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Fabrication or Induction of Illness in Older People

Esther Ngambi

CARL Research Project

CARL
COMMUNITY - ACADEMIC
RESEARCH LINKS
University College Cork, Ireland

Name of student(s):	Esther Ngambi
Name of civil society organization/community group:	Age: Wisdom and Hope, Cork County
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Name and year of course:	Master of Social Science (Social Policy)
Date completed:	24th September, 2015

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- promote and support public access to and influence on science and technology;
- create equitable and supportive partnerships with civil society organisations;
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Fabrication or Induction of Illness in Older People by Carers

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24th September, 2015

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Declaration of Authorship

I hereby declare that the thesis presented here is, to the best of my knowledge and belief, entirely my own original work except where otherwise indicated. I certify that this thesis has not been submitted, either in part or whole, for a Degree at this or any other University. I am aware of the University's regulations concerning plagiarism. I further declare that any use of the works of any other author is referenced and attributed to that author accordingly.

Signed:

24th September 2015

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Abstract

Fabrication or Induction of Illness (FII) in older people (65 and above) is an extraordinary type of abuse in which carers (spouse, family member, companion, professional or nonprofessional worker) exaggerate, invent or induce illness in an older person under their care in older to gain attention or praise for helping them (Bennett, 2007). A group of professionals called Age: Wisdom and Hope (community partner) who deal with the welfare of older people recorded a number of case examples that led to the partnership with Community Academic Research Links (CARL) of University College Cork (UCC) to undertake this qualitative research study in order to develop public and professional awareness. In view of the fact that this dissertation was a collaborative research process, the community partner and UCC through the student researcher worked together from design to some dissemination activities by holding a number of meetings (McNiff, 2013). Eight medical and non-medical participants were selected through purposive sampling technique (Silverman, 2010) and participated in one Irish location (not mentioned to preserve anonymity).

The findings in this dissertation suggest that although FII has been well-documented in children, there is a major lack of information on FII in older people. A comprehensive search strategy involving leading databases found no formal studies and only six published cases from around the world, none of which were from the Republic of Ireland. This reveals that FII in older people by carers is uncommon; the phenomenon has been underresearched, leading to its being underreported. This problem is compounded by the absence of any policy guidelines, best practice or legal framework that recognises FII, coupled with the difficulty in diagnosis and limited public and professional awareness. Furthermore, the findings suggest that FII could take place in any setting in which older people receive long-term care, including medical or nonmedical settings. The motivations of perpetrators are complex but include attention-seeking, self-praise, and/or the desire to be seen as a wonderful carer. However, some participants in this dissertation did not rule out financial gain as a motivating factor. In addition, signs and symptoms of FII comprise the carer being overprotective individuals who make persistent complaints to professionals and interfere with treatment. Additionally, there are different viewpoints regarding the mental health status of perpetrators. While some perpetrators' behaviour can be linked to mental health challenges, others would not have had a history or formal diagnosis of the same. Moreover, perpetrators may not always meet the criteria for mental health diagnosis which may not justify the claim that perpetrators are consistently those with mental health issues. Participants in this research mainly recommend professional and public awareness, while other long-term recommendations pertaining to policy and legislation are discussed, and details of dissemination outlined.

CHAPTER ONE

Introduction

1.1 Introduction

Fabrication or Induction of Illness (FII), commonly known as Munchausen Syndrome by Proxy (MSBP) in an older person (65 and above), is an exceptional form of abuse in which a carer or a person with a care role (spouse, family member, companion, professional or non-professional worker) fabricates or induces illness in an older person under their care in older to gain attention or self-praise for helping them (Bennett, 2007). This form of abuse can involve professionals from various settings playing a role unknowingly through carrying out unnecessary medical or non-medical procedures, assessments and tests conducted in the name of treating the feigned illness, which can lead to stress and even death of the victim (Gilbert, 2014).

The unique contribution of this collaborative study is to present the findings of a rigorous review of the literature on FII in older people and then explore the subject through qualitative research into FII in older people in Ireland and internationally, ultimately providing recommendations in line with the findings as to future practice, policy, and research with a view to improving protections for older people in Irish society. A search strategy (see 2.2) revealed six published case reports on FII in older people internationally, indicating that this form of abuse is a possibility, even though it has been underreported and underresearched. This introductory chapter provides a context for the questions explored, outlining the topic, its background, rationale, aims, and research questions, as well as defining key terms in the research title and outlining the layout of the study.

