

Older women and chronic illness: Learning to live with diabetes

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The first author, Ms Adili, is a nursing PhD candidate at the University of Newcastle. This paper is a part of her PhD studies. She has started her studies in July 2007. She has some experience to work and research with people with chronic illness especially diabetes. The second and the third authors, Prof Higgins and Prof Koch, are Ms Adili's supervisors. They are professors of Nursing at the University of Newcastle. Prof Higgins is experienced in older people's research and Prof Koch is experienced in the participatory action research.

ABSTRACT

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 focused on researching with people living with, type 2 diabetes. Although type 2 diabetes has been well researched over the years, particularly from a medical focus, there were, to date, few studies that explored what happens when a person was first diagnosed. It had been observed that when people were diagnosed with diabetes they must dramatically modify their everyday lives, but the way in which these changes take place had not been studied. More importantly, what could be learnt researching with people as they took the results of a chronic condition into their lives had not been studied. The aim of this study was to explore how older women learnt to live with diabetes during the first year post diagnosis.

This study was a qualitative study, participatory action research (PAR). The participants of this study were eleven women who were newly diagnosed with diabetes and their family members/friends where agreed. The participants were recruited from the participants of the diabetes classes of the Hunter New England NSW Health. One to one interviews were used over a twelve month period from December 2008 until the April 2010. The participants were also invited to share their learning with each other in the PAR group meetings for six months. Data generation and analysis were guided by Stringer (2000) 'Look, think and act' framework and Koch and Kralik's (2006) storytelling approach.

The findings of this study suggested that the women learnt to manage their condition in a multitude of different ways in accordance with their readiness and capacity to learn. Over time, following the initial formal diabetes classes, the women seemed to acquire greater understanding of their condition motivated by curiosity, trial and error, and from their own readings, partners, friends and relatives understandings and to some extent trial and error. During the PAR group meetings the women learnt from each other and

shared their learning with each other. The women learnt how they could overcome to their feeling post diagnosis, changing their eating and cooking habits, doing more exercise and checking their blood sugar level. Having support from the family/friends was an important factor in the women's learning process.

During the group meetings, the women suggested some reform strategies to the health care professionals to improve the diabetes classes and services for the future people with diabetes. These reform strategies could be such as; providing short diabetes classes, diabetes recap classes, diabetes support group and introducing the suitable books for type 2 diabetes with diet and exercise control. The state of readiness was an important factor during the diabetes learning journey. The women suggested the health care professionals to consider the people's readiness before starting any training to the people who are newly diagnosed with diabetes.

Key words: older women, chronic illness, learning, diabetes, participatory action research

I. INTRODUCTION

The World Health Organization (WHO) produced an "Innovative Care for the Chronic Conditions (ICCC) framework" in 2002 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 are articulated as having a focus on equity and social justice in health care practice, health promotion and working with clients and community. These principles were appealing to this researcher particularly as they sanction research with participants, and in this study, allowed me to research with the participants "learning to live with" a chronic condition.

Whilst there were 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 focused on researching with people living with, diabetes. Although diabetes had been well researched over the years, particularly from a medical focus, there were, to date, few studies that explored what happened when a person was first diagnosed. It had been observed that when people were diagnosed with diabetes they must dramatically modify their everyday lives, but the way in which these changes took place (or may not take place) had not been studied. More importantly, what could be learned researching with people as they took the results of a chronic condition into their lives had not been studied. In line with PHC principles, another question to be answered was how health care professionals could improve their practice and created environments where newly diagnosed people could be facilitated to learn to live with a chronic illness and thrive.

Before I could create environments in which people could thrive, I needed to understand what happened when people were first diagnosed. It was necessary to research with participants for the subsequent year post diagnosis (the longitudinal arm of this study). In the "Participatory Action Research" (PAR) study proposed here, this meant the researcher would walk alongside participants for at least one year, to explore what happened in their lives as they learnt to live with diabetes, to explore what happened in the context of their family and to observe changes in their immediate environments.

The participants for this study were the women who were newly diagnosed with diabetes. In this inquiry I built relationships with newly diagnosed women through one to one interviews, and overtime, and recruited the family members who were willing to talk with me. I observed the way in which women learnt to incorporate this chronic condition into their lives and the way in which their learning occurred. In discussion with each woman/family, I invited the participants to share their learning in a participant's group, if they desired to do so. Utilising PAR, group meetings were be facilitated by me. The health care professionals were informed about the reform strategies which were suggested by the women.

II. CONTEXT

Both the World Health Organisation (WHO) and International Diabetes Federation (IDF) (2008) define the diabetes pandemic as a “growing epidemic” in developing as well as industrialised countries. According to the WHO, about 180 million people lived with diabetes around the world in 2005. It is anticipated that this figure will increase to 366 million in 2030.

Australia is not exempt from high rate of diabetes. Recent investigation (Dunstan et al., 2002) indicates that 7.4% people over 25 years have diabetes type 2 in Australia. However, these are only the reported cases and it is probable that there are more people who are not yet diagnosed with diabetes. In Australia the statistics given predict that the 941000 Australians diagnosed in 2000 will increase to 1,673,000 by 2030. Diabetes is a health issue which increasingly affects not only young people, but also older ones. 2 – 4 % of the Western population have diabetes. It is predicted that more than 75% of diabetic people have diabetes type two. Around 10% of people older than 25% had diabetes. The study underlines a very important point, that the prevalence of the condition is not equally distributed among age groups, but increases with age. It is probable that 20 % of older people who are 60 or more have diabetes. The people with diabetes type 2 have been increasing threefold within the last 20 years (Dunstan et al., 2002).

Clearly these statistics are alarming and it is important to focus first on prevention and secondly on the reduction of complications. In the discussion on complications arising from diabetes, key national and international, such as Diabetes Australia (2008) and IDF (2008) have reported on the high rates of chronic complications and their consequences among people living with diabetes.

The literature suggests that people living with chronic conditions can adjust, adapt and make their lives more manageable (Koch et al, 2001). Certainly governments emphasise self-management in regard to living with diabetes as crucial (Commonwealth 2000). Self-management programmes could empower people and improve the quality of their lives (Koch et al., 2004). People living with chronic conditions are the prime health concern of the 21st century (Kralik et al., 2001). Chronic illness self-management is the most important health focus in Australia (Commonwealth Health, 2000).

The efficacy of self-management programs in changing behaviour and improving health outcomes for people with chronic illnesses is well established (Gibson et al.2003; Lorig 2003; Wagner et al. 2005; Groves et al. 2005). In USA, Lorig initiated a model for managing chronic conditions, specifically, arthritis. The Lorig (1998) program has taken hold across the world and is now used to address other chronic conditions. It takes six-weeks to be trained in managing this condition in the USA and is related to enhancing self-efficacy and changing behaviours. The fundamental of this course is its use of peer groups and it's the focus of the “learner” and “teacher” method.

Whilst diabetes education programs abound and there is a major focus on treatment compliance and medical self-management, I do not know what happens when people are newly diagnosed with diabetes in terms of adjustments made, challenges overcome and decisions about the best way to manage the self. When women are newly diagnosed with diabetes it is not known how they will deal with this new condition in their lives. Many people ‘move on’ and learn to take the results of the chronic condition into their lives (Koch and Kralik 2002) but there are no research studies which have involved participants longitudinally to explore what happens during this newly diagnosed phase and its aftermath. It is important to explore what is learned and how learning is facilitated as participants incorporate (or not) the consequences of living with diabetes and subsequent changes in their lives. Therefore this study focuses on what can be learned from a PAR study with older women newly diagnosed with diabetes.

Moreover, I know that it is likely that a new diagnosis of diabetes could impact on the person’s family, but these relationships have not been studied in depth. When a person learns to live with the consequences of a chronic condition, it does not just affect the individual but it probably also influences the other family members. This study presents an opportunity to research alongside the person newly diagnosed and their family to explore their roles. Although I may assume that a woman’s family would be affected by this new

diagnosis this has to be confirmed by the research study. Further it could not be assumed that all women would have supportive families.

In this study I recruited the older women who were the clients of the Diabetes Clinic in the Newcastle metropolitan area of Hunter New England (HNE) NSW Health. The diabetes service to which women had been referred holds diabetes training classes for three sessions. Classes were conducted by diabetes nurse educators, dieticians and podiatrists from this service. Women attending this service had access to these classes. What happened after these diabetes classes in terms of their private lives such as; fulfilling their familial or social roles, managing emotional issues, shopping, cooking and communication, issues which were crucial for people who were newly diagnosed, had not been studied. Most importantly it would be interesting to observe the way women learn to self-manage this chronic condition.

Being diagnosed with diabetes was not just a “shock” for the older woman but it involved their families as well. Not all families had the same reaction to older women with diabetes. Some families could support older women at home. Some women may not have families to support them. Therefore, it was interesting to discover the role of the family, or extended family, in regard to the women’s learning to live with diabetes.

I know that gender responses to living with chronic illnesses vary (Kralik and Koch 2002; Couteney et al, 2000; Ahmed et al, 2000). In Koch et al’s (2000) study of men living with diabetes, the participants provided an outline of the PAR groups and the result of this study showed that men could live with their conditions. They may question their self-esteem and sense of masculinity, however, as there was a general idea that men should control everything. In contrast, another research by Koch et al (1999) demonstrated that women did not have a normal life because they also had to change their lives in ways such as; the style of cooking and general daily life. It was clear that the men and the women respond to illness differently, but there were not enough studies to describe whether there was difference in their story telling and how they perceived their lives.

There is an agreement that women follow their health problems more than men (Australian Bureau of Statistics, 2002; Newman, 2006; Courtenay, 2002; Hudson, 2007; Denner, 2004; Nocross et al, 1996) while the men are more involved of their work and social commitments and do not take their minor medical issues very seriously until faced by a critical situation such as cancer or a condition which prevents them from working. Kralik and Koch (2002) conducted several studies with men and women in separate groups. Findings show that they dealt with diabetes and other chronic conditions quite differently and they argued the importance of considering women’s health issues using a PAR approach as this gives them a “voice” to talk about their particular issues.

The previous studies have given experiential snapshots of learning to live with diabetes; in contrast, I built close relationships with the participants and in collaboration with them explored their experiences over time as they managed their lives. Involvement of the family was rare in research studies. I invited the family members/friends to share their experiences so that their role was investigated. Insight about learning was shared within the PAR group meetings. In this study I provided the women’s suggestions to the health care professionals to reform in health care practice.

III. LITERATURE REVIEW

The research question was: How did older women, who were newly diagnosed with diabetes, learn to live with their condition” in the first year post diagnosis? This review attempted to answer the question from the available literature. A Google Advanced Scholar search and some nursing/health data bases such as; CINAHL and Pubmed were used to search for research papers, using the terms “living with a chronic condition”. The search contained more than 1080 papers and book chapters. I focussed on recent papers, 2000-2008. However some studies such as; Lorig et al, 1998; Baily, 1996; Charmaz, 1983; Taylor et al, 1997, were seminal works in chronic illness research so these were also included in the review. I did not select irrelevant papers such as; dealing with children, as the participants were the older women. I reviewed

more than 100 papers with the research question in mind. Moreover, I read current textbooks and several PhD theses. I wanted to read about how people learn to live with a chronic illness.

The main points to address in this literature review in relation to women were the ways women learnt to live with diabetes including; *learning to live with chronic condition, Learning to change a chronic, learning and storytelling, The process of transition and learning, Chronic condition self-management, Diabetes self-management, Chronic condition and family support, and the impact of gender on health seeking behaviours.*

IV. LEARNING TO LIVE WITH CHRONIC CONDITION

Although a chronic condition is a constant situation, it can be manageable and people can adapt and empower themselves to live with it (Kralik et al, 2004; Charmaz 1983, 2000; Lorig et al, 1998).

Living with a chronic condition can influence all parts of human life (Charmaz, 2002, 2000; Morse, 1997; Bury, 2001), and interfere with routine life as it was prior the illness. Interference in life situations once a chronic condition has taken hold are, life style, fulfilling familial and social roles, social isolation, fatigue often described as depression (Jenkin, Koch and Kralik 2004), feeling as a burden to the society or family (Ohman et al, 2003; Charmaz 2000).

In addition, Bury (2001) believes that a chronic condition is a “Biological disagreement” by which he means that the body requires changes in biography and self-conception and that the body is disturbed by a new situation manifesting as a chronic condition. Besides, Toombs (1995) added to Bury’s statement and identified that when a chronic condition happens both body and self are involved in it.

Kralik & Koch (2003) identified that people who live with chronic conditions learn to live with their new situations by referring to their previous experiences and through trial and error. According to Ohman et al (2003) some people have the experience of the “Body as a Hindrance”, which means that they perceive the body as weak, hindered by pain and constrained by a loss of independence and “being alone in illness”.

Self-help groups can provide a great role in their learning. It is suggested that people learn to live with their new situation from others with the same condition (Bonimi, 2002). This has the effect of preventing them from being overwhelmed by the situation, therefore, giving them an opportunity of feeling better rather than depressed and they may return to their ordinary lives, although changed by their diagnosis.

As part of a group, they communicate with other people and are not isolated. They learn to live in a new situation. Moreover, studies by Delmar et al, (2005), McCracken (1997), Shaul MP (1997) suggest that people who experience chronic conditions learn to become aware of and accept their situation and try to provide a balance in their normal lives, which at the time of their diagnosis may not have seemed possible.

It is interesting to note that some people maintain a positive attitude, despite a diagnosis of a chronic condition. They remember their former wellbeing and capabilities and as a result feel healthier, while accommodating to the reality of day to day coping with their condition, thereby minimising their perception of illness, and maximising their well being and enjoying life (Corbin et al, 2003).

In contrast, some people are not happy with living with a chronic condition and become angry about their new situation and it takes time to return to their ordinary lives (Aldrich et at, 2008) if they ever do.

According to Paterson et al (2001), Thorne et al (2003, 2000), people with chronic conditions are empowered to make further decisions about their lives and compliance with medical treatment and maintaining as much normalcy as possible in their lives and learn to “listen to the body”.

A. Learning to change when living with a chronic condition

Most of studies agree that people with chronic conditions gain benefit and gather useful information about accommodating to and managing their lives from peer group, health care providers, or trial and error (Wagner et al, 2001; Wooley et al, 1978; Bonomi et al, 2002; Paterson 2001; Glasgow et al, 2002; Lorig et al, 2003). Kralik et al (2003) demonstrated that people with chronic conditions make changes in their daily lives through trial and error. They identify their limitations and focus on their abilities and cope with the new condition. Besides, Wagner et al (2001) believed that the business of ‘people change’ is increasing. People change their lives to gain a better ‘quality of life’ by addressing their anxieties and depression, adjusting their lifestyles, adopting or accepting helpful medical regimens and increasing their general physical, psychosocial, and social well being. Lorig et al (2003) agreed with Wagner and considered other elements in adopting life changes such as, learning to manage personal roles, problem solving skills, decision making, action planning, and self-tailoring of accommodation strategies, as being important to general health. In contrast, Wooley et al (1978) placed greater emphasis on the social element of adaptation to chronic conditions, behaviour modification methods, social skills training and family support and stated that satisfactory outcomes are possible and that participants are still capable for finding joy in life, despite their illness experience. I believe that people who “live with chronic conditions” require adjustment to their new situation and learn to return to a sense of ordinariness in life. It could be possible to learn from the peers, friends, family, mass media and health care professionals.

Bonomi et al (2002) however pointed to the link between community resources and people engaging in life changing behaviours such as making suitable decisions, and managing their own condition well. Paterson (2001) also mentioned the role of the environment for changing the illness experience to one which has a “wellness foreground”. She attempts to develop personal skills through a supportive environment and addressing the feeling of ‘victimisation’ often associated with a diagnosis of a chronic condition, stressing the individual’s capacity for self management and empowerment even in such a situation. Bidaut-Russell et al (2002) examined collaborative methods of change and self management in chronic condition and illustrated that changes could be ‘person centred’ rather than medical staff-centred. They did not dictate that ‘patients’ follow strict plans but rather they suggested. “Let’s try out something different and see how it works”, and provided some community resources, and information.

B. Learning and story telling

It is claimed that people who experience illness benefit when given a voice and when they are able to express their concerns through storytelling, or narrative (Hurwitz, 2000; DasGupta, 2003; Greenhalgh, 1999; Charon, 2001; Ironside, 2003; Diekelmann, 2001; Gadsow, 1999; Skott, 2001; Benner, 1991; Parker et al, 1992; Nehls, 1995; May et al, 1997; Bailey, 2002, 1996; Ironside, 2003; Charmaz, 2002; Frank, 2000). Story telling is a central facet of social life and is a means through which people establish and maintain their identities and life stories: human beings live their stories. It ought to be recognised by clinicians that what people present are their rendition of events, rather than merely ‘something to say’: Story telling deals with identity and self (Hyden, 1997). Narrative has a specific role in chronic illness for demonstrating people’s situation and how they learn to deal with their issues in their lives. A person’s identity will be changed through a diagnosis of any illnesses, such as diabetes, and storytelling has a crucial role in helping people to make sense of their new lives and accommodating to a radically changed life and expectations (DasGupta, 2003).

Kleinman (1988) believes that narrative is also a chance to give a voice to an individual’s suffering, while Frank (1995) added to Kleinman’s theory by saying that story telling is not only the way for revealing suffering but by exercising their voices people are able to articulate their experiences apart from illness and they have a good opportunity to discuss and negotiate their life and illness. The narrative may take various shapes, such as; just illness, illness events or illness experience and it may be told with the voices of people with a chronic condition, their family and the health care providers. It may be recorded in oral or written forms.

Moreover, Charon (2001) and Diekelmann (2001) point out that story telling is an important part of solving issues which people face. It is a means of making sense out of one's world, of 'reality checking' with others, and has had a role in social cohesion since humans first used language. It is a universal way of transmitting information. Narrative plays an essential role in improving the lives of people "with a chronic situation", in communication with their families, medical staff with whom they collaborate and in optimising their health and in expressing their feelings and experiences (Bailey, 1996).

Benner (1991) maintains that it is possible for people to lose their identity, their essential 'sense of self' when diagnosed with a disease, particularly one that involves a chronic condition, and how they engage with their 'new self' has important cultural ramifications, which must be seriously considered. There is a consensus that through the use of narrative, people attempt to change their worlds, including their individual, familial, work and social worlds (Koch et al, 2006; Hyden, 1997; Kleinman, 1988; Frank, 2000). I would like to research with people with a chronic condition and invite them to have a voice and share their learning with me and other participants.

C. The process of transition and learning

There are various studies which focus on the transformative theory of transition from health to the process of change to live with a chronic situation (Shaul, 1997; Kralik, 2002; Kralik et al, 2005; Kralik et al, 2006; Kralik et al, 2003; Visentin et al, 2006; Mezirow, 1991; Taylor, 1997; Pea, 1994; Mezirow, 2000, 1997).

According to Kralik et al (2006), transition describes the way people respond to change from one status to another. Transition is an important phase in living with chronic conditions, as it denotes the recognition of a change in the life of the person from well, to ill. There is an agreement that changes in any aspect of life effects others: developmental, personal, relational, situational, and social change, and that people generally adapt to their new situation. Although all changes involve transition from one state to another, not all transitions are of major importance. The transition under consideration here has a major impact on future life expectancy, and is therefore to be considered of vital importance. Time is a significant factor in transitional stages, which Kralik has delineated as a process having four phases (Kralik et al., 2006).

Kralik (2007) suggested that these phases in the transition of acceptance of a chronic illness are; "familiar life, the ending, in limbo, becoming ordinary again". In the 'familiar life' phase, people take for granted their health and life paths, are familiar with their roles and expectations in life. With a diagnosis of a disease likely to be chronic, however, in 'the ending' phase people will pass their previous lives and maybe have some fears related to losing their former lives. "Limbo" is entered. People confront this period differently, depending on their learned coping strategies. During the period "in limbo" they move between the past and the future, in a present filled with questions and the necessity of gathering information while accommodating to changed life demands. Over time, as familiarity with the new situation is established through the integration of a changed way of knowing oneself, new routines learned and different dreams are sought, a return to "the ordinary" is eventually found. Information delivered during the "limbo" phase may not be well retained, and must be re-iterated as "ordinariness" is accepted. Kralik (2002) states that transition from the previous life to the new situation, and gaining ordinariness, requires support.

Mezirow (1997) expressed the view that transformative learning is "a change in a frame of someone's idea" or an epistemological change, which is related to cognitive and emotional elements. He mentioned communicative learning and a problem solving approach in this theory. Some of the most important components of transformation, he stated, similar to Kralik and Koch, are self-reflection, social and cultural issues. Taylor (1997) agreed with Mezirow's idea, however, and argued to broaden the theory of transformation to encompass the nature of facilitation in this process, and lessen the emphasis on critical reflections. Moreover, he mentioned the role of culture in the transformative processes. I agree with Kralik et al (2006, 2003) that most people will pass through these transformative phases until a sense of "ordinariness" is regained.

D. Chronic condition self-management

Many studies have focused on self-management in chronic conditions, expressing various points of view from around the world (Lorig et al, 2006; Paterson et al, 2001; Koch et al, 2004; Kralik et al, 2004; Wright et al, 2003, Taylor, 2001).

According to the Lorig et al (2006), every self-management process involves:

- a. Engaging with the results of the illness.
- b. Learning to make decisions and find self-esteem and the communication between medical people and the “patient”, that is, the person who is afflicted by the disease.
- c. Medical staffs have responsibility for the medical treatment of the disease and the patients should just take responsibility for their daily lives.

Chodosh et al (2005) and Creer et al (2006, 2005) have devised another self-management model, suggesting that it is a ‘systematic intervention for their (the individuals) self monitoring (of symptoms or of physiological process) or decision making (managing the disease or its impact through self-monitoring)’ which has some similarities with Paterson’s (2001) idea. Francis et al (2007) have applied Lorig’s self-management model and provided the process of planning, training and support in their self-management study. The literature (Koch et al, 2004, 2002; Kralik et al, 2007; Lorig et al, 2006; Frendin, 2003; Holman & Lorig 2004; Thorne & Paterson, 2003, 2001; Holman, 2005; Holman & Lorig, 2004) also explores the usefulness of medical treatment and compliance with it. While the different studies deal with medical education, the ‘self’ in self-management has been excluded.

According to the Lorig and Holman (1998) “self management model”, a model adopted in the controlling of pain, making decisions, decreasing the number of visits to doctors and having an enjoyable life. It is exceptional in that there is a focus on collaborating with the person who is ill. ‘The Lorig Programme’ has taken hold across the world and is related to managing arthritis. Its focus is related to changing behaviour and modifying self efficacy. It contains a group model of learning. Lorig and Holman made an effort to apply this programme for all chronic conditions. They say that it is based on “medical, role and emotional management”. It requires some skills such as; “problem solving, decision making and using resources”

Moreover, the motivation of people to attend self-management programs and learning appropriate and effective decision making has been expressed by Anderson et al (1991) and Paterson et al (2001) as creating better illness and disease outcomes. Many studies, however, focused on self-management meaning and its long term consequences (Paterson et al, 2001; Thorne & Paterson, 2001).

Koch and Kralik (2004) demonstrated that self-management means strategies which may be used by people in taking action to normalise and manage their lives. Except for Koch et al, there are not many studies investigating ‘self-management’ of chronic conditions. My study will build on their work and addresses a gap in the research literature, in that *the way in which people adapt to and learn these strategies* has, as yet, not been studied.

In addition, Kralik et al (2004) describe the elements of self-management programs as being; understanding the limitations, using the accessible recourses, consideration of self-identity, making plans and learning prioritisation. With consideration to ‘self’ in the self-management process, I agree with Koch that valuing self-determination and the life experience of people “with chronic conditions” (Koch et al, 2004) is vital. Giving people a chance to have a voice in telling their stories to medical staff is crucial in order to encourage people to manage their lives around a chronic condition (Telford et al, 2006).

E. Diabetes self-management

There are different approaches to diabetes self-management (Paterson & Thorne, 2000; Funnell et al, 2008; Glasgow et al, 2002; Heisler, 2002; Kralik et al, 2001, 2000, 1999; Broom, 2003). According to

Throne et al (2001) an exploration of the definition of diabetes self-management includes attempts to balance physical and emotional aspects of life and prevent further problems. Paterson et al (2001) and Funnel et al (2008) agreed with Throne and emphasized the social and individual factors for diabetes self-management, whereas Heisler (2002) added another important factor which is peer support for successful management of diabetes. Sousa et al (2004), added that peoples' behaviours in everyday situations are impacted by their thoughts and the image of their personal competence. Furthermore, the combination of diabetes knowledge and social support, taken together, positively affects diabetes self-management. Enhancing an individual's knowledge of diabetes and facilitating social support (by way of a support group) may be a strategy which can promote better engagement in diabetes self management.

Glasgow et al (2002) focused more on patient education about diabetes management in order to establish self-management via different group sessions and classes.

Based on Koch and Kralik's studies (2004) there exists an understanding that diabetes self-management is crucial and it is also important to know how people live with diabetes.

Improving quality of life is possible when living with chronic illnesses through a constant process which includes being vigilant of bodily responses, careful planning and learning new approaches for life (Koch et al., 2004), all points with which I agree, and has observed in my clinical practice.

F. Chronic condition and family support

There are few studies which report on the role of family support in learning to live with diabetes. According to Wen et al (2004), by accessing family support "people with diabetes" can manage their illness better than those who do not and they are more motivated to learn to care for themselves. Epple et al (2003) emphasized familial help in managing diabetes and their study showed that active family support is significantly associated with control of triglyceride, cholesterol, and HbA(1c) levels. It has become apparent that the support of families and friends is an important factor in diabetes care, as those thus supported fare better than individuals living alone. The Wang et al (1996) study, goes on to say, that significant differences were found between a group with "family-plus-friend" support and a group without such support in relation to universal self-care among diabetic people. Moreover, Gallant et al (2007) demonstrated that family support in training sessions resulted in better medication use, diet, exercise management, appropriate decision making and coping with illness and the associated psychological accompaniments. Baanders et al (2007) however, stressed the negative effect of diabetes on family members, especially partners.

Judging by the literature, if people with diabetes have more support from their families they can learn and manage their illness better in comparison with people who have no such support. However, this assumption will be tested in this study.

G. Health seeking and gender

Gender differences in seeking health services, is a widespread issue around the world.

Galastro (2007) indicated that women's health seeking is increasing and men pay more attention to their work rather than investigating their health issues. On the other hand, in some non-Western countries there is still discrimination against women in accessing medical services and this discrimination in related to their gender, roles and power (Patterson, 2004).

There is an agreement that women follow their health problems more than men (Australian Bureau of Statistics, 2002; Newman, 2006; Courtenay, 2002; Hudson, 2007; Denner, 2004; Nocross et al, 1996; McCaughan et al, 2007; Mendoza, 2007) while men are more involved in their work and social commitments and do not take their minor medical issues very seriously until faced with a critical situation such as cancer or any conditions which prevents them from working.

The Australian National Health Survey in 2002 corroborated this information and showed that women were more likely to look after themselves when compared with men (81% women compared with 70.3% men). In addition it is believed that asking for help is easier for women than men and would like to solve their health concern and control their lives and men do not like to consult with medical staff about their health issues and would like to be assertive and do not care about their disease symptoms (Beringer, 2007; Broom, 2003; Evans et al., 2005; Ahmed et al, 2000; Oliffe, 2007).

However, Pritchard (2005) demonstrated that some women do not follow their health problems in regarding losing their job and they do not have flexible work environment for more medical treatment day off or afterwards they could lose their career because of disease stigma. Besides, Courtenay (2002, 2000) reported that in some societies men are more respectful as the masters and people who control the life and they are more referred to the health system.

Some factors influence women's health seeking such as; culture, age, familial and social roles and their work, accessing to the medical centres, affordability, financial issues(Doyal, 2001). Therefore women's response to the illness and their health seeking is so different than males and they have completely varied reactions and managing their situations. Moreover, Broom (1998) shaped that previous illness could affect the recent health problem and finding medical treatment. Kavanagh et al (2006) agreed with Broom but believes social environment is another important consideration. By social environment she means work, social contact with the other people and family relationship.

Therefore I explored the way in which women learn to 'manage' their illness post diagnosis, because according to the literature review, men and women have different reaction to the chronic illness and even their learning to live with their new condition.

V. PURPOSE OF THE STUDY

A. Overall aim

To explore with women ways in which they learn to live with diabetes.

B. Objectives

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 was happening in their lives and explored individual and family members learning processes since the woman's diagnosis with diabetes.
2. Using the 'look, think and act' PAR 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 was tracking points in her day to day life where she had learned a new strategy, or had an experience which she remembers, associated with a change in her attitude to her diabetes.
4. To invite the women and their families to join a PAR 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 was running concurrently to the individual interviews with the women and/or family conversations.
5. Share suggested reform strategies with the health care professionals. In the effort to create environments in which people could thrive, consider ways in which these

findings could be shared with the participants, families and the medical staff who deliver care.

VI. RESEARCH QUESTIONS

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

A. *Related questions are: change tense below*

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

VII. PLAN FOR DATA GENERATION

A. *Study design*

This study was a PAR which had focused on the ability of all people, as equals, to collaborate in researching their own life experiences. PAR has three operational characteristics: "look, think and act" but these occur in cycles and not always in this order. Moreover, researchers facilitate the participants' reflection about having a voice and telling their stories and helping them to help themselves (Koch et al., 2006).

The inquiry was collaborative whereby research participants occupy a central place as they were facilitated to explore their own situation, reflected and considered actions they could take to enhance self-management. Further, as a PAR group, the women set the discussion agenda to describe ways in which learning had occurred and decided how to share this new information with the health care professionals. In other words, the older women with type 2 diabetes researched, alongside the researchers of this study, in exploring how the women learnt to live with newly diagnosed diabetes. The PAR approach had strength as a method in that it allowed for the participants to collaboratively explored their life worlds.

VIII. GAINING ACCESS TO A HEALTH CARE SETTING AND POTENTIAL PARTICIPANTS

After ethics approval from the Hunter New England NSW Health and the University of Newcastle ethics committees and the safety clearance, the study was started to conduct. The setting of this study was the diabetes centre of the Hunter New England NSW Health service which was located in the metropolitan area of Newcastle. There were three diabetes classes in the diabetes centre which were running by the diabetes nurse educator and the dietician. The content of the classes was related to giving more information about diabetes, signs, symptoms, treatment, medical management, measuring blood sugar level, eating, cooking and foot care. Its focus was generally the medical management.

There was no opportunity for the participants to share how they were learning to live with their disease.

IX. RECRUITMENT OF THE PARTICIPANTS

According to the HNE NSW Health 1,966 people diagnosed with diabetes entered a program of education in 2005 and of this number 904 type 2 diabetes people were newly discovered.

A. Selection and or exclusion criteria

In consultation with our colleagues at HNE NSW Health I proposed to recruit the women when they were first diagnosed with diabetes.

Selection criteria:

1. Women attending the HNE NSW Health, Newcastle, diabetes clinic and were geographically located within the Newcastle area
2. Diagnosed with type 2 diabetes in the preceding six months
3. Aged 55 and over
4. Able to speak English
5. Able to understand the information sheet
6. and signed consent

Exclusion criteria:

- No serious mental health problem
- No physical disability, which would prevent free and easy communication and participation in interviews or the PAR group

Participants were recruited among the older women who were newly diagnosed with diabetes (less than six months) in the metropolitan area of the Hunter New England NSW Health.

With permission from the diabetes nurse educators during the second diabetes class, I provided a short information session (around two minutes) about the study and provided a package containing an information sheet about the study, a consent form with instructions regarding submission via a locked box which was clearly labelled and located in the diabetes education centre and self addressed and sealable envelope. The information sheet provided the details about the study including the eligibility criteria.

At the third diabetes classes, I reminded the participants if they were interested in participating in the study they should submit their expression of interest to the locked box 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, answer any questions and gain consent as appropriate.

Recruitment also included an invitation to the family members should the woman desire this. This was established once a relationship had been built with the woman as noted below. Family members were provided with an information letter about the study along with a letter of consent.

X. DATA GENERATION

A. Women

Eleven women were interviewed individually in their homes or other mutually agreed space such as their work place or backside of their cars. The purpose of the interviews was to gain an understanding of how the women learnt to live with diabetes. I explored the women's feelings, their response to diabetes, day to day issues such as; shopping, cooking and housework, and the way learning was occurring.

B. Family (join the conversations)

Once a relationship had been built with the women and where I had been a regular visitor to the women's homes, I invited other family members to participate, if they wished, in the conversations.

C. PAR group (women and their families)

After the individual interviews with the women and conversations with their families, they were invited to the PAR group meeting. The purpose was to share the women's learning with each other, focusing on knowing and understanding how the women learnt to live with their chronic condition, in the first twelve to eighteen months following the diagnosis of diabetes.

The PAR group meetings were held in Wallsend diabetes centre of HNE NSW Health as the venue that was mutually agreed with the participants and the researchers. The research team consists of the PhD candidate, and one of her supervisors, who was more expert in running the PAR group meetings, and helped to facilitate these meetings.

During each individual and group meeting the participants' dialogues was audio-recorded and analysed straight after each meeting. Feedback was provided before the next group meeting. Analysis of the transcripts was based on the "look, think, act" process associated with PAR.

D. The health care professionals

Finally after twelve to eighteen months a report was written and presented to the health care professionals of the HNE NSW Health service. This report contained the suggestions for the service improvement proposed by the women and their families to the health care providers such as; the diabetes nurse educators and the dieticians.

XI. DATA GENERATION AND ANALYSIS

There were five data sources:

1. Audio-recorded one to one interviews with eleven women over a period of twelve to eighteen months, where open-ended questions were answered by each woman. At the first interview the demographic and educational information was sought.
2. Audio-recorded family conversations over a period of three to six months
3. Audio-recorded PAR group meetings with the women and/or families for six months
4. Accumulated data from the above three sources reported and delivered to health care professionals at twelve to eighteen months
5. Researcher's reflective journal, maintained throughout the study and analysis period of twelve to eighteen months.

A. One to one Interviews

In depth interviews with participants was conducted in privacy in the participants' homes or other agreed venues. Guiding questions at the first few interviews were:

- Could you please let me know your age, medical problem/history, occupation, family situation, family support, and educational background?
- Could you please 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 did you think that was your family coping with these changes?

As researchers, I was not be in a position to provide information on diabetes, but I paid particular attention to questions raised by the women and instead I could help identify who might be able to answer the question such as; the diabetes nurse educator and the dietician. These first interviews were recorded,

transcribed and analysed by the PAR operational framework “look, think, act” prior to the meeting with the woman again. Whilst the feedback about the previous interview was given to the woman before the next conversation was commenced, subsequent interview questions built on the previous conversation and might include such questions as:

- Could you tell me what did you think about the feedback I had given you?
- Did you like to change in my record of the conversation’s main points?
- Could I discuss some of these points further?
- What would you like to let me know about your diabetes and life?
- What did you think helps you to come to understand your life with diabetes?
- Could you tell me how these changes impacted on your life?
- Could I talk about how you managed the changes in your life?
- Would you share with us what did you do to control your condition?
- How were you trained in these methods?
- What about services, what role had they played in your diabetes self management?
What could be improved?
- Could you please, tell me about something that you were most proud of in your management?
- How did you think that your family were coping while you were learning to live with this condition?
- Did you think that there anyone in the family who might like to talk with me?
- Did you talk about your diabetes with any of your friends, or the rest of your family?

Interviews were recorded and transcribed verbatim. Participants and their families were received feedback and their own story line. This story line was evolved as the participants absorbed the feedback, were encouraged to think about their situation and reflected on what had been learnt. The analysis framework was ‘look think and act’ from Stringer’s work (2000) and Koch and Kralik’s (2006) PAR text.

‘Looking’ meant defining and describing the situation; even the silence, body language and their gestures could have some meaning.

‘Thinking’ was related to discovering, analysing, and describing. It was accepted that each participant brings her construction to the condition. Data generation and analysis took place concurrently and before each meeting the participants’ were received the previous meeting feedback. This process was ongoing and participants confirmed the analysis.

‘Action’ was the development, implementation and evaluation of plans of action devised by the participants. The action could take place individually or by the group. Actions were assessed by eliciting from the participants the identification of what strategies/changes they had put in place. How they had identified their needs and resources, and what, they had done about that, and when the actions were taken.

B. Family conversations

After the first six months visiting the women and talking with them, if the family members were interested, I had a conversation with the women and asked them about their feeling as a family member of the participant, how they were involved in the woman’s adaptation to diabetes, what their issues were and concerns, and what barriers they had experienced, if any. These conversations continued if they were

interested. I gave the women a feedback and analysed their dialogue using the three principals of the PAR already outlined.

C. Participatory Action research (PAR) group meetings

In 2009-10, when ongoing interviews with women and conversations with families have been recorded and analysed, participants and their families will be asked to volunteer and attend PAR groups, to be facilitated by me, the PhD candidate, and assisted by my supervisors. The purpose of these PAR groups is for all the participants to share their learning experiences with each other, continue the learning journey and discuss what health care professionals might like to consider, to improve their practice.

PAR questions will be influenced by questions of the type 'look, think and act' (Koch et al., 2006). 'Looking' refers to the exploratory phase, in which participants will be asked to tell their stories about living with diabetes type 2. 'Thinking' is conducted when the researcher ask from the participants to describe his/her story: "what is occurring?" and "why the things are like this?" The 'action' phase will occur when participants are asked to think about aspects of their diabetes self-management that they are interested to modify or talk about with other people. In every PAR session, the facilitator will give a brief explanation of the research and help to define the 'norms' of communication in the PAR group. A document that will contain a preliminary analysis of individual interview data will be presented to the participants at the first PAR group meeting. Discussion will take place around each of the themes and validation of findings will be noted. In an effort to extend group discussion, the "look, think and act" principals are related to a cyclic phenomenon but it is not always linear. Over a period of approximately six months, the participants will attend 6 times to continue their discussion around how they learn to manage their lives I relation to diabetes every month. This cyclic method will motivate the participants to give their reflections and engage a structured way of examining them, provide experiential accounts of their situations, and explain their plans to solve their issues.

D. Report to the health care professionals

After finishing the individual and PAR groups, about twelve-eighteen months after commencement, I gave a report of the research to the medical staff.

E. Researcher's reflective journal

A reflective journal was maintained throughout the inquiry. An example of the researcher journaling was the observation and recording of the researcher's thoughts regarding the interviews and the research process. As soon as I left the interviewee or the group meeting I recorded our observations in the journal. I recorded how I thought the interview could be improved, which question gave us rich data, what I might do differently next time, what I thought the main learning points were, what strikes us as the most interesting aspect of the conversation, other family members I may have noticed in the background. I reviewed the literature again. Reflective journaling was important in PAR in order to monitor each step of the PAR approach in terms of the process and the progress. In addition, rigour was enhanced because nuances about the voices of the participants were noted as well as the reflections on what was happening.

XII. LIMITATIONS OF THE STUDY

Since the participants were recruited among the older people of the metropolitan area of the "Hunter New England NSW Health" the results was not possible to generalise to the all older people with diabetes in other health areas or around Australia. While a single study may not impact on the whole Australian health system, the outcomes of the research and the comments for changes to policy and practice for caring of the women who were recently diagnosed with diabetes was instructive.

XIII. OUTCOMES

A. *According to the individual interviews:*

Being diagnosed with diabetes was not the same for all women. Some of them they did not expect it and it was described as a 'shock', 'surprise', 'devastating', 'disappointment', as they did not know the cause of that and the same for their families. Just a few of them, Helen and Alison, (all of the mentioned names are fictions names) expected diabetes as they had family history of diabetes or because they were overweight and even they were informed before getting diabetes that if they did not look after themselves they would get diabetes. When they got diabetes they thought they were diagnosed as pre diabetes as they were just on diet and exercise control rather than tablet or insulin. But their doctors clarified that people could get type 2 diabetes and they could be just on diet and exercise control. At the beginning being diagnosed with diabetes it was not easy to cope with that and it took a while for women to cope with their feelings and take actions. However, Bella, Barbara, and Elizabeth took some actions straightaway as they accepted diabetes and they were attempting to manage it. Some women who had other chronic conditions, such as arthritis, asthma, cancer...could accept diabetes easier than others who never had a chronic illness. Elizabeth and Marlene could overcome their feelings as they heard that getting diabetes was better than cancer as they could control it. Some women such as Kathrin and Barbara realized that if they overcome their feelings they could take some actions which could prevent further problems. But it took a while for the other women to accept the fact and take some actions on board. Although some women could not overcome to their feelings straightaway, however, they made some aims and motivated them to move on.

Some of women, Barbara, Bella, Anna, and Elizabeth had good family or friend support and this support such as attending in diabetes classes with women, sympathy with them accept their diet and encourage them to keep going on their diet and exercise helped them to overcome to their feelings and diabetes management as an important factor. They believed that their condition did not affect their families. Some women had good support from their Dr and could talk about their situations with them. Some women had a good support from their friends and it helped them to keep going. Kathrin, Sara and Rose found some support from diabetes classes. Pam and Sara had cat. They believed that their cats were very good accompanies for them and did not let them feel lonely. However, although the rest of women did not have family or supportive family or friends they did their best to manage their diabetes.

Women learned from different resources such as; diabetes classes, Diabetes Australia magazine, books, internet, television and radio, relatives and friends. All of participants attended diabetes classes which were provided by Hunter New England NSW Health diabetic centre. They learned more about diabetes and diabetes management such as 'cooking, eating, doing exercise, label reading and controlling their blood sugar level. Some of the participants such as; Alison and Kathrin were working and they were busy and could not attend all diabetes classes. But they learned a lot from these classes. Diabetes classes were not the only way of our learning. They had learned about living with diabetes from 'Diabetes Australia's magazine', 'books', 'internet', 'relatives', 'friends', 'television' and 'radio'. Anna and Pam believed that it was not possible to learn everything from diabetes classes or books and they learned from their mistakes. Some of them such as Bella, Pam and Barbara believed that 'as time goes by' they got more used to living with diabetes and learned based on their needs. They got lots of information from different resources. However the most applicable ones were based on their own situations or issues in their lives. For example, Bella was not sure how to check her blood sugar level with glucometer at the beginning however she practiced to use it and then she was comfortable to check her blood sugar level. Pam had difficulty in counting the number of carbohydrates at the beginning. But gradually she learned how to count it from the diabetes classes resources and then she could count it herself. Some participants, Pam, Barbara, Katy, Kathrin and Alison, had other chronic conditions and they approached to diabetes learning the same as the other conditions as they had. For example, Alison and Katy were diagnosed with breast cancer last year and then they were survived from cancer and then they got strengths from their previous chronic condition. Kathrin had kidney problem, depression and high blood pressure and visited her doctor regularly therefore

she learned from her other chronic conditions to check her situation with her doctor, take her medications on time and look after herself. Then she did the same for her diabetes. She visited her doctor regularly, checked her blood sugar level and took her diabetes tablet on time. Some women like Helen and Anna learned from the others with diabetes such as their relatives or friends. Helen liked her self-learning and learned based on her needs. Elizabeth and Pam believed that they were not learning about diabetes per se. They were learning about healthy choices in their lives. They thought diabetes management was good for them as they learned to have healthy life style such as; doing exercise and watching what and how much they are eating which were good for everybody. Pam and Anna would like to learn by themselves from simplified books rather than asking from people. They were not question people as they believed that they were not very educated and they did not understand very technical medical terminology and jargons. They preferred to find the answer of their questions from simplified and informative resources such as books and magazines.

Learning process was not without challenges for women. They raised different issues from diabetes classes and their learning. Some of them such as; Anna and Katy did not like group classes and they preferred to learn individually. One of the challenges as it was raised it was related to understating the meaning of per serve. Almost all women believed that diabetes classes were very long and they could not absorb everything in three hours in each class or the number of participants in the class did not let them talk about their issues. Label reading¹ was not easy for all participants at the first time and it seemed that it was one of the biggest challenges in their learning. Besides sometimes labels were not reliable as the low fat foods had more sugar or vice versa. One of the other challenges for women was eating temptation and craving. They used different strategies such as; not buying unhealthy foods, skipping chocolates in the shops, finding healthy foods and be honest to themselves and reminding themselves that they did not need that particular unhealthy food to overcome with this issue. Some of the participants such as Bella, Barbara and Alison were good travellers and they were out of routines while they were travelling. However they did their best to choose proper foods and checked their blood sugar level. Women learned about diabetes management such as 'healthy eating', 'recipes', 'cooking', 'label reading', 'exercise', 'losing weight', and 'check their blood glucose level'. Healthy foods were described as low fat and carbohydrate foods. It was important for women to watch how much they were eating. According to diabetes classes they were allowed to have nine to ten carbohydrates per day. Therefore they ate certain amount of carbohydrates in each meal. They did not buy unhealthy foods such as; chocolates or foods which had high carbohydrates. Some women learned new recipes from diabetes classes, Diabetes Australia magazine, books and their relatives and friends. For example, Anna's sister-in-law had diabetes, as well. Therefore, Anna learned from sister-in-law some diabetes recipes. After being diagnosed with diabetes women learned to change their cooking style. They used less fat in their cooking and they were aware of using certain amount of carbohydrates in their diet. They cooked healthy vegetables. Women read label of packages carefully based on the diabetes classes' guidelines. They learned from diabetes classes to choose foods which they had low fat especially low saturated fat. As I mentioned earlier every fifteen grams of carbohydrates per serve meant one carbohydrate exchange. Therefore, women could look at packages and find low carbohydrate foods. Doing exercise was very important part of women's learning. They learned to walk or joining to exercise classes. Some women learned from Diabetes classes to walk regularly which could decrease their blood sugar level. Some women believed that by doing exercise and control their diet they could lose weight. They learned that losing weight was important in diabetes management as insulin could work better in their bodies. After being diagnosed with diabetes some women learned to check their blood sugar levels from diabetes classes. They believed that by checking their blood sugar level they could get idea about their body and its reactions to the foods and carbohydrates. After diagnosis with diabetes some women such as Pam, Bella, Helen, Anna, Katy, Alison, Elizabeth and Rose were checking their blood

¹. 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 gr of carbohydrates per serve in each package was counted as one carbohydrate exchange.

sugar level regularly to get insight about how their body was going. However, changes had different meaning for every single person. For instance some women such as Anna, Katy, Barbara, Bella, and Pam had arthritis and did exercise based on their level of movements.

Almost all of women mentioned that now they felt more relaxed than the beginning as they had learned to look after themselves. They believed that as they had learned how to look after themselves therefore they felt more settled down than before. They knew that how much they should eat and what sort of exercise they could do. They mentioned that during time whatever they learned from diabetes classes could find its place in their minds and then got clear for them. '...When I compare myself with the beginning being diagnosed with diabetes, I feel that I am more settled down, calm and get used to diabetes than before.' Some women such as Helen and Barbara did not like the idea of taking medications and insulin and this issue motivated them to keep going to look after themselves.

Some women had some strengths and proud in their lives which could be relevant to their diabetes management or generally in their lives. These strengths could be such as; losing weight, not eating unhealthy foods, doing exercise, getting driving licence, overcome to eating temptation and craving. All of women were proud of their actions and these points were good reminder to them that they could keep going on managing diabetes and living with that. Elizabeth, Alison, Kathrin, Rose and Barbara were proud of losing weight. Women gave some suggestions for women who are newly diagnosed with diabetes from their own experiences such as attending in diabetes classes, take advice from their doctor and dietician, do exercise and diet.

B. According to the group meetings:

During the first group meetings, the women talked about their feelings and what it was like for them at the beginning of being diagnosed with diabetes. Diabetes diagnosis feeling was different among the women. Some of them did not expect the diabetes diagnosis and it was described as a 'shock', 'surprise', 'devastating', 'disappointment', as they did not know the cause of that and the same for their families. Just a few of the women, Helen and Alison, expected diabetes as they had a family history of diabetes or because they were overweight and even they were informed before getting diabetes that if they did not look after themselves they would get diabetes. When they got diabetes they thought they were diagnosed as pre diabetes as they were just on diet and exercise control rather than tablet or insulin. But their doctors clarified that people could get type 2 diabetes and they could be just on diet and exercise control. I recognized that at the beginning being diagnosed with diabetes it was not easy for the women to cope with diabetes and it took a while for the women to cope with their feelings and take actions. However, Bella, Barbara, and Elizabeth took some actions straightaway as they accepted their diabetes and they were attempting to manage it. Some of the women who had other chronic conditions, such as arthritis, asthma, cancer...could accept their diabetes easier in comparison with others who never had a chronic illness. Some of the women, Elizabeth and Rose, could overcome to their feelings as they heard that getting diabetes was better than cancer as they could control over and manage it by diet, exercise, losing weight and medications. Some of the women such as; Kathrin and Barbara realized that if they overcome to their feelings and take some actions which could prevent further problems such as taking insulin or losing their eyes. But it took a while for the other women to accept their diabetes diagnosis and then manage it. Although some of the women could not overcome to their feelings immediately after being diagnosed with diabetes, however, they made some plans to motivate them to move on.

During the group meetings, the women mentioned that having the supportive family/friends could be very helpful to overcome to their feelings and keep going on the diabetes management. In other words, support was one of the main motivator for the diabetes management among the women. Some of the women, Barbara, Bella, Anna, and Elizabeth had support from their family or a good friend. This support was such as; attending in the diabetes classes with the women, driving them to the group meetings and having sympathy with the women. The women believed that their condition did not affect their families. It was interesting that some of the women had good support from their doctors and could talk about their

situations with their doctors. During the group meetings, some of the women indicated that they had a good support from their friends and it helped them to keep going. It was interesting that Kathrin, Sara and Rose found some support from the diabetes classes and the participants of the classes. Women's support was not limited to the humans. Pam and Sara had cat. They believed that their cats were very supportive and they did not feel lonely with their cats. However, some of the women did not have any supportive family or friends and it was hard to live with diabetes without having any support.

During the group meetings, the women mentioned that they had learned from different resources such as; diabetes classes, Diabetes Australia magazine, books, internet, television and radio, relatives and friends and the group meetings. All of the women attended the diabetes classes. The women learned more about diabetes and diabetes management such as 'cooking, eating, doing exercise, label reading, shopping and controlling their blood sugar level'. Some of the women such as; Alison and Kathrin, could not attend all diabetes classes as they were working fulltime and could not leave their work to attend the diabetes classes. The diabetes classes were not the only source of the women's learning. The women had learned about living with diabetes from 'Diabetes Australia's magazine', 'books', 'internet', 'relatives', 'friends', 'television' and 'radio' and the group meetings. Some of the women such as; Anna and Pam believed that it was not possible to learn everything from the diabetes classes or books and they learned from their mistakes. Some of the women such as; Bella, Pam and Barbara believed that 'as time goes by' they got more used to living with diabetes and learned based on their needs. For example, Bella was not sure how to check her blood sugar level with the glucometer at the beginning, however, she practiced to use it and then she was comfortable to check her blood sugar level. Pam had difficulty in counting the number of carbohydrates at the beginning of her diagnosis. But gradually Pam learned how to count it from the diabetes classes materials and then she could count it herself. Some of the women such as; Pam, Barbara, Katy, Kathrin and Alison, had other chronic conditions and they approached to their diabetes learning the same as the other conditions, as they had before. For example, Alison and Katy were diagnosed with breast cancer last year and then they were survived from cancer and then they got strengths from their previous chronic condition to manage their diabetes. Kathrin had kidney problem, depression and high blood pressure and visited her doctor regularly therefore she learned from her other chronic conditions to check her situation with her doctor checked her blood sugar level and took her diabetes tablet on time. Women were happy of the group meetings and they could learn some points such as; reading the labels, introducing low carbohydrates products, diabetes recipes, doing exercise and checking their bold sugar level. Besides Rose had a good contribution in the group and she brought dome diabetes and losing weight powders, low carbohydrate yogurt package, as well. Barbara, Bella and Pat shared their diabetes books and magazines with the group. After the first group meetings, women had some questions and I invited the diabetes nurse educator and the dietician to join to the groups for couple of minutes to answer the women's questions. These health care professionals talked about different issues about the diabetes management such as the meaning of type 2 diabetes, signs and symptoms of type 2 diabetes, the meaning of carbohydrates, low carbohydrate foods, counting the carbohydrate numbers in each food, how much food women were allowed to eat, exercise, medications, checking blood sugar level, reading the labels, diabetes tests and the role of support from the family/friend in the diabetes management. Katy learned some points about her medications from the diabetes nurse educator. During group meetings, Elizabeth and Pam believed that they were not learning about diabetes per se. They were learning about healthy choices in their lives. They thought that their diabetes management was good for them as they learned to have healthy life style such as doing exercise and watching what and how much they are eating which were good for everybody. Pam and Anna would like to learn by themselves from simplified books rather than asking their questions from people. They were not question people as they believed that they were not very educated and they did not understand very technical medical terminology and jargons. They preferred to find the answer of their questions from simplified and informative resources such as books and magazines.

During the group meetings, the women mentioned that the learning process was not without challenges. The women raised different issues from diabetes classes and their learning. Some of the women such as;

Anna and Katy, did not like the diabetes classes as there were lots of participants in the classes. The women preferred to learn individually. One of the learning challenges was related to understating the meaning of per serve. During the diabetes classes the women believed that the diabetes classes were very long and they could not absorb everything in three hours in each diabetes class. The number of the participants in the class did not let the women talk about their issues. The other issue which was raised from the group meetings was 'the state of readiness for learning'. The level of readiness to learn about the diabetes was not the same for all of the women. Some of the women such as; Rose, Helen and Sara, were in the shock phase of the diabetes diagnosis and they were not ready to lean about diabetes. Label reading was not easy for the women at the first time and it seemed that it was one of the biggest challenges in their learning. Besides sometimes labels were not reliable as the low fat foods had more sugar or vice versa. The other challenge for the women was their eating temptation and craving. They used different strategies such as; skipping the chocolates in the shops, finding the healthy foods, being honest to themselves and reminding themselves that they did not need that particular unhealthy food to overcome to their craving. The other challenge for the women for managing their diabetes was related to their trips or special occasions such as; Christmas and Easter holiday.

During the group meetings the women mentioned about their changes and actions such as 'healthy eating', 'recipes', 'cooking', 'label reading', 'shopping', 'exercise', 'losing weight', and 'check their blood glucose level' which I explain as follow. The women made some changes in their foods. They had healthy foods such as; low fat and low carbohydrate foods. It was important for the women to watch how much they were eating. Some of the women learned new recipes from the diabetes classes, Diabetes Australia magazine, books and their relatives, friends and each other. For example, Rose and Pam shared some diabetic and low GI recipes with the women in the group meetings. These recipes were confirmed with the diabetes nurse educator and the dietician and then I made a copy of them for the women in the group and shared the recipes with the women. After being diagnosed with diabetes the women learned to change their cooking style. The women used less fat in their cooking and they were aware of using certain amount of carbohydrates in their diet. The women mentioned that after attending group meetings, they could read the label of packages carefully based on the diabetes nurse educator advice and learnt from the other women in the groups. The women indicated that doing exercise was an important part of their learning in the group meetings. The women learnt to walk or join to the exercise classes. They learnt that walking regularly could decrease their blood sugar level. Bella bought a 'step-meter' and she introduced it to the women in the group to encourage them to walk more. Some of the women believed that by doing exercise and controlling their diet they could lose weight. The women learnt that losing weight was important in the diabetes management. Some of the women who did not check their blood sugar level before, they started to check their blood sugar level based on their learning in the group meetings. Some of the women such as; Pam, Rose and Katy started to do exercise and lose weight. However, changes had different meaning for every single person. For instance, some of the women such as Anna, Katy, Barbara, Bella, and Pam had arthritis and did exercise based on their level of movements.

The women believed that they felt more relaxed than the beginning of their diagnosis and more settled down than before. After a year post diagnosis, the women knew that how much they should eat and what sort of exercise they could do. They mentioned that during time whatever they learnt from the diabetes classes could find its place in their minds and then got clear for them. During group meeting, women were worried about their future of the diabetes management. They were worried about insulin injection and this issue motivated them to keep going to look after themselves. In fact they were worried about the future of the diabetes and how it would be.

During the group meetings, the women talked about their strengths and proud in their lives which could be relevant to their diabetes management or generally in their lives. These strengths could be such as; losing weight, not eating unhealthy foods, doing exercise, getting driving licence, overcome to eating temptation and craving and attending the group meetings. The women were proud of their actions and

these points were good reminder to them that they could keep going on managing diabetes and living with that. Elizabeth, Alison, Kathrin, Rose and Barbara were proud of losing weight.

During group meetings, the women gave some suggestions for the other women who were newly diagnosed with diabetes from their own experiences such as attending diabetes classes, take advice from their doctors and dietician, do exercise, control their diet and get support from the other women with diabetes.

During the group meetings the women suggested some points and I followed these issues with them. These issues were such as; shopping tour, support group, recap classes, diabetes kitchen, diet and exercise controlled diabetes books, diabetes recipes and diabetes shop. As I said earlier, during the first group meetings, the women suggested to attend 'a shopping tour' to learn more about reading the labels of the packages. I did my homework and found out that Diabetes Australia is running a 'Shopping Tour'. I participated one of these tours and shared its material with the women in the following group meeting. The women were looking for a diabetes support group. They found good friends in the group meetings and they were searching to know whether there were any other group meetings or not. I found a support group which was running by the Diabetes Australia. Some of the women such as Elizabeth, Pam, Bella and Barbara believed that they could not absorb all of the information from the diabetes classes and they suggested 'recap classes'. These recap classes could be the summary of the diabetes classes in regular basis such as every couple of months. I passed this request to the diabetes nurse educator and the dietician to consider it. The other idea which came from the group meetings was related to the diabetic kitchen. Women mentioned that there were not any diabetic restaurants in Newcastle and the normal foods at the restaurants were full of carbohydrates and fat. The women in the group meetings mentioned that they bought lots of diabetic books. However, most of them did not have enough information about type 2 diabetes and particularly about managing type 2 diabetes with controlling diet and exercise. I searched to find the required books and then I got a list of books from the Diabetes Australia and then I shared this list with the women in the group meetings. I let the diabetes nurse educator and the dietician know about the women's request, as well. I noticed that during group meetings, the women were interested in learning more diabetes recipes and they shared their recipes with each other. Before sharing these recipes, I checked the appropriateness of the recipes from the number of carbohydrates point of view with the dietician and the diabetes nurse educator and then provided a copy of the recipes for the women. Some of the women believed that Diabetes Australia's shop was located in the Hunter Street the city centre of Newcastle and it was not easy for the women to access there because of limited and the parking was not free. They wish there was a diabetes shop somewhere else instead of its location in the city centre of Newcastle.

XIV. SUMMARY

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 focused on researching with people living with, type 2 diabetes. Although type 2 diabetes has been well researched over the years, particularly from a medical focus, there were, to date, few studies that explored what happens when a person was first diagnosed. It had been observed that when people were diagnosed with diabetes they must dramatically modify their everyday lives, but the way in which these changes take place had not been studied. More importantly, what could be learnt researching with people as they took the results of a chronic condition into their lives had not been studied. The aim of this study was to explore how older women learnt to live with diabetes during the first year post diagnosis. This study was a qualitative study, participatory action research (PAR). The participants of this study were eleven women who were newly diagnosed with diabetes and their family members/friends where agreed. The participants were recruited from the participants of the diabetes classes of the Hunter New England NSW Health. One to one interviews were used over a twelve month period from December 2008 until the April 2010. The participants were also invited to share their learning with each other in the PAR group meetings for six months. Data generation and analysis were guided by Stringer (2000) 'Look, think and act' framework and

Koch and Kralik's (2006) storytelling approach. The findings of this study suggested that the women learnt to manage their condition in a multitude of different ways in accordance with their readiness and capacity to learn. Over time, following the initial formal diabetes classes, the women seemed to acquire greater understanding of their condition motivated by curiosity, trial and error, and from their own readings, partners, friends and relatives understandings and to some extent trial and error. During the PAR group meetings the women learnt from each other and shared their learning with each other. The women learnt how they could overcome to their feeling post diagnosis, changing their eating and cooking habits, doing more exercise and checking their blood sugar level. Having support from the family/friends was an important factor in the women's learning process. During the group meetings, the women suggested some reform strategies to the health care professionals to improve the diabetes classes and services for the future people with diabetes. These reform strategies could be such as; providing short diabetes classes, diabetes recap classes, diabetes support group and introducing the suitable books for type 2 diabetes with diet and exercise control. The state of readiness was an important factor during the diabetes learning journey. The women suggested the health care professionals to consider the people's readiness before starting any training to the people who are newly diagnosed with diabetes.

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