HEALTH LITERACY:

KNOWLEDGE AND EXPERIENCES OF TRAVELLER WOMEN

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SUMMARY

AIM OF RESEARCH

The aim of this research is to gain more understanding and insight into the knowledge and experiences of Traveller women in the area of health literacy using a use narrative inquiry approach with an education focus and to explore implications and make recommendations based on the outcomes of the research.

METHODS USED

A method of narrative research was used to gather data through in-depth conversational interviews with Traveller women exploring their experiences of health literacy, education and from a perspective of insider research based on prior relationship of working with Traveller women on health literacy.

CONTRIBUTION OF THIS RESEARCH

The research has exposed a number of factors within the area of health literacy in the Traveller community, including;

- That the critical theory approach to health literacy education can be effective in addressing the empowerment of individuals to improve their health literacy
- That the method of peer educators is a positive approach to raising awareness of health in the Traveller community
- A cross sector health and adult education approach is needed to help address Travellers health literacy

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1.1 Introduction

This thesis poses the following question; what are the knowledge and experiences of Traveller women in relation to health literacy? I will address this research question by investigating their knowledge and experiences using a Narrative Inquiry Approach.

What first drew me to the area of health literacy was primarily my experience of working in a health education and community development programme with Traveller women. Consequently, I feel it is important to give the reader an overview of my work with Traveller women firstly, as this provided the starting point for this research project. I did not work from a defined concept of health literacy – instead my thinking about health literacy was shaped by first hand experience of it with the Traveller women and the different ways that it manifested itself throughout our work in community development and health promotion (as described further below).

1.2 Background to Research

For over five years I have been working with Traveller women in a community education programme. The Peer Led Primary Health Care for Travellers Project (PHCTP) derived from Traveller Health: A National Strategy (2002-2005) in which the project was identified as the 'cornerstone' of the strategy. It outlined that Primary Health Care Projects should be developed in conjunction with Traveller organisations in all health board areas where there is a significant Traveller population. Significantly, the idea of a two pronged approach with the Health Service Executive (HSE) and Traveller Organisations reflected the determining ethos of the programme – built on a foundation of community development principles and health promotion. (The background and policy context of the programme is discussed later in section 2.1) The strategy reflected a growing recognition of the benefits of primary health care projects and an understanding of 'equity' within health care provision. It makes it clear that by respecting and acknowledging the distinct culture and identity of Travellers, a more equitable health care system can be achieved (Traveller Health: A National Strategy, 2002-2005).

This approach is supported by theoretical literature on health literacy (see later sections) including Nutbeam (1998) who outlines the definition of primary health care from the WHO (1978) Alma Ata Declaration as everyone having access and being involved in primary health care. He also goes on to say that the primary health care approach encompasses equity and community involvement and participation. In line with the community development and participatory ethos of the PHC Project the women involved in the course were, from the beginning able to shape the health education programme from a knowledge and experience of the community. This helped to develop an equitable health outreach programme to Travellers based on the needs of the community.

My experience

My experience with the Primary Health Care Project (PHCP) as a Coordinator has been to develop this community participation through peer education. My role as Coordinator of the PHC project for five years has led me to this research project. I believe health literacy is a combination of the tools of health promotion and adult education married together and that adult education has a role to play in health education of adults. Previous to my work with the PHCP I completed an undergraduate degree in Health Promotion and more recently a Postgraduate Diploma in Adult and Community Education. The combination of these set of beliefs drawn from my years of study and from my experience as a Primary Health Care Coordinator with Traveller women has led me to the concept of health literacy. My experience working with Traveller women in the project has given me a major insight into the factors that affect the health of the community, some of which will be addressed in this research. In addition, this experience has also given me a wealth of experience and learning.

The Women involved in the Research

The women involved in this research are in employment as Community Health Workers (CHW's). Each of the three women interviewed had undergone an adult education programme called a Peer Led Traveller Primary Health Care Project (as described in

section 2.1), which had been facilitated by a Traveller Organisation grounded in the ethos of adult education and community development principles. This training ran for three years and addressed a variety of subjects ranging from personal development and preparing for the workplace to health components such as nutrition, family health and developing health promotion events for the community. Each of the three women is now in their second year of employment as 'Community Health Workers'[1].

1.3 An Overview of the Research Process

The methodological approach I have used in this research to explore more deeply the knowledge and experiences of Traveller women in Health Literacy belong to Narrative Research Approaches. This research is important because I believe adult education has a role to play in health education of adults. (This will be examined further in chapter two). The aim of this research is to measure the women's knowledge and experiences of health literacy which led me to Nutbeam's (2000) theory of health literacy which includes the notion of critical health literacy which I believe best reflects the aim of the research. I believe the use of narrative research can capture this dynamic nature of critical health literacy and can probe and develop answers more suited to the narrative and oral style of this group.

1.4 A Brief Outline of each chapter

Chapter Two: Review of Literature

In the review of literature I will firstly give the reader an insight into the Traveller community in Ireland. Then, I will go on to examine the key theories and knowledge surrounding health literacy and its impact on the Traveller community and the role of the adult education sector.

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[1] The role of the Community Health Worker includes a number of elements; acting as a link between service providers and the community, disseminating health information and signposting to the Traveller community, identifying the health needs of Travellers as well as contributing to culturally appropriate health promotion materials.

Chapter Three: Methodology

I will be using narrative inquiry approaches to find out more about Traveller women's knowledge and experiences of health literacy. In this chapter I will outline why I have chosen this approach and I will explore my position in relation to my research topic, give a description of the research process and how the data was interpreted through thematic analysis.

Chapter Four – Findings & Analysis

In this chapter I will examine the findings of the research thematically in the context of the review of literature and discuss the outcomes and implications of the research.

Conclusion & Recommendations

Here I will discuss the contributions of the research and make recommendations for further research and policy making

<center>**CHAPTER TWO**</center>

<center>**REVIEW OF LITERATURE**</center>

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2.1 Travellers

Background and Culture

While historically there has been little research carried out on Travellers and their way of life, we do know that Travellers were craftsmen, entertainers, message carriers, horse traders, tinsmiths and were engaged in buying and selling goods. They were involved in specific economic activity throughout history that can be associated with a nomadic way of life. As industrialisation brought new methods of communication and commerce – in particular cheap plastic goods - Travellers, as with other groups in Ireland, began to experience a change in their role in Irish society and had to adapt their lifestyle to accommodate these changes. Common features in the Traveller identity include; an oral tradition, their own language, value system and of course a nomadic way of life. This distinctive culture and the lifestyle of the community set Travellers apart from the sedentary population or 'settled people'.[2] McCann et al (1994) draws on the work of Ni Shuinear (1994) who argues for the recognition of Travellers ethnicity and concludes that there is a need to recognise Travellers as a distinct cultural minority.

The Report of the Task Force on the Travelling Community (1995) outlined what is meant by culture; 'everybody has a culture - it is the package of customs, traditions, symbols, values, phrases and other forms of communication by which we can belong to a community. The belonging is in understanding the meanings of these cultural forms and in sharing values and identity. Culture is the way we learn to think, behave and do things' (1995:5).

Traveller Health: A National Strategy (2002-2005) examines the implications of culture on health and says 'this provides a challenging framework within which to define the relevance of Traveller culture to the design and delivery of health services' (THNS, 2002-2005:14). It states that Traveller culture has both tangible and intangible elements. It describes the tangible elements as being associated with behaviour and tradition - for example in nomadism, the way Travellers organise their economic activity and in the family structures within the community. It describes the intangible elements as being associated with values and beliefs which are less visible and harder to define; however

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[2] http://www.nccri.ie/cdsu-travellers.html#1 accessed on 21/05/12

'they are fundamental because they are at the root of different behaviours and they are the key to how issues are perceived or addressed'(THNS, 2002-2005:14).

Nutbeam (1998: 353-354) defines community as;

> 'specific group of people, often living in a defined geographical area, who share a common culture, values and norms, are arranged in a social structure according to relationships which the community has developed over a period of time. Members of a community gain their personal and social identity by sharing common beliefs, values and norms which have been developed by the community in the past and may be modified in the future. They exhibit some awareness of their identity as a group, and share common needs and a commitment to meeting them'

Pavee Point outlines that historically, Travellers played a role as bearers of culture, music and storytelling and through their travelling brought songs and stories from parish to parish. Travellers inhabit two worlds - the settled world and the Traveller world which their culture reflects.[3]

Accommodation: criminalisation of nomadism

Nomadism was an integral part of Traveller culture, but many Travellers are no longer nomadic, either by choice or due to lack of support and criminalisation of nomadism. [4] In 2002, the Government enacted the Housing (Miscellaneous Provisions) Act which made trespass, previously a civil offence, into a criminal offence. Currently, camping on private or public land is punishable by one month in jail, a 3,000 euro fine and the confiscation of property. This means that Travellers living on the roadside - awaiting accommodation and with nowhere else to go - are criminalised. This can be perceived by Traveller advocates as an attack on the nomadic part of Traveller culture which in

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[3] http://www.paveepoint.ie/fs_culture_a.html accessed on 21/05/12

[4] http://www.nccri.ie/cdsu-travellers.html#1 accessed on 20/05/12

turn can be seen to punish Travellers for the Government's failure to provide permanent and transient halting sites.[5]

Discrimination

Travellers also experience more widespread forms of discrimination and racism in Irish society and live with the daily reality of being refused access to a range of services including shops, pubs, hairdressers and laundrettes. The efforts made to assimilate Travellers into the dominant population are based on the unproblematised assumption that it was the best interests of everyone. This can be seen in reports such as the Commission on Itinerancy (1963) which equated Travellers with vagrants, social misfits and deviant or saw them as an impoverished underclass in need of rehabilitation.[6] Subsequent policy and practice centred on housing Travellers as the most effective means of assimilation. The Report of the Travelling People Review Body (1983) acknowledged this assimilation practice as unacceptable however, the Task Force Report on the Travelling Community (1995) seek to acknowledge Traveller culture and identity in a more positive light.

There are two types of discrimination that Travellers may face on a daily basis. One is direct discrimination which refers to when a person is treated less favourably than others on, for example, grounds of 'race', colour, ethnic origin, nationality or citizenship. The other type of discrimination the community can face is indirect discrimination which is a more subtle form of discrimination. Indirect discrimination can often be unintentional but occurs nevertheless because of policies, practices, terms or conditions having an adverse effect on particular groups, including minority ethnic groups[7]. In a submission by Pavee Point (2006) to the HSE on Mental Health Policy, they highlight how Travellers' experience of racism and discrimination can lead to feelings of being a social outcast, having low self-esteem, lacking pride in one's ethnic identity coupled with anxiety about losing one's identity and experiencing feelings of inferiority. Due to

[5] http://www.paveepoint.ie/fs_accom_a.html accessed on 21/05/12

[6] http://www.nccri.ie/cdsu-travellers.html#1 accessed on 20/05/12

[7] http://www.paveepoint.ie/fs_racism_a.html accessed on 20/05/12

Travellers experiences of discrimination, the effect on their health status can be detrimental. [8] Cemlyn (2008) argues that Travellers are more likely to experience anxiety and depression due to a violation of human rights across many dimensions. She goes on to advocate for a human rights argument that she believes could 'support a more powerful shift to unsettle sedentarist assumptions, interrogate structures and policies that limit and distort Travellers' cultural rights, and potentially introduce a further paradigm shift in favour of marginalised people'. (Cemyln, 2008; 167) and McElwee et al (2003) also argue that Travellers are a distinct ethnic culture and that while are native to Ireland remain inherently separate from mainstream society (McElwee, 2003:116).

This is supported by findings from surveys on prejudice and discrimination in Ireland by McGreil (1996) and McVeigh (1992) and more recently Pavee Point' (2010) in which only 39.6 per cent of people surveyed would welcome a Traveller "as a member of the family". The main reasons why the majority of respondents would not welcome a Traveller into the family were because of their "way of life" and because it was "not socially acceptable". Most alarming is that 18.2 per cent of respondents said they would deny Irish citizenship to Travellers.[9]

Health Status

Discriminatory and racist treatment of Travellers in healthcare provision is unlawful under the provisions of the Equal Status Act (2000-2004). It can be argued that at times Travellers also experience discrimination and racism in service provision, largely as a result of inbuilt prejudices and stereotyping as discussed above (Pavee Point, 2010, MacGreil, 1996, McVeigh, 1992 and below in the AITHS, 2010). Such experiences also have implications for how many Travellers will present themselves and interact with health services. For these reasons, dignity, respect and non-discrimination need to be part of the approach to Travellers in healthcare settings.[10] Unfortunately Travellers

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[8] http://paveepoint.ie/submissions/06-Mental-Health.pdf accessed on 21/05/12

[9] http://paveepoint.ie/sitenua/wp-content/uploads/2012/02/VAW-Best-Practice-Guidelines-for-Service-Providers.pdf page 2, accessed on 20/05/12

[10] http://www.hse.ie/eng/services/Publications/services/SocialInclusion/InterculturalGuide/Traveller/Traveller.pdf accessed on 10/05/2012

experiencing discrimination in a health care setting will also more than likely find obstacles against informing themselves about their needs; therefore it can be argued that this discrimination will indirectly affect health literacy.

The All Ireland Traveller Health Study (2010) was the first systematic study of Travellers health in 23 years and some 400 Travellers from around Ireland, mostly women, acted as peer researchers for the study. The results expose the harsh reality of the health status of the Traveller community in Ireland. The age structure demonstrates that the majority of the community are young with 63 per cent under the age of 25. Only 3 per cent of Travellers are aged 65 and over compared to 13 per cent of the general population. This reflects the higher mortality levels of the community with Traveller women living on average 11 years less than settled women and Traveller men 15 years less.   Both Travellers and health service providers interviewed in the survey acknowledged that social determinants were the main cause of the poor health status of Travellers[11]. These social determinants include; accommodation, education, employment, poverty, discrimination, lifestyle and access and utilisation of services. The determinants of health as Nutbeam (1998: 354) outlines, can be multiple and interactive. Some determinants are not modifiable (age, sex and gender etc). However the range of modifiable social determinants listed above are mostly outside of the control of the community and in order to address these areas health education tools need to be developed in with that in mind.

