of tobacco consumptions, making efforts to ban tobacco advertisement and raising tobacco tax. The other proposed actions for the local health systems, in relation to the WHO plan are related to promoting healthy diet by supporting breastfeeding, developing national policies for nutritional foods such as low fat, low salt and low sugary foods and providing accurate nutritional information, promoting physical activity by developing and implementing national guidelines on physical activity for health, implementing physical activities in schools based on the WHO recommendations and providing safe environments for exercise.

The last suggested action for the local health systems is related to reducing the harmful use of alcohol by creating relevant frameworks in the community such as alcohol free beverages, alcohol free zones and alcohol consumption guidelines, in particular
targeting underage drinking, binge drinking, women’s alcohol consumption and foetal alcohol syndrome, alcohol related violence and the impact on traffic accidents (WHO Action Plan, 2008).

The fourth objective is to improve research for the prevention and control of chronic conditions. The proposed actions for the local health systems include: investing in epidemiological, behavioural and health system research and encouraging to establish national networks to research on socioeconomic determinants, gender, the cost-effectiveness of interventions, affordable technology, reorientation of the health system and workforce development. The WHO proposed developing a research agenda for chronic conditions based on the World Health Organisation global research strategy: prioritising the research agenda for translating knowledge into actions, assessing the burden of chronic conditions in low and middle-income countries, monitoring the impact of poverty, assessing the national capacity for prevention of chronic condition and finding the gaps, evaluating the community based programmes for reducing the risk factors of chronic conditions, evaluating the secondary prevention of chronic conditions programmes and encouraging the research centres to collaborate with the World Health Organisation. Proposed actions for international partners include: supporting the low and middle-income countries in capacity building, working with regional, national and international level research on modifying lifestyles to prevent chronic conditions and collaborating with the World Health Organisation centres in controlling chronic conditions (WHO Action Plan, 2008).

The fifth objective of this action plan is to promote partnerships for the prevention and control of chronic conditions. The proposed actions, for the local health systems are:
participating in regional and subregional chronic condition prevention activities and involving the stakeholders in control and prevention of chronic condition programmes.

The actions for the WHO are; establishing strategies and reviewing them with the collaboration of the World Health Organisation centres, encouraging the regional and global sectors in monitoring the global strategies of chronic condition prevention and encouraging the collaboration of the global sectors to work together and use the World Health Organisation policies in chronic condition prevention and controlling it. The proposed actions for the international partners include: collaborating with the member states and the secretariat in global prevention and control of chronic condition strategies, giving priority to the international and regional activities to strengthen the health systems based on the primary health care and supporting the established global and regional networks for the prevention of chronic conditions (WHO Action Plan, 2008).

The final objective is to monitor chronic diseases and their determinants and evaluate progress on national, regional and global levels. The proposed actions for the local health systems are strengthening surveillance systems and standardised data collection on risk factors, chronic condition incidence and mortality by using the WHO strategies, with a particular eye to variance in people based on their age, gender and socioeconomic groups.

The WHO Action Plan proposes developing and maintaining chronic disease prevention programmes; establishing a group to study the epidemiology of the chronic diseases; strengthening technical support for the local health care systems with their data collections regarding mortality and mortality statistics; asking stakeholders about the
impact of implementing the Action Plan at national levels and preparing a progress report about the various strategies. The proposed actions for international partners are collaboration between the local health systems and the WHO in the above activities and moving necessary resources to support the regional and global preventive action plans (WHO Action Plan, 2008).

**Diabetes Prevalence Worldwide**

One of the main chronic conditions is diabetes and there are different global organisations which deal with diabetes, such as the WHO and the International Diabetes Federation (WHO, 2010a). The world prevalence of Type 2 Diabetes among adults (aged 20-79 years) was 6.4%, affecting 285 million adults, in 2010, and these will increase to 7.7% and 439 million adults by 2030. Between 2010 and 2030, there will be a 69% increase in the numbers of adults with Type 2 Diabetes in developing countries and a 20% increase in developed countries (WHO Report, 2010b). The global mortality rate of Type 2 Diabetes is 3.2 million people and it is responsible for over one million amputations each year. It is a major cause of blindness and if nothing is done, the healthcare budgets will be unable to pay for the cost of Type 2 Diabetes care. While Type 2 Diabetes is not yet curable, in many ways it is preventable.

Clearly these statistics are alarming. It is important, therefore, to focus first on prevention and secondly on the reduction of complications associated with Type 2 Diabetes. In discussions on complications arising from Type 2 Diabetes, key national and internationals, such as the WHO (2010c) and International Diabetes Federation
(2009) have reported on the high rates of chronic complications and their consequences among people living with diabetes.

The World Health Organisation Diabetes Unit is based at Headquarters within the Department of Chronic Diseases and Health Promotion. This department is also working on the surveillance, prevention and management of chronic conditions, including cardiovascular conditions, chronic respiratory conditions, cancers and diabetes (WHO, 2010b). The Diabetes Unit works closely with the International Diabetes Federation and with over 25 collaborating centres throughout the world.

The overall goal of the Diabetes Unit is to improve health for the surveillance, prevention and control of diabetes and its complications particularly in low and middle-income countries. This goal is guided by focusing on some core functions. These core functions include: considering the international standard norms in diabetes diagnosis, treatment, complications and risk factors, promoting the surveillance of diabetes and its complications, mortality and risk factors, contributing in capacity building for the prevention and control of diabetes, raising awareness about the importance of diabetes as a global health issue and advocating for prevention and control of diabetes in vulnerable populations (WHO Report, 2010c).

There is a ‘diabetes action now’ programme through the collaboration between the WHO and the International Diabetes Federation (2009). The World Diabetes Foundation (WDF), non-governmental organisation, and the World Health Organisation fund this programme. The overall purpose of ‘diabetes action now’ is to stimulate and
support the adoption of effective measures for the surveillance, prevention and control of diabetes in low and middle-income countries and communities (IDF, 2009).

As a result of these programmes, some global and regional activities take place, including World diabetes day which is on the 14th of November each year and the WHO and International Diabetes Federation (IDF) celebrate this day, Regional declaration on diabetes with the collaboration between the WHO and IDF for focusing on diabetes in each region, diabetes congresses, conferences and workshops to provide scientific information to improve prevention and health care (IDF, 2009).

**Chapter Summary**

In this chapter I described the setting I was researching, in the HNELHN Service. This local setting comprises the diabetes centre situated in Newcastle, HNELHN Service Australia. Then, in an effort to contextualise this study, the Council of Australian Governments (COAG) and the growth of chronic disease programmes available around Australia, were discussed. I outlined the World Health Organisation, its chronic disease health statistics, the perceived global epidemic and its chronic disease framework. I examined major chronic disease programmes influenced by the World Health Organisation framework.

The reason that I selected to explain these three contexts was to begin with the actual setting of this study and then enlarge the frame of reference to the national and then the international frames, to situate it in an understandable context.
Bearing in mind all of the programmes and frameworks already in place, I nevertheless wondered whether they are sufficient for people with chronic diseases. Might it not be possible to ask people actually experiencing a chronic disease to let the health care professionals know what they really want? The gap in the chronic disease programmes and frameworks might be the voices and firsthand experience of people with a chronic disease and the experiences they share with others of similar diagnosis. When someone is newly diagnosed with a chronic disease, he/she might need to have time to think about what is really happening. They might like to gather information about the situation in which they find themselves, but as there are many different sources it may not be easy. What is really trustworthy and suitable? I am interested in asking women how they deal with their diagnosis and what it is like for them. Family members, who are also affected by the diagnosis, might be interested in sharing their own stories too, from all of which clinicians might learn.

In the next chapter, I outline the available research literature about this study. To fulfil this purpose, I reviewed the studies that provided information about how older women, who are newly diagnosed with a chronic condition, such as Type 2 Diabetes, learn to live with their condition. This learning is discussed in light of theories, definitions and models of chronic condition, chronic illness and transition, chronic illness management and adult learning. The other part of the literature review is about the role of support in learning to live with a chronic condition; older women and how they can learn to live with a chronic condition; learning to live with a chronic condition and storytelling; learning to live with newly diagnosed Type 2 Diabetes; learning to manage the newly diagnosed Type 2 Diabetes and gender differences in learning to live with the newly diagnosed Type 2 Diabetes.
CHAPTER TWO

LITERATURE REVIEW: LEARNING TO LIVE WITH A CHRONIC ILLNESS
Introduction

"Tell me and I will forget, show me and I may remember, involve me and I will understand."

Confucius.

"For the things we have to learn before we can do them, we learn by doing them."

Aristotle

Persian Miniature: Apprentice herbalist

In the previous chapter I described the local, Australian and global contexts for this study and I described the policies and programmes that focused on diabetes self-management. I provided information about the HNELHN Service’s profile, demographic information and the service delivery for people with diabetes and I included the details of the diabetes educational classes so that I could elucidate what knowledge was acquired by my participants and areas that were to require further information.
In this chapter I review the relevant literature surrounding chronic conditions that pertains to my research question. It is usual to review the literature and then formulate a research question, but in my case, as a novice participatory action researcher, I pragmatically selected to build on Kralik’s (Kralik, 2000, 2002; Kralik, Brown, & Koch, 2001a; Kralik & Koch, 2001b; Kralik, Koch, & Brady, 2000; Kralik, Koch, & Eastwood, 2003; Kralik, Koch, Price, & Howard, 2004; Kralik, Koch, & Telford, 2001c; Kralik, Koch, & Wotton, 1997; Kralik, Paterson, & Coates, 2010; Kralik, Seymour, Eastwood, & Koch, 2007a; Kralik, Telford, Campling, Koch, & Price, 2005a; Kralik, Telford, Price, & Koch, 2005b; Kralik, & Van Loon, 2007b; Kralik, Van Loon, & Telford, 2006a; Kralik, Visentin, & Van Loon, 2006b) research relating to transitions during illness. This means that the literature review will require an in-depth exploration of people’s self-management of a chronic condition and the emerging theory of transition. I aim to further the theoretical understanding of transition by studying the experience of older women newly diagnosed with diabetes. I believe the most appropriate methodology to walk alongside women for twelve months is participatory action research. In this way, the literature review covers both topic and methodology as I intend to use Koch and Kralik’s (2006) participatory action process.

Search Strategy

I used “Google advanced scholar, CINAHL, PUBMED, Proquest and gray literature”, using the terms such as: chronic illness definitions, chronic illness and transition, chronic condition self-management, learning to live with a chronic condition, theories of adult learning, readiness to learn, motivation to learn, learning and storytelling,
family/friend support in learning to live with a chronic condition and chronic condition self-management and gender difference.

The questions, which I kept in the forefront of my mind as I perused the literature, were:

• What are the distinguishing factors of a chronic illness and the ways in which people are able to accommodate their chronic illness experience in their lives?
  How do people learn to live with a chronic illness?
• What is the lived experience of having a chronic illness such as Type 2 Diabetes?
• What are the debates surrounding chronic illness?
• What are the findings from studies that have explored the way in which people learn to live with chronic illness?
• What does learning in this context, actually mean?
• What does learning mean in the context of group dynamics?
• What does chronic illness transition mean?
• What are the distinctions in the ways in which men and women learn to accommodate a chronic illness, and how do they experience this in their lives?
• Are there any studies that focus specifically on women living with diabetes?
• Is there any research work around tracking women with newly diagnosed diabetes, and researching alongside them longitudinally?
• Can I deduce from this literature review that the research I plan has not been attempted elsewhere/or if it has, how does my proposed study build on previous work or differ from it, and what may my study contribute’
Chronic Illness

First of all, it is important to distinguish between a disease and an illness. Health care professionals often erroneously use these two terms interchangeably. Disease refers to a disorder or pathological malfunction in an organism, in this case the human organism. Illness, on the other hand, refers to the human experience of “unwellness” and may, or may not, involve actual physical disease; perception is an important function of illness (Kralik, Telford, Campling, Koch, & Price, 2005a) and while it is important to recognise the biomedical aspects of a chronic disease, the illness experience is more notable for people with chronic diseases (Lubkin & Larsen, 2002, 2006).

Chronic illness is defined variously. According to Webster’s New World Medical Dictionary (2010) chronic illness is an illness that persists for a long period of time. The term "chronic" comes from the Greek (kronos: time), meaning to last a long time or constantly recurring. Based on the United States Centre for Disease Control and Prevention (CDC), a chronic illness is one which lasts for three months or more (CDC, 2010).

The debates around ‘disease’ or ‘illnesses’ reflect the relationships between ‘patient’ and health care professionals. Health professionals bring expertise in the general understanding of disease, its aetiology, diagnosis and prognosis, and the advice about treatment options, associated risks and probable health outcomes. Patients have the expertise in the specific experience of illness, their social situation, levels of risk they are prepared to accept, and their own values and preferences. Increasingly, there is a reversal in ‘expertness’. The focus of this inquiry was to understand the way in which
women, who were to participate in this study, learned mastery or became ‘self-expert’ (or not).

There are some attempts to make philosophical sense of the concept of illness. Carel, (2010) a UK philosopher and a young woman in her 30s living with lymphangioleiomyomatosis (LAM), asked what illness is. Is it a physiological dysfunction, a social label, or a way of experiencing the world? Further, she asked how the physical, social and emotional worlds of a person change when they become ill. She had firsthand experience and the theoretical tools to answer these questions. She believed that the person is an embodied being, experienced illness primarily as a disruption of the lived body rather than as a dysfunction of the biological body. She argued that medicine traditionally focused on returning the biological body to normal function and had therefore worked from within a problem-focused, deficit perspective, which ignored the lived body. She believed that a phenomenological approach could provide a framework for incorporating the experience of illness into the medical naturalistic account, by providing a rich description of the altered relationship of the ill person to her world. Phenomenology, the way Carel described it, is the description of lived experience. In a way, the storytelling phase of Koch’s and Kralik’s (2006) PAR methodology, similar to Carel’s approach, is based on privileging the first person experience.

**Medical Literature about Diabetes**

It is important to give a brief summary of Type 2 Diabetes or mature-aged diabetes mellitus. The objectives of medical treatment are the relief of symptoms, improvement
in the quality of life and the prevention of acute and chronic complications (Burant, 2008). The principles for medical treatment of this metabolic disorder are dietary adjustment, reduction of obesity, blood lipid lowering therapy, adequate physical assessment and oral anti-diabetic medication. Self-monitoring of metabolic control is pushed as the key element in therapy for persons with diabetes. The medical literature views adults with diabetes as just an embodied collection of ‘problems’, and diabetes as a disease which can lead to blindness, kidney failure, arterial disease and gangrene of limbs.

Diabetes can mean decreased quality of life, excess mortality, acute metabolic complications, hyperlipidemia and chronic complications including peripheral vascular disease and ischemic heart disease, hypertension leading to stroke or cardiac failure, neuropathy, a symptom of which is often diabetic ‘foot’ pain, amputations and cataracts. Management and compliance to prescribed treatments occupy much of this literature. In the medical literature non-compliance to suggested therapeutic regimes is cited as the most important problem in the management of diabetes (Funnell, Brown, Childs, Haas, Hosey, Jensen, et al., 2008). It is usual that ‘self’ management education is provided for the person with diabetes and significant others (Tang, Gillard, Funnell, Nwankwo, Parker, Spurlock, et al., 2005). These education programmes have been evaluated.

**Chronic Illness Experience Research Programme**

Commencing their research programme in the 1990s and covering over 40 independently funded studies, Koch and Kralik have researched alongside people who live with chronic conditions. The chronic illness experience research programme has
been consolidated by collaboratively researching with more than 300 men and women who were living in the community with adult-onset chronic illness (Koch, 1998; Koch, Kralik, & Sonnack, 1999; Koch & Kelly, 1999; Kralik, Koch, & Brady, 2000; Koch, Kralik, Eastwood, & Schofield 2001; Koch, Selim, & Kralik 2002; Koch, Jenkin, & Kralik, 2004; Koch, Mann, Kralik, & Van Loon, 2005; Visentin, Koch, & Kralik, 2006). Recruitment of participants has crossed diverse medical diagnoses and relied upon the participants’ own construct of living with the consequences and symptoms of chronic illness (Kralik, 2000; Kralik, Brown, & Koch, 2001a).

These authors have researched with people who have multiple and complex diagnoses including cancers, Crohn’s disease, multiple sclerosis, fibromyalgia, asthma, arthritis, schizophrenia, Human Immunodeficiency Virus (HIV)-acquired immunodeficiency syndrome (AIDS) infection and diabetes. Findings have revealed that symptoms such as fatigue and pain, and the consequences of illness, such as changes to self-identity, relationships and employment are often experiences that are shared by people across these medical diagnostic category groups. Using a collaborative approach, this participatory action research process usually commenced with storytelling. The authors argue that the biographical work or storytelling celebrates a particular mode of self-expression and individualised versions of experience.

Findings from personal narratives strongly support that illness disrupts a person’s way of being in the world and that telling one’s story is helpful for reflection, prompts further self understanding and motivates self-management (Koch, Jenkin, & Kralik, 2004). The actual telling of one’s story, as an intervention, fosters transition as participants reflect and learn to incorporate the consequences of living with an illness.
into their lives. Although storytelling is the first phase of Koch’s and Kralik’s (2006) participatory action research (PAR) process, in its second phase, researchers invite all participants to join them in ongoing PAR group conversations. These group discussions often result in social action and occasionally major health care reform. For example, people with human immunodeficiency virus and fatigue made an appeal to the South Australia and federal parliamentary ministers responsible for local government and Home and Community Care (HACC) scheme about the lack of uniformity between different agencies that provided facilities for people with HIV-AIDS fatigue. (Jenkin, Koch, & Kralik, 2006).

**Chronic Illness Management**

There are debates around the way chronic illness is managed and who manages it: the person, the healthcare professional or a partnership. Lundman and Jansson (2007) argued that a chronic illness could be managed by constant self-care in order to prevent further disability. Fisher, Brownson, O'Toole, Shetty, Anwuri, and Glasgow (2005) and Feldman (2001) emphasised the individual’s responsibility in managing chronic disease. They described chronic disease as a condition requiring a high level of self-commitment for successful day-to-day management and minimising illness experience. In other words, the responsibility is with the person who has the chronic illness; the person has to summon commitment.

Gines, 1984a; Lorig, Laurin, & Holman, 1984b; Lorig, Ritter, Laurent, & Fries, 2004; Lorig, Ritter, & Plant, 2005; Lorig, Ritter, Stewart, et al., 2001; Lorig, Ritter, Villa, & Armas, 2009; Lorig, Seleznick, Lubeck, Ung, Chastain, & Holman, 1989; Lorig, Sobel, Stewart, et al., 1999). The ASMP is a six-week course that was developed by Lorig and colleagues at Stanford University (Lorig, et al., 1998), initially designed for people living with arthritis (Lorig & Holman, 1993). This ASMP programme is now available around the globe and has been made applicable across all chronic illnesses. The emphasis of the model is problem-solving, changing behaviour and modifying self-efficacy, in order that people experiencing a chronic illness increase their capacity to make self supporting decisions, problem-solve effectively and access resources provided, while also being actively involved in their care. The focus has been on behaviour change and has been ‘taught’ in a group format with a “train-the-trainer” approach. Although the model is basically a medical model, the people with chronic illness are aligned as “helpers” in maintaining the optimum physical wellness possible, but it “misses the boat” in accepting the need to address the psychological aspect of illness perception and the impact of a diagnosis on a person’s emotional wellbeing (Koch & Kralik, 2006).

The motivation to absorb the education provided by self-management programmes had assumed that if people knew the reasons why and how they would make effective self-management decisions (Lorig, Ritter, Villa, & Armas, 2009). Authors reported that self-management had been central to successfully living with arthritis, because people had an improved chance for a rewarding lifestyle when they educated themselves about the disease and took part in their own care (Lorig & Holman, 1993; Barlow, Wright, & Lorig, 2001). It seems that much of chronic illness self-management literature has been
from the perspective of health professionals (Dubouloz, King, Paterson, Ashe, Chevrier, & Moldoveanu, 2010; Dunning, 2009). In the reliance on a prescriptive, education focus, the professionally driven programmes have the underlying assumption that if the individual is provided with adequate education, they will self-manage their chronic condition. What may be overlooked is the process needed for people to incorporate self-management strategies into their lives.

Another self-management model is that of Paterson (Paterson, 2001, 2001b, 2003; Paterson & Hopwood, 2010; Paterson, Russell, & Thorne, 2001c; Paterson & Thorne, 2000; Paterson, Thorne, Crawford, & Tarko, 1999; Paterson, Thorne, & Russell, 2002), in Canada. This model works to empower people with chronic illness through factual education about the illness from the beginning of their diagnosis with the intention of increasing treatment compliance. The empowerment is endowed by well-meaning health professionals, rather than experienced by the affected individuals, and does not address the human need for self-efficacy. This model is different from Lorig’s (1996) model, in that it relies only on information, delivered by medical staff, regarding the disease process and those directly experiencing it. There is not a particular programme for training people with the chronic condition, addressing the life changes required to accommodate to such a state; it gives those affected no voice and does not take into consideration their ability to govern their own lives, as do Koch and Kralik (2006).

I thought it would be important to explore the Expert Patient programme in the United Kingdom as this may have relevance for this inquiry. In the UK, health and social care policy has increasingly focused on supporting and encouraging people to take control of their own health and well-being, with the aim of both improving the quality of their
lives and providing more cost-effective care. Within the Department of Health, Quality, Improvement, Productivity, Prevention (QIPP) programme, there is a new emphasis on improving quality and productivity across care pathways for people with long-term conditions. Improved management of long-term conditions, as an outcome of self-management support, can enable commissioners and services to achieve the challenge of quality and productivity. This understanding is central to the philosophy and provision of self-management support. Self-Management for Life offers organisations a range of products and services which aim to fully engage patients and clinicians in self-management. The ‘Expert Patients Programme’ offers a range of self-management courses. These courses are free and provide tools and techniques to help people with chronic illnesses such as Arthritis, Asthma, Diabetes, Epilepsy, Heart Disease and Multiple Sclerosis to take control of their health and manage their condition better on a daily basis. The majority of Expert Patients Programme courses are delivered by trained tutors who have personal experience of living with a long-term health problem. Courses usually run over six weekly sessions and include topics such as dealing with pain, extreme tiredness, coping with feelings of depression, relaxation techniques, exercise, healthy eating, communicating with family, friends and health care professionals and planning for the future. However, the participants in these courses should learn based on the fixed topics by the tutors rather than learning what they really want to (UK Expert Patients Initiative, 2011).

Chodosh, Morton, Mojica, Maglione, Suttorp, Hilton, et al. (2005) meanwhile suggested, as did Lorig and Holman (2003) and Koch and Kralik (2006), that adults experiencing the effects of a chronic condition could monitor their own symptoms and
make decisions to look after themselves, if given adequate information and feedback pertinent to their illness process, from health professionals.

Along the way, Koch and Kralik (2006) explored chronic illness self-management. It was their belief that people with a chronic condition should have a voice in the decisions that affect their lives. They proposed that health care professionals would gain from listening to this group of people, rather than simply advising them or ‘telling what to do’. It was seen to be important that health care professionals supported people with a chronic illness and these authors emphasised the individuals’ strengths rather than their limitations.

It was their opinion that people with a chronic condition needed to be valued and that they possess the capacity to set their own agenda for managing their condition. These authors emphasised that the aim of their research programme was to promote self agency or ‘patient as expert’. In one of their projects, researching with people living with asthma, Koch, Jenkin, and Kralik (2004) identified three management models: the first a Medical Model of Self-Management, the second a Collaborative Model of Self-Management and the third, a Self Agency Model of Self Management. The authors noted that despite a continued emphasis on medical management and literature insistence on using the term ‘patient’, there was a move away from the medical authoritative model toward a collaborative model of self-management.

Collaborative models such as those developed by Holman and Lorig (2006) state that when people living with a chronic condition are given education, support, clinical care and monitoring in a partnership with health care professionals, self-management is
enhanced. According to Koch, Jenkin, and Kralik (2004) those who have a long learning history of self-management are often experts in their care, especially when they have lived with this condition most of their lives. Locating the ‘self’ in self-management meant that health professionals acknowledging that many people living with a chronic condition are already self-determining and their expertise should be acknowledged as such. In my research, women will be newly diagnosed and have not yet had time to build their expertise.

The attention given by Koch and Kralik (2006) to the actual individuals, as embodied beings with the ability to voice their concerns regarding their care, may have a positive impact on the care of others with similar illnesses, at the same time also being part of change in practitioner behaviour and care delivery, a unique approach with which I feel a strong empathy.

**Community-Based Health**

Community-based participatory research (CBPR) is increasingly being used as an alternative research approach. Israel, Eng, Schulz and Parker (2005) defined community-based health as “a collaborative approach to research that equitably involves all partners in the research process and recognises the unique strengths that each beings. CBPR begins with a research topic of importance to the community. Its aim is the combing of knowledge toward action and social change and so to improve community health and eliminate health disparities (p. 5). Community-based participatory research has used in public health and nursing. The term community-based participatory research has achieved growing popularity, especially in the United States. The other substitute
The term is action research which is used widely in UK, Australia, and New Zealand. In Canada Community-based research is the preferred term (Flicker & Savan, 2006). Participatory action research and participatory research are popular in many developing countries. The most recent terms are mutual inquiry, feminist participatory research, and community partnered participatory research (Jones & Wells, 2007). The community-based health principles are included: it is participatory, cooperative, engaging community members and researchers in a joint process in which both contribute equally, co-learning process, it involves systems development and local community capacity building, it is an empowering process through which participants can increase control over their lives and it achieves a balance between research and action (Minkler & Wallerstein, 2008).

According to Conrad, Boyle, Mutch, Dean, Dick and Del Mar (2006) community based health organisations (CBHOs) provide a range of support services which may benefit patients with chronic illness. Conrad et al., conducted a study of people who contacted CBHOs, and subjective and objective outcomes of contact. A telephone survey of people who contacted CBHOs was underway in partnership with eight CBHOs that addressed chronic conditions such as cardio-vascular diseases, arthritis, diabetes and hepatitis. Data included: health and socio-demographics; reasons for and perceived benefits of contact; capacity for self management; and other service usage. The survey was part of a study funded by the Australian Primary Health Care Research Institute to develop and evaluate a strategy to improve referral pathways between general practice and CBHOs. A side study examined psychosocial implications of chronic illnesses to aid the development of self and doctors’ mediated management strategies for chronic illnesses. According the findings of this study, CBHOs were a unique element of the
health system but little was known about their contributions. The CBHO contact survey provided valuable information about the characteristics of those who engaged with CBHOs and the outcomes of contact. Findings from a randomised control trial informed a doctor referral strategy and offered insights into the role of CBHOs in chronic illness care. Recognising the current and potential role of CBHOs in the Australian primary health care system has implications for policy and practice in relation to future linkages between the general practice and community sectors for improved chronic illness care.

**Transition**

My aim is to build on the theory of ‘transition’ developed by Kralik (2000, 2002; Kralik, Van Loon, & Telford, 2006a; Kralik & Van Loon, 2007b), so my first assignment is to understand transition so that I can develop it further. Before I talk more about Kralik’s work I will explain the theoretical development of transition in nursing.

The theory of transition in nursing has been largely driven by Meleis (1987) who introduced the concept in 1975. Meleis suggested that transition is movement, but later Chick and Meleis (1986) expanded the definition of transition as:

*A passage from one life phase, condition, or status to another ... transition refers to both the process and the outcome of complex person-environment interactions. It may involve more than one person and is embedded in the context and the situation. Defining characteristics of transition include process, disconnectedness perception and patterns and response.* (p.239)
Schumacher and Meleis (1994) found considerable consensus relating to personal and environmental factors that influenced transitions. They described these transition conditions as (1) creating meanings or subjective appraisal and evaluation of transition on one’s life (2) recognising that expectations are influenced by previous experience (3) meeting demands of a new situation in line with the level of knowledge or skill (4) resources available, including social support (5) planning and taking control (5) emotional and physical wellbeing; recognising that stress and emotional distress were common and may be related to changed roles and perceptions of self, along with physical discomfort and unpredictable bodies. Schumacher’s and Meleis’ (1994) analysis showed that there were also indicators of ‘healthy’ transitions, which they described as a sense of wellbeing, role mastery, and the wellbeing of relationships.

Meleis (1987) stated that transition was a practical concept for nursing as they are in an ideal position in health care delivery to facilitate or assist people to ‘move on’. In their research, transition was used both as a research perspective and as a framework, or model, that could articulate and reflect relationships among the components of transition. Meleis, Sawyer, Im, Messias, and Schumacher (2000) argued that transition possessed universal features that enabled the consideration of patterns of responses, rather than single responses. The authors argue that the concept of transition requires ongoing research toward strengthening these theoretical understandings.

Schumacher and Meleis (1994) identified universal properties of transition: processes that occur involving development, flow or movement; processes in which change occurs, the nature of which relates to identities, roles, relationships, abilities and patterns of behaviour in individuals and families. Research reviewed by Meleis,
Sawyer, Im, Messias, and Schumacher (2000) also demonstrated that, whilst all transitions were characterised by movement over time, the time spans themselves were not always bounded and did not necessarily follow similar chronological trajectories. Critical events and turning points were integral components of most transitions and were perceived as compelling experiences and realisations that led to change understanding and meaning. It will be important to note if turning points or critical events spur transition when I am researching alongside the women participating in my study.

I will now address the major construct of transition in illness that has emerged from Kralik’s (2000) work. In her work, people experienced transition as a convoluted movement between states of ‘Extraordinariness’ and ‘Ordinariness’ (Kralik, 2002). In her initial PhD research, focusing on the chronic condition experiences of mid-life women, Kralik (2000) conceptualised the transition experience as a ‘quest for ordinariness’. Subsequent work has described the process as one of ‘moving on’ in which the reconstruction of a valued self identity was essential (Kralik, Visentin, & Van Loon, 2006b). These notions were encapsulated in the definition of transition as:

*a passage or movement from one state, condition, or place to another; it proposes an array of properties and dimensions of transition; and its relationship to nursing therapeutics, environment, client, and health are examined. Transition is a process of convoluted passage during which people redefine their sense of self and redevelop self agency in response to disruptive life events (p.321).*
To which Koch and Kralik (2006) later added “transition was a messy life process” (p.159).

Although transitions or change were part of everyone’s life, their research programme had focused on people living with a chronic condition. Their transition theory provided a continuum of chronic illness experience. In researching alongside participants these authors had been able to observe the movement of participants’ experience, the way their perceptions and actions change. Movement was observed over time, hence my decision to research with participants over a longer period of time (twelve months). The experience of transition as ‘movement’ was a process of change, a fluid and complex movement. Kralik, Visentin, and Van Loon (2006b) wrote that ‘when people are living with a chronic condition, it is paramount to learn and develop adaptive capacity in a world of challenge and transition’ (p.320). I am interested in the way in which women learn and develop adaptive capacity.

Transition, it was argued (Meleis, Sawyer, Im, Messias, and Schumacher, 2000) could only occur if the person was aware of changes that were taking place. When a person has been diagnosed with diabetes, these changes are not immediately obvious, as there are no immediate physical ramifications. Rather, the person is ‘warned’ about complications should they not adhere to a new lifestyle. If the person is aware, she may seek information or support, identify new ways of living and being, and modify former activities. She begins to evaluate current circumstances. Meleis et al. (2000) argued that a person’s level of awareness may influence her level of engagement and a lack of awareness about the need for change may signify that she was not ready for transition. Kralik, Telford, Campling, Crouch, Koch, and Price (2005) stated that this was
sometimes referred to as readiness to change (or not), but, according to Kralik, Koch, Price, and Howard (2004), transition was not just another word for change. Transition was the movement and adaptation to change, rather than a person returning to a pre-existing state. Instead, the person had to let go of familiar ways of being in the world, a process, which required time as people gradually disengaged from old habits and behaviours. Describing the process of transitional movement, Visentin, Koch, and Kralik (2006) noted that a person’s activity could shift from old ways of being to mastery or being expert in one’s own management.

Kralik (2000) in Australia and Patterson (1999) in British Columbia, originally set up separate chronic illness research programmes in nursing, but they have recently joined forces to research collaboratively and the outcome is a next book: Translating Chronic Illness Research into Practice (2010). While the chronic illness literature is extensive, only the work of Kralik and Patterson focuses on transition.

Koch and Kralik (2006) have identified several transition constructs (1) Familiar life (2) Ending (3) Limbo, extraordinary (4) Becoming Ordinary. What was the person’s familiar life? It was usually connected to one’s family, relationships, work and routine, living arrangements, physical and social activity. What was challenged when the person became ill? Which aspects of familiar life were subjected to change? When becoming ill, the familiar life ended. Being ill was a disruptive event that was usually unexpected or forced. The person had little, if any choice of the event occurring. What was taken for granted now required re-examination of life and initiates reflection? Through the disruption of illness the person might have a sense of being damaged or fear of change, and feel disconnected from the familiar. Sorting out what was happening in one’s life
might instigate reflection, a phase Kralik (2002) called the “extraordinary”, when the person seemed to be self-absorbed while sorting out ‘what was going on’, although also recognising that not everyone had the capacity for reflection, or might chose not to do so.

This ‘extraordinary’ phase was often referred to as being in limbo, straddled between old ways and the new. Being ‘extraordinary’ and self absorbed meant there was an ‘overwhelming sense of being different which compounded feelings of isolation, vulnerability, loss, guilt and dependency’ (Koch & Kralik, 2006, p. 156). This period of self-absorption might alienate the person from others, particularly family members. The familiar was gone (ending) and was to be mourned, but the new beginning had not arrived. The person might feel unanchored or confused as customary life patterns were slowly being replaced by new ideas and actions when the person was starting to work through the transitional processes.

Becoming ‘ordinary’ was the process of new beginnings to accept the changed situation as ‘normal’. The confusion and disruption began to give way to new possibilities and the end of the previous way acknowledged, when sense was made of what was happening in her life. She was reorganising a new way to live and able to respond to contingencies. The process of surfacing awareness involved noticing what had changed and how things were different. Through reflection and introspection it was possible for the person to grow stronger and flourish in the opportunities that change had brought into her life.
These constructs are not rigidly set; each individual brings her own life story and negotiates the change in life status according to their character, resilience and experience. Some, when confronted with the diagnosis of a chronic condition, may contemplate their mortality, or be so overwhelmed by the degree of lifestyle changes; it can be a very frightening time, when support from both family and health care professionals is necessary to make a successful transition.

In 2005a, Kralik, Koch and Price as researchers and Telford and Campling as participants of research, published a paper collaboratively about the process of transition or 'moving on' when living with a chronic illness. Participants lived with a chronic illness and joined the researchers in daily email conversations. Collaboratively, participants and researchers drew out seven interrelated themes which are seen to constitute the process of ‘moving on’. These themes were: (1) knowing one’s responses to illness (2) developing inner conviction (3) refraining from making comparisons (4) prioritising what is important (5) sharing stories with others (6) awareness of shifting one’s self identity (7) in tune with the process of learning. Using the women’s voices, these themes are explored and their place in the experience of living with a chronic illness. The authors refer to the concept of readiness to change (Dalton & Gottlieb, 2003) as a means of emphasising the relationship between potential learning as a result of living with illness and ‘moving on’. The reason for including this particular study is that moving on is described and the themes were relevant for the women with whom I researched. This paper addresses the involvement of the participant in the entire PAR research process and, in this case, three of the participants published alongside researchers. Commencing with her PhD work, Kralik’s (2000) work on transition has been collaborative with participants. The emerging theory of transition speaks to those
living with a chronic illness precisely because they helped develop it theoretically. Participants can relate to its ‘movement’ and understanding transition is meaningful in their lives.

Olshansky and Sereika (2005) used Kralik’s (2000) transition approach when interviewing people with a chronic condition. Based on their analysis, these people reported that their identity had been changed by the diagnosis and then they were afraid in their new situation, feeling that they were different from others. Over time, however, they adapted and again felt ordinary in the community. I will explore the way in which women in my inquiry make the journey from diagnosis to accommodating their chronic condition into their lives and remain mindful of Kralik’s (2000) emerging theory of transition as I do the analyse.

**Learning to Live with Chronic Illness**

My research question is how do older women, who are newly diagnosed with diabetes, learn to live with their condition during the first year post diagnosis? My understanding of learning is that for learning to have taken place, it needs to be accompanied by a change in behaviour, however there may be other theories that I may need to take into account. Alongside developing further understanding of transition, I will be ideally placed to observe learning.

Moss, 2001). A person’s initial focus when diagnosed with a chronic condition may be about loss of control over their lives (Paterson, 2003). With a diagnosis of a chronic condition, a person faces the challenges of adapting to a new status (a “sick” person, or a “patient”). This person may be aware of a change in bodily function, potentially affecting all aspects of their lives, encompassing the personal, relational, situational and social.

Change in lifestyle may involve a different way of socialising; if alcohol consumption is a health issue, the individual may have to forsake the camaraderie of the pub, or opt for alcohol-free beverages. The transition from ‘well’ to ‘sick’ may also have implications for life expectancy, an important factor in the individual’s hopes and expectations of life, and those to whom the individual is close; it may be accompanied by a range of emotional experiences, including grief and anger. It takes time for people with chronic condition to regain control of their lives (Anderson, Funnell, Nwankwo, Gillard, Oh, & Fitzgerald, 2005).

There is a range of different theories of adult learning and I will focus on those theories most relevant to my inquiry.

According to Knowles (1984), adults are self-motivated learners, having identified a need to gather information about a particular subject. He postulated that adults responded better to flexibility than a fixed curriculum and acceptance by the teacher that they were aware of their own needs and were capable of valuable intellectual exchange in the learning setting, even when new information was imparted and absorbed. In the case of this inquiry, there is a need to learn more about Type 2
Diabetes and how best to make the transition back to ‘ordinariness’ (Kralik, Koch, Price, & Howard, 2004).

Adults could design, implement and evaluate their learning over time. They learn in many ways other than in a classroom, through utilising such resources as books, the Internet and associating with others with a common interest, like the women participating in my inquiry. Of course without readiness, a perception of need for information and motivation, no learning would occur (Knowles, Holton, & Swanson, 2005). I am interested to see how the women in my inquiry learn to live with their chronic condition and whether the way in which the women learn is in accord with such theory or not.

A central tenet of Mezirow’s (1975) ‘transformative learning theory’ was that the accumulation of knowledge led to a re-evaluation of assumptions and beliefs accepted as givens in childhood, and he described the process as "becoming critically aware of one's own tacit assumptions and expectations and those of others and assessing their relevance for making an interpretation" (p. 101). The concept of transformative learning had been much researched as it related to andragogy (Taylor, 1997).

I have been involved in my own transformative process, since arriving in Australia, as I described in the introduction to the thesis. It is also a concept, which fits well with the PAR framework. Mezirow (1978) described transformative learning as occurring in three phases: critical reflection, reflective discourse, and ultimately, action, and recognises that transformative learning often elicited deep, powerful emotions when beliefs were challenged. The transformation was evidenced in action. At the core of the
transformative learning theory, was the process of "perspective transformation", with three dimensions: psychological (changes in understanding of the self), convictional (revision of belief systems), and behavioural (changes in lifestyle) (Mezirow, 1981).

Transformative learning was the expansion of consciousness through the transformation of basic worldview and specific capacities of the self; transformative learning was facilitated through consciously directed processes such as appreciatively accessing and receiving the symbolic contents of the unconscious and critically analysing underlying premises. (p.4)

Mezirow (1975) described actual transformation of belief systems as usually resulting from a “disorienting dilemma”, which was triggered by a life crisis or major life transition, such as that which was faced by people having to accept a diagnosis of a chronic condition like diabetes. It might also result from an accumulation of transformations in meaning schemes over a period of time, like that which people in war-torn countries accommodated in their worldview, or a woman in an abusive marriage. Less dramatic predicaments, such as those created by a teacher, also promoted transformation (Mezirow, 1995) and the change implicit in learning identified by Knowles.

An important part of transformative learning was the change in worldview resultant from a critical appraisal of original assumptions instigating actual behavioural change, consistent with that change in perception; a fundamentally rational process (Mezirow,
1995) which was a major bone of contention, because beliefs, are emotionally laden and not often accessible to rational critique.

Robert Boyd (1988) developed a theory of transformative education, influenced heavily by depth psychology. According to Boyd:

\[
\text{transformation was a "fundamental change in one's personality involving [together] the resolution of a personal dilemma and the expansion of consciousness resulting in greater personality integration." (p. 262)}
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During this process, in a critical phase, in Boyd’s estimation, one grieved and accepted the necessity of contemplating "alternative expressions of meaning”, as the ground falls out from under one’s feet; the familiar is no longer relevant and the struggle to live in alignment with one’s authentic self was embraced, when new patterns of thought and behaviour were integrated. This concept of transformative learning regards the individual also as a member of a society, with mores, which under pressure from the changes undergone by individuals, also changing. While the current study group would explore personal stories with the aim to change their lives, it would not be a psychotherapeutic group. Boyd’s approach to transformative learning was different from that of Mezirow (1978), who focused on reason and logic, whereas Boyd emphasised self and ego in relation to transformative learning via a psychological process.

Another learning theory relevant to this inquiry is ‘Action Learning’ (AL), with a similar underpinning to Knowles’ theory, in that it recognised the importance of
working on real life problems by actively engaging collaboratively with other members of a group in finding solutions through practice (Revans, 1982). It is the type of framework that I envisage adopting while supporting the women of my PAR group in meetings in exchanging ideas and information.

“Such partnerships actually created themselves when different people with different ideas engaged whole-heartedly with each other to resolve each others’ points.” (Zuber-Skerrit, 2002, p. 115)

The model marked a fundamental shift in learning theory, in that it regarded those who were learning as actual researchers themselves, as did the concept of PAR, identifying points that they wished to explore and about which they wished to gain more information, and through a truly collaborative effort find answers, rather than absorbing information which might or might not be relevant, delivered by an ‘expert’ who had decided what was needed to be learned (Revans, 1980). People thereby recognised their own capacity for responsibility for what they needed to know in order to grow (Revans, 1982).

Merriam and Caffarella (1999) described their theory of ‘Self Directed Learning’ (SDL), to address adults who often learn independently of a formal classroom setting. The theory accommodated the fact that adults would pursue knowledge with the aim of personal growth. One of the arguments against SDL was that it was based on individualistic attitudes and values of the post-modern capitalist society, linking
personal growth to wealth acquisition and workforce development (Rowland & Volet, 1996). Braman (1998) found a significant relationship between readiness for SDL and individualism. As outlined above, the changes engendered by personal growth had the potential for instigating societal changes, (Merriam & Caffarella, 1999) or they might run contrary to social norms to such an extent that the individuals were sanctioned or left, as I have done, when I left the country of my birth, Iran. Braman (1998) therefore argued that an examination of SDL, from a cross-cultural perspective, was needed. No one can be completely autonomous all of the time and in all situations and some writers challenged the exclusive emphasis on the ‘autonomous self’ (Merriam & Caffarella, 1999) and called for wider recognition of the potential gain of the interdependent and collaborative aspects of SDL, pointing out that group learning was in essence empowering (Singh, 1994).

The process of reaching understanding, through ‘reality checking’, or what Habermas (1992) termed “communicative reality”, was that on which O’Donnell (1999) based his concept of ‘selves-directed learning’ where he described the purpose of learning in this construct as the emancipation of individuals from domination and exploitation with which Merriam and Caffarella (1999) mentioned. Maehl (2000) questioned this assumption and asked if SDL served to accommodate learners to prevailing social and political benefits while conveying an illusion of individual control and O’Mahony and Moss (1996) suggested that SDL could be used just as any other approach to deliver a traditional curriculum of dominant ideology by way of available resources. Although with ready availability to a vast cornucopia of information on the Internet, this was a proposition difficult to support.
Gray (1999) proposed that the Internet was the most powerful tool for knowledge acquisition and emancipation, although dependent on availability, which was reduced in economically marginalised communities and those with some disabilities (Kerka, 1994). SDL and lifelong learning had become part of a way of life in the developed world in response, in part, to the pressure of global competitiveness and economic development, even in the domain of healthcare where individuals were expected to return to being fully functional entities in an economically driven society. Of the models of SDL that Merriam and Caffarella (1999) reviewed, they found that Hammond and Collins (1991) was the only one that explicitly addressed the goal of promoting emancipatory learning and which held social action as a central tenet. Bedard (1997) believed that more and more learning would take place outside of traditional teacher-student interactions. It will be interesting to see the degree to which SDL influences the information gathering of the participants in my inquiry.

**Motivation to Learn**

The literature emphasised that one of the most important points in adult learning was motivation (Knowles, Holton, & Swanson, 2005). Moor (2005) stated that motivation was the first step in the learning process and might be different for every single person. What are motivators? Accreditation and advancement in the workforce, gaining the individual kudos and perhaps an increase in wages, are good motivators to further learning, as are the prospect of better understanding of one’s physical well-being and improved health (Bénabou & Tirole, 2003). These motivators may be intrinsic, that is, self motivation, or extrinsic, motivation generated by an outside influence (Mezirow, 2004); for instance an intrinsic motivator in the sphere of chronic condition self-
management may be the desire for maximum “wellness” as opposed to “illness”, in the sphere of adult employment, it may the self-motivation of actualising one’s potential, or extrinsic, in living up to the expectations of parents, spouse or peers.

The ‘Hawthorne effect’ is an experimental effect in the direction expected but not for the reason expected; for example, a significant positive effect that turns out to have no causal basis in the theoretical motivation for the intervention, but is apparently due to the effect on the participants of knowing themselves to be studied in connection with the outcomes measured. The term "Hawthorne effect" refers back to a series of experiments on managing factory workers carried out around 1924-1933 in the Hawthorne works of the Western Electric Company in Chicago. However there is no one precise meaning for the term, since the results were puzzling to the original experimenters, and their interpretation continues to be sporadically debated. Generally, references to the Hawthorne effect all concern effects on an experiment's results of the awareness of participants that they are the subject of an intervention. The Hawthorne effect provides a confirmation of how action researchers may successfully interact within a social context to bring about a positive change in both attitudes and task performance (McCarney, Warner, Iliffe, Van Haselen, Griffin, & Fisher, 2007).

Lee, Cheung, and Chen (2005) believed extrinsic motivation may also come in the guise of encouragement, as seen in mentoring of troubled young people. Positive early learning experiences and a home environment which values education might prime people to further their education as adults. The internal satisfaction achieved through problem solving might be another personal motivator (Ryan & Deci, 2000). For
example, an electrician might have identified a problem with the distribution of power in a community, which he resolved by installing solar generators and the people in the community gained easy access to electricity for the use of electrical appliances such as televisions, fridges and computers, not previously available (Grolnick, Kurowski, Dunlap, & Hevey, 2001).

**Readiness to Learn**

In the literature, readiness was the most important pre-requisite for learning (Rubenson, 1997). Adult readiness for learning might be both physically and psychologically determined (Knowles, 1984) and often situational (Watson, 2005). People might be prepared for learning by having emotional support from their family or friends or they might need mechanical help such as mobility aid or access to a computer and appropriate resources (Berg & Upchurch, 2007). Family or work commitments might have an impact on readiness to learn (Holloway, 2007). Learning is a continuous process, needing breaks for integration of knowledge, before the next phase can begin (Kerka, 1998), as has been illustrated by many scientific ‘break throughs’ and moments of inspiration.

As mentioned above, adults need preparation and motivation to begin learning and maintain the impetus to continue. It is important to understand this in relation to the women with whom I will be researching and follow the state of readiness to engage in the process of learning for each woman. As I am going to listen to the participants’ stories to find out their learning process, I describe learning and storytelling in the following section.
Storytelling

This inquiry will use the storytelling approach in participatory action research (Koch & Kralik, 2006). My adoption of their methodology consists of two distinct phases, the first of which is storytelling (one-to-one interviews). During the time that we are involved in the enquiry, I will invite the participants in my study, to share their stories, listening without judgment to how they relate their experiences and what they have learned about the best way to manage their changed lives. Generally, “a story was a common term for a recounting of a sequence of events, or for a statement regarding the facts pertinent to a situation in question” (Riessman, 2004, 2008).

In recent years, more definitions and applications regarding ‘the story’ emerged. Abbott (2002, 2008) defined ‘storying’ as making sense of life and used it to explain an event of life, which could be prolonged or short-lived. Usually the story was sequential, having a beginning and an end, and was usually told in a person’s own vernacular containing also elements of feeling content associated with the event: temporality might be confused with the narrator slipping between the past and the present. As this might be confusing for the researcher engaged in recording the story, it was imperative that she asked the participant to review her record of the story. Labov and Waletzky (1976) proposed that story is a translation of the lived experience into a sequence of verbal clauses, which made grammatical sense, and they introduced the six elements of stories: abstract, orientation, complicating action, evaluation, result or resolution, and the coda.

According to Kleinman (1988, 1995, 2006) and Hyden (1997) storytelling is the central part of people’s lives and through recounting events to others, they constructed a reality,
which made sense of those events and themselves in relation to the listeners (Riessman, 1995), particularly when a disruption occurred, which did not readily fit with the normal scheme of things; the diagnosis of illness and the experience of it were such disruptions. Storytelling helped people make sense of the disruption and form a worldview accommodating the new experience; it also functioned to include others in the storyteller’s journey and changed world (Charmaz, 1983, 1990, 1991, 2000a, 2000b, 2002a, 2002b, 2004, 2008). Kleinman (1988), a psychiatrist and medical anthropologist, maintained that narrative also provides an opportunity to give a voice to an individual’s suffering, while Frank (1995, 1997, 2000, 2002, 2004) added that there was more to an illness than suffering and the telling of positive experiences was as important as recounting the pain or misery; in fact more important, as doing so reduced the illness experience and the impact of the condition on an individual’s life. It also functioned as a ‘reality test’, especially if the stories were shared with others contending with similar diagnoses or life events.

Mishler (1986) agreed with Kleinman (1988) with regard to the importance of respectful listening although he maintained that the ‘medical story’ was vastly different than the ‘lived’ story of chronic disease and illness. Mishler (1986) felt that it was more useful to concentrate on the lived experience rather than the diagnosis, a phenomenological approach to addressing the distress of living with a chronic condition. People experiencing a chronic condition might tell different stories about themselves, however, to their doctors or family to satisfy their listener, rather than telling them their real experience. Frank (1995) added that people could have different stories of their illness or life experience for themselves, the health care professionals or their families. The stories could be in oral or written form. The way in which people would tell their stories
depended on how they wanted to be heard and to what extent they were prepared to share it. Bailey (1996, 2002) agreed with Frank (1995) and he stated that stories had an important role in the lives of people with a chronic condition through their communication with their families, friends and the medical team, thereby enabling them to improve their health through stories that focused on their abilities rather than their deficits which helped in coping and adjustment to their new life.

Benner (1991, 2000) and DasGupta (2003) suggested that people with a diagnosis of a chronic condition might lose their pre-diagnosis identity when involved with the health care profession: they became a ‘patient’ with, (or simply) a ‘diagnosis’ and struggled to maintain a sense of themselves as people with stories: they were no longer the person whose name was familiar in their family and circle of friends, they were ‘the diabetic’, ‘the heart infarct’ or ‘the schizophrenic’. Being able to engage in the story that was ‘them’ with another, formed a bond of commonly inhabited ‘thought-space’, presenting the individual with a sense of relief to be heard and thus valued, when navigating through the transition of ‘extraordinariness’ back to ‘ordinariness’ (Kralik, 2002). In this process a new ‘story’ by which to live, which incorporated the adjustment to a new way of life and means of self-validation, was created.

Bury (1982, 1991, 2001) observed that coping was enhanced by the creation of this new framework to make sense out of the disruption. Meanwhile, Charon (2001a, 2001b) and Diekelmann (2001) suggested that storytelling was an important part of resolving points which people with a chronic condition might face, by sharing the full spectrum of experiences with a sympathetic listener. Bailey (1996) defined storytelling as a basic medium of communication with others by drawing them into the storyteller’s world, a
sometimes-difficult task when engaging with health care professionals, who had been
taught to maintain ‘professional distance’. It was this point that I considered of
importance to my inquiry, as it was one I experienced, in the position as a health
professional, while engaged in non-participatory action research studies in Iran.

**Participatory Action Research and Group Dynamics**

As I am to engage women and family members in PAR group meetings, it is essential
that I understand and outline issues pertinent to group dynamics and so I present the
reviewed literature below.

There is a wide range of theories to explain group dynamics (Lewin, 1946, 1947, 1951;
most agreeing that groups go through a number of phases, or stages, if they exist for an
extended period. It was clear, for example, that people tended to want to know
something about the other members; had to develop a degree of interdependence in
order that the group or team might achieve its tasks and be satisfying for its members;
and had to learn at some level to deal with conflict if it was to survive (Forsyth, 2006).
The most influential model of the developmental process had been that of Tuckman
(1964), developed out of his observations of group behaviour in various settings. He
proposed initially that groups went through four stages: ‘forming, storming, norming
and performing’; in collaboration with Jensen, he later added a fifth stage: that of
‘adjourning’ (Tuckman & Jensen, 1977, p. 419). Members of a group might well
recognise the behavioural changes accompanying the phases without being aware of the
ramifications of those changes; implying that if there was a conscious appreciation of
the actual dynamics, group function and effectiveness could be improved and maximised (Tuckman, 1984), a point of which I need to be mindful, when conducting the PAR group meetings.

Tuckman (1996) explained that groups initially concerned themselves with ‘forming’, by testing the boundaries of what was required and acceptable behaviour; at the same time relationships of interdependence were negotiated and shaped. As relationships became stronger, emotional issues surrounding those relationships were raised and tension increased as they were tested, leading to conflict, or ‘storming’; this was a critical stage in the coalescence of a group. If the creative potential for the storming energy was channelled appropriately, resistance was overcome and cohesiveness and safety were established to the point where intimacy and a group identity was shared, standards of behaviour were agreed and roles were adopted, that is when, ‘norming’ was accomplished and the stage set of ‘performing’ when the group became an effective functional unit (Tuckman, 2003). The phase of ‘adjourning’, marked the phase at which the group went through a process of anticipatory grief as interdependency dissolved, when tasks were completed (Forsyth, 2006).

Relational Being and Belonging

In ‘Relational Being: Beyond self and Community’ by Ken Gergen (2009), he compared the individual aspect of a man with his relationships. When the relationships are open and continuing they would make transformation. The main point in making relationships with people is dialogue. People can make relationships with conversations. However, he believes that even in the conventional action research which is based on
the practical relationships to other people, the individual developing plays an important role. The vision, relational being, seeks to recognize a world that is not within persons but within their relationships, and that ultimately erases the traditional boundaries of separation. Bell Hooks (2008) believes that a place where we belong is a constant subject of our minds. People would like to live on the earth peacefully. Bell Hooks eloquently encapsulates a foundational human concern to understand one’s place in, not only the physical world, but also in the social spaces in which we move, and to which we may feel affinity or distance. The theme of Place, Belonging, and Otherness encourages an examination of a broad range of relationships in order to better understand the human social condition, whether in the early twenty-first century or at antecedent historical points.

**Family/Friend/Social Support in Learning to Live with Chronic Illness**

Support in this study means some external help for people with a chronic condition, to facilitate their self-management. This support could come from the family, friends, peers, society or health care professionals (Wang, Morrel-Samuels, Hutchison, Bell, & Pestronk, 2004). As people with a chronic condition, such as diabetes, need support to manage their condition, it is important to know how and where they can find that support, another point of investigation in my inquiry.

Rosland, Heisler, Choi, Silveira and Piette (2010) conducted a cross-sectional study of family support for 439 people with a chronic condition (diabetes and heart failure) in the United States of America (USA). It was found that family members were a vital source of support, provided this support was not accompanied by pressure to perform in a
particular way or focusing solely on specific aspects of the illness management. Positive support was given when the affected person was included as much as possible in family activities such as meals or outings, assisted with medication routines and daily hygiene or in coping with emergency situations. The review also identified a model of family involvement in care, based on training in communication and coping strategies, for the whole family, including addressing behavioural traits, which fostered illness, rather than wellness with modalities such as Cognitive Behavioural Therapy (CBT) and treatment compliance. One of the limitations identified in the review was the paucity of studies with sufficient numbers of participants on which to base any useful hypotheses.

A barrier to appropriate self-management amongst those with Type 2 Diabetes and/or Chronic Cardiac Failure (CCF) was a perception that family members tended to ‘nag’ about medication or diet, having to be differentiated from the rest of the family because of dietary needs and carrying a burden of perceived guilt because of the added load on family members, created by their condition and special needs (Rosland, Heisler, Choi, Silveira, & Piette, 2010).

Wen, Shepherd, and Parchman (2004) in America reported that amongst older Hispanic adults, most of whom were women, with Type 2 Diabetes, those who had family support had less dietary barriers in their self-care. An important consideration amongst this group of people was the high quality of family relationships and the positive impact of the extended family network, reducing individual ‘burden of care’ and reinforcing the notion that the individual was a valued person in the family network. A barrier to care, however, was accommodation to two different diets; one for the person with diabetes and one for the rest of the family, which was of particular difficulty for older people,
who met the challenge of engaging in quite radical behavioural changes (Boothroyd & Fisher, 2010) and did so more effectively if given social/family support.

Peer and social support seems to vary across cultures; hence programmes created to meet the needs of educating peers in the USA are not necessarily appropriate in other countries. Peer and social support programmes are under construction, to accommodate trans-cultural needs, by the WHO, The International Diabetes Association, the Heart Foundations and other global and regional health systems (WHO, 2010a; IDA, 2010; Heart Foundation, 2010).

Macpherson and Sullivan (2004) reported that it was worthwhile to provide peer/social support through regular telephone contact and in helping to maintain behavioural changes, while Alley and Brown (2002) suggested that support groups could assist in a bond of belonging which was important to treatment compliance, problem solving and which were a good forum for formal education about diabetes and self-management strategies.

Gallant (2003) reviewed of the empirical literature examining the relationship between social support and chronic illness self-management identified 29 articles. The majority of research in this area concerned diabetes self-management, with a few studies examining asthma, heart disease, and epilepsy management. Taken together, these studies provided evidence for a modest positive relationship between social support and chronic illness self-management, especially for diabetes. Dietary behaviour appeared to be particularly susceptible to social influences. In addition, social network members had potentially important negative influences on self-management. There was a need to
elucidate the underlying mechanisms by which supported influences self-management and to examine whether this relationship varies by illness, type of support, and behaviour. There was also a need to understand how the social environment may influence self-management in ways other than the provision of social support.

Kokanovic and Manderson (2006) established that people with Type 2 Diabetes also needed support from their health care professionals, citing a perception that the diagnosed women of their study felt that their doctors had no time to listen to them, and gave little useful information regarding the management of their condition, which had a negative impact on both their treatment compliance and clinic visits.

The literature, therefore, supported my contention that it is important to explore the role that families play when someone is diagnosed with diabetes. It will be interesting to observe the sort of support gained from family, friends, peers and medical professionals and, if support is forthcoming, see the effect of support in the women’s learning process.

**Chronic Illness Self-Management and Gender Difference**

As there are gender differences in most facets of life, it is important to establish if this also pertains to illness perception and self-management, because this will influence future policies and programmes addressing education, both individual post diagnosis and raising community awareness about Type 2 Diabetes.
Chiu and Wray (2011) conducted a research on 1,619 adults (758 men and 861 women) with type 2 diabetes from the Health and Retirement Study and its diabetes-specific mail survey. They reported on gender difference from the biological, behavioural and psychological aspects of diabetes self-management in the USA. The participants’ age ranges were from 42 to 96 years of age. The biological factors measured in the study were the glycosylated haemoglobin (HbA1c), blood pressure, body mass index (BMI) and early diabetes complications (dizziness, tingling, chest pain in resting, burning sensation and swelling ankle). The behavioural factors were engaging in exercise, dietary changes, medication compliance and self-monitoring blood glucose levels. The psychological factors were the ability to control diabetes, self-efficacy in the face of diabetes, depressive syndromes, family support and coping with diabetes. It was found that women were less active than men, although their ability to maintain an appropriate diet and monitor blood glucose level was higher. The women’s HbA1c, blood pressure, BMI and early diabetes complications were higher than those in men. The women coped less effectively with diabetes, had less support from their families, had lower self-efficacy scores and showed more depressive behaviours than men. It appeared that depressive scores were negatively correlated to exercise and family support impacted negatively on self-care and following medical advice, so while women seemed more vigilant, they were less effective in actual self-care, although surprisingly, there was no gender bias in medication compliance.

The results were similar to those of Gucciardi, Wang, DeMelo, Amaral, and Stewart (2008) from Canada, although the Canadian study reported that there was a higher incidence of familial Type 2 Diabetes amongst women and that they were better educated than men regarding the disease, had higher expectation from their diabetes
self-management and got more support from health care professionals. Women’s BMI was higher than men’s, with an increase in cardiac complications. The implications of these results were that health care professionals needed to take gender differences into account in educational and support programmes, information acted upon by the Canadian group, instigating separate courses for men and women.

Taru (2008) investigated Japanese gender differences in diabetes dietary self-management by measuring HbA1c, T-Cholesterol, HDL-Cholesterol and BMI. There was a significant relationship between eating and body mass index in both women and men: the higher the carbohydrate intake, the higher the HbA1c levels, which also reflected increased blood glucose levels and an increase in co-morbidity with coronary disease. As in the previous study in the USA, men tended to be more physically active and attended better to their diet with concomitant lower HDL-cholesterol levels; on the other hand, they also tended to take longer meal breaks and consumed more alcohol during their meals. This would indicate the necessity to educate men about the risks of both alcohol consumption and over consumption of food during long meals. Salt intake appeared to be difficult to mediate for both genders, as women most often cook for both and the families. Women again reported higher distress levels, resulting in frequent ‘snacking’.

**Chapter Summary**

In answer to the questions outlined at the beginning of the chapter, the literature suggests that people had different strategies for accommodating a diagnosis of a chronic illness. Kralik (2002) suggested that a person’s knowledge about chronic illness and the
state of readiness to make changes in their lives may motivate them to transit from ‘extraordinariness’ to ‘ordinariness’. People’s perception of illness varied, being governed by such things as their educational status, gender and life experience. Similarly, there were individual ways of seeking and acquiring information particularly in the field of adult learning. The family/friend support to deal with chronic illness was discussed as they could facilitate or make boundaries in chronic illness self-management. The focus of this inquiry was to understand the way in which mastery or becoming an expert was learned (or not). In this review, models of self-management were explicated and this relationship between patient and health care professionals was portrayed in partnership terms and toward self agency. The discussion about group dynamics focused on whether people with chronic illness might like or not to transit within the groups.

The review of transition literature was vital if I am to build on Kralik’s transition theory. I extracted Kralik’s main transition constructs in a person’s quest toward Ordinariness: familiar life, ending, limbo and becoming ordinary. It is my intention to expand on these and contribute to transition theory. This participatory action research approach will allow me to observe ‘movement’ or transition as I am with participants for twelve months post diabetes diagnosis.
CHAPTER THREE
GUIDING PRINCIPLES AND PRACTICES OF PARTICIPATORY
ACTION RESEARCH
“Participatory research is defined as systematic inquiry, with the collaboration of those affected by the issue being studied, for purposes of education and taking action or effecting change.”

Green, George, Daniel, Frankish, Herbert, Bowie, and O’Neill (2003, p. 419)

Introduction

In the previous chapter I reviewed the relevant literature surrounding chronic conditions that pertain to my research question, including the process of accommodation and transition, learning theories, group dynamics, family support and gender specificity of response and the role of storytelling in those processes.

In this chapter I trace the beliefs and philosophy underpinning Participatory Action Research (PAR): the rationale for selecting the model, feminist considerations and the researcher’s position, PAR in relation to the role of the facilitator, storytelling, theory building and rigour and quality.
The Beliefs and Philosophy Underpinning PAR

This research model had its origins in social psychology and activism and reactions against rigid pedagogy (Lewin, 1946; Freire, 1970, 1981, 1994, 1996; Kemmis & McTaggart, 1988a, 1988b, 2005; Reason & Bradbury, 2001, 2006; Stringer, 1996, 1997, 2007; Koch & Kralik, 2006) and was brought to international attention when Orlando Fals-Borda (1987) organised the first international PAR conference in Colombia. It has since spread around the world, with now a “dizzying array of definitions” (Minkler & Wallerstein, 2003) mutating to suit regions and researchers with some of the most important input from Australia and the field of Nursing Research. It is a hermeneutic phenomenological methodology, accepted towards the end of the twentieth century, as a valid alternative research methodology in the social sciences. Although there are some differences in these PAR approaches, there are fundamental commonalities (Greenwood, 2007).

Wadsworth (1998) writes that participatory action research is not a different and separate matter from science at all, instead she argues that all science in the wake of the wave of thinking that is popularly being called the ‘new physics’. This ‘new physics’ or ‘new approach science’ in the natural physical world seems to her to match a ‘new approach science’ in the social world. She identifies ‘participatory action research’ not as an optional variant or specialist technique, but as one of the more inclusive descriptions of this new understanding of social science. She believes that ‘Participatory action research’ is a description of social research per se (albeit social research which is more conscious of its underlying assumptions, and collectivist nature, its action consequences and its driving values).
According to Park (2006), participatory research was a research model in which ordinary people in communities could take action to make changes based on their everyday-needs.

*Put simply, action research is “learning by doing” - a group of people identify a problem, do something to resolve it, see how successful their efforts were, and if not satisfied, try again (O’Bien, 1998, p. 2).*

I am also guided by Minkler and Wallerstein, 2003 who wrote:

*Community-based participatory research (CBPR) (in health) is a collaborative approach to research that equitably involves all partners in the research process and recognises the unique strengths that each brings. CBPR begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community (health). (p.1)*

**Theoretical Considerations**

There is a scarce literature about theory building in action research (Dick, 2004). Dick defined the theory as a grand word for knowing, understanding and making sense of everyday activities. Kurt Lewin (1946) developed more precise theories of social change, as the cycle of planning action and fact-finding described previously, which Kemmis and McTaggart (1988b) varied as ‘plan, act, observe, reflect’ and Stringer (1996) as ‘look, think, act’. Koch and Kralik (2006) further developed Stringer’s PAR
process by emphasising the importance of storytelling and the reconstruction of experiences through stories, which had the potential to increase the quality of the lives of individuals and communities. Freire (1970), coming from the field of education and interested in social emancipation, stressed the need for theory to arise from dialogue and actual practical understanding of a situation. All seem to agree from the outset action that research (AR) is about a combination of theory and practical experience. Generally speaking, Dick (2006) stated that, although there was diversity in building theory in AR, there were many similarities, particularly in that all of the theories in AR contribute to an effort in making connections between the experience and subsequent constructive action and the theory makers’ goal to help others in making changes that they have identified as necessary to their wellbeing.

As mentioned above, the goal in health care action research is making a difference. I believe that theory is defined by its application in society. My engagement with people who live with chronic conditions has enabled me to build on transition theory using participatory action research. Building theory with the participants who are newly diagnosed with Type 2 Diabetes adds to theoretical understanding about transition.

One of the important key developers of participatory action research was Jacob Levy Moreno (1889-1974). He was a Jewish Romanian-born Austrian-American leading psychiatrist, thinker and educator, the founder of psychodrama, and the foremost pioneer of group psychotherapy. During his lifetime, he was recognized as one of the leading social scientists. Moreno picked up where Freud left off, with his theory of interpersonal relations, and the development of his work in psychodrama, sociometry, group psychotherapy, sociodrama, and sociotry. In 1932, Moreno first introduced group
psychotherapy to the American Psychiatric Association. In his monograph entitled, "The Future of Man's World", he describes how he developed these sciences to counteract "the economic materialism of Marx, the psychological materialism of Freud, and the technological materialism" of our modern industrial age. Moreno (1953) defined sociodrama “as a deep action method dealing with group relations” (Eckloff, 2006, p. 260). According to Moreno (1955), “the aim of sociometry is to help the formation of a world in which every individual, whatever his intelligence, race, creed, religion or ideological affiliations, is given an equal opportunity to survive and to apply his spontaneity and creativity within it” (p.19). Within his theory Moreno outlines a democratic standpoint, where anyone can participate and be a part of society.

In Europe, in 1915 Joseph Cardijn a catholic priest in the tradition of the primitive communists of the 1830s, invited young workers and trade unionists to reflect about the situation they found themselves in. He developed an action orientated investigative method typified by the “to see, to judge and to act” – a project also happening in the protestant churches of the period. In some ways it is close to the ‘Look, think and act’ approach. In the United States, there were several action research predecessors, some associated with the Settlement movement from the 1980s onwards, others with Frances Perkins, the later Labour Secretary under Roosevelt, who was instrumental in initiating the rather brilliant alternative research efforts during the Great Depression…the importance of those, obviously, is that they were directly addressing issues of disadvantage, health, et cetera and they emerged from the context of the people and activities themselves, rather than from academia (Genat, 2008).
As discussed, Kurt Lewin (1947), one of the founders of organisational and social psychology, developed action research approaches in the 1940s as an extension of his Group Dynamics model (1947), with a belief that by understanding the dynamics of a situation it was possible to instigate change. In stark contrast to later models, he did not engage the participants in his research in setting the agenda or decision-making, but the basic elements of generating knowledge and changing social system are his. He described action research as an iterative process of plan, action, evaluation and new actions following a concept of three stages of change: ‘Unfreeze (preparation for change), Change, Freeze (or Refreeze)’, although this theory had been critiqued for being too simplistic. In his model, ‘preparation’ involved getting to a point of discomfort with the present situation, in order to precipitate investigation and move from the comfort of the status quo: the greater the discomfort the greater the motivation to make change. In this stage ‘pros’ and ‘cons’ were weighed up and as the weight increased against the ‘pros’ the imperative for change increased in urgency: it was what Kurt Lewin called the Force Field Analysis, where the forces (pros and cons) were analysed by people in their growing awareness of the necessity for action to achieve change. Ideas that are appealing to me and that found a place in this research are people’s preparation and awareness to make changes in their lives.

Lewin (1947) recognised that all change, social or organisational, was an on-going process. The second stage, according to his model was the process of transition, when people made the changes that were needed and a new way of being was enacted. This stage was often the most difficult as people were unsure or even fearful of a situation, which was now unfamiliar and new mores, were negotiated. Support was imperative at this stage and could be in the form of training, coaching and expecting mistakes as part
of the process. Using role models and allowing people to develop their own solutions also helped to make the desired changes, at the same time communicating a clear picture of the desired change and the benefits to people so that they did not lose sight of where they were heading. The third stage of Lewin’s theory (1947) was ‘Freezing (or refreezing)’. In this stage, changes were accepted and became the new norm accompanied by new habits and routines. In reality, there was little time to ‘re-freeze’ because the process of change was continuous, often chaotic and an essential component of life, leading Lewin to observe that deep changes were short-lived (Lewin, 1947) and that it was insufficient to simply define a desired change; concrete action and reinforcement were required. It was a model for change, however, which was easily understood at a personal level.

The ‘participatory’ part of PAR, was conceived by Paolo Freire (1970) in his work as an educationalist amongst impoverished Latin American peasants, from which his book ‘Pedagogy of the Oppressed’ resulted. He was completely opposed to the traditional style of teaching, which infantilised the adults he was teaching to read and disregarded their innate capacity for philosophy and problem solving capacities; he therefore invited his students to collaborate in researching a change in means of attaining the literacy they craved. By doing so, he demonstrated that when respected and asked to join in a process of social change, it was shown that they could ‘learn by doing’, self-awareness (or consciousness raising) and social responsibility increased amongst his students: it was a revolutionary method so threatening to the ‘system’ that he was forced to flee his homeland, but he continued to transform the lives of impoverished illiterate children for the better around Latin America. In reading of Freire, ideas that guided my study were
participation, self-awareness or consciousness raising and liberty in learning to live with chronic illness.

In Australia, Kemmis and McTaggart (1988b) built and expanded on Lewin and Freire’s ideas. They emphasised that the first steps of PAR were to bring people together and understand their concerns and desire for change and by collaboration would be enabled to bring about the desired changes. Kemmis (2001) proposed that by coming together in PAR projects, people in communities gained an understanding of each other’s problems, increasing social cohesion at the same time as finding solutions to issues that they had identified as requiring attention: it was a model used in community development projects, including health sector communities. Kemmis and McTaggart’s (1988b) principles are based on Lewin’s theory of action research and offers a model, which emphasised collaborative consciousness raising, social involvement, social justice, and iterative engagement with an issue requiring change, in accord with the core PAR concepts.

According to Kemmis and McTaggart (2005) action research “investigates reality in order to transform it and action research also transformed reality in order to investigate it” (p. 567).

Reason and Bradbury (2006) went further than Kemmis and McTaggart (2005) and Winter (1998) and worked on a type of action research, which emphasised a combination of action and reflections and applying theory in practice in finding solutions for people’s concerns. They suggested that PAR was a dynamic method where the participants had a voice in their contribution to community-based research, with a
similar respect for the community members as initially enunciated by Freire (1970). Further, they suggested that action research was a participatory process concerned with developing practical knowing in the pursuit of worthwhile human purposes and view the PAR methodology as a philosophy guiding the practice of systematic development of knowing and knowledge. Their approach elucidated five principles, which were knowledge in practice, practical issues, human flourishing, participation and democracy and emergent developmental form, where the research was emancipatory and relevant to the participants in their day-to-day lives by contributing to the total wellbeing of the community at large, creating an equitable and sustainable ecology. Action research, following this approach, might therefore be seen as working toward practical outcomes and creating new forms of understanding, since action without reflection and understanding was blind, just as theory without action was meaningless. My understanding of these ideas in relation to my study is the combination of action and reflection, applying theory to practice and giving voice to the participants in the community.

Action research is multi-interdisciplinary, although education has published the majority of papers; recently PAR in Australia has been taken up in health research by Koch and Kralik (2006). Their application of PAR is underpinned by the philosophical hermeneutics of Gadamer (1994) and his phenomenology of understanding and the constitutive conditions of knowing. Guided by Gadamer, questions about what is going on whilst researching are sought in reflection, and storytelling initiates their PAR process. I was guided by Koch’s and Kralik’s ideas on reflection and storytelling in my study.
I have already referred to ideas from Lewin (1946), Freire (1970), Kemmis and McTaggart (1988b), Reason and Bradbury (2006), and Koch and Kralik (2006) which guided my study but it is important to clearly articulate the principles that guided this inquiry. Winter (1998) provided a comprehensive overview of six key PAR principles. These principles were: reflective critique, dialectical critique, collaborative resource, risk, plural structure and theory, practice and transformation. The principle of reflective critique ensured people reflected on issues and processes and made explicit the interpretations, biases, assumptions and concerns upon which judgments were made. In this way, practical accounts could give rise to theoretical considerations. Reality, particularly social reality, was consensually validated, which was to say it was shared through language.

According to Winter (1998), phenomena are conceptualised in dialogue; therefore a dialectical critique is required to understand the set of relationships both between the phenomenon and its context and between the elements constituting the phenomenon. The key elements to focus attention on are those constituent elements that are unstable, or in opposition to one another. These are the ones that were most likely to create changes. Participants in an action research project are co-researchers. He also argued that the principle of collaborative resource presupposes that each person’s ideas are equally significant as potential resources for creating interpretive categories of analysis, negotiated among the participants. The other Winter’s principles are accepting risk as an inevitable aspect of creative practice, demonstrating a plural structure which accommodates a multiplicity of view-points, and showing the transformation and harmonious relationship between theory and practice (McNiff & Whitehead, 2009).
Heron and Reason (2008) introduce the ‘co-operative inquiry’ as a form of second person action research in which all participants work together in an inquiry group as co-researchers and co-subjects – not research on people or about people, but research with people. As co-researchers work together through cycles of action and reflection they engage in an ‘extended epistemology’ of experiential, presentational, propositional and practical ways of knowing.

Stringer’s (2007) work as an action researcher regarded PAR as a methodology for facilitating emancipation. He has articulated the process of ‘Look, Think, Act’ (LTA); briefly: ‘Look’ means how people look at their situation and give information about it. Looking is an information gathering process. In this inquiry I asked participants to tell a story about their experience being diagnosed with diabetes, and while in the process of talking, it may prompt their social history and perceptions. When using the term ‘Think’ Stringer refers to how the participants reflect on their lives. In my study, the participants’ reflections regarding living with their chronic illness represent the ‘thinking’ stage. Action is the outcome of thinking. ‘Act’ shows how participants deal with their situation and the actions’ they take as a result.

Koch and Kralik (2006) further adapted the ‘look, think and act’ (LTA) process as a data generation and analysis framework. In their work, LTA did not always happen sequentially. It might be better described as an iterative spiral. For instance, some people looked at their issue and then thought about it for a long time without making any changes in their lives, or they might take action which they could not maintain and returned to the thinking or looking stages (Koch & Kralik, 2006).
In this inquiry, I was guided by Koch and Kralik’s (2006) PAR approach to work with people who were newly diagnosed with Type 2 Diabetes and learning to live with their chronic condition.

**Feminist Considerations**

In addition to the PAR data generation and analysis framework, which guides this inquiry, I am also influenced by a feminist approach to research; one of the aspirations of this study is to improve the lives of women through promoting emancipatory action. It was hoped that this may be fulfilled through the collaboration of researcher and participants as equals. Reflection in the ‘look, think and act’ process invites consciousness raising. Following Kralik, Brown & Koch (2001a), the key elements of feminist guided PAR are addressing gender inequality, the concept of identity, the power of the voice, individual life experience and the role of power in a community.

I considered these aspects as I was researching. In reviewing the literature, (Bravette, 2001; Kemmis, 2001; Fals-Borda & Rahman, 1991) most early Action Research projects were conducted by men and focused on the lives of men. In this study, I used PAR to collaborate with women in an effort to equalise social power inequality and raise women’s awareness of their potential power and strength to create the changes they wanted in their communities (Koch & Kralik, 2006).

The debate in feminist research in terms of power leads me to the literature of the nature of empowerment and power relations. In her book ‘Feminist Participatory Research’, Patricia Maguire (1987, 2006) discussed feminist PAR and power in the community,
suggesting that if women are included and valued as co-researchers they would be comfortable enough to explore the points of their personal lives within a group of other women, rather than in mixed gender groups, tapping into the commonality of gendered experience and Webb (1993) added that the researchers and the participants could engage non-hierarchically.

**Selection of the Participatory Action Research Approach**

I elected to use the Koch and Kralik’s 2006 PAR process because it aligns with my own principles regarding my belief in democratic principles - social justice, social equity, freedom of speech and human rights, which I discussed in the Introduction to this thesis. These principles embrace a democratic, collaborative approach to research that equitably involves all persons (facilitators/researchers and participants) in the research process. In principle, I recognise the unique strength that each person brings to the study. I believe that their voices should be heard and I attempt to break down the distinction between facilitator/researcher and participants. Breaking down distinctions means bearing in mind that there is an inherent power imbalance in the process, as I am the person who brings the concept of research to the participants and it is my PhD research project. When researching alongside people collaboratively, I work towards building a sustainable relationship for the women by encouraging them to continue meeting beyond my project work and PhD. I recognise the PAR group as a community of women with a community of common interests. I endeavour to build capacity and emphasise their strengths and the resources within the PAR group. As a facilitator/researcher, I help this community to work together to improve their lives and the lives of those to whom their voices will reach in the future.
It was important to understand the women’s experiences and to listen to their stories and to give them a voice to express their experiences. Based on my earlier research in Iran, I recognised that my study participants wanted to tell me more than was required to answer the questionnaires that we used. It is also the underlying philosophy of PAR, as described earlier, that promotes participants to talk about their lives in one-to-one interviews. And whilst they were in conversation with me, it was envisaged that they could be able to express their “learning” and transitions to live with their chronic condition. As I was in the field for twelve months, I was able to track their learning and transitions during this time.

I also invited the family and friends to tell their stories in an attempt to understand more about the impact of chronic illness on people within the home environment and to explore the role of support. This was an important factor in understanding how women learn to live with their Type 2 Diabetes diagnosis and learning to take its consequences into their lives. As the participants of my inquiry were older women who were newly diagnosed with Type 2 Diabetes, I also took a feminist view into consideration. As the facilitators have important roles adhering to the principles supporting a PAR project, I also expand on this point in the following section.

**The Role of the Facilitator in Participatory Action Research**

In reading about PAR approaches in the literature, the role of facilitator needs to be carefully considered. Participatory action research (PAR) is democratic and participative. However, democracy has to be learned (Lewin, 1947) and this meant I had to learn to be a democratic facilitator. I needed to appreciate that my participants
determine the agenda, drive the research and decide on actions and/or reform. I aimed to reduce my authority as facilitator and attempted to avoid behaviours that could hinder group interaction such as judging, controlling, superiority, certainty, indifference and manipulation. As the facilitator, I aimed to be conversant with the fluidity of the ‘look, think and act’ processes and although in “apprenticeship mode”, guided by my supervisors throughout the process, I developed the skills necessary to capitalise on these ‘stages’ to accomplish forming a productive, cohesive group. I recognised that group dynamics, based on my earlier readings, was a critical factor in group performance. In order to capture some of this, I maintained a reflective journal of proceedings and my observations.

Guided by work of Koch and Kralik (2006), the role of the facilitator in a PAR project is to foster the participants’ strength and build capacity. This is achieved through the facilitator’s capacity to have discussions with participants and engage them in a process of exploration, problem/strength identification and solution finding, where ideas are respected (Stringer, 2007). I endeavoured to ensure that changes were consensually agreed upon by the PAR group. To abide by the principles underpinning this PAR process, changes should be driven entirely by the group and not be the results of the facilitator’s precepts (Reason & Bradbury, 2006).

To be a good facilitator is to create an environment, which is experienced as safe, where ideas, concerns and experiences are commonly shared and respected and openly discussed, primarily achieved through clear communication. As a facilitator I was also mindful of the possibility for distress in such frank discussions and group negotiations; hence, I had in place a referral system for counselling, should any participant require it,
and I also stressed the need for confidentiality if emotionally laden issues were divulged. Fortunately, the women agreed to the need for confidentiality and counselling services were not needed in this inquiry.

**Storytelling and the Participatory Action Research**

Within the context of the PAR method, the storytelling component was unique to Koch and Kralik (2006); it was a component which added great depth to the data and uniquely involved the individual in an intimate sense by inviting her to explore her experience, her ability to find support and her worldview, one-to-one with the researcher; all important considerations in her adaptation to the diagnosis of a chronic condition and fundamental to her illness experience.

Storytelling in relation to a diagnosis of a chronic condition has been outlined in the previous chapter; however, I shall expand on it as it relates to PAR here.

Arthur Kleinman (1988) was trained both to listen empathically to, and respect, a person’s description of their internal world and their experience in that world; also to observe the cultural nuances and mores that form much of that internal world and worldview. He stresses the centrality of “the story” in the construction of reality for both the individual and the society. For the individual, the process of telling the story to another affirms their sense of identity and membership of the society through the story’s believability; the social role of storytelling lies in its capacity to create cohesion, relay history and reinforce both mores and worldview, with which Hyden (1997) agrees.
Kleinman also involved family members in the therapeutic work with Chinese people, in recognition of the pivotal role of the family in their culture; in essence, therefore, though not identified as such, Kleinman carried out modified PAR with each person/family who consulted him. Riessman (1993, 1997) described ‘the story’ as an interpretive sociology, arguing that ‘story’ fills the gap of understanding between the people who experienced an illness and those with whom they communicated, when the listener engaged in collaborative analysis of the story by asking questions about the story and the way it was presented, getting clues from what was left out and what was emphasised. It was also important to recognise that people’s stories would change, in line with their circumstances. Hyden (1997), Frank (1995) Kleinman (1988) and Mishler (1986) were clinicians and all agreed that there exists a power differential between ‘clinician’ and ‘patient’; putting it bluntly, the wellbeing of the one rests in the expertise of the other, a fairly significant means of establishing power; in addition, the clinician is trained and exhorted to maintain ‘professional distance’.

Frank (1995) maintains that ‘story’ has an important role in self-identity and equalising that power imbalance which is restorative to a sense of valued self and enables the person to find the way that they want to regain a sense of life direction; it also serves to create true empathy and alignment. However, still there is a critique about the Frank’s idea that there would be a power different between patients and the practitioners as finally the practitioners should cure the patients and give them advice. Atkinson (1997) argues for the therapeutic role of individual or group voices in the social context; further, that those stories are not just personal or private experiences, rather, they are social actions and they should be analysed as social phenomena which could be channelled to promote changes in the community and re-distribute power. It is possible
to change public awareness and attitudes to chronic conditions through the stories of
direct personal experience; the stories then take on a different complexion and could be
seen as socially beneficial, for example, the television informational advertisement
regarding smoking, delivered by a forty-two year old mother, ‘Jenny’, knowing that she
is terminally ill from tobacco related lung cancer.

Charon (2001) and Diekelmann (2001) opened a new world of storytelling by pointing
out that it is a universal means of problem solving as evidenced by the power of
homilies, myths and ‘fairytales’; it links the person diagnosed with a chronic illness
with the community at large.

Koch and Kralik (2006) postulated that people with a chronic condition are able to
express their feelings and experiences through their story and when in a group of similar
people, have the opportunity of sharing their experience in a climate of mutual
understanding, thereby also potentially learning from each other. In this storytelling
approach, there is no hierarchy between the researchers. The participants and what
participants chose to share, and how much they chose to reveal is entirely up to them.

The participants of this inquiry have the power to make comments about how I present
their stories and delete parts.

**Participatory Action Research Rigour and Quality**

It is important to have this inquiry considered as trustworthy and worthy of contributing
significant findings. I use the terms trustworthiness, validity, credibility, rigour and
believability interchangeably. The main point is that I sought to create an inquiry that is credible to the reader and to show that I carried out this research and that the findings are not falsified. I review key readings on trustworthiness in the following and show how I applied them in my inquiry.

According to Stringer (2007), ‘rigour’ in PAR is defined based on checks between researcher and participants, to ensure that the outcomes of research are trustworthy, that they do not merely reflect the particular perspectives, or worldview of the researcher and that they are not based solely on superficial or simplistic analyses of the issues investigated. Lincoln and Guba (1985, 2005) described rigour as an assessment of the ‘Credibility’ (the plausibility and integrity of the study), ‘Transferability’ (the possibility of applying the outcomes of the study to other contexts), ‘Dependability’ (research procedures that are clearly defined and open to scrutiny) and the ‘Confirmability’ (evidence that the procedures described actually took place) of a study.

Koch and Kralik (2006), guided by Stringer (2007) and Lincoln and Guba (1985), added their perspective to these approaches when they extend the questions to include: ‘What is the worldview?’ ‘What are the values and interests researchers bring to the inquiry?’ and ‘Is the work accessible?’ Checks for trustworthiness were established through the researchers having rigorously established the veracity, truthfulness, or validity of the information and analyses that had emerged from the research process by procedures such as a visible paper trail, recorded steps in analysis and the researcher’s process diary.
In terms of rigour, I understand that the trustworthiness of this inquiry depends on the transparency of the process so that readers can decide for themselves whether the stories I tell are believable. I researched alongside women and they engaged in writing their stories with me. My aim was to make sure that all women’s and their families’ voices were included in the text. It is for this reason that I created a multi-voiced text, that is, all the voices are represented. Participants were included in all aspects of the validation process in the storytelling and PAR group process. Cycles of feedback were part of the constant validation process. Consistent with my participative worldview, I was motivated to generate authentic information that was useful for participants. Participants had the final say in making the decision about an inquiry’s veracity and quality.

Transferability is possible by describing the context of the setting and giving a profile of the participants. This inquiry with women living with diabetes may show that the transition thesis could be supported and its findings could be transferable.

In terms of dependability, I give a detailed description of the way in which data was generated and analysed. In the introduction to the thesis I described my values and that I understood that my values and interests would affect my interpretation of events and data. Reflection for me was a new skill to be learned along with the idea of constantly reflecting and analysing my data. My social and cultural background and my experience as a non-participatory action researcher no doubt influenced the way I researched. It is for this reason that I kept a diary as a reminder to me to record and analyse influences, at least those accessible to me, whilst researching. My decisions and choices made whilst researching were captured through the use of my diary and the process of reflective journaling.
Building relationships was pivotal when researching with women and their families. The relationship dimension draws attention to the quality of the interaction developed in the inquiry. I visited the women at home in their own space, I attended to creating a safe accessible PAR group environment and I provided appropriate refreshments for people with diabetes. I also thought about seating arrangements and other details to create a comfortable and safe environment.

**Chapter Summary**

In this chapter I discussed the beliefs and philosophy underpinning PAR, theoretical considerations, feminist considerations, the rationale for selection of the PAR approach; the researcher’s position; principles to guide the inquiry, PAR and the role of the facilitator, storytelling and, finally, the way in which the research inquiry may be considered as a rigorous study.

In the next chapter, I address the aims and objectives of the study and the research methods. I also discuss the setting for the study, how I gained access to the participants including the recruitment process, the ethical considerations of the study and the data generation methods used, including the use of one-to-one interviews with older women, PAR group meetings and how I maintained a reflective journal. The participants for the study are described as well as the data analysis process and how rigour and quality were ensured in this study.
Introduction

In the previous chapter I discussed the principles to guide this study. I described the beliefs and philosophy underpinning participatory action research, theoretical considerations, feminist considerations, the rationale for the selection of the participatory action research approach, and the researcher’s position, participatory action research and the role of the facilitator, storytelling and participatory action research, and participatory action research rigour and quality.

In this chapter, I outline the aims and objectives of the study, the research methodology and the rationale for its selection. I discuss the setting for the study, how I gained access to the participants, including the recruitment process and information about the participants. I explain the way in which I intended to generate and analyse data for both phases of this participatory action research process, (1) one-to-one interviews and (2) group meetings. I discuss rigour and ethical considerations.
Research Question

“How do older women, who are newly diagnosed with diabetes, learn to live with their condition during the first year following diagnosis?”

As it is important to know how people who are newly diagnosed with diabetes learn to live with their condition and make changes in their lives, I was interested to follow the women’s learning during this time of transition.

The overall aim of this inquiry was to explore with women ways in which they learn to live with Type 2 Diabetes. The objectives were:

1. In the first phase of this PAR process, to engage with women (and then their families) in ongoing interviews and conversations to ‘look and think’ about what is happening in their lives and explore individual and family members learning processes since the woman’s diagnosis with diabetes.

2. Using the ‘look, think and act’ participatory action research process, to concurrently analyse ongoing interviews with the women and conversations with their families, and provide feedback on actions and document progress (or otherwise).

3. To track ‘learning events’, in each woman’s life trajectory/transition since diabetes was diagnosed, achieved through sustained involvement with the family; that is tracking points in her day to day life where she has learned a new strategy, or had an experience which she remembers, associated with a change in her attitude to her diabetes.
4. To invite women and their families to join a participatory action research group, and, in collaboration with this group, explore possible reform strategies that the participants may suggest in health promotion activities and service delivery. This group will run concurrently with the individual interviews with women and/or family conversations.

5. Share suggested reform strategies with health care professionals. In the effort to create environments in which people can thrive, consider ways in which these findings can be shared with the participants, families and the medical staff who deliver care.

**Selection of PAR Approach and Rationale**

As stated previously, through my exposure to the work of Koch and Kralik (2006), I became interested in the notion of storytelling as I required a research process which would allow me to understand how people experienced life after receiving a diagnosis of Type 2 Diabetes.

It was a pragmatic decision to utilise Koch’s and Kralik’s PAR methodology and to contribute to the theoretical development of transition, as not only did this provide the guidance I needed as an apprentice in participatory action research, it also allowed me to expand my understanding of people living with diabetes, a topic I was familiar with from my previous study and work in Iran.
I understood that the adoption of Koch’s and Kralik’s methodology emphasised storytelling which meant I was able to invite participants to talk about their lives whilst learning to live with their chronic condition. More importantly, it allowed me to follow the participants in their daily lives and observe change and/or transition as I researched alongside them for twelve months. The approach also allowed me to ask family members about the impact of being diagnosed with diabetes. After all, having to change their lifestyle was likely to have an influence on those living nearby. It was hoped that I would be able to bring the participants together in a group to continue the conversations.

I was particularly interested in the storytelling phase of Koch’s and Kralik’s methodology because I considered it to be important for understanding the transition or shifts in the ways in which the women learned to live with Type 2 Diabetes, particularly as this has not previously been studied immediately post diagnosis. Most research studies were with people who had been diagnosed with diabetes many years earlier (Koch, Kralik, & Taylor, 2000; Koch, Kralik, & Sonnack, 1999). In this way, I hoped that I would be contributing to the theoretical development of transition.

**Preparation**

I gained approval from HNELHN Service and the University of Newcastle Human Research and Ethics committees and I was also required to gain safety clearance because I was to be generating data through fieldwork in the community. The ethics and safety approval letters are located in appendix C of this thesis. The safety approval was deemed necessary as safety precautions and/or preventive steps I was to take would protect me from the potential harm when I visited families/friends of
the women in their own homes. Undertaking safety precautions alerted me to the possibility of facing suspicious situations in private residences and homes and the potential for violence, such as in dog attack. The safety approval process required me to set up mechanisms for reporting my whereabouts, home visits and completions to my supervisors. These mechanisms supported my general feelings of safety and health and wellbeing while I was visiting the participants. After receiving approvals from all committees I was ready to start recruitment for the one-to-one interviews.

I liaised with the key nursing staff, the Dietitians of the HNELHN Services diabetes centre and clinical consultants. I consulted with them about the study, delivered information about the study and proposed recruitment strategies. I met with the coordinator of the diabetes centre, the Dietitians and the Diabetes Nurse Educators on several occasions. I built a good relationship with them and they helped me to gain access to potential participants. I attended their regular series of three diabetes classes. During the six months while waiting for Ethics clearance, I was able to be present for these classes as a non-participant observer which allowed me to gain insight into the content of the classes and, most importantly, become a ‘known face’ to potential participants. The contents of these classes are provided in appendix B.

As explained in chapter one, there were three diabetes classes, each was held for three hours, or nine contact hours over consecutive months. This was a standard offer, across the HNELHN Service diabetes centres for all people newly diagnosed with diabetes. Most class participants were diagnosed with Type 2 Diabetes. Other participants were family members or friends of the person with diabetes. The content of the first diabetes class covered diabetes as a disease, its causes, signs and
symptoms and medical treatment. The principles of dietary management, making healthy food choices, the importance of physical activity and diabetes self-management were covered in these classes. These diabetes classes were provided by the Diabetes Nurse Educators and Dietitians.

The content of the second diabetes class focused on the daily self-management of diabetes and encouraged people to set individual goals and develop an action plan. Participants were given information about reading food packages labels, information about medications prescribed for diabetes. The importance of doing daily exercise was stressed in this class as well.

The content of the third diabetes class focused on promoting diabetes self-management and identifying hypoglycaemia and hyperglycaemia. The impact of fast foods on blood glucose levels was discussed, with alternatives suggested when not eating at home. Information given was devoted to self-management should the person become sick, what to take into consideration when travelling and dietary advice. The impact of stress on blood glucose levels was also discussed. A podiatrist emphasised the importance of foot care.

Recruitment of the Participants

The participants were women who fulfilled the following criteria:

- Women attending the HNELHN Service, Newcastle, diabetes centre and geographically located within the Newcastle area
- Diagnosed with Type 2 Diabetes in the preceding six months
- Aged 55 and over
- Able to speak English
- Able to understand the information sheet
- Able to give informed consent

**Exclusion Criteria Were:**

- Any serious mental health problem
- Any physical disability, which would prevent free and easy communication and participation in interviews or the PAR group meetings

**Recruitment**

Participants were recruited among older women who were newly diagnosed with diabetes (less than six months) in the metropolitan area of the HNELHN Service and who attended the diabetes classes (this involved three diabetes classes over a period of six weeks) from January to August 2008.

During the second diabetes class, I provided a short information session for the potential participants (around two minutes) about my inquiry and provided a package containing an information sheet (see, appendix D) about the inquiry, a consent form (see, appendix E) with instructions regarding submission via a locked box (was clearly labelled and located in the diabetes centre) and a self addressed and sealable envelope. The information sheet provided details about the inquiry including the eligibility criteria.
At the third diabetes class I reminded the participants in the diabetes class that if they were interested in participating in this inquiry they could submit their expression of interest to the locked box which was on display in the room for this purpose. Upon receipt of an expression of interest I made contact to arrange a meeting time to discuss the details of the study, answered any questions and gained consent as appropriate and started one to one interviews.

After six months of one to one interviews with the women, recruitment also included an invitation to family members or friends should the woman desire this. This was established once a relationship had been built with each woman. Family members/friends were provided with an information letter about the inquiry along with a letter of consent.

**Ethical Considerations**

Participants were informed that their participation in this inquiry did not affect their care or treatment with the HNELHN Service. No monetary or other inducement was used to attract participants in joining this inquiry. This inquiry did not involve any life threatening situation, there was not any emotional discomfort or distress. However, the participants were told that if they experienced any emotional discomfort during the interviews or PAR group meetings they were free to withdraw from the inquiry whenever they liked or they could refuse to answer any questions without fear of retribution. This was clearly noted on the information letters provided.
All participants were given an explanation about this inquiry and they were given an information sheet which was provided with simple and clearly written language. All participants were invited to ask any questions regarding the inquiry from me or my supervisors. I encouraged the participants to take some time to think about their commitment and to discuss their participation with family members or friends. Only people who could communicate in English and participate in the interview were eligible to participate and give consent.

No identifying details of the participants were recorded. Pseudonyms was used in the transcribed interviews and when reporting the outcomes of the inquiry, unless the participants specifically wished to be named. Participants within the focus groups were told of the importance of confidentiality within the group and that the content of group conversations was not to be shared with anyone outside of the PAR group meetings, although it was recognised that this confidentiality could not be enforced. Consent to participate in the PAR group process was also an agreement to confidentiality within the PAR group meetings.

Only the supervisors, I and participants had access to the information from the inquiry. The information, records and transcripts were kept in a locked cabinet during the inquiry. Interview data will be destroyed after finishing the inquiry, based on the policy of both the University and HNELHN Service ethics committees. All transcribed data were saved to a DVD and password protected and will be kept in a locked filing cabinet within the School of Nursing and Midwifery for the statutory period of five years. The participants were informed that their information was part of the inquiry report and thesis and that papers based on the study would be published in journals or presented at
national and international conferences. The participants were assured that their confidentiality was respected, unless, as mentioned above, they specifically requested that they be named.

The participants could leave the inquiry whenever they liked for any reasons. They were free to make their own decision to participate or not in the inquiry. The participants were informed that if they became distressed when sharing their experiences they would be invited to seek counselling and support and provided with the details of available professional counsellors or to seek support from their general practitioners.

The issue of disengagement from the women who participated in this research was perceived as an ethical issue. Disengagement is the state that researchers achieve when they finish their research and ‘leave the field’. This was difficult as relationships had been formed and participants perceived they had benefited from being involved in PAR groups. Women enjoyed the reciprocity and learning about diabetes collaboratively. The dialogic process was over. It was necessary to reduce the moment of time I was spending with the women. I started to distance myself from the women with a card and letter that thanked them for their involvement. I wanted each woman to feel she had made a valuable contribution to the research. It was not an easy process to begin to disengage because of the way in which we had journeyed together. I had been immersed in their lives and we had developed close relationships. I used empathy, tact and diplomacy to leave the relationships that had been established. When relationships thrive, resultant individual and group action is likely to be sustained. The close relationships we developed made disengagement difficult for some women, because they had used me as a good listener. In fact some women felt that the participatory
action research had a therapeutic effect for them. Although I will not be present for meetings in the future, the women decided amongst themselves that they will continue to meet.

The Participants

Apart from Elizabeth, who wanted to be known as such, the women carry the fictional names of Anna, Barbara, Bella, Alison, Helen, Katy, Sara, Kathryn, Rose and Pam. The average age of the participants was sixty six (66) years of age; the youngest person was fifty five (55) years of age and the oldest woman was eighty two (82) years of age. The women had been newly diagnosed with Type 2 Diabetes\(^1\) recently, within the previous six months. Six women, whilst being newly diagnosed were told that they were “pre-diabetic”\(^2\) some months or years prior to the diagnosis. For these women, the diagnosis of diabetes still came as a surprise to them. Nine participants were self funded retirees or received an aged pension sponsored by the Australian Government. Only two women were in the work force. One participant had recently been made redundant from her job following the financial crisis in Australia in 2007-8. All women lived in the urban Newcastle area.

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\(^1\) According to World Health Organisation Type 2 diabetes (formerly called non-insulin-dependent or adult-onset diabetes) is caused by the body’s ineffective use of insulin. It often results from excess body weight and physical inactivity.

\(^2\) According to the Diabetes Australia (2010) pre-diabetes (impaired glucose metabolism) is defined by Impaired Fasting Glucose (IFG) and Impaired Glucose Tolerance (IGT).
One to One Interviews

I commenced one to one interviews with the eleven women who consented to participate in this inquiry. During these interviews I was able to explore the ways in which they grasped and assimilated the information from the formal HNELHN Service diabetes classes and other informal sources, and what they were learning about living with Type 2 Diabetes. Precisely because I maintained contact with women over an extended period of time I was able to track their learning. Before I share their stories, I explain the practical issues around data generation.

Interviewing Women

The venue for the one-to-one interviews was usually in the woman’s home, but on a few occasions, for one of the women the interview was held at her work place and for another woman the interviews were conducted in the backseat of a car which was parked alongside a large park land area. Alison was working full time and she preferred to meet during her lunch time break or early in the morning before she started her work. Elizabeth was babysitting her grandchildren and while Elizabeth was waiting for her grandchildren to come out of school, I interviewed her in the back seat of her car. This was Elizabeth’s preference.

Date and Time of the Interviews

It was important to set a date and time for interview that was acceptable to all parties. There was an apprenticeship process in place for learning PAR and my supervisor
accompanied me during the first individual one-to-one interviews with eleven 
women and so three people needed to be accommodated in terms of time and place. 
Once I had completed my PAR apprenticeship I was able to independently continue 
with ongoing interviews. I met with the women regularly every fortnight over 
twelve months.

**Safety Issues**

In addition to my apprenticeship period when gathering information about 
participatory action research, there were safety aspects that needed to be considered 
as mentioned previously. Theses safety issues were considered because I did not 
know the participants before starting the interviews. In fact the safety issues were 
part of the ethics committees’ rules as mentioned them before. My supervisor and I 
observed safety precautions for each of the first individual meetings. We wanted to 
make sure that it would be safe to carry on independently thereafter, however, when I 
visited the participants alone and before entering their homes I sent a text message by 
mobile phone to my supervisor to let her know the name of that particular 
participant, home address and the time of interview. Then after finishing each 
interview, I sent another text message to let her know that my interview was finished 
and I was safe. My supervisor acknowledged receipt of my messages each time by 
returning a response by text. My mobile was always set to triple zero, the local 
emergency number just in case I needed to get help urgently. I also carried a safety 
alarm to protect myself. I checked entrances and exits to homes in case I needed to 
make a quick escape and I was vigilant for pet dogs or signs indicating their
presence. After I knew the participants I was more relaxed and could trust the participants.

**At the Beginning of the Interviews**

At the beginning of one-to-one interviews, I introduced myself to the women and showed my university identification card. I paid attention to my appearance; I always dressed neatly and had a cheerful disposition. I talked briefly about my interest and research background. I always followed the ethical requirements such as checking the informed consent, reminding the participants of their rights; reminding them that they could withdraw from the study anytime without having to give any reasons and that they could choose not to answer any questions if they did not want to.

**The Digital Recorder**

In terms of rigour and the stated research protocol, to protect both participant and researcher, I used an Olympus digital recorder to record all conversations verbatim. At the beginning of each interview, I recorded the date, time and the participant’s name. I placed the recorder in between the participant and myself and checked to see that it was recording. I always checked the performance of the recorder and the two batteries before starting each interview. I carried two spare batteries just in case I needed to replace them because of failure. After finishing each interview I captured some of my own reflections and then transferred the recorder file into my laptop, for transcription and subsequent analysis, and then I made a backup copy on a DVD. The audio recording and the transcriptions were stored securely in the laptop which
was password protected and the DVD was stored in a locked filing cabinet at the university.

**Building Rapport with the Participants**

In this PAR process, the richness of data and open disclosure depends on the trust and relationships the researcher is able to build with participants. I had to restrain my own talkativeness and refrain from exercising my opinions. Instead, I listened carefully to the women and let them talk. I noticed that women liked to express their special interests such as talking about their family, eating habits, good memories in their lives and exercise. Moreover, I was careful not to judge or provide advice; rather, I fostered an environment where they could talk comfortably or tell their story in whichever way they wished. Over time, the women looked forward to my visits and so did I. I enjoyed tea and biscuits with the women and their family members and the PAR groups were relaxed and congenial.

**Listening to the Women**

The other important issue during the individual interviews was listening to the women actively and following their conversation. I invited them to tell their story from when they were first diagnosed with diabetes. When the women were talking, I maintained good eye contact with them and I listened to them with full interest. Whenever the women talked about aspects of their lives that they were not happy with, I empathised with them. I did my best to understand the women’s feelings. I
disclosed my own experience in journeying alongside my mother as she was learning to live with a chronic heart condition. I shared my mother’s situation with them.

**Supervisory Feedback after each Interview**

During my PAR apprenticeship period and immediately after each interview, my supervisor, Professor Higgins and I reflected upon and talked about the interview, my questioning techniques and interview skills, the participant’s responses to the situations, what we observed at the participants’ homes and we reflected upon the “silences” and tone of each participant’s voice. This feedback gradually helped me to improve my questioning and interview techniques and the interpretation of each interview. It also helped me to reflect on the process.

**Interviews with the Women**

I asked women to tell their story starting with being diagnosed with diabetes. I learned to ask fewer questions, but a more usual approach in gathering stories is to interview in a non-prompting way by saying things like ‘tell me more’ or seek clarity for meaning. Participants were encouraged to talk about whatever they wished. I had completed the literature review around storytelling (chapter three) and I was on alert not to talk too much and to let the participants talk and have voice. One of the most important books which I was guided was written by Koch and Kralik (2006) as they had examples of PAR individual interviews. Sometimes, I used prompts as follows:
• Could you please let me know your age, medical problem/history, occupation, family situation, family support, and educational background?

• Will you tell me what happened after you diagnosis?

• What was your feeling in that first few weeks after diagnosis?

• What kind of changes have you made for your life?

• Would you tell me more about the ways in which your life has changed?

• How do you think that your family is coping with these changes?

• Can you tell me what you think about the feedback I have given you?

• Do you like to change in my record the conversations?

• Can we discuss some of these points further?

• Can you tell us about yourself from the time you were diagnosed with diabetes to the present time?

• Can you give an example of an incident or episode that really changed your life?

• How do you feel about what is happening to you?

• How has diabetes affected your lifestyle?

• What sort of things (people or services) helped you to manage successfully?

• Tell me one of your biggest changes?

• What would you like to let me know about your diabetes and life?

• What do you think helps you to come to understand your life with diabetes?

• Can you tell me how these changes have impacted on your life?

• Can we talk about how you have managed the changes in your life?

• Would you share with me what you do to control your condition?

• How are you trained in these methods?

• What about services, what role have they played in your diabetes self management? What could be improved?
• How long after you were diagnosed did you attend the diabetes classes?

• I am really interested in what you have to say about these classes because I think we can always learn from our participants and improve the service.

• Did you attend all diabetes classes?

• What were the diabetes classes like overall?

• What did you learn?

• Is there one particular aspect of the diabetes class that you found helpful?

• Did you think they were worthwhile?

• What did you like about them?

• What did you not like about them?

• How could they be improved?

• Do you think you were ready to take in the diabetes classes so soon after your diagnosis of diabetes?

• What do you recall from those classes that really helped you understand?

• Since we last met what have you been reading/consulting/doing that has helped you to understand self management of diabetes even more?

• Can you tell me about something that you are most proud of in your management?

• How do you think that your family are coping while you are learning to live with this condition?

• Do you think that there is anyone in the family who might like to talk with me?

• Do you talk about your diabetes with any of your friends, or the rest of your family?

• What is your suggestion to women who are newly diagnosed with diabetes?
Before the interview commenced, another ethical consideration was reminding participants that if they became distressed whilst talking or if thinking about their situation made them sad, there were professional counselling services available. Fortunately, however, the need for counselling was not required in this study.

In each of the subsequent interviews the participants talked a little bit about their lives. Sometimes the story was repeated as the women wanted to emphasise on aspects of their story or they were not ready to take actions in their lives. For example, Sara always started from the first time she was diagnosed with diabetes and then talked about her feelings post diagnosis and the actions she had taken. Learning was identified as women were making changes in their lives, I had observed a change in their behaviour or the woman told me what she had done differently.

**Inviting the Family/Friends**

After I had been meeting and talking with the women for several months, and if the family members, friends or support persons were interested to share their experiences, I invited their participation in this inquiry. I delivered an information sheet and consent form for the family/friends to join the inquiry which is located in appendices F and G. In the interview with significant others, I asked the family/friend about their experience and feelings as a family member of the participant, if and how they were involved in the woman’s adaptation to diabetes, what their issues and concerns were, and what barriers they had experienced, if any. These conversations with the family continued throughout my contact with the women.
Verbatim Transcription

After each interview all digital recordings were transcribed verbatim. This was a challenge as not only is English a second language for me, I also had to become familiar with the Australian colloquial language. In an effort to increase my understanding, I attempted to capture every utterance as I was transcribing; this included all ums, uhs, false starts, stutters, repetitions and remarks, such as “you know”, “like,” and distracting speech patterns, such as “right” and “yeah” and “um-hum”. It also included pauses, laughter, crying, coughing, interruptions, and external noises, such as “shuffling papers,” “starting a DVD,” etc. However, sometimes I could not understand them as maybe the participant forgot to explain something or the sentence was incomplete or I misunderstood what they were saying and thought I heard something else rather than their actual word or expression. For example, once I heard ‘proper lies’, rather than ‘broccoli’. In my mother tongue we pronounce ‘broccoli’ differently to the Australian accent. Therefore, I recognise that I may have misinterpreted some points of conversation.

As I explained earlier, my first language is not English and I learned English with an American or British English rather than Australian accent. Therefore sometimes I was not sure about the Australian accent of a word or the meaning of an expression. I returned my interpretation of each participant’s story to them and invited them to make corrections as needed. At this time, they made corrections to my grammar and helped me to correct some of the language. I also learned more about the Australian food culture and, most importantly, whilst researching alongside women who are newly diagnosed with diabetes, Australian eating habits.
One to One Storytelling Analysis

There are different storytelling analysis methodologies. For example; Oke (2008) and Kirkman (2003) draw the themes from the narratives and make stories in a meta-narrative. With narrative analysis, rather than categorising situations or episodes as instances of a general type, commonalities and a basis for understanding take place by means of analogy. They use analogy as a means of comparison, as well as categorising of episodes into general types. For creating the stories and developing the storyline and analysis, I applied Koch 2011 ‘one to one storytelling analysis protocol’.

To follow the protocol during my inquiry, I asked the participants about their stories. Then the stories were transcribed verbatim by me. In my inquiry, I realised what was spoken rarely follows a neat sequence of events. Also storytelling episodes lasting 60-90 minutes of digital recording on average create about twenty pages of single spaced text, and the first draft storyline varies between 1500-3000 words. For instance, Sara’s transcript was 7500 words but the storyline given to the participant was 2,250 and its short version 600 words. I read and reread the transcription by asking what was going on here? And I considered tone and repetition.

I paid attention to words selected, particularly the verbs which relate to ‘looking, thinking and acting’. I asked what was going on (look coded in red), what was being reflected on here (think coded in orange) and what action was proposed (act coded in green). When clustering I asked what really mattered to the participant, what was important to her? I asked what were the participant’s strengths in this emerging storyline? I noted the tense in which the story was told. At the second level of clustering
text was coloured into look, think and act colour codes. Then I clustered text around strengths, self identity, relationships, social context, events, opinions, perspectives, feelings, experiences, similar content and similar phrases, deleted repetitions, noted images and metaphors.

Each cluster was written in a paragraph and it was called a construct. The first line of each paragraph was considered as a significant statement and later these significant statements were collected when there were multiple stories. The repetition was deleted. However, it was also important to ask why this information was being repeated. Perhaps the participant had repeated the important parts of their stories. Perhaps she was beginning to find her voice and it was novel being heard, instigating a revelation that was worth repeating.

The storyline was developed by joining the paragraphs chronologically. The long storyline was made by participants’ words and the coherence and the flow was considered. The short story line was made by connecting all significant statements. The list of all significant statements was made. Short stories are located in chapter seven and each story was followed with discussion. Each significant statement/construct of the stories was explained in my own words. Following the discussion, I wrote about my reflections/observations about the interview process.

In chapter five, the person and the context of the interview(s) are introduced to the reader and short stories are inserted using the participant’s own words. The story is also supported by a discussion in my own words. Therefore, I show how I had a grasp on the
main constructs in relation to my research question. Then the reflections about the interview process were written.

This process was followed and repeated for each participant. When all data had been generated, all significant statements were collected from all interviews into a list. Then all significant statement/constructs were clustered. The commonalities were viewed for prioritising them. Each commonality/main construct was discussed.

In chapters five and six the main constructs are introduced. Each common construct is in the order of priority or the way it made more sense with my research question in mind, is discussed. To finish, a summary of the major points are written as a common story which is located in chapter six. I included accumulated reflections about the entire interview, storytelling and analysis process in chapter six.

This storyline was then given to the participant for further co-construction. Feedback also mentions strengths observed. The final story was a co-construction between facilitator/researcher and participant. Storytelling continued until the participant was satisfied with her story. Constant, validation of the story enhanced methodological rigour.

**Providing Feedback and Confirmation**

Provision of feedback is central to this PAR process, ongoing validation of summaries given to participants meets the rigour requirements but, most importantly, secures the involvement of participants. In this inquiry, I wrote the story in the way I
described above and this story was returned to each of the participants. Then, in collaboration with the individual participant, ‘we’ edited and expanded the story as our relationship grew. The story evolved as new information was generated, movement and actions were monitored. I gave written feedback before meeting with the participant and the women validated their stories each time. I re-constructed the stories by using the participants’ and my supervisors’ comments. The stories were continually validated by the participants, thus enhancing the rigour, the trustworthiness and the credibility of this study.

Sara’s Story

I give an example of a short story I provided as feedback to the participants in the following. The participant is Polish and the expressions are, in her words, ‘broken’ English. I have used first person statement for the feedback to promote ownership. Sara said:

I was born in Poland in 1941. I was an agricultural technician. My parents died because of stroke. In 1980 I came to Australia. Then I got married to a Polish fellow and got divorce. All my family are in Poland. I just live by myself here. I went to Newcastle College to Learn English for two and half years. I was working in Coca Cola Company for two years and had back problems and then I am on disability pension. Later on I am doing voluntary works. I have heart problem since 2003. I was diagnosed with diabetes four months ago. I am controlling my diabetes by diet and doing exercise. So far my diabetes is good. The diabetes does not affect me so much. I take everything easy. When I was diagnosed with diabetes I was so devastated. I
had mixed feelings. But it was not a surprise for me because I was vulnerable to get high blood glucose level. I pulled myself together. I changed my lifestyle. I haven’t talked about diabetes with my sister because she is very sick and I try not to add on her problems. I just talked about it with one of my neighbours. I was waiting for two months to go to diabetes classes. I was a little bit worried because I wanted to go to the diabetes classes earlier and gather information. I attended all diabetes classes. I learn about diabetes through books, magazines, television and diabetes classes. I learn from classes to check my blood glucose level, eating low GI foods\(^3\), portions, eating on time, shopping and label reading and I changed my eating habits. I think my diet is the same as what I have eaten for my heart condition. I am careful about saturated fat and triglyceride because it is still high. I eat nuts, avocado margarine and cheddar cheese. I could cut down my sweets. I enjoyed all parts of the diabetes classes because always I have learned something new. The classes gave me an idea how to cope with diabetes. I think it was enough to learn but if I need more information I will ask them.

When I go shopping I look at the labels and read it especially about blood glucose level, carbohydrates, saturated fat and fibres. I am conscious about sweets, cakes and biscuits. I do not buy cakes. The biscuits do not have much fat. Sometimes I eat processed foods and sometimes I eat chicken liver. These things increase your cholesterol but they have vitamins. Sometimes I buy diabetic foods but you cannot trust the labels. Sometimes when I go shopping sweets are very attractive and I have temptation about them. Sometimes I buy dark chocolates. Chocolates are good for you. I do physical fitness with my

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\(^3\) According to Diabetes Australia (2010) a low GI food is a food with a low glycaemic index is one with carbohydrates that break down slowly, releasing glucose gradually into the bloodstream.
arm and lifting. I am using two water bottles for lifting. I just walk around the house. I think I put on a little bit weight. Maybe it is winter and I am not walking every morning.

My Thoughts and Reflections Post Interview

I met Sara at the diabetes centre in June 2009. She was diagnosed with diabetes a few months ago. She told me that she was divorced and that she did not have any children. She lives in a house in urban Newcastle. Sara has good relations and communications with her neighbours.

It is nearly thirty years since she migrated to Australia. She still thinks that she needs to improve her English and was apologetic about her language use. But I told her that she communicated very well. In my opinion she has had a hard life but she appeared to be very independent and determined to manage her chronic condition.

On the day of the first interview she welcomed me and was expecting me in her home. She told me that she does not eat sweets but when she invited me for a cup of coffee she presented me with a range of sweet biscuits. Of course I do not know if she had bought them just for the occasion. She justified that biscuits were acceptable in her diet and explained that they are not as sweet as chocolates.

It was very interesting visiting and interviewing someone at home because not only do we have an opportunity to gain insight into their daily lives, we also see what is going on in their kitchens. We were shown around her kitchen and asked to examine
her food shelves: Brazil nuts, walnuts, almonds, peanuts, Nescafe, cake, big family biscuits package, cheese, butter and so on. It looks as if fat reduction is not in her plan, but I understand that the diet with which she must have grown up, traditionally Polish, is very high in fat content. She eats chicken livers and rationalised that livers contained vitamins and she claimed that biscuits do not have much sugar but appeared to ignore the fat. She said that she has changed her diet after her heart problem but she may not have the correct information about her diet.

On a personal level I thought her situation was very difficult as she did not have any family she could count on. This was particularly difficult when she was sick; as she did not have anybody to help her. However, her responses were always optimistic and she was keen to take control of her sickness and pain.

I noted that she was organised because she had filed her doctor’s results and tests in a folder and called it ‘Health’. At the end of our conversation, she shared more about her daily life and living in Australia. I think it was a good sign that she trusted me to share her experiences.

I was interested in information ‘grasped and assimilated’ from a variety of sources and I summarise these as Sara would prefer to learn from books about diabetes and even make changes creatively such as doing exercise with bottles. The research question refers to the way in which woman learn to take this chronic condition into their lives. I was particularly observant in tracking Sara’s moving on over twelve months. I summarise her learning as the group learning. She preferred to learn about diabetes from the other people with diabetes and learn from their experiences.
Reflection

As I explained in chapter three, I learned to think about my own role as researcher. I observed the gaps in her story, and what I would ask next time we met. Theoretically I need to think more about co-morbidities and this participant’s exposure to her previous experience in living with a chronic illness. Perhaps there is a hierarchy of chronic conditions (e.g. I would rather have a diagnosis of diabetes than cancer). What is striking is the amount of text (number of words) used to describe diet and food. It is almost a preoccupation with food products and I wonder if this is part of learning to live with diabetes so soon after diagnosis or it might also reflect her early experience of chronic hunger in post war communist Poland. I realised how much people like to talk about their lives.

The final short story was made in collaboration with the participant. I developed a table about the Context of the storytelling with the women living with diabetes and their families (see, table 4.1.)

<table>
<thead>
<tr>
<th>Participant's Pseudonym Age</th>
<th>Date Diagnosed with diabetes</th>
<th>Researcher Contact made with Person</th>
<th>Family members involved</th>
<th>PAR group Sessions &amp; timeframe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pam, 73</td>
<td>December 2008</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes Six months</td>
</tr>
<tr>
<td>Barbara, 76</td>
<td>August 2008</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes Six months</td>
</tr>
<tr>
<td>Bella, 72</td>
<td>August 2008</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes Six months</td>
</tr>
<tr>
<td>Helen, 58</td>
<td>March 2009</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Kathrin, 55</td>
<td>March 2009</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes Two months</td>
</tr>
<tr>
<td>Anna, 82</td>
<td>January 2009</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Name</td>
<td>Date</td>
<td>Participate</td>
<td>Involvement</td>
<td>Reflections</td>
</tr>
<tr>
<td>-------------</td>
<td>------------</td>
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<td>Sara, 69</td>
<td>April 2009</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Alison, 57</td>
<td>June 2009</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Katy, 66</td>
<td>March 2009</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Elizabeth, 63</td>
<td>June 2009</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Rose, 59</td>
<td>June 2009</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>

**Preparation for the Group Meetings**

After conducting the one-to-one interviews with the women and their families I conducted the PAR group meetings, which I will describe below. It was important to be organised and prepared before each participatory action research group meeting. Being organised demonstrated that I was serious about the process and so encouraged women’s involvement. Preparation consisted of: calling each of the women and personally inviting the women and their family members or friends to a participatory action research group meeting as per the information letter for the study, organising a suitably accessible and familiar venue, ensuring the timing of the meetings was appropriate to their availability, ensuring all women had suitable transportation to meetings, negotiating an agenda for the meetings with the women or building agenda items based on discussions from the previous meetings, creating a comfortable and safe environment, arranging seating before starting the participatory action research group meetings, providing suitable and/or appropriate refreshments for people with diabetes, checking and re checking the functioning of the audio recorder, conducting literature searches and reviews as needed and based on items discussed at meetings, consultation with experts as needed or requested by the women, recording my reflections immediately after each meeting and writing these into my journal after each meeting. I will expand on these aspects in more detail below.
Inviting the Women and their Families/Friends

I invited all the women and their family members and/or friends to participate in the PAR group meetings. Invitations were extended to everyone giving two months’ notice. The first participatory action research group was to be held in November 2009. Not all the women agreed to participate in the group meetings for a range of reasons. One person was on annual leave, another had a doctor’s appointment and one woman was unwell for the first participatory action research meeting.

Many of the family members were spouses who felt that the group meetings were “the women’s business” and as a result opted not to participate in the group meetings. Instead, they were happy to show their support by driving their partner to the venue for the meetings and picking them up later at the meeting’s end. Other family members were daughters or sons or friends of the women who worked in full time employment or had family commitments.

The Venue

In terms of selecting the venue for the group meetings, I introduced three options to them which were 1) a conference room at the University of Newcastle, 2) a meeting room at the HNELHN Service diabetes centre in the city, and 3) a meeting room of HNELHN Service diabetes centre in Wallsend, an outer suburb of Newcastle with accessible and good public transport and where, incidentally, the Diabetes Education Centre was situated. They selected the meeting room located in the health care facilities at Wallsend as parking at the University of Newcastle was difficult and public transport,
although available, meant walking a distance on hilly terrain, the second was located in one of the busy streets of the city centre of Newcastle where parking was difficult and not free. Almost all women were familiar with the Wallsend venue as they had attended the diabetes classes here at some stage in the recent past and, importantly, it was easy for them to park their cars and they did not have to pay a parking fee. Access to venue and use of space was confirmed with the Diabetes Nurse Educator at this HNELHN Service diabetes centre.

**Timing**

My plan was to facilitate at least ten participatory action research group meetings between November 2009 and April 2010. Meetings were to be held fortnightly, excluding the weeks over Christmas and New Year. As discussed, I confirmed space availability with the Diabetes Nurse Educator but as I was in a participatory action research group apprenticeship mode, I checked these dates with one of my PhD supervisors. Part of the apprenticeship was learning to facilitate participatory action research group meetings and we agreed that the first three PAR group meetings would be collaboratively facilitated.

In collaboration with all partners, we confirmed a suitable date and time. Most women preferred Mondays for two hours in the afternoon. These two hour meetings provided the women with enough time for introductions, socialising, enjoying refreshments and catching up on events since their last meeting, it allowed them to talk about their gathering information about diabetes and what actions they were taking in the light of their gathering information about diabetes, and it provided adequate time for the
Diabetes Nurse Educator or Dietician to come along to answer the women’s questions. The preferred time of day, the afternoon, suited most of the women because some of them went to the gym (Barbara, Katy and Rose), or had doctors’ appointments (Anna, Pam and Bella), baby sitting commitments (Elizabeth and Pam) or they worked fulltime or part time in the mornings (Alison and Kathryn). This time of the group meeting was preferred by the family members as well as, they were able to drive the women to the venue of the group meetings. Rose and Helen asked me to give them a reminder call about the scheduled meetings because they felt they could not rely on their memory. Rose, Sara and Katy asked me to call them on the morning of each group meeting to remind them.

Transportation

Most of the participants came to the group meeting in their own cars or their partners drove them. Pam came by bus; however, it was a short walk to the venue. I offered Pam a taxi voucher but she liked to walk as part of her daily exercise.

Creating a Comfortable and Safe Environment

During the group meetings, it was important to provide a comfortable and safe environment for the women to talk together. As the meeting room was located in the HNELHN Service diabetes centre, other people, such as the staff and their clients, had access. I shut the door of this room during the group meetings. Closing the door meant that the women were helped to protect their privacy and it allowed them to disclose their concerns comfortably. Serving refreshments also helped the women to socialise and
enjoy friendships with each other. The women ate and talked to each other comfortably and it allowed them to talk more easily at the beginning of the group meetings. In addition, given the meetings were held during the hot Australian summer months around the November to February period, an air-conditioned environment also ensured the women’s comfort.

**Seating**

Seats were arranged in an open circular inward facing format. I made sure that everybody could see each other. I sat among the participants. I wanted to make a comfortable situation for the participants to talk to each other and so share their lives about gathering information about diabetes and to live with diabetes. I felt that they accepted me as a part of their group.

**Refreshments**

Prior to each group meeting, I provided suitable refreshments for people with diabetes. As the women were on ‘healthy’ diets, I consulted with the Diabetes Nurse Educator about what was appropriate for the women. I provided afternoon tea consisting of cups of tea or coffee, fruit, scones, butter and jam as refreshments. However, in December 2009 I wanted to create a festive atmosphere for the women, so I provided Christmas hats, cherries, strawberries, almonds, walnuts, coffee, tea, milk and ‘diabetic’ fruit cake purchased from the cake shop that traded in the provision of ‘diabetic’ delights. The purchase of the cake was based on a suggestion from a participant, however we all realised that there is no such thing as a ‘diabetic’ cake! We all got a lesson from this
experience: to think carbohydrate load and not be persuaded by inappropriate labelling as in the ‘diabetic cake’.

**Digital Recording**

As I needed the women’s conversations during group meetings for analysis, I recorded all meetings. At the beginning of the group meeting, I rechecked consent from the women to use the Olympus Digital recorder. I put the recorder at the centre of the circle of seats either on the floor or on a low table. Before each group meeting, I checked the function of the recorder whether it was working or not and I always had spare batteries and plenty of digital recording space. After each group meeting, I transferred the recorder file to my laptop computer and then made a backup to the DVDs. All these digital records were password protected. I deleted recorded files from the actual recorder so as to have enough memory for the next group meetings. All data were analysed concurrently using Koch’s and Kralik’s ‘look, think and act’ framework.

Recording and transcribing the meeting conversations added to the rigour of this study. It helped to transfer the women’s conversation into text and capture what was going on in each group meetings. Out of each group meeting transcription I highlighted the main items of that specific meeting and made a summary. Then, before starting the next group meeting, I gave a summary of the previous meeting to the participants who read it and gave me their feedback and comments; comments to validate my summary and to consider improving an understanding of the women’s conversations in the group meetings and also my writing.
Analysis of PAR Group Meetings

For analysing the PAR group meetings, I applied Koch’s (2011) protocol. Although I had developed a common storyline and these were presented to women prior to the first PAR meetings, some women wanted to retell their stories in the group. I digitally recorded the PAR group meetings. PAR group meetings were transcribed verbatim by me for the first few PAR group meetings. In this way I secured a record of the norms, described later in the thesis that participants had agreed upon. Having a verbatim recording meant that I could further develop each woman’s individual storyline, which of course was revalidated by the women once I had rewritten their account.

The analysis, reflection and writing process for PAR dialogues followed these steps. I read through the transcripts with an ‘attunement’ to both the content of the words and the actual experiences of the participants. I noted if women selected to continue their storytelling in the ‘public’ group. If yes, I developed their storylines in collaboration with the women during the following weeks. It was interesting to note the differences in storytelling when told in a larger group and I reflected on the way public accounts were similar but not the same as the woman’s private one to one interview accounts. There were differences in the way they construct past events and actions, recount their histories – what they emphasise and omit. As I had a verbatim recording, I could then continue to develop individual storylines and these could be validated with the women. Some women chose not to talk about their lives in public, rather they wanted to focus on practical and technical topics they might share and learn from each other. I identified group dynamics, power play and voice (were all voices heard) and made notes about ways I could improve group facilitation.
I reflected on my role as facilitator, clustered dialogue under the ‘look, think and act’ analysis framework and identified individual woman’s or group strengths. A draft answer to my research question was developed and continued to build on this draft in subsequent PAR group meetings. I developed constructs (a list of main items discussed and some actual quotes to provide evidence) for use in the discussion section to follow after PAR group meetings ceased. A short feedback document was developed to give to women prior to the next PAR group meeting, which was a short summary of the meeting, it included their strengths and focused actions decided on.

An agenda was developed based on the women’s interested topic to discuss. This agenda was provided with the feedback (as described previously) prior to the next PAR group meeting. The feedback was validated for enhancing methodological rigour. All of the above, through subsequent PAR cycles with particular focus on actions/reform instigated, was recorded and monitored. Women’s new understandings were congruent with their experiences.

These ‘findings’ were brought back to the next PAR group meeting for discussion and validation. I maintained my reflective journal of the entire set of PAR group meetings. What actually happened and was achieved in each PAR group meeting was systematically reported. These events are located in chapter seven. The ethical and rigour considerations and ways I could leave an audit trail for the reader to show methodological, theoretical and practical decisions were noted. The principles that guided this inquiry were paid attention to make sure they were embraced throughout the entire process. Finally the entire process was evaluated.
Principles Guiding the Inquiry

The principles selected to guide this inquiry were based on my beliefs previously described and which embrace my participative worldview. While in the field, I attempted to break down the distinction between facilitator/researcher and participants. When researching alongside people collaboratively, I worked toward building sustainable relationships. I recognised that the PAR group was a community and I built on strengths and resources within that community. As a facilitator/researcher I helped this community to work together to improve their lives living with diabetes.

Literature Review and Readings

The women’s agenda and discussion in each group meeting prompted me to review relevant literature which I used to help me understand what might be happening for the women, to give me insight into their situation and condition to inform deliberations at subsequent meetings. I usually searched a range of different resources such as ‘Google Scholar’, ‘Pub-Med’, and books and the magazines that the women were likely to use.

I would bring readings to the women in the following group meeting. For example, I reviewed the role of support for coping with a chronic condition (Rosland, Heisler, Choi, Silveira, & Piette, 2010; Skerrett, 2003; Tang, Gillard, Funnell, et al., 2005; Wang & Fenske, 1996; Wilson & Mayor, 2006) through the literature. I reviewed literature relating to the ‘shock’ (Roberto, Gigliotti, & Husser, 2005; Telford, Kralik, & Koch, 2006; Turner & Kelly, 2000; Yi, Vitaliano, Smith, Yi, & Weinger, 2008) after being diagnosed with a chronic condition to become more familiar with the women’s
conversation in the group meetings. I also searched topics such as: how it felt to be
diagnosed with diabetes (Samson & Siam, 2008; Sanguins, 2006; Sprague, Shultz, &
Branen, 2006; Thorne & Paterson, 2000; Thorne, Paterson, Acorn, Canam, Joachim, &
Jillings, 2002; Wallis, Boxer, Chaboyer, Grant, Bardsley, Carlson, et al., 2006; Weinert,
Cudney, & Spring, 2008; Willoughby, Kee, & Demi, 2000); what constituted a diabetic
diet (American Diabetes Association, 2006; Thorne, Paterson, & Russell, 2003;
Townsend, Wyke, & Hunt, 2006; Watson, 2005; Whittemore, Bak, Melkus, & Grey,
2003; Whittemore, Melkus, & Grey, 2005); and the nature of effective exercise regimes
for the women (Thorne, Ternulf Nyhlin, & Paterson, 2000; Visram, Bremner,
Harrington, & Hawthorne, 2008; Wen, Shepherd, & Parchman, 2004). I will discuss
these in the chapters to follow.

Consultation

During the group meetings, I often consulted with the Diabetes Nurse Educator, the
Dietician and my supervisors. Topics for consultation ranged from the type of
refreshments and the reading material that the women brought to the group meetings
such as recipes for diabetics. The women enjoyed sharing their reading materials with
each other, however, I was wary of them sharing incorrect information and therefore I
always consulted with health care professionals at the HNELHN diabetes centre. Where
the Dietitian or the Diabetes Nurse Educator deemed recipes appropriate, I made copies
and gave them to the women in the group.

Women amongst themselves talked about how they could make themselves busy as
most of them did not work and they introduced each other to voluntary work groups,
such as work at a Salvation Army shop. Sometimes the women asked me direct questions about diabetes and I refrained from answering these as it was outside the scope of my researcher role; instead I sought help from health care professionals at the centre. For example, I consulted with one of the Dietitians from Diabetes Australia to search about the women’s request for a suitable book for the Type 2 Diabetics with both diet and exercise control.

I also consulted with my supervisors about ways I could encourage the women to share their information about diabetes with each other and how to prepare myself for the next group meetings. Most importantly, I consulted with the women; I sought their suggestions to improve the group meetings and this constituted part of the process evaluation.

**Reflective Journal**

I reflected actively on the meetings beforehand and afterwards. I often wondered what would come out of the meetings and how they might be related to my research question. In each group meeting, I thought about what, how and when women were gaining information about diabetes itself and also about how to live with diabetes.

**Rigour Considerations**

In the previous chapter I outlined the ways in which rigour and quality are established in PAR and by the veracity checks of all transcripts by the participants and their engagement in the PAR group, ownership of the process was squarely theirs.
understood that the trustworthiness of this inquiry depended on the transparency of the process, so that readers could decide for themselves whether the stories I had told were believable. I researched alongside women and they were engaged in writing their stories. My aim was to make sure that all women and their families’ voices were included in the text. My claim is that this inquiry is credible; I have not falsified data, and this was obvious as I had created a multi-voiced text in which all the voices that were heard and represented adequately. Participants were included in all aspects of the validation process in the storytelling and PAR group process. Cycles of feedback were part of the constant validation process. Consistent with my participative world view I was motivated to generate authentic information that was useful for participants. Process evaluation of the study suggested resultant actions, individual growth and improved diabetes self-management were meaningful and relevant in their lives. Participants had the final say in making the decision about an inquiry’s quality.

I was tempted to write about generalisability and realised that this concept belongs to the non-participatory action research approach. This study is not generalisable. Instead I will refer to this study’s transferability. Transferability is possible if I have described the context of the setting and given a profile of participants. This inquiry with women living with diabetes showed that the transition thesis was supported and its outcomes were transferable. I suspect that if I had researched alongside a similar group of women in Melbourne the findings would be similar; they too would be preoccupied with diet and exercise. Gender differences might have shifted my understandings of transition and I suggest it would be interesting to do a similar follow up study with men who have been diagnosed with diabetes. From previous research (Koch, Kralik, & Taylor, 1999b),
men were not preoccupied with food and its preparation; they had wives to undertake this task.

Is this inquiry dependable? I have given a detailed description of the way in which data were generated and analysed. My decisions and choices made whilst researching were made visible through the use of reflective journaling. I believe that theoretical, methodological and analytic choices have provided a framework and have been recorded. Readers should be able to follow my methodological decision trail.

In the introduction to the thesis, I was at pains to describe my values and that I understood that my values and interests would automatically affect my interpretation of events and data. Reflection was a skill to be learned and the idea of constantly reflecting and analysing those reflections was strange initially. I understood that my social and cultural background and my experience as a non-participatory action researcher would influence the way I researched. I kept a diary as a reminder to record and analyse influences, at least those accessible to me, whilst researching. Maintaining a daily journal and analysing its contents was the strategy here. My previous experience in Iran with people diagnosed with diabetes had resulted in evaluating the benefits or not of an exercise plan. When I was first in Newcastle, I was absorbed in the technicalities of diabetes self-management, for instance I tended to ‘measure’ everything against physical activities achieved before and after diagnosis. However, when I really started to listen to women, I heard that their preoccupation with food was a much larger issue for them to deal with. In subsequent conversations, they started to dwell on personal issues and I gradually began to understand that learning to live with diabetes required technical, practical and emotional work.
The women in my inquiry became rather protective, helped me with the English language and wanted me to succeed. Participants may have been unsure about attending the PAR group meetings at the start, but once in the circle and listening to others in the group, it seemed to foster commitment to each other and I believe, to me. In this way relationships were reciprocal. Whenever possible, I built on the strengths of the group. Instead of focusing on problems women were experiencing in their daily lives, I encouraged them to celebrate every learning event in living with diabetes. I stimulated plans and activities that women were able to accomplish themselves; I believe we built an environment where relationships can continue to thrive, even now after I have left the field.

It was important to me that this work is meaningful and has the potential to make a difference. I believe that a longer period in contact with my participants meant that there was the possibility for outcomes across three categories: technical, practical and emancipatory (Kemmis & McTaggart, 2005). When I first commenced working alongside participants, outcomes tended to be technical and practical and that was my focus too. In the first year of the inquiry, participants were hungry for medical information. Technically, women have had access to good information about diabetes via the staff at the diabetes centre; previous contradictory advice has been curbed. In practical terms, women are self-managing their diabetes with increased mastery. Self-management refers to the activities women have undertaken to create order, discipline and control in their lives. And women set the agenda for meetings and have assumed power to continue to meet with each other which speaks to the emancipatory aspects of this inquiry.
Chapter Summary

In this chapter I have described and outlined the aims and objectives of the study, the research methods and the rationale for their selection. I also discussed the setting for the study, how I gained access to the participants, consisting of the recruitment process, ethical considerations, the data generation methods used; one to one interviews with older women recently diagnosed with Type 2 Diabetes; PAR group meetings; and my reflective journal, data analysis and finally how rigour and quality were ensured in this study.

In the next chapter I explain one of the study’s objectives, which was ‘to engage with the women and then their families in ongoing interviews and conversations about what was happening in their lives following the diagnosis of Type 2 Diabetes’. In the first phase of this participatory action research process, the women and their families were engaged in ongoing conversations with me to ‘look and think’ about what was happening in their lives. I explored the individual and family/friend group learning processes since diagnosis. I concurrently analysed the interviews so that I could track the women’s ‘learning’ in their life trajectory since Type 2 Diabetes was diagnosed, which were also monitored through the sustained contact I had with the women and their families/friends, in two to three weekly contact meetings with me over a period of twelve months.
CHAPTER FIVE
ONE TO ONE INTERVIEWS WITH WOMEN, STORYTELLING,
ENGAGEMENT WITH FAMILIES AND DISCUSSION
Introduction

As noted in previous chapters, my study was guided by the approach to participatory action research as articulated by Koch and Kralik (2006). My adaptation of their methodology consists of two distinct phases. **Phase one** is storytelling (one to one interviews), feedback and construction of a storyline. In principle, I recognise the unique strength that each person brings to the study, and I insist that voices are heard and I attempt to break down the distinction between facilitator/researcher and participants.

As discussed previously, there are many versions of participatory action research but the appeal of Koch and Kralik’s methodology is the storytelling component which in my study preceded group activity. I view storytelling as a vehicle for human encounter and communication. A story emerges through the pull and push between the people’s telling and the world in which the story is told (Mattingly & Garro, 2000). Not only are stories products of language, so many versions can be told as we constantly construct and
reconstruct ourselves to meet the needs of the situations we encounter. We tell stories with the guidance of our memories of the past and hopes and fears of the future.

Storytelling allowed me to invite participants to talk about their experience. In listening to their stories it allowed me to follow the participants’ daily lives and to understand the major changes they had had to make in their lives. I was particularly interested in the storytelling phase of Koch’s and Kralik’s methodology because I considered it to be important for understanding the way people have made transitions in their lives. I asked each woman to tell me their diabetes diagnosis story. Without using too many prompts, I listened and recorded. I transcribed one to one interviews verbatim—a process that took at least ten to sixteen hours for each interview—and analysed interviews as described in chapter four.

In the following section, I will reintroduce the women and present their short stories. I believe it is important to hear the stories in the women’s own voice; however, here the short stories are presented in the third person. This decision was made in order that individual women’s personal quotations, carefully selected to illustrate specific major learning episodes, could be incorporated in the group story. Each woman’s story will be told followed by the family member’s first person account and sharing my thoughts and reflections will comprise the third data set.
Anna

Anna is eighty-one (81) years of age. She married Chris fifty five years ago and they had seven children. She does not have a family history of diabetes. Prior to being diagnosed in January 2009 she was diagnosed with two co-morbidities: arthritis and hypertension.

Anna’s husband was not surprised when she was diagnosed as he had noticed that she had been drinking a lot of water. When diagnosed with diabetes she was disappointed and it took her six months to adjust her feelings. She had good support from her husband which meant that managing her diabetes was made easier. Her medical management consisted of taking one drug called Diamicron.

Anna’s initial gathering information to live with diabetes can be described as follows. Immediately after being diagnosed Anna attended diabetes classes at HNELHN Service diabetes centre. She claimed to have learned cooking tips, food portion control, label reading and understood the importance of doing exercise. She was generally satisfied with these diabetes classes except she found that three hours was not enough time to absorb information and it did not give her time or space for asking questions. Her gathering information about diabetes self-management was impeded as she did not like the idea of a group setting in the diabetes class.
Anna believed that she was managing her diabetes by ‘trial and error’. Her sister-in-law had diabetes and she listened to her words of advice. Label reading was the hardest part of gathering information for Anna and this made shopping for food more complex. Rather than plan the future she took her diabetes management day by day. She wanted to exercise but her arthritis did not let her move as much as she desired. Generally, she felt all right about her diabetes management and she managed it by controlling her diet and with limited exercise.

**Anna’s Husband’s Story**

Anna’s husband is eighty-two (82) years of age. He said:

> When Anna was diagnosed with diabetes I was not surprised because I had observed that she was drinking lots of water and going to toilet a lot for some days. Then the doctor confirmed that Anna has diabetes. I accompanied her to attend the diabetes classes. I think generally diabetes classes were good and I have learned about correct blood glucose level range. This meant I could help Anna to check her blood glucose levels with the blood glucose meter. I think reading the food packages labels is one of the hardest things in shopping and I read them with Anna. There are labels ‘no added sugar’. But when you read the table it is ninety six (96) percent sugar per serving. We have differences of opinion: Anna thinks that watermelon is not sugary, but I do not think so. I cut down my sugar intake too because I was diagnosed as pre diabetic recently. So we both keep an eye in controlling our sugar intake and we have cut down fat and salt from our food. We still have problems with serves. I guess every
fifteen grams of everything means a serve. We could ask about it... However, after a couple of months we have settled down and we are not worried about diabetes any longer. Anna has learned that she needs to look after herself.”

Researcher’s Reflective Journal about Anna and Chris

I was still in my apprenticeship phase when we went to Anna’s home for the first time. Chris said that he did not remember me and claimed that we did not have an appointment. I later understood that Chris had mild dementia. We agreed to talk with this couple the following day. This was a reminder to check on the day as well as setting the date in advance.

Chris and Anna lived in a cosy, well maintained house in Kotara. I noted that Anna had a hearing problem and when her husband talked to her sometimes she asked for repetition. Chris and Anna were sitting side by side during interviews. Anna and Chris always offered me a cup of coffee at the end of our conversation. This suggested to me that they were comfortable with me. This social activity helped build relationships.

I was able to track Anna’s learning since she had been diagnosed. Her learning style is best described as mutual learning with her husband. Together they gathered diabetes information from books and magazines and read these together. They discussed the best way to manage diabetes with each other. I noticed that they were not ready to gain information immediately post diagnosis of diabetes. They
mentioned that it was hard to make a transition from their previous life as they were familiar with that for a long time.

They did everything together as I had noticed that Anna went to the diabetes classes with her husband, which she claimed helped her to learn. Anna preferred one-to-one tuition in diabetes education because she had a problem hearing and liked to talk about her situation so she adjusted her information gathering to suit herself. They went shopping together and Chris helped Anna with reading the food package labels. Anna liked doing exercise but she had arthritis and could not move a lot.

I saw how much Chris supported Anna and he bought resistance bands¹ for her, which allowed her to move better. It took a few months for Anna to sort out how to re-arrange her life and make life-style changes. I noticed that Anna’s cooking was changing over time; guided by the diabetes education cooking advice and despite not liking vegetables, I noted that she was attempting to eat more than before. The most difficult life style modification for Anna was not eating sweets, which she loved, but even though it was difficult she managed to cut down her sugar intake. Over time, I recognised that Anna was interested in knowing more about diabetes from the diabetes classes and books. She had also acquired a diabetes identification bracelet.

Generally, I enjoyed talking with this older couple. My realisation, as a researcher, was how nice it was to listen to their stories. Anna was interested in sharing her story with me. I believed that I was improving my interview techniques and I felt more

¹ Resistance bands are defined as the stretchable bands with different colours and strengths, which are good for people who cannot do exercise (Diabetes Australia, 2010).
relaxed. Whenever I found gaps in Anna’s stories I asked her about these during the subsequent interview. I always gave Anna and Chris their short story from the previous interview before starting our conversations and made sure to emphasise Anna’s strengths, such as her passion to gain information about diabetes. I felt privileged to know this couple and enjoyed talking with and listening to them.

**Barbara**

Barbara is seventy five (75) years of age and had married Bob a long time ago. She was diagnosed with Type 2 Diabetes in August 2008. Her other chronic condition when diagnosed with diabetes was asthma.

Being diagnosed with diabetes was expressed as a shock. Barbara did not know what had triggered diabetes. Prior to being diagnosed she had believed that you had to be obese to have diabetes. She was not obese, therefore, she was taken aback when she was diagnosed with diabetes. She believed that having diabetes was part of the ageing process.

On a formal level, Barbara attended all three diabetes classes at HNELHN Service diabetes centre health and she was satisfied with them. She claimed that she learned from these diabetes classes especially reading labels and portion control. She admitted that she did not really know much about diabetes before attending diabetes classes.
Over time, Barbara learned to self-manage her diabetes. After the initial shock she appeared to accept her diabetes and took action by doing exercise and taking control of her diet. Her doctor monitored her blood glucose level and she was pleased that it was within normal parameters. She controlled her dietary intake and reduced her food portion size. Reading labels was the hardest part in her gaining information but she intended to re-address this by going back to the diabetes classes held at HNELHN Service diabetes centre. She was determined to exercise and lose weight. Her action included going to ‘Heart Moves’, ride a bicycle and moving her limbs in the hydrotherapy pool. She reported being very proud of losing weight.

Her gathering information was assisted by support from her family, her husband and her son. When she was diagnosed with diabetes, her son bought her a book about diabetes. She was an avid reader and learned mostly from books. So she acquired several books which informed her about healthy living with diabetes, subscribed to Diabetes Australia magazines and these provided guides to shopping. She also used the Internet. Her doctor, she claimed, was supportive.

Having diabetes did not deter her travelling around the Australia and abroad. Her routines were well established. When she travelled, she looked at the menu every time and checked what she could order. She always avoided fatty foods.

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5. Heart Moves programme is organised by Australian Heart Foundation for people over fifty years of age. The exercises in this programme are slower than the other physical activities and it is suitable for people with heart conditions and diabetes (Heart Foundation, 2010).
Barbara’s Husband’s Story

Bob is seventy-five (75) years of age and he is Barbara’s husband. He said:

When Barbara was diagnosed with diabetes I was shocked. I was thinking why Barbara because always she was walking and exercising. However, being diagnosed with diabetes did not interrupt Barbara for doing exercise. She just kept on her walking and exercising, I supported her to deal with diabetes. Always we are supporting each other.

I think reading the food packages were not easy for us at the beginning and it took a long time. However, now we know which brand is which and it is not necessary to read the same brands all the time.

I like Barbara’s cooking style and I am on the same diet. I believe that it is very healthy. I do not eat sugar and salt. I just have pepper with my food. The only difference between me and Barbara in our eating is I eat a little bit more bread as I am bigger than Barbara. We have good habits as we do not have snacks. We just have a dark chocolate once a week for a treat. Generally, I think Barbara is doing very well in her diabetes management and I am proud of her. Even I feel that she does not have diabetes any more.

Researcher’s Reflective Journal

I have known Barbara since December 2008 at the diabetes centre. She lived in a new and big house in Hamilton. She was always well dressed and looked healthy. It was interesting that she had support from her son and that he gave her a book about
diabetes. Barbara’s husband, Bob, was very supportive as well, as he did not criticise Barbara. Barbara did not like to talk about her diabetes with anybody as she felt that she was a strong woman and she could manage her diabetes. Barbara liked to learn more about diabetes by her own exploration through the different resources such as books, magazines and the internet.

It was interesting that Barbara lived a healthy life and had so for her whole life. She did not have a ‘sweet tooth’\(^6\). Barbara mentioned that she just sometimes had a small piece of cake with her tea.

It was noticed that Barbara seemed to be surprised at the beginning of her Type 2 Diabetes diagnosis. However, as she had access to good diabetes resources, books and magazines she could move on shortly after her diagnosis. She could deal with her emotions post diagnosis and did her best to move on. Therefore, she made changes in her cooking, eating and her exercise.

Barbara stated that she was troubled using the blood glucose meter to check her blood glucose level and in addition she did not want the routine testing to be part of her everyday life. Barbara preferred her doctor to monitor her blood glucose level. She was reassured that her blood glucose level was normal. When first diagnosed, and hearing that her blood glucose level was within the normal range, she wondered whether her diabetes had ‘gone away’. On the other hand, Barbara appeared to know that when officially diagnosed with Type 2 Diabetes, it would be with her forever.

\(^6\) Sweet tooth was defined by Barbara as she did not get used to eat sweets and she was not craving for sweets (Barbara, 2010).
During the first interviews, Barbara talked to me very briefly and I was unsure whether she would continue her participation in this study. However, over time, Barbara trusted me and she talked more about the changes she was making in her diabetes management. I realised that it was not easy for people to talk about their lives with a stranger. Not only was there an age difference as I was talking with a much older Australian woman, but also my Iranian cultural background meant I need to give time toward building relationships. It takes longer to make sense when using two languages. In fact it was only our gender we had in common. As discussed, this was one of the reasons for researching alongside women instead of men. She mentioned that she was doing very well by watching her food portions and doing regular exercise.

Bella

Bella is seventy two (72) years of age. Her husband’s name is Andrew. She was diagnosed with Type 2 Diabetes in August 2008.

When she was first diagnosed with diabetes, Bella and her husband were shocked. But she pulled herself together. She then used her diagnosis as a turning point in her life and thought that she could start looking after herself. She said that she did not know anything about diabetes at first; however she took action to learn about her chronic condition straight away by attending the HNELHN Service diabetes classes, diabetes ‘workshop’, joining Diabetes Australia and checking her blood glucose levels.
She believed that checking her blood glucose level was a good management indicator for her and she learned to make the connection with her food intake and her blood glucose levels. Affirmation that her diabetes was under control was when her blood glucose levels were acceptable.

In the formal education process, she learned from HNELHN Service diabetes classes and Diabetes Australia magazine. She was quite assertive at these diabetes classes and asked many questions. She attended two of these diabetes classes. The most important thing she learned from the diabetes classes was label reading, how much she could eat, how to calculate carbohydrates, sugar and fat. She found information on low GI food very helpful and understood that these foods were very slow to be digested and could therefore delay her hunger.

It took her a little while to learn to live with diabetes. Changes needed to be made. She changed her cooking habits and watched her meals more than before her diagnosis and she placed her meal on a smaller plate and reduced foods, like potato. Fortunately, her husband liked her ‘new’ cooking. She was more relaxed about managing her diabetes as months went by.

Part of the diabetes self-management was taking control. She was determined to overcome her temptation to eat foods that she knew the ‘black’ list. In the supermarket, she skipped by the foods she did not want to buy. On the whole, she was proud of cutting down her chocolates and lollies but gave herself an occasional treat with a small portion of dark chocolate.
Most importantly, she learned that when she ate the right things she lost weight. When shopping, she practiced reading package labels and increasingly found this easier. She tried to keep herself active through walking and gardening. She motivated herself by listening to IPod music as she walked.

She knew how to look after herself even while she was travelling around Australia and she shopped for food judiciously when outside her normal environment. She was satisfied with her doctor and family support. To date, her diabetes management is controlled by diet and exercise.

**Bella’s Husband’s Story**

Andrew is Bella’s husband and he is seventy-two (72) years of age. He said:

> When Bella was diagnosed with diabetes I was a little bit upset. But it was not a real shock because I thought Bella might have diabetes even before her doctor picked up her diabetes. It was pretty easy to understand that Bella is going to get diabetes, because her doctor said that Bella’s blood glucose level was a little bit over the border and she was a little bit overweight. When Bella was diagnosed with diabetes I was attempting to help her. I wanted just to make sure that she does everything as she was supposed to do. Therefore, I read all of the diabetes materials and the Diabetes Australia’s magazine. I tried to help her by reading the food packages labels. We do not buy junk foods.
I like Bella’s vegetables and diabetes jellies. We are on the same diet and we avoid using sugar and salt in our foods. I am proud of Bella as she lost weight by walking and watching her food. But still, I think Bella needs more walking every day. Her blood glucose levels are always perfect.

**Researcher’s Reflective Journal about Bella and her Husband**

I knew Bella from the diabetes centre in January 2009. Bella was a talkative person and she lived in Georgetown. Always, Bella was confident with her diabetes management and she did not feel that a diabetes diagnosis affected her life. She was a sociable person and talked about her diabetes with other people.

When Bella was diagnosed with diabetes she expressed herself being in shock. As she had a good relationship with her husband, even her husband was shocked as well because they did not expect Bella’s diagnosis as she believed that she had a healthy lifestyle. This couple could not imagine Bella’s diagnosis. However, they pulled themselves together and dealt with ‘ending’ their previous life and transition to a new life by learning more about diabetes. Bella attended some diabetes workshops and made herself ready to move on in her new life situation.

Bella had good support from her family. Her husband, Andrew, did not mind Bella’s food and ate her diabetes food. Perhaps he was interested in being on a diet or he was encouraging Bella to eat proper foods to manage her diabetes.
Bella had a good relationship with her doctor and visited her doctor regularly. Having support from the family and the health care professionals was important in Bella’s diabetes management.

Bella received information about diabetes by asking her questions to the Diabetes Nurse Educator and the Dietician of the diabetes classes. She loved the group setting through the diabetes classes. After finishing the diabetes classes, she was gathering more information about diabetes through books and the Diabetes Australia magazine. Bella was happy with the Diabetes Australia shop as she could buy the discounted strips and needles for her blood glucose meter from there.

Always, before starting our conversation, I gave Bella her story and she read it full of interest and then gave me her suggestions and confirmed it. We always celebrated her strengths together. She was always comfortable while she was talking with me. Bella always believed that ‘nothing is impossible’. She kept a good routine for her diabetes management.

Alison

Alison is fifty six (56) years of age and was still in the work force. She was diagnosed with diabetes in June 2009. Alison had a pre-existing chronic condition breast cancer had been diagnosed and treated in Newcastle. She explained that for her, diabetes was just another medical condition and she would just need to learn to manage it. At the time of the first interview, Alison was on diabetes medication. Her daughter was concerned about diabetes as hereditary.
When Alison was diagnosed with diabetes she was not really surprised. She had known that she carried too much weight around her abdomen. She was more concerned about the complications of this disease.

Alison believed that she was approaching diabetes in the same way as she did with her breast cancer. She sought information as she needed to manage her diabetes. Her formal gathering information about diabetes was from the HNELHN Service diabetes classes. Unfortunately, she was only able to attend two of the classes, given her full time work situation. She was satisfied with the diabetes classes and liked working in the diabetes class group. In particular, she appreciated the diabetes centre staff and thought it was very useful to have food products on display so that their labels could be examined. In addition she joined Diabetes Australia and therefore had access to their magazine. The Internet was also an important source of information.

Initially, knowing that she had diabetes preoccupied her mind. Then she slowly learned to accept that changes were required if she was to successfully live with diabetes. Information sought about this chronic condition meant she could make lifestyle choices. Alison monitored her blood glucose levels two to three times a day and she believed this regular checking was a good indicator to guide her management. She ‘watched’ what she ate paying close attention to all aspects of her food intake. She exercised and took her medication regularly. Although she drove her car to work, sometimes she parked her car a distance away so forcing her to walk. When shopping, she was very determined to overcome her temptation to buy sweets through bypassing the supermarket shelves that carried the chocolates.
Researcher’s Reflective Journal about Alison

I know Alison from the diabetes centre in June 2009. As Alison was working full time, she asked me to visit her at work during her morning tea. She was always very welcoming even though she was clearly busy in her job and held a key leadership position where she worked.

It was interesting when Alison mentioned that she was not surprised when she was diagnosed with diabetes because she expected it. She was not surprised post diagnosis with diabetes as the other women were. Alison could move on with her diabetes diagnosis easier than her previous chronic illness as she drew strengths from breast cancer survival. People’s previous experience of being diagnosed with another chronic illness may help them in transition with another chronic illness. Alison had access to good resources for her diabetes management. These resources were her previous experience, books, magazines and the Internet.

It was sad that Alison did not have much support from her family as she lived on her own and therefore, she did not have anyone motivating her.

Alison was gathering information about diabetes from the diabetes classes as well as her own way of diabetes management. She was gathering information from a course that she was teaching on leadership and change. This course introduced different choices for new situations. Therefore, Alison believed that it was the time to take on board her teaching. Alison had different choices in her diabetes management. She chose to look after herself by controlling her diet and doing more exercise.
Alison was strong and she made changes in her life post diagnosis with diabetes. She cut down her ‘take away’ foods. She started to do exercises, such as walking. Therefore, she lost weight and she was proud of that.

I noticed that Alison was organised. She talked about her feelings, lifestyle changes, diet and exercise. We celebrated Alison’s strengths together. Alison felt comfortable while she was talking to me. Alison claimed that she was becoming more expert in managing her diet and exercise very well.

Helen

Helen is fifty eight (58) years of age. She is a divorcee, with three adult children and she currently lives with her brother. She has a family history of diabetes. Diagnosed with diabetes in March 2009, her management is diet control and exercise.

When diagnosed with diabetes she was not shocked as much as disheartened. Being diagnosed with diabetes did not surprise her because of the family history of diabetes. Nevertheless, it took a few months to overcome her disappointment. She actively tried to think positively. Her brother, who also has diabetes, gave her advice. These siblings did not necessarily agree on the best way to self-manage diabetes.

Helen attended the HNELHN Service diabetes classes and she had learned to change her cooking methods and use different products. She loves food, so this lifestyle change was a big decision for her. Helen recognised the need to make changes in her life. One of her first activities was starting to walk. After she started walking she felt
much better. She was very pleased when she lost weight. This was her biggest change. Checking blood glucose levels became routine. She continued to learn about new food products as they were coming out in the market.

Helen’s doctor was supportive and pleased that she was losing weight and that her blood glucoses indicated that her diabetes was under control. Generally she was pleased about her self-management and would like to keep going with diet and exercise and was happy not being on medications.

**Researcher’s Reflective Journal about Helen**

I know Helen from the diabetes centre diabetes class in April 2009. Helen lived in an old house with her brother. Helen had a monotonous voice which might have indicated that she was depressed and it was somehow hard for the purpose of the transcription. At the beginning she did not like to talk about herself. However, after a few visits she trusted me and she shared more about herself such as the way she had changed her life after being diagnosed with diabetes. During the interviews she was passing one of the hardest chapters of her life which was related to getting divorced from her husband. However, gradually, she thought that her decision was logical and then she could concentrate more on her diabetes management.

Although Helen expected her diabetes diagnosis because of her family history of diabetes, however, when she was diagnosed she was in shock for a couple of months. Helen mentioned that it was hard to move on from her previous life and make changes in her life style. Therefore, she did not look after herself during this period.
of time. When she attended diabetes classes and talked to her brother as he had diabetes, she could get ready to move on her diabetes management.

At the beginning of being diagnosed with diabetes, Helen had challenges in gathering information about diabetes such as how much fish and egg she could eat. However, after some time, Helen had learned more about her eating and cooking from the diabetes classes’ materials such as the cookery book. Therefore, she cut down her mashed potatoes and fat intake. She changed her eating style and she ate more vegetables. The other way of her gathering information about diabetes was from the Diabetes Australia magazine which introduced diabetes recipes. One of the biggest changes for Helen was about avoiding ‘Take away’ which meant that she was determined to manage her diabetes.

As a researcher, I noticed that everybody’s life situation was different. Helen knew about the suitable foods to improve diabetes management, however, these foods were expensive and she was not able to afford to buy them. Helen was given her story and she provided feedback when confirming her accounts.

Elizabeth

Elizabeth is sixty two (62) years of age. She is married and has three adult children. She was diagnosed with diabetes in March 2009.

Shocked would be the best way to describe Elizabeth’s reaction when first diagnosed. She thought she would be immune to diabetes as she had led a healthy
lifestyle. She quickly realised that she could take control whereas taking charge with other illnesses e.g. cancer would not be up to her. Her husband appeared to take her diagnosis in his stride and he was not really surprised as he had been telling her for many years not to eat so much. Despite this observation he was caring and supportive. Life style changes were supported as Elizabeth’s husband cooked most of the time.

Elizabeth learned that walking and losing weight would be conducive to improved diabetes self-management. After being diagnosed with diabetes she had made decisions to walk more and lose weight. She checked her blood glucose levels regularly and she wrote down her readings in a notebook.

Elizabeth’s formal gathering information about diabetes was through HNELHN Service diabetes classes. The most important thing learned in diabetes classes was to drink a lot of water. She also learned about making healthy choices and did not focus just on disease. She carefully observed her body’s reaction to the food. Although her husband prepared the meals, she continued to shop for food and in so doing avoided buying ‘black’\(^7\)-listed foods. Elizabeth believed that her biggest achievement was losing weight. Her plans were to keep going with her walking, continue to lose weight and stay active.

\(^7\) Black-listed foods lists means the food which have high carbohydrates and high fat which are not suitable for diabetes (Dunning, 2008).
Researcher’s Reflective Journal about Elizabeth

Elizabeth and I had known each other from the diabetes centre in June 2009. We always met each other at the backseat of her car near a park as she did not like to show her untidy daughter’s house. The park was near her grandchildren’s school and after the interviews she could pick up her grandchildren from their schools. Although it was a noisy place, for Elizabeth it was more convenient there. Elizabeth was a talkative woman who liked to explain everything in detail, which was amazing.

Elizabeth and her husband had lived together for more than forty years and they had a very close relationship with their children. Elizabeth’s husband was very supportive and usually he cooked for her as Elizabeth was always busy looking after her grandchildren. Even Elizabeth’s husband supported her to deal with her feelings post diagnosis with diabetes and then in her gathering information about diabetes. He read all of Elizabeth’s diabetes materials and he applied this information in his cooking.

Although Elizabeth and her husband were surprised by the post diabetes diagnosis of Elizabeth, because of Elizabeth’s husband support they could move on to gain information about diabetes management quicker. Elizabeth’s husband took responsibility to walk alongside Elizabeth’s diabetes diagnosis journey. He made everything easier for Elizabeth to move on in her diabetes management. Even he changed his cooking style to a diabetes diet and made himself involved in Elizabeth’s diabetes management. In fact, family support could be very important to encourage Elizabeth to move on in her new life.
Elizabeth’s main source of gathering information about diabetes came from the diabetes classes. However, it took a while for her to attend the diabetes classes as she was always busy and could not attend the earlier diabetes classes. After attending the diabetes classes, she enjoyed all parts of the diabetes classes and she shared the material she gathered from the diabetes centre with her husband. This made Elizabeth’s gathering information manner unique as her husband contributed in Elizabeth’s eating changes. Her husband was guided by these materials for his cooking and he cooked based on these guidelines.

Elizabeth made another change in her life which was related to her walking. She walked before her diagnosis with diabetes, however after her diagnosis she started to walk more than before. She was a good walker and parked her car far from her destination. This way she could walk and lose weight. Therefore, Elizabeth lost lots of weight and this was her best achievement in her life after being diagnosed with diabetes. To date, she was doing very well and her doctor was happy with her.

**Katy**

Katy is a retired nurse and she is sixty five (65) years of age. She is a divorcee. Other co-morbidities were high blood pressure, arthritis and she had recently recovered from breast cancer treatment. She was diagnosed with diabetes in March 2009 and she was on diabetes medication.

When diagnosed with diabetes, Katy was shocked. There was no-one with diabetes in her family and so she was not expecting this diagnosis. She explained that despite
being shocked she believed that she self-managed her diabetes very well possibly because of her nursing background.

Her formal education was at HNELHN Service diabetes classes. She attended all diabetes classes and her information about diabetes became clearer. She was satisfied with the diabetes classes. The way diabetes is managed today is quite different from previous years and for Katy she was now up-skilled to appreciate new approaches to healthy eating, food selection and preparation. In addition to diabetes classes, she purchased books and relevant magazines.

She had learned to adapt her life style to incorporate healthy eating, diet and exercise. When she travelled she bought and prepared her own food. She was proud of losing weight by going to the gym. However, sometimes it was hard to exercise when Katy’s arthritis was troublesome. Generally, Katy feels that her diabetes management is going very well and it is under control.

**Researcher’s Reflective Journal about Katy**

Katy and I have known each other from the diabetes centre in June 2009. She was always welcoming. She had a medium sized house full of furniture and magazines. Katy always seemed tired as she was still recovering from her breast cancer.
Katy had a sense of humour which was interesting and it helped her not to take life too seriously. However, sometimes people did not understand her sense of humour and misunderstood her funny behaviours.

When Katy was diagnosed with Type 2 Diabetes, she was shocked. However, her previous experience of breast cancer and her nursing background helped her to make changes in her life. It took her a couple of weeks to think about what was going with to her and then she made plans for changing her life style. Her priority was going to the gym and eating based on diabetes classes guideline.

The main source of Katy’s gathering information about diabetes came from her nursing background and then it was up-dated by attending the diabetes classes and reading the Diabetes Australia magazine. Katy had a favourite seasonal magazine about living with diabetes and she learned about the new ways of diabetes management and took diabetes recipes from it.

Katy loved cakes, muffins and cordials. Occasionally, she had sweets as she felt that she was past the recovery days from post cancer and her body required them. Sometimes, Katy’s arthritis interfered in her doing exercise. However, she managed it by taking pain killers before starting any exercises. As a consequence of her diet and exercise, she lost weight and her blood glucose level was normal. Always Katy gave me comments about her feedback. Sometimes she corrected my grammatical errors which were interesting for me.
Sara

Sara’s story and the researcher’s reflective journal were given in chapter four.

Kathryn

Kathryn is fifty five (55) years of age and a divorcee. She held a full time job, although she was on a short term contract. She was acutely aware of this and the need to be able to support her mother and teenage daughter who lived with her. Several other co-morbidities were already diagnosed: depression, kidney and thyroid problems. She was diagnosed with diabetes in January 2009. She is currently on medication, Diabex. She has a family history of diabetes and was overweight when diagnosed.

Kathryn described being disappointed when diagnosed with diabetes. However she readily accepted this condition and realised that it would be partly her responsibility to avoid the need for insulin in the future.

Kathryn confided that she felt that her family did not really support her. They did, however, advise her not to eat too much and do more exercise but she did not like it.

Two formal diabetes classes were attended at HNELHN Service, Kathryn missed the third as her working life conflicted with the times these diabetes classes were available. She liked the combination of Diabetes Nurse Educator and Dietician
classes. She claimed that she received ‘good’ information about diabetes and could understand the medical information. She learned how to read labels. She learned that if she continued to look after herself she would not need insulin injections in the future.

It was several months before Kathryn became confident about food shopping and checking labels. She taught herself and tried to choose the correct products but initially this was confusing. She was challenged in her shopping because, when she was looking for low carbohydrates foods, often had more fat or sodium in them or vice versa.

She planned to be on the right track and change her lifestyle. These plans were writing down what she ate, doing more exercise and being more aware about foods. Kathryn would like to be more conscious about her health and has started watching her eating and food.

**Kathryn’s Mother’s Story**

Penny is Kathryn’s mother and she is eighty-four (84) years of age. She said:

> *When Kathryn was diagnosed with diabetes I was not surprised as I predicted it. I observed that Kathryn ate too much food, sweets and that she drank too much alcohol. We have had a big struggle in regard to modifying her eating style. However, Kathryn believed that she was working full time and she deserved to eat what she wanted.*
Then after her diagnosis, I noticed that she had not changed her cooking and eating style and I advised her to look after herself. But it did not work. Then, after a while she understood she needed to take actions to look after herself from the programmes on television. She was good for a couple of months. However, she found a new boy friend and Kathryn accompanied him to have dinner and alcohol together most of the time which was not good for her. Kathryn’s daughter, Emily and I have stopped advising her. Hopefully she will realise in time that her behaviour needs to change. I love Kathryn and I do not like to break her heart by reminding her how much she is allowed to eat. I am sure that Kathryn is very determined and if someday she wants to change her life style she could do it easily. I trust her.

Researcher’s Reflective Journal about Kathryn and her Mother

I knew Kathryn from the diabetes centre since March 2009. Kathryn lived in a new house in Charlestown near the shopping centre. She was always very friendly and welcoming.

At the beginning when Kathryn was diagnosed with diabetes, she felt surprised. She could not imagine her diabetes diagnosis and she was blaming herself by asking ‘why me?’ Her daughter and mother were blaming her rather than helping her. She had too much stress in her life: she needed a full time job but was having trouble securing a job and full time work. Her daughter wanted to travel like her friends and she was concerned about her mother as she was the primary carer. She was not
getting any encouragement from her family/friend to move on and make changes in her life.

At the beginning of being diagnosed with diabetes she diligently documented what she ate and her daily exercise in a table. Sometimes her daughter and mom reminded Kathryn to not eat too many foods and she did not like to be advised. One of the hardest parts of Kathryn’s life was living with different generations, mom, daughter and her own generation. Therefore, sometimes these generations conflicted with each other.

Kathryn’s information about diabetes experience was coming from the diabetes classes and she learned to read the food packages labels and control her eating portion. Kathryn loved gathering information about diabetes from the others during the diabetes classes. Sometimes, she gathered information about diabetes from the medical programmes on television to manage her diabetes. However, at the beginning of being diagnosed with diabetes, it was hard for her to overcome her eating temptation. She was determined to say no to sweets while she was shopping. She was planning to go back to normal and follow the diabetes classes’ diet and exercise guideline.

Kathryn was always interested in sharing her story with me. After some time, my interview techniques improved by not asking too many questions and letting Kathryn talk. Her story emphasised her strengths and she was happy with this. She always confirmed her story by reading it and giving me her comments.
Rose

Rose is fifty eight (58) years of age and was diagnosed with diabetes in August 2009. She was married thirty three years ago and she and her husband have two daughters. Her brother has diabetes as does her husband. Rose claims that her husband does not self-manage his diabetes very well.

When she was diagnosed with diabetes she found it difficult to accept. However she thought that at least diabetes was not as bad as being diagnosed with cancer. Rose realised that the main plan of action involved diet and exercise.

Formal gathering information about diabetes was organised through the HNELHN Service diabetes classes. She attended two diabetes classes. She liked the group setting in these classes and benefitted from the support participants gave each other. After attending the diabetes classes she knew more about the food groups and portion sizes.

Rose planned diabetes self-management which included trying to lose weight. She attempted to change her lifestyle, ate ‘healthier’ food and did exercise. Mentally, she prepared herself by thinking ‘diabetes is not the end of everything’. She monitored and checked her blood glucose levels regularly and then she cut down her food intake based on advice from the diabetes educators and lost weight.

Rose did not receive much support at home. Her husband was intent on telling her what to do and she resented his interference. She did not talk to her husband about
her feelings because he had his own opinion about health issues. She had support from her doctor.

Informally Rose said she learned from specialised diabetes magazines and books such as ‘Traffic Light Guide to Foods’ from the Diabetes Australia shop. She attended HNELHN Service diabetes class on low GI foods. Rose commenced an exercise class and lost weight. She was very determined to control her purchases when shopping and tried to manage her craving for sweet foods. She was proud of herself as she did not buy chocolates anymore and she was planning to lose more weight. As a result Rose, was fitter and slimmer and she claimed to feel more energetic. Her biggest life style changes were changing her diet, losing weight and doing exercises.

**Rose’s Daughter’s Story**

Liza is Rose’s daughter and she is thirty-five (35) years of age. She said:

> When mom was diagnosed with diabetes, *I could not say that really I supported her as I was busy with my son all the time and the work commitments. However, when my parents come to my house I cook proper food for mom. At the beginning of mom’s diagnosis, she did not talk to me about her diabetes or with anybody and she helped herself a lot. She did not ask for help from me as she did not want to place me under stress. I was expecting that my dad could help her. However, he did not. I think mom needs support from my dad. Dad is really crabby (angry). He eats too much. Dad*
has diabetes, as well. He needs to check his eyes and feet. However, he does not mention his diabetes to his doctor.

Mom made changes straight away, such as changing her cooking and eating style and walking more than before. I know that how much it is hard for her not to eat what she likes as mom loved eating before. She cut down her eating portion and eats vegetables mainly.

Generally, I believe that mom is doing very well. I am glad that mom could control her diabetes by doing exercise and diet. I am proud of her.

Researcher’s Reflective Journal about Rose and her Daughter

Rose and I met each other at the diabetes classes in August 2009 for the first time. She lived in Glendale in a big house with her husband. She was very friendly and talkative. During the first interviews she had lots of stress. She did not have much support from her husband and sometimes he was angry about her diabetes management. Her daughters were busy with their lives and sometimes they asked Rose to baby sit their children.

When Rose was diagnosed with Type 2 Diabetes, she was shocked. She could not believe her diagnosis and make changes in her life. Even her husband who was diagnosed with Type 2 Diabetes a couple of years earlier than Rose was shocked and he did not like to move on in his diabetes management. Rose was motivated to make changes in her life by getting support from the other women in the diabetes classes. It
took her a couple of weeks to deal with her feeling of shock and get diabetes under control. Then she was attempting to move on by doing more exercises and eating less carbohydrates and sweets.

Rose was a strong woman and she was gathering information about diabetes from different resources such as the diabetes classes, low GI classes, Magazines and especially her books. One of her books was a “traffic light” diabetes cook book. Rose could find the answers to her questions through this book. This colourful book encouraged Rose to cut down her food and avoid buying sweets. It was like a policeman to her; it was someone who could tell her what she could have and how much she could eat.

At the beginning of being diagnosed with diabetes, it was very hard for Rose to cut down her carbohydrates. However, she was very determined and she did it gradually. She started to do more exercise to lose weight.

Over time Rose was working hard to stay on her diet and to exercise. Always Rose’s blood glucose level was normal and her doctor was happy about her diabetes management. Rose always validated her story by reading and making comments.

**Pam**

Pam is seventy two (72) years of age and is now a widow as her husband died ten years ago. She has four children. Sometimes her daughter Sally lives with her. She
was diagnosed with Type 2 Diabetes in September 2008. Her diabetes management at the moment is diet and exercise.

When Pam was diagnosed with diabetes she was disappointed because according to her she had not ‘done anything wrong’. Her family was also surprised because she always ate the ‘right’ things. Her daughter expressed that she was worried about the diabetes ‘gene’.

Pam, as she said earlier, led a very ‘healthy’ life style. After being diagnosed with diabetes she walked more than before, did gardening and took even more care about food and eating.

Formally Pam attended all three HNELHN Service diabetes classes and enjoyed most of it. She learned more about food. Knowing more about the medical side of mature onset diabetes made her realise that having this chronic condition was not a matter of life and death. She became efficient at reading labels.

She had comments about diabetes classes. She believed that one of the classes was boring and it was too much to take in. She felt resentful at times. She thought when she understood something she could enjoy it. Pam learned that there were reliable sources of information on diabetes management. Although she did not ask many questions, her preference for gathering information about diabetes was through reading so she collected many resources. She collected material from the diabetes classes, the Diabetes Australia magazine, specific books and general books. Her strength was not to give in to craving of ‘forbidden’ foods.
Her main source of support was from her doctor and a neighbour. Sometimes she went out for a day with her neighbour and enjoyed social life. She checked her blood glucose level occasionally and learned how she could better manage her diabetes. Pam was planning to practice what she had learned about diabetes management, tried not to eat in between meals and cut down on her bread. All in all, she was happy with her diabetes management and everything was under control.

**Pam’s Daughter’s Story**

Sally is Pam’s daughter and she is forty-five (45) years of age. She said:

*When mom was diagnosed with diabetes I was worried that maybe I have diabetes genes and diabetes could be heredity in my family. I do not want to get diabetes when I get older like my mom. I do not support mom very much and even sometimes I ask her for help by staying with her and not paying rent.*

Mom has been gathering information about diabetes from the diabetes classes’ materials and the simplified books. Mom always eats healthy foods and even I believe that mom’s food is really boring. She is really a healthy eater. I admit that I cannot eat like her. Mom eats lots of vegetables. You cannot find any sweets in her place which is disappointing for me because I love chocolates and sweets. Mom walks a lot and she does not eat outside.

*I trust mom’s decision for looking after her. Always mom’s doctor is happy about her test results. She is doing very well.*
**Researcher’s Reflective Journal about Pam and her Daughter**

I have known Pam from the diabetes centre in December 2008. Pam lived in a small house in Waratah. She had melanoma ten years ago, however she survived that. She was always very friendly.

At the beginning of being diagnosed with diabetes, she was angry because she believed that she always ate healthy food and had an active life. However, it just took Pam couple of weeks to pull herself together and move on to manage her diabetes. As she had the experience of melanoma before, this time she could make a transition from her chronic illness diagnosis quicker. She made changes in her eating and exercise.

Pam did not have any family support. It was very sad that Pam’s daughter was mainly worried about herself to get diabetes in future because of her family history of diabetes rather than helping her mom. The daughter also sometimes criticised her mom’s healthy lifestyle and mentioned it was ‘boring’. Having looked after my own mother I was confused by her attitude.

Pam attended all three diabetes classes. However, she was somehow confused by the load of diabetes class information. She believed that it was too much information through the diabetes classes. She was not an educated person herself. At the early phase of diabetes diagnosis I wondered how much she was ready to learn about diabetes.
Pam liked the Diabetes Australia’s magazine as there were stories from other people with diabetes and there were short factual “titbits” or summaries about diabetes. However, she did not look through the diabetes centre’s recipe booklet as much, she thought because it was boring, it was just a black and white text, without pictures. However, Pam found the Diabetes Australia magazine more helpful because, it was illustrative and colourful. It looked to me like the ‘Women’s Weekly’ –lots of interesting pictures, short stories and information/fact items. Pam loved to learn about diabetes at her own speed through the simplified books.

Pam did not like cooking. She ate healthy foods. But sometimes she could not avoid eating sausages and meat pies. She was still active but slower as she felt she was aging. She enjoyed gardening by herself.

Pam checked her blood glucose level before each meal every day. Always, her blood glucose level was normal. She had a friend with Type 2 Diabetes as well. Therefore, Pam was gathering information about diabetes from her friend most of the time. Pam trusted her doctor and asked her many questions. She believed she was doing very well and that her diabetes was under control through diet and doing exercise.

**Engaging with the Family**

I interviewed six family members. Anna, Barbara and Bella encouraged me to interview their husbands. I interviewed Kathryn’s mother, Rose’s daughter and Pam’s daughter.
Anna’s husband was recently diagnosed as a ‘pre diabetic’ so they were both concentrating fully on the dietary changes they wanted to make and were equally puzzled about food label reading. The support Anna received from Chris was a total partnership; they shopped, prepared the food and measured carbohydrates together. Chris claims it only took a few months to settle into a new routine.

Bob, Barbara’s husband was shocked when a diagnosis was made because he described her as fit and healthy. He revealed that Barbara was very determined and that she was exercising even more now. He claimed he was proud of his wife in her management of diabetes. This couple supported each other. Barbara and Bob expressed that they had difficulties reading food labels and that they were still learning. Fortunately Bob liked his new diet without sugar and salt.

Bella’s husband Andrew was upset when his wife was diagnosed but not surprised. Andrew, Bob and Chris read the information brochures so that they could understand and support their wives in the best possible way. It sounds as if Andrew provides some surveillance when he said: ‘I want to make sure she does everything as she was supposed to do’. Again the subject food label reading was brought up. Andrew was also proud of his wife and her self-management programme, which included losing weight and watching her diet. He said that he thought Bella was back to normal.

Helen, a divorcee, lives with her brother but he was not interviewed. Elizabeth’s husband was not interviewed but I was told that he had read all the information about diabetes and had taken up cooking ‘healthy’ foods using the guidelines provided. Katy is a divorcee and lived alone as did Sara.
Kathryn’s mother was interviewed and remarked that she was not surprised when her daughter was diagnosed with diabetes as she was overweight and liked to eat sweet foods and drink alcohol. There were some tense moments between mother and daughter about ‘healthy’ eating. Initially Kathryn rejected the need to change her lifestyle immediately. However Kathryn changed her diet for a few months but then reverted back to her old habits of eating and drinking. Her mother claimed she had given up on Kathryn and so had the rest of the family.

Liza, Rose’s daughter was interviewed. There was a family history of diabetes, which included Rose’s husband; Liza said that she did not have time to support her mother as she had a young family, besides, she thought her father should provide support and was dismayed when he did not. Liza talked more about her father than her mother, stating that he ignored his diabetes status and neglected his own management. Liza was impressed with her mother’s immediate response to make changes in her life taking on both diet and exercise.

Pam’s daughter was interviewed. Sally lived with her mother from time to time, when her economic situation was tight. Sally was more worried about herself than about her mother, thinking she might have the diabetes gene. This mother-daughter relationship continued as before, in one direction, Pam continued to support Sally in most of her life decisions but her daughter did not have time to support her. Nevertheless Sally was proud of her mother’s self-management of diabetes and remarked that the ‘healthy’ diet her mother was on was boring.
Four women were in long standing marital relationships and they were in close partnership with their husbands in coming to terms with life style changes as it affected them as couples. Eight people changed their food shopping and eating habits, occupied themselves reading food labels, read most the information about diabetes that had come their way. The men encouraged their wives to exercise. All were pleased with the progress being made. Four women out of eleven were in supportive relationships.

Two younger women were interviewed about their mothers, Rose and Pam, demonstrated that in these mother-daughter relationships not much had changed; in fact, roles appeared to be the same as before, with mothers providing ongoing support for their daughters. Having a mother diagnosed with diabetes had no impact on their lives. Nevertheless, daughters were proud of their mothers’ achievements in self-managing diabetes. Kathryn’s mother was interviewed and she was dismayed with her daughter behaviour. She wanted to support Kathryn but help and advice was rejected.

Regardless of the quality of relationship, family members interviewed were proud of the way in which their relative had taken diabetes into their life and their determination to move on.

**Reflective Journal**

My reflective journal was maintained throughout one to one interviews with women and their families. An example of my reflective journal was the observation and
recording of my thoughts regarding the interviews and my research process after each individual meeting with the women and their families. As soon as I left the interviewee, I recorded my observations in my journal. I recorded how I thought how the interview could be improved, which questions gave a better and/or a richer story, what I could do differently next time, what I thought about the main points and what struck me as the most interesting aspect of the conversation. I have recorded these reflections in the section above.

In the analysis of my reflective journal I found gaps in my understanding of the women’s learning and their transitions. Therefore, I reread transition literatures and searched the literature about the aspect of change in lifestyle the women had mentioned, and tried to make links with transition. Reflective journaling was important in this participatory action research in order to monitor the research process. In addition, rigour was enhanced because nuances about the voices of the participants were noted as well as my reflections on what was happening.

**About the Interview Process**

While in the company of women I could not always control the environment: a dog barking, lawns being moved, ambulance sirens. Once I interviewed in the back of the participant’s car near a public park. I was learning about PAR as I was doing it; this was my ‘apprenticeship’. One of my supervisors, Professor Isabel Higgins, accompanied me on the first interviews and I learned from her experience. It was not possible to learn about the participatory action research process from textbooks. My other supervisor (Professor Koch) was in contact with me via e-mail and telephone
and shared her experiences with me. I have learned from both supervisors about interview techniques, listening to the participants actively and giving feedback to the participants. For example, once one of the women did not talk about her diabetes and my supervisors encouraged me to share my mother’s chronic illness experience with that participant. Then the woman appeared to feel comfortable to talk with me.

We (supervisors and me) read the transcripts and we discussed the interview process. I admit that the first few interviews were not easy to conduct as it was my first experience. Although I had read much about storytelling, actually doing it was quite intimidating. At the beginning of this study, instead of letting the woman take charge and tell her story, I sometimes asked direct questions, or I talked too much. I had trouble to memorise the prompts. Sometimes the participant did not have time to answer a question in detail before I jumped to the next question.

I thought that I could ask my questions in the order I had them on the page. However, my supervisors gave me feedback about my interview techniques. I gradually changed my interview techniques. I learnt to let the women tell their stories in any way they liked. If I had any questions – and there were fewer as I learned to trust the interview process, I could ask them after the woman had finished talking. I relaxed more and learned to go with the flow. During the interview women often asked me clinical questions about diabetes management. These questions were not answered as it was not a diabetes expert to provide diabetes information. I noted these questions and at the end of the conversation and after the recorder was switched off, I referred the woman to the most appropriate person in the diabetes centre who could answer their medical or diabetes management related questions.
I provided each woman with her story. As my first language is not English, sometimes the participants gave me feedback about my writing style and made grammatical points. I am sure that I was not always aware of cultural and social implications of researching alongside these older women, but they became quite protective and attempted to help me. In this way, the relationship was reciprocal. They had someone to listen to them. Listening may be viewed as therapeutic, as listening to one’s illness is usually greeted with a yawn (Koch & Kralik, 2006). I was really interested in what they could tell me and they could sense my strong interest in their everyday lives. And I was able to be an apprentice researcher, and at the same time learn more about Australian culture and ways of living. For instance, I noticed that the most important meal for the women was dinner in the evening, however, in Iran, certainly in my home, the main meal is consumed at lunch in the middle of the day.

**Analysis of Stories**

Stories were analysed using the ‘look, think and act’ framework as described in chapters three and four. Although this framework assists with bringing the story line together it also focused on actions generated by women toward *learning to live* with Type 2 Diabetes and I was able to turn my attention to the concept of ‘transition’. I compiled a list of all significant statements from each of the women’s long stories. For clarification, Sara’s long story and analysis is located in appendix H. In my own words I then wrote up the commonalities which will be presented below.
**Being Diagnosed with Diabetes**

One of the common features was women’s vivid recall of being diagnosed with diabetes. Although the event being diagnosed was etched on their minds, their experiences were dissimilar. Some women described it as a ‘shock’, a ‘surprise’, ‘devastating’, and a ‘disappointment’. These women were baffled by the diagnosis of diabetes as to them it had appeared out of the blue. It was the same for their family members; they shared being shocked and bewildered. Barbara had believed that people with diabetes were obese and she was not overweight or obese. She had led a healthy lifestyle her entire life. In contrast, Helen and Alison expected their diagnosis of diabetes as they had a family history of diabetes and they were overweight. They had been forewarned by health care staff that if they did not look after themselves they would develop this condition. Alison said sadly:

> When my doctor told me that I have got diabetes I was devastated.  
> I had mixed feelings. But it was not a surprise for me because I was vulnerable to get diabetes.

Pam said with sigh:

> When I was diagnosed with diabetes I was not surprised because I carry so much weight in my abdomen. I am so worried about complications; becoming blind, losing my feet to gangrene or damaging my kidney.
Women may have disclosed diagnostic information briefly but then did not talk about their diabetes with the others. Helen, Rose and Katy believed that Type 2 Diabetes was not a life-threatening condition and therefore there was no point in telling their families or friends. This led to complications at family/friends gatherings as they could not and would not eat some of the foods being served. At Christmas feasts, family members/friends expected that special foods prepared would be consumed with gusto. Women did not want to disclose their diabetes yet they could not offer relatives a reason for refusing the food. Disclosure is viewed in some literature (Kralik, Telford, Campling, Koch, & Price, 2005a) as having come to terms with one’s diagnosis. These authors wrote that:

*Having the confidence to choose to disclose or not disclose was important. Disclosure means having to deal with the reactions of others and with potentially negative assumptions about what the illness or disability means. Being able to choose which situations you will disclose in and how results in a sense of being in control of personal information, and consequently protection of self. (p.18)*

Perhaps when women did not reveal their diagnosis to their relatives they were not ready and still in an ‘extraordinary’ phase of their illness transition.

When diagnosed with diabetes it took a while for the women to come to terms with their feelings and to consider modifying their lifestyle. Bella said with a deep breath:
I accepted that I have got diabetes and I cannot change the fact, however my actions could prevent the further outcomes such as going on insulin.

Barbara’s opinion was that:

Perhaps diabetes could be a part of the ageing process like asthma. I just accepted my diabetes and I then took actions by doing exercise and being on a diet.

It was not unusual for women to attribute diabetes and other chronic conditions to the ageing process, despite this being erroneous.

Kralik (2002) mentioned that chronic illness diagnosis would be felt as an ‘extraordinariness’ and it would take time to move on. DeCoster and Cumings (2005) emphasised the fear, sadness, anxiety and irritation as the most common emotions after a chronic illness diagnosis. These emotions, DeCoster and Cumings explained, were because of uncertainty about the future and impending mortality. Peres, Gonçalves, and Peres (2009) reported that their research participants - after being diagnosed with a chronic condition- expressed feelings such as rage, anger, sadness, fear, shock and fright. Gillbrand and Flynn (2001) supported the other studies and suggested that people in receipt of a diabetes diagnosis are described as being in shock, anger and surprise in despair and with anxiety in varying degrees. It was not easy for people with chronic conditions to hear their diagnosis but my participants talked only about shock and fear of complications. Participants in Turner and Kelly’s (2000) study indicated that a chronic illness diagnosis could be stressful for people
and they had a good reason to be depressed. Most of the women, except Helen were not depressed at the beginning of their diabetes diagnosis.

After being diagnosed and the consequences of a chronic illness, people compared their new situation with their previous lives. The women in my inquiry had the same feeling post diagnosis with diabetes. They made dramatic changes in their lives but initially they focused on information exchange and the practical ramifications of dealing with their lifestyle changes. They did not talk about or suggest lack of control over their situation as most of the literature suggested (Alley & Brown, 2002; Debono & Cachia, 2007; Fisher, Brownson, O'Toole, Shetty, Anwuri, & Glasgow, 2005).

Abdoli, Ashktorab, Ahmadi, Parvizi, and Dunning (2008) stated that when their research participants were diagnosed with diabetes their major concerns were about complications; going blind or losing their feet to gangrene or becoming dependent on other people. Pam was very worried about complications and Barbara did not look forward to having to go on insulin in the future. As they mentioned, at the beginning of being diagnosed with diabetes, people could have lots of fears which could prevent them to manage their diabetes. People do not like to lose their independence and they are afraid of being dependent on their families and put them in trouble by their illnesses. Abdoli, Ashktorab, Ahmadi, et al. (2008) and Koch, Mann, Kralik and Van Loon (2005) suggested that these fears prevent people from actively concentrating on diabetes self-management. I observed that women in my study were looking after themselves by doing exercise, eating less carbohydrates and checking their blood glucose level to not face diabetes complications.
Glasgow, Boles, McKay, Feil, Barrera (2003) stated that the fear retards self-management of diabetes, and these authors referred to fear of death or increasing the realisation that they were mortal beings. Women in my inquiry, Helen and Sara, had the same feelings and it hindered them to manage their diabetes at the beginning. It took them time to deal with their fears and then make changes in their lives.

People with chronic illness might have other co-morbidities which could affect their chronic illness management (Adriaanse, Dekker, Spijkerman, Twisk, Nijpels, Hm, et al., 2004).

**Living with Chronic Illness and Other Co-Morbidities**

Seven women had co-morbidities alongside being diagnosed with diabetes. These chronic conditions were arthritis, asthma and cancer. When a woman had a pre-existing chronic condition the diagnosis of diabetes appeared to be less overwhelming than others for whom diabetes was their first chronic condition. Alison explained:

> I accepted my diabetes diagnosis. I thought it is just another medical condition and I could manage this as I have had to deal with a chronic illness before.

Elizabeth and Rose had a previous diagnosis of cancer. They said that getting diabetes was better than cancer as they felt they could control it. Elizabeth explained with a deep sigh:
I realised that I can control some factors in diabetes. It was better than cancer which is not really under my control.

It took a while for women to make a transition following diagnosis and instigate changes in life style. Bella stated positively:

It took me a little while to overcome my feelings post diagnosis with diabetes.
Then I started thinking positively about my diabetes management and I began looking for diabetes information.

As mentioned, women were making themselves ready to ‘transit’ from their feelings post diagnosis. It took them time to move on in their diabetes self-management.

Peel, Parry, Douglas, and Lawton (2004) suggested that people who have a family history of diabetes had reacted less dramatically to their diabetes diagnosis. These authors stated that this group of people might expect a diabetes diagnosis even before being diagnosed and they may be less shocked or surprised by their diagnosis. In my inquiry, this was certainly the case for Helen and Kathryn as they were not really surprised, nevertheless their responses of having had a previous experience of being diagnosed with another chronic illness made women confident to manage a new chronic illness. This idea, supported by Charmaz and Rosenfeld (2006), was that being exposed to other chronic illnesses and being practiced at self-management may induce people to accept the new condition with less turmoil.
People with chronic illness might or might not have support from family/friends or their health care professionals (Alley & Brown, 2002; Baanders & Heijmans, 2007).

**The Nature of Support: Family Support**

There were some studies to talk about the role of family/friend support in chronic illnesses. Wen, Shepherd and Parchman (2004) suggested that by accessing family support people with diabetes could be more motivated to learn to look after themselves. In this inquiry, I was able to explore the involvement or otherwise of family. I encouraged families to talk with me. A common feature to emerge from the women’s stories was related to the role of family/friend support after the woman was diagnosed.

The women believed that they were physically independent in their diabetes management. They did not need to be supported in activities of daily living although some of the husbands offered to cook or clean. The women claimed that they needed to be supported emotionally. They wanted encouragement to modify their lifestyle and support for maintaining changes in their lives. Four women, Barbara, Bella, Anna and Elizabeth had support from their families. I recognised that Barbara, Bella, Anna and Elizabeth had a good support from family and/or friends. As discussed, a few family members attended the diabetes classes with the women, and this support encouraged the women to explore management of their diabetes. Barbara declared:

*My husband and my son are very supportive. When I was diagnosed with diabetes, my son bought me a book about diabetes.*
Anna stated happily:

*My husband is very good. He does all shopping and he reads all of the food packages labels for me. We have a strong marriage.*

Elizabeth expressed:

*As I am very busy most of the time my husband cooks. And after being diagnosed with diabetes my husband now prepares food based on the diabetes centre’s guidelines. He knows how much carbohydrates I am allowed to have each day.*

The other women managed their lives without family support although some would have appreciated reinforcements. But their families were busy with full-time work or other family commitments. In fact, Pam, Rose, Sara and Alison did not want to worry their family members.

While the literature suggested that families were very important, I would say, based on my findings, not all of the women had family support; rather, Barbara, Bella, Anna and Elizabeth, were in ‘good’ marriages and they benefited from close relationships. As the family members did not expect the women to be with diabetes and this might be one of the reasons the family/friends sometimes were not supportive. The other reason would be because of their full-time work or family commitments.
Brody, Kogan, Murry, Chen, and Brown (2008) suggested that active family support was significantly associated with control of triglyceride, cholesterol and HbA1c levels. Their research demonstrated that the support of families and friends was an important factor in diabetes care, as those thus supported fared better than individuals living alone. Authors made a case for being in a permanent relationship, such as marriage, which was said to be important in improving self-diabetes management. It was argued that married people had more motivation to look after themselves.

Moser, Van der Bruggen, Widdershoven, and Spreeuwenberg (2008) indicated that ‘family caregivers’ had a significant part in every single self-management step of people with diabetes. It was suggested that family members could help people with diabetes in meal preparation or help them in emergency situations. People with chronic illness might face emergency situations such as a hypoglycaemia episode and it would be wise to have someone close on standby to alert health services. If the family members could be aware of that and have enough information to behave appropriately, such as giving sugar or call the ambulance. My assessment of this claim is that it is worthwhile having someone on standby for emergency situations. But women in this inquiry became increasingly capable of making their own meal decisions. If the participants had been men, they may have benefited from having meals prepared. This was the finding in Koch, Kralik, and Taylor’s (1999b) study with men living with diabetes. They found that men’s wives dealt with the shopping, preparation and dietary decision for the men and that the men were free to ‘move on’ in their lives without the additional burden of food related activities. In fact, men talked about being diagnosed with diabetes as a turning point in their lives. It made them more conscious of exercise, losing weight and making other lifestyle changes.
In terms of ‘support’, gender and cultural manifestations there is much learned. For instance, in an Iranian study by Abdoli, Ashktorab, Ahmadi, Parvizi, and Dunning (2008), women with diabetes gained support from their daughters rather than from the other family members. Strong support from daughters appeared to be rooted in an Iranian culture because it is a traditional cultural expectation. In the same way I am a key support for my mother.

While some people may not have a supportive family or friends, Gallant, Spitze and Prohaska (2007) demonstrated that those who had family members, sometimes saw the latter blaming the person with a chronic illness and holding them responsible for their diagnosis. Baanders and Heijmans (2007) observed the negative effect of a diabetes diagnosis on family members, especially partners. Family members could not adapt themselves to the new regimes at home. According to Rayman and Ellison (2004) the families were not always supportive. An example was given about making two sets of meals because their family could not adjust with the new dietary changes. Or alternatively, people with chronic illness did not like to force their family to have the same diet they had to follow. My observations relating to the women in my inquiry were that Pam’s and Kathryn’s daughters were blaming their mothers’ diet and they did not eat the same food as their mothers did. The women made different food for their daughters and they felt guilty about their diabetes diagnosis.

The Nature of Support: Support from Friends

A few women had good support from their friends. Sara stated excitedly:
I talk about my diabetes with one of my neighbours. She is very good. My neighbour feels I am her daughter. Every day we meet each other and have a conversation. She makes me calm.

Pam explained:

My next door neighbour is wonderful. She was diagnosed with diabetes earlier this year. She helps me a lot to manage my diabetes. She even gave me a blood glucose meter to check my blood glucose level. Without this good friend I would not know how to check my blood glucose level. She encourages me every day.

The Nature of Support: Support from Others

Kathryn, Sara and Rose had ideas about self-management reinforced from staff at the diabetes classes. These women claimed that learning to live with diabetes was a solitary endeavour and that they felt lonely before attending the diabetes classes. However, after joining these classes they recognised that they were not the only person living with diabetes and they gained comfort from others attending. They made friends at these classes. Rose said:

I like the diabetes classes because I found support from the other people with diabetes there. I could find friends from the classes, as well.
Kathryn said with a great deal of emotion:

*I did not pay attention to my diabetes management very much, however, after joining these classes I found good support from the other people and I improved taking care of myself.*

The Nature of Support: Support from the Health Care Professionals

I noticed that the support was not only related to family or friends. Some of the women had good support from their doctors. This kind of support was viewed as important for the women who did not have supportive family/friends. Katy said contently:

*I have support from my doctor. He listens to me and can understand my limitations. For example, as I have arthritis I cannot walk for long. Therefore, my doctor introduced me to the alternative option such as the resistance bands and going to gym. He always makes me calm.*

Sara indicated that:

*I do not have any family here in Australia. I can talk to my doctor and her nurse when I meet them. They always give me good advice about looking after myself. They introduced me to the diabetes classes to learn more about diabetes.*
Helen and Anna listened to neighbours and friends who had experience in managing their own diabetes. Helen explained:

My brother gave me advice about diabetes as he has diabetes, as well. He is very experienced in diabetes management. For example, he advised me to cut down my food.

The Nature of Support: Support from Pets

Pam and Sara lived alone for a long time and they did not have support from family or friends. They had cats and they believed that these pets were good companions. By having cats they did not feel lonely. Pam said happily:

I have had a cat more than ten years. I always talk to her. My cat understands everything as I say. I do not feel I am by myself. Always there is somebody who would like to see me healthy. I feel that I am living for her.

Sara mentioned with a sigh:

I had a lovely cat for more than twenty years until just recently; a car ran over my cat. I lost my old buddy. When she was alive I talked to her. She understood everything. She sat on my lap and listened to me.

In conclusion women talked about their different sources of support during the first year post diagnoses. The women who had supportive family/friends moved on and
made transitions apparently faster than the others. For example, Anna, Bella, Elizabeth and Barbara had supportive partners. The partners encouraged the women to move on to make changes in their lifestyles such as eating less carbohydrates and fat. In fact these family members contributed in women’s diet by eating the same food. This way the women were encouraged to move on in their diabetes management. On the other hand, finding support from neighbours, others attending the classes and pets should not be underestimated.

Gathering Information about Diabetes

One of the common features in the women’s stories was about gathering information about diabetes from a variety of different sources, such as; diabetes classes, Diabetes Australia magazines, diabetes books, internet, television and radio, relatives and friends. The women gathered information from the diabetes classes about diabetes management such as cooking, eating, doing exercise, reading food packages label and controlling their blood glucose level. Further, Bella mentioned happily:

I attended all of the three diabetes classes and I am happy with them. I learned a lot from the classes. The best point from the classes was getting information about reading the food packages’ labels and portion control. I did not really know about the diabetes before attending the classes.

Alison and Kathryn were employed and their work responsibilities prevented attendance at all of the diabetes classes. Alison explained gratefully:
I attended only the first diabetes class. I could not attend the rest of the classes. I liked this diabetes class as it was held in a group. Resources available at the centre were empty food packages on their shelves. I appreciated going through reading package labels.

The diabetes classes were not the only way women gathered information. They had read widely. Anna stated enthusiastically:

I am gathering information about diabetes from the Diabetes Australia magazine. I found out about particular socks and shoes suitable for ‘diabetic’ feet. I have bought these socks. They are very good.

Pam and Anna selected reading materials where information was accessible in language that avoided medical or technical jargon.

Lin, Anderson, Hagerty, and Lee (2008) did not have faith in the ability of their clients to run the educational classes by themselves claiming that they would not gather the required information appropriately and the self-organised educational classes are an invitation to chaos. In contrast, Paterson (2003) stated that chronic illness educational programmes which were mostly designed by the health care professionals without involving the people with chronic illness’ suggestions would not be beneficial. They implied that people with chronic illness would feel that their suggestions were not valued by the health care professionals and they would feel that they did not have authority in their chronic illness management.
Challenges in Modifications of Lifestyle

When first diagnosed with diabetes, women were required to change their eating habits. They tried to gather information about food products through reading labels. Reading the food packages label was one of the biggest challenges reported by the women. Sometimes the food packages labels were contradictory. For example, the food labels showed low fat but they had more sugar or vice versa.

Kathryn explained gravely:

\[ \text{Label reading is the hardest part. When I go for the main shopping it takes me a long time to read the labels. I cannot trust the labels when I go shopping as they are not consistent.} \]

The other challenge reported by women was related to food cravings. The women used different strategies to overcome eating temptations. These strategies were: not buying the ‘unhealthy’ high carbohydrate or high sugar content foods, skipping past the chocolate shelves in the supermarket and identifying and buying only ‘healthy’ foods. Alison said strongly:

\[ \text{At the beginning of being diagnosed with diabetes, it was hard to overcome my eating temptation. When I go shopping I just pass the chocolates shelf. Sometimes I buy a little dark chocolate. That does not hurt.} \]

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8. Label reading in this study meant the dietary table of food packages which showed how much carbohydrates, fat, sodium or other dietary factors existed in that particular package which was important for diabetes management. For example, every fifteen grams of carbohydrates per serve in each package was counted as one carbohydrate exchange.
Bella, Barbara and Alison travelled a lot. Routines were disrupted while they were travelling. However, they did their best to choose ‘healthy’ foods and checked their blood glucose levels. Bella expressed:

*I travel occasionally and then I am out of routine. My doctor said when I travel I am not too worried about my eating. So I am more relaxed about travelling now.*

The women learned mostly about the medical self-management of diabetes from diabetes classes. There existed a medical discourse which women learned about the signs and symptoms of hypo-and-hyper glycaemia, excessive thirst, diabetes excessive eating, excessive passing of water, tingling, dry mouth, blurred vision and vaginal thrush. They could describe all these medical signs and symptoms. The women learned about the aetiology of diabetes, its patho-physiology and its medical treatments.

Koch, Jenkin, and Kralik (2004) emphasised that people with chronic illness mostly received medical self-management and they were not included in their chronic illness self-management. They believed that health care professionals could facilitate people toward self-agency so that they become experts in their own chronic illness ‘self’ management. As the women in my inquiry were newly diagnosed with Type 2 Diabetes, it took them some time to become independent ‘self’ managers. Koch et al. (2004) also recommended that health care professionals could provide an environment for people with chronic illness to collaborate in their self-management, and grow and learn about their illness until they achieve self-agency.
Clearly there was evidence that women in my inquiry had acquired medical knowledge. And some women were in a partnership relationship with their doctors. Self-agency or becoming expert or gaining mastery, however, had not been ‘reached’ by these women.

Paterson, Russell, and Thorne (2001c) advocated that people with chronic conditions could be empowered to make decisions about their lives and so enhance compliance with medical treatment. This power could come externally such as from the health care professionals. It meant that medical staff would give people with chronic illness information and empower them. However, the women in my inquiry had another idea. They preferred to build on their own capacities and strengths. They wanted to have their own voice and to have their individual needs considered in their diabetes management. They did not like to be told what to do. They wanted to drive the journey of chronic illness management based on their own interests and to pace themselves and much of this also depended on their stage of transition in terms of their illness diagnosis.

Francis, Feyer, and Smith (2007) in Australia, supported Paterson, Russell, and Thorne’s (2001c) ideas about enhancing self-management. They believed that the process of self-management could be organised by having plans made by the health care professionals and then train people to manage their chronic illness and finally give them support to keep going in their self-management. In this approach there was no space for people with chronic illness to make their own decisions. It was not supported by the women with Type 2 Diabetes in my inquiry as they preferred to set their own goals and gather information about diabetes based on their needs.
Battersby, Lawn, and Pols (2010) were in concord with my inquiry as the women preferred to have their own way of gathering information about diabetes. These researchers emphasised trusting people with chronic illness in managing their conditions. These authors disagreed with the purely medically orientated chronic illness management. They believed that people with chronic illness could be valued in their gathering information about their condition by the health care professionals.

Koch, Jenkin, and Kralik (2004) recommend that people with chronic illness could make their own plans in their learning process. These plans could be different for every single person based on her own needs, preference and readiness. It was important to let people with chronic illness make decisions based on their own needs and strengths. This recommendation was highly supported by the women’s expressed desire during my study. Women believed that the best person who could make plans for them were they themselves as they were aware of their own strengths and limitations. These plans were more achievable than exported plans by the others.

**Transition**

One to one interviews were ongoing and I was able to observe over time the insights women gained about living with diabetes. I refer to these insights as women learning to take this chronic condition into their lives. I have summarised each woman’s learning trajectory as observed as changes in their behaviour or as they have made modifications in their life style. I will attempt to bring these theoretical insights together. As discussed earlier, my definition of learning was related to the women’s
‘transition’ in their life post diagnosis with diabetes, evidenced by changes in behaviour.

Building on the transition thesis of Kralik (2000), I observed the participants’ experiences, the way their perceptions and actions changed. When participants were first diagnosed with diabetes there were no immediate physical ramifications. Rather, the person is ‘warned’ about complications: visual impairment, loss of limbs and so on, should they not adhere to a new lifestyle. One of the first efforts was to regain control by gathering as much information as possible. Change in their life style was dependent on their readiness and there was variation to being ready to change amongst participants. What was taken for granted now required re-examination of life. Sorting out what is happening in one’s life instigates reflection: ‘what is going on?’ While reflecting, the person is preoccupied with the self while sorting this out. Kralik (2002) called this phase ‘extraordinary’. Learning to take a chronic illness into one’s life takes time. Transitional processes require time as people gradually disengage from old habits and behaviours.

The main point here is that the adjustment period or being in an ‘Extraordinary’ transition mode appeared to be much longer than anticipated. Certainly this has not been revealed in other research studies (Beaglehole & Yach, 2003; Bridges, 2004; Broom, 2003; Charmaz, 2000b; Cheng & Boey, 2000; Koch & Kralik, 2006).

Transition shows that people can and do move on when a chronic condition intervenes or disrupts their lives, however, we should not underestimate how long it takes to reorganise one’s life style: even if what requires changing immediately is diet and
exercise. Much more is at stake than changing a routine and breaking lifelong habits. Information, much of it contradictory and complex, is sought and has to be digested. Food shopping needs advance planning, new skills in food preparation need to be learned, and constant self-surveillance such as monitoring blood glucose levels is required. Slotting in exercise based on the professionals’ advice into the daily life schedule requires commitment and reorganisation of priorities and lifestyle. A life lived without regular exercise is quite different from a life with regular exercise. It requires scheduling and it needs to be tailored in accordance with the individual’s interests, wants, needs and desires. And then there is the family’s response to her diabetes. What is the impact of her diagnosis and its management on those who share her life? What else had to change?

My observation of the women’s stories showed that learning had different meaning for each of them. For example, Anna and her husband learned from each other. They had been married for a long time and they did everything together. They went to the diabetes classes together; they went shopping together they read the food packages’ labels together. Elizabeth was married and her husband, as family cook, took on board food selection and preparation she had learned from the diabetes classes. Bella preferred to learn by asking her questions from the healthcare professionals. Barbara was a good reader and she was self directed, using books, magazines and the internet. Katy was a retired nurse and she drew on her previous understandings about diabetes and she updated her knowledge by attending the diabetes classes and she learned how to exercise with pain and arthritis. Alison learned to make different life style choices which improved her diabetes management. Kathryn, Sara and Rose preferred
group learning. They exchanged information with others. Pam and Helen were self directed and learned more about diabetes using books or magazines resources.

Generally, the women gathered information about diabetes ‘medical’ management, eating healthy foods, recipes, cooking, reading the food packages label, doing exercise, losing weight, and checking their blood glucose level. They talked about eating ‘healthy’ foods with low fat and measured amounts of carbohydrate. It was important for the women to watch how much they were eating. According to the information the women had received from the diabetes classes, they were allowed to have nine to ten carbohydrates per day. Therefore, they could only eat a certain amount of carbohydrates in each meal. The women did not buy ‘unhealthy’ foods: chocolates or foods which had high carbohydrates content. Women learned new food recipes from the diabetes classes, the Diabetes Australia magazine, the books and from their relatives/friends. Anna’s sister-in-law had diabetes, therefore Anna has access to her recipes. The other change observed was about cooking style.

The women stated that they used less fat in their cooking and they were more aware of using a certain amount of carbohydrates in their diet. The women cooked more vegetables and they read the labels of the food packages carefully, based on the diabetes classes’ guidelines. The women learned from the diabetes classes to choose foods which had low fat, especially those foods low in saturated fat. They were reminded that every fifteen grams of carbohydrates per serve meant one carbohydrate exchange.
Doing exercise was an important part of the women’s change in behaviour. The women opted to walk or join the exercise classes. They understood that they should exercise at least thirty minutes every day and they were exploring the best way to incorporate this advice into their lifestyle. They understood that by doing exercise and controlling their diet they could lose weight. Women paid attention to advice that by losing weight the insulin could work better in their bodies.

Kathryn said:

\[I \text{ write down what I eat every day. This constant reminder helps me control the number of carbohydrates I eat. And it helps me to lose weight.}\]

Bella mentioned proudly:

\[I \text{ sometimes walk. I sometimes garden. It depends on the weather. My son gave me an IPod so when I walk I can listen to music. This is a good motivation for walking.}\]

Pam, Bella, Helen, Anna, Katy, Alison, Elizabeth and Rose checked their blood glucose level regularly. Pam stated with a smile:

\[I \text{ check my blood glucose level every couple of days. I write the result of that in a notebook. I learn from my glucose level how my diabetes is going. It is a good indicator of diabetes management.}\]
Although all woman made life style changes and/or changed their behaviours, they did so individually based on their preferences and understandings. Anna, Katy, Barbara, Bella, and Pam had arthritis and they exercised with those joint limitations. Anna sighed and said: ‘I like to do exercise and I sometimes walk and do knee exercise. But because of my arthritis I cannot do much exercise’.

All women made life style changes and made adjustments but it was a matter of degree, based on their own interests and understandings. Sara believed that she could have every food as ‘a little bit of everything did not hurt’. Elizabeth cut out her intake of fatty foods and she started to increase her walking distance and the time taken to walk.

Self Report of Feelings a Year Post Diagnosis

Women reported their feelings after a year post diagnosis. Women stated that they felt more relaxed than at the beginning of their diagnosis as they had learned to look after themselves. Bella said happily:

When I compare myself when first diagnosed with diabetes, I feel that I am now used to my diabetes. I am more relaxed than at the beginning.

Barbara even doubted that she had diabetes as she was managing so well, she said:

My diabetes self-management is going very well. I think perhaps I do not have diabetes, because my blood glucose is within normal range. I just cut
down my food and control my portion size. I feel that my diabetes has been settled down. I am not disappointed any more.

Helen and Barbara wanted to avoid the need for insulin in the future and this motivated the women to look after themselves. Helen stated enthusiastically:

Generally I am pleased about looking after myself. I watch my food and do exercise to prevent having to take diabetes medications or insulin.

**Evaluation of One to One Interviews**

When one to one interviews were completed one year later, I asked the women to give me their comments and evaluate this study. Women claimed they were happy to evaluate the process. Women said that they felt comfortable when they talked to me. Having regular talks with others had a healing, educative and overall positive effect on participants which is compatible with the Hawthorne effect (McCarney et al., 2007) as explained in chapter three. Pam, Bella and Rose believed that this study made them think more about themselves and this reflection improved their self management. Pam said:

This study made me think more about my situation. When I talked to Fatemeh I felt that there is someone else who is interested in listening to me to know what was going on with me since I was diagnosed with diabetes.
The women were more motivated to gather more information about diabetes from a variety of sources and make changes in their lives. Rose stated gladly:

*I am glad that I could talk with the researcher. It has motivated me to make plans to look after myself. Now I am going to gym to lose weight and I watch what I eat.*

Bella explained enthusiastically:

*It was a good time to talk about my diabetes management. I felt that I have had support. Talking with her (the researcher) meant there was somebody who encouraged me to think more about diabetes management. Involvement in this study helped me think about taking control of my diabetes and check my blood glucose levels.*

**Chapter Summary**

This chapter has been about storytelling (one to one interviews) with eleven women and their families, feedback and construction of a storyline. My reflections are included a short discussion about commonalities of experiences. The main emphasis in this chapter is the theoretical contribution toward understanding transition.

Building on the transition thesis of Kralik (2000), I observed the movement of participants’ experience, the way their perceptions and actions changed. Transition or ‘movement’ was observed over twelve months post diagnosis. When participants were first diagnosed with diabetes there were no immediate physical ramifications. Rather,
the person is ‘warned’ about complications should they not adhere to a new lifestyle. One of the first efforts was to regain some of that control by gathering as much information as possible. Changing their lifestyle was dependent on their readiness and there was variation between participants. Transitional processes require time as people gradually disengage from old habits and behaviours. I was able to talk with family members. What was taken for granted now required re-examination of life. Sorting out what is happening in one’s life instigates reflection on ‘what is going on’? While reflecting, the person is preoccupied with the self while sorting this out. Kralik (2002) called this phase ‘extraordinary’. I noted that women were in the extraordinary phase or in limbo for most of the twelve months post diagnosis. Learning to take a chronic illness into one’s life takes time. Participants were slowly changing and their behaviours were being replaced by new ideas and actions.

Chapter six describes the PAR process as I researched alongside eleven women in a group, guided by the principles of participatory action research and following the cyclical processes of ‘looking, thinking, and acting’ as an iterative process. I describe the preparation involved in each meeting, the agreed norms for the group meetings, PAR group processes and my role as facilitator. My reflections about the PAR process are incorporated throughout the text. Most importantly, I draw close attention to the way in which this PAR group functioned and further explore group dynamics.
CHAPTER SIX

PARTICIPATORY ACTION RESEARCH GROUPS AND DISCUSSION
Introduction

In phase two of this PAR approach participants were invited to take part in participatory action research groups. Phase two was researching alongside participants in a group guided by principles of participatory action research I had selected. Eleven women attended PAR group meetings at regular intervals but their spouses and/or other family members stayed home. We met for ten group meetings, at fortnightly intervals, on Monday afternoons, for two hours.

In this chapter I will share the common story line which was presented to the women prior to their participation in the group. I will explain how norms of group behaviour were established by the women and what they placed on the agenda for discussion. My reflections about the PAR process throughout the text. I recognised the PAR group as a community and I attempted to build on strengths and resources within that community. As a facilitator/researcher I helped this community to work together to improve their lives. I will have my research question in the back of my mind as I am describing the
research process: “How do older women, who are newly diagnosed with diabetes, learn to live with their condition in the first year post diagnosis?”

**Group Norms**

It was important that the group members shared their stories in a comfortable situation by setting the norms. Group norms are the ‘rules’ set by the participants about how they preferred to run the group. The PAR group norms were designed to reduce and to some degree eliminate ‘storming’ such as conflict during the group meetings. During the first PAR group meeting, I asked the participants to discuss the norms. I gave women examples of norms to stimulate discussion. The women not only agreed with their suggested norms and respected them but also reminded each other of the norms during the group meetings. The norms agreed to were about the use of names, privacy, confidentiality, time to talk, respect, and attempt to avoid conflict. These agreed norms are outlined below.

**Use of Names**

One of the norms the women set during the first group meeting was related to what they could call each other. The women had two options; to use the false names or pseudonyms for the purpose of reporting the study or their actual first names. The women agreed to use their real names during the group meetings with each other. Bella said that she would like to be called by her real name as she had lived with this name and calling her by a false name during the group process would be confusing to her. However, the other women preferred to use fictional names for subsequent reporting of
the study, except Elizabeth who said that ‘talking about diabetes was not a murder and anonymous’ and she was happy to be called by her actual name.

**Privacy and Confidentiality**

The need for privacy was an accepted group norm, and it was agreed that the PAR group should be run as a ‘closed group’ in that once commenced, no other participants would be accepted, with the exception of attendance by my supervisors, the Diabetes Nurse Educator and the Dietician who attended the group meetings when the women requested additional input. They also agreed to maintain the privacy of the group by closing the door before the beginning of each meeting: any latecomers were to shut the door behind them.

Privacy also included confidentiality regarding disclosure of conversations outside the confines of the PAR group. It was agreed that if personal lives were to be discussed, it required the safety of confidentiality and mutual trust.

**Time to Talk**

One of the main focuses of PAR is the value of ‘the participant’s or co-researcher’s voice’. It was therefore understood that an important norm to adopt would be respectful time and opportunity to talk, one at a time, without interruption or interjection. If somebody was talking more than the others, the women asked her politely to let the others have their say. For example, Bella was excited to share new information she had found, about diabetes and Katy reminded her politely to let others talk, saying kindly
that Bella could have another chance to talk later. The women in the PAR group set the norms and more importantly, adhered to them throughout the PAR process.

**Respect**

Respect was a recognised and agreed group norm. They accepted the need to be respectful of each other during conversation and not laugh at each other’s stories, to which they adhered throughout the time of the PAR group and they were consistently polite and friendly.

**Conflict Management**

A way to avoid conflict was that women would set their own agenda for discussion. Focusing on the group meeting agenda meant if somebody talked about something not on the agenda the other women reminded them to return. The other strategy was having an appreciation that there are different points of view and rather than challenging these, diversity was honoured. The norm the women set was to respect another’s beliefs and points of view.

**Facilitation of Norms**

During the first group meeting, I explained to the women what I believed was my role as a facilitator in this setting, as they had all had individual experience of me in the role of interviewer. I re-emphasised that they would set the agenda for discussion, but I agreed to be responsible for maintaining harmony in the group by attentively listening
to what was being said in the group meetings. In terms of avoiding conflict I said that if necessary, I would remind them to respect norms which they had set, including listening to each other’s points of view and letting each other talk about their own interests, attitudes and beliefs. My role would be to record and monitor their progress toward achieving the goals they had devised.

**Preparation for the First PAR Group: Sharing the Common Story**

It was important that women take control of the process and set the agenda. During the first group meeting, I reminded the women about their rights during the group meetings and the purpose of the study as described in the information letter (see, appendix D).

The first group meeting required me to consider ways I could facilitate their involvement. I could ask each woman to talk about herself, or tell her own story, in the first introductory meeting. Stories as told by participants are usually an important phase in developing relationships. Attentive listening to each other fosters cohesion within the group. Alternatively, I could take the common story and give this to each woman prior to the meeting so that the group process would have a starting point. Women selected the common story rather than engage in individual storytelling stating that it would be a more efficient use of their time.

First I will show how this story evolved. With common features in mind I wrote a common story. The common story is as follows:
When we were diagnosed with diabetes it was such a ‘shock’, a ‘surprise’. For some of us it was ‘devastating’ news and a ‘disappointment’ in terms of our health. We did not know what caused diabetes. Some of our family members were also shocked. But a few of us, Helen and Alison, had a family history of diabetes so we were not as surprised. We knew we were overweight and besides we had been warned that if we did not look after ourselves we would develop diabetes. It took a while for us to come to terms with our feelings and make lifestyle decisions. However, some of us, Barbara, Bella and Elizabeth took action straightaway and started exercise and diet change. We understood that we had this chronic condition and that we would need to learn how to manage it. However we hoped that by making lifestyle changes and actions would prevent the further treatments such as going on insulin or getting complications. We recognised that diabetes will be with us for the rest of our lives and we believed we could manage it. Some of us, Barbara, Bella, Anna and Elizabeth had good family support (husbands) and this was considered to be important. Although not all of us have family or supportive friends we will do our best to look after ourselves.

All of us attended diabetes classes which were provided by HNELHN Service diabetes centre diabetes educational classes. However, some of us were not really ready to attend the diabetes classes as we were still in shock. But most of us thought attending classes was the first action to gather information about this chronic condition. We heard about ‘cooking, eating, doing exercise, food packages label reading and controlling our blood glucose level’. Diabetes classes were not the only

Nearly one year later we are used to living with diabetes and have learned based on our own needs. We have lots of information from different resources, however, we carefully select what is most understandable and select content that resonates with our experiences. Since being diagnosed with diabetes the shock has diminished and we now feel we are more ‘settled down’, ‘calmer’ and more ‘used to’ it. We plan to ‘keep going on doing right things’ and ‘stay on the right track to manage our diabetes’. We want to ‘help each other’ and participate in these groups.

This common story, a merger of similar aspects of the individual stories, was given to participants at the first group meeting and it was envisaged it would stimulate group discussion and engagement.

**PAR Group Meetings**

The first PAR group meeting was held in HNELHN Service diabetes centre. As discussed, the purpose of sharing the story was to stimulate discussion. And it was also an opportunity for women to provide feedback.
About the First PAR Meeting

The first PAR meeting was held on the 9th of November 2009. As discussed previously, I was serving ‘an apprenticeship’ as a PAR facilitator, so it was agreed that my supervisors would accompany me for the first few meetings. I had prepared refreshments and I noticed that the women generally started by eating and talking with each other informally. With the seating arranged as described before, and with the recorder in the centre, we commenced. I had prepared a ‘power point’ presentation for the first group meeting to share ideas about the PAR process with the women, setting their own agenda and their rights, and as stated above, I handed out draft copies of the common story for their confirmation. The women then commented on the common story but because time was short, they agreed to take it home and provide feedback the following PAR meeting. The idea that the common story would facilitate discussion about gathering information regarding learning to live with diabetes was, unfortunately, erroneous. Eventually the confirmed group story was constructed as presented above.

Rather than what I had in mind, quite a discussion about ‘storytelling’ and misunderstandings, did take place, however, and I was shocked to hear Elizabeth say that she had not come to the group meetings to hear other women’s stories. Luckily, my supervisor rescued the situation and asked Elizabeth to explain more about her diabetes management, about which she had been telling us during the introductions, and Elizabeth ended by saying that she was going ‘with the flow’. After she finished with her story and had ‘broken the ice’, everybody ‘opened up’ with their ‘stories’ and talked without a stop for a couple of hours. This may be viewed as the storming stage using
Tuckman’s (1964) model or, as to the ‘looking’ stage of Koch’s and Kralik’s (2006) model, the ‘look, think and act’ process is rarely linear.

I learned something important about ‘story’, because I realised that there were multiple concepts about storytelling and what I had in mind, that their conversations were ‘stories’, did not necessarily conform with their understanding. The participants, unfamiliar with the terminology that I used to describe their narration, seemed to have misinterpreted the term ‘story’. I had not understood that in common parlance a ‘story’ is generally a fictional rendition of events. I recognised that there were also different renditions of the same ‘story’ to take into consideration.

It occurred to me later to take more notes during the PAR group meeting, particularly because my supervisor had noted Elizabeth’s original comment and was able to bring it back into the conversation. Thereafter I noted details as the group was progressing and this allowed me to return some points to them, which fostered expansion of the women’s thoughts or feelings. On the whole, this group meeting was a good experience for me to reflect on facilitation skills. In that role, I focused on their strengths and actions, whenever possible, whilst they were talking with each other.

Second PAR Meeting

This group meeting was held on the last day of November 2009. At the second PAR group meeting, I provided a summary of the previous group meeting. I was still in apprenticeship mode as in retrospect it would have been better if they had received this feedback in the post before the next meeting. Although we had a two hour meeting time
planned, dealing with feedback one by one, was possibly not the best use of time. I suspected the women would be less critical when asked about their comments in a group. On this occasion they stated that they were happy with the summary.

There was another misunderstanding. The women had shared an idea of what I thought was a diabetic kitchen, in the first PAR meeting; I thought they wanted to run a diabetic kitchen together. In their correction of my feedback summary, it transpired that what they had meant they wished for was to go to a ‘diabetic’ restaurant rather than the usual restaurants, which would cater to their needs and have proper healthy food choices.

At this second meeting women talked about their diabetes management after being diagnosed. Bella and Elizabeth believed that ‘as diabetes was a lifelong condition’ they would need to learn to manage it. Elizabeth and Katy took responsibility for what they ate and what ‘they put in their mouths’. Taking control of their management meant being committed to changing their lifestyle and they were relying on themselves to make those changes, even if they had support from others.

Much of the conversation was about food. Barbara and Pam talked about nibbling in between meals. They said that they were not nibblers and nor did they eat snacks in between meals but treated themselves with a little bit of dark chocolate, a way of reconstructing what they were doing to fit with an external expectation, that is, not snacking between meals to reduce carbohydrate intake, while maintaining their sense of control over that situation; it was just ‘a little bit of dark [not sweet] chocolate’. It was a good illustration of the struggle in adapting to a fundamental change in mindset.
regarding food, in the process of accommodation to the reality of diabetes and the link with food.

At this early stage of coming to know and trust each other, they stayed on safe ground and discussed the practicalities of learning to live with diabetes and talked about ways to measure the glucose level in their blood. Pam and Bella raised the possibility of checking their blood glucose levels at home with a blood glucose meter, which led to a discussion about their experience of using one and interpreting the readings. Anna confided that she did not know how to use a blood glucose meter at first, but her husband helped her for a few days until she was confident to check it herself.

Attending diabetes classes was acknowledged as a good way to learn about normal readings, and following this discussion many women kept a dedicated notebook in which to write their results. Barbara and Helen, though, were nervous about regularly checking their blood glucose levels and they preferred their doctors to take the responsibility. In addition, Barbara viewed checking her blood glucose level as a chore, which she did not like. The other women tried to persuade her to monitor her blood glucose level and explained to her that by checking it, she would know what was going in her body and help her to control her carbohydrate intake.

The women agreed that an instrumental function of the classes at HNELHN Service diabetes centre was gathering information about the rudiments to self-management of diabetes. Generally, the women were happy with these classes, however there were difficulties. For example, Pam and Anna explained that they were not ‘ready’. They spoke about being bombarded with a load of information, which they had difficulty
absorbing. Elizabeth and Bella explained that after the first diabetes class they felt as if they were in a heavy fog, which lessened with the subsequent two classes about diet.

One of the actions from this PAR group was a suggestion that the diabetes classes are re-scheduled and they recommended that the Diabetes Nurse Educator and the Dietician provide a recapitulation class. ‘Readiness to learn’ was emphasised by this group when they claimed that they could not take in all information from the diabetes classes when first diagnosed. In addition, the women suggested that health care professionals follow up was required after class attendance. The women expressed a desire to relate the way they were managing their diabetes and have an opportunity to ask questions when they were ‘ready’ for information. In fact, the women stipulated that their preference would be to have on-going access to the HNELHN Service Diabetes Nurse Educator and Dietician, especially in the first six months post-diagnosis.

**My Reflections about the Second PAR Meeting**

I recognised that during the second PAR group meeting women appeared to be more comfortable with each other and talked with each other more easily. It was interesting that the major topic of conversation was food: its purchase, preparation and its dietary values. It could be that preoccupation with food was because of the centrality it had in their lives or because the responsibility for food preparation is usually their terrain or perhaps because changing their diet also has an impact on their families.

‘Storming’ (Tuckman, 1964) continued at this PAR group meeting; there was another misunderstanding about diabetes kitchen and restaurant which I mentioned earlier.
I understood that Pam, Bella and Sara had difficulties in reading the food package labels, when they placed label reading on the agenda for discussion at the third PAR meeting.

‘Looking’ collaboratively meant taking control of their management and being committed to changing their lifestyle. Barbara checked her blood glucose levels, but viewed it as a real chore in her life. Women tried to persuade Barbara to monitor her blood glucose level and explained to her that, by checking, she would know what was going in her body and helped her decide how much carbohydrate she should eat. In this way, women advised others in the group. This type of confrontation was possibly similar to ‘unfreezing’ in Lewin’s terms.

Attending diabetes classes had increased their knowledge about diabetes, but they made a point by stating that not everyone was ready for this information so soon after being diagnosed. I understood from these conversations the phenomenon of ‘readiness’ to learn. I recognised that the state of readiness was variable for women. I suspect that being ready often coincided with their experiences within the family. Based on my understanding of their family lives, I thought that, if women had family support, they were more likely to be ready to learn earlier. Readiness may be accelerated if they were already living with another chronic illness, such as heart disease, where they had already learned to take on the other chronic illness into their lives. Here, adjustments that needed to be made were not as cumbersome. I noted that the women with other co-morbidities appeared to be ready for information sooner than the other women. I speculated that if it is the first time someone is diagnosed with a chronic condition, the prospect of one’s mortality may need to be confronted. The experience of being
diagnosed with the other chronic illnesses prior to being diagnosed with diabetes may mean that women have dealt with mortality queries and they are emotionally ‘ready’ sooner.

**Third PAR Meeting**

The third PAR meeting was near Christmas Day, the 9th of December 2009. I attempted to create a Christmas atmosphere for the women by providing bon-bons, almonds, walnuts and strawberries and cherries. I set the table with a Christmas cloth. I had been told by one of the participants that there was a cake shop in Newcastle which made ‘diabetic fruit cake’, which I, therefore purchased to add to the general festivities. The Diabetes Nurse Educator dropped in to say hello to everybody and she noticed the cake. Much to our chagrin and disappointment, she made mention that were no ‘diabetic’ cakes as every cake had carbohydrates, but agreed nevertheless that the women could have a small piece of this cake which would be counted as one to two carbohydrate exchange portions, so we still had our Christmas Cake.

The importance in having a close family to assist with adjusting to living with a chronic condition was highly regarded by a few women. Kathryn revealed that she did not have a supportive family, relating that her mother and daughter always criticised her rather than supporting her. Kathryn looked for other sources of support in her diabetes journey and she found her doctor met her needs for support, as he always listened to her.

We placed reading food package labels on the PAR group agenda and the group wanted to action this request by seeking help from the Diabetes Nurse Educator and the Dietician. Shelved at the centre, were empty food packages that could be used for
practice so I asked the staff if they could spare time to join the group to help the women practice reading food packages labels, to which they acceded.

Another topic raised by the women was weight loss and the women shared strategies they had found successful. Kathryn and Rose wrote a food diary and this constant surveillance made them aware of what they ate, which they claimed, helped them to eat less and therefore lose weight. Others measured all food to be eaten or stopped eating between meals.

I was surprised to learn from the women how stress could affect their lives. The women explained that stress could come from a job, the family or life circumstances. I learned that women respond to stress differently. On the whole, most women had a family, but not all were supported and this lack of support could cause stress. Some women had the responsibility of being breadwinners for their families and some women were responsible for the wellbeing of others, such as their aged mothers. Subconsciously, the women may have made a connection of the stress with the onset of diabetes, but this relationship was made more apparent in subsequent conversations within the group.

One of the actions resulting from this PAR group was that women requested a shopping meeting to buy appropriate food wisely and wished for this food shopping to be guided by health care professional staff.

**My Reflections about the Third PAR Meeting**

The third PAR group meeting was held with a small number of women. Unfortunately one of women had developed a foot injury, another was called in to work as they were
short of staff, and yet another woman had apologised previously. This time I felt more relaxed and enjoyed listening to the participants.

At this group meeting women appeared to be more comfortable with each other or norming as Tuckman (1964) would call it, whereas Koch ad Kralik (2006) would emphasise this was evidence of relationship building in the ‘looking’ phase. It was interesting that the major topic of conversation was still on food: its purchase, preparation and its dietary values.

In conversation, women claimed that attending the three formal diabetes classes had increased their knowledge about diabetes but not everyone had been ready for this deluge of information so soon after being diagnosed. The state of readiness to learn was variable for women. Women would like an opportunity to relate the way they were managing their diabetes and ask questions when they were ‘ready’ for information.

Being ready to absorb information often coincided with their experiences within the family: if women had close family support they were more likely to be ready to learn earlier. The importance of having a close family to assist with adjusting to living with chronic illness was highly regarded by a few women.

My journal entry revealed that I could now understand that I learned PAR group facilitation ‘through doing’, and I guessed this was part of my apprenticeship. I had delved into PAR methodology books in 2008 and early 2009 and, at last, they began to make sense but I felt that I could improve my interview techniques further. Applying the ‘readiness to learn’ phenomenon to myself as well as to the women learning about
diabetes, I saw the similarity in my understanding about PAR, as I recognised that I was now ready to absorb information previously read on the PAR group process.

I noted that there were still gaps in the stories told by women when gathering information about living with diabetes. I needed to ask more about being diagnosed with diabetes, what it was it like, how they managed transition, how family or friends could help them when first diagnosed and what their opinion was about such support several months later. I wanted to know if they could compare their progress (or recognise if little had changed). In order to answer my research question, I questioned if I had enough data to describe how they learn. I made a list of things I needed to follow up at the next PAR meeting and I saw the necessity of preparation. I wrote in my journal that I would find out more about ‘shopping tours’ and ‘diabetes support groups’ and share this information with the women.

**Fourth PAR Meeting**

This PAR group meeting was held on the 25th of January of the New Year, 2010. The women talked about how much they enjoyed the holiday, but they had experienced challenges during this Christmas, their first post-diagnosis when there were social expectations to eat traditional Christmas fare. The group participants feared eating too much and eating too many ‘wrong’ things. Although they were experts at managing their own diet whilst at home or even selecting food wisely in restaurants, being invited to celebrate Christmas within their wider social circle was more complicated, where the setting meant that they experienced less control over what they ate and drank. Katy mentioned that she was invited for Christmas Eve, however, the food was served too
late and she began to feel ill as her blood glucose level dropped. She said that she learned more about diabetes from this experience than any amount of information and would now take control earlier in similar situation by organising ‘her own food on time for the further Christmas parties’.

In this meeting, the women described what they had been reading and brought in books and magazines. Thirsty for knowledge, in this way they were gathering information about diabetes together. In the section to follow I will discuss which books were regarded favourably:

1. ‘The New Traffic Light Guide to Food’, published in 2005, is available in Diabetes Australia’s shops in two versions: a small handbook and one larger, using a larger font for those visually impaired; the content about food is the same. Foods are classified in three categories with ‘traffic light colours’, that is red, orange and green. The recommended foods, for people living with diabetes are shown as green, food that could be consumed occasionally shown in orange and restricted foods in red. In addition, almost all of the food brand names were given with carbohydrate content calculated. Women recognised this as useful to guide shopping.


3. It was interesting that women thought the ‘Coles’ monthly magazine was useful. They explained that its content was about healthy eating and that they could make their own decisions about adapting recipes to their requirements.
4. ‘*Natural Solutions to Live with Diabetes*’ (2005), was liked because it was divided into two parts; the first about food portions and the second about exercising.

5. ‘*The Heart Book*’ (*Dutton, 1980*) was brought by one of the women as its content was about general healthy living, and it seemed applicable to this group. It explained diabetes management, its causes, diet control and specifically talked about low fat foods. We were told that it was available in news agencies and that a new version was soon to be released.

6. Finally, *Low GI booklet (2005).* This booklet was available in Low GI classes. Women said that this book was important because they could find low GI recipes. Low GI foods digest in their bodies slowly and they felt less hungry.

I found it interesting that Pam, Helen and Bella preferred to learn from books such as ‘The Traffic Light’ book and ‘Natural solutions to live with diabetes’, which present information in an easily understood format. People *learn* when the book’s content is immediately applicable in their lives and that the language used is easily comprehended. Alison and Barbara liked to read more medically orientated books as they worked in the medical system or had medical knowledge. Perhaps the main point is that there is great diversity in the sources from which people gather information and the level of complexity that they require to satisfy the amount of information they seek; this observation applied as much to the women in the study group in their search for information to help accommodate to diabetes, as to anyone else. Besides, these women were collaborating in each other’s gathering information about diabetes and learning from each other’s experience in the group meetings.
The action coming out of this PAR group was about the collective need for a ‘shopping tour’. On the agenda from the previous meeting was their desire to learn more about reading the food packages labels.

My Reflections about the Fourth PAR Meeting

I facilitated this PAR group meeting independently: my apprenticeship was over but I was slightly concerned about facilitating the group toward action. However, I saw how much the women took the ownership of the group and they could run the group by themselves.

Placed on the PAR group agenda was reading food package labels. The group sought help from the Diabetes Nurse Educator and the Dietician to ‘perform’ in their lives as Tuckman (1964) mentioned. Women requested a supermarket shopping session, guided by these professionals. The ‘action’ coming out of this PAR group was about the collective need for a ‘shopping tour’ and learning to read labels. Women brought books and magazines to the group sessions. In this ‘thinking’ phase women offered rationales for selecting books. It seems that the women were getting information about diabetes to share their resources such as books and magazines with each other and they were delighted to do that. The women were eager to help each other.

In the discussion about books, I noticed that most of their content was about food; exercise was yet to be discussed, even though they had learned at the diabetes centre classes that it was an important issue. Anna and Katy could not do all exercises suggested, as they were limited by arthritic pain. The women helped each other to
explore different ways of exercising, Bella suggesting to the others that ‘stretch bands’ (resistive exercise bands) were useful and she demonstrated the chair exercises. Rose and Bella also used the ‘watch step’ device attached to slacks or trousers, which measured how far they walked during a day and they found it a good motivator.

Again, the problem surrounding the reading of food package labels was brought to the fore. I realised that I could stimulate action by asking the Dietician to come to the PAR group to meet this information need.

Although women were enriched by the support they gave each other, they were already exploring whether other support groups were available once the PAR group ceased to function as they felt lonely in their individual diabetes journeys. Of course, I had hoped that the women would continue to meet after I left this research study but at this stage they had not identified this as an option.

Another aspect of sharing information in this PAR group was the way women introduced each other to the concept of low GI foods and encouraged each other to eat this kind of food. The other important issue for the women was losing weight. Rose was happy with the ‘weight loss’ powder that she had every day with her breakfast and she believed that taking this powder was a successful strategy, which was validated by the Diabetes Nurse Educator and the Dietician when asked.
Fifth PAR Meeting

This group meeting was held on the 15\textsuperscript{th} of February 2010. As usual, I had given the women the feedback summary of the fourth PAR meeting and waited for their confirmation. I decided to respond to their request for further information about food labels and had invited the Diabetes Nurse Educator and the Dietician to join this group for a few minutes to answer questions. Pam, who also has painful arthritic joints, asked about the best exercise she could do because she did not like to go to a gym. Walking every day for half an hour was re-emphasised and another option, which Bella had demonstrated at the previous meeting, proposed. In this way, gathering information about diabetes and exercise was reinforced. Pam and Rose had brought food packages like cereal, yogurt and chips and they invited the group to share label reading. Together they calculated carbohydrates and the Diabetes Nurse Educator and the Dietician, also examining the products validated their observations, which was a boost to their growing confidence.

We shared the result of our search to find out more about a ‘diabetes support group’. Although not a ‘support’ group as such, I found an ongoing education group held at Diabetes Australia held on the fourth Friday of each month. Each month a health care professional was invited to give a talk which ranged from dental care to foot care, eye care and diet. Pam, Bella and Rose decided to attend the next meeting at Diabetes Australia to determine whether it met their needs and I decided to go too so that I would have exposure to this group and let them know how I experienced the support group.
Action women requested at the fourth PAR group was the ‘Shopping Tour’. Together we researched possibilities and found that Diabetes Australia was running this tour again. I gathered information from Diabetes Australia and made copies for the women and handed these out. Barbara, Katy and Helen were planning to attend one of these shopping tours, and I thought about also doing so. In addition to books and magazines shared by the women at the previous meetings, I had researched and found a list of books as well as diabetes products from Diabetes Australia. It occurred to us that Diabetes Australia certainly had very good resources for gathering information about living with diabetes.

My Reflections about the Fifth PAR Meeting

I saw that the women were relaxed and helped themselves to cups of tea or coffee. Feedback was received and commented upon. In this meeting there was an easy exchange of information. I invited health care professionals at the centre to come into the group and it was an opportunity for the women to ask their questions about diabetes. Not only had the women brought packages from their shopping to the PAR group, but there were also shelves of empty food packages in the diabetes centre where the women could practice supervised label reading, which was very much appreciated by the participants. Afterwards, the women were still unsure about the normal range of HBA1c and they asked the Diabetes Nurse Educator to explain.

The group asked their questions from the Dietician to ‘perform’ (Tuckman, 1964) the new information in their self-management.
At all meetings so far, the Diabetes Nurse Educator or the Dietician were on hand to answer any queries that women may have, and it was certainly in the first five PAR groups that their need for additional information was in the foreground. Initially they were hungry for information and then they appeared to settle into supporting each other.

Sixth PAR Meeting

The sixth group meeting was held ten days after the previous group meeting. The summary of the previous group meeting was given to the women and they confirmed the contents and this time had little to add to the summary.

The women talked again about their satisfaction with supervised food package label reading and stated that they felt more confident. It was interesting that they wanted to discuss labelling again and I suspect this repetition was necessary to consolidate their growing knowledge. They reiterated the importance of looking for the total fat content on the food packages, the group members, confirming for each other that the recommended proportion is to be less than a total of ten grams per hundred grams, with less than three grams to be saturated fats. They also identified the need to check total carbohydrate content and agreed that every fifteen grams of carbohydrates per serving is counted as one carbohydrate exchange. Gathering information about reading the food packages labels, I believe, was an important milestone in their diabetes self-management programme.

Rose, Elizabeth and Katy had benefitted from the discussion on carbohydrates. This referred to the advice given to them by the Diabetic Nurse Educator at the previous
meeting, having been told that they needed to take in less than ten carbohydrates exchange per day. Pam had planned to cut her carbohydrate intake completely from her food, but after this PAR meeting she realised that everybody needed a certain amount of carbohydrates per day as the brain needs sugar which comes from carbohydrates, prompting her to revise her decision to go on a carbohydrate free diet. Subsequently the women said that they understood how they could divide their daily carbohydrate intake between their meals: for instance, they knew that they could have three carbohydrates for each main meal, making a total of nine carbohydrate exchanges or they could have two carbohydrates for breakfast, one carbohydrate for morning tea, two carbohydrates for lunch, one carbohydrate for afternoon tea, two carbohydrates for dinner and one carbohydrate for supper which was made up of nine carbohydrates exchanges, as well. These points were shared enthusiastically in the group. This is a good example of sharing information and consolidating knowledge about diabetes collaboratively.

My Reflections about the Sixth PAR Meeting

The women came early to help me to set the table with refreshments and foods. It was a good opportunity for us to eat together and in so doing continue to build relationships somewhat informally. I was pleased with this opportunity to see how things were going with everyone. I noticed that Rose, who did not talk much at the first meetings, appeared more confident and talked with the other women more easily and happily as she shared her pride in losing weight through watching her food intake. The women mentioned that they found support from each other and a few adding that they felt that their situation was better understood in the PAR group then at home with their family, accentuating that these group meetings were guilt free; no one blamed them for their
choices in food, eating or their weight. On an emotional level, members in this group understood each other and on a practical level they shared ideas about food and exercise.

I was now a facilitator on the group’s periphery, the women led the group and I noticed that my voice was rarely ‘heard’ on the transcript because they did not only set the agenda for discussion but they were also totally engaged with each other, now voluntarily sharing the stories of their lives with each other; a fascinating change from their reticence at the beginning. Kathryn, for instance, recounted a family disagreement. She felt that her mother and daughter continually found fault with her eating habits rather than helping her. The group provided emotional support for her, with suggestions like making a ‘food diary’. Kathryn replied with: ‘ah ha…that’s a good way because really I need to watch my food’.

They all admitted that they did not really like being told what to do; instead they preferred to retain some control over their own lives by being given options from which they could select. They also readily acknowledged that they appreciated suggestions about how to modify their lifestyles, and yet still make their own decisions. Alison strongly believed that people could make up their own minds about what suited them.

It became apparent from this discussion that there was agreement that one of the best ways for women to learn to live with diabetes was for them to be presented with the best possible information and, depending on their readiness to absorb, they could then make individual decisions about food and lifestyle changes from a range of options.
A good example of decision-making based on the best information, occurred when the issue of the carbohydrate exchange was answered by the Diabetes Nurse Educator, when she explained the concept of exchange of carbohydrate portions between the meals of a day. I noted that the women had not understood enough about carbohydrates, but it was explained in such a way that they could make choices based on this clear information. They were noticeably relieved to learn more about their choices in food selection and information was transformed into knowledge.

Armed with additional knowledge gained from the Diabetes Nurse Educator about exercise and food choices, the women were able to contemplate actual ways to lose weight. They heard that they could eat less and be more satiated, do more exercise and yet gain energy, and I noticed that the women were smiling and nodding their heads this time. They were ready to take this information on board. At this meeting, women queued to weigh themselves on the scales found in the centre, which they continued to do in subsequent meetings and collaboratively celebrated their weight loss. Women were performing using Tuckman’s model (1988).

I was interested to deepen my understanding of the concept of ‘readiness to learn’ and the transformation of information into understanding, by watching what was happening in our group meetings.
Seventh PAR Meeting

This group meeting was held in early March 2010. As with previous group meetings, this meeting was held in the HNELHN Service diabetes centre and I gave the women the summary of the previous PAR group meeting.

First of all, the women were interested to talk about doing exercises. Everybody was excited to talk about their own experience. Barbara made it clear that she was walking for half an hour every day as well as exercising three days in the hydrotherapy pool, doing ‘heart moves’ and riding her bike. Pam and Elizabeth were proud of taking long walks and expounded that they were enjoying walking as much as they could. Katy was happy about going to a gym and Rose talked about going to an exercise class through which she hoped to lose more weight and they preferred women’s only gym in which they felt more comfortable.

Weight loss and ways to lose weight were on the agenda. Pam, Rose, Bella and Barbara routinely weighed themselves and monitored their weight. As discussed previously, Rose talked again about weight loss powder, which had low carbohydrates and claimed this was helpful for losing weight.

The Dietician was invited to join the group and she kindly answered the women’s questions. Pam still was not sure about carbohydrate intake and the Dietician explained it again. In this meeting, the women were given more to read: the diabetes clinic cookery book and the ‘Living with Diabetes’ magazine. The Dietician emphasised that all articles in this magazine were based on research and, as an example, she described
an innovative tattoo, which was sensitive to the level of sugar in the body, its colour would change if the blood glucose was high. Rose wanted to know about the meaning of light on food labels. The Dietician explained that the food could be light in colour, flavour and texture but it did not necessarily mean that every light product had less carbohydrates or fat, so this was somewhat misleading. Bella described being exhausted after having a long walk or going shopping. The Dietician explained that although fatigue often accompanies Type 2 Diabetes, it was important to note that if women increased their exercise they might also need more carbohydrates. Helen mentioned that sometimes she did not feel well enough or motivated to walk or do exercise, experiencing the condition associated with her chronic condition, Type 2 Diabetes. The Dietician replied that it was a good idea to set incremental goals for exercise, and that it might be more appealing to be walking with a dog. Katy, who lived alone, revealed that she enjoyed eating in front of the television, however, the Dietician pointed out that this was probably not a good habit because directing attention away from eating might mean that the quantity of food consumed was not as closely monitored.

**My Reflections about the Seventh PAR Meeting**

As usual, we started by having drinks and snacks. Some of the women mentioned that they had lunch before coming to the group meeting and they no longer ‘snacked’. Instead they took a cup of tea or coffee without a scone or if they ate, their preference was just a piece of fruit. This appeared to be evidence of gathering information about diabetes and a change to more ‘healthy’ eating styles, as the women were not only watching carbohydrate quantities, but they were choosing low GI index, fresh fruit over a high GI index processed wheat product.
I was interested to note that the group members wanted to talk about exercising, sharing their experiences, and were ready to learn from each other. Action had been taken individually and women were ‘performing’ (Tuckman, 1964). They compared benefits about going to the gym, joining the ‘Heart Moves’ programme, bicycle riding, walking and Tai-Chi. Pam, whose exercise potential was limited by arthritic joints, took advice and said she would consider resistance bands for moving her limbs. They considered joining a walking group each Sunday so that they could walk together. I noted that Rose sighed and said ‘yes this is what I need because I feel lonely when I walk by myself’. Helen required motivation to walk and group activity was appealing. Katy introduced the women to the availability of a gym just for women, which was appreciated.

I observed that even at this seventh PAR meeting women were still eager for more information about managing their diabetes although by now, most of the information given by the Diabetes Nurse Educator and Dietician was revision. This again demonstrates that gathering information about diabetes is incremental, requiring repetition. In this meeting, women expressed eagerness to learn more about carbohydrates. The Dietician explained that food grown in the ground is usually heavy in carbohydrates although Bella came to understand that the milk she added to her tea or coffee is also counted as carbohydrate intake, because of the milk sugar, lactose, and she shared this new information with the rest of the group. I had noted that Sara looked tired, and when she talked to the Dietician about this she appeared to realise that it was important to coordinate her activities with carbohydrate intake, increasing the carbohydrate intake to match the carbohydrate required for added energy expenditure when walking more. The group were asked to reconsider their eating habits and it was explained that eating in front of the television was not recommended because of the
reduction in attention to what one ate. Women were generous in sharing their experiences with each other. They were now a cohesive group, which contributed to a collaborative hunting for information about diabetes.

**Eighth PAR Meeting**

The eighth group meeting was held by the end of March 2010. Meeting at the HNELHN Service diabetes centre was well established. Having a cup of tea or coffee together informally, led to finding out how things were going with everybody. Pam was pleased to find low fat milk, which tasted the same as full cream milk although it was more expensive. Rose and Katy were excited to share their recipes consisting mainly of chicken, vegetables and a little bit of rice. The Dietician affirmed their suitability, and so I offered to make copies of them for the other women.

On the agenda this meeting was diabetes self-management. Bella and Barbara agreed that self-management was a combination of diet and exercise, whereas Katy, Anna and Kathryn paid attention to the role of medication and talked about taking anti-diabetic drugs for lowering blood glucose levels. Further hints about food were shared. This time, one person had misunderstood the amount of sugar in watermelon, had eaten too much and experienced the unpleasant effect of a sudden increase in her blood glucose level.

The women were realising that finding information about living with diabetes was a continuous project, because their previous assumptions about food were constantly challenged and the amount of information was too great to absorb in the short diabetes
classes, although they did enjoy attending these group meetings to reinforce their need for more information about diabetes. Helen, Rose and Bella believed that being in a group and listening to each other was a powerful way to learn, so they liked the informal gathering, as it was based on what they really needed to take on board with people who had the same condition. In addition, information resources were made available to the women as the Diabetes Nurse Educator and Dietician invited them to come to see them any time.

My Reflections about the Eighth PAR Meeting

Women arrived early for the meeting perhaps confirming that they valued group meetings because they were also noticeably excited to see each other again. They now came to the meeting fully laden with food products and parcels, and were keen to demonstrate what they had discovered in the previous week. Pam appeared to self-manage her diabetes very well, adhering to a healthy lifestyle and introduced the new low fat creamy tasting milk to the others. It is a shame that this milk, as with many ‘healthy’ foods, is more expensive than ‘normal’ products.

As usual, group discussion was preoccupied with food and food preparation, the focus this time being on food value and content, which was validated by the Dietician. Elizabeth built on her previous information about diabetes stating that ‘how much people ate was not as important as what they ate’, and added, ‘the food’s taste is important and of course the number of calories should be counted’.
Exchange of information had become customary in this group. Barbara and Katy, though, still did not check their blood glucose level with a blood glucose meter and the others explained to them the importance of monitoring their blood glucose levels. Bella, who was now very experienced in checking her own blood glucose level, was prepared to show them how to do it and also explained that blood glucose meter batteries were replaced free of charge at the Chemist shop. This was, in a sense, repetition, but in this instance, it was not ‘an expert’ who was demonstrating a task, or ‘handing down’ information; it was a mutually caring group of women sharing newly gained expertise with each other, as a result of engaging in a PAR group. Rose demonstrated her increased confidence in diabetes self-management, when she told us about her neighbour wanting to give her ‘advice’ about diabetes, which, as a result of her own reading about diabetes, she realised was incorrect. The women all appeared to enjoy the increased sense of ‘mastery’ that was being shared during this meeting.

I noticed that the women had built close relationships with each other when Barbara mentioned that she would undergo knee surgery and everybody in the group hoped that she would be all right and they all said that they would visit her in hospital.

During this PAR group meeting, conversations had been a result of ‘thinking’ (Koch & Kralik, 2006) and I noticed many individual life style changes had been made. As yet, there was no talk about collective ‘action’.
Ninth PAR Meeting

This group meeting was held on the second week of April 2010. A summary of the previous group discussion was delivered to the women prior to the meeting after the Easter break.

Whenever there were festivities, on this occasion, a reason for families and friends gathering at Easter, the women were not yet fully prepared for the food and diet challenges such social situations would present. They said that sometimes their families forgot the dietary needs and routines associated with diabetes. In addition, it was clear that pre-existing tensions were raised by these social situations. Rose claimed that her family was disinterested in her food and diet requirements and they expected her to join them with lots of sweets and cake, as per their usual social ritual, which she was very disappointed about; her needs had to be subsumed to those of the family. On the other hand, Bella was happy with the respect that her family showed with their accommodation of her dietary needs.

The Dietician joined the group meeting and once more there was a need to reiterate diet information, particularly information requested about snacks between meals, which Rose said she preferred to avoid. The Dietician asserted that they were to have three meals per day and if anyone did not feel that she needed to boost her caloric intake between meals, she should trust her own preferences.

Pam wanted clarification about when to check her blood glucose levels, so asked the Diabetes Nurse Educator and was told that the best time was before any meal or two
hours after eating. Bella wondered why her blood glucose level was higher immediately after exercising. And the Dietician explained that the body uses sugar when exercising and if the women checked their blood glucose immediately after exercising, the blood glucose level would be higher than normal because of its release into the blood and it was therefore suggested that they give their bodies time to rest before checking the blood glucose level. People with diabetes, said the Dietician, were allowed to have nine to ten numbers of carbohydrates each day and they could divide these carbohydrates access each meal. This information had been covered in the diabetes classes and also in previous PAR meetings, but the repetition seemed necessary, in order to become actual knowledge, hence there was congruence between seeking and repeating information about diabetes.

There was finally a change from their concerns about food shopping, preparation and eating, as the focus of conversation in this meeting was exercising. Although we had talked about exercise a little previously, they took the opportunity this time to go into great detail about their daily exercise routine. It was agreed that it was best for everyone to exercise as and how they saw fit, rather than a prescribed routine followed by a long discussion about resistance bands and chair exercises. The resistance bands, we were told, had different colours depending on their degree of resistance, people gradually building up to stronger bands, which helped in toning and strengthening muscles.

**My Reflections about the Ninth PAR Meeting**

This group meeting was held at the HNELHN diabetes centre. The Diabetes Nurse Educator and Dietician were invited to answer yet more questions, the women’s thirst
for clarification of previously delivered information suggested that there was an ongoing process of knowledge creation. As they came to understand their diabetes better they shared and tested their knowledge about diabetes with neighbours, friends and relatives. It is often argued that people learn best when teaching others.

Some information about planning meals ahead was shared amongst the group as a result of the Easter holiday and I noticed that Rose and Katy were unhappy about their family’s apparent negligence over Easter regarding their dietary needs and the reality of their diagnosis with an actual disease which could, and did, result in experiencing illness, if not treated responsibly. It was agreed that disclosure and open discussion about having diabetes before any gathering with family or friends was a good plan, and responsible self-management. At least if family and friends are forewarned about the woman’s chronic condition, Type 2 Diabetes, which necessitated certain dietary changes, it might make eating and celebrating in these social situations less stressful and even enjoyable.

The group of women had been meeting for six months and were clearly comfortable with each other. Although I had prepared them, when I reminded them that the next group meeting would be our last, there were expressions of dismay. However, I suggested that they continue with group meetings without me and they agreed that this was a good thing to do, and they could go on as a self-supporting group.

During this PAR group meeting, the women agreed that learning to live with diabetes was an ongoing life project. They liked this kind of informal learning as it was based on
what they wanted to ‘act’ (Koch & Kralik, 2006) and it was done with people who had the same chronic condition.

**Tenth PAR Meeting**

The last group meeting was held at the end of April 2010. As usual, I gave the women the summary of the previous group meeting. They read it and gave me their comments.

The women said that they were proud of information and knowledge they had gathered during the six months of the PAR group, and all they had learned about living well and thriving with diabetes as a new factor to incorporate in their lives. They felt more relaxed and settled compared to six months earlier. Bella, Rose, Katy and Pam all said that they gradually got used to living with diabetes and felt more confident about their self-management, even though Anna and Pam still had difficulty checking their own blood glucose levels, it was becoming a routine. Food package label reading had been a difficulty, however with additional input from health care professionals at the PAR group meetings and practical help in practicing on actual packages at the diabetes centre, confidence and expertise increased.

There was a return to a discussion about medication because Anna and Katy were taking hypoglycaemic medication as part of their diabetes management and they were concerned about the best time to take it. The recommendation was for it to be taken with meals and it was recognised to also suppress appetite, promoting weight loss. I found it interesting to see that the women were still consolidating information and knowledge about diabetes.
I invited the group members to evaluate the PAR group meetings. The women confirmed that the group meetings were very helpful for gathering information and gaining confidence about living with diabetes and found support from the others as they learned from each other’s experience. The inclusion of the diabetes centre health care staff was a highly recommended contribution. Rose thought that these group meetings made her to think more about her diabetes management, because after being part of the group, she changed her diet and started to walk more. She also felt more confident and relaxed about disclosing and talking about diabetes with the other women, because they were ‘all in the same boat’, learning to integrate the ramifications of their recent diagnosis, a point confirmed by the others. Collaborative information seeking about diabetes was held to be an enjoyable way of learning, because they did so at their own pace and sought information on what they thought necessary. The vibrant exchange of information about what and how much to eat was also valued and they all agreed that their new-found knowledge and confidence was a help in being able to effectively manage their diabetes.

The women were grateful for the mutual support and social interactions provided through their membership of this PAR group. They felt less alone, realising that there were others gathering information about living with diabetes too and that some of their peers also struggled to learn alongside them made them feel stronger. Women believed that the best way to learn was the supportive relationships they had built during the group. Their main source of gathering information about diabetes, it was claimed, was from each other.
My Reflections about the Tenth (Final) PAR Meeting

This was the final group meeting held at the HNELHN Service diabetes centre where a well-established routine had grown, also giving the women access to the resources at the centre. I had been walking alongside them for more than a year on a one-to-one basis and then meeting with them all together in these PAR groups and as this was the last meeting, I knew that it was time to say goodbye to let them decide how they wanted to continue their relationship: to continue as a group or visit each other.

The women openly made comparisons between the initial period after being diagnosed and a year later. When first diagnosed with diabetes, the practicalities of their management were troublesome as there was so much to take on board. Interpreting the blood glucose level reading proved difficult for Rose and Sara, and reading all food package labels was an additional burden for everyone. Gathering information about food shopping, preparing and eating a suitable healthy diet was cumbersome, but, as time went on, their expertise increased and their self-management improved. These group meetings had helped the women know more about their blood glucose level, eating carbohydrates and its effects on their bodies. Shared readings had been a helpful and informative way of accumulating knowledge about ways to integrate the ramifications of Type 2 Diabetes, living well and thriving with it as a part of their lives.

We had been meeting as a group for six months and women were clearly comfortable with each other. Although I had prepared them, when I reminded them the project was nearing closure and this group meeting would be our last, again there was a sense of
dismay. Tuckman (1964) called this adjournment. Regardless, women felt more relaxed and settled in comparison with six months earlier.

The women exchanged telephone numbers and agreed to be in contact with each other and they sought permission from the HNELHN Service diabetes centre staff to continue to meet with each other without the facilitator.

**Discussion: Look, Think and Act**

Eleven women attended PAR group meetings at regular intervals. The text was analysed concurrently using the ‘Look, think and act’ framework and apart from my observation, I attempted to capture the group’s dynamics. Aspects of the PAR group meetings were summarised, particularly actions the group had decided on taking.

**Looking**

As I mentioned in chapter three, ‘look’ means building a picture and gathering information (Koch & Kralik, 2006). Women ‘looked’ at: gathering information about diabetes, aetiology and treatment of diabetes, their reaction to being diagnosed, eating habits, exercise possibilities, how other people manage their diabetes, ways to engage others (family and friends) for support, strategies to lose weight, developing tactics for eliminating ‘sweet’ foods from their diets, what constituted carbohydrates, checking their blood glucose level and all aspects of food shopping and its preparation, suitable recipes.
Thinking / Reflecting

Thinking/reflecting is about interpreting and explaining (Koch & Kralik, 2006). Women reflected: how they were feeling post diagnosis, about the cause of diabetes, how they could improve their understanding about diabetes, about ways to change their eating habits, overcoming cravings, the most suitable exercise programme to meet their needs and capabilities, about changing their food preparation styles and adaptation of new recipes, shopping prudently for food, ways to reduce their carbohydrate intake, how to acquire better information about diabetes, ways to engage others (family and friends) for support, strategies to lose weight and checking their blood glucose level and noticing how others were taking action to improve their self management.

Acting

Acting is about resolving issues by formulating actions (Koch & Kralik, 2006). The group functioned very well: the women supported each other. They listened to each other. Collaboratively they gathered and shared information resources on diabetes and related topics. But they were still hungry for information; they invited the Diabetes Nurse Educator to answer questions and to help them understand some of the more complex issues such as reading labels for carbohydrate content. Reading food labels carefully became a daily activity. One of the major changes they had to make was to do with food. There is evidence that women lost weight. They encouraged each other to change their diets, adapt recipes, read labels carefully and in particular to watch their carbohydrate intake. They shared information about low fat food products, shared low GI recipes. Carbohydrate intake was reduced, cooking styles were changed, and low fat
diets were commenced. Reduced food portions were trialled. Some women kept a food intake diary; others placed their food on smaller plates. A few women declared that they would not ‘nibble’ or eat in-between meals. Blood glucose levels were being monitored and these showed that diabetes self-management strategies were working. There is further evidence that actions were taken: women attended gyms and exercise classes, walked, heart moves, cycling, hydrotherapy, resistance band exercises, chair exercises and stretches.

Learning from each Other

PAR group meetings had an important role in women’s learning about diabetes. In conversation, women claimed that attending the three formal diabetes classes had increased their knowledge about diabetes but most had not been ready for this deluge of information so soon after being diagnosed. ‘Looking collaboratively’ meant taking control of their management and being committed to changing their lifestyle in terms of diet and exercise. In ‘thinking collaboratively’ women discovered that if they had co-morbidities, their adaptations to learning to live with yet another chronic condition was not as problematic. In this ‘thinking’ phase women brought their favourite resources to share with the group and offered rationales for selecting these. Women helped each other to explore different dietary and exercise options.

Women were still eager for diabetes and life style information one year post diagnosis. Although women needed some recommendations to modify their lifestyles, they also liked to make their own decisions about their lives and lifestyles. In the PAR group, information about diet and exercise requested was often repeated and this need for
repetition was surprising. Information exchange amongst the women meant they were able to contemplate ways to modify their lives.

Life style modification occurred in the woman’s own life, but ‘collective action’ was in abeyance. I observed the women’s thirst for information and knowledge in the twelve months post diagnosis. Women were engrossed with themselves. They were absorbed by life style modifications that they had to make almost immediately. PAR group activity usually results in outcomes: actions undertaken by participants may refer to personal development and/or at group reform level. I observed that women’s behaviour had changed over twelve months and that they were self-managing diabetes with increased confidence. However major reform or collective action did not occur.

**Improved Diabetes Self-Management but Limited Larger Reform**

Although I knew that it was usual for a PAR group to reach out, act and reform situations (Koch & Kralik, 2006), to date these women were engrossed with themselves and the immediate life style modifications that they had to make. Absorbing new information at a rate that was compatible with individual learning styles was made clear. Learning to live with diabetes in the first year post diagnosis fits very well with Kralik’s (2002) notion of being ‘extraordinary’, that is, women were preoccupied with themselves; they were their own centre of attention during this first year. Although in a process of transition, they were not yet ready for ‘ordinariness’ after twelve months of being diagnosed with diabetes.
Participants sought a balance between accomplishing learning tasks such as label reading and building interpersonal relationships in the group. Whilst in Tuckman’s (1964) model this appears to be a movement between the stages of norming and performing, I argue that relationship building is central and accompanies all stages of the ‘look, think and act’ (LTA) model (Koch & Kralik, 2006). Small groups tend to follow a fairly predictable path toward action, both individual and/or group. It was clear that women’s behaviours had changed and that learning had occurred in terms of managing diabetes much better, however, major reform such as writing a book about being diagnosed with a chronic illness as the resultant outcome of this PAR process did not happen.

Women’s Suggestions to the Health Care Professionals at the Diabetes Centre

Women suggested that classes for people newly diagnosed with diabetes should be recapitulated. They were not ready to take in all of the information at the first sessions so soon after diagnosis. In terms of content of courses provided, women wanted to practice more food label reading, and explore recipes during class. Women suggested that diabetes centre staff provide an illustrated recipe book and an easy to read information book on diabetes. Exercise choices based on their age, capability and accessibility were important considerations for women although it sounds more like a one to one assessment was required. Women requested that they be allowed to continue to meet at the centre so that their meetings with each other could continue. They also asked if the diabetes centre staff could set up a support group for women newly diagnosed with diabetes, believing that sharing their experiences and the support given to each other in the group was rewarding and beneficial.
Feedback to Health Care Professionals

PAR group meetings provided a really a good opportunity for the health care professionals to see, for the first time, the way women were continuing to learn post diagnosis. Even after women’s attendance at three formal diabetes class sessions, health care professionals were intrigued, as were researchers, by the constant need for repetition of information. Involving diabetes centre staff in this way has alerted them to take alternative educational strategies into their diabetes classes and to a degree addresses objective five of this study. In addition, an open door policy has been instigated by the health service, so that women can call the diabetes centre staff at any time in the future.

Evaluation of PAR Group Meetings by the Women

At the end of the group meetings, I asked participants to give me their comments about this study to evaluate this participatory action research. It was important for me as a researcher, how the women evaluated this study to find out the strong points and weakness so as to improve my further research. The women found a therapeutic, educative effect from the group meetings and they could grow their diabetes management together which is supported by ‘Hawthorne effect’ (McCarney et al., 2007). For instance, Pam stated:

I am grateful for attending this study. Belonging to this group meeting let me learn more about living with diabetes and could clear my questions in
my mind. It was good to get some support from the group and it encouraged me to keep going to look after myself.

Bella was happy with attending the group meetings and had gained more information about diabetes as compared to attending just the diabetes classes per se.

Bella mentioned with a smile:

Gathering information about diabetes to live with diabetes is a constant experience. It is not possible to learn everything just during the three diabetes classes. This is why I enjoyed attending these group meetings to reinforce my information about diabetes.

Rose was happy with her lifestyle changes after attending the group meetings and she admired me for providing this opportunity for the women to get together and share their experiences together.

Rose expressed:

Thanks Fatemeh for these group meetings. I have got good support from the women in this group. I found some new friends. They helped me to overcome my concerns. Look at me I lost weight and I have more hope in my life. Thanks for thinking about us.

Katy was happy to learn more about diabetes in the group meetings and the attendance of the Diabetes Nurse Educator and the Dietician to answer her questions in a simple way.
Katy stated:

I see that I have got information about diabetes from the group meetings and the Diabetes Nurse Educator and the Dietician. This group setting made my getting information about diabetes process more enjoyable. I appreciate the Diabetes Nurse Educator and the Dietician’s way of teaching. They made everything in a simple way.

Barbara found these group meetings very helpful and she got information about diabetes and some tips in her eating. Barbara said proudly:

I have got information about diabetes that diabetes is not a limitation. I should just be conscious about what and how much I eat. Before I thought I should restrict myself to some foods but after attending these group meetings I see that I can have everything. I should just watch how much I am eating.

Kathryn believed that after attending these group meetings she became more confident and she could make better decisions in her diabetes management. Kathryn explained enthusiastically:

Thanks for providing these group meetings. I have some more information now and it makes me confident to make decision about eating choices. I feel that I am more powerful than before and I know about the number of
carbohydrates in each meal. I can choose the right foods. That is wonderful. I appreciate it.

According to the Diabetes Nurse Educator the best way of getting information about diabetes is getting it from peers. She said happily:

*I am happy that you shared information about diabetes with each other and I am pleased that we could answer your questions. Please, feel free to contact us or book the room in the HNELHN diabetes centre to get together with each other. We are here to help you.*

One of the outcomes of this participatory action research is that it will be continuing. Women indicated that they would like to maintain their friendship and continue learning collaboratively. The Diabetes Nurse Educator agreed to arrange the venue for the women’s gathering. The sustainability of this process is now up to the women.

**My Role as Facilitator**

My role as a facilitator was in apprenticeship mode for the first few sessions. On reflection, reducing the authority of the facilitator was my aim. Avoided were behaviours that could hinder group interaction: judging, controlling, superiority, certainty, indifference and manipulation. I was conversant with the fluidity of the ‘look, think and act’ processes and possessed the skills necessary to capitalise on these ‘stages’ to accomplish forming a productive, cohesive group. Group dynamics is a critical factor
in group performance. I constantly analysed whether the group was ‘looking, thinking or acting’ and pondered about ways in which I could motivate the group.

I invited participants to ‘think’ about aspects of the story which helped refocus the energy of the circle from merely ‘looking’, to ‘thinking’ and eventually to stimulate action. I was alert to group dynamics which meant being ready to focus on the strengths of individuals and the group. Women took control of the process and set the agenda. Occasionally, some comment or guidance was required and I suggested when it was time to have a break. Participants managed the process, and if someone talked too much or a person was too dominant, women were reminded of the norms. Norms kept women ‘on track’. The cyclical nature of the PAR process promoted reflection and learning that led to the enhancement of these women’s lives.

The value of this inquiry using the PAR process was to observe how participants coped with the new realities in their lives as a result of their learning within the group. It was shown that women learnt through mutual engagement in activities. Health care professionals were invited on request and brought into the group. The organising of diabetes self-management ideas was assisted through the medium of brief lectures and handouts. This was effective and demonstrates that the basic allegiance of the PAR group was to facilitate learning for its members.

**Feedback Cycles**

It was important for me to give feedback about the previous group meeting as a summary to the women prior to the subsequent group meeting for discussion and
confirmation. The participants gave me their comments about the previous group meeting feedback. Participants confirmed the summary of the previous group meeting at the beginning of the next group meeting. It was a part of cyclic feedback of the participatory action research in this inquiry. In this manner, data were generated with the women and new understandings emerged with findings of the inquiry with the participants getting information about their diabetes journey. I made a summary of each meeting in collaboration with the women and they confirmed these summaries by giving me their feedback. In fact the women were co-researchers. This enhanced the rigour of the research approach. It also helped for the women to plan for the next meeting. At the beginning of each group meeting, the participants discussed the main items from the previous group meeting. This is similar with Heron and Reason’s statement (2008) as they believed that in a cooperative inquiry research groups have explicit aims around co-research and shared inquiry and collaboration. This is perhaps quite different group dynamics in comparison to Tuckman’s (1964) earlier work with teams and organisations.

The process of feedback during the PAR group meetings derived from Lewin (1947) as he believed that feedback was an essential aspect of fostering group dynamics. Feedback was a routine activity of the PAR cycle described by Koch’s and Kralik’s (2006) processes; after each PAR group meeting a summary was created. Before a PAR group meeting recommenced each participant was given a summary of the previous meeting’s conversations and actions clearly identified. It is called the group members’ co-operation which is explained in chapter three (Heron & Reason, 2008).
Researcher Journal and Reflection

Whenever the participants were talking in the group meeting, I wrote my observations and reflections in a notebook and then, after finishing each group meeting, I thought more about that group meeting and wrote my reflections and analysed these. Reflective journaling was important in this participatory action research in order to monitor the research progress. In addition, rigour was enhanced because nuances about the voices of participants were noted and incorporated into the text as well as my reflections on what was happening as I was researching. I shared my reflections with my supervisors and discussed the group dynamics with them.

Group Dynamics

I did not expect the exchange of information and collaborative learning in the PAR group to be so vital and dynamic. In fact, I think most of the women’s learning took place in this group. This new observation triggered a desire to explore the literature around group dynamics. As I explained briefly in chapter two, I had touched on Tuckman’s (1964), Lewin’s (1947) and Heron and Reason (2008) work in chapter three but I knew that I must read these texts again to find explanations about what had occurred in this PAR group. So I will briefly summarise some of the literature surrounding group dynamics.

Group dynamics is the study of small groups and also a general term for group processes. These processes include norms, roles, relations, development, need to belong, social influence and effects on behaviour. Group process refers to the understanding of
the behaviour of people in groups as the group tries to solve a problem or make a decision. The implication for studying group processes is that it should be possible to enhance group effectiveness and functioning.

Groups appear to go through a number of phases/stages if they continue to meet for an extended time. As discussed in chapter three, the most influential model derives from psychology, especially Tuckman’s (1965) - forming, storming, norming and performing. First, forming refers to orientation and introductory activities that constitute the group process. The second, storming, is characterised by conflict and polarisation around interpersonal issues. Storming is often a confrontational experience when participants let down the politeness barrier. This resistance is overcome in the third stage, in which in-group feeling and cohesiveness develop and this is termed norming. In the norming stage, participants become used to each other and start to develop trust and move toward productivity. The fourth stage shows that interpersonal structures become evident and group energy is channelled into action and this stage is labelled as performing. Tuckman later suggested a fifth stage called 'adjourning' (Tuckman 1977). Adjourning involves dissolution or the group disbands. Forsyth (2006) described this stage as 'mourning', given the loss that is sometimes felt by former participants. Tuckman (1984) maintained that these phases are all necessary and inevitable in order for the team to grow, to face up to challenges, to tackle problems, to find solutions, to plan work, and to deliver results. This model has become the basis for subsequent models.

Lewin's (1947) work had a profound impact on our appreciation of experiential learning, group dynamics and action research. One of the legacies Lewin (1947) left us
is the ‘action research spiral’; I use ‘look, think and act’ in this study’s version of PAR and also talk about it as a spiral. However, Lewin (1947) points out that action research is not a ‘method’ or a ‘procedure’ for research ‘but a series of commitments to observe a series of principles for conducting social enquiry’ (McTaggart, 1997, p. 249). The Koch and Kralik (2006) PAR process is congruent with the need for commitment but avoids problematisation; rather its focus is on strengths, (both individual and group). Facilitators foster relationships among participants based on strengths.

Although I have talked about Lewin’s (1947) work before, I want to reemphasise two key ideas from his field theory that are crucial to an appreciation of group process: interdependence of fate (a group exists when people in it realise their fate depends on the fate of the group as a whole), and task interdependence (if the group’s task is such that members of the group are dependent on each other for achievement, then a powerful dynamic is created). However, Lewin (1947) argues that democratic principles must be learned anew in each generation and within each group. Therefore, the setting of norms is crucial to learning democratic principles. One of the norms selected by participants is usually to have a voice and to represent one’s self. Democratic leadership in groups has become deeply influential in action research. Two other key aspects are relevant in Lewin’s (1947) group dynamics: feedback and unfreezing.

Feedback is an essential aspect of fostering group dynamics. Feedback was found to ‘be most effective when it stemmed from here-and-now observations, when it followed the generating event as closely as possible, and when the recipient checked with other group members to establish its validity and reduce perceptual distortion’ (Yalom, 1995, p.
Feedback is a routine activity of the PAR cycle described by Koch’s and Kralik’s (2006) processes; after each one to one interview, a story line is created, the individual’s story is returned to the participants for verification, a group story line is also created and presented to the group at the first meeting. Here the group story is verified and used as a way of reflecting on common experiences. Before a PAR group recommences, each participant is given a summary of the previous meeting’s conversations and actions are clearly identified.

Unfreezing describes the process of disconfirming a person’s former belief system. Motivation for change must be generated before change can occur. One must be helped to re-examine many cherished assumptions about oneself and one’s relations to others (Lewin, 1946, 1947, 1951). Learning is best facilitated in an environment where inputs from each perspective are freely given and can be challenged. A learning environment occurs with remarkable vitality and creativity when democratic processes are honoured. Koch and Kralik (2006) use the term ‘learning circle’ to describe group interaction. The facilitator’s attention is focussed on the group’s ‘looking, thinking and acting’ when generating data and analysis. Most conflict is usually experienced in the ‘thinking’ phase and skill is required to assist the individuals with the group to be heard, valued and to move on.

In recent years Heron and Reason (2008) introduced the co-operative inquiry research group which has quite explicit aims around co-research inquiry and the participants’ collaboration. These ideas are new post Tuckman’s early work. Tuckman’s model is linear and it is hard to cut each stage.
I have used Koch’s and Kralik’s (2006) ‘look, think and act’ model as another way of naming phases/stages or experiences to describe group process. However, these processes are frequently characterised by variability and flux. Our previous research experiences with PAR groups show significant deviations from the path laid out by stage theories, including ‘look, think and act’. 'Stages' may be missed out on. It is not unusual to look and act, missing the ‘thinking’ stage or to look and think but never to act. There is some overlap between the different stages as with Tuckman's model, the demarcation is not clear-cut. Changes do not occur in a steplike sequence'. There are rarely clear boundaries between stages in Tuckman’s model (Forsyth, 2006; Koch & Kralik, 2001).

**TABLE 6.1**

<table>
<thead>
<tr>
<th>Koch’s &amp; Kralik’s PAR learning circles</th>
<th>Tuckman’s group dynamic model</th>
<th>Lewin’s action research spiral</th>
</tr>
</thead>
<tbody>
<tr>
<td>Look</td>
<td>Form</td>
<td>Unfreeze &amp; learning about an interdependence of fate</td>
</tr>
<tr>
<td>Think</td>
<td>Storm &amp; Norm</td>
<td>Feedback &amp; task interdependence</td>
</tr>
<tr>
<td>Act (outcome sustained &amp; group continues to meet)</td>
<td>Perform (group adjourns)</td>
<td>Action / reform</td>
</tr>
</tbody>
</table>

In this study group dynamics can be observed during the cycles of ‘looking thinking and acting’ in PAR, the latter being the reform that results as the outcome of the group.

**Discussion**

I was not surprised about the thirst for information and knowledge about diabetes immediately post diagnosis, but I was astonished that women requested so much
repetition which might be a function of the complexity of the material, such as reading the food packages labels.

As researchers and not as experts in diabetes, having access to professional diabetic staff expertise in the health centre was timely and fostered learning. It was interesting that not all the women were at the same stage for learning about diabetes in terms of the processes ‘looking, thinking and acting’. These processes are not linear but it was clear that some women were already at an action phase and wanted to make changes in their lives before other women were ready to even reflect or think to make self-management decisions. For example, while Rose, Sara and Helen were looking at diabetes food choices, Pam, Kathryn and Katy were thinking about changing their diet to the low carbohydrate and Barbara, Katy and Elizabeth had already changed to a low carbohydrate diet. These group meetings demonstrate in some way the utility of such meetings whereby women encouraged each other to move forward towards action; at the same time, they learned from each other, and they supported and nurtured each other through stages of transition. It positively influenced the way they were looking, thinking or acting in relation to their diabetes. This is supported by Alley and Brown (2002) that people with diabetes need to get support from other people in the same situation to solve their problems.

Although I knew that it was usual for a PAR group to reach out, act and reform situations (Koch & Kralik, 2006), to date these women were engrossed with themselves and the immediate life style modifications that they had to make. Absorbing new information at a rate that was compatible with individual learning styles was made clear. Perhaps learning to live with diabetes in the first year post diagnosis fits very well with
Kralik’s (2002) notion in being ‘extraordinary’, that is, women were preoccupied with themselves; they were the centre of attention during this first year. Although in a process of transition, they were not yet ready for ‘ordinariness’.

Reflection

As facilitator I was preoccupied with many other novice researcher tasks, and did not pay attention in the first few PAR groups although it was my intention to do so. With encouragement from my supervisor, I was asked to observe dynamics more closely because she believed something very interesting was happening. I became ready to focus on the strengths of individuals and the group. I noticed how women took control of the process and set the agenda. Occasionally, some comment or guidance from the facilitator was required, e.g. whether it was time to have a break, but participants managed the process, particularly if someone talked too much or were too dominant; they were reminded of the norms. Norms had been established, the group as a whole kept itself ‘on track’.

The cyclical nature of the PAR process promoted reflection and learning that led to the enhancement of these women’s lives. I was further briefed by my supervisors to trust the process and to trust the power of the women sitting in the PAR learning circle. On reflection, reducing my authority of the facilitator was the aim. As mentioned previously, I avoided behaviours that could hinder group interaction: judging, controlling, superiority, certainty, indifference and manipulation. I became conversant with the fluidity of the ‘look, think and act’ processes and I learned about the skills necessary to capitalise on these ‘stages’ to accomplish forming a productive, cohesive
Group dynamics, I assert, is a critical factor in group performance. I constantly analysed whether the group was ‘looking, thinking or acting’ and pondered about ways in which I could motivate the group. I invited participants to ‘think’ about aspects of the story which helped refocus the energy of the circle from merely ‘looking’, to ‘thinking’ and eventually to stimulate action.

The value of research of this PAR process was to observe how participants coped with the new realities in their lives as a result of their learning within the group. It was shown that women learnt through mutual engagement in activities which was defined by the negotiation of meaning both inside the group and outside with health care professionals, or, what Fuller, Hodkinson, Hodkinson, and Unwin (2005) called legitimate peripheral learning. Health care professionals were invited on request and brought into the group. The organising of diabetes self-management ideas was assisted through the medium of brief lectures and handouts. This was effective and demonstrates that the basic allegiance of the PAR group was to facilitate learning for its members.

PAR group meetings provided a really good opportunity for the health care professionals to see, for the first time, the way women were continuing to learn post diagnosis. Even after women’s attendance at three formal diabetes class sessions, health care professionals were intrigued, as were researchers, by the constant need for repetition of information. Involving diabetes centre staff in this way has alerted them to take alternative educational strategies into their diabetes classes and is geared toward addressing objective five of this study. In addition, an open-door policy has been instigated by the health service, so that women can call the diabetes centre staff at any time in the future.
It seems clear that participants sought a balance between accomplishing learning tasks such as label reading and building interpersonal relationships in the group. Whilst in Tuckman’s (1964) model this appears to be a movement between the stages of norming and performing, I argue that relationship building is central and accompanies all stages of the ‘look, think and act’ (LTA) model (Koch & Kralik, 2006). In my understanding of the PAR group process, small groups tend to follow a fairly predictable path toward action, both individual and/or group. It was clear that women’s behaviour had changed and that learning had occurred in terms of managing diabetes much better, however, major reform as the resultant outcome of this PAR process did not happen. If I had continued with PAR group meetings, I speculate that wider community interest may have emerged as they made the transition to become ‘ordinary’. This is possibly a key finding in this study, that is to say, it is my thesis that women, when first diagnosed with diabetes, are self-absorbed for the first year post diagnosis and until they learn to take this chronic condition into their lives, they are not ‘ready’ to take on other activities or consider a wider community reform agenda.

Chapter Summary

I have shown what took place inside the workings of the PAR group because I wanted to share what was happening in the group and demonstrate the way in which women learned collaboratively. In summary, women claimed that attending the three formal diabetes classes had increased their knowledge about diabetes but most had not been ready for this deluge of information so soon after being diagnosed. Readiness to learn was a key finding. Being ready to absorb information often coincided with their experiences within the family. ‘Looking collaboratively’ meant taking control of their
management and being committed to changing their lifestyle in terms of diet and exercise. In ‘thinking collaboratively’, women discovered that if they had co-morbidities, their adaptations to learning to live with yet another chronic condition was not as problematic. In this ‘thinking’ phase, women brought their favourite resources to share with the group and offered rationales for selecting these.

Women helped each other to explore different dietary and exercise options. Women were still eager for diabetes and lifestyle information one year post diagnosis. Although women needed some recommendations to modify their lifestyles, they also liked to make their own decisions about their lives and lifestyles.

In the PAR group, information about diet and exercise requested was often repeated and this need for repetition was surprising. Information exchange amongst the women meant they were able to contemplate ways to modify their lives. Life style modification occurred in the woman’s own life, but ‘collective action’ was in abeyance. I observed a thirst for information and knowledge in the first year post diagnosis. Women were engrossed with themselves and in the life style modifications that they had to make almost immediately. PAR group activity usually results in outcomes: action may be personal development and/or at group reform level. Although I observed that the women’s behaviour had changed over that year and that they were self-managing diabetes with increased confidence, major reform or collective action did not occur.

My research question was “How do older women, who are newly diagnosed with diabetes, learn to live with their condition in the first year post diagnosis?” It was my thesis that older women, when first diagnosed with diabetes, were self-absorbed
immediately post diagnosis, and in support of Kralik’s (2002) transition theory; they were in ‘Extraordinary’ mode. Diagnosis disrupted their daily lives and the necessity to make lifestyle changes immediately was often impeded. Women were not ‘ready’ to learn about ways to take the consequences of this condition into their lives and ‘move on’ or make a transition. In the first year, they were preoccupied with technical and practical aspects of diabetes self-management; they were driven to gain knowledge about food and exercise. However, in their second year post diagnosis they were learning to master activities to create order, discipline and control in their lives. They were not yet ready to consider a wider community reform agenda. Learning from each other in a group was a powerful motivator to make changes in their lives.

The women’s learning process in these PAR group meetings made a theoretical contribution to our understanding of group dynamics. My part in furthering transition theory is my main theoretical contribution.
CHAPTER SEVEN

CONCLUSION
Introduction

Although there was a body of research on and with people diagnosed with Type 2 Diabetes, a researcher staying in the field for twelve months alongside eleven women immediately post diagnosis constituted a new approach in participatory action research methodology. The other novel aspect in this inquiry was the involvement of the women’s family. I will answer the PhD research question: “How do older women, who are newly diagnosed with diabetes, learn to live with their condition in the first year post diagnosis?”

Building on Transition Theory

Building on the transition thesis of Kralik (2000), I observed the movement based on the participants’ experiences, and the way their perceptions and actions changed. When participants were first diagnosed with diabetes, there were no immediate physical ramifications. Rather, the person is ‘warned’ about complications: visual impairment, loss of limbs and so on, should they not adhere to a new regime, which precipitated efforts to regain control, by gathering as much information as possible. Implementing changes in their life style was dependent on their ‘readiness’ in which there was variation between participants. Kralik (2002) called this early phase of accommodation to a diagnosis ‘extraordinary’. The transitional process of learning to take a chronic condition into one’s life takes time, as people gradually disengage from old habits and behaviours. The main point here is that the adjustment period or being in a transition mode of ‘extraordinariness’ appeared to take much longer than anticipated. Importantly, this has certainly not been revealed in other research studies.
Limitations of the Research and What could be done Differently Next Time

There were time constraints in this research project, and I could only manage ten PAR group meetings. Had I continued with group meetings, perhaps reform representing a wider community interest may have emerged with the women developing resources themselves, as this would not be an unusual outcome of this type of research. If I had stayed in the field, I may have witnessed women learning to self-manage evolving into becoming ‘ordinary’. The self-absorption for the first year post-diagnosis, when many life style considerations such as eating impinged on their ‘readiness’ to take on other activities or consider a wider community reform agenda. The group is continuing to meet and it would be interesting to follow their activities in the future and as successes in PAR studies are usually judged by their sustainability of outcomes, this study can be deemed a success because of the group’s continuation. I will not be there to facilitate, but I suspect these women will initiate group support for others, newly diagnosed with diabetes. After all, they now occupy space in the same diabetes centre.

My Limitations

I have been engaged in the field for twelve months and learning to undertake research in participatory action has been challenging. I now realise that I was not well prepared. Although I had close supervision, my critical reading and understanding of major constructs was limited. I have certainly improved but a critical reading course prior to enrolling in my PhD would have been beneficial, specifically because of the complete difference in the didactic educational style of Iran and the individually driven exploratory style of Australia, something with which I know other International students
struggle. Although I passed the ELICOS tests very well, the level of English language required for interpreting the subtleties of participatory action research were bewildering so that I often pondered about word meanings and their significance for an indeterminable length of time, particularly when colloquial language was used. I also found myself still thinking in Farsi, so that a double translation occurred, resulting in some amusing mix-ups.

I adopted the Koch and Kralik (2006) PAR methodology and Kralik’s (2000) transition theory for pragmatic reasons, given the supervision available. Despite the above mentioned constraints, I have made a contribution, on a theoretical level, toward an understanding of transition when a person is first diagnosed with a chronic condition such as Type 2 Diabetes and I have closely observed group dynamics, I believe, giving original insights about group process. I am therefore very pleased to be able to play a part in the theoretical debate. This study was the beginning of developing Kralik’s (2000) transition thesis. It forced me to think more about the lives of people with chronic conditions and the transitions they must negotiate which I would hope to develop further in future research.

**Rigour and Ethical Considerations**

In terms of rigour, I understand that the trustworthiness of this inquiry depends on the transparency of the process so that readers can decide for themselves whether the narrative I have told is believable. I researched alongside women and they were engaged in writing their stories. My aim was to make sure that all women and their families’ voices were included in the text. My claim is that this inquiry is credible; I have not
falsified data, and this is obvious as I have created a multi-voiced text, that is, all the voices are heard and represented adequately. Participants were included in all aspects of the validation process in the storytelling and PAR group process. Cycles of feedback were part of the constant validation process. Consistent with my participative worldview I was motivated to generate authentic information that was useful for participants. Process evaluation of the study suggest resultant actions, individual growth and improved diabetes self management, was meaningful and relevant in their lives. Participants have the final say in making the decision about an inquiry’s quality.

I was tempted to write about generalisability and realised that this concept belongs to the non-participatory action research approach. This study is not generalisable. Instead I will refer to this study’s transferability. Transferability is possible if I have described the context of the setting and given a profile of participants. This inquiry with women living with diabetes shows that the transition thesis is supported and its findings are transferable. I suspect that if I had researched alongside a similar group of women in Melbourne the findings would be similar; they too would be preoccupied with diet and exercise. Gender differences may have shifted my understandings of transition and I suggest it would be interesting to do a similar follow up study with men who have been diagnosed with diabetes. From previous research (Koch, Kralik, & Taylor, 2001) men were not preoccupied with food and its preparation; they had wives to undertake this task.

It this study dependable? I have given a detailed description of the way in which data were generated and analysed. My decisions and choices made whilst researching are made visible though the use of reflective journaling. I believe that theoretical,
methodological and analytic choices have provided a framework. Readers should be able to follow my methodological decision trail.

In the introduction to this thesis, I was at pains to describe my values and that I understood that my values and interests would automatically affect my interpretation of events and data. Reflection was a skill to be learned and the idea of constantly reflecting and analysing those reflections was strange initially. I understood that my social cultural background and my experience as a non-participatory action researcher would influence the way I researched. I kept a diary as a reminder to record and analyse influences, at least those accessible to me, whilst researching. Maintaining a daily journal and analysing its contents was the strategy here. My previous work in Iran with people diagnosed with diabetes had resulted in evaluating the benefits or not of an exercise plan.

When I was first in Newcastle, I was absorbed in the technicalities of diabetes self-management; for instance, I tended to ‘measure’ everything against physical activities achieved before and after diagnosis. However, when I really started to listen to women I heard that their preoccupation with food was a much larger issue for them to deal with. In subsequent conversations, they started to dwell on personal issues and I gradually began to understand that learning to live with diabetes required technical, practical and emotional work.

Building relationships was pivotal when researching with women and their families. I was in the field for twelve months. The relationship dimension draws attention to the
quality of the interaction that has been developed in the inquiry. There are several points I should mention that helped build these relationships. I visited them at home in their own space. I paid attention to creating a safe, accessible PAR group environment. I provided refreshments and thought about seating arrangements and a million other details to create a comfort zone.

I have described the women’s initial reservations about researching with a younger Iranian woman, but I believe this was overcome by their desire to help me. They became rather protective, helped me with the English language and wanted me to succeed. Participants may have been unsure about attending the PAR group at the start, but once in the circle and listening to others in the group, it seemed to foster commitment to each other and I believe, to me. In this way, relationships were reciprocal. Whenever possible, I built on the strengths of the group. Instead of focusing on problems women were experiencing in their daily lives, I encouraged them to celebrate every learning event in living with diabetes. I stimulated plans and activities that women were able to accomplish themselves; I believe we built an environment where relationships can continue to thrive even now after I have left the field.

The issue of disengagement from the women who participated in this research was perceived as an ethical issue. Disengagement is the state that researchers achieve when they finish their research and ‘leave the field’. This was difficult as relationships had been formed and participants perceived they had benefited from being involved in PAR groups. Women enjoyed the reciprocity and learning about diabetes collaboratively. Although I will not be present, the women decided that they will continue to meet. When relationships thrive, resultant individual and group action is likely to be sustained.
It is important that this work is meaningful and has the potential to make a difference. I believe that a longer period in contact with participants lead to outcomes across three categories: technical, practical and emancipatory. When I first commenced working alongside participants, outcomes tended to be technical and practical, possibly as that was my focus too. In the first year of the inquiry, participants were hungry for medical information. Technically, women have had access to good information about diabetes via the staff at the diabetes centre; previous contradictory advice has been curbed. In practical terms, women are self-managing their diabetes with increased mastery. Self-management refers to the activities women have undertaken to create order, discipline and control in their lives. And women set the agenda for meetings and have assumed power to continue to meet with each other, which speaks to the emancipatory aspects of this inquiry.

**The Implications of This Research for Nursing Practice, Educational Programmes, Management and Research**

This study has some implications for nursing practice and the future diabetes educational classes. The women in this study would like to be asked whether they were ready to get information about diabetes before starting the diabetes classes. Therefore, it is worthwhile that the Diabetes Nurse Educators seek the people with diabetes’ state of readiness before inviting them to the diabetes educational classes. It would be beneficial for the participants of these classes to give them voice and let them talk to each other rather than running the diabetes classes just by the Diabetes Nurse Educator and the Dietician. It would be worthwhile not give all the information about diabetes through the diabetes classes and consider what really the participants want to know about
diabetes. One of the most important points in improving the diabetes classes would be related to the shorter and briefer classes. The Diabetes Nurse Educators would provide recap classes every couple of months for people who passes the introductory diabetes classes and see how it is going to people after a while and seek what the people with diabetes would like to know. The other nursing practice implication of this study would be related to providing an atmosphere for people with diabetes to come to the diabetes centre as they liked and share their information and practice it with each other. The women need support from the health care professionals just to answer their questions rather than advise or criticize them.

The implication of this study for the management would be related to reviewing the required information for people who are newly diagnosed with diabetes. The other aspect of the management implication of this study would be related to reform the strategies and the policies for the chronic conditions such as diabetes. For example, there is not much support for people with newly diagnosed with diabetes to consider their feelings and dealing with their condition and later on following their required information about diabetes. Besides, there is a gap to consider what really happen in people with diabetes’s family post diagnosis and how the family would support people who are newly diagnosed with a chronic condition. Therefore, it is necessary to make some policies to not only support the people with chronic condition also it is vital to provide some supportive policies for the family members, as well. On the other hand we should not imagine that all of the people who are newly diagnosed with a chronic condition have family or supportive family. Therefore, it is important to make some supportive policies and reforms for this group of people to get some support from the community by making peers and the health care professionals’ support groups.
The implication of this study for the research would be related to make further research for considering more about what is really happening to the lives of people who are newly diagnosed with a chronic condition and their families. It would be worthwhile to research how and when people who are newly diagnosed with a chronic condition would like to get information about their condition. People with chronic condition would set their own agenda to say what and when really like to learn about their condition. The other implication of this study into the research would be related to working with a male group who are newly diagnosed with Type 2 Diabetes and compare the outcomes of that study with my study to see the gender difference in dealing and learning with a new chronic condition. This study was done in Newcastle one of the New South Wales cities in Australia. It would be worthwhile further researchers would be done other parts of Australia or around the world and them compare the resultant actions and the outcomes. It would be interesting to see the impact of different culture in dealing and learning about a new condition.

In the following section of this chapter, I would like to remind the readers one more time about the aims, objectives and the research questions and see whether I could achieve them or not.

**Objectives**

In the first year of this participatory action research process, I engaged with women and then their families in ongoing interviews. We had numerous conversations and I used the ‘look and think’ analysis framework to explore what was happening in their lives post- diagnosis. I attempted to understand what the women were learning and what
influenced or motivated their learning. If learning is a change in behaviour, they did not change their lives initially as they were preoccupied with making sense of their situation, but they were hungry for knowledge and information. I provided a storyline and incorporated their feedback.

I attempted to track ‘learning events’ in each woman’s life trajectory, since diabetes was diagnosed, achieved through sustained involvement with the family. I was able to track technical and practical innovations (food and/or exercise) in each woman’s life and I was able to monitor her growth and development as she incorporated these into her daily routine. I invited women and their families to join a participatory action research group, although the women came without their families, and, in collaboration with this group, we explored diabetes self-management strategies. The women gave suggestions about service improvements for the staff at the diabetes centre and while it was envisaged that we would initiate reform strategies in the wider community, this did not transpire, precisely because the women were not yet ready to move beyond their own lives. The proposed reform initiative is the only objective not met in this study, which was an unusual outcome, as previous studies involving participants who live with a chronic condition showed that they wanted to reach out and help others in some way; this group, however, was not yet ready to reach out.

**Answering the Research Question**

“How do older women, who are newly diagnosed with diabetes, learn to live with their condition in the first year post diagnosis?” It is my thesis that older women, when first diagnosed with diabetes, are self-absorbed immediately post diagnosis, and in support
of Kralik’s (2000) transition theory, they were in ‘extraordinary’ mode, although longer than anticipated. Diagnosis disrupted their daily lives and the necessity to make quite significant lifestyle changes immediately was often impeded as these women were not ‘ready’ to learn about ways to take the consequences of this condition into their lives and ‘move on’ or make a transition. In the first year they were preoccupied with technical and practical aspects of diabetes self-management; they were driven to gain knowledge about food and exercise; however, in their second year post-diagnosis, they were learning to master activities to create order, discipline and control in their lives. They were not yet ready to consider a wider community reform agenda although learning from each other in a group was a powerful motivator to make changes in their lives.

The women’s learning process in this PAR group makes a theoretical contribution to our understanding of group dynamics. My part in furthering transition theory is my main theoretical contribution.
<table>
<thead>
<tr>
<th>Term</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABHI</td>
<td>Australian Better Health Initiative</td>
</tr>
<tr>
<td>AIHW</td>
<td>Australian Institute of Health and Welfare</td>
</tr>
<tr>
<td>AL</td>
<td>Action Learning</td>
</tr>
<tr>
<td>ASMP</td>
<td>Arthritis Self-Management Programme</td>
</tr>
<tr>
<td>BEACH</td>
<td>Bettering the Evaluation and Care of Health</td>
</tr>
<tr>
<td>CBPR</td>
<td>Community-Based Participatory Research</td>
</tr>
<tr>
<td>CBT</td>
<td>Cognitive Behavioural Therapy</td>
</tr>
<tr>
<td>CDC</td>
<td>Centre for Disease Control and Prevention</td>
</tr>
<tr>
<td>BGL</td>
<td>Blood Glucose Level</td>
</tr>
<tr>
<td>Chronic Conditions</td>
<td>Chronic conditions are those with which people deal over extended periods of time: Type 2 Diabetes, cardiovascular diseases, stroke and heart failure, cancer, asthma, chronic obstructive pulmonary disease, arthritis and musculoskeletal disease, dementia, multiple sclerosis and mental health problems and disorders.</td>
</tr>
<tr>
<td>CCF</td>
<td>Chronic Cardiac Failure</td>
</tr>
<tr>
<td>CCSM</td>
<td>Chronic Condition Self-Management</td>
</tr>
<tr>
<td>CDS</td>
<td>Chronic Disease Surveillance</td>
</tr>
<tr>
<td>COAG</td>
<td>The Council of Australian Governments</td>
</tr>
<tr>
<td>DART</td>
<td>Diabetes Australia Research Trust</td>
</tr>
<tr>
<td>Diabetes Australia</td>
<td>Diabetes Australia is a national federated body comprising state and territory organisations supporting people with diabetes both types 1 and 2 and those professional and research bodies particularly concerned with the treatment and prevention of diabetes.</td>
</tr>
<tr>
<td>Diabetes Educational Classes</td>
<td>When a person has been diagnosed with Type 2 Diabetes he/she is invited Diabetes Educational Classes. These classes are free to clients and conducted by Hunter Area Diabetes Services at Hunter and New England Area Health Service, Newcastle.</td>
</tr>
<tr>
<td>Disease</td>
<td>A medically defined pathological organ/system malfunction</td>
</tr>
<tr>
<td>ELICOS</td>
<td>English Language Intensive Courses for Overseas Students</td>
</tr>
<tr>
<td>FBG</td>
<td>Fasting Blood Glucose</td>
</tr>
<tr>
<td>FHBHHRU</td>
<td>Flinders Human Behaviour and Health Research Unit</td>
</tr>
<tr>
<td>GDM</td>
<td>Gestational Diabetes Mellitus</td>
</tr>
<tr>
<td>Acronym</td>
<td>Description</td>
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<tr>
<td>---------</td>
<td>-------------</td>
</tr>
<tr>
<td>HACC</td>
<td>Home and Community Care</td>
</tr>
<tr>
<td>HADS</td>
<td>Hunter Area Diabetes Services</td>
</tr>
<tr>
<td>HbA1c</td>
<td>Glucose adheres to the haemoglobin molecule to make a 'glycosylated haemoglobin' molecule, called HbA1C.</td>
</tr>
<tr>
<td>HDL</td>
<td>High Density Lipoprotein</td>
</tr>
<tr>
<td>Heart Foundation</td>
<td>It is a non-governmental federation to help people with, and at risk of, cardiovascular disease by providing comprehensive information and guidance on how to minimise their risk.</td>
</tr>
<tr>
<td>HIV-AIDS Infection</td>
<td>Human Immunodeficiency Virus (HIV)-acquired immunodeficiency syndrome (AIDS) infection</td>
</tr>
<tr>
<td>HNELHN Service Diabetes Centre</td>
<td>Hunter and New England Local Health Network Service diabetes centre</td>
</tr>
<tr>
<td>HNELHN Service</td>
<td>Hunter and New England Local Health Network Service.</td>
</tr>
<tr>
<td>ICCC</td>
<td>Innovative Care for Chronic Conditions</td>
</tr>
<tr>
<td>IDF</td>
<td>International Diabetes Federation</td>
</tr>
<tr>
<td>IEP</td>
<td>Insulin Education Programme</td>
</tr>
<tr>
<td>LDL</td>
<td>Low Density Lipoprotein</td>
</tr>
<tr>
<td>Low GI food</td>
<td>A food with a low glycaemic index is one with carbohydrates that break down slowly, releasing glucose gradually into the bloodstream.</td>
</tr>
<tr>
<td>LTA</td>
<td>Look, Think, Act the cyclical process of participatory action research</td>
</tr>
<tr>
<td>mmol/L</td>
<td>Millimole per Litre, eg: one thousandth of a mole: It is the amount of a substance that corresponds to its formula mass in milligrams.</td>
</tr>
<tr>
<td>MVP</td>
<td>Mitral Valve Prolapse</td>
</tr>
<tr>
<td>NDSS</td>
<td>National Diabetes Services Scheme</td>
</tr>
<tr>
<td>NRAR</td>
<td>National Reform Agenda Recognise</td>
</tr>
<tr>
<td>NSFD</td>
<td>National Service Framework for Diabetes</td>
</tr>
<tr>
<td>PAR</td>
<td>Participatory Action Research</td>
</tr>
<tr>
<td>PHC</td>
<td>Primary Health Care</td>
</tr>
<tr>
<td>QOL</td>
<td>Quality of Life</td>
</tr>
<tr>
<td>SDL</td>
<td>Self-Directed Learning</td>
</tr>
<tr>
<td>TG</td>
<td>Triglyceride</td>
</tr>
<tr>
<td>TTM</td>
<td>Transtheoretical Model</td>
</tr>
<tr>
<td>Type 2 Diabetes</td>
<td>Mature onset diabetes. It is a metabolic disorder that is characterised by high blood glucose level in the context of insulin resistance and relative insulin deficiency.</td>
</tr>
<tr>
<td>WDF</td>
<td>World Diabetes Foundation</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organisation</td>
</tr>
</tbody>
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among rural African American adults with diabetes mellitus type 2. *Health Psychology*, 27(Supp1), S88-90.


http://books.google.com/books?id=J6qGsHBJ7nQC


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and don't know about chronic illness experience. _Annual Review of Nursing 
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Appendix A

List of Chronic Conditions Self-Management Plans Website

http://www.epilepsyaustralia.net/
http://www.osteoporosis.org.au/
The First Diabetes Class

The first diabetes class is about understanding diabetes types, diagnosis, causes and treatment of diabetes. Then it is followed by principals of dietary management and making healthy food choices. Then this session is about physical activity and self-management.

<table>
<thead>
<tr>
<th>Time</th>
<th>Topic</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>10 mins</td>
<td>Welcome &amp; Introduction Icebreaker or activity (optional)</td>
<td>• Hand out “Taking change of your diabetes” work sheets</td>
</tr>
<tr>
<td>5 mins</td>
<td>Brief introduction to self-management principals</td>
<td>• Body link or</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Overhead CHO/Insulin chart</td>
</tr>
<tr>
<td>30 mins</td>
<td>What is diabetes?</td>
<td>• Introduction to role of CHO in diabetes management and CHO exchanges</td>
</tr>
<tr>
<td></td>
<td>• An overview of Type 2 Diabetes including insulin resistance</td>
<td>Fat, insulin resistance and weight gain</td>
</tr>
<tr>
<td></td>
<td>• Role of blood glucose monitoring in diabetes management</td>
<td></td>
</tr>
<tr>
<td>40 mins</td>
<td>Nutrition</td>
<td>• Weight/waist measurement (optional self measurement)</td>
</tr>
<tr>
<td></td>
<td>• Making healthy food choices</td>
<td>Monitoring desired</td>
</tr>
<tr>
<td></td>
<td>• Healthy snacks ideas</td>
<td>Parking meter walk</td>
</tr>
<tr>
<td></td>
<td>• Tea/coffee</td>
<td>Networking</td>
</tr>
<tr>
<td>15 mins</td>
<td>Breaks and activity</td>
<td>• Guidelines for physical activity. What, when, how often and how much!</td>
</tr>
<tr>
<td></td>
<td>• Healthy snacks ideas</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Tea/coffee</td>
<td></td>
</tr>
<tr>
<td>30 mins</td>
<td>Self-Management Module</td>
<td>• Introduction to self-management</td>
</tr>
<tr>
<td></td>
<td>Understanding Your Diabetes (Logging sheet linking food, activity &amp; BGLs)</td>
<td>• CHO sources and exchanges</td>
</tr>
<tr>
<td>30 mins</td>
<td>Role of physical activity in diabetes management and getting started</td>
<td></td>
</tr>
<tr>
<td>10 mins</td>
<td>Self management:</td>
<td>• Discuss what they think they may need to change</td>
</tr>
<tr>
<td></td>
<td>• Are you ready for change?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• What ideas do you have?</td>
<td></td>
</tr>
<tr>
<td>10 mins</td>
<td>End of session activity &amp; closure</td>
<td>• Select optional activity</td>
</tr>
</tbody>
</table>
**The Second Diabetes Class**

This diabetes class is about daily self-management of diabetes and setting goals and developing action plans.

<table>
<thead>
<tr>
<th>Time</th>
<th>Topic</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>10 mins</td>
<td>Welcome &amp; Introduction</td>
<td></td>
</tr>
<tr>
<td>10 mins</td>
<td>Icebreaker (optional)</td>
<td></td>
</tr>
<tr>
<td>20 mins</td>
<td>Self Management Module</td>
<td>Understanding Your Diabetes Activity</td>
</tr>
<tr>
<td></td>
<td>Understanding Your Diabetes Activity Logging sheet</td>
<td>(Logging sheet linking food, activity &amp; BGLs)</td>
</tr>
<tr>
<td>45 mins</td>
<td>Nutrition</td>
<td>• Food labels</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Low fat cooking and recipes</td>
</tr>
<tr>
<td></td>
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<td>• GI</td>
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<td></td>
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<td>• Alcohol</td>
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<tr>
<td>20 mins</td>
<td>Practical exercise options</td>
<td>• Weight/waist measurement</td>
</tr>
<tr>
<td></td>
<td>• What to go for exercise programmes/activities?</td>
<td>• Parking meter walk</td>
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<tr>
<td></td>
<td></td>
<td>• Tea and coffee</td>
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<tr>
<td></td>
<td></td>
<td>• Networking</td>
</tr>
<tr>
<td>25 mins</td>
<td>Practical exercise options</td>
<td>• Demonstrations or Videos</td>
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<tr>
<td></td>
<td>• Where to go for exercise programmes/activities?</td>
<td>• Heart Moves/Tai Chi</td>
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<td></td>
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<td>• Chari based exercise</td>
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<tr>
<td></td>
<td></td>
<td>• Body band and resistance card</td>
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<td></td>
<td></td>
<td>• Relevant handouts</td>
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<tr>
<td>10 mins</td>
<td>Medications</td>
<td>• DA Medications for type 2</td>
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<td></td>
<td>• The right ones for you</td>
<td>• Relevant handouts</td>
</tr>
<tr>
<td>15 mins</td>
<td>Diabetes Health Assessments</td>
<td>• Use risk reduction chart and management cards</td>
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<tr>
<td></td>
<td>• Long term self-management goals</td>
<td>• Relevant handouts</td>
</tr>
<tr>
<td></td>
<td>• Risk reduction and preventing complications</td>
<td></td>
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<tr>
<td>15 mins</td>
<td>Goal Setting</td>
<td>• Review Goal setting</td>
</tr>
<tr>
<td></td>
<td>• Identification of barriers and opportunities</td>
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<tr>
<td></td>
<td>• Developing Action Plans</td>
<td></td>
</tr>
<tr>
<td>10 mins</td>
<td>End of session activity &amp; Closure</td>
<td>• Select optional activity</td>
</tr>
</tbody>
</table>
**The Third Diabetes Class**

This diabetes class is about checking progress and solving problems and ongoing diabetes and dietary management.

<table>
<thead>
<tr>
<th>Time</th>
<th>Topic</th>
<th>Activity</th>
</tr>
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<tbody>
<tr>
<td>10 mins</td>
<td>Welcome &amp; Introduction</td>
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<tr>
<td>10 mins</td>
<td>Icebreaker (Optional)</td>
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</tr>
<tr>
<td>30 mins</td>
<td>Self-Management Activities</td>
<td>• Understanding Diabetes Activity Sheet&lt;br&gt;“Taking charge of Your Diabetes- a plan of Action” work sheets</td>
</tr>
<tr>
<td>10 mins</td>
<td>Break (may be integrated into case study session)</td>
<td>• Weight/waist measurement&lt;br&gt;• Parking meter walk&lt;br&gt;• Tea and coffee&lt;br&gt;• Networking</td>
</tr>
<tr>
<td>60 mins</td>
<td>Problem Solving and outstanding issues</td>
<td>• Small group activity&lt;br&gt;• Problem Solving sheets&lt;br&gt;• Case studies</td>
</tr>
<tr>
<td></td>
<td>Case studies to address at least one aspect of diabetes self-management or self-care.</td>
<td>• Hypos &amp; Hypers&lt;br&gt;• Foot care&lt;br&gt;• Eating out/take away&lt;br&gt;• Sick Day Management&lt;br&gt;• Travel Planning&lt;br&gt;• Stress and diabetes</td>
</tr>
<tr>
<td>45 mins</td>
<td>Self-Management</td>
<td>Smart Goals &amp; Problem Solving Sheet</td>
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<tr>
<td></td>
<td>• Getting back on track</td>
<td></td>
</tr>
<tr>
<td>15 mins</td>
<td>End of session activity &amp; closure</td>
<td>• Select optional activity</td>
</tr>
<tr>
<td></td>
<td>• Follow up if required</td>
<td></td>
</tr>
</tbody>
</table>
31 October 2008

Dr Isabel Higgins
Professor of Nursing, Older Person Care
School of Nursing & Midwifery
University of Newcastle

Dear Professor Higgins,

Re: Older women and chronic illness: Learning to live with diabetes
(08/08/20/5.05)

HNEHREC Reference No. 08/08/20/5.05
HREC Reference No: 08/HNE/218
SSA Reference No: 08/HNE/219

Thank you for submitting an application for authorisation of this project. I am pleased to inform you that authorisation has been granted for this study to take place at the following sites:

- Hunter New England Health

The following conditions apply to this research project. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval:

1. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and which are submitted to the lead HREC for review, are copied to the research governance officer;
2. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project, are to be submitted to the research governance officer.

Yours faithfully

Lisa Woseen
Research Governance Officer
Hunter New England Health
20 October 2008

Professor Higgins
Professor of Nursing, Older Person Care
School of Nursing & Midwifery
University of Newcastle

Dear Professor Higgins,

Re: Older women and chronic illness: Learning to live with diabetes (08/08/20/5.05)

HNEHREC Reference No: 08/08/20/5.05
NSW HREC Reference No: 08/HNE/218

Thank you for submitting the above protocol which was first considered by the Hunter New England Human Research Ethics Committee at its meeting held on 20 August 2008. This Human Research Ethics Committee is constituted and operates in accordance with the National Health and Medical Research Council’s National Statement on Ethical Conduct in Human Research (2007) (National Statement) and the CPMP/ICH Note for Guidance on Good Clinical Practice. Further, this Committee has been accredited by the NSW Department of Health as a lead HREC under the model for single ethical and scientific review.

I am pleased to advise that following receipt of the requested clarifications and revised information sheet and consent form by the Professional Officer, the Hunter New England Human Research Ethics Committee has granted ethical approval of the above project.

The following documentation has been reviewed and approved by the Hunter New England Human Research Ethics Committee:

- The Participant Information Sheet for women with Diabetes (Appendix A version 2 dated 10 October 2008);
- The Consent Form for Women with Diabetes (Appendix B);
- Interview Questions for Women with Diabetes (Appendix C);
- The Information Sheet for Family Member or Friend/Support Person (Appendix D version 2 dated 10 October 2008);
- The Consent Form for the Family Member (Appendix E);
- Questions to be asked during conversation with the family member (Appendix F)

For the protocol Older women and chronic illness: Learning to live with diabetes (version dated 13 June 2008)

Approval from the Hunter New England Human Research Ethics Committee for the above protocol is given for a maximum of 3 years from the date of this letter, after which a renewal application will be required if the protocol has not been completed.

The National Statement on Ethical Conduct in Human Research (2007), which the Committee is obliged to adhere to, include the requirement that the committee monitors the research protocols it has approved. In order for the Committee to fulfil this function, it requires:

- a report of the progress of the above protocol be submitted at 12 monthly intervals. Your review date is October 2009. A proforma for the annual report will be sent two weeks prior to the due date.

Hunter New England Human Research Ethics Committee
Locked Bag No 1
New Lambton NSW 2305
Telephone (02) 49214 950 Facsimile (02) 49214 818
Email:hnehrec@hneh.health.nsw.gov.au
Noreen.nicola@hneh.health.nsw.gov.au
Lisa.woseen@hneh.health.nsw.gov.au

• A final report be submitted at the completion of the above protocol, that is after data analysis has been completed and a final report compiled. A proforma for the final report will be sent two weeks prior to the due date.

• All variations or amendments to this protocol, including amendments to the Information Sheet and Consent Form, must be forwarded to and approved by the Hunter New England Human Research Ethics Committee prior to their implementation.

• The Principal Investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including:
  - any serious or unexpected adverse events
    • Adverse events, however minor, must be recorded as observed by the investigator or as volunteered by a participant in this protocol. Full details will be documented, whether or not the investigator or his deputies considers the event to be related to the trial substance or procedure.
    • Serious adverse events that occur during the study or within six months of completion of the trial at your site should be reported to the Professional Officer of the Hunter New England Human Research Ethics Committee as soon as possible and at the latest within 72 hours.
    • Copies of serious adverse event reports from other sites should be sent to the Hunter New England Human Research Ethics Committee for review as soon as possible after being received.
  - Serious adverse events are defined as:
    - Causing death, life threatening or serious disability.
    - Cause or prolong hospitalisation.
    - Overdoses, cancers, congenital abnormalities whether judged to be caused by the investigational agent or new procedure or not.
  - Unforeseen events that might affect continued ethical acceptability of the project.

• If for some reason the above protocol does not commence (for example it does not receive funding); is suspended or discontinued, please inform Dr Nicole Gerrand, the Professional Officer of the Hunter New England Human Research Ethics Committee as soon as possible.

The Hunter New England Human Research Ethics Committee also has delegated authority to approve the commencement of this research on behalf of the Hunter New England Area Health Service. This research may therefore commence.

Should you have any queries about your project please contact Dr Nicole Gerrand as per her contact details at the bottom of the page. The Hunter New England Human Research Ethics Committee Terms of Reference, Standard Operating Procedures, membership and standard forms are available from the Hunter New England Area Health Service website:

Internet address:

Please quote 08/08/20/5.08 in all correspondence.
You are reminded that this letter constitutes ethical approval only. You must not commence this research project at a site until separate authorisation from the Chief Executive or delegate of that site has been obtained.

The Hunter New England Human Research Ethics Committee wishes you every success in your research.

Yours faithfully

For: Dr M Parsons
Chair
Hunter New England Human Research Ethics Committee
HUMAN RESEARCH ETHICS COMMITTEE

APPROVAL TO CONDUCT HUMAN RESEARCH

To Chief Investigator or Project Supervisor: Professor Isabel Higgins
Cc Co-investigators / Research Students: Ms Fatemeh Adili

Re Protocol: Older women and chronic illness: learning to live with diabetes
Date: 25-Mar-2011
Reference No: H-2008-0385

Thank you for your recent application to the University of Newcastle Human Research Ethics Committee (HREC) for approval of the protocol identified above.

Details of previous approvals for Initial, Renewal and Variation applications are available upon request.

A Certificate of Approval is enclosed.

THE CERTIFICATE AND THIS ADVICE ARE TO BE RETAINED
THEY ARE IMPORTANT DOCUMENTS

Note any comments related to the approval.
Where the HREC is the lead or primary HREC, if the research requires the use of an Information Statement, ensure the Reference No. is inserted into the complaints paragraph in the approved document(s) prior to distribution to potential participants.
Where the research is the project of a higher degree candidate, it is the responsibility of the project supervisor to ensure that the candidate receives this approval advice.

Conditions of Approval

This approval has been granted subject to you complying with the requirements for Monitoring of Progress, Reporting of Adverse Events, and Variations to the Approved Protocol as detailed below.

PLEASE NOTE:
In the case where the HREC has "noted" the approval of an External HREC, progress reports and reports of adverse events are to be submitted to the External HREC only. In the case of Variations to the approved protocol, you will apply to the External HREC for approval in the first instance and then register that approval with the University’s HREC.

Monitoring of Progress

Other than above, the University is obliged to monitor the progress of research projects involving
human participants to ensure that they are conducted according to the protocol as approved by the HREC. The Certificate of Approval identifies the period for which approval is granted and your progress report schedule. A progress report is required on an annual basis, you will be advised when a report is due.

- **Reporting of Adverse Events**

1. It is the responsibility of the person first named on the Certificate to report adverse events.
2. Adverse events, however minor, must be recorded by the investigator as observed by the investigator or as volunteered by a participant in the research. Full details are to be documented, whether or not the investigator, or his/her deputies, consider the event to be related to the research substance or procedure.
3. Serious or unforeseen adverse events that occur during the research or within six (6) months of completion of the research, must be reported by the person first named on the Certificate to the (HREC) by way of the Adverse Event Report form within 72 hours of the occurrence of the event or the investigator receiving advice of the event.
4. Serious adverse events are defined as:
   - Causing death, life threatening or serious disability.
   - Causing or prolonging hospitalisation.
   - Overdoses, cancers, congenital abnormalities, tissue damage, whether or not they are judged to be caused by the investigational agent or procedure.
   - Causing psycho-social and/or financial harm. This covers everything from perceived invasion of privacy, breach of confidentiality, or the diminution of social reputation, to the creation of psychological fears and trauma.
   - Any other event which might affect the continued ethical acceptability of the project.
5. Reports of adverse events must include:
   - Participant's study identification number;
   - date of birth;
   - date of entry into the study;
   - treatment arm (if applicable);
   - date of event;
   - details of event;
   - the investigator's opinion as to whether the event is related to the research procedures; and
   - action taken in response to the event.
6. Adverse events which do not fall within the definition of serious, including those reported from other sites involved in the research, are to be reported in detail at the time of the annual progress report to the HREC.

- **Variations to approved protocol**

If you wish to change, or deviate from, the approved protocol, you will need to submit an Application for Variation to Approved Human Research. Variations may include, but are not limited to, changes or additions to investigators, study design, study population, number of participants, methods of recruitment, or participant information/consent documentation. Variations must be approved by the (HREC) before they are implemented except when Registering an approval of a variation from an external HREC which has been designated the lead HREC, in which case you may proceed as soon as you receive an acknowledgement of your Registration.

**Linkage of ethics approval to a new Grant**
HREC approvals cannot be assigned to a new grant or award (ie those that were not identified on the application for ethics approval) without confirmation of the approval from the Human Research Ethics Officer on behalf of the HREC.

With best wishes for a successful project.

Professor Alison Ferguson  
Chair, Human Research Ethics Committee

For communications and enquiries: 
Human Research Ethics Administration

Research Services  
Research Integrity Unit  
HA148, Hunter Building  
The University of Newcastle  
Callaghan NSW 2308  
T +61 2 492 18999  
F +61 2 492 17164  
Human-Ethics@newcastle.edu.au

Linked University of Newcastle administered funding:

<table>
<thead>
<tr>
<th>Funding body</th>
<th>Funding project title</th>
<th>First named investigator</th>
<th>Grant Ref</th>
</tr>
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HUMAN RESEARCH ETHICS COMMITTEE  
Certificate of Approval

<table>
<thead>
<tr>
<th>Applicant: (first named in application)</th>
<th>Professor Isabel Higgins</th>
</tr>
</thead>
</table>
| Co-Investigators / Research Students:  | Ms Fatemeh Adili  
Professor Tina Koch |
| Protocol:                               | Older women and chronic illness: learning to live with diabetes |

In approving this protocol, the Human Research Ethics Committee (HREC) is of the opinion that the project complies with the provisions contained in the National Statement on Ethical Conduct in Human Research, 2007, and the requirements within this University relating to human research.

Note: Approval is granted subject to the requirements set out in the accompanying document Approval to Conduct Human Research, and any additional comments or conditions noted below.

Details of Approval
HREC Approval No: H-2008-0385

Date of Initial Approval: 13-Nov-2008

Approved to: 19-Oct-2011

Approval is granted to this date or until the project is completed, whichever occurs first. If the approval of an External HREC has been "noted" the approval period is as determined by that HREC.

Progress reports due: Annually.

If the approval of an External HREC has been "noted", the reporting period is as determined by that HREC.

Approval Details

Authorised Certificate held in Research Services

Professor Alison Ferguson
Chair, Human Research Ethics Committee
I wish to advise that the following Research Project has been granted safety clearance. Based on the information received with your application we are satisfied that appropriate controls have been implemented for the hazards identified. **If there is any variation to the protocol that affects the safety outcomes an additional application for safety clearance is necessary.**
In order to comply with the OHS Act 2000 Chief Investigators must ensure that all, reasonably foreseeable, occupational health and safety risks arising out of their research activities are effectively controlled. A risk assessment must be completed to achieve this control. Effective controls follow on through the elimination (preferable), or minimisation, of these risks. Risk assessments are only validated once they have been signed and dated by the author and authorising supervisor. They must be reviewed annually and the review process needs to be documented (signed and dated).

Control measures for research activities include (but are not limited to):

- Effective site orientation/induction of all personnel to their work area and equipment, first-aid locations, and emergency procedures and equipment
- Written standard operating procedures (SOP’s) for equipment and processes
- Training in SOP’s for all personnel engaged in hazardous operations (with appropriate records)
- All documented control measures must be implemented
- Any injury/incident occurring during the activity is reported on a University Incident Report Form
- Actions required in the attached evaluation report are undertaken
If you have any enquiries in relation to this safety clearance ((Off Site) please do not hesitate to contact me.

Ms. Natasha Cooper
Dear Sir/Madam

My name is Fatemeh Adili. As a part of my study at University of Newcastle I am inquiring to know “How do older women, who are newly diagnosed with diabetes, learn to live with their illness in the first year post diagnosis?” This issue will help older women, their families and diabetes nurse educators to deal with this condition.

You are free not to join to my study and attending in this research does not affect any services from nurses or doctors at the Hunter New England NSW Health for you.

If you agree with participating in this study, you will be asked for two issues:

1) Talk to me in some occasions (about three to six months every fortnight)
If you agree I would like to talk to you about your learning to live with newly diagnosed with diabetes, your thoughts, feelings, and managing your life. I need to talk to you in some occasions when and where suits both of us and talk freely and feel comfortable. Moreover, to insure that I take correct information I will record your voices by a recorder and not missing any points and make notes. The records will be transcribed by typing word by word then.

2) Attend in group discussion session (about three to six months every fortnight)

If you agree after individual talk, we will have group discussion sessions which contain enthusiastic participants who would like to share their learning with the other ones. During this time I will record the voices and make notes from them.

Your information will be confidential and your names do not mention in any reports of this study. All information will be kept in a lucked cabinet filing and used just for fulfilling the purposes of this study. Only the researcher and her supervisors have access to this information. After finishing this study, the information will be destroyed. The result of this study will be published, but it is not possible until 2010. In publications the individual names and institutes will not mention and be kept confidential. If you are interested to see a copy of the result you can contact me by the number which is included in this study.

If you agree to participate in this research, your rights are protected as following:

- You have rights to ask your queries from the researcher
- You have right to refuse attending in this study any time without fear to receive any changes health services from the Hunter New England NSW Health
- You have a right not to answer any questions as you do not like to talk about them without mentioning your reason.
✓ You have a right to withdraw from the study at any time by letting know the researcher or the diabetes nurse educators.

Yours Sincerely,

Fatemeh Adili.

School of Nursing and Midwifery.
APPENDIX E

The Women’s Consent Form

Fatemeh Adili
School of Nursing and Midwifery
Tel: 4921 6651
Fax: 4921 6301
e-mail: fatemeh.adili@studentmail.newcastle.edu.au

Learning to live with diabetes

Consent form for women with diabetes

I have received the information from the “Learning to live with diabetes” study to be conducted by Fatemeh Adili from the University of Newcastle, and all of my questions are answered satisfactory.

I agree to take part in this study and give my consent freely.

I recognise the study which is explained in the information statement, a copy of which I have received. I understand that my involvement in this study does not affect any services I receive from the Hunter New England NSW Health.

I also recognise that I can withdraw from the study at any time and it is not necessary to express my reason for this decision.

Printed Name ……………………..

Signature …………………………………………………

Date………………………………
Learning to live with diabetes

Information Sheet for family member or friend/support person

Dear Sir/Madam,

My name is Fatemeh Adili. As a part of my PhD study at the University of Newcastle I am inquiring into “How women, who are newly diagnosed with diabetes, learn to live with their condition in the first year post diagnosis?” My supervisors are: Professors Isabel Higgins and Tina Koch.

Although diabetes has been studied for some time, there are, to date, few that explore what happens when a person is first diagnosed. It has been observed that when people are
diagnosed with diabetes they need to modify their everyday lives. In the study proposed here I am interested in understanding the experiences of women who are newly diagnosed with diabetes. I want to know how women learn to live with diabetes during the first year following diagnosis. I want to explore how learning occurs in relation to diabetes by exploring what happens in day to day life, relationships with family members and or friends, and what changes occur within the immediate environment. I also want to explore what it is that women would want health professionals to know or change that would improve the experiences of women who are newly diagnosed with diabetes

**What would you be asked to do?**

1. Meeting with me, the researcher, on a regular basis, approximately every fortnight or as negotiated for interviews/discussions with your family member/friend about how she is learning to live with diabetes. I acknowledge that you may have obligations including paid or unpaid work and child care. Meetings will need to be over a period of twelve months in order for me to understand how your family member or friend learns to live with diabetes during this time. These discussions will be conducted in privacy in your home or some other agreed venue for about an hour each time. Discussions will be recorded for transcription later so that I can reflect on and analyse what has been said. Transcripts will be given back to you and your family member or friend for review at the beginning of the next meeting. A summary document of our previous discussion will also be provided at each meeting. Subsequent discussions will build on previous conversations over the 12-18 month period. During meetings I will be interested in exploring your thoughts and feelings about such things as your relationship with family members and friends, issues with
shopping or cooking and generally what it is like for your family member or friend to live with diabetes.

2. Towards to end of the nine to fifteen month period of time we have been meeting I will invite you and your family member to attend a series of group discussion (n= 3) sessions with other participants of the study and their family member/friend. The group meetings will be facilitated by the PhD candidate assisted by one of her supervisors. Each session will take around two hours. The purpose of these meetings is for all the participants to share their learning experiences with each other and discuss recommendations for health care professionals aimed at improving the care and support for women who are newly diagnosed with diabetes.

**What choice do you have?**

Your participation in this research project is entirely voluntary, your decision not to participate will not affect your relationship with Hunter New England Health or the University of Newcastle.

**Are there any risks or benefits of participating?**

Discussions about your family member/friend’s experiences about being newly diagnosed with diabetes may cause you some distress. If this occurs the researcher will check to see if you wish to discontinue the discussion. She will also offer you information about contacts for professional counsellors or suggest you seek a referral for counselling from your GP.

**How will your privacy be protected?**

No identifying details of any of the participants will be recorded. Pseudonyms (false names) will be used for transcribed interviews and when reporting the findings of the study, unless you specifically wish to be named. Participants within the group meetings will be
told of the importance of confidentiality within the group and that the content of group conversations should not be shared with anyone outside of the group, although it is recognised that this confidentiality cannot be enforced. Consent to participate in the group process is also an agreement to confidentiality within the group.

All information will be kept in a locked filing cabinet in my office at the university and will only be used for the purposes of this study. Only my supervisors and I will have access to this information. At any time during the time of the study you may ask to have access to the recordings and/or transcripts of the conversations should you wish to change or edit conversations? The results will be marked as edited. At completion of the study, the information will be destroyed, although the tapes/discs will be kept for 5 years in the School of Nursing and Midwifery secured archives.

**How will the information collected be used?**

The results of this study will be published after 2010. None of the names of any individuals (unless specifically asked to be named), or institutions, will be mentioned in any publications and all information will be kept confidential. If you are interested in a copy of the findings you can contact me or my supervisors on the phone number which is included in this letter.

**What are your rights?**

If you accept attending in this research, your rights are protected as following:

1. You have the right to ask questions of the researcher
2. You have the right to refuse to participate in this study and your refusal will not change how you are treated by any member of Hunter New England Health or the University of Newcastle.
3. You have the right to refuse to answer any question, should you choose, and need not give any reasons for your refusal.

4. You have the right to withdraw from the study at any time by letting me or the diabetes nurse educators know, and you do not have to give a reason for your withdrawal, and it will in no way change your medical treatment.

**What do you need to do to participate?**

If you wish to participate in this study, please return the signed consent form in reply paid envelope via the postal service to the University of Newcastle as noted on the envelope.

The researcher will then contact you to arrange a suitable time to meet you.

Yours Sincerely,

Fatemeh Adili.

School of Nursing and Midwifery.

*This research project has been approved by the Hunter New England Area research Ethics Committee, Hunter New England HREC Reference No: 08/08/20/5.05 NSW HREC Reference No: 08/HNE/218. Should you have any concerns regarding your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or if an independent person is preferred to:*

*Dr Nicole Gerrand*

*Professional Officer (Research ethics),*

*Hunter New England Area Human Research Ethics Committee*

*Telephone: (02) 4921 4950  Fax: (02) 4921 4818*

*Email: Nicole.gerrand@hunter.health.nsw.gov.au*
Learning to live with diabetes

Consent form for the family member

I have received the information from the “Learning to live with diabetes” study to be conducted by Fatemeh Adili from the University of Newcastle, and all of my questions are answered satisfactory. I agree to take part in this study and give my consent freely.

I recognise the study which is explained in the information statement, a copy of which I have received.

I understand that my involvement in this study does not affect any services which are received from the Hunter New England NSW Health to my relative.

I also recognise that I can withdraw from the study at any time and it is not necessary to express my reason for this decision.

**Printed Name** .................................................................

**Signature** .................................................................

**Date** .................................................................
APPENDIX H
Sara’s Long Story

Sara is sixty nine years of age, was born in Poland. She was an agricultural technician. In 1980 she came to Australia. Then she got married. She said “my husband was older than me and after six months we got divorce. He was so possessive man and very jealous. When he bashed me I saw a doctor and she said that it is better to live by myself before something serious happens to me later on. After my divorce I did not know where to go.” She has a good perseverance such as learning English. She said “I did not speak English at all. I did not know any words even thank you or something. It was so hard. Then I went to English classes and courses to learn English. I went to Newcastle College to learn English for two and half years. Then I learned accounting. I always had some problems with my English and I had a dictionary with myself. Sometimes the lectures were very quick and I could not take notes.”

She had a hard life and worked very hard. She said “I found a job in Coca Cola Company in New Lambton. I worked there for two years and had some back problems and then I am on disability pension. My job in Coca Kola was a physical job. Sometimes I did work overtime on Saturdays. When women at worked got together they did not invite me because my English was not good. They made fun of me. Sometimes somebody bought food for the others but never asked me.” She does have salaried work now, but she does some voluntary work.
She does not have any family support. She said “I do not have any children. All of my family members are in Poland. I had bad experience at first when I came here. My parents died because of stroke. My dad had stroke when he was seventy six. My mother was taking care of him at home. When my father died my mother got stroke. My sister looked after my mom. Later on my mom could not speak, as well. After my mom death my sister came here to visit me in 1991.” She does not have any relatives here in Australia. Therefore, always she helps herself to get over her stressful situations such as accident. She said “I do not have anyone here. Sometimes I get trouble when I am sick. When I had an accident and was at hospital sometimes people came to see other patients. No one came to see me. My heart was really very broken. I am always very determined. Sometimes I am very sick and in pain. But something in my head says I have to do, I have to, I have to do….everything because there is no one does it for me. It is not very easy.”

She has heart problem and she tries to makes herself strong. She said “In 2003, I had angiography and angioplasty and then went to rehabilitation section at John Hunter Hospital to learn about my condition with the other patients and learn how to cope with my situation.” She was diagnosed with diabetes in April 2009 as her blood glucose level was high. Then she took some actions to mange her diabetes such as exercise, diet and checking her blood glucose level. She said “On that time my blood glucose level was high. My doctor sent me for checking my blood test. I am controlling my diabetes by diet and exercise. So far my diabetes is good. The diabetes does not affect me so much. I take everything easy.”
When she was diagnosed with diabetes she was upset. But she took some actions straight away and helped herself. She said “When I was diagnosed with diabetes I was so devastated. I had mixed feelings. But it was not a surprise for me because my specialist a few years ago warned me to be careful about my food because she said that I am vulnerable to get high blood glucose level based on my blood test. I was thinking how it can happen. When I was diagnosed with diabetes I was a little bit upset and it put me down. But later on I thought that I can do nothing.

I put myself together. I put myself on diet. I changed my routines, and lifestyle, especially with food and eat small portions.” She does not have family support. She just talks about her diabetes to her neighbour and gets support from her. She said “I have not talked about diabetes with my family. I just talked about it with one of my neighbours. My sister is very sick and I try not to add on her problems. I have no one here to help me. Just I should live by myself. I have a lady neighbour, she is 88. Sometimes she comes to have coffee with me. My neighbour’s husband had diabetes and she cooked for him and he passed away.”

She attended diabetes classes based on her doctor’s advice. She wishes she could attend the classes earlier. She said “After being diagnosed with diabetes my doctor sent me to the diabetes classes to get idea how to cope with this disease. It was nearly two months I was diagnosed with diabetes until attending in diabetes classes. It took time to make an appointment. I was a little bit worried because I wanted to go to the classes earlier and get some information about food, which food is good or not good for diabetes and fat.” She got some support from the dietitian and the nurse educator at the diabetes centre. She has
learned to check her blood glucose level from diabetes classes. She said “Diabetes educators and dieticians are very kind and helpful. I learn to have a small machine to check my blood glucose level. Sometimes I check my blood glucose level four times a day in different times before lunch and two hours after the lunch. Sometimes I check my blood glucose level before breakfast and two hours after that.”

She did all diabetes classes. The main important thing as she has learned is about food. She said “I finished diabetes classes. Especially I learned about foods. It is very important and how much you can take it. Eat small portions. I enjoyed all parts of the classes because always I have learned something new.”

She has learned from diabetes classes to cope with her feelings. However sometimes she could not learn some points as English is not her first language. She said “The classes gave me some idea how to cope with diabetes. I learned about foods, portions, eating on time, shopping and label reading. I think it was enough to learn but if I need more information I will ask them. Even sometimes after the classes I asked them my questions because sometimes the problem is related to my English because most of the participants of the diabetes classes are Australian and they know what the educator says.” She has learned lots of points from diabetes classes such as what and how much she should eat. She said “After attending in diabetes classes I understood that I should change my diet, eat in different times and I have to eat regular. I should be careful what sort of food I have to eat, eat in small portions and eat low GI food to takes time to digest. Before attending the diabetes classes I did not eat fat and I am the same now. For my breakfast I normally have porridge,
I put oats, bulgur, almond, walnuts and soymilk or sometimes different types of milk in it. I hate skim milk especially in coffee. Soymilk is very good. I heard that soymilk is not good because it has some ingredients which stop digestion, but I am not sure about it. For lunch I have hot meals. Sometimes I have chicken breast or fry something a little bit of olive oil. I eat some pieces of bread. I put low saturated fat margarine, and sometimes avocado on that.”

She believes that her diet is the same as before being diagnosed with diabetes except she is more conscious about her fat intake and sweets. She said “I think my diet is the same as what I have eaten for my heart. I should be careful about saturated fat and triglyceride because it is still high. I could cut down my sweets.” She has learned to eat on time and follow diabetes diet. She said “Before I ate so much and it wasn’t so good. I changed my food and eat it on time. I just used to my diet and diabetes to cope with my feelings. I think I have to do it.” She believes that nuts are helpful for her.

She loves coffee and cake. She said “I found that Brazil nuts decrease my heart problem. I bought it. It is in the kitchen. I can show you my nuts. I use bulgur because it has lots of fibre. I eat almond and hazelnut. I found them in health food shop. My sister told me that almond is good for my digestion and immune system. The pumpkin seeds are very good. I use lots of garlic. When I fry something I use garlic. I eat low sugar yogurt, less cakes. Sometimes I like to eat good coffee and soft cakes.” She reads packages labels very carefully when she goes shopping. She said “When I go shopping I look at the labels and read it especially about sugar level and carbohydrates, saturated fat and fibres. I am
conscious about sweets, cakes and biscuits. I should be careful about them. I do not buy
cakes. The biscuits do not have much fat.”

Sometimes she eats something as she knows they are fatty but she feels she can get energy
from them. She said “Sometimes I eat processed foods and sometimes I eat chicken liver.
Sometimes I heard that liver is very good because it has some vitamins. Sometimes I buy
diabetic foods but you cannot trust the labels. I bought avocado margarine and it does not
have much fat as the other margarines. It is good. Avocado and macadamia are very good.
Sometimes I eat cheese. My friend bought me this cheese. It does not have so much
cholesterol. I think this is good. I found that cheddar cheese is very good. Sometimes they
advertise something and I think they are just commercial to say that it is good and make
others to buy it. I think everything is the same and they just changed the labels. That’s it.”

She has some difficulty with labels as she feels that they are not consistent. She said “I
cannot trust the labels. Sometimes the label says that it does not have much saturated fat but
still it has it. When the manufacture specialist tests it, he will discover that it has too much
fat in it.” She has some temptation when she goes shopping. But she reminds herself that
some foods are full of fat. She said “Sometimes when I go shopping sweets are very
attractive and I have some temptation about them. I like to buy white bread and some
butter, nothing more. But butter is so fatty and I have to be careful. Sometimes I buy dark
chocolates. Chocolates are good for you.”
She has done some exercise and she has a creative mind and does exercise with some bottles. She said “I do some exercise since my heart problem. I do some physical fitness with my arm and something lifting. I am using two water bottles for lifting. I do exercise every morning in my bed because I had a car accident in my right hip in 1999. I had problem with my broken pelvis. I used to walk before but now I face to lots of problems with my right knee. I cannot move it properly because of arthritis, especially my back. I used to walk to university and Birmingham Gardens, Jesmond and Wallsend and returned home. It took me two hours. Now I just walk around the lake in Warabrook. But not so much as I have a knee problem, now.”

She feels she put on weight and she needs to do more exercise. She said “I think I put on a little bit weight. Maybe it is winter and I am not walking every morning. Every morning, I do some exercise, have shower and I eat my breakfast and then I feel different. After doing some exercises I have better appetite and eat healthier and more energetic foods. Then I can do something. But when I stay home I am not very good. I do not know. I feel some pain in my knee.”

She is learning about diabetes from diabetes classes, books, magazines, television and radio. She said “I learn about diabetes through books, magazines, television and diabetes classes. I have read lots of books. Sometimes I am reading some books about prevention of disease and they give me some idea. I bought some of them and sometimes my friends give me theses books. Sometimes I read general magazines and they have some healthy points. I bought some medical terminology books and even sent some of my medical books for my
mom in Poland. At television and radio I watch and hear something good especially something about medical issues. I read sometimes magazines, books and bulletins and learn something about prevention. For example, watermelon and blueberry are very good.” She is an organised person and she has a particular folder to keep her health issues. She said “I have a folder here which its name is ‘Health’. It contents of doctor’s copies and the result my tests in that.”

Analysis of Sara’s Story

I am Sara. I was born in Poland in 1941. I was an agricultural technician. In 1980 I came to Australia. Then I got married with a Polish fellow. He was older than me and after six months we got divorce. After my divorce I did not know where to go. I did not speak English at all. I did not know any words even thank you or something. It was so hard. Then I went to English classes and courses to learn English. I went to Newcastle College to Learn English for two and half years. Then I learned accounting. I always had some problems with my English and I had a dictionary with myself. Sometimes the lectures were very quick and I could not take notes.

I found a job in Coca Cola Company in New Lambton. I worked there for two years and had some back problems and then I am on disability pension. My job in Coca kola was a physical job. They always sent me to the hard part. Sometimes I did overtime on Saturdays. Women at worked got together but because my English was
not good they behave me like a stupid person. They made fun of me. Sometimes somebody bought food the others but never asked me.

Later on I am doing some voluntary works in Community Counsellor, Red Cross in Newcastle and Multicultural Neighbourhood Centre in Broadmeadow and some ‘meals on wheels’ in Mater Hospital in Oncology Unit, counting wages and doing some statistics. I don’t have any children. All my family are in Poland. I just live by myself here. I got divorce a few months later after coming to Australia. I had bad experience at first when I came here.

My parents died because of stroke. My dad had stroke when he was 76. He was very active and worked on farm. The stroke took his speech. He could not say something. My father lived with stroke for three years. My mother was taking care of him at home. When my father died my mother got stroke for three years. My sister looked after my mom. My sister worked as architecture. I asked her to stop working and looks after mom. Later on my mom could not speak, as well. After my mom death my sister came here to visit me in 1991.

I do not have anyone here. Sometimes I get trouble when I am sick. When I had an accident and was at hospital sometimes people came to see other patients. No one came to see me. My heart was really very broken. I am always very determined. Sometimes I am very sick and in pain. But something in my head says I have to do, I have to, I have to do….everything because there is no one does it for me. It is not very easy.
In 2003, I had angiography and angioplasty and then went to rehabilitation section at John Hunter Hospital to learn about my condition with the other patients and learn how to cope with my situation.

When I was diagnosed with diabetes my blood glucose level was high. My doctor sent me for checking my blood glucose test. I am controlling my diabetes by diet and exercise. So far my diabetes is good. The diabetes does not affect me so much. I take everything easy.

When I was diagnosed with diabetes I was so devastated. I had mixed feelings. But it was not a surprise for me because my specialist a few years ago warned me to be careful about my food because she said that I am vulnerable to get high glucose level based on my blood glucose test. I was thinking how it can happen. When I was diagnosed with diabetes I was a little bit upset and it put me down. But later on I thought that I can do nothing. I put myself together. I put myself on diet. I changed my routines, and lifestyle, especially with food and eat small portions. *

I have not talked about diabetes with my family. I just talked about it with one of my neighbours. My sister is very sick and I try not to add on her problems.

I have no one here to help me. Just I should live by myself. I have a lady neighbour, she is 88. Sometimes she comes to have coffee with me. I have good neighbours here. My neighbour’s husband had diabetes and she cooked for him and he passed away.
After being diagnosed with diabetes my doctor sent me to the diabetes classes to get idea how to cope with this disease. It was nearly two months since I was diagnosed with diabetes until attending diabetes classes. It took time to make an appointment. I was a little bit worried because I wanted to go to the classes earlier and get some information about food, which food is good or not good for diabetes and fat.

Diabetes Nurse Educators and Dieticians are very kind and helpful. I learn to have a small machine to check my blood glucose level. Sometimes I check my blood glucose level four times a day in different times before lunch and two hours after the lunch. Sometimes I check my blood glucose level before breakfast and two hours after that. I checked my blood glucose level today before lunch it was 6.1.

I finished diabetes classes. Especially I learned about foods. It is very important and how much you can take it. Eat small portions. I enjoyed all parts of the classes because always I have learned something new. The classes gave me some idea how to cope with diabetes. I learned about foods, portions, eating on time, shopping and label reading. I think it was enough to learn but if I need more information I will ask them. Even sometimes after the classes I asked them my questions because sometimes the problem is related to my English because most of the participants of the diabetes classes are Australian and they know what the educator says.

After attending in diabetes classes I understood that I should change my diet, eat in different times and I have to eat regular. I should be careful what sort of food I have to eat,
eat in small portions and eat low GI food to takes time to digest. Before attending the diabetes classes I did not eat fat and I am the same now. For my breakfast I normally have oats, bulgur, almond, walnuts and soymilk or sometimes different types of milk in it. I hate skim milk especially in coffee. Soymilk is very good. I heard that soymilk is not good because it has some ingredients which stop digestion, but I am not sure about it. For lunch I have hot meals. Sometimes I have chicken breast or fry something a little bit of olive oil. I eat some pieces of bread. I put low saturated fat margarine, and sometimes avocado on that.

I think my diet is the same as what I have eaten for my heart. I should be careful about saturated fat and triglyceride because it is still high. **I could cut down my sweets.**

**Before I ate so much and it wasn’t so good.** I changed my food and eat it on time. I just used to my diet and diabetes to cope with my feelings. I think I have to do it.

I found that Brazil nuts decrease my heart problem. **I bought it. It is in the kitchen. I can show you my nuts.** I use bulgur because it has lots of fibre. I eat almond and hazelnut. I found them in health food shop. My sister told me that almond is good for my digestion and immune system. The pumpkin seeds are very good. I use lots of garlic. When I fry something I use garlic. **I eat low sugar yogurt, less cakes. Sometimes I like to eat good coffee and soft cakes.**
When I go shopping I look at the labels and read it especially about sugar level and carbohydrates, saturated fat and fibres. I am conscious about sweets, cakes and biscuits. I should be careful about them. I don’t buy cakes. **The biscuits do not have much fat.**

**Sometimes I eat processed foods and sometimes I eat chicken liver.** Sometimes I heard that liver is very good because it has some vitamins. **Sometimes I buy diabetic foods but you cannot trust the labels.** I bought avocado margarine and it does not have much fat as the other margarines. It is good. Avocado and macadamia are very good. **Sometimes I eat cheese. My friend bought me this cheese.** It does not have so much cholesterol. I think this is good. **I found that cheddar cheese is very good.** Sometimes they advertise something and I think they are just commercial to say that it is good and make others to buy it. I think everything is the same and they just changed the labels. That’s it.

I cannot trust the packages food labels. Sometimes a label says that it does not have much saturated fat but still it has it. When the manufacture specialist tests it, he will discover that it has too much fat in it.

Sometimes when I go shopping sweets are very attractive and I have some temptation about them. I like to buy white bread and some butter, nothing more. But butter is so fatty and I have to be careful. Sometimes I buy dark chocolates. Chocolates are good for you.

I do some exercise since my heart problem. I do some physical fitness with my arm and something lifting. I am using two water bottles for lifting. I do exercise every morning in
my bed because I had a car accident in my right hip in 1999. I had problem with my broken pelvis. I used to walk before but now I face lots of problems with my right knee. I cannot move it properly because of arthritis, especially my back. I used to walk to university and Birmingham Gardens, Jesmond and Wallsend and returned home. It took me two hours. Now I just walk around the lake in Warabrook. But not so much as I have a knee problem, now.

I think I put on a little bit weight. Maybe it is winter and I am not walking every morning. Every morning, I do some exercise, have shower and I eat my breakfast and then I feel different. After doing some exercises I have better appetite and eat healthier and more energetic foods. Then I can do something. But when I stay home I am not very good. I don’t know. I feel some pain in my knee.

I learn about diabetes through books, magazines, television and diabetes classes. I have read lots of books. Sometimes I am reading some books about prevention of disease and they give me some idea. I bought some of them and sometimes my friends give me those books. Sometimes I read general magazines and they have some healthy points. I bought some medical terminology books and even sent some of my medical books for my mom in Poland. On radio I could hear something good especially something about medical issues. I read sometimes magazines, books and bulletins and learn something about prevention. For example, watermelon and blueberry are very good. I have a folder here which its name is ‘Health’. It contents of doctor’s copies and the result my tests in it.