Diagnosis and Disclosure of Dementia

A Comparative Study of Attitudes and Experiences of
General Practitioners in Ireland and Sweden

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Declaration

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Abstract

This study is concerned with the attitudes and experiences of Irish and Swedish General Practitioners (GPs) regarding the diagnosis and disclosure of dementia. Using a qualitative approach, five Irish and four Swedish GPS were interviewed using in-depth semi-structured techniques. The interviews were translated and transcribed, and coded for themes and categorised. The data that emerged from the interviews was examined using a qualitative thematic approach.

The themes which emerged through the interview data showed that with two exceptions, Irish and Swedish GPs generally shared the same attitudes and experiences when it comes to diagnosing and disclosing dementia. Regarding diagnosis, the GPs all relied heavily on the patient or the patient’s family to alert them to a cognitive problem; also, despite all the GPs acknowledging that diagnosis was important, they still showed a reluctance to diagnose. In the disclosure process, the word “dementia” was only used by three of the nine GPs, while the remaining GPs went to considerable lengths to avoid using the term.

All GPs except one recognised that dementia was a stigmatised illness, however they also displayed therapeutic nihilism regarding the disease. Two areas where the GPs differed were those of specialist training and quality of services: the Swedish GPs generally had more exposure to training and were satisfied with the quality of services on offer for the persons with dementia and their carer, while the Irish GPs did not have the same access to training and were at large very dissatisfied with the community services available.
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1. Introduction

The purpose of this study is to examine the attitudes and experiences of Irish and Swedish General Practitioners (GPs) when it comes to diagnosing and disclosing dementia. Diagnosis of dementia and the disclosure to the patient is of crucial importance, however a number of issues exist in this area which may impede the GPs ability to be more efficient and supportive in the process. Therefore, this study wished to focus on the GP attitudes and experiences, with the aim of attaining further insight into the issues.

The word “dementia” is derived from the Latin demens, meaning literally ‘without mind’ (SBU 2008). Dementia refers to a group of diseases characterised by a progressive and in most cases irreversible decline in the cognitive functioning of the person with dementia. The most common type of dementia is Alzheimer’s disease, followed by vascular dementia and Lewy body dementia (O’Shea and O’Reilly 1999). There is no single cause of dementia, and apart from medication that may temporarily halt the decline, there is no cure.

GPs tend to be the first port of call for people when they experience cognitive problems, and are therefore crucial to the detection and diagnosis of dementia. A timely and adequate diagnosis of dementia and a thorough and person-centred disclosure has been widely described in the literature as the best approach to the process. However, due to a number of reasons, this is not always the case.

In this qualitative study, nine GPs participated in semi-structured in-depth interviews in an attempt to explore their attitudes and experiences around the issue. The decision to compare two countries, Ireland and Sweden, was taken as it was hoped that the comparative angle could illuminate areas that were similar as well as areas where
differences were apparent. Differing attitudes between the two countries could be due to a number of issues, such as for example the structure of the health care system. Similarities may indicate areas where the experience of dealing with dementia, rather than the structure of the care, had an effect on the GPs behaviour and attitudes.

Chapter Two explains the methodological approaches used in this study. The motivations behind the methodology and the research design are described, and the rationale behind using a qualitative framework and methods of research. The process of data analysis is explained in detail to ensure the reliability and validity of the study. Also, the recruitment of participants and the sampling strategy used is detailed, as are ethical considerations and the limits and challenges of the research.

Chapter Three discusses the literature around the subject, both regarding the processes of diagnosis and disclosure and GP behaviour and experiences. The importance of a diagnosis is discussed in detail, as is the process of disclosure. Drawing on previous studies done on GPs regarding diagnosis and disclosure of dementia, a picture of the issue is given, with special emphasis on Irish and Swedish experiences.

Chapter Four reports and analyses the findings that came out of the data, and discusses the implications of the results. Using the participant GPs voices to illustrate the findings, a picture of their attitudes and opinions, and their similarities and differences, is provided.
2. Methodology

2.1 Benefits of the Research

The key research questions explored in this thesis are how do General Practitioners (GPs) in Ireland and Sweden approach the issue of diagnosing and disclosing dementia.

Understanding the process of diagnosing dementia is significant in a number of respects. As dementia is a disease that is on the rise due population ageing, a more in-depth and comprehensive understanding of the process of diagnosis is important from both a public health care perspective and on a personal level for the person affected by it. Early awareness of the disease facilitates the process of acceptance for the person with dementia and their family, and also gives them time to prepare and plan for the future, particularly with regard to legal and financial affairs. Disclosure of the diagnosis is an essential part of this process.

Apart from legal and financial planning, preparation for living with dementia can come in many forms, such as patients themselves being informed about the disease and what is going to happen, to accessing services and community care structures. Mainly, early diagnosis may also avoid the pressures of the disease reaching a crisis point, when events such as the illness of a carer may lead to the home care situation being unsustainable and the person with dementia being moved into institutional care. Also, despite the fact that dementia is irreversible, an early diagnosis facilitates the treatment with cholinesterase-inhibitors which can slow down the progress of the disease (Socialstyrelsen 2010).
As GPs are generally the first point of contact within primary care for people with cognitive issues (Hansen et al 2008), their knowledge of dementing symptoms and attitudes to the illness are central. However it is noted that a number of issues relating to the process of diagnosis and disclosure exist (Iliffe et al 2009, Hansen et al 2008, Woods et al 2003, Turner et al 2004, Lecouturier et al 2008), and impede the GPs ability to play a more supportive role and to be more efficient in their treatment of the person with dementia. A deeper understanding of these issues is essential to identify best practice, as well as to detect gaps in the care system.

### 2.2 Aims, Objectives and Key Questions

As stated in the introduction of this chapter, the core focus of this research study is on the diagnosis and disclosure of dementia by GPs from two countries, namely Ireland and Sweden. The aim is to examine these two groups and the GPs underlying attitudes and experiences of these processes, and how they deal with them. The objective is to understand what may influence the GPs said attitudes and actions, and what may be the cause. Key questions are:

1. What makes the GPs suspect dementia?
2. What do GPs do once they suspect a person has dementia?
3. How do GPs disclose information about dementia and to whom?
4. In the context of disclosure, how does the GP handle the process and what information and support is given to the person with dementia and their families?
What facilities in the area of health and social care services is the GP familiar with, in relation to what is available for the person with dementia and their carer?

What would facilitate the GPs task and make the process more structured?

To what extent is the stigma that is connected to dementia present in the GPs experience?

2.3 Research Design

Deciding how to study the social world has always given rise to a number of key philosophical debates (Snape and Spencer 2003), and albeit on a much smaller scale, the theoretical framework surrounding this research is no different. At the core of this particular study is its exploratory nature; the wish to fully grasp the attitudes of GPs towards diagnosing early stage dementia and the process of disclosure.

The philosophical discourse guiding this research is that of exploration, of wanting to get as much detailed information about the GP’s attitudes and experiences as possible, and get the most from their participation and openness. Previous research on Irish GPs and dementia has involved surveys and focus groups – it was therefore decided that a qualitative approach of an in-depth nature was the most suitable for this project, as it is an additional option for grasping attitudes and experiences. The decision to do a cross-comparative study between Irish and Swedish GPs was made in order to give more depth: it was felt that comparing the experiences of two different health and
social care systems would yield valuable results as well as introduce interesting comparisons and contrasts.

2.3.1 Research Methods and Data Collection

The method most suitable for data collection in this study was believed to be semi-structured in-depth interviews. In-depth interviews facilitate understanding the interviewee’s perspectives on their lives, experiences and situations as expressed in their own words (Kumar 2005). Moreover, in-depth interviews are “particularly well suited to research that requires an understanding of…responses to complex systems, processes or experiences because of the depth of focus and the opportunity they offer for clarification and detailed understanding” (Ritchie 2005, pp. 36-37). By their nature, qualitative interviews examine the thoughts, feelings and actions of the participant and can be a way of exploring different aspects of a situation (Arksey and Knight 1999), which in the case of this research is the two groups of GPs’ attitudes to and experiences of diagnosing and disclosing dementia.

The semi-structured approach was chosen as it provides a frame while at the same time is flexible and allows the structure to change. It gives freedom to explore topics not anticipated that might surface during the interview, and allows both participant and researcher to elaborate points of interest (Denscombe 2007). While the researcher had a set interview schedule, the semi-structured approach allowed for varying the format and for following up on responses that were seen as especially significant (Bryman 2008). The questions were of an open-ended nature, which allowed the subjects space to answer in natural and unconstrained manner, as well as giving the researcher an opportunity to analyse the depth in the answers.
The fieldwork was based on in-depth interviews with nine GPs. Five of these were based in Ireland and four in Sweden. The Swedish fieldwork entailed travel to Sweden, where three in-depth interviews were conducted with GPs whose practices were based in a major urban centre, and one in-depth interview was done in a large rural town. Amongst the five Irish in-depth interviews, three were done in a major urban centre, one in a rural village and one in a mid-size rural town. All interviews were done face-to-face using a Dictaphone, except one Irish interview, which was a telephone interview at the participant’s request. In this case, the participant was informed that the interview was being recorded.

Participants were given two forms, a Participant Information Sheet and a Consent Form. The Participant Information Sheet was sent to them upon agreement to participate in the interview, and again given to them in hard copy at the time of the interview. The Consent Form was signed at the time of the interview, except for the participant who was interviewed over the phone, who instead consented verbally.

2.3.2 Sampling

As recruiting a sample of GPs to a research study of this nature would prove difficult, it was decided that initial subject recruitment efforts would be made through informal networks such as friends and colleagues. Through these informal connections, contact with GPs was established that led to so-called “snowball sampling”, where the GPs that had agreed to participate were asked to suggest additional people for interviewing (Babbie 2008). This sampling technique does have disadvantages that were considered by the researcher; chiefly that the entire sample is dependent on the choice of the initial individuals contacted, which in turn can cause bias in the study (Kumar
Bias in this case would be due to the individuals involved referring sharing an interest in the issue, which could potentially make them more knowledgeable on the subject than the average GP. Nevertheless, as the GPs interviewed were based in two different countries, and a number of them, as opposed to just one, were asked to suggest further contacts for the researcher, it was felt that access to more than one network of contacts was obtained (Bloch 2004). However, in interpreting the results these issues about the non-random sampling need to be kept in mind.

Other issues which need to be considered in relation to the sample include the fact that there were more female than male GPs in the sample (three males and six females), and more urban compared to rural GPs (six urban and three rural). This gender and rural/urban divide was a result of the nature of snowball sampling: the researcher picks a subject who features the criteria necessary for the research and through their recommendations find other subjects with the same characteristics (Gobo 2004). The reliance on snowball sampling was in line with finding a representative sample “…set in dialogue with field incidents, contingencies and discoveries” (Gobo 2004 p. 447). The criteria for the sampling was simply that the person needed to be a currently practicing GP; it was deliberately kept as open as possible, since the aim was to get a view of the broad general knowledge of, and attitudes towards, dementia among GPs.

2.4 Data Collection Instruments

To attain comprehensive information about GP attitudes, a semi-structured interview schedule was designed. The interview schedule was divided into four main sections: Socio-Demographic Background Questions; Diagnosis; Disclosure; and Services. It
was believed that this gave structure to the areas of interest, while allowing as much flexibility as possible within the different topics.

It is worth noting again that the interview questions were generally open-ended. This was done to ensure maximum freedom for the interviewees to reply to the questions in a way which they sought fit. It also allowed for the answer to delve deeper into aspects that might not have come up in a close-ended question, at the same time as it gave the researcher the opportunity to follow up on themes and topics mentioned.

The Descriptive Questions were chiefly concerned with demographic data, such as the size of the GP’s surgery, the number of their patients that over 65 years old, and questions on their medical training and any possible dementia-specific training.

The questions on Diagnosis were concentrated around the GPs practical experience around diagnosis, such as what they do when they suspect dementia, what symptoms they notice, how many cases they diagnose annually, and whether they are familiar with any national guidelines. They were also asked to comment about their attitudes around diagnosis, such as what they believe is the hardest aspect of diagnosing dementia, and whether they feel it is important to make a diagnosis.

The third part of the interview schedule dealt with disclosure. This was divided into two parts: suspicion of dementia and the disclosure of the diagnosis. The questions used ranged from whether they disclosed their suspicions of dementia, and what they said once the diagnosis was confirmed. Other questions explored were whether the GP included the patient, the carer or both in the disclosure process. The issue of following up the patient and/or their carer once the diagnosis had been confirmed and disclosed was also asked of all nine GPs.
The fourth and final part of the interview schedule dealt with Services; in other words, what support is available for the patient and/or the carer after the diagnosis has been confirmed. The nine GP’s opinions were sought on what services were available, which were the most important, and what services at this point in time were lacking. Also, questions were asked about the support and services available for the carers. The existence and value of community-based dementia-teams was also explored with the sample of GPs during the interviews, and a question was asked about whether the GP had any experience of working with these teams, or if they would be a useful addition to the care offered to the patient.

The interview schedule ended with the question “Do you think dementia still is a stigmatised disease? If so, why?” The latter open-ended question was considered very important in determining the factors that might affect the GPs and their attitudes. This question was put at the end of the interview to allow the GP speak freely without feeling that what was being said could be conceived as stigmatising; it was decided that opening the interview with this question might inhibit the GP or make him or her overly politically correct while answering questions.

2.5 Data Analysis

The methodological approach used to analyse the data collected was qualitative thematic analysis (Seale 2004). All the interviews were transcribed verbatim by the researcher. The transcripts from the in-depth semi-structured interviews were read and re-read to ensure researcher familiarity with the interviews (Denscombe 2007) and to ensure no subtleties had been missed. The next step was to code the interviews: the codes were developed to reflect the initial aim of the research project, as well as to
include unexpected points and issues that emerged during the interviews (Seale 2007). The codes were then organised into categories, and recurrent themes and important points were identified. Further relationships and points of disagreement between and within the themes and categories were identified, enabling concepts, information and generalisations to be extracted and then discussed in the Findings and Analysis chapter (Denscombe 2007).

The process of coding is important as it facilitates the discovery of patterns within the data, patterns that point to a theoretical understanding of the information gathered (Babbie 2008). The codes are made in relation to the information that each participant gives, and is guided by the nature of the research problem (Denscombe 2007). Thorough and systematic coding is significant not only to extract meaning and information from the interview, but also to ensure that the data collected is analysed in a way that guarantees reliability and validity.

Reliability is the attempt to certify that the research is as robust as possible by carrying out internal checks on the interpretation of the data, as well as the quality of the data; also, by providing information about the research method, the reader is assured that the research has been performed according to a method (Lewis and Ritchie 2003). Validity is the process whereby the researcher shows that he or she is accurately reflecting the phenomena under study by analysing the choice of sample, the capture of the phenomena, labelling and identifying the phenomena, interpreting the data, and portraying the findings accurately in relation to the data gathered (Lewis and Ritchie 2003).

The need to systematically prepare the data for analysis is imperative in qualitative analysis, as there is a need to clarify not only the full research process, but also the
process by which interpretation has been attributed or theory developed, and the reliability and validity of these (Lewis and Ritchie 2003). Also, another important point when analysing the quantitative data is the fact that the analysis is the product of a process of interpretation, where researcher bias is always a possibility (Denscombe 2007). It is therefore important that the researcher provide as much information as possible regarding the technical details of research conduct and any potential bias, to clarify the objectivity of the research (Snape and Spencer 2003). Thus, based on the necessity of demonstrable reliability and validity, the researcher of this study has attempted to illustrate in detail the methods used to undertake the study, as well as clearly describe the reasoning and interpretation behind the reading and analysis of the data collected.

2.6 Ethical Considerations

The study received ethical clearance and was approved by the School of Social Work and Social Policy’s Research Ethical Approval Committee. All participation was completely voluntary, and the participants were informed of their right to withdraw from the study at any stage on the Participant Information Sheet, as well as the Consent Form. Also, the researcher stated this at the start of each interview. Moreover, the participants were also informed that the recordings of the interviews would be kept safely and destroyed in December 2010. Participation would be kept confidential, and the participant’s names and any other identifying factors changed to maintain anonymity. They were also informed that the interview would take approximately 30 minutes.
One potential ethical consideration was the use of two languages for the interviews. The researcher is a Swede living in Ireland and speaks both languages fluently. Accordingly, there was no risk that either group of GPs would feel constrained by not being able to express themselves in their first language. However, the translation of the interview schedule from English to Swedish, and the translation of the transcribed Swedish interviews into English had to be done with great care and consideration for the linguistic nuances and variances present.

During the interviews, there was no breech of patient confidentiality. On occasions, the GPs referred to patients in re-telling experiences, but always in the general format of “I have one patient, who…” The GP always maintained patient-doctor confidentiality, and the interviewer did not ask the GPs to disclose or recount any experiences they may have had with individual patients.

2.7 Limitations and Challenges

A number of challenges and limitations affected this research project. An outline of these are detailed below in order to fully grasp the processes whereby the results were reached.

2.7.1 Recruiting the Sample of GPs

The original intention was to recruit a larger number of approximately 16 GPs for the in-depth interviews, and aim at having a similar number from both countries. However, accessing the sample of GPs, especially in Sweden, proved harder than anticipated. Due to time constraints and the fact that July is holiday season in Sweden,
it was decided that the Swedish interviews would take place first. As this involved travel to Sweden, contact was made with GPs early to ensure that enough participants could be found. Nevertheless, despite attempts ranging from networking, informal contacts, calling GP practices, as well as asking those who had already agreed to participate if they could recommend anybody, only five participants could be sourced. Of these five, one cancelled on the day of the interview, leaving no time to source another one.

As previously mentioned, the non-random nature of the sample of GPs is a limitation to the study. As snowball sampling is a process of accumulation through the located subject suggesting another subject, this leads to the sample having questionable representativeness (Babbie 2008). There is thus a need to interpret the results cautiously.

2.7.2 Translation

One challenge was ensuring that the interview schedules matched each other linguistically. Larkin et al argue that “different languages construct different ways of seeing social life, which poses methodological and epistemological challenges for the researcher” (Larkin et al 2007, p. 468). This was very much the case in this study, and as the researcher was also the translator, the importance of the accuracy and the integrity of the translations was significant. The Swedish interviews were conducted in Swedish, and although the same interview schedule was used with both the Swedish and Irish GPs, it was essential that the translated Swedish version captured the tone and the meaning of the original schedule. Kvale and Brinkman argue that “the interview process occurs through speech, and the interview products are
presented in words. The medium, or the material, with which interviewers work is language” (Kvale and Brinkman 2009, p. 219). An accurate and correct interpretation and translation of this medium is therefore crucial.

Translating the interview schedule from English to Swedish held its own special challenge. As noted by Larkin et al (2007), overly structured questions do not make allowances for the degree of difference between and within languages, as well as limiting the researchers ability to clarify and develop; moreover, the potential breadth of responses in an interview in a different language can make possible inference from the data difficult to interpret. Therefore, it was of paramount importance that the researcher adopt a sensitivity towards not only the language used and the nuances in it, but understand that the translation also “…should acknowledge the capacity of each language to create its own meaning…” (Larkin et al 2007, p. 469).

Another challenge of doing the interview in two different languages was the cultural aspect. Schäffner (1995) argues that interlingual communication extends beyond the mechanics of linguistics, and that language is the most complex set of habits of a particular culture. This was evident for this researcher, who noted this exhibit of culture chiefly in the Swedish interviews. The Swedish respondents tended to be more subdued in their answers, leaving more unsaid but yet conveying meaning in what they did not say. This is both a linguistic and cultural difference which could be picked up by the interviewer who is Swedish; nevertheless the unspoken points still needed to be said which at times presented a challenge. Venuti (1995) argues that through translation, the texts are inscribed with the linguistic and cultural values that are intelligible to specific domestic constituencies. The challenge for the researcher was thus to translate these values and meanings in a way that was easy for the English-speaking reader to understand, while yet remaining true to the language used
by the interview subject, and the essence of the meaning that the participant was conveying.

An additional aspect of the use of two languages was the potential bias of the researcher. While being fluent in both languages and the cultural difference between Ireland and Sweden being marginal, there is still the possibility of the researcher having presumptions and biases. Therefore, it was important for the researcher to ensure that the translation process moved in “…at least two directions at the same time: [laying] bare the latent presumptions of the culture represented by the researcher, on the one hand, and the subjects, on the other” (Alasuntari 1995, p. 135). Choice of words used by both the researcher and the subjects in the interviews were thus analysed in the translation to ensure that a natural, flowing but yet accurate picture was conveyed in the English translation. The presence of these nuances highlighted the importance of capturing this distinction, and ensuring that nothing got lost in translation.
3. Literature Review

3.1 Introduction

The focus of this study is on the attitudes and experiences of GPs from two different countries in their approaches to diagnosing and disclosing dementia. The aim of this study is to collect cross-national qualitative data from Ireland and Sweden about GPs current attitudes and practices in relation to said issues: the study also seeks to examine the type of support services GPs believe are important to their patients and the caregivers at this stage of the illness, and their view of the adequacy of the current supply of these services.

Until the early 1980s, the topic of dementia was virtually ignored in most standard medical texts: since then, a great deal has been written about dementia in medical journals and other forums (Downs 1996). In order to access this literature, numerous searches were done in databases and search engines. The search engines used were Web of Science, CINAHL, JStor, Cambridge Journals Online, and PsychInfo: key search terms were dementia, diagnosis, disclosure, GPs, Ireland, and Sweden. These terms were used in a number of combinations using Boolean search tactics.

A wealth of information was available on the issues of diagnosing and disclosing dementia and the role of the GP in these processes. Through the literature, a sense emerges of the importance of a deeper GP understanding of the symptoms of dementia and the process of diagnosis. Of equal weight is the disclosure of the diagnosis of dementia, which is crucial for the understanding of the illness and the progression of the disease for the person with dementia and the carer. A more person-centred approach to the disclosure process is discussed, as is the role that the stigma of dementia plays.
3.2 Diagnosis

Population ageing is a worldwide phenomenon, and dementia is a cognitive disability that increases exponentially as populations age (Waldemar et al 2007). Based on projections from the United Nations, the number of people in the developed world that will be living with dementia is set to rise by 161% by 2050 (Waldemar et al 2007). It is estimated that there are just under 40,000 people currently living with dementia in Ireland; this is set to rise to over 70,000 in 2026, and over 100,000 in 2036 (O’Shea 2007).

In Sweden, the number of people with dementia is approximately 140,000, and this number is set to rise to just below 250,000 people by 2040 (SBU 2008, Socialstyrelsen 2005). The prevalence of dementia and the projected rise in numbers presenting with this illness thus makes it not only a public health challenge, but also reinforces the necessity of implementing policies and efficient practices when it comes to dementia detection, care, and services.

Dementia is one of the main causes of disability in later life and contributes to 11.2% of all years lived with disability in terms of Global Burden of Disease – this can be compared to stroke (9.5%), musculo-skeletal disorders (8.9%), heart disease (5%) and cancer (2.4%) (Iliffe et al 2009).

The prevalence of dementia and the projected increase expected heightens the importance of fully understanding the issues surrounding the disease. People with dementia and their carers need to have easy access to optimal services, including diagnostic services and support during the progression of the disease, something that is depended on the structure of the primary care system and the social and community supports that are in place. These vary from country to country, and have a big impact
on the quality of services available for the person with dementia and their family and carers.

GPs play a crucial role in the diagnosis of dementia (Downs 1996), as they are central to the provision of primary care to elderly people, and the health care professionals most often consulted by carers of those living with dementia (Hansen et al 2008). Their role in the diagnosis and disclosure of dementia and the follow-up, support and access to services which they provide after diagnosis is of uttermost importance since they are the initial gatekeepers to services (Downs 1996).

An early diagnosis of dementia has been described as a gateway for care, as access to services is restricted, future planning is made difficult, and no drug or non-drug treatments can be given without one (Knapp et al 2007). The feeling that something is wrong but not knowing what burdens the person and the carer alike, and forces the person and the family into an uneasy situation which disrupts their daily existence. A diagnosis is an important transition from the uncertainty and ambiguity of the early cognitive and behavioural change to a phase in which the person with dementia, and their family, adjust and learn to live with the impairment and the loss of function (Woods et al 2003). It also gives them time to come to terms with the diagnosis and receive information that prepares them for the future. An early diagnosis facilitates full involvement of the person with dementia and their carer in planning the medical, educational and psychosocial interventions suited to their needs and wishes (Waldemar et al 2007). Also, it has been shown that early diagnosis and intervention may delay nursing home admissions (Turner et al 2004).

There is a consensus that a diagnosis should be made as early as possible to enable the person with dementia and their families to benefit from educational, social,
psychological and pharmacological interventions, and plan ahead (Knapp et al 2007). Early diagnosis also means that a person with dementia may be able to become involved in his or her own care planning, as well as organise any financial or legal arrangements (Iliffe et al 2003), including obtaining an enduring Power of Attorney.

3.2.2 Reasons for Late Diagnosis

Unfortunately, despite this consensus regarding the importance of an early diagnosis, many people with dementia do not get diagnosed until late. There are a number of reasons for this, all which affect the person with dementia and their carer and thereby add to further insecurity. Uncertainty about a diagnosis is problematic, not only as people generally prefer clarity but also as it makes it difficult for the person with dementia and their family to discuss, prepare and plan for their future (Lecouturier et al 2008). Also, a late diagnosis often means that people with dementia do not come into contact with health and social services until a serious crisis situation occurs, involving the person, their carer, or both (O'Shea and O’Reilly 1999). A crisis could be anything from the illness or death of the carer; or a severe degeneration in the person with dementia; or simply that the carer, who is most likely not accessing support or services (as there is no involvement with the health services due to lack of diagnosis), is unable to cope. Moreover, a crisis situation like this tends to mean that the person with dementia is no longer able to be cared for in the home.

The reasons for the late diagnosis of dementia are many, and include the vague symptoms and diffuse character of the early stages of the disease, initial reluctance on behalf of the person and/or the family to seek help, and access to specialist services (Downs 1996). However, a crucial factor is that of the involvement of GPs, and the
issues on their part of accurately detecting the illness; their reluctance to diagnose due to the degenerative nature of dementia; and their failure to effectively and clearly disclose the diagnosis to the person and their family. There are a number of reasons for these failures, such as lack of knowledge of dementia symptoms and the stigma that is attached to the condition (Vernooij-Dassen et al 2005).

Dementia is by its nature difficult to diagnose, as the symptoms can be both varied and vague. Also, the pathology of the disease professes itself in different ways from individual to individual (Downs 1996). The difficulty of diagnosis is one of the reasons that dementia tends to be under-diagnosed by GPs; the problem is an international one, with similar problems being reported across Europe, North America and Australasia (Iliffe et al 2003). A number of other issues also factor in as barriers to an early diagnosis. On average, it takes 30 months from the initial symptoms noticed by either the person with dementia or their families before a medical evaluation takes place (Vernooij-Dassen et al 2005). There may be reluctance on the part of the person with dementia, or the carer, to raise the concern that something is wrong. People in the early stage of the disease tend to mask their problems, and do often not complain about memory problems (De Lepeleire et al 1998). Also, symptoms of early dementia are less likely to be memory problems but are more likely to be emotional problems and a decline in thinking and planning (Hansen et al 2008). Even when a cognitive problem is recognised, the person with dementia and their family may delay medical consultations for over a year after symptom onset (Waldemar et al 2007). Also, family members may unconsciously begin to gradually take over social roles and other functions from the person with dementia, without necessarily being aware of what they are doing (Iliffe et al 2009).
Despite this potential patient or family reluctance to seek help, it is the GP who is the person most central in noticing and recognising symptoms and diagnosing dementia. The majority of patients with dementia visit their GP for other complaints than cognitive problems (Ólafsdóttir et al 2000), which decreases the likelihood of the GP detecting early stage dementia. However, as a GP sees a patient a number of times per year and has generally known them as a patient for some time, he or she should be able to detect the subtle cognitive changes that indicate early dementia (Ólafsdóttir et al 2000).

3.2.3 GP Training

Due to the above-mentioned difficulties, it is especially important that the GP is aware of early signs of dementia and knows how to recognise them. Since symptomatic patients may not seek help for their cognitive problems, a proactive approach by the GP is needed for an early diagnosis -- however, GPs tend to work in a reactive rather than proactive way (Iliffe et al 2005). Compounding this issue further is problems with how GPs notice symptoms and diagnose dementia, one of which is lacking knowledge of dementia symptoms. Generally, an index of suspicion is needed to construct a diagnosis -- this suspicion is triggered by a symptom within the patient’s story that the GP is unable to pick up if he or she is not aware of the early signs of dementia (Iliffe et al 2005). Further training of GPs has been suggested to improve the diagnostic process, and it is often something that the GP wants as well (Jedenius et al 2008, Cahill et al 2006, Turner et al 2004, Hansen et al 2008, Waldemar et al 2007).
Turner et al (2004) surveyed GP knowledge on dementia and found that one third of GPs expressed limited confidence in their diagnostic skills. Further, Iliffe et al (2003) found that GPs felt insufficiently trained for the task of early diagnosis; they also felt that the diagnosis was difficult to accept for professionals and patients alike. In a Swedish study 71% of GP wanted to increase their knowledge on dementia, and only 20% agreed that their knowledge and experience was satisfactory to detect patients with dementia (Ólafsdóttir et al 2001). In a survey of Irish GP, Cahill et al (2006) found that 90% of GP surveyed that had no dementia-specific training and 83% expressed a wish for this. A number of studies have shown that GPs feel that their knowledge in diagnosing and treating dementia is inadequate, that they lack confidence in their ability to diagnose (Waldemar et al 2007, Hansen et al 2008), and many also blame themselves for the late diagnosis (Cahill et al 2008).

Ólafsdóttir et al completed a survey of Swedish GP to try to identify why the detection rate of dementia was so low in primary care (Ólafsdóttir et al 2001). They found that the GP had a good knowledge of the clinical features of dementia. Nevertheless, their results showed that GP tended to underestimate the occurrence of dementia, indicating many undetected patients. Also, one telling fact was that whilst 57% of GP reported that they readily discuss cognitive disturbances with their elderly patients, only 12% admitted to discussing their patient’s continued holding of a drivers licence. This suggests that Swedish GPs do not readily talk about these issues in depth and may be reluctant to get overly involved in the diagnosis process. A majority of the GPs surveyed in the Ólafsdóttir et al study felt that the most efficient way to improve the detection of dementia was for them to be able to spend more time with each patient. Moreover, they also stated that the presence of a dementia co-ordinator, such as a specially trained social worker or a nurse, was very valuable.
Specially dedicated and trained so-called ‘dementia teams’ exist in about half of the municipalities in Sweden, and take over some tasks from the GP such as visiting patients in their home and performing an MMSE (Mini-Mental State Examination) with them (Alzheimer Europe 2010). These teams take some of the work load off both the GP and the specialist services such as geriatricians and memory clinics, and are also at hand to support the person with dementia and their carers through disseminating information, helping them access the community support functions, and aid them with daily practical issues and questions.

In Ireland, one major study of GP and dementia undertaken in 2004 and reported in the literature in 2006, ’Dementia in primary care: the first survey of Irish GPs’ (Cahill et al 2006) and later in 2008, Cahill et al ‘The attitudes and practices of GPs regarding dementia diagnosis in Ireland’ showed that a majority of GPs tended to blame themselves for the low and late detection of dementia; a smaller number blamed the family, the patient, the illness, or the health care system. The main barriers to diagnosis identified by the GPs were difficulty differentiating dementia from normal ageing, lack of confidence and concerns about the impact of the diagnosis on the patient. Also, delays in access to geriatric, old age psychiatry and neuropsychological services were also seen as an issue, as further access to services and clinical treatment were often dependent on specialist diagnostic input. GPs had an overwhelming desire for further education in the area of dementia and recognised that this had been a deficiency in their training. An overall reluctance existed on the part of the GP to disclose dementia to the patient. The low disclosure rates in Ireland contrast with those in other countries, and may be due to the late presentation of dementia because of stigma and the absence of any GP specialist training in the area of dementia.
Stigma was also reported to prevent GP from taking the initiative to investigating possible dementia.

Although the Swedish study about GPs and dementia is not as detailed as the Irish ones, a strong similarity is the fact that both Swedish and Irish GPs felt that they need further training to help them diagnose more efficiently. Studies have shown that when GPs are trained in the diagnosis of dementia, the detection rate reaches an acceptable accuracy, and that decision-making software and practice-based workshops greatly aid this process (Jedenius et al 2008, Downs et al 2006). The need for increased GP training in diagnosing dementia is thus clear. Professional development needs to focus on investing in training, and allocate resources to develop good practice (Iliffe and Manthorpe 2004). In addition to this, one way of improving the detection and diagnosis of dementia is the development of national guidelines.

National guidelines are helpful for the GP as it gives the process of diagnosis structure and clarity. Apart from the aforementioned studies in Ireland and Sweden, there exists a European Dementia Consensus Network – a group of experts who have expressed their concern with the low rate of recognition of dementia, and the lack of clear guidelines in most European countries (Waldemar et al 2007). In Sweden, The National Board of Health and Welfare (Socialstyrelsen) published guidelines in 2010 for care and treatment for dementia (Socialstyrelsen 2010b). These national guidelines have been developed mainly for management in municipalities and other areas that are responsible for health care, and recommend among other issues the type of resources which should be allocated and what educational needs exist.

The Swedish guidelines also express support for diagnosing dementia as early as possible, and outlines the basic tools of dementia detection. The guidelines were
issued as the National Board of Health and Welfare have noted the great need for
guidance that exists within the area of dementia care (Socialstyrelsen 2010a). In
Ireland, the Irish College of GPs in collaboration with the Health Service Executive
(HSE) have set up a steering group to develop key priority areas on Mental Health in
Primary Care, which includes “Dementia – tools for Primary Care and Care
Pathways” (Irish College of General Practitioners 2010), however it is unclear
whether any guidelines will come out of this.

3.2.4 Stigma

The general absence of guidelines on dementia diagnosis and the lack of in-depth
knowledge on the part of GPs in detecting early dementia is clearly a concern. One
additional reason for the low detection rate of dementia is that many GPs do not view
dementia as a well-defined disease with various treatment possibilities (Ólafsdóttir et
al 2000). This is noted by Cahill et al (2008) who state that therapeutic nihilism still
prevails when it comes to dementia, and there exists a need to convince GPs that
dementia is a condition for which much can be done.

Hansen et al (2008) noted in their Australian study a view among GP that early
diagnosis extends the period of illness, and that this particular illness is one that is
highly stigmatised and without cure. These negative perceptions of dementia as a
stigmatising disease as noted in this Australian study are also widespread across
Europe (Iliffe et al 2003). Stigma emerges as an important factor in the delays of
detection and diagnosis in primary care through concealment, minimisation or
ignoring of early signs and symptoms, and the belief that there is little to offer in form
of help as it is a degenerative disease, as well as pessimism about prognosis (Vernooij-Dassen et al 2005).

Vernooij-Dassen et al (2005) continue to argue that dementia creates a double-negative labelling, namely that of being old and having a psychiatric disorder; also, the strong association of dementia solely with its last phase heightens the perception that people of dementia have no capacity of pleasure or that they lack awareness. In Ireland, the designated service for treating behavioural disturbances in dementia is Psychiatry of Old Age, thus compounding the stigma surrounding it (Iliffe et al 2005). Iliffe et al also argue that this stigma is very present among GPs, as their “…fear of the disease itself, their embarrassment about discussing memory loss, functional losses and incontinence, and their reluctance to damage long-standing relationships by giving bad news…” (Iliffe et al 2005, p. 4) are all obstacles for the GP in recognising and diagnose dementia. However, it has been noted that stigma plays a minor role among the general population in countries with stronger Alzheimer’s societies, and the widest range of dementia care services (Vernooij-Dassen et al 2005). This is promising as an increase of information, education and understanding of the illness will help foster acceptance and reduce the stigma.

The importance of early diagnosis and the structure it provides for the person and their family is paramount. However, as Iliffe and Manthorpe discuss in “Hazards of Early Recognition (2004), early diagnosis also brings with it risks. They argue that while the emphasis on early diagnosis and disclosure reflects “…a change in the information preferences of citizens and a shift from a patriarchal towards a more autonomous model of health” (Iliffe and Manthorpe 2004, p. 99), this could have a number of unintended consequences. These include an increase in false positive diagnoses, overloading of specialist services and could also potentially lead to an
under-treatment of tractable conditions such as depression. Also, the person who has received an early diagnosis may experience both paternalistic attitudes and the stigmatisation of mental illness, as well as increasing the stress burden of the carers. However, Iliffe and Manthorpe argue that this can be dealt with by encouraging GPs to provide education about dementia to the patient and their families, by offering psychological support for carers, and by assisting the person with dementia and their families in social support and other services.

In summary, therefore, whilst this body of literature strongly points to the benefits of an early diagnosis of dementia both for the individual and for family caregivers, it is important to be aware that an increase in early recognition will put additional demands on both health and social care services, and will lengthen the person’s period of illness and the pressure which comes with that. That said, however, these issues can be dealt with through improvements in GP and specialist services, and an effort to challenge the attitudinal barriers which undermine early diagnosis: the benefits clearly outweigh the negatives.

### 3.3 Disclosure

The stigma attached to dementia and the extent to which that influences GP behaviour and attitude is also reflected in the disclosure process. Once the diagnosis has been made, the way in which the diagnosis is shared and the support that the GP gives the person and their families and carers, both at the moment of disclosure and the time following it, greatly influences how they deal with the information. Most ethical guidelines that deal with disclosing dementia to a patient strongly promote the disclosure of the diagnosis to the affected individual on the basis of a principle of
autonomy (Fisk et al 2007). However, this does not always happen, and GPs have been shown to deal with disclosure in a number of different ways.

Some GPs have reported that explaining the diagnosis of dementia is particularly difficult, and at times they claim that giving the diagnosis may do more harm than good as the person and/or relatives do not want to be confronted with this reality (Turner et al 2004). Other reasons for non-disclosure are the lack of absolute diagnostic certainty from clinical information, the absence of effective treatments for progressive dementia, the questionable ability of patients with more advanced dementia to understand the diagnosis, and the potential for adverse psychological responses to the diagnosis (Fisk et al 2007).

This reluctance can be seen in various studies on GP disclosure rates. For example in one Irish study, almost half (41%) of Irish GP reported that they never or rarely disclosed a dementia diagnosis to their patients (Cahill et al 2006). In contrast, in a Swedish study, a total of 39% of Swedish GP reported they would always or often tell their patients their diagnosis of dementia. Such disclosure patterns in dementia can be compared to a 95% disclosure rate in cases of terminal cancer (Ólafsdóttir et al 2001).

The withholding information about diagnosis and attitudes such as those described go against best practice advice, which is to diagnose dementia as early as possible to give the patient and their family time to come to terms with it and adequately prepare for the future (Knapp et al 2007). When the GP is vague or even reluctant to disclose the diagnosis, the uncertainty experienced by the patient and the family is prolonged. Studies have shown that non-sharing or unclear information about the diagnosis is experienced by patient and carer as confusing, upsetting and difficult (Iliffe et al 2009). In Ireland, the Action Plan for Dementia (1999) argues that people with
dementia should be informed of their condition at the earliest possible moment, unless there are very strong medical or social reasons for withholding the information.

3.3.1 Avoiding the Word

Other writes have noticed that when disclosing a dementia diagnosis, some GPs tend to avoid using terms such as ‘dementia’ or ‘Alzheimer’s disease’ and instead speak about ‘memory problems’ or ‘confusion’ (Lecouturier et al 2008, Woods et al 2003). Furthermore, GPs tend to adopt the principle of ‘do no harm’ in disclosing an illness that is widely accepted as negative and life changing (Iliffe et al 2003). However, disclosure of diagnosis and the chance to discuss and understand the diagnosis is reported as positive by people with dementia (Iliffe et al 2003). Woods et al argue that disclosure should be viewed as a process rather than an event; information must be geared to the individual, taking into account the patients perception of the difficulties with the diagnosis (Woods et al 2003).

In the case of patients with severe dementia, it is often the carer and not the person who is given the diagnosis, due to a supposed lack of insight on behalf of the patient and issues with retaining information. However, this should be assessed on an individual basis and there should be no assumption that diagnosis should not be conveyed to the person because of the perceived severity of the disease (Iliffe et al 2009). Also, an inability to fully appreciate the implications of a diagnosis need not exclude the possibility of the patient deriving some benefit from disclosure (Fisk et al 2007).
The very nature of the cognitive impairment requires greater attention and effort on behalf of the GP to ensure that the diagnosis is understood by the individual who experiences the symptoms. Nevertheless, there is evidence that GP spend little time on elaborating or explaining the diagnosis (Lecouturier et al 2008). This further strengthens the need for what Iliffe et al describe as a “…social model of disability around dementia informing…[the GP]… perspective that patients had rights to a diagnosis, information, and choices about routes or methods of assessment (Iliffe et al 2003, p. 379). The Swedish 2010 Guidelines for Dementia Care recommend that the patient is treated as an individual with experiences, a sense of self, and rights, despite cognitive problems and potential lack of understanding (Socialstyrelsen 2010b).

Whilst as mentioned earlier, the stigma of dementia impacts on diagnostic practices and diagnostic rates, stigma also plays a key role in the disclosure process. Some GPs have reported a reluctance to disclose a diagnosis on the basis the impact would have on the person because of the stigma associated with dementia (Cahill et al 2006). The stigma of mental illness is also a factor in dementia, not only through the potential appearance of behavioural disturbances, delusions and hallucinations, but also through the fear of loss of independence, autonomy and dignity, and the prospect of having to move to a nursing home (Iliffe et al 2005).

It is such stigmatising perceptions that continue to affect patients and carers, and are reinforced by GP reluctance to deal with the diagnosis and the disclosure. However, a shift from the view of dementia as an acute disease to a chronic problem approach, and a change in focus from a person with a disease to an individual in interaction with his/her family and the direct environment (De Lepeleire and Heyrman 1999) may help reduce this stigma.
3.3.2 Psychological Effects of Disclosure

The fear that disclosure of what is a degenerative disease will have adverse psychological repercussions on the person with dementia and their families is a strong factor in non-disclosure. Cahill et al found that GP perception of their patient’s ability to comprehend the diagnostic information was the main factor in determining the disclosure or non-disclosure of the diagnosis (Cahill et al 2006). Iliffe and his colleagues have argued that disclosing the diagnosis could be destructive in some cases, as it may create anxiety and provoke a depressive attitude to the bleak outlook that dementia brings (Iliffe et al 2003). Patients who receive an early diagnosis of dementia may experience low self esteem, self stigmatisation, feelings of isolation, lack of information as the information is usually aimed at the carer and not the person, fear of becoming a burden and also a sense of loss of control (Iliffe and Manthorpe 2004).

However, the literature shows that catastrophic reactions to the disclosure are not as common as might otherwise be believed (Lecouturier et al 2008). Drastic reactions such as suicide are rare, and interestingly, studies have shown that patients with dementia who remain undiagnosed are at greater risk of committing suicide than the general population. Therefore one must consider not only the short-term consequences of disclosure, where shock, denial, anger and depression can be common, but also the long-term consequences in which the benefits of disclosure are evident (Fisk et al 2007).

It is also interesting, in the light of these discussions and debates regarding the disclosure of dementia, that audio-recordings of disclosure meetings in one study suggest that some physicians paid little notice to enhancing comprehension of the diagnosis, and used numerous techniques to minimise the seriousness of the diagnosis
and avoid detailed discussion (Lecouturier et al 2008). While the diagnosis must be clear and the GP must ensure that the person with dementia and the carer have understood the diagnosis and the impact it will have, it is also important that the GP remains positive and provides support to the patient and carer and aids them psychologically as well as just diagnostically.

3.3.3 Pharmacological Interventions and Person-Centred Approach

Another critical factor pointing to the importance of dementia disclosure is the recent advances made in pharmacological interventions and especially the development of cholinesterase inhibitors or anti-dementia drugs. These cholinesterase inhibitors are the drugs that are chiefly used to aid cognitive abilities, behaviour, functions, and assist activities of daily living (Socialstyrelsen 2010b). Cholinesterase inhibitors modify symptoms in approximately 30% of people with Alzheimer’s disease (Wilcock et al 2009), nevertheless there is a continuing debate about the effectiveness of pharmacological interventions in dementia (Waldemar et al 2007). The extent of the benefit of these drugs remain uncertain as cognitive functional test may not accurately portray improvements in practical functioning; also, withdrawal rates from two types of cholinesterase inhibitors have been roughly 25% due to adverse side effects (Iliffe and Manthorpe 2004). The UK National Institute for Clinical Excellence (NICE) published guidelines on the usage of the cholinesterase inhibitors in 2001: it is noted this may have had a beneficial effect on GP recognising the importance of early diagnosis (Woods et al 2003), as the use of medication could potentially slow down the progress of the disease if diagnosed early.
The potential use of cholinesterase inhibitors underscores the significance of involving the person with dementia in his or her treatment plan. The literature argues that disclosure should not only take a person-centred approach that maintains the personal integrity of the individual, but it should also instil a sense of hope while also assessing the immediate psychological impact of the diagnosis (Fisk et al 2007). The process of adjustment to the diagnosis tends to take place largely without professional involvement, making it important for the GP to provide a supportive social context in which the person and the carer can undergo the process (Lecouturier et al 2008).

It is also noted in the literature that continuous support for a person who has received a diagnosis of dementia is the responsibility of primary care, and should include being able to respond to the shock, fear and grief that may appear as a result of the diagnosis (Iliffe et al 2009). One way the GP can aid the person and the carer after disclosure is by helping them get in contact with the services that are available to them. Services such as day centres, home help and respite care, or simple practical tips such as ways to change the home to facilitate for the person with dementia are all ways of helping the person and the carers and facilitate their daily existence. The caregiver, if not given any help or support from the GP or the available community services, otherwise runs a risk of failing to cope, especially if the carer is an elderly spouse. Providing the person and the carer with psychosocial interventions that help reduce the carer’s burden and the patient’s symptoms while improving the caregiver’s sense of well-being, knowledge and competence (Waldemar et al 2007) goes a long way in helping them accept and live with the diagnosis of dementia. Also, there is evidence that by supporting the caregiver, early institutionalisation can be avoided (De Lepeleire and Heyrman 1999).
Swedish GPs have stated that the most difficult part of managing dementia is the assessment of the social circumstances of the patient and organising social support (Ólafsdóttir et al 2001). Adequate healthcare resources should be channelled to improve access for patients to diagnosis and treatment, and to ensure that patients get the care they need; also, resources should be dedicated to change the nihilistic attitudes surrounding dementia (Waldemar et al 2007). Cahill et al (2006) acknowledged the critical support that practice and community nurses give to the person with dementia and their families, and suggest that in order to improve the dementia care counselling programmes for the patient and the carer need to be developed, hospital social workers need to be up-skilled, and further educational support need to be designed; these improvements would not only be of support for the patient and the carer, but may also help GP feel less bleak about diagnosing dementia. By providing a social care structure that is effective and works on behalf of the needs of the person with dementia and their carer, diagnosis and disclosure might be made easier for the GP, as there would be a back-up system and support to refer the patient to.

Further GP education and a concerted effort to change the perception of dementia from one of a non-communicative person with no cognitive abilities to one where the persons individuality and unique capacities to connect, respond and participate in various stimulations and activities is respected and valued, can help change the current nihilistic view of dementia and instead give the person living with dementia and their families structure and hope. Also, the importance of the services available to the person, their carer and the GP are highlighted through the help these services provide to all those involved. Failure on the part of the GP to accurately detect symptoms of dementia; deficiencies in training on dementia; insufficient knowledge
of the disease; poor levels of disclosure; reluctance to diagnose and disclose; and the overarching stigma that influences all these issues; all show that the benefits of early diagnosis and the supportive and clear conveying of the diagnosis is of uttermost importance.

In summary, the literature suggests that in most cases, a full and unequivocal disclosure is important for all involved parties, not only for physical health reasons but also psychological and personal ones. Without properly and clearly explaining the diagnosis and the outlook, the person with dementia and their carers are left to gather information alone, or may still be unsure about the ailment that is affecting them. Involving the patient fully in disclosure and adopting a patient-centred approach might show family and carers that the patient is respected as an individual regardless of their condition (Fisk et al 2007). Openness to the idea of dementia as a disability rather than a mental health issue will have beneficial effects on the relationship and communication between professionals and people with dementia, reducing the embarrassment and anxieties felt by both sides (Iliffe et al 2005). The GP is in a pivotal position to diagnose and disclose and offer supports to people with dementia and their family caregivers by making appropriate referrals to community services.
4. Findings and Analysis

4.1 Descriptive Data

Nine GPs participated in this study. Four of the GPs were from Sweden: two male and two female, and three of these were based in a major urban centre and one in a rural town. Five GPs were from Ireland and consisted of one male and five females. Three were based in a major urban centre, one in a rural town, and one in a rural village.

Both the Swedish and the Irish sample were fairly similar in terms of age and length of time in practice. Findings showed that amongst the Irish GPs, the mean age was 51, and they had been in General Practice for on average 24 years. For the Swedish participants, the mean age was 53, and the corresponding time spent in General Practice was 22 years.

Of all the GPs, one was in practice alone; the remaining ones (N=8) all worked in shared practices. The approximate percentage of patients over 65 for both groups of GPs was similar: for the Swedish GPs, patients over the age of 65 made up an average of 26%, while for the Irish GPs the number was 25%.

The GPs were asked a series of questions in the in-depth interviews regarding diagnosis and disclosure of dementia, and their familiarity with and opinion of services available for the person with dementia and their families. Transcripts were read and re-read: similarities and differences were noted and a number of common themes across the nine GPs were recognised. Codes were identified from the data and organised into categories, where they were divided into themes. All GPs were given pseudonyms to protect their anonymity.
Where similarities between the two groups of GPs were found, emergent themes have been grouped into the following major headings: (i) Symptoms and Diagnosis – A Certain Ambivalence (ii) Disclosure – Avoiding the Word and (iii) Stigma. Where differences were found, the emerging themes were (iv) Education and (v) Quality of Services.

4.2 Symptoms and Diagnosis – A Certain Ambivalence

Analysis of the qualitative data revealed that the main way in which GPs recognised symptoms of dementia was through a reliance on the family or the patient to bring to their attention concerns and suspicions. This finding is paradoxical as dementia, by its very nature, might not always be recognised by the person or family members due to the diffuse pathology of the disease.

Whist a range of symptoms were mentioned, the main cause for GP concern was that of family or patient complaints. For example, when asked, “What symptoms lead you to suspect dementia?” the GPs reported the following rather diverse symptoms:

“…behaviour, the contact [pauses] and above all the eyes, that’s where I think I see it” Berit, age 42, Sweden

“…I suppose the commonest thing would be people doing things out of character…” Deirdre, age 42, Ireland

“…short-term memory, you notice when you ask a question, because the long-term memory usually is intact, they remember in detail what happened in the 1920s and 1930s and all aunts and cousins and that …” Åsa, age 62, Sweden
“…often it is disorientation and those thing also, that they misplace things and sometimes they even become paranoid…” Johan, age 56, Sweden

“…sometimes they will have a, maybe a fixation with their bowels, or a fixation with that they are not right, or there is something not right about them, something a bit nebulous, you may not be able to put your finger on it but that may lead you to being suspicious…” Barry, age 63, Ireland

“…physical symptoms, sometimes, if they are not eating well or they are fatigued or things like that…” Moira, age 52, Ireland

The GP responses to this question show the myriad of ways in which dementia can present and the varying indicators they use to recognise the illness. Despite the above mentioned signs and symptoms of dementia, a clear theme that emerged from the in-depth interviews was that the GPs were not proactive in making diagnosis and relied very heavily on the family or the patient to report their concerns.

“V: ok, and generally what symptoms would make you suspect dementia in a patient?
S: the patient speaks about memory problems
V: mmm, ok, and sometimes if they don’t mention it themselves, but you can suspect they might have dementia yourself, does that happen?
S: well, in that case it is the family that raise the alarm, about ¾ family and ¼ the patient themselves” Stig, age 58, Sweden

“if nobody told me, if there isn’t a family member at home to tell me…I am not quick at picking it up from the patient…” Frances, age 48, Ireland
As mentioned in Chapter 3, patients with memory and cognitive problems often do not seek help for these, but rather for other physical ailments (Iliffe et al 2005). As dementia symptoms are vague, they can be difficult to diagnose: it has been estimated that a confident diagnosis requires clinical evidence for the duration of up to six months (SBU 2008).

The dementia literature reviewed for this thesis emphasises the critical importance of a comprehensive and timely diagnosis (Woods et al 2003, Waldemar et al 2007, Knapp et al 2007, Iliffe et al 2003). This issue also emerged in this research when the nine GPs were questioned about diagnosis. However, while each agreed that early diagnosis was imperative, certain ambivalences were noted in their discussion about the issue.

Analysis of transcripts revealed the importance of diagnosis in relation to a number of areas, for example access to services.

“[a diagnosis] is very important, and it is important in Sweden you plan the care and the treatment around the dementia diagnosis, so people can get help and support in their home if you have a diagnosis of dementia…[to] coordinate everything, respite care…” Stig

“I do [believe a diagnosis is important] once it’s causing a problem at home, so they can access services” Frances

Diagnosis was also considered important by some in order to prescribe medication in a timely fashion.

“…there are more options in terms of treatment, and the anticholinesterase inhibitors may delay the development of it, plus I think, you know, you can
put in place services and interventions in a more timely way than when it emerges at first point in an acute hospital setting” Moira

“it probably is really, from the point of view of various medications that are available, that if you start them early you have some chance of helping…” Deirdre

There was a feeling that dementia needed to be diagnosed to properly treat the patient:

“sometimes it depends, if it is, how far the disease has progressed, because it can be dangerous for their physical health as well…they take their medication incorrectly or not at all, they don’t eat…body and soul are connected…” Berit

“…it’s like making a diagnosis with anything, you have to be definitive about it, you make a diagnosis and you treat on the diagnosis” Barry

Nevertheless, two Irish GPs commented about how early diagnosis might be harmful, and expressed the worry that the diagnosis may have an adverse psychological affect.

“…I think it’s also very important not to scare people witless in maybe what could be the very early stages of dementia…and you don’t want to plunge someone into a depression, they are going to go completely mad in 6 months, you have to be very sensitive to how someone is going to take any information…” Maeve, age 52, Ireland

“…I’m a bit reluctant to diagnose it early on, although I know there’s posters out there saying pick it up early, but I’m not, I’m not 100% sure that telling a person that they have dementia is any benefit to them…” Frances
The research interviews indicated that several of the GPs tended to fear the reaction that a diagnosis of dementia would have on the person: therefore, they obscured the diagnosis. This conduct is in line with the GP behaviour discussed in the literature.

Data analysis showed that GPs in this study talked about patient/family denial and claimed that delayed diagnosis was often caused by denial and by the behaviour of the patient or the patient’s family.

“denial is a very strong feature of the human condition…it can be very easy to explain things away, like ‘my mother just died’ or ‘I just got a hip replacement and I haven’t been well’ and ‘memory’s been bad’ they’ll explain things away…” Maeve

“there would be a lot of collaboration, and a lot of denial, and a lot of ‘we can look after our own’, so there would be a good bit of that, people who would like to be able to look after say their elderly parents or something like that, and anything but having to put a name on it’” Deirdre

This finding can be linked to the reliance on families raising the alarm of the suspicion of dementia. Several GPs in the study also referred to people living alone, or not having strong family support as a further problem and possible barrier to diagnosis.

“because they may be living alone…they are socially isolated…and have possibly slipped into a dementia without it ever having been known, especially in isolated rural communities” Barry

“…[they have been] living alone, or with an adult child that they meet now and then, and then there often is in dementia when you start, when you are
alone and you don’t have any stimulation…[you] withdraw from the world, and you can live that way for quite a while…” Åsa

“…also I think if your cognitive ability is affected, it also affects your initiative to maybe go and do something about it, especially if someone doesn’t have a strong advocate or strong family around them…” Maeve

The participants described the phenomenon whereby the patient, or the family, may be overlooking symptoms or may have adapted to them unconsciously as they evolve overtime. Also, some patients may delay visiting a doctor out of fear of the potential diagnosis (Hansen et al 2008). This experience was shared by all the GPs interviewed.

Interestingly, and rather unexpectedly, several of the GPs interviewed mentioned the large number of people coming to their surgeries who were prematurely worried about dementia and really in their view had no reason to be:

“there are many who seek way too early as well, for normal name-forgetting and think that they have dementia and want a memory investigation” Johan

“…the people who come in to me and say they are forgetful are the ‘worried well’ usually there is nothing wrong with them and I end up doing tests on them and they are normal’ Frances

The comments made by these two GPs were reinforced by another Swedish GP who also highlighted the number of people seeking help from her for normal forgetfulness. In the latter case, and after the termination of the formal interview, this Swedish GP described how she repeatedly sees patients who are afraid that they have dementia and have come to her for a second opinion, as nothing had shown upon the test with their previous GP. This, she said, might be attributed to the increased public awareness of
dementia in Sweden, and the demographic makeup of her patients. She also stated that it is alarming, as it creates unnecessary waiting times and is a drain on resources.

In summary, these findings suggest that by and large GPs had different ways of recognising the signs and symptoms of dementia and relied on their patients and/or their family caregivers to bring to the GPs attention memory and cognitive problems. Whilst the majority believed that early diagnosis was important, a few stated that they were reluctant to diagnose early, as they felt that the diagnosis was a very depressing and difficult one to give and receive. A new and rather unexpected finding was the fact that several GPs also mentioned the issue of having to deal with patients presenting with ‘alleged’ memory difficulties but in fact not have any organic problems. The data analysis thus showed that most of the Irish and Swedish GPs reveal a certain level of doubt and uncertainty on both recognising the symptoms of dementia and the value of diagnosis.

4.3 Disclosure – Avoiding the Word

Analysis of data revealed that when dementia was suspected, and even after diagnosis was made, most of these GPs tended to avoid mentioning the word dementia to their patients. The transcripts showed that throughout the entire process, from the first time a cognitive impairment was noticed to the stage where medication was being prescribed, great lengths were taken by the majority of the GPs to avoid naming the illness. This strong theme is present in virtually all interviews in all aspects of GP-patient interaction.
When explaining what tests they are doing and why, many of the GPs gave the patient the information in instalments:

“…I would just explain that we need to do a number of tests, and we’d like to get a multi-disciplinary team input including a geriatrician or psycho-geriatrician and once we have all that back we’ll be able to see what the diagnosis is then…” Moira

“…in general practice you have the ability to maybe feed out a little bit of information at a time…you have to drip-feed information like that, and you have to gradually introduce the concept to a patient where things might not be going too well” Maeve

As mentioned earlier, there was a tendency on the part of GPs to avoid using the word dementia -- this issue is constantly revisited throughout the interviews.

“if I suspect, then I probably don’t say ‘dementia’, but I say a memory disturbance of some kind, because it’s so charged, the word ‘dementia’ and ‘Alzheimer’s’ and all those, but try to explain why you do a certain type of investigation” Berit

“I never use the word ‘dementia’. I tell them you’re a bit forgetful, and that you might need help just to make sure that that forgetfulness doesn’t get any worse, that’s all…” Frances

“…you can be wrong, so you have to be really careful, and even mentioning the word dementia, it’s a bit like mentioning the word cancer, you have to be really really careful, and I’m not suggesting you keep anything from the patient, certainly answer all their questions but I think you have to be very
sure of yourself before you have an interview with the patient and say, you
know, I think you might be developing dementia…” Maeve

The reluctance to use the word “dementia” continued to be a strong theme in the
actual disclosure of the diagnosis as the following narratives of both Irish and
Swedish GPs show:

“… I would say, straight that there is a memory problem there that they have
with their memory or with their recognition of events from day to day, or with
coping with everyday skills and that we would need to treat in an overall way,
both with medication and support services…” Barry

“well, you, you usually, possibly talk about memory disturbances, that you
have a memory disturbance and now you will get medication that can slow
this down and maybe even to some extent improve the memory…you have to
adjust the information you give after who it is and how receptive they are…”
Johan

Two GPs even overtly described how they went to great lengths to avoid using the
word ‘dementia’:

“you know, I do tell them [the diagnosis] without actually labelling it as
dementia, because, honestly, if there is something fixable and especially if on
a repeat test they score better, perhaps we are looking at maybe depression or
something, so I would just tend to tell them that there are issues, and that we
need to explore them a bit more” Moira

“[when asked how she proceeds in disclosing dementia] with the actual
patient? Oh, I think I wouldn’t break it directly, no, I’m afraid not…[mentions
the case of a previous patient]…I don’t, I’ve ever said it to him directly, you
know, “You have”, no, I’ve never said that, I don’t think I would have been
able to say it to him…” Deirdre

In general this qualitative data thus shows that in the process of disclosing the
diagnosis, most GPs avoided using the word “dementia” and instead used softer terms
such as memory problems or memory disturbances. These findings about disclosure
and an avoidance of truth telling are in line with the GP behaviour discussed by

There were three people in the sample of GPs, two Swedish and one Irish, who
interestingly reported they used the word “dementia” in the disclosure process. One of
these said that when she suspected dementia she would usually approach the
disclosure as follows:

“…I say well we have done one of these tests and there we see that there are
some things that you got a bit wrong, you got a lot right but some, it can mean
that it may be a preliminary stage to dementia…in this grey area, when you
suspect, then I say that I have to continue to find things out…to get a
diagnosis I have to refer you on and we’ll see…” Åsa

By stressing the fact that it “may be a preliminary stage to dementia”, she mentions
the word while at the same time de-dramatising it. Analysis of the data suggests that
this approach may well offer clarity to patients and families keen to obtain an
explanation:

“V: what kind of reaction do you normally get?
B: ‘that was what we thought’
V: really? Almost like a relief?

B: yes, and an explanation to a lot of strange things that have happened…”

Berit

The GPs who reported they talked about “dementia” openly to their patients also made the point that they were concerned with making sure that the patient understood the diagnosis.

“…its hard to think, really, but [pauses] you try and say the word dementia, and give them a bit further information, maybe report back what your report was, to make sure everybody knows all the information, and then answer their questions or the carer’s questions… “ Maeve

Data analysis showed that all GPs reported they involved the family carer in the disclosure process, if the person with dementia was in agreement. In one unusual case, however, the GP acknowledged that she informed the family rather than the patient.

“D: ...Just thinking of the last lady [pauses] she would have been in her late 50s, she’s probably in her early 60s now, it was obvious it was coming and we all knew it was coming, it was more with the husband and the daughter and we knew that rather than straight to the lady…just thinking of another man…there would have been a certain amount of collaboration to keep him as normal as possible, but it was very obvious, you know, as the time went on.

V: and so you base the not telling…

D: it would be more with the family in the sense that know there’s something going on…” Deirdre
This case is interesting since in this GP’s description, she appears to be going to extremes to avoid using the word dementia and demonstrating how the patient, in other words the person with dementia, is not informed of his or her diagnosis -- rather the GP and the family are discussing what is happening without informing the patient. The interview data here showed little evidence of the sort of person-centred care in which the care structure should strive to understand what is best for the person with dementia from that individual’s perspective, and view the person with dementia as an active partner in the care (Socialstyrelsen 2010b).

In summary these findings on disclosure show how six of the nine GPs interviewed for this study appeared to avoid using the term dementia when disclosing a diagnosis of dementia to their patients. One GP said she would only ever inform the family caregiver of the real diagnosis, and six appeared to go to great extremes to camouflage the illness. Only three GPs claimed they would normally talk about dementia and use the term when disclosing their concerns to their patients.

These findings are of interest since government policy in both Ireland and Sweden places the person with dementia at the centre stage (O’Shea and O’Reilly 1999, Socialstyrelsen 2010b). For example, according to the Action Plan for Dementia (1999) the person with dementia is the centre of the process of care and not an object of the process of care and should be fully informed of their condition. The inclusion of the name of the disease in the disclosure process is therefore paramount. Apart from the three GPs who did mention the word dementia during the process of disclosure, analysis of the interview data showed that this is very much not the case in this sample.
4.4 Stigma

In response to another question, “Do you think dementia still is a stigmatised disease? If so, why?”, virtually all the GPs interviewed agreed that dementia was to some extent a stigmatising illness. It could also be argued that in their avoidance of using the word “dementia” many of these GPs revealed their own nihilistic views about the illness and how news of a stigmatising illness such as dementia might affect these people.

When asked to further comment about stigma some GPs claimed that stigma appeared to be part of the reason why a person with dementia delayed seeking medical help.

“there are disease that you think are difficult and that you are ashamed of, and that is one of those diseases, you think it is terrible that you can’t remember so the self-consciousness around a disease like this is very high…until when you seek for this it has gone very far” Stig

For other GPs, being both old and also forgetful was a central part in what makes dementia stigmatising:

“you say in the past, “are you forgetful”, to be forgetful is a sign that you are old and a bit behind and dense and not following and things like that…” Åsa

“…an intellectually very active person who then notices that he is falling away, remembering, memory, he thinks it is very, very bothersome, the wife…[has]to start to be ashamed of him, you’d rather sweep those things under the carpet, I’ll tell you that, that it’s no fun at all…” Stig

“well, anything that I suppose that affects your social abilities is going to stigmatise you to a degree…but I mean it does contribute to being socially
isolated, because you are not such a socially performing animal anymore…”

Maeve

Data analysis revealed that stigma was most strongly seen in the GPs reluctance to use the word dementia.

"…we suspect that this is a memory disturbance in the first instance, you might not speak so much about dementia directly really…” Johan

“…I think dementia is a very depressing diagnosis, and frightening, especially in the early stages…so I’d be reluctant to label them” Frances

Here, the GPs also expressed the belief that a dementia diagnosis is fundamentally depressing and there is very little that can be done about it. The relationship between stigma, therapeutic nihilism and the reluctance to provide an unambiguous diagnosis is clearly visible in these research interviews.

The pain that the diagnosis causes the person with dementia is also mentioned; this in turn conveys the sense within the GPs that dementia is a disease for which there is very little to be done. This is in line with Cahill et al (2008) findings of exactly the same phenomenon in their study on Irish GPs.

In the current study, results showed that Swedish GPs were no different from the Irish GPs. The four Swedish GPs also expressed this sentiment, highlighting again the therapeutic nihilism that exists towards dementia among GPs.

“…when everything is moving, it is very anxiety-inducing, but then they often enter a calm period when they are so gone that they don’t suffer from it…”

Johan
“…also then, when you know, in the early stage when you are cognitively wilting while you are noticing it and understanding it, so it is of course painful to be aware of that “I have dementia, I am going to sail into the fog”…” Åsa

Analysis of the qualitative data also showed that there was a sense among the GPs of a personality transformation that accompanies the progression of dementia, and it was this changed behaviour which may also have contributed towards the stigma associated with dementia.

“…it is probably one of the worst diseases, I think, amongst the elderly, it affects physically but also everything, the personality changes and disappears, it is, I think so, and in the early stages, the patients get that diagnosis, and it is a huge grief, for the carers so they don’t want to talk about it, because everybody knows the progression, that’s the way it is I think” Berit

“well, it is that it is such a radical break in your life pattern really, to be sawed off but yet live, to look like you are well but you are completely in your own world, so that is a horror for many who get dementia, especially if you have family who have been affected by it, that is a ghost constantly for them maybe…” Johan

For some, dementia appeared to be associated with mental health problems which are also stigmatising:

“…anything inside your head is always regarded as a stigma, it’s regarded as a weakness, a failing in the family, you know [pauses] but it’s not” Frances

“…dementia might be a sign that you are stupid in some way, that they don’t fully understand that it is an organic change…” Åsa
“…as mental illness has also been stigmatised, I think dementia was stigmatised in that way also…” Barry

Despite the strength of the theme of stigmatisation which runs through all the interviews, when asked if dementia was a stigmatised disease, not all GPs agreed.

“…I wouldn’t have thought that there was a great stigma attached to dementia, people realise that it’s not people’s fault…but I wouldn’t have used the word stigma, to be fair, I don’t think it’s a stigma, I think it’s a disability, especially as it gets worse, but I think people with dementia are terribly vulnerable…” Maeve

Although Maeve would prefer to not attach the word ‘stigma’ to dementia, she is likening it to a disability, which, like mental health, is an area that suffers much stigmatisation and discrimination.

Only one GP believed that there was no stigma attached to dementia.

“no, I don’t think so [pauses] no [pauses] well [pauses] do I? Ach, there probably is a certain amount…I don’t know, I don’t think so…I don’t think people hide it, that they wouldn’t tell you that their relative has dementia for a fear of stigma, no, I don’t think so’ Deirdre

It is worth noting that this is the same GP who would not inform the person with dementia straight of their diagnosis, but would rather tell the family out of fear of the patient’s reaction.

One Irish GP expressed the view that the stigma around dementia was partially caused by the poor level of services and support in Ireland.
“I think it’s just like that simply because we don’t have enough community support, and that’s the reason why it is [stigmatised], because a person in their own home has an identity, and has a little bit of control of their environment, but when somebody is hospitalised or in a nursing home they surrender huge amounts of their identity and that’s the reason why I think it is so hard to deal with dementia in this country” Maeve

The connection back to community services is interesting as it highlights the gaps in the system in Ireland, and how they are accepted. The Action Plan for Dementia (O’Shea 1999) emphasises the lack of urgency that exists in dealing with the problems of people with dementia and their carers, and that this would not have been tolerated in other areas of the health service. It is hard not to wonder if this ‘lack of urgency’ is somehow connected to the stigma surrounding dementia: the sense that the issues of dementia care are somehow not as pressing as other health issues, and can be neglected.

4.5 Education

The topic of specialist training was explored with the GPs during the in-depth interviews and each was asked the following two specific questions:

- Have you done any dementia-specific training, either during your medical training or after?

- Have you ever been offered dementia-specific training from your local health board or similar?
On the first question, whether they done any dementia-specific training during or after their medical training, five of the GPs reported that they had done dementia-specific training, and four stated they had not. Interestingly, only two out of the five Irish GPs had received specialist training, whilst three of the four Swedish GPs had specialist training. When asked if they had ever been offered dementia-specific training from the local health board or any similar contingency, all of the Swedish respondents had, but only one of the Irish ones had been offered such training.

The importance of education and the need for more specialist education and training was a theme which emerged throughout the interviews, albeit not as strong as the other themes. The literature stresses the need for a more in-depth understanding on the part of the GPs of the symptoms of dementia and of the challenges this illness poses to the individual and to family caregivers. Although the numbers are small, findings from this study reflected differences in the exposure to dementia-specific training between the Irish and the Swedish GPs. The questions asked regarding training were open-ended and did not quantify the level of training or delve deeper into the specifics of the training.

In addition to the differences in level of exposure to dementia-specific education, an interesting comment made by the Irish GPs was their observation that the number of people in Ireland who would in the future present with dementia was likely to increase. This will require more in-depth knowledge on their part:

“…I suppose with the way things are meant to go in the future, I think it would probably be more important, statistically things are going to increase, the problem is going to increase” Barry
“yes, because we are going to encounter an awful lot more, I have an awful lot of patients with dementia, well of the patients, considering I have a small practice…” Frances

As Ireland presently has a younger population than Sweden, but population ageing is now happening in Ireland, the expected increase in prevalence of dementia was clearly on the mind of some Irish GPs. Accordingly, some felt a need to increase their knowledge about dementia and keep up to speed with changes:

“oh we are always open to education and everything is changing, things are changing all the time, both in the diagnosis and the managing and the support structures, so we have to keep on top of all of these areas, and dementia would only be one small area within general practice…” Maeve

Compared with the Irish GPs, the Swedish GPs expressed a wish to be updated on the changes in pharmacological developments, although some were somewhat cynical about the value of such interventions and about the type of help received from the pharmaceutical industry:

“…sure, we need training, especially if there are new medicines that arrive, now nothing has really come that is especially new or promising, but still” Åsa

“…and you get some kind of training from the pharmaceutical company representatives who come here with their medicines, so there is a little bit of this and a little bit of that!” Johan

In summary, and in relation to education, the GPs interviewed for this study each claimed that they would value further education on dementia, as they believed that diagnosing and caring for patients with dementia will in the future become a large
part of their professional life. The small disparity between the Irish and Swedish GPs in terms of exposure to specialist training is a finding that is important in the light of the projected rise in the number of cases of dementia in Ireland. The need for more specialist training for GPs has been highlighted in Irish literature on the subject, and is also something that the GPs have expressed a wish for.

4.6 Quality of Services

A series of open-ended questions were asked about service needs and service usage around the time following a dementia diagnosis. Analysis of this data showed that the availability, quality and adequacy of services emerged as an area where vast differences existed between the Irish and Swedish GPs.

Whilst the social care services deemed as most important for a person recently diagnosed were similar between all nine GPs, with the emphasis being on public health nursing, caregiver support, home help, and respite care.

“...the public health nurse goes in and sees what the living circumstances are like, just to make sure that the home is liveable and that there is hygiene and stuff like that, especially if someone lives on their own, and if there are any occupational therapist needs…” Frances

“…most patients would be managed in the home situation, by a carer or by a family member who then becomes a carer, then you would have the follow up with a public health nurse and the services of the day centre here, then you need as well respite care for the patient and respite care for the carer, they are the main things…” Barry
“…the dementia day centres, that they are collected in the morning and spend the day there and have lunch there, until one or two o’clock…and there they have some activities, some stimulation, they read out loud for them, they cook together…then you can get home help of course and food home, some are single, and then they need help from the home health care, and the public health nurse…” Johan

“…adjusting the home for a person with dementia…and then also nutrition that is a part of that with the municipality [the area which is responsible for health care] that they get food, I mean they can’t be expected to shop for groceries and cook [pauses] all these things that you do every day, in your life” Åsa

However, in relation to another question asked about the adequacy of the services available, the difference between the Irish and Swedish GPs was very obvious. The Irish GPs interviewed for this study expressed an extremely negative view about social care services and their adequacy, and about strategies used to access these services. One of the Irish GPs stated:

“they [the services] are not [adequate]. They are not, the occupational therapists, I don’t know what their staffing is…there just aren’t enough of them, same with the physiotherapists, really the support structures in the community are very poor, public health nurses are amazing, they are absolutely fantastic, but my perception would be that supports in the community are inadequate, the home helps are fantastic, they’ve pulled back completely on home helps…they’ve been cut terribly, and I think that’s a huge problem” Maeve
Another Irish GP reported:

“..little or no physiotherapy, I find that a particular problem, little or no, no may I say, no speech and language therapy, and extremely limited home help services, you could get a couple of hours if that a day, and also costs of supplementing the service on top of what the HSE provides is extremely tough on a lot of families and patients…” Moira

The frustration experienced by the Irish GPs about service provision following dementia diagnosis is in line with findings reported by O’Shea in The Time for Action Is Now (2007). In this document, O’Shea stresses that the weaknesses of community care services have affected people with dementia and their carers in a very real way.

Further analysis of the data showed that some Irish GPs were not quite as critical as others about service availability, yet several argued that services were not well functioning or sufficient for the type of demands placed on them. One of these GPs claimed that service access was contingent on caregiver assertiveness:

“I think if you have a very active and progressive family member [the services] are fine, but if you don’t, if you have somebody who has really little ability to obtain those services, you won’t get them, you get nothing without pushing, because the public health burshe is overstretched…” Frances

Another believed that whilst current services were adequate, a problem might arise in the future:

“ I think that they would be at the moment they would be just about adequate, but you’d have to wonder with the expected increase in the future as to what’s
going to be around the corner, because it does demand a lot of care and therefore a lot of financial support” Barry

As regards the carer, the general sentiment among the Irish GPs is that the services available for them are not enough.

“…anything that relieves the day to day stress for the carer, so anything that gets the patient out of the house for three or four hours…it’s very difficult, the public health nurse says their budget is really really restricted…” Frances

“I think it would be lovely if there was an arrangement whereby carers in a crisis, that there could be a 24/7 type backup for carers in crisis, so I think really having that available would be terrific, even a drop-in centre, even a couple of hours in the morning whereby a carer could go in and look at equipment, look at skills, be taught how to lift, be taught how to do things, these would all help” Moira

Here, the GPs echo the fact that almost two-thirds of carers of people with dementia in Ireland feel completely overwhelmed by caring (O’Shea 2007). Also, what O’Shea calls “…an information vacuum about the disease, about services and about potential support structures for carers” (O’Shea 2007, p. 19) is alluded to.

Some of the GPs had a more benign view of services in Ireland that targeted family carers, however the paucity of services was still a problem.

“yes at the moment I think they are [adequate]…[some] patients feel they don’t have enough time, that the carers don’t have enough times, cutbacks all around” Barry
“…even sitting services and stuff like that would be greatly appreciated, and you know, there are then other aids and appliances and stuff like that that are possible, but that would be a general thing rather than necessarily associated with dementia” Deirdre

Findings from the in-depth interviews showed that the Swedish GPs were, on the other hand, on the whole satisfied with the quality and quantity of the services available for people with dementia at this stage in the course of the illness:

“no, I am impressed, I am very impressed by the municipalities efforts, very impressed [pauses] but you can always wish for more, huh [laughs]! But I don’t know, there is as much done as possible for people with dementia in this time…” Stig

“yes, I think it is, pretty optimal, I don’t know what you could do additionally, there is a kind of care structure there that I think works pretty well” Johan

Nevertheless, despite a general satisfaction with the Swedish services, there still exist for two of the four Swedish GPs areas that could be improved, primarily regarding special housing for people with dementia.

“you would wish for them to get another housing much, much earlier. It is, they stay at home until everything has declined a long time ago, and I think they should be moved to special housing…” Berit

“…I think it would be good if you had more special housing quite simply, housing and also respite centres…” Åsa
As regards the caregiver support services in Sweden, there was also a general sense of the system working well, especially concerning the access to information for the carer.

“yes, well I guess there is never enough [support] maybe, but this is as far as we’ve gotten, but it is very good if there could be more than one carer to help out if there are any…it is pretty heavy to be the sole person responsible for the sick family member, no matter what it concerns really” Johan

“…the Alzheimer’s Association have for the carers…and the memory clinic have offers to come there and talk but that is nothing I send to them, but they get that with the information there, when they are at the clinic [pauses] well, most carers go online and find what’s there, so they already know what’s available” Berit

In summary and in relation to the question asked about support services at the time of diagnosis, the broad consensus among the Swedish GPs thus seems to be that the system works well, albeit with some shortfalls. This was a far cry from the Irish GPs, who express their dissatisfaction over the service shortages and the effect it has on not only the person with dementia and their carers, but also how it affected their ability to do their job. This frustration of the Irish GPs was best captured in this lengthy quote from Maeve who said:

“…if the amount of money that was put in to making reports and publishing papers were put into actually giving one dementia nurse to an area…it’s lip service and it has always been lip service, and as long as the HSE continue in their present form it will always continue to be lip service because the last people on their priority list are the patients and the clinician and the support
structures [pauses] they don’t care, they don’t care about public health nurses being overworked, they don’t care about patients not having services [pauses] it’s very frustrating, and there is a lot of people out there who have paid taxes all their lives and they deserve a decent health service in their latter years who don’t get it” Maeve

The differences in levels of satisfaction with service provision following diagnosis seemed particularly obvious between the Swedish and Irish GPs. By and large the Irish GPs tended to believe that service provision was inadequate and even when services were available their quality was sub-standard. The analysis of the qualitative data showed that the Swedish GPs tended to be happy with the services offered – there was also a feeling that it made their job easier, in the sense that they had a firm structure to rely on to care for the patient in addition to their own efforts. This could not be more different from the Irish GPs, who, together with the person with dementia and their carers, had felt the impact of budget cuts, overstretched community functions and a general scarcity of services.

4.7 Discussion

The themes which emerged following data analysis revealed a number of issues. One very interesting aspect is the extent to which the behaviours and attitudes of both the Irish and the Swedish GPs were in accordance with literature findings. Also, apart from two disparaging themes, GPs from both countries expressed the same ambivalence in diagnosing dementia, and the wide reluctance to use the term “dementia” while disclosing the diagnosis, as well as sharing the same general attitudes in relation to stigma.
The ability of the GP to recognise the symptoms of dementia are crucial. No two people with dementia will be affected in the same way, but are rather likely to present with a combination of symptoms or other additional complications (O’Shea 2007). This adds weight to the need of the GP to be fully aware of the various signs of dementia and how they might present themselves. Despite the varied nature of the symptoms of dementia, the GPs interviewed mainly found cause for concern when told about the family or the persons own suspicions. This finding is in keeping with the literature where it has been noted that GPs tend to work in a reactive rather than proactive way (Iliffe et al 2005): the reliance on family and patients to report their cognitive unease which was apparent through the analysis of the data reinforces this observation.

The research interviews also showed that most of the Irish and Swedish GPs reveal a certain level of doubt and uncertainty about the issue of diagnosing dementia. This fear of early diagnosis from the perspective of the GP is discussed in the literature on dementia; however, as Lecouturier et al (2008) have argued, catastrophic reactions are not as common as might be believed. While dementia is a condition that exacts a great physical, mental and emotional toll on both patient and family (O’Shea 2007), it is important not to conceal it in any way. To do so would contribute to what Knapp et al refer to as a “culture of concealment, minimisation or ignoring of early signs and symptoms” (Knapp et al 2007, p. 6).

While from the perspective of the GPs, it is wise to be cautious and avoid unnecessary alarm with a diagnosis as serious as dementia, the research interviews showed that by and large and for most GPs interviewed, caution took precedence over clarity and transparency. Woods et al (2003) describe disclosure as a process rather than an event, which would potentially encompass the inclusion of the patient in the doctor’s
suspicion. Woods et al (2003) also stress that the information must be geared towards the individual and take into account that individual’s needs and perceptions. Interestingly, the three GPs who reported using the word “dementia” in their disclosure to their patients seemed reassured by noting the relief their patients and families showed in getting a simple and unequivocal diagnosis.

Some attitudes of the participants towards diagnosis and disclosure and found in the qualitative data may be unbeknownst to them actually influenced by the stigma surrounding dementia. All nine GPs could recognise that there were aspects of the disease that were stigmatised, and the reason why this was, such as the shame of getting older and forgetful, the transformation of the personality of the person, and the association between dementia and mental illness. However, the extent to which this stigma may also influence them was illustrated by the fact that one of the GPs, despite agreeing that aspects of the disease are stigmatised, stated that she did not believe dementia was a stigmatised illness.

As mentioned in the literature, Iliffe et al (2005) note that it is the appearance of disturbed and unusual behaviour, delusions and hallucinations in dementia that connects it to mental illness and generally stigmatises it. Also, Iliffe et al describe the stigma around ageing as the “…negative attributes attached to ageing as a degenerative and disabling process…” (Iliffe et al 2003, p.3). In this context, ageing is seen as a process whereby the person is inevitably going to become old and irrational, and the ageist perception is that there is no reason to attach too much significance to it. This is also related to the loss of social ability, which may occur as the disease progresses, leaving the person with dementia isolated, and further stigmatised.
Whilst this was an in-depth qualitative study and consequently no casual analysis is possible, nonetheless it is likely that GPs own inherent attitudes to dementia and their own beliefs about the stigma of the illness may have resulted in their avoiding using words such as “dementia”. Accordingly their attitudes and beliefs may have resulted in their conveying news of the illness to patients in vague and woolly language in order to protect their patients. The theme of fearing to disclose the diagnosis because of the stigma and the irreversible nature of the illness was apparent throughout the analysis of the transcripts.

While a diagnosis of dementia is naturally very distressing for the patient, a more person-centred approach where the impaired person is given more autonomy might make the experience a bit easier. The Irish Action Plan for Dementia argues that “the person with dementia, by virtue of their very existence, their emotions, their senses, must take centre stage…” (O’Shea and O’Reilly, p.18). An approach where the person is participating to the best of their abilities might also alleviate the dread felt by the GP, who thereby has more to offer the person. It may also help against the therapeutic nihilism many GPs feel when caring for a person with dementia (Downs 1996).

As the findings from the interviews have shown, the two groups of GPs were generally similar in their attitudes to diagnosis and disclosure, but differences emerged between the two groups when interviewed in relation to their experiences of specialist Education and Quality of Services. The different levels of exposure between the Irish and Swedish GPs to specialist training that were found in the analysis of the data may be due to a difference in emphasis on training by each individual country’s government.
In the 2010 National Guidelines for Dementia Care, the Swedish National Board of Health and Welfare reiterated their current effort at further educating those working in the care of people with dementia, such as GPs, nurses and carers. This is being done in order to raise the level of competency among those working with people with dementia, thereby improving the quality of care. Through increased training and knowledge about dementia in Sweden it is believed that attitudes and behaviour towards people with dementia will be positively affected. Also, further training would improve the level of satisfaction of their work for the GPs, nurses and carers, through better experiences and interaction with the patients (Socialstyrelsen 2010b).

In Ireland, the situation is distinctly different. The level of training that the Irish GPs reported in the research interviews are in line with the findings of Cahill et al (2006), who reported that 90% of Irish GPs surveyed in their study had no dementia-specific training. The Action Plan for Dementia (O’Shea and O’Reilly 1999) recommended in 1999 that training and information should be provided for GPs, as they are the ones who first deal with people with dementia. Yet, the 2007 follow-up to the Action Plan for Dementia, The Time for Action Is Now (O’Shea 2007), again states GPs especially should be urged to participate in more training; however, there is very little evidence of any provision for this. O’Shea (2007) argues that this is due to a reluctance to commit significant addition resources to dementia: an unwillingness that persists despite everyone agreeing that implementing the Action Plan for Dementia is a good idea.

This reluctance by the government to provide additional training is hampering the ability of the Irish GPs to attain deeper knowledge. When asked if they believed that it would be beneficial for them as GPs to receive such training, all nine respondents
said it would be. Thus, the data analysed showed that there exists not a lack of will, but mainly a lack of opportunity, for the GPs to receive further specialist training.

The lack of provisions for specialist training were mirrored in the lack of adequacy of services that the Irish GPs reported. The frustration echoed by the Irish GPs in the research interviews regarding the level of services available were even more noticeable due to the absence of any similar dissatisfaction among the Swedish GPs.

There has traditionally been an emphasis in Sweden on good social care, and the fact that over 140,000 Swedes have dementia have highlighted the need for proper services and adequate dementia care (Socialstyrelsen 2010b). The Swedish 2010 National Guidelines for Dementia Care recommend educational and psychosocial support structures for carers, as well as a number of respite care options and combination structures, which might include day centres and home help which allow the person to remain in the home while still offering support for the carer. The effective functioning of this system is seen throughout the research interviews in the general satisfaction with the system among the Swedish GPs.

The inadequacies of the Irish dementia services were expressed not only by the Irish GPs in this study, but also by O’Shea (2007) who argues that the stated government policy of allowing older dependent people to remain in their homes for as long as possible has been compromised by the “…failure of successive governments to allocate sufficient resources to community care” (O’Shea 2007, p. 15). O’Shea continues to argue that the community-based structure needs radical overhaul if services are to be able to satisfactorily assist people with dementia.

The shortcomings which the Irish GPs in this research study have described seem to be a direct result of a lack of funding and a lack of importance attached to community
services in general and dementia provisions in particular. Analysis of the data showed
that Irish GPs felt this impacted not only on their ability to effectively do their job, but
also on the people with dementia and their carers who had to face the dearth of the
services that are offered.
5. Conclusion

The aim of this qualitative study was to gain an insight into the attitudes and experiences of GPs in Ireland and Sweden regarding the diagnosis and disclosure of dementia.

Overall, the themes that became apparent through analysis of the data collected showed that Irish and Swedish GPs generally shared the same attitudes when it came to diagnosing and disclosing dementia. The issue of noticing symptoms of dementia was marked by a heavy reliance on the person with dementia or the family to notify the GP of the problem. In the area of diagnosis, there was a sense that while the GPs recognised that it was an important issue, they were still reluctant to diagnose. This apprehension was evident in the disclosure process, where most of the GPs interviewed not using the actual word “dementia”. This reluctance may be connected to the stigma that surrounds dementia: the GPs reported an awareness of the stigma, yet data analysis indicated their attitudes may be influenced by stigma.

There were two instances in the research interviews where the data analysis showed a difference in attitude and experiences between the Irish and Swedish GPs. These differences emerged in relation to Education and Quality of Services, with the Irish GPs interviewed revealing a lesser exposure to specialist training and a low opinion of the service provisions available to a person with dementia and their carer. Reasons for this may be connected to an unwillingness on behalf of the Irish government to allocate resources to offer specialist training to Irish GPs on the topic of dementia, as well as to adequately fund the care structures and service provisions.

The results that came from the qualitative data analysis thus shows that by and large the Swedish and Irish GPs shared similar attitudes towards the processes of
diagnosing and disclosing dementia. The experiences which they shared in the in-depth interviews have been in line with the GP behaviour that has been found in the literature. The contrasting experiences that emerged between the Irish and Swedish GPs in the areas of Education and Quality of Services are an interesting indicator that the Swedish GPs were overall more satisfied with the structure a more adequately funded health service provided.

In conclusion, this qualitative study found many similarities but also significant differences between the Irish and Swedish GPs attitudes and experiences of diagnosing and disclosing dementia. The extent to which these are influenced by the reliability and adequacy of the fundamental health care structures that support the GPs, and the stigma and therapeutic nihilism that surrounds dementia, are areas that warrant further examination.
6. Appendix

6.1 List of GP Participants

“Barry”, 63 years old, Ireland
“Berit”, 42 years old, Sweden
“Deirdre”, 42 years old, Ireland
“Frances”, 48 years old, Ireland
“Johan”, 56 years old, Sweden
“Maeve”, 52 years old, Ireland
“Moira”, 52 years old, Ireland
“Stig”, 58 years old, Sweden
“Åsa”, 62 years old, Sweden
6.2 Participant Information Sheet -- English

Diagnosis and Disclosure of Dementia
A Comparative Study of Attitudes and Experiences of
General Practitioners in Ireland and Sweden

Who Is Conducting the Study?
My name is Vanessa Moore, and I am currently a student of MSc Applied Social Research in the School of Social Work and Social Policy at Trinity College Dublin.

Aims and Objectives of Study
Diagnosing early stage dementia is said to be a difficult process, as the symptoms are often diffuse and can be indicative of a number of other issues. In addition, disclosure to the individual and family members requires great sensitivity. General Practitioners are in a unique position as they are often the first port of call for people who notice issues with their cognitive health. The General Practitioner may also be the one who notices the symptoms first.

In this qualitative study, I hope to describe the attitudes General Practitioners have about diagnosis and disclosure in two different countries, Ireland and Sweden. Through learning more about their understanding and experiences, and building on their knowledge, it is hoped that a more in-depth understanding of the process of diagnosis and disclosure will be obtained.

Who Is Being Asked to Participate in this Study?
I am attempting to contact 16 General Practitioners, eight in Ireland and eight in Sweden.

Interview
With your consent, I wish to talk to you in-depth using a semi-structured interview schedule. All information will be gathered and kept confidential, and no names or identifying data will be disclosed. You are entitled to withdraw from the project at any time. The types of issues that will be explored in this interview includes your approach to recognising and screening for dementia, diagnosing dementia, the process of disclosure and the follow up available to your patient and the family caregivers.

The interview data will be kept for the duration of the College year, and will be destroyed in December 2010. The research is being done for the purpose of completing a Masters dissertation.

I am very grateful to you for considering taking part in my research. If you wish to participate, my contact details are:

Email: moorev@tcd.ie    Phone: 086-8656307
6.3 Participant Information Sheet -- Swedish

Diagnosis and Disclosure of Dementia
A Comparative Study of Attitudes and Experiences of General Practitioners in Ireland and Sweden

Vem genomför studien?


Avhandlingens syfte och mål

Att ställa en demens-dia gnos är en komplicerad process, då symptomen kan vara vaga och kan beskriva en rad olika åkommor. Att berätta för en person och deras anhöriga att diagnosen är demens är även det en svår process, som kräver takt, finkänslighet och medkänsla.

Husläkare är i en unik position då de ofta är den första anhalten för en person som misstänker att den har kognitiva problem, eller så är det husläkaren som upptäcker symptom som tyder på demens, och skickar patienten till en specialist. Husläkarens kunskap, inställning och erfarenhet i att hantera sådana situationer är därför mycket intressant och ger en inblick i demens-vården och etiken som leder den.

I denna avhandling hoppas jag att studera och förmedla husläkares perspektiv och tankar runt dessa frågor i två olika hälsosystem, nämligen de i Sverige och Irland. Genom att använda husläkarens erfarenhet och kunskap hoppas jag att precisera hur processen av att ställa en demens-dia gnos och att förmedla den till familjen sker, och vad de två ländernas olika system kan lära sig av varandra.

Vem är ombedd att medverka i studien?

Jag kontaktar totalt 16 husläkare, åtta på Irland och åtta i Sverige, och ber dem medverka i individuella intervjuer som sen kommer att användas som bakgrund till min Master-avhandling.

Intervju


Jag är väldigt tacksam att du funderar på att ta del i mitt projekt. Om du vill medverka är mina kontakt-detaljer följande:

Email: moorev@tcd.ie telefon: 08-7678202
6.4 Participant Consent Form -- English

Diagnosis and Disclosure of Dementia
A Comparative Study of Attitudes and Experiences of General Practitioners in Ireland and Sweden

Consent Form

I am willing to be interviewed by Vanessa Moore from the School of Social Work and Social Policy in Trinity College Dublin for the thesis entitled “Diagnosis and Disclosure of Dementia A Comparative Study of Attitudes and Experiences of General Practitioners in Ireland and Sweden”.

The purpose of the research has been explained to me, and I have been given an opportunity to ask any questions I have about the research. I understand that my participation will contribute to research on attitudes to dementia, diagnosis and disclosure, and that it will be used for a Masters thesis.

I understand that my participation is entirely voluntary and that I can end my participation at any time.

I agree that any information gathered in the interview may be used by the researcher for the purpose of writing the thesis, as long as my anonymity and confidentiality are maintained.

Signed: ______________________________

Date: _______________________________
6.5 Participant Consent Form -- Swedish

Diagnosis and Disclosure of Dementia
A Comparative Study of Attitudes and Experiences of
General Practitioners in Ireland and Sweden

Consent Form

Jag är villig att bli intervjuad av Vanessa Moore från The School of Social Work and Social Policy i Trinity College Dublin för hennes Master- avhandling “Best Practice? Diagnosis and Disclosure of Early Stages Dementia A Comparative Study of the Attitude of General Practitioners in Ireland and Sweden”.

Jag har förstått ändamålet av denna intervju, och jag har haft tillfälle att ställa frågor om projektet. Jag har förstått att min medverkan kommer att användas till en Master-avhandling, och även bidra till forskning om tillvägagångssätt runt demens; att ställa diagnosen och att dela den med personen och dess anhöriga.

Jag har förstått att min medverkan är helt frivillig och att jag kan dra mig ur när som helst.

Jag samtycker till att informationen som samlas i intervjuen får användas för att skriva Master-avhandlingen, så länge som min anonymitet uppehålls.

Signatur: ______________________________

Datum: _________________________
7. Bibliography