Peer Led Primary Health Care Projects

Traveller Health: A National Strategy (2002-2005: 61) draws attention to the process of recruitment and training of Community Health Workers (CHWs) who are drawn from the Traveller community itself and credits similar projects with bringing real and substantial benefits to the Traveller communities where they are located. Part of the CHW's role is to work with health professionals, which has led to remarkable improvements in levels of access to child health services including immunisation, women's health services, family planning and oral / dental health services. It outlines that a balance in approach between health and community development is particularly

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[11] http://paveepoint.ie/pdf/Summary%20of%20main%20findings.pdfh accessed on 10/05/12

appropriate and the process of facilitating community participation in the project has resulted in the empowerment of Travellers and has led to them taking more control of their health situation. The strategy also states that Travellers attitudes to the health system have changed and that this in turn has brought about a change in their ability to access the system.

One of the main aims of the Peer Led Primary Health Care Project for Travellers is to promote a more culturally appropriate health service provision through liaising with health professionals and the community. The US Department of Health and Human Services (2009) refer to this as 'cultural competency' and believe that this can contribute to health literacy. It defines it as the ability of health organisations and practitioners to recognise the cultural beliefs as well as values, traditions and health practices of a community and use this to produce a positive health outcome.[12] Kickbush et al. (2008) advocates that health information needs to be culturally appropriate to the target individuals while ensuring that the most effective and meaningful language and communication is being used input for the target audiences[13]. 83 per cent of the Travellers interviewed in the AITHS (2010) said they got their health information and advice from Primary Health Care for Traveller Projects and Traveller organisations.[14] Parker (1995) states that low literacy in a population is associated both directly and indirectly with a range of poor health outcomes. I want to examine this issue in more depth as I feel, based on Traveller health status and the results of the health literacy survey in Ireland, the area of health literacy as a concept is significant for this community.

Role of the Community Health Worker

Community Health Workers (CHW's) work from the social determinants model of health which is located within a community development approach. This means to address the individual within 'the range of personal, social, economic and

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[12] http://www.health.gov/communication/literacy/quickguide/ accessed on 10/02/12

[13] http://www.emhf.org/resource_images/NavigatingHealth_FINAL.pdf accessed on 17/05/12

[14] http://paveepoint.ie/pdf/Summary%20of%20main%20findings.pdfh accessed on 10/02/12

environmental factors which determine the health status' of the community in question (Nutbeam, 1998: 354). CHW's role has a number of elements which include; links between service providers and the community, disseminating health information and signposting to the Traveller community, identifying the health needs of Travellers as well as contributing to culturally appropriate health promotion materials.

2.2 Health Promotion

Nutbeam's Health Promotion Glossary draws on the World Health Organisation's (1948 & 1986, cited in Nutbeam, 1998: 353) definition of health and describes it as 'a state of complete physical, social and mental wellbeing and not merely the absence of disease' and health promotion as 'a process of enabling people to increase their control over the determinants of health and thereby improve their health' (ibid). He argues that people have to be at the centre of health promotion action and decision making processes in order for them to be effective. Nutbeam (1998:354) defines determinants of health as 'the range of personal, social, economic and environmental factors which determine the health status of individuals or populations'.

Health promotion recognises that individuals wishing to adopt a healthy lifestyle may be prevented from doing so by environmental and socio-economic factors, which are often beyond their individual control and for Travellers in particular, the lack of culturally appropriate education and training materials has contributed to the low uptake and utilisation of preventative action and curative services (THNS, 2002: 46). According to Hohn et al. (1997:10) 'health education and health promotion activities are accomplished primarily through print material written at tenth grade level by skilled readers for skilled readers'. In addition, it certainly can be argued that methods used to reach people who have literacy difficulties are developed with people of a mainstream educational background in mind (Norton et al, 1998).

2.3 Defining Adult Literacy

The National Adult Literacy Agency (NALA) define literacy as not just involving listening and speaking, reading, writing, numeracy but that it includes personal, social

and economic dimensions. 'Literacy increases the opportunity for individuals and communities to reflect on their situation explore new possibilities and initiate change'.[15] The National Adult Literacy Agency's (NALA) definition of literacy above is included in their Strategic Plan (2007-2010:7) where they also describe how literacy has evolved.[16] The 1997 International Adult Literacy survey (IALS) found that 25 per cent of the Irish population was at level one on the literacy level which meant people could not understand the directions on a popular headache packet. (IALS, 1997). Even more shocking is that 30 per cent of the population is at level two which means that these people can only deal with material that is simple or find it difficult to extract information from more complex text.[17] Rudd (2009) outlines that the OECD has previously shown the link between literacy and health status when it stated that 'people with higher educational attainment have healthier habits and lifestyles, and are more educated towards the management of their own health through access and understanding of information and preventative health practices'[18]. It can be argued that literacy levels which are usually, but not always related to levels of education, are important predictors of not only employment and active participation in the community, but of health status also. (Health Canada, 2001: 3.)

2.4 Health Literacy in Ireland

In Ireland, Health Literacy is a relatively new concept and briefly featured in the National Health Promotion Strategy (2000-2005) where it states that 'poor literacy skills ... limits access to health information and health services'[19]. However in government policy, health literacy has not been discussed or referred to as a stand alone issue. The

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[15] http://www.nala.ie/sites/default/files/documents/cmcnally/Strategic%20Plan%202007%20-%202010.pdf accessed on 20/12/11

[16] http://www.nala.ie/literacy-ireland accessed on 20/12/11

[17]http://www.nala.ie/sites/default/files/documents/cmcnally/International%20Adult%20Literacy%20Survey%20-%20results%20for%20Ireland_0.pdf page 23, accessed on 11/05.12

[18] http://healthliteracy.ie/wp-content/uploads/2010/11/Rima-Rudd-Advocacy-Group-Report-Feb-2009.pdf accessed on 2/6/12

[19] http://www.dohc.ie/publications/pdf/hpstrat.pdf?direct=1 pg 20 accessed on 17/05/12

National Traveller Health Strategy (2002-2005) also briefly addresses the link between poor literacy and health status as discussed above; however; it has been completely omitted as an important factor in addressing health needs. The National Adult Literacy Agency's research and policy report on health literacy (2002) is the most recent document that addresses this area and states that 'this report marks the first time literacy has significantly entered the health debate in Ireland'.[20]

The results of the 2007 Irish Health Literacy Research, sponsored by MSD and NALA, revealed that; one in five Irish people are not fully confident that they understand all the information they receive from their healthcare professional, 43 per cent of people would only sometimes ask their healthcare professional to clarify the information if they did not understand something they had said, one in ten people have taken the wrong dose of medication because they didn't understand instructions and that two thirds of people have difficulty understanding signs and directions in Irish hospitals.[21]

According to the European Health Literacy Survey, four out of ten people in Ireland have low health literacy and outlines that vulnerable groups such as those experiencing long term illness, financial hardship and those from lower socioeconomic groups were seen to have the lowest levels of health literacy. It concludes that low levels of health literacy results in poorer health, poor quality of self care and self management of disease, ineffective use of the health service and a decreased ability to advocate for oneself in the health care arena. [22]

2.5 Defining Health Literacy

Upon researching literature in the area of health literacy it is clear that there are a number of definitions available based on different interpretations of the area. As it is a

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[20] http://healthliteracy.ie/wp-content/uploads/2010/11/Health-literacy-policy-and-strategy-2002-research-report.pdf pg 5 accessed on 17/05/12

[21] http://www.healthliteracy.ie/what-is-health-literacy/health-literacy-in-ireland. accessed on 31/3/12

[22] http://healthliteracy.ie/four-out-of-10-people-in-ireland-have-low-health-literacy/ accessed on 17/05/12

relatively new concept, there has not been a universally adopted definition for health literacy. Therefore, over the next few pages I will discuss the various different theories and arguments for and against the concept of health literacy and will draw on existing research in the area to gain a clearer insight into what is meant by health literacy.

Some key writers in the field discuss health literacy as a variety of skills while others argue that health literacy refers to a more limited definition of basic knowledge and understanding (e.g. being able to find ones way around a hospital, read a medicine bottle etc). However, most writers agree that a broader definition is one which encompasses the need to understand and act on messages that are central to making critical judgements and decisions not only in health related settings but also about health (Peerson et al 2009). Some definitions which offer a broader definition of health literacy include;

Nutbeam (1998) outlines health literacy;

> 'it represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health' (Nutbeam, 1998: 357).

Kickbusch (2008) defines it as;

> 'The capacity to make sound health decisions in the context of everyday life – at home, in the community, at the workplace, in the health care system, the marketplace and the political arena'.[23]

Both writers agree that an individual needs to possess the capacity or social and cognitive skills in order to make healthy decisions. Kickbusch (2002, 2004) views health literacy as fundamental to the concept of health promotion and recognises it as a distinguishable concept from health knowledge, health education and health promotion in that it helps to develop the skills and confidence to act on knowledge. She also talks about health literacy and empowerment, acknowledging that information is crucial but will never be sufficient to address many of the major challenges faced by disenfranchised and marginalised populations. Kickbusch (2004) goes on to conclude

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[23] http://www.emhf.org/resource_images/NavigatingHealth_FINAL.pdf accessed on 17/05/12

that components of health literacy such as access to information and knowledge, informed consent and negotiating skills must constitute part of the overall development effort.

Peerson and Saunders (2009) address the differences between medical literacy and health literacy and conclude that the health sector can influence medical literacy but is less able to influence health literacy. They state that health literacy is a very complex thing to measure and influence. I believe that writers have identified the importance of health professionals being aware of a person's literacy levels and as a result adjusting the medical literacy to help that patient to understand. While I also acknowledge that health literacy is difficult to measure I believe in order to improve health literacy a multidisciplinary approach should be adopted with responsibility not just solely laying with the health sector, but the education sector also. This question of the educational aspects of health literacy underpins this research project.

Levels of Health Literacy

Nutbeam (2000) has been at the forefront of the debate on health literacy and he has developed a model which he believes describes the different levels of health literacy of individuals. He classifies levels of health literacy based on what people are able to do into three types of health literacy; basic/functional, communicative/interactive and critical.

Basic/Functional: He describes functional health literacy as basic skills in reading and writing encompassing a narrow definition of health literacy based on patients having the ability to read appointment cards, medicine bottles etc.

Interactive: Interactive health literacy skills he describes as a more advanced skill which together with social skills can be used to actively participate, extract information and meaning from forms of communication.

Critical Health Literacy: This, he describes it as more advanced cognitive skill, building on the levels described above to **critically analyse information**. He likens this third level with the style of education for critical consciousness advocated by Freire (1970). **He believes that this concept of raising consciousness in adults can help**

them achieve critical health literacy skills. I will discuss this further when addressing the links between health literacy and adult education (Nutbeam, 2000:263-264).

Clear Communication

Dr Rima Rudd is another prominent writer in the area of health literacy and has been instrumental in raising awareness of health literacy internationally as well as being involved in developing health literacy policies in the US. Rudd (2009) on a recent roundtable discussion in Ireland addressed how she believes there are two sides of the coin when it comes to health literacy; the skills of the individual and the expectations of the health sector. She stresses the importance of clear communication in a way that is easy to understand. She mentions barriers such as medical terminology, assumptions of health care professionals, and health materials exceeding reading skills. Rudd (2009) advocates the importance of cross sector collaboration between public health agencies and adult education organisations. She goes on to recommend that Ireland adopt a similar approach to Canada in health promotion materials whereby all literature should be piloted before mass distribution and also the use of alternative mediums [24]

Arguments against Health Literacy

Through the wide body of theories in this area, Tones (2002) argues against health literacy in his paper 'health literacy: new wine in old bottles'. He believes that defining health literacy as a stand alone concept in the area of health promotion is merely repackaging an already developed concept and so is unnecessary and risks confusion to health education and health promotion theory. He also argues that the concept of critical consciousness-raising is already developed and has been applied to health education.

> 'Education is indeed essential to achieving a wide range of health goals, but it is important to note at the outset that education is concerned with much more than literacy – just as health education has more extensive concerns than the achievement of health literacy' (Tones, 2002:287)

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[24] http://healthliteracy.ie/wp-content/uploads/2010/11/Rima-Rudd-Advocacy-Group-Report-Feb-2009.pdf) accessed on 31/3/12.

Kickbusch (2002) acknowledges Tones' arguments but maintains that it is necessary to introduce this term and concept even in a complex health promotion itinerary. I agree that health literacy as a concept should be a public health goal and recognised as an issue for the health of the population, in particular the Traveller community due to the wider health implications that this community faces as outlined in the study.

Measuring Health Literacy

Nutbeam (2008) discusses the different tools used in the US to measure health literacy. These tools are mainly used by clinicians and are mostly measuring functional health literacy (outlined above). However, he feels that this is a limited measurement tool due to its inability to measure critical health literacy. He mentions that different definitions of health literacy have implied that there are different measurement tools but argues that they are not comprehensive. He believes there needs to be more work done in developing a tool to measure critical health literacy – how people access, understand and use health information. Nutbeam (2008) concludes that this will require an additional assessment of oral literacy and social skills. As I will outline in chapter three, the research design used in this study will echo Nutbeam's (2008) views that questionnaires alone will not be sufficient in measuring critical health literacy.

Why is Health Literacy Important?