1.1 Background to the Research

This research was initiated by a community partner in Ireland, namely, Age: Wisdom and Hope, who worked with myself, a University College Cork (UCC) Master of Social Science (Social Policy) student through Community Academic Research Links (CARL) of

UCC in accordance with the *National Strategy for Higher Education to 2030* (Department of Education and Skills Training, 2011). The topic under investigation was generated by the community partner, Age: Wisdom and Hope, comprising a diverse group of professionals who sought to collaborate with UCC to obtain information on FII in older people. The need to commission this research arose from an issue submitted to the group by one of the residents of a local residential care setting for older people. Subsequently, a few similar cases were brought to the attention of the group, who felt it was necessary to find out what is known about FII in older people in Ireland and internationally, and whether there exists an assessment tool that can help professionals identify and protect victims, as well as prevent its occurrence. Accordingly, the group presented a request to CARL of UCC for the research to be undertaken (Age: Wisdom and Hope, 2013):

> CARL provides participatory research support in response to concerns experienced by Civil Society Organisations such as Age: Wisdom and Hope. Through CARL academics are engaged in community based research by supervising students who undertake the research in collaboration with civil society groups (CARL, 2015, p. 1).

The *National Strategy for Higher Education to 2030* (Department of Education and Skills Training, 2011) advises that higher education institutions work with community partners to respond to the concerns of the community through collaboration and shared responsibility:

> Higher education institutions serves communal development as well as individual development, and this is exemplified in the spirit of enquiry that higher education fosters as a resource of independent insight into matters that impact on society (Department of Education and Skills Training, 2011, p. 38).

Recognising that this is a vitally important but underresearched area, as a student researcher I therefore selected this topic for in-depth study and undertook to apply the principles of community-based research in collaborating with Age: Wisdom and Hope in the research design and the undertaking of research and dissemination, as highlighted in the subsequent chapters.

1.2 Rationale

Although hundreds of reports exist on FII in children (Schreier, 2002), it was unclear to Age: Wisdom and Hope whether any research on FII in older people in Ireland or internationally had been published. However, the community partner had recorded a number of cases that suggested that some carers in Cork County were falsifying or inducing illness in older people. This led them to undertake an initial search on FII in older people to discover what is known about the phenomenon and subsequently inform professionals and the general public (Age: Wisdom and Hope, 2013). This research highlighted a lack of information on FII in older people, which poses a challenge for professionals dealing with the welfare of this vulnerable group. Furthermore, while policy pertinent to older people exists in Ireland such as the *Safeguarding Vulnerable Persons at Risk of Abuse, National Policy and Procedures* (Health Service Executive, 2014), none of the policy documents highlight FII in older people. Even the definition of abuse outlined in the available policy documents and legislation does not highlight FII in older people, which complicates identification, management and treatment (Lazenbatt, 2013). With limited professional and public awareness, a paucity of research, difficulties in diagnosis and underreporting there are clearly potential risks with life-threatening consequences for older people, particularly if FII remains unexplored, unrecognised and unchecked (Lazenbatt, 2013). Momtaz *et al.* (2013) argue that the changing role of older people removes them from the workforce and reduces their independence, making them vulnerable to maltreatment.

There is therefore a clear need for research in this area, one which this dissertation addresses. As highlighted by the case examples referred to by Age: Wisdom and Hope, the phenomenon of FII is thought to exist in Ireland, but its identification and treatment is problematic in the absence of adequate public and professional understanding. Engaging with professionals who deal with older people, this research examines the validity of the claim that FII exists. This research project addresses the deficiency in public and professional knowledge, gathering information that can inform both public and professional awareness. It therefore provides a vital contribution to research, policy-

formation, and practice, enhancing the identification and protection of older people from this form of abuse.

1.3 Aims of the Research

The aims of the project as collaboratively developed by the student researcher with the community partner (the 'team') are as follows:

i. To establish whether FII in older people exists;
ii. To ascertain what body of literature on FII in older people is available in Ireland and internationally;
iii. To identify what signs, symptoms, and behaviours constitute FII in older people; and
iv. To find out the setting or context in which FII in older people is most likely to take place.