According to NALA (2002), health literacy is a complex problem that requires a range of responses and is not an isolated problem but embedded in a range of wider social issues. It is important to remember that while access to good information is a priority in health literacy, this is not enough.[25] It can be argued that information alone is not useful to people who feel they do not have the power to act - which means that strategies such as community development and participatory health education are key. [26]

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[25] http://www.emhf.org/resource_images/NavigatingHealth_FINAL.pdf accessed on 6/6/12

[26] http://www.phac-aspc.gc.ca/ph-sp/literacy-alphabetisme/literacy2-eng.php#n4 accessed on 27/3/12

In Canada it has been shown that however health is defined or measured, people with limited literacy skills are worse off than are others an that literacy levels affects health directly, for example when a failure to read or to understand instructions results in medication errors or accidents. However the major impacts of literacy on health occur indirectly, which means that literacy affects and interacts with almost all other determinants of health.[27] According to the American Medical Association, poor health literacy is a stronger predictor of a person's health than age, income, employment status, educational level or race it has also been proven that populations most likely to have low health literacy are older adults, certain racial and ethnic minorities, people with less education and people with low income levels.[28]

It is evident from research that education is an important social determinant of health. It can be said that at an individual level, the knowledge, personal and social skills provided through education can better equip individuals to access and use information and services to maintain and improve their own and their family's health. Improved understanding of the relationship between education and health will help to identify where intervention is most appropriate and effective in improving both individual and population health. [29]

2.6 Travellers and Health Literacy

Pavee Point outlines in a health policy submission (2008) that;

> 'The majority of adult Travellers have very little or no literacy. The way the health and health education services are designed assumes everyone can read and write and has basic understanding of messages, appointments etc. This is not the case, and some Travellers often don't understand they have to take a

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[27] http://www.phac-aspc.gc.ca/ph-sp/literacy-alphabetisme/literacy2-eng.php accessed on 31/3/12

[28] http://healthliteracy.ie/wp-content/uploads/2010/11/Time-to-Talk-What-is-Health-Literacy.pdf. accessed on 31/3/12

[29] http://www.publichealth.ie/sites/default/files/documents/files/Health%20Impacts%20of%20Education.pdf accessed on 25/05/12

number in a clinic, they can't understand the instructions on their medication and they can't read or understand any of the health education brochures.[30]

Literacy difficulties are very much part of the barriers experienced by Travellers in relation to health. The capacity to understand health promotion and prevention is restricted by the high level of literacy difficulty estimated at up to 80% [31] compared to the general population at 39 per cent.[32] More recently in the All Ireland Traveller Health Study 38.5 per cent of 30-44 year old Travellers and 25.8 per cent of 45-64 year old Travellers had primary education only.[33] In the qualitative section of the study, 28.8 per cent of Traveller families reported difficulty in reading.[34] It is clear from the research and from policy submissions from Traveller groups that low literacy is a huge issue within the community and is high among the agenda. As a result this has detrimental consequences for the health status of the community. In addition to this, non-literacy friendly health information materials lead to barriers even accessing the health services. A Traveller woman commented in the study that '...there on Monday my father was in the local GP – went up because he wasn't well, and he went and got his prescription, within two days it he had the antibiotics gone – because he couldn't read – he has a literacy problem. And the doctor never explained to him how to take them – never the chemist or the local GP'. It was concluded that many Travellers found it difficult to communicate with the health professionals and as a result internalised communication breakdown as a personal problem associated with their inability to read, write or understand the doctor or chemist'.[35]

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[30] paveepoint.ie/pdf/Health%20Info%20Bill%20Submission.doc accessed on 17/05/12

[31] http://healthliteracy.ie/wp-content/uploads/2010/11/Health-literacy-policy-and-strategy-2002-research-report.pdf accessed on 17/05/12

[32] http://healthliteracy.ie/four-out-of-10-people-in-ireland-have-low-health-literacy/ accessed on 17/05/12

[33] http://paveepoint.ie/pdf/Summary%20of%20main%20findings.pdf accessed on 17/05/12

[34] http://pavee.ie/ourgeels/wp-content/uploads/2010/09/Technical-Report-3-Final.pdf accessed on 17/05/12

[35] http://pavee.ie/ourgeels/wp-content/uploads/2010/09/AITHS2010_SUMMARY_LR_All.pdf pg 130 accessed on 17/05/2012

According to the Institute of Medicine (2003) in America, culture plays a part in shaping perceptions of illness and health, which will in turn influence people's experience and attitudes towards health and the health system. Culture, which influences ideas and perceptions about health, adds another layer of complexity and Pouresalmi (2007) comments that centralising culture in specifically targeted forms of media can facilitate effective educational interventions[36]. It has been accepted that culture affects how people communicate, understand and respond to health information.[37] Rudd and Nutbeam (2007: 3) both agree that 'health literacy needs to be seen as a pathway not only to improving the health of individuals but also to transforming the structures that perpetuate marginalisation'.[38] This is significant to the Traveller community who repeatedly experience marginalisation in every aspect of their lives not just health.

2.7 Health Literacy and Education

It has become clearer that education is a direct factor which influences the level of individuals' health literacy. As discussed earlier Rudd (2009) outlines that OECD has previously shown that 'people with higher educational attainment have healthier habits and lifestyles, and are more educated towards the management of their own health through access and understanding of information and preventative health practices'.[39]

It is important to draw attention to the issue of equality and education; (this notion is discussed further in chapter four) 'if one's cultural traditions and practices are not a valued part of the education one receives, if they are denigrated or omitted, then education itself becomes a place where one's identity is denied or one's voice is silenced' (Lynch, 1999:17). It can also be said that;

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[36] http://www.ccl-cca.ca/NR/rdonlyres/ED97299E-46AF-429E-9EAE-55AE806ECD2D/0/HLKCSymposiumReport07.pdf accessed on 11/6/12

[37] http://www.cdc.gov/healthliteracy/pdf/Simply_Put.pdf accessed on 11/6/12

[38] http://www.ccl-cca.ca/NR/rdonlyres/ED97299E-46AF-429E-9EAE-55AE806ECD2D/0/HLKCSymposiumReport07.pdf accessed on 11/6/12

[39] http://healthliteracy.ie/wp-content/uploads/2010/11/Rima-Rudd-Advocacy-Group-Report-Feb-2009.pdf accessed on 2/6/12

'Educational disadvantage is closely linked to the issue of poverty…individuals from poorer socio-economic backgrounds and communities are more likely to underachieve in the education system... [evidence shows] a negative association between material deprivation and the inclination, resources, and capacity of parents to encourage and help their children succeed at school. Furthermore, poverty that involves the enforced lack of socially defined necessities, can have a wide range of long-term consequences; dependence on welfare or illicit earnings, high rates of school dropout, teenage pregnancy, negative self-esteem…depression, powerlessness, criminality, and…health.' (Kellaghan et al. 1995: 30-1).

Participatory Health Education

Rudd (2002) examines the history of health literacy in the US and suggests that health topics in an adult education setting would motivate the adult learner. Rudd (2002) acknowledges that while the expertise does not lie in the adult education field, collaboration between health and education practitioners is however needed. Rudd (2002) concludes that the way forward is not giving total responsibility to the health professional but rather to encourage them to improve their communication skills while also increasing the literacy skills of the adult learner in a more participative approach. This approach is addressed by Norton et al (1998: 245). The writers advocate that one method of overcoming low health literacy is to enable people to help themselves through participatory education and discuss a programme that was developed for a group of women with the objectives of integrating literacy development with health promotion; individuals being able to take control over their health and that of their families and community. The objectives of the programme helped women learn skills and strategies to access information and resources they needed to make positive changes that can improve health. The project provided important social support for the women who participated and also helped them to develop knowledge and skills to improve some aspects of their health (Norton, 1998). It is worth noting here that the women highly valued being with their peers. The women defined their own learning needs being involved in the development stages and how this contributed to the success. This outcome can be compared to the work of the PHC Project whereby trusted peers within

the Traveller community can promote positive changes in health. Health Canada (1998) makes some similar points on how to address the issue of health literacy by advocating community development and participatory health education. It acknowledges how most people with low literacy will get most of their health information through word of mouth and as a result health professionals need to act in partnership with others in the community for example using 'peers'.[40]

This type of model discussed above bear's resemblance to the ethos to the Peer Led Traveller Primary Health Care Projects in which health information is accessed by the Traveller community through the Traveller women peers themselves – sometimes being seen as a trusted source who can convey the information in a culturally accessible manner. As mentioned earlier the Projects have had substantial impact on the health of Travellers in their locations and the CHWs have been responsible for remarkable improvements in levels of access to health services such as child and women's health services (Traveller Health: A National Strategy, 2002-2005:61).

Health Literacy and Lifelong Learning

The concept of health literacy can be described as a lifelong learning process and a dynamic concept. Rudd (1999) captures this dynamic nature of health literacy when she says people continually learn new information in order to keep making healthy decisions. Therefore, in policy making it must be remembered that improving population's health literacy must be aimed at all ages on a continual basis. She also advocates that health literacy should be integrated into the European Commission's policy of lifelong learning.[41] Ratzan (2001) also advocates a lifelong learning approach with the idea of children learning about health all through life and the health information we learn about evolves as we age. He mentions the concept of generational transference of health literacy.

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[40] http://www.nald.ca/library/research/howdoes/howdoes.pdf accessed on 11/6/12

[41] http://www.emhf.org/resource_images/NavigatingHealth_FINAL.pdf accessed on 11/6/12

Health literacy and Adult Education Partnership

Findings from a survey by Rudd et al (1999) where the perceptions of adult educators on health issues and topics in adult basic education programmes were examined to support an active partnership between the education and health sectors. However, rather than building the health knowledge of adult educators, Rudd et al (1999) argues that a more effective method would be for both the adult educator and health professional to bring their expertise to the table and together contribute to an effort to build functional health literacy. Kickbusch (2004: 5) argues that 'health education improves health literacy by creating opportunities for learning about healthy behaviour' but states that it must take a health promotion approach in order to be effective. This method would foster knowledge and development of life skills through learning to improve health literacy.

When discussing what can be done to improve health literacy, Ratzan (2001) focuses on what he believes is the best approach - effective communication. Within this he discusses education and agrees that it is not just about knowledge about health but that the goal should be a change in social norm of developing it at a level commensurate with age, mental capacity, gender and environment. It is also interesting to note that The National Health Promotion Strategy (2000-2005) includes; incorporating community development approaches into health promotion interventions so that communities are empowered to take control and improve their health collectively as one of the aims of the strategy.[42]

Cross sector approach to health literacy

As I have already referred throughout the research I believe that adult education has a role to play in improving the health of the community and it is important that both sectors collaboratively through cross sector participation take responsibility in the process of developing a more health literate population. It is important that policies in these areas are not looked at in isolation due to the spill over effect in both sectors

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[42] http://www.dohc.ie/publications/pdf/hpstrat.pdf?direct=1 pg 11 accessed on 17/05/12

therefore a systematic coordinated approach by relevant departments should be taken.[43] The next section will look more closely at this area.

2.8 Health Literacy and Critical Theory

Looking at the World Health organisation definition of health literacy in Nutbeam (1998):

> 'Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health'.

It implies the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions (Nutbeam, 2008). He then goes on to say that health literacy is not just about being able to read a pamphlet, if a person's access to health information and ability to use it effectively is improved, then **health literacy is critical to empowerment**. Nutbeam (2008) adds to this definition by proposing that the WHO (1998) definition should be widened to address more than the transmission of health information to one which people develop confidence to act on the knowledge and support others. He believes **this will be best achieved through community-based educational outreach**. This can be linked back to the ethos of the Traveller Peer Community Health Workers. It has been shown nationally that outreach health projects have been successful in raising awareness and knowledge on health in the community.

Nutbeam (2008) also believes that responding to low levels of health literacy in populations involves improving access to effective school education and providing adult education for those who missed out. It could be argued that **a key factor in improving a population's health literacy is to involve the arena of adult education in providing communities with the opportunity to empower themselves to make more informed decisions on their health**. Nutbeam (2007:3-4) further discusses health literacy as critical health literacy which draws on 'Frierian notions of using adult education, not only as a way to function in a dominant society, but as to become aware

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[43] http://www.publichealth.ie/publications/healthimpactsofeducationareview accessed on 17/6/12

of the ways in which the system perpetuates marginalisation'. Nutbeam goes on to describe this form of education as the needs of the learner being centralised instead of the traditional sense where education is curriculum based on knowledge deficits.[44]

The White Paper on Adult Education (2000:28) lists consciousness raising as one of the priorities in providing a template for the sector and describes it as 'the capacity of Adult Education to enable people to realise their full human potential in a way that draws on the links between their individual personal experiences and wider structural factors. It embraces a view of Adult Education as an empowering process of self-discovery towards personal and collective development'. The White Paper places the responsibility with the adult education sector as being an instrument in empowering people through education.

Freirian Approach

It is important to look at the Freire's approach to adult education in order for us to understand what is meant by Critical Health Literacy.

Freire is one of the most influential thinkers about education and provides us with a philosophy of education and development. He developed a set of ideas on teaching and learning and introduces the notion of critical consciousness. These ideas derived form his work in Brazil in the 1960's where the population was experiencing inequality, poverty and illiteracy.

Freire advocates that education must begin where people are at, which also takes into account their culture. Freire talks about problem posing education through dialogue. He believes dialogue is crucial in the process of transformation. 'Teacher-student with student-teacher. The teacher is no longer the one who teaches but is also taught in dialogue with the student, who in turn while being taught also teaches' (Freire, 1970: 61). He talks about the dominant system and traditional education as a banking system of education where the teacher fills the student with knowledge. He argued that education should raise critical awareness and become to know what you know in a

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[44] http://www.ccl-cca.ca/NR/rdonlyres/ED97299E-46AF-429E-9EAE-55AE806ECD2D/0/HLKCSymposiumReport07.pdf accessed on 11/6/12

different way or to act on their situation in order to improve it. The cycle of refection and action is also central to the process of transformation. What Freire means by this is that a community will be constantly aware of their successes and analysing critically their mistakes which will lead to them becoming more capable of transforming their lives. This process is called 'praxis' (Hope 1995:21).

When Freire talks about literacy he expanded it from being able to read and write to being able to read the world around you and take a critical look at their reality. Freire refers to this as conscientization or developing consciousness. He has developed methodologies which include development of critical awareness with learning to read and write. 'Transformation is not something that one person can do for somebody else. Transformative education is based on the hope that that it is possible to change life for the better' (Hope 1995:14,16).

Minkler et al (1980) in discussing Freirian methods to the application to health care settings concluded that it has shown to improve health conditions while also creating a critical awareness of the causes of problems and a readiness to take action. The writer draws these conclusions based on an evaluation of a programme in the Republic of Honduras where Freire's philosophy of critical consciousness was applied to health education programmes. The programme was a health promotion project based on 'conscientizacion'. The process of conscentizacion was grounded in the project and was explored before health content through dialogue which addressed issues such as; the reality of Honduras and women's roles. Then the project went on to address nutrition from a global perspective and the link between poor health and marginalisation. The women were taught how to facilitate dialogue to critically analyse their reality in order to bring about radical change. As a result the women motivated the men to make changes; for example building a school. The writer states this process; 'Concentrates on helping people change the structure of society rather than simply integrating them more successfully into the existing structure' (Minkler et al 1980, 288).

The Capabilities Approach Model

Kickbusch (2001) has identified the capabilities approach as an important conceptual model fro health literacy as empowerment (Kickbusch, 2001: 294). Nussbaum (2000)

describes the capabilities approach to enhance health and wellbeing as; 'when we think of health for example we should distinguish between the capability or opportunity to be healthy and actual healthy functioning: a society might make the first available and also give individuals the freedom not to choose the relevant functioning (2000:14). Kickbusch (2001) argues that this approach firmly places the capacity of citizens to act within their social environment (Kickbusch, 2001: 294).

2.9 Feminist Theory & Education

The grounded nature of feminist knowledge bears relevance to this research. As outlined below feminist education is centred around the woman and her needs which reflects the nature of the PHC Project whereby the participants develop an outreach health promotion programme rising form the needs of the community with Traveller women passing on relevant health information to other Traveller women while also giving a voice to those women which drives the work of the project. Feminist education can be defined as 'where women decide what they need to know and how they want to use that knowledge' (Symth 1999:23 as cited in Mc Cann). McCann (1999:24) outlines McMinn (1996) description of goals for women's education which includes;

- building confidence, self esteem, personal growth and self awareness

- gaining skills learning by doing, passing on skills and knowledge to other women

- encouraging women to think critically about existing social structures from feminist perspectives

- supporting women in getting involved more in their own community

It is also interesting to note that this process reflects the idea of critical health literacy as first developed by Nutbeam (1998). McCann (1999:25) discusses Nyland's (1996) ideas when she talks about feminist education and community development as facilitating consciousness raising. She describes this as analysing the relationship between individual feelings, life situations and the broader socio political context'. Overall

women's education should provide a forum for women to become more aware of their situation and build the confidence to change it for the better. Similarly becoming more health literate through the process of consciousness raising will empower the woman to make healthier decisions about her and her families health. The White Paper on Adult Education (2000: 111) outlines that education starting with the reality of women's own lives is not only principles of feminist education but also demonstrates a core principle of adult education activity with marginalised groups. This is in contrast with starting with a curriculum; it starts from the women's experience as reflects Freire's theory on traditional education approach as the 'banking model' where the educator fills the learner with their knowledge (Hope et al 1995: 19).

Women in the Traveller Community

When looking at the area of feminism, Connolly (1999:2) talks about the variety of different viewpoints and definitions but believes there are common themes within. She believes feminism 'places a high value on women' and that it recognises the need for social change on behalf of women. She also goes on to say that it can be an unpopular term and has no unified body of theory and practice even though it is portrayed as a single entity.

Traveller women play an important role in their immediate family and the wider Traveller community. They have responsibility for the home, family and children. Most of the time they are the ones that communicate with service providers and often take a lead role acting on behalf of the community. As discussed above, feminist education can support women in getting involved in their own community. Therefore, it can be said that Traveller women as a result of being participants in feminist education [45] are now becoming advocates in their own community. It can be argued that Traveller women experience triple discrimination: discrimination as women, discrimination as Travellers and discrimination as Traveller women. Currently however it is Traveller women who play key roles in the Traveller movement throughout Ireland. They articulate the issues,

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[45] http://www.paveepoint.ie/pdf/Factsheet-women.pdf accessed on 20/05/12

and in particular the experience of Traveller women, at local, national and international levels.[46]

Traditional gender roles in the Traveller community, unequal power relations between men and women, mean that Traveller women face the dual discrimination of patriarchal norms within their own community that restrict options open to them as well as facing racism and discrimination from the majority population. Many Traveller women are more easily identifiable than Traveller men, and are therefore more likely to experience discrimination.[47]

Women and Health Literacy

Proliteracy Worldwide [48] (in Women and Literacy) discuss how it has been widely accepted that women provide a key role in keeping their family healthy. In the developing world, malnutrition, inadequate health care, poor education and gender discrimination are among the reasons for women's health problems. It has been noted that women's health is endangered by their culture's response to their gender. It has been shown that the highest rates of illiteracy among women are found in places that report high rates of infant mortality, low life expectancy and poor nutrition. The UN have outlined the transformative effect on families and the wider community when a woman is literate and also how this helps them become more self reliant and engaged in their community. It also refers to the 'positive ripple effect' that women can have on the community.[49]

Bandyopadhyay et al (2009) in speaking about women's health literacy and health promotion initiatives in India, underline the importance of taking a gender perspective on health as it recognises the differences in health status of men and women; for example in the type of their diseases and ailments. The writers also argue that women's

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[46] http://www.paveepoint.ie/pdf/Factsheet-women.pdf accessed on 20/05/12

[47] http://paveepoint.ie/sitenua/wp-content/uploads/2012/02/VAW-Best-Practice-Guidelines-for-Service-Providers.pdf accessed on 20/05/12

[48] http://www.proliteracy.org/NetCommunity/Document.Doc?id=36 accessed on 20/05/12

[49] http://www.un.org/apps/news/story.asp?NewsID=35859&Cr=literacy&Cr1 accessed on the 2/6/12

health literacy should bring about a change in women's lives and to also make women independent seekers of health related information.[50]

2.10 Conclusion

'In general those with lower reading levels are between one and a half and three times more likely to have an adverse health outcome than people who can read at higher levels'.[51]

It is clear that in Ireland people are struggling with health information and do not feel capable in decision making. Key writers and advocates in the area of health literacy agree that a national policy on health literacy is urgently needed in the country. NALA have carried out research and in their report Health Literacy Policy and Strategy (2002) they concluded that 'health literacy means more than just reading information'.[52]

Within the concept of health literacy, there are arguments as to how important it is to define health literacy within the theory of critical consciousness. I have addressed why I believe it to be important to research the area and particularly in the context of Traveller women due to the poor health status and literacy levels in the community. I also believe that adult and community education has a role to play in addressing the gaps in health literacy within the community. If we look more closely at the area of critical consciousness we can see the similarities in the achievement of critical health literacy. The White Paper on Adult and Community Education (2000) defines consciousness raising as it embraces a view of Adult Education as an empowering process of self-discovery towards personal and collective development. The research will be centred on the experiences and knowledge of the traveller women and may expose the relevance that adult education theory has to health literacy.

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[50] http://www.ifla.org/files/hq/papers/ifla75/145-bandyopadhyay-en.pdf accessed on 6/6/12

[51] http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1492599/ accessed on 5/6/12

[52] http://healthliteracy.ie/wp-content/uploads/2010/11/Health-literacy-policy-and-strategy-2002-research-report.pdf pg 5, accessed on 18/05/12

At a global conference on health literacy in Canada (2007:16) where a number of key speakers in the field discussed the concept measurement and practice of health literacy, a participant remarked that;

> 'Don Nutbeam's conceptualisation of Frierian education is important and relevant when we speak of health literacy. It makes the connection between literacy and power. Without empowerment you can be stripped of your dignity and you can be stripped of your health'.[53]

In the next chapter I will be outlining the methods I used in the research and will give the reader a background into why I decided to do this research and why I think it's important.

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[53] http://www.ccl-cca.ca/NR/rdonlyres/ED97299E-46AF-429E-9EAE-55AE806ECD2D/0/HLKCSymposiumReport07.pdf accessed on 11/6/12

METHODOLOGY

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3.1 Introduction

Methodology is referred to a 'perspective' or broad theoretically informed approach to research, which stems from the researcher's epistemological stance or philosophical/political position (Antonesa et al, 2006:70). The government outlines that 'Research is a key factor in promoting health, combating disease, reducing disability and improving quality of care'.[54] The following chapter will give the reader an insight into why I chose this area of research and how the research was carried out as well, as discussing the challenges and learning that took place along the research journey.

3.2 Narrative Research as a Paradigm

The methodological approach I have used in this research to explore more deeply the knowledge and experiences of Traveller women in health literacy belong to Narrative Research Approaches which I believe enables the validity of the lived experience of the women interviewed. Clandinin & Connelly (1990: 2) describe the study of narrative as the study of the ways humans experience the world. In this case, I wanted to capture and gain an insight into the experiences and thoughts of the women who took part in relation to the area of health literacy.

In addition to this it has been said that narrative approaches are often strongly autobiographical. Our research interests come out of our own narratives of experience and shape our narrative enquiry plotlines (Clandinan & Connolly, 2000: 121). This is a valid point as I have come to this research area with my own thoughts and subjectivities in relation to the area. When I first decided to research the area of health literacy by exploring the experiences and knowledge of Traveller women, I knew that I would have to ask those women involved in the study to be honest and tell me their views on this area. From having over five years experience working with Traveller women (as discussed earlier in chapter one) I knew that it would be important to give each woman

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[54] http://www.dohc.ie/publications/pdf/mkwfh.pdf?direct=1 pg 5, accessed on 15/05/12

time to tell their stories based on their experiences as it is said that Traveller identity is significantly marked by an oral tradition. [55]

3.3 Why Narrative Research?

Narrative inquiry can be defined as an umbrella term that captures personal and human dimensions of experience over time, and takes account of the relationship between individual experience and cultural context (Clandinan and Connolly, 2000). This description captures the elements of why I felt this is the method most suited to my research. I want to capture the experiences and knowledge these women have in relation to health literacy as a concept while recognising the cultural context within this issue.

Narrative inquiry can gather memorable and interesting knowledge that brings together layers of understandings about a person and their culture.[56] I thought this best reflects what I have set out to do in a way that complimented the women's culture. As mentioned above a strong oral tradition is part of the culture as portrayed through the development of the Traveller communities own language or 'cant'. This oral tradition is a distinct and important part of Traveller culture (as discussed earlier in Chapter Two, section 2.1) and as a result I believe this methodology is the best approach. As discussed in more detail previously and below, Nutbeam (1998) a leading writer in the field of health research, has commented that there needs to be more work done in developing a tool to measure critical health literacy and that this will require an additional assessment of oral literacy and social skills.

3.4 Ontological & Epistemological Perspectives

Ontology derives from the Greek word for being; it refers to theories on the nature of existence. It refers to theories of knowledge, or, when we say we know something. I like to position ontology as a snapshot of how I perceive the world to be. Epistemology is a

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[55] http://www.nccri.ie/cdsu-travellers.html#1 accessed on 21/05/12

[56] http://www.keele.ac.uk/media/keeleuniversity/facnatsci/schpsych/documents/counselling/conference/5thannual/NarrativeApproachestoCaseStudies.pdf accessed on 5/6/12

study of how people or systems of people know things and how they think they know things. The nature of knowledge, what constitutes valid knowledge, what can be known and who can be a knower. Post positivist research includes a process of investigating your own epistemologies and understanding how they affect you as a researcher in a way that assumes learning rather than testing role (Antonesa, 2006: 15).

I believe this research to be important because my ontological position is that health literacy is a combination of the tools and philosophies of health promotion and adult education married together. I believe that adult education has a role to play in educating adults in health. I will now outline how I came to this idea and my epistemological position or why I believe this to be true.

My position in relation to my research topic

The area of health literacy is an under researched and relatively unknown concept in Ireland, which is not recognised as an issue of its own value by Government (as discussed in Chapter Two). However, it is something that will continue to affect the health of a high percentage of the population on a day to day basis; 4 out of 10 people in Ireland have low health literacy.[57] I believe strongly that more emphasis within the health sector should be placed on effective health promotion and health education for adults. It is important that health education not only informs people of the ways to maintain a long and healthy life, but also equips the population with the capability to make informed healthy lifestyle choices with confidence. This notion is clearly outlined by Nutbeam (1998:353) as discussed in Chapter Two (section 2.5), when he expands the definition of health education to 'fostering the motivation, skills and confidence or self efficacy necessary to take action to improve health'. When I first started on this research journey I had a clear idea this was a cornerstone of my beliefs on the roles of health and education. As I progressed into the journey it was enlightening to discover this information to back up my beliefs and furthermore gave me a focus to give a voice to these Traveller women on this issue.

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[57] http://healthliteracy.ie/four-out-of-10-people-in-ireland-have-low-health-literacy/ accessed on 21/05/12

The right to be healthy is a fundamental human right whereby everyone should have access to basic resources for health, as discussed in Nutbeam (1998: 351). Nutbeam's theories and approaches to health literacy capture my own position and beliefs. He outlines the WHO (1948) definition of health as 'a state of complete physical, social and mental wellbeing, and not merely the absence of disease or infirmity'. I believe if we are focussing on the cure rather than prevention, the issue of poor health literacy will continue to manifest itself over time. As I mentioned earlier, I identified the area of health literacy through my work with a health education programme for Traveller women. I also came to this programme with my own set of beliefs having spent four years of an undergraduate degree in health promotion. Within health promotion theory it is believed that 'people have to be at the centre of health promotion action and decision making processes in order for them to be effective' (Nutbeam 1998: 354). Nutbeam (1998: 351) expands the theory of health promotion for the individual to 'changing social, environmental and economic conditions' which also addresses alleviating those conditions on the public. He states that participation is the essential component in order to sustain health promotion action. This can be linked to adult education's focus on social, environmental and economic conditions that underpin people's lives and impact their learning such as when Freire talks about adult education working as an agent to raising consciousness about peoples own situations (as discussed earlier in Chapter Two, 2.8). Nutbeam (1998: 351) also goes on to say that access to education and information is essential to achieving participation and the empowerment of people and communities'. As a result my research design and choice of methods were influenced by these background beliefs on health promotion and adult education. The idea of using a narrative research approach reflects the beliefs of each in that I wanted to allow the women a space to voice their opinions in a conversational manner without a pre-structured agenda (outlined further below).

3.5 The Research Process

The Research Sampling Process: Who and Where

I planned to carry out four one to one interviews with Traveller women. At the time I was hoping to get a mix of women that had been participants on the health education

programme (see details below) and women that never took part in the training. However, gaining access to women outside of the project proved difficult. I was unable to interview a Traveller woman outside of the project. One of the women asked a woman she knew to take part and I made contact with her; however, it became clear that this woman wasn't comfortable taking part in the research, upon reflection it may have been due to non familiarity. Therefore in-depth narrative interviews were carried out with the three Traveller women that I have worked with for over five years. I intentionally decided to choose three of the five women I had worked with. The three women that took part in the research were not chosen in any particular order rather whoever I managed to speak to first. Due to the work-based relationship with the interviewees I decided it best to use a different location to take the focus away from work and help encourage a non-work environment. I booked a small room from the local St Vincent De Paul which was easy to access for everyone and also somewhere familiar.

Interviewee and Project Profile

Each of the three women interviewed had undergone an adult education programme called a Peer Led Traveller Primary Health Care Project (as described in Chapter Two, section 2.1), which had been facilitated by a Traveller Organisation grounded in the ethos of adult education and community development principles. This training ran for three years and addressed a variety of subjects ranging from personal development and preparing for the workplace to health components such as nutrition, family health and developing health promotion events for the community. Each of the three women are now in their second year of employment as 'Community Health Workers'[58] a role which was the guiding principle of the project. Successful primary health care projects have emphasised a process that values empowerment, partnership and advocacy when designing and implementing health care interventions. The inherent approach is to work

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[58] The role of the Community Health Worker includes a number of elements; acting as a link between service providers and the community, disseminating health information and signposting to the Traveller community, identifying the health needs of Travellers as well as contributing to culturally appropriate health promotion materials.

'with' the Traveller community in order to develop a Primary Health Care project based on the Traveller community's own values and perceptions so that positive outcomes can have a long-term effect (Traveller Health: A National Strategy, 2002-2005; 60-61) The work of the 'Project' involves promoting health within the wider context of factors that can impact on the health of a community; social determinants of health, for example, poor living conditions, discrimination and access to services etc. Part of the role of the Project is to raise awareness on these issues with health service providers and others.[59]

Each of the women who took part in the research will remain anonymous and for the purposes of discussing the findings and analysis and will be named using the letters A, B & C. The following is an overview of each of the interviewee's findings from the research to set the context for the analysis discussion.

Interviewee A

Interviewee A - was the first woman that I interviewed and as a result gathered quite a lot of data with some not so relevant to the study. However, she was comfortable and didn't take much guiding from me. I addressed the general areas I wanted to research during the narrative interview. The interview was very much a collection of stories based on her personal experiences with health and being a Traveller. She spoke a lot about discrimination and health and discussed in length about trust and understanding between the settled and Traveller communities. She also addressed Traveller culture and compared the old and new culture and as a result the changes in Travellers lifestyles and attitudes.

Interviewee B

The second interview carried out was with a woman who has a long history of being an advocate in her community for years within the town. As a result she is well known and

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[59] http://paveepoint.ie/pdf/PrimaryHealthCare05.pdf pg 30 accessed on 15/05/2012

respected among the Traveller and settled community. She spoke with confidence and experience and also with a sense of purpose with her role as a Community Health Worker. She also spoke about the lifestyle changes in the community and the gender roles. Health promotion for the Traveller community was an area that was discussed as well as the affects of discrimination and poor literacy levels on health.

Interviewee C

The third interview I conducted wasn't as long as the first. This time I felt I was a lot more focussed on what I wanted to find out. Also the interviewee was not speaking as freely as interviewee A or B. This was due to the fact that she felt uncomfortable with public speaking and was a little put off by the recorder. She explained this to me beforehand and knowing her I understood. During this interview I had a constant underlying awareness of making her feel more comfortable and making sure that the experience she had was a positive one. I didn't want to leave her with a bad experience with research. However that said, she did offer a differing insight into her experiences and that of her extended family. She felt discrimination was not an issue for her or her family but spoke about the low literacy levels of some of her family members and the impact that has on them. She also didn't speak as strongly about her identity as a Traveller as the other two interviewees.

How – Techniques Used to Collect Data

The following sections outline the methods used to collect the research data including; research design, what changed during the process and details of methods used.

Research Design

Questionnaires tend to be the most dominant research tool used to measure health literacy (as illustrated in the research cited in the literature review) however; the aim of this research was to measure the women's knowledge and experiences of health literacy. It became clear that a questionnaire was not the preferred method of research to gain an

insight into these areas. Upon reading all of the research previously conducted in the US, Canada and Europe it was clear that using a questionnaire or a more qualitative approach did not capture a measure of critical literacy which I felt was core to this research project. All of the tools developed to measure literacy measured functional health literacy and not critical health literacy. Because I wanted to find out more about their knowledge and experiences of health literacy I felt that this reflected what was defined by Nutbeam (2000) as critical health literacy - more advanced cognitive skill, building on the levels described above to critically analyse information. He likens this third level with the style of education for critical consciousness advocated by Freire (1970). Nutbeam believes that this concept of raising consciousness in adults can help them achieve critical health literacy skills. Therefore due to the fact that there is no tool developed to measure this area I felt anxious about how I could ask the right questions. Nutbeam (2008) feels that the questionnaires used to measure health literacy are a limited measurement tool due to an inability to measure critical health literacy in favour of a concentration on the measurement of functional health literacy (basic skills in reading and writing encompassing a more narrow definition of health literacy based on patients having the ability to read appointment cards, medicine bottles etc. according to Nutbeam, 2000). He believes there needs to be more work done in developing a tool to measure critical health literacy – how people access, understand and use health information which will require an additional assessment of oral literacy and social skills. I believe the use of narrative research can capture this dynamic and reflective nature of critical health literacy which can probe and develop answers more suited to the narrative and oral style of this group.

The Narrative Interview

The qualitative narrative research method I chose based on reasons outlined above led me to an unknown path of an unstructured narrative interview. The nature of this unstructured interview means that the researcher does not have a developed set of questions to read from in the interview. Instead the researcher will follow the flow of the conversation while adhering to a number of topic areas that he/she wants to gain knowledge on. Etherington (2011) describes how reflexivity is necessary component in this research process whereby the researcher is having an 'ongoing conversation while

simultaneously living in the moment' and talks about research through collaboration and being co constructed.[60] This type of research captures the participant's experience of health literacy rather than a more quantitative 'functional health literacy'.[61]

It took me some time to be content with how important it is to allow the conversation to flow and develop without having an agenda or questionnaire in front of me. I did however outline the areas I wanted to address which included the following;

- Explaining to the women what is meant by health literacy – a simple definition

- Finding out about Traveller culture, what it's like to be a Traveller, a Traveller woman and what it means to them

- Their previous experiences in education and going back to education as an adult

- Travellers and literacy – their insight into literacy difficulties in the community and how it affects their health

- What does being healthy mean to the community, what affects Travellers health, accessing health information, experiences with health care professionals and in health care settings

Methods used

The methods used to collect the data were a voice recorder and a phone recorder. At the beginning of each interview I spoke to each woman about using the recorder and made sure they were comfortable with it.

At the beginning of the interview I explained a simple definition of health literacy [62] to the women and gave an example relating to their work to help set the context of what I

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[60]

http://www.keele.ac.uk/media/keeleuniversity/facnatsci/schpsych/documents/counselling/conference/5thannual/NarrativeApproachestoCaseStudies.pdf accessed on 5/6/12

[61] Functional Health Literacy is described as basic skills in reading and writing encompassing a narrow definition of health literacy based on patients having the ability to read appointment cards, medicine bottles etc (Nutbeam, 2000:263-264)

wanted to find out more about. I felt it was important to ask the women about Traveller culture for two reasons, firstly to set the context with the backdrop of the literature but also to help ease the women into a flow of conversation. In some instances I knew a lot of what was being discussed but I had explained to them that in order for the reader to gain knowledge they needed to forget that I already had some of this knowledge myself from our years of working together. Another piece of learning for me was how important it was and is to listen to the women without having an agenda; I felt that it was a very insightful process for me personally as well as professionally. Clandinin & Connelly (1990) refer to the importance of the researcher listening to the participant's story which will in turn give them a voice to gain the validity of that story (Clandinin & Connelly, 1990:4).

I also asked some background questions about their level of education, their experiences in school and why they decided to go back to education and consequently their experiences as adult learners. This helped me explore some more into their attitudes on education, how they have evolved from childhood and if it has become a priority for their children. I wanted to gain an insight into the prevalence of literacy difficulties within the community and how that affects health. I felt it was important to get the women to think about the link between health and education and their opinions on it. I also asked the women about health information. Where they got their health information? Where they felt that members of the Traveller community accessed health information and if the information is accessible and culturally appropriate? I mentioned experiences with health professionals and got them to elaborate on what they believe health means to them and their community.

Techniques used to Interpret Data

All of the interviews were transcribed fully. I decided the best way to interpret the data was to identify themes which were used as coding categories to identify and organise themes throughout the interview transcripts. This worked well for me as I felt the

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[62] Health literacy means being able to understand basic health information in writing for example a health promotion leaflet or in person for example the GP and to also be able to use this knowledge to make healthy decisions. Adapted from healthliteracy.ie definition available at http://healthliteracy.ie/what-is-health-literacy/ accessed on 21/05/12

conversations fell naturally into areas such as education, culture and health. I read carefully and in detail through the transcripts to identify the areas that I felt was re-emerging and developed them as the overall themes and sub themes. I drew up a table of topics that were discussed and categorised them thematically (fig 1.1). Five major themes emerged from the research. Two areas; discrimination and transformation dominated the data and ran throughout all of the themes. The other three themes reflected the review of literature I had conducted and the three main areas I chose to research in the narrative interviews - Traveller culture, education and health. Within these themes emerged a number of sub-themes which will be addressed in the analysis under each major theme heading. The chart below (fig. 1.1) illustrates how the themes and subthemes are positioned and it reflects the commonalities and diversities of the research data.
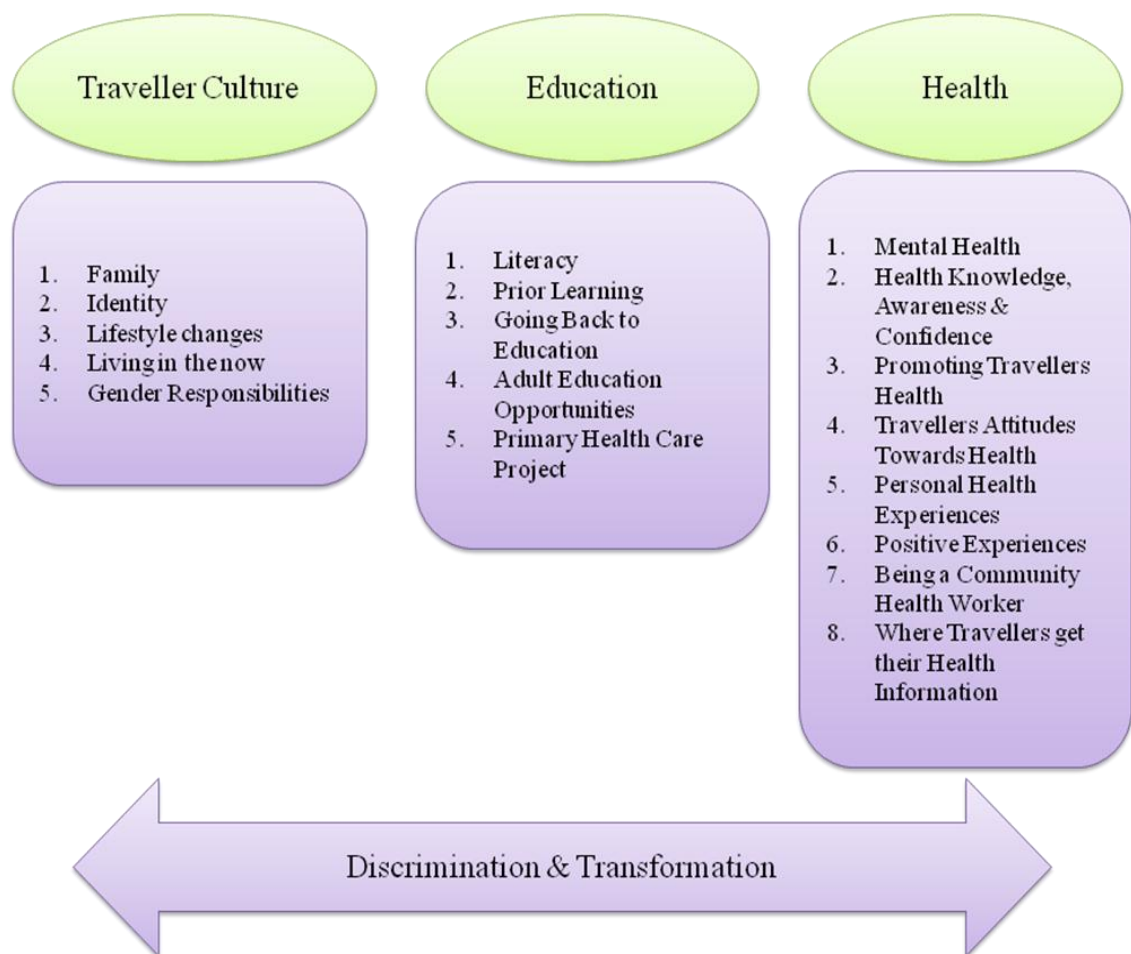

Figure 1.1

3.6 My reflection on the process: challenges and limitations

What worked and what I could have done differently

 I did consider taking a medicine bottle or label into the interview and decided against it later on. The reason why being I was reluctant to make the interview about functional health literacy (Nutbeam, 2000). I felt that this would have led me down another path - one which is a valid research area - but which may make me lose sight of what I set out to do. I felt that this may also develop a measurement or 'testing culture' in the interview which I wanted to avoid and would not be conducive to the nature of the research area. Instead I wanted to develop a narrative conversation style interview that would flow naturally to each of the topics I wanted to investigate as outlined above. Upon reflection, each interview went very differently. Two of the women were extremely comfortable with talking with the recorder; however one of the women felt nervous and intimidated by it. During that interview I put a lot of time into putting her at ease and being more direct with my questions. I was anxious about her having a bad experience with this type of research and I didn't want it to knock her confidence as she gave me a different and valid insight into the issue than the others.

Taking the interviews out of the workplace setting was a positive experience as it created an opportunity to have an honest discussion without the weight of role expectations. I made it very clear from the outset that I was not there as their Coordinator and to look at this as a conversation rather than an interview. However, the downside of doing it in another location was the difficulty in finding the time of day to suit the women outside of their working hours without impacting on their family time.

Personal Learning Journey

Due to my experience in working with these women I had quite a lot of insight into each woman's life and educational circumstances. That said I do feel that the interviews offered me a different insight to that of being a colleague. I felt enormously privileged to have an opportunity to discuss their stories. Before conducting the research I felt that it may be a negative impact that I already had a relationship with these women on a work capacity. Interestingly, I believe that that relationship encouraged a very honest

response and therefore more valid research data. This in part was due to a pre-existing mutual trust between the interviewer and the interviewee. It has been said that one of the elements required for narrative inquiry is trust and openness in the research relationship.[63] From the outset I was concerned with giving a voice to these women in an ethical way as I feel that it is imperative to all research with vulnerable groups that the researcher has a responsibility to stay true to the voice of the interviewee.[64] When I made contact with the women I had a very positive response. All three were very interested in taking part, not just because of the relationship between interviewer and interviewee but also because they wanted an opportunity to have a voice on the issue. I felt as their Coordinator for five years there had been a massive progression in confidence and trust. This confidence and trust had got them to a point where they felt very comfortable sharing honest stories with me. Clandinin & Connelly (1990) state the importance of all participants having a voice in the relationship which implies a connected knowing relationship between participant and the researcher, this way of knowing they believe helps give the participant a voice (Clandinin & Connelly, 1990:4).

Challenges & Limitations

Looking back at the research process I am really glad I persevered with a narrative approach as it was the right method to use for this research; however it did not come without its challenges to me as a researcher. As outlined above the nature of the unstructured interview was new ground and challenged a quantitative method of questioning more associated with health research. Also not being able to interview the fourth woman who was not a part of the Primary Health Care Programme was a disappointment at first. However, it did guide the research into a more focused area of critical health literacy. Some other limitations included the vast amount of narrative data collected in the first interview which took its toll on the transcribing process. Also, keeping a focus on the area I wanted to research was a challenge in itself due to the wealth of information gathered on a range of areas from the women.

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[63]http://www.keele.ac.uk/media/keeleuniversity/facnatsci/schpsych/documents/counselling/conference/5thannual/NarrativeApproachestoCaseStudies.pdf accessed on 5/6/12

[64] http://www.bera.ac.uk/system/files/3/BERA-Ethical-Guidelines-2011.pdf accessed on 2/6/12

3.7 Ethical Considerations

From the outset I was constantly aware of my responsibility in representing these women's stories and opinions in a way that reflected truthfully. I also felt a sense of responsibility about giving these women a voice. My consent form was written in a manner that included simplified language with a simple definition of health literacy. At the beginning of each interview I allocated time to the interviewee to read it and ask questions after I read it aloud first. The British Educational Research Association (BERA) outline that researchers must take the steps necessary to ensure that all participants in the research understand the process in which they are to be engaged, including why their participation is necessary, how it will be used and how and to whom it will be reported. They also outline that researchers must recognise the participants' entitlement to privacy and must accord them their rights to confidentiality and anonymity.[65]

3.8 Conclusion

Overall, I believe the methods used to collect the data were positioned as the most appropriate for this research. Narrative inquiry encouraged an honest and insightful space for these women to express their knowledge and experiences of health literacy, what it means for them individually, their families and their community. As a researcher it was a challenge to not base my data collection on a questionnaire and to not focus solely on measuring reading and writing skills. However, it is noted that measuring 'critical health literacy' is a difficult process and one which has no previously developed research tools. In the next chapter I will discuss the findings and analysis of the data.

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[65] http://www.bera.ac.uk/system/files/3/BERA-Ethical-Guidelines-2011.pdf accessed on 5/6/12

CHAPTER FOUR

FINDINGS & ANALYSIS

4.1 Introduction

4.2 Traveller Culture

Discrimination

Values and Identity
Identity
Family
Religion
Living in the Present
Gender Issues
Changes in Culture – Effects on Lifestyle

4.3 Education

Prior Educational Experiences
Going Back to Education – the Primary Health Care Programme
Literacy
How Education Affects Health

4.4 Health

Being Healthy & Travellers Attitudes towards Health
Generational Transference of Health Information
Word of Mouth

Barriers Affecting Travellers Health Status

Fear & Understanding

4.5 Health Literacy

Experiences

Knowledge

Literacy Friendly & Culturally Appropriate Materials

Being a Community Health Worker

4.6 Transformation

Confidence

Consciousness and Awareness

Change in Attitude/Perspectives

4.7 Conclusion & Recommendations

4.1 Introduction

The following chapter discusses the implications of the findings of this research in the context of the review of literature. The analysis will be based on the themes that emerged from the data and will examine and discuss the meaning of each topic area.

4.2 Traveller Culture

When I asked the women about their culture, there were commonalities in their response including the following elements: the culture changing over time, the strong value on religion and family and the role of women or mothers in the community;

> 'Traveller culture has both tangible and intangible elements. The tangible elements are associated with behaviour and tradition. They can be seen in Traveller nomadism, in the way Travellers organise their economic activity and in the family structures within the Traveller community. The intangible elements are associated with values and beliefs. These are less visible and harder to define at any particular moment. (Traveller Health, A National Strategy, 2002-2005: 14).

As outlined earlier in the study it can be said that culture plays a major part in shaping perceptions of illness and health, which will in turn influence peoples experience and attitudes towards health and the health system (American Institute of Medicine, 2003).

Discrimination

It can be said that Travellers experience widespread discrimination and racism in Irish society. As discussed in the review of literature, a study recently conducted by Pavee Point found that 60.1 per cent of respondents would not welcome a Traveller into the family because of their "way of life" and because it was "not socially acceptable".[66] The

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[66] http://paveepoint.ie/sitenua/wp-content/uploads/2012/02/VAW-Best-Practice-Guidelines-for-Service-Providers.pdf page 2, accessed on 20/05/12

women researched expressed to me a sense of pride in their identity and although discrimination is a challenge, it will not impact on their strong sense of identity. However, due to the women interviewed being positioned in a lead role within the community and working closely with service providers, they expressed that their experience of discrimination is of as lesser extent to the rest of the community. In addition to this, one woman (B) said she never has experienced direct discrimination and said it is not an issue for her and her family. The others who have dealt with the impact of discrimination in the past or to family members talk about how it is hard to explain the feeling to someone who has never experienced it, the *'embarrassment'* and *'feeling small – like a doormat'* and they mention the implications for mental health. One woman (A) places a lot of value on how important it is to earn trust with the settled community. She spoke about how she was reared with settled people and as a result has an understanding and a respect in the place where she grew up. However, she described the difficulties to me when she moves to another town and this trust is no longer there. She said *'I can get on with them and they can get on with me ... but I think if I wasn't taught how I was taught when I was growing up that there would have been a barrier of some kind'*. She also said that bad experiences can be passed down from one generation to another unless the cycle is broken. She talked about *'trying to build up a foundation with them* [the settled people]*.'* She admitted that this is challenging as it is *'an awful feeling'* but she also says it can be a good feeling *'when I get that appreciation'*. She said that the responsibility to make changes lies with both communities.

The AITHS (2010) findings outline the negative impact of discrimination and disadvantage on Travellers' health and wellbeing and that as a result this will have a damaging effect on self efficacy and self esteem. This mirrors the data here when the women describe the emotions associated with being a victim of direct or indirect discrimination as *'feeling small'*. The women in this study recognise themselves the damaging affect this has on mental health in their community. Perhaps the most shocking of findings from the AITHS (2010) is that suicide in the Traveller community is 6 times the rate of general population and accounts for approx 11 per cent of all

Traveller deaths which proves that mental ill health is a real issue within the community.[67]

Values and Identity

Identity

When discussing what it means to be a Traveller the women as previously mentioned, had a strong sense of identity and pride in being a member of the community, while also recognising the challenges that comes with it. (A) recounted *'I'm proud of the way I am, but in certain parts and times in life it's tough', 'I don't care what people call me, I am what I am'*. One of the women (B) reflected on her role within the community and how that impacts on her identity when she says *'It's hard enough to be a Traveller ...there is still a lot of discrimination out there ... I'm a Traveller but I'm also a Primary Health Care Worker working here with my community ... I find I am doing good ... I am proud to be a Traveller'*. Another woman (C) said *'being a Traveller means normal because I've always been a Traveller so it doesn't mean anything different ... being a Traveller means very much to me'*.

Family

It was easy to depict from the research that Travellers values include; family and the wider family unit and religion. When the women spoke about family, they expressed that no matter what the circumstances family comes first. For example, one of the women (A) left school at an early age due to her mother being ill so she could take care of the other children. *'they wanted us back in school for permanently but no I couldn't do it because I had to wait at home and help with the family because my mother wasn't well god? be good to her'*. This decision wasn't seen as a choice because *'family always came first'*. One of the other women (C) also expressed the same view and draws comparisons with the settled people when she says *'all the family lives sorta together, all the settled people move away and they can live all over the country but we don't. We sorta stay together'*.

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[67] http://paveepoint.ie/pdf/Summary%20of%20main%20findings.pdf accessed on 24/05/12

Religion

One woman (C) when I asked her about religion answered that *'I wouldn't go saying to people that 'oh religion is big to me' because it is big to them as well. But in the Traveller community, like religion would be like communions, confirmations and things like that, weddings. They go to more expense, not even expense, more big days than the settled people would do'.* She then went on to say that these are the steps going towards marriage. None of the women spoke directly about marriage but in this case it is a given that it will be an outcome in every Traveller child's life.

Living in the Present

The women also spoke about how Travellers live each day as it comes and very much live in the present. A talked about *'Were all living and day by day, we cant take anything for granted...I wont plan nothing for tomorrow...I hate planning diary'*. We spoke about how Travellers would generally have an attitude of living in the present. She also spoke about putting the sign across her face in the morning and hope for the best that day. This reflects on the strong undercurrent of religious beliefs and faith that the community has. One woman (A) also placed value on teaching her children to earn trust and a way in life. She believes these to be of most importance and says *'you gonna earn it and you're gonna respect it, you're not going to take it for granted'.*

Gender Issues

Two of the women described the role of the woman in the community and spoke about how this has also changed over the last few years. *'The mother, a woman in the Travelling community, your expectations is to be at home to look after your children, to clean ... to do whatever you have to do, to have kids and be there' (B).* A lot of weight is placed on the role of the woman being a mother and child-bearer. She spoke about her own experiences as not adhering to the cultural expectations and as a result she believes things are changing for women. However, she did not believe that things have changed for Traveller men and says that he was always the head of the house, the dominant

figure that the boys would follow. The second woman (C) said that she is not the norm in her community as she is *'well able to speak up for herself'* and that her husband wouldn't be a normal Traveller man *'like other Traveller men probably boss their wives a lot but that wouldn't go on in our house'*.

As discussed earlier, it can be argued that Traveller women experience triple discrimination: discrimination as women, discrimination as Travellers and discrimination as Traveller women[68]. The Traveller culture is characterised by proud patriarchal dominance (AITHS, 2010: 125) and as outlined in the data generally within this community, it is common place that the women obey the men.

When I asked about the role of women in the health of the community, interviewee B said that today *'they would [have a role], the mother would be the one that would investigate more into it and find out more ... brings the child to the hospital'*. Another (C) said *'she has to do that, when they're sick or sore it's the mothers job ... immunisations ... feeding them, its all down to the mother'*.

Traveller women play an important role in their immediate family and the wider Traveller community. They have responsibility for the home, family and children. Most of the time they are the ones who communicate with service providers and often take a lead role acting on behalf of the community.

This is supported by the literature that suggests that women are more likely to take responsibility of the health of their children and relatives. This therefore implies that women are a key conduit to health promotion and education within communities[69] (Kickbusch et al, 2008).

Changes in lifestyle – Affects on Culture

When talking about Traveller culture, two of the women felt that the culture had changed or is changing from what it was and expressed that this has negative

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[68] http://www.paveepoint.ie/pdf/Factsheet-women.pdf accessed on3/4/12

[69] http://www.emhf.org/resource_images/NavigatingHealth_FINAL.pdf accessed on 11/6/12

connotations as a result. One of the women (B) spoke about how Travellers are trying to keep their culture but it is *'dying away slowly'*. Another woman (A) expressed that drugs and alcohol is a major problem in the community and she says that '*if the way of Travellers life was left the way it was going back a few year ago it wouldn't be happening in our community today'*.

They spoke about Travellers moving from the roadside to houses and that this has happened due to a number of factors. The women listed the unavailability of land or property to park and constantly being moved along by local authorities. The women (A & B) describe the eradication of nomadism to me as being *'put into houses'* and *'forced off the road'* and most notably having *'no choice'* about it. But also, one of the women spoke to me about the changes in attitudes towards nomadism in the community when she says, *'my family now they're going to want houses, they're going to want homes, it's not going to be caravans ... there's no such thing as people in properties letting Travellers wait there today'*.

The results of the All Ireland Traveller Health Study (2010; 119) echo the women's view on nomadism in its findings that the Travellers that took part in the study wanted to reserve the right to travel. This general feeling of a loss of nomadism reflects the actions taken criminalising trespassing as discussed in section 2.1.

4.3 Education

I asked each of the women about their previous educational experiences in school and their perception of the impact education has on Travellers' lives and health status. I also enquired what it was like for them to go back to education as adults and their opinions on literacy levels within the community today. The following is an account of those findings. All of the women involved in the research spoke about the importance of education for individuals and the community and expressed a link between education and health status.

Prior Educational Experiences

All three of the women interviewed said they left school at an early age. This seems to be common practice in the community and not one restricted to the older generation (as evidenced by the experiences of one of the women interviewed who is under 30). The reasons why the women left school at primary level were various but centred on a responsibility towards the family, getting married and to earn a living. Another reason was due to a bad experience making the transition to post primary level; *'you were just threw, sixth class was great, teacher was great the whole way up ...when you go over to the bigger school you were just threw in with all the other children... you're made to this and made do that and you wouldn't be able to do it'* (C). The woman (A) who left school due to family commitments spoke about learning through the other children when she was at home and her own children; *'I was picking up from them as well [her siblings] ... and for looking at them and watching them they gave it to me [her children]'*. She went on to say that she has told her children that *'mammy doesn't know it and I need ye to go to school because mammy didn't have the opportunity to do this and I want ye to get it and do it because I know how bad it is ... it affects your everyday life'*.

Going Back to Education – the Primary Health Care Programme

When addressing going back to education all of the women spoke positively about that experience generally; however starting out caused some embarrassment. One of the women (A) spoke about the opportunistic way in which she enrolled in the Primary Health Care Programme[70] and had that not happened she would not have sought out a place in an adult education programme due to embarrassment; *'it was all through embarrassment that you just wouldn't look for a class through my age and having six kids'*. She said the course *'was a godsend'* and it worked out for her financially to attend. She said it was hard at first but; *'this is want I want, this is what I want to do'*

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[70] The Primary Health Care Project was first established in Pavee Point and after it being outlined in the Traveller Health: A National Strategy (2002-2005) as the cornerstone of the strategy it was rolled out to all areas with a significant Traveller population. The project was an education programme which trained Traveller women over 3-4 years on health promotion for their community. The outcome of the project was that those women would qualify as Community Health Workers. The project was based on community development principles and typically was co-ordinated by Traveller Organisations.

and her aim was *'to be of some help to somebody'* as a result. Another woman (B) was always involved in her community through courses and *'was always interested in my community'* and actively *'looked out to see if there was anything else I could come into'*. She highlighted the restriction of literacy as a barrier in access to education for many other Travellers as *'a lot of them want to go back to education, a lot of people would like jobs but they cannot read or write'*. The third woman interviewed (C) said she was glad she went back to education due to the long term aim of the programme to bring health to the community.

Earlier the theory of participatory health education was examined in relation to how health literacy can be addressed within the adult education sector. Rudd (2002) believes health topics in an adult education setting would motivate the adult learner when analysing the collaboration of both sectors. In evaluating a participatory health education programme Norton et al. (1998:245) observed that the participants developed knowledge and skills to make improvements to some aspects of their health but also they valued being with their peers. The Primary Health Care Project is based on women learning about health with their peers with the aim of becoming peer educators themselves. Health Canada (1998) acknowledges how important partnerships are with the health sector and peers within the target community. It can also be argued, similar to the findings of AITHS (2010, 126), that the opportunity for these women to train in the project has afforded contact, support, trust, knowledge, payment, structure, social separation (from spouse, family and home) and promoted self esteem and confidence.

Literacy

All of the women interviewed spoke about literacy issues within the Traveller community. The older of the two (B) said *'when I was growing up there was no literacy, none of them knew how to read or write. There was school alright but you could be here today and gone tomorrow* [referring to the nature of nomadism] *and it's no fault of the schools or anything else, like its just that we were people that travelled around ... we never stopped enough in a place to get education'*. It is interesting to note here her response to the broader systemic discrimination of an education system that

didn't respond to Travellers cultural values or norms and as a result she internalises this to defect the social responsibility.

The other woman (C) spoke about the literacy difficulties within her own family when she said; *'my father cannot read, my two brothers cannot read or write'*. She described how her brothers also left school early due to bad experiences – she says *'there was never any time for him, he was never learned how to read or write, they just wanted him out of the school'*. When I probed her if this was due to discrimination, she didn't believe so and attributed it to him being a *'trouble maker'* due to the majority of Travellers attending the same school. It can be said again here that the education system and schools were unwilling or unable to respond to the needs of the children whether it is due to cultural or behavioural issues. Kathleen Lynch (1999) acknowledges this in her work on equality and education when she says 'if one's cultural traditions and practices are not a valued part of the education one receives, if they are denigrated or omitted, then education itself becomes a place where one's identity is denied or one's voice is silenced' (Lynch, 1999:17). Hargreaves et al (1996) also addresses the failure of the system in supporting young adolescents when they say

> 'the failure of large numbers of secondary schools...to support and care for young adolescents effectively is one of the most striking themes in the literature on the sources of dropout and on the nature of secondary school life …Yet, the personal and social needs of early adolescents are paramount for their well being now, and for their chances of academic success, social responsibility and personal fulfilment in the future. Much of the rhetoric of educational reform…show[s] a distinct lack of sympathy for anything that is not tightly disciplined, strictly academic and narrowly focused on the immediate task of learning.' (Hargreaves et al, 1996: 56)

She insightfully talked about literacy itself; *'literacy comes in a lot of forms isn't it? It's not just reading you need to be able to understand, it comes in loads of different forms like'*. When we discussed Travellers' opportunities in education such as having the opportunity to attend a programme similar to what she trained in (the PHCP), she said *'would you get them to do it? It could be embarrassing enough; it would be great though ... for people that couldn't read'*. She also said there should be more

opportunities for Travellers with literacy difficulties within adult education provision *'to get them through life'*.

It is interesting to note that all of the women recognise that literacy is not just the ability to read or write; instead it is much more than that. The women attribute their personal experiences with literacy to the education sector; it could be argued that the inability to support the culture of nomadism in educating Traveller children and the mainstream provision of learning without support for children who learn in different ways contribute to Traveller adults' literacy difficulties.

How Education Affects Health

Two of the women spoke about the impacts that education has on an individual. One woman said;

> *'without education you haven't go anything ...you cannot read a label on a bottle ... you haven't got the confidence, you haven't go the self esteem to stand up and ask the doctor anything because you're made so low because you don't, if only you had a bit of education, reading or writing to read that letter that comes through your door, not having the embarrassment of asking your neighbour. These little things and also if you haven't got, I think affects your health' (B).*

The status and role of the medical profession as being unquestionable and authoritative can be compared to the notion of the teacher - student relationship of the teacher as the expert as developed by Freire (1970). Freire (1970) refers to this as the 'banking model' where the teacher fills the student with the knowledge deficit thereby disempowering the student in their own learning. The other woman (C) interviewed echoed the similar thoughts as the previous participant when she said *'without education you have nothing really at the end of the day coz it you haven't go your education you cannot read ... you don't know what's wrong with you'.*

4.4 Health

Health, along with education was the major themes throughout the research and within that a number of subthemes reoccurred throughout all three narratives. All of the women interviewed referred almost immediately to their role as Community Health Workers.[71] The other featured commonalities included: the link between education and health, the link between literacy and health, their view on being healthy, barriers affecting Travellers health status and literacy and culturally appropriate health promotion materials.

Being Healthy & Travellers Attitudes towards Health

At the start of each interview, I asked each of the women about what being healthy means to them and their community. I felt this was a good starting ground which would give an insight into their attitudes and views on health and what health means to them. Interestingly, two of the women spoke about mental health and stress here. One woman (A), when asked how she would describe being healthy, told me it's *'everything, your mental health especially, if your mental health is not fine you could be sick and you wouldn't know ... your mental health has a lot to do with your everyday life'.* This woman also drew a link between the effects of discrimination and mental health and said how upsetting it can be when a Traveller experiences direct discrimination[72] and the stress that that can cause an individual. Another woman said that she feels Travellers are now becoming more aware of their health which has also been reinforced by the visiting Community Health Workers continuously raising awareness within the community of health topics. However, she felt that the results of the All-Ireland Traveller Health Study (discussed in the review of literature) suggests that there are real tangible health issues within the community as reflected in the shocking statistics on life expectancy - the gap in life expectancy between Traveller women and settled women is

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[71] The role of the Community Health Worker includes a number of elements; acting as a link between service providers and the community, disseminating health information and signposting to the Traveller community, identifying the health needs of Travellers as well as contributing to culturally appropriate health promotion materials.

[72] Refers to when a person is treated less favourably than others on, for example, grounds of 'race', colour, ethnic origin, nationality or citizenship http://paveepoint.ie/submissions/06-Mental-Health.pdf accessed on 21/05/12

11 years and Traveller men and settled men is 15 years.[73] She said the results of the study have influenced Travellers and the way they view their health. She explained '*when the results came back we were able to give it to them on a dvd and they seen that there is ways out there to help*' she also said Traveller organisations nationally have drawn media attention to these results which have also contributed in raised awareness among the community '*primary health care women on television programmes talking about health*'

Generational Transference of Health Information

Some of the women spoke about the importance of passing on health information to their children and how being a part of the Primary Health Care Programme has helped them influence the health of their families for the future; to '*make changes for your children. It's how you're brought up from the seed up' (A)* outlining that health information is passed down in the community by the parents. This is supported by Ratzan (2001) who advocates a lifelong approach to health literacy through constant learning about health all thorough life and introduces the idea of generational transference of health literacy. This form of health literacy should be recognised within the health sector and Primary Health Care Programmes as another method of addressing Travellers' health status over time.

Word of Mouth

One of the women (A) described how Travellers pass information to each other through oral traditions of word of mouth and says it's never through printed materials. She told me that families would talk a lot about health between each other and would learn from each other as a result. If health information were to be promoted in this way, she said '*it will be carried on*'. Health Canada (1998) as addressed earlier in the study acknowledged that many people with low literacy levels will get most of their health information through word of mouth. This idea of Travellers passing information on

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[73] http://paveepoint.ie/pdf/Summary%20of%20main%20findings.pdf accessed on 22/05/12

through word of mouth is recognised, adopted and used by the Primary Health Care Programme in their work in addressing the health status of the community.

Barriers Affecting Travellers Health Status

Fear & Understanding

When talking about Travellers' poor health status, the women gave an insight into some of the factors contributing to this. One woman (A) said *'Travellers are very private and tend to keep a lot to themselves, a lot of them is afraid of going to the doctor, of what he or she is going to say to them and half the times if they went in and found out the majority of them will be alive today'.* She also went on to say that some Travellers do not understand the long-term importance of maintaining their health. She gave the example of immunisations; *'Because they think the child is alright that there's no need to go'.* This could be reflected as discussed earlier in Travellers attitudes of living in the present and religious beliefs of religious faith towards the health of the family.

4.5 Health Literacy

All of the women spoke about the importance of literacy in an individual's life as well as its links to health status. They referred to the literacy issues within their own community and families as discussed earlier, the barriers associated with complicated language used in the health service and health promotion materials and the area of health literacy. As outlined earlier (Chapter Two, Section 2.4), health literacy has a number of different definitions reflecting different interpretations of the term. However, for the purpose of this study Nutbeam (1998:357) definition will guide the research 'health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health'. In addition to this definition it is also crucial to add that information only is not enough to address the many challenges faced by marginalised communities (Kickbusch, 1998). Therefore health literacy is also about the

empowerment of individuals and communities to achieve better health literacy. Which leads the study to the concept of applying Freire's theory of consciousness raising to achieve critical health literacy[74].

Experiences

One of the women (A) talked about her experiences before she went back to education, describing the impact her low level of literacy had on her family' health at that time: '*I used to get somebody to read it for me ... appointments for my brothers and sisters, I usen't be able to read digital time, I knew the other time ... I often asked a neighbour and they'd read the digital time to me, I'd get them to read the letter again to me so I got it right, so that I'd know*'. AITHS (2010:48) showed that 49.6 per cent of Travellers reported difficulty in reading the instructions on prescription medications. This is compared to 9.4 per cent of medical card holders from the SLAN Survey (2002). This illustrates that nearly half of all Travellers have difficulties in functional health literacy. This in itself coupled with the data from this research exposes health literacy as a major issue within the Traveller community which in turn has massive detrimental affects on their health as outlined in earlier chapters.

Knowledge

Another one of the women (B) talked about her view on health literacy when she said '*to ask a question when you go into the hospital and your child is sick and you think right I'm handing him over to the nurses and doctors will you be able to stand up and say can you tell me what is wrong with that child? Can you tell me what's you've given my child? ... Do you have the confidence to stand up and say that? As I do say to the Traveller women, yes you have a right to ask what they are doing or what they're not doing'.* It can be noted here that she is challenging the expert authority of the doctor and encouraging women to question this notion of the banking model as developed by Freire

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[74] Critical Health Literacy according to Nutbeam (2000) is described as a more advanced cognitive skill, building on basic and interactive health literacy to critically analyse health information liken to the Freire style of education for critical consciousness.

(1970). At the end of the interview she said *'if you cannot read or write, naturally your health is not going to be the best and there's not a thing you can do, you could go into your doctor he could be talking about your blood pressure and you wouldn't know what's written on that, it could be 180 over 90 and you wouldn't have a clue'.*

This reflects on the theory of clear communication as developed by Rudd (2009) when she stressed the importance of clear communication in easy to understand language within the health sector. She mentions the barriers of medical jargon, the assumptions of health professionals of patient's literacy levels and health materials' reading levels. She advocates strongly that the health sector has a responsibility in clear communication but in addition to that cross-sector collaboration between public health and adult education is needed to address these issues.

The third woman (C) interviewed talked about her experiences with health literacy with her family. She spoke about her father being stressed as a result of poor literacy and how being asked to fill in forms is '*a shaming thing for him'* or being at the doctor and her mother calling the doctor to find out what happened as her father wouldn't be able to explain it. She also talked about her Grandparents' experiences *'they have to come back, back like with the letter and they have to bring it to someone to read to for them. Or if she's* [her Grandmother] *down town in the shop she'd have to take the sticker off the thing down town that she's looking at and bring it back to see how much it is. It's not; it's an awful way to be living'.*

Literacy Friendly & Culturally Appropriate Materials

All of the women agree that health information materials should be easier to read and literacy friendly for the whole population not just Travellers. They believe also that doctors have a responsibility to speak in simpler language to people with literacy difficulties and to be more aware that patients may have difficulties. The National Adult Literacy Agency (NALA) have been developing resources and campaigning to raise

awareness among the medical profession in using plain English in health materials and in oral health messages[75].

'For the Travellers that cannot read, it's very hard for them to know what's wrong with them? They might know what's wrong with them but it,s very hard for them to know what they're looking for at the doctor and the doctor comes out with all these big words, it's hard for people to understand'. (C)

Another woman (A) talked about making health information materials more accessible to the Traveller community and the wider community with literacy difficulties; '*in some ways they should be more appropriate to Travellers but in some others that have education and if they haven't got it, their chider would have it to read and write'*. When I asked her about whether she thinks they should be more literacy friendly she said *'yeah not as big words ... and more pictures explaining what this leaflet is about'*. She talked about how this is a barrier to the health of the community and referred to her own father not being able to ask the doctor what he meant if he didn't understand something. She felt that Travellers should be saying to the doctors '*doctor what did you mean by that word?.'* She said that some Travellers will not ask this question. She told me she encourages her own children to ask the doctor if they do not understand something. She said '*I'm not saying that Travellers is dumb, but what I mean is ... there's settled as well that don't understand words'*. She expressed the view that the doctor should be explaining health information in plainer English, slower and not using the big words because she said *'the big word they were using could be the word to save their life and they mightn't understand what is mean'*.

Another woman (B) said '*we still as members of the Traveller community have a lot of difficulties with medical jargon'*. She went on to say that '*I've been at meetings where I have seen educated people better than myself and they are not able to make out some of the jargon that's out there, like so it's not just Travellers'*.

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[75] http://www.nala.ie/content/plain-english-campaign-0 accessed on 6/6/12

As outlined in the earlier in Chapter Two (Section 2.5) Kickbusch et al (2006) advocates for health information to be culturally appropriate in targeting an audience and also in order for meaningful language and communication to being used input from that target audience is essential.[76] Also earlier in the study it was outlined by Hohn et al (1997) that health education is accomplished primarily through print material for skilled readers and Norton (1998) agrees that these methods used to reach populations are developed with people with mainstream educational backgrounds. This can also be reflected in the health promoting materials produced by the HSE and NALA's campaign advocating for the health sector to introduce plain language materials[77] to address these issues. However it needs to be recognised by the Government that literacy difficulties is not just about reading and writing but also has an impact on the health of communities as we have seen here the Traveller community.

Being a Community Health Worker

The women spoke positively about their role as Community Health Workers and attributed that role as an instrument to generate change in the health status of the community. Some of the comments on their role included;

'Us to make a better life for Travellers now' (A)

'Us going out ... they practically know us around here now, they're used to us now, do you know what I mean? That when they see us they expect something off us... it has a big influence on them [Community Health Workers Outreach work] *because... it's the trust because when we are sitting down talking to them like you know ... and I'm giving them this leaflet and I'm telling them read it when you get time'. (C)*

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[76] http://www.emhf.org/resource_images/NavigatingHealth_FINAL.pdf accessed on 6/6/12

[77] http://www.nala.ie/news/free-plain-english-training-health-sector accessed on 24/05/12

'We work with services and we try to break all these things down [medical jargon] so that the Travelling community that they cant read or write or no education at all that they can understand this...' (B)

'We are getting a lot of things out there for our community that they wouldn't know anything about'(C)

I think it's a very positive thing [Community Health Workers' outreach role] *and I don't just think it's the Traveller community that needs Primary Health Care groups out here also the settled community. There's a lot of poverty stricken people within the settled community, isolated people that Primary Health Care is a great thing and its a thing that can get in contact you know a third person for that person that needs it'.* (B)

'Women is very open to you coming in and talking I think they like to see you coming with news about, well not news but information about well this is going on and that is going on. Because if we weren't, true to the best, if we weren't going around they wouldn't know. Just like the Breast Clinic van... they didn't know about that until we went around about it and there's a lot of information that nearly every house you'll go to with and they'll talk to you because they don't know what's going on. They'll be glad to see ya coming to the door to tell them something'. (C)

The National Traveller Health Strategy (2002-2005:61) attributes what it refers to remarkable improvements in levels of access to health services to the work of the Community Health Workers and most recently in AITHS (2010) survey, 83% of the Travellers interviewed said they got their health information and advice from Primary Health Care for Traveller Projects and the Travellers organisations[78]. This high percentage could be attributed to the methods of health information that the PHC Programme and Traveller Organisations are using; for example, culturally appropriate and literacy friendly materials. Also it could be argued that peer educators and trust are factors that would encourage Travellers to access health information from PHC Programmes and Traveller Organisations.

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[78] http://paveepoint.ie/pdf/Summary%20of%20main%20findings.pdf accessed on 24/05/12

4.6 Transformation

Confidence

The women repeatedly mention how going back to education has increased their confidence and awareness in their lives. One woman (A) said; *'I have more education today, more confidence... the course that I started done it all ... the work [being a Community Health Worker] has been a great influence in my life, it changed me big time I mean that'.*

Another woman expressed that she is *'definitely more confident ... I started going to the doctor and asking more questions [about my health].*
The AITHS (2010:163) outlines that people who are most empowered are more likely to make life changes that promote their health. Freire (1970) refers to education as having a role in empowerment and transformation which can be reflected in the women's sense of self efficacy and in turn has fostered the process of critical health literacy as developed by Nutbeam (1998).

Consciousness and Awareness

It was also clear to see from the women's feedback that the process of the course had raised an awareness of health. *'I learned a lot more than I knew, it just gave me more confidence more aware... especially in your health. Not just the confidence it gave me but on our health perspectives'* (A). Another (B) said *'I never had any thought at all about health before because not alone would I have been a bit younger but it also never would have been an issue or never come up for discussion I would never have spoke about it but now since we did the health study* [All Ireland Traveller Health Study Peer Researcher] *I think it has opened my eyes an awful lot'.* She also said that she has become very conscious of her health and her children's health and keeping them at school *'you want to see them doing better, you know that the only way to go is education if you want them to get further afield that's the only step there is to go'.* Another woman (C) spoke about how she is more aware of things to look out for in her

children's health and that she is more inclined to go to the doctor quicker with them than before.

Freire (1970) again argues that education should raise critical awareness as should health literacy as developed by Nutbeam (1998) in order to help people become to know what they know in a different way or to act on their situation in order to improve it. Freire (1970) talks about being able to read the world around you and take a critical look at reality and refers to this as conscientization or developing consciousness as does Nutbeam (1998) when he builds on Freire's theory in the process of enabling people to improve their critical health literacy. It can be argued here that the women have through the process of learning about their health embedded in adult education practice, developed an awareness of their reality and the reality of the community they belong to.

Change in Attitude/Perspectives

It also seems apparent that there has been a change in attitude towards health and education. One woman (A) said *'I look at health differently, and my children and family and friends differently'* when I asked her about having confidence to make decisions she said *'big time it helped me, it changed my way of living and it changed what I think of things now when I see them and not alone my children but other people'*. Another woman (C) said she was glad she went back to education particularly on a primary health care course due to the fact that the long term aim was about bringing health to her community *'it was nice to think you were doing that ... I learned an awful lot from it. It would be great if people did go back to education it really would help them along the way of life'*. She also expressed that her attitude and outlook on life now includes health, especially of her children. She says *'before the course I wouldn't have bothered about dieting and what proper to eat ... but now that I know what to put into your body I suppose it's better and it's all down due to the course. I suppose it would be great if Traveller women knew what do, not just Traveller women, all women knew what to do'*. As mentioned earlier, AITHS (2010) concluded that individuals who have become empowered are more likely to be able to make changes to their lifestyle. This is reflected in interviewee C's statement about now having the knowledge and motivation to change her diet. Again it can be seen here that the process of transformation has

occurred and through the critical awareness of their own health and that of their community.

In the review of literature I examined the similarities between critical health literacy and education for critical consciousness as developed by Freire (1970) and widely adopted in adult education practices. Applying these philosophies to educating adults about health has also been proven to be successful in raising awareness and building confidence regarding health issues. Due to the Primary Health Care Programme being grounded in the principles in community development which has an embedded philosophy of becoming critically aware of the world around you, the programme thus provided a space for these women to build confidence and question their realities. It has given the women an opportunity to stand back and gain perspective beyond the individual to the systems that perpetuate the barriers to health of the Traveller community. Minkler et al (1980) also advocates for applying Frierian methods to health education and says this has shown to improve health conditions while also creating a critical awareness of the causes of problems and readiness to take action. I think this critical awareness and readiness to take action is strongly reflected in the data. The women repeatedly mention the benefits of the health promotion outreach carried out by the project and the importance of education opportunities for adult Travellers in order to address the area of literacy. It is clear from the data that the women also believe that improving Travellers education is a crucial part in addressing the health needs in the community.

4.7 Conclusion & Recommendations

One of the major findings of this research is that all three women spoke very positively about their roles as Community Health Workers. I felt they also conveyed a sense of responsibility with that role to members of their wider community and families. They all seemed to be aware of the position that they are in as leaders in the community advocating for better health for Travellers. It is worth noting also the role that the Community Health Workers have to play in addressing the issue of health literacy in the Traveller community.

During the research the women were able to express the honestly their own individual transformation after participating in a programme of health education including a gained confidence, an increased awareness of health issues and a change in attitude towards their health and the health of the community. As described above the women were very definite that this change in health behaviours was due to the learning and experiences in the project. It can be argued that this is due to the adoption of adult education philosophies in the health education programme which fostered the transformation of the women through capacity building in confidence and knowledge it is also important to acknowledge that the women have had important shifts in their capacity from a learning role to that of a community peer educator role. This is a vital part of community education. An issue to explore further would be to examine the gender implications of this role and further research into the dynamic of male Traveller culture and the implications of their individual and community learning could be carried out.

The research also further exposes the fact that trust is of major importance in the Traveller community is that within the community and with the wider settled community. As mentioned earlier the fact that there was a relationship already established between myself as the researcher and the women as the participants positively reflected in the validity of the outcomes. It is of major importance that authentic and valid research with this community must be based on this foundation of trust and also be ethically appropriate.

The women were also unanimous in their views on literacy friendly health promotion materials and on the utilisation of plain language within the health sector. They believe these steps will go a long way towards helping Travellers understand health information and improve access to health services. As discussed below, it is also important here that the passing of information orally as practiced by the community be factored into the promotion of health materials.

It has also raised the idea of health literacy as an important factor in lifelong learning which is particularly relevant to the Traveller community due to the generational transference of information orally and be addressed on a continuum basis over an individual's lifetime

This notion of health literacy as a component of life long learning offers transformative possibilities on a long term basis and can offer recognition to the community's cultural norms of information being passed down through. This can also offer much broader educational possibilities outside of health literacy. This oral component of Traveller culture needs to be factored into education, health and research engagements as a core part of their learning and be recognised as part of their knowledge construction and communication.

It draws attention to the literacy difficulties within the community which is not just an issue for the older people but that it affects young Travellers too due to early school leaving and a non culturally supportive school environment. It can be also argued that one of the factors of success of the project is due to a culturally supportive learning environment for the women. More often our assumptions of learning environments are culturally situated for the general population. It is important here to examine the mainstream assumptions about learning environments in the context of Traveller culture.

Health literacy needs to be recognised as a stand alone public health issue for the Traveller community in order to be effectively and consistently addressed over a continuum basis. Recognising health literacy as a separate issue could help the development of inter departmental approach in tackling it.

It has exposed that low levels of adult literacy is a major issue within the Traveller community and as a result I would suggest that more research to be done to measure the current status of literacy within the Traveller community in order to examine the full affects of health literacy in the community. Once a better insight is gained into the status of literacy within the community, only then can health literacy be addressed.

It is important that critical health literacy is recognised in addition to functional health literacy as a goal to achieving overall better health literacy. Critical health literacy as a concept needs to be addressed as a goal in achieving full health literacy due to its elements of raising consciousness in order to give adults the skills needed to practice healthy behaviours throughout life. It is also essential that a tool for measuring critical health literacy be developed and adopted.

The use of narrative inquiry approach to measure Travellers critical health literacy is a culturally appropriate method which provides the space for Travellers to reflect and engage fully in the research and gives an insight into the wider issues affecting their health literacy

It can be said that this research has opened up an important discussion which needs to be addressed by both the health and education sectors. The research exposes the need for health literacy as a real health issue in itself to be recognised and as a policy in public health. But most importantly adult education has a role to play in improving the health of the community and it is important that both sectors collaboratively through cross sector participation take responsibility in the process of developing a more health literate population.

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