1.4 Research Questions

Aveyard (2007) argues that research questions provide the context for a literature review as well as highlighting unexplored areas, contradictions and perspectives that have not been considered before. Research questions also dictate the kind of data needed, as well as the method of its collection and analysis (White, 2009). In this regard, having brainstormed with the community partner, the following research questions were developed to achieve the aims of the study:

i. Does fabrication or induction of illness in older people by carers exist in Ireland and internationally?
ii. In what setting does it exist and what are the motivating behaviours in these contexts?
iii. How can FII in older people be identified by professionals?
iv. What policies, best practice, or legal frameworks are available to protect victims or potential victims of FII by carers in Ireland?

1.5 Methodology

In order to gain insight into what was known about FII in older people in Ireland, this dissertation used qualitative research designed to help explore, describe, and explain experiences and concerns of professionals who work with older people. Participants were selected using purposive sampling methods from one location in Ireland and were interviewed using an interview guide (Denscombe, 2010). Consequently, data was analysed using Braun and Clarke's (2006) thematic approach (See Chapter Two for details on methodology).

1.6 Definitions

Fabrication or induction of illness: in this dissertation fabrication or induction of illness was taken to mean an unusual form of abuse in which a carer invents or encourages illness in an older person under their care, which can result in unnecessary medical procedures as well as involvement of various professionals and can lead to death of the older person (Tamay *et al*., 2007).

Older person/ older people: any person aged 65 and above who depends on the support of others for their daily existence; this dissertation adopted the age of 65 and above based on the Central Statistics Office of the Republic of Ireland (Central Statistics Office, 2011).

Carer: Any person aged between 19 and 64 who provides care and assistance to older people on a regular basis in a family setting, community or in an institution, whether such persons were paid, unpaid, professional or non-professional; in the context of this study carers of older people are the principal focus. A carer can be a spouse, family member, partner, companion and/or personnel in an institution who has a responsibility of providing support to people who cannot cope without their support (Blackburn *et al*., 2005).

1.8 Overview of Chapters

This research study is divided into five chapters as follows:

- *Chapter One: Introduction*

  Introduces the research study and sets up the questions explored.

- *Chapter Two: Research methodology*

  Discusses the search strategy, community based research, research design, method of data collection and analysis, sample size, and ethical considerations, as well as limitations of the study.

- *Chapter Three: Review of policy and academic literature on FII in older people by carers*

  This chapter examines literature on FII in older people in a global and domestic context.

- *Chapter Four: Findings, analysis and discussion*

  Presents findings, analysis, and discusses the findings so as to address the research questions, taking into consideration the literature discussed in Chapter Three.

- *Chapter Five: Conclusions and Recommendations*

  Highlights the conclusions established on the basis of the findings and literature and subsequently provides recommendations.

1.9 Conclusion

As has been shown in this chapter, there is a clear need for research that addresses the lack of current public and professional understanding of FII in older people so as to identify, treat, and manage the phenomenon and thereby protect a vulnerable social group. This dissertation considers key research questions devised by the student researcher with the community partner in order to achieve the aims of ascertaining whether FII in older people exists, what the current state of knowledge is on the subject, and what its motivating factors, signs, symptoms, and settings are, which professionals may be able to observe. Having set the background and defined the aims and research questions, the subsequent chapter outlines the methodology developed by the research team of student researcher and community partner in engaging with the complex and underresearched topic of FII in older people, as well as limitations and ethical considerations of the study.

CHAPTER TWO

Research Methodology

2.1 Introduction

As noted in Chapter One, this study is informed by community-based research on Fabrication or Induction of Illness (FII) in older people by carers, in which the community partner, Age: Wisdom and Hope, worked in collaboration with myself as a student researcher in initial design of the research methodology (Whyte, 1991). In this chapter, the methodology collaboratively developed by myself and the community partner is presented in order to achieve the aims of this project. The chapter starts by highlighting the search strategy or method that was used to research available documentation on FII in older people. The chapter then discusses the process of community-based research and how it informed the choice of the design, sampling technique, the sample size and the data collection and analysis methods that were used in this study. The chapter ends by discussing limitations as well as ethical considerations of the study. Overall, as this chapter highlights, the collaboration of community partner and student researcher brought a variety of strengths to the research process and led to the development of a multi-faceted and effective research design.

2.2 FII in older people: search strategy

Before considering what research design to use, it was deemed important to ascertain what documentation existed on FII in older people nationally and internationally. Therefore, a comprehensive search of literature was undertaken using leading academic journal databases (outlined below in Table 1), which were selected because they were relevant, comprehensive and covered a wide range of subject areas. The results identified literature on FII, which focused mainly on children. There were, however, also at least 13 cases of FII in adults aged 19–82 years reported by various authors. Burton *et al.* (2015) outlined 13 of these cases, of which seven involved adults aged 19–64. However, these did not fall into the spectrum of this research, which focuses on adults aged 65 and above. The search did

identify six case reports on older people who fall within this spectrum (see Chapter Three for case summary), and showed that the key words 'fabrication or induction of illness in older people' were, however, not as commonly used as 'Munchausen Syndrome by Proxy'; Table 1 outlines the details of the search strategy, including these keywords. One case from Switzerland with a short abstract in English involved a 66-year-old woman whose 'medical chart revealed many discordant elements leading to FII. The patient had been treated over a period of 20 years at a clinic for a variety of symptoms concerning virtually all organs. Her son's chart also contained discordant elements, raising the suspicion of FII' (Kaufma-Walther and Laederach, 1997, p. 850). This case did not meet the criteria of this research because although the patient was 66 she had suffered much earlier prior to turning 65, and she herself seemed to be the perpetrator in the case of her son.

Below is a summary of the search strategy:

Table 1: Search strategy

No.	Data base	Keywords used to search	Search Results
1.	**Academic Search Complete-EBSCO host**	Fabrication or induction of illness in older people	76,294 results, none of which dealt with FII in older people.
		Munchausen Syndrome by proxy in an elderly	Found 1 result relevant to older people.
2.	**JSTOR**	Fabrication or induction of illness in older people	Of the 7,704,34 search results none concerned FII in older people.
		Munchausen syndrome by proxy in an elderly	Of the 777 results none concerned FII in older people
3.	**OCLC Firstsearch**	Fabrication or induction of illness in older people or the elderly	281,347 results, none of which concerned FII in older people.
		Munchausen syndrome by proxy in an elderly	4 results, 2 of which dealt with FII in older people.
4.	**Science Direct**	Fabrication or induction of illness in older people	10,044 results, none of which concerned FII in older people
		Munchausen syndrome by	Of the 105 search results 2

		proxy in an elderly	dealt with FII in older people.
5.	**Scopus**	Fabrication or induction of illness in older people or the elderly	No results.
		Munchausen syndrome by proxy in the elderly	40 results, 3 of which dealt with FII in older people.
		Munchhausen in an old woman	12 results, 4 of which concerned FII in older people, 1 of these articles was in French, and only the abstract was accessible from Scopus.
6.	**Web Science**	Fabrication or induction of illness in older people	518,174 results, none of which related to FII in older people.
		Munchausen syndrome by proxy in an elderly	3 results, 3 of which concerned FII in older people.
		Munchausen syndrome by proxy in older adults	19 results, 3 of which related to FII in older people.
7.	**Pub Med**	Fabrication or induction of illness in older people or the elderly	475 results, none of which dealt with FII in older people.
		Munchausen syndrome by proxy in an elderly	8 results, 2 of which dealt with FII in older people.
8.	**Oxford Journal Search**	Fabrication or induction of illness in older people or the elderly	No results related to FII.
		Munchausen syndrome by proxy in an elderly	81 results, none of which related to FII in older people.
9.	**Google Scholar**	Fabrication or induction of illness in older people or the elderly	20,400 results, none of which dealt with FII in older people.
		Munchausen syndrome by proxy in an elderly	3,190 results, 5 of which related to FII in older people.
		Munchausen syndrome by proxy in older adults	4,260 results, 5 of which dealt with FII in older people.

The search results above found a total of six articles related to FII in older people, five of which were accessible in English, while one published in French concerned an 82-year-old woman was not accessible in English due to time and language constraints. Of these six articles, two originated from the United Kingdom, and one each from Israel, Australia, Poland and France. All six articles were case reports and not formal studies; and all were published in medical-related journals. Consequently, the literature search demonstrated an extremely limited scope of research concerning FII in older people. In addition, no case report was identified in Ireland. The case reports are examined further in Chapter Three. In light of the outcome of this search strategy, the student researcher and the community partner had a meeting to discuss the design of the study and shared responsibilities.

2.3 Community-Based Research

In view of the fact that there was a scarcity of information on FII in older people, the professionals in Age: Wisdom and Hope, as a community-based organisation, felt it necessary to find out what is known about FII in older people in order to inform professionals dealing with the elderly. McIlrath *et al*. argue that community-based research begins with the development of a research question of concern to the local community (in this case the organisation Age: Wisdom and Hope) (2014, p. 103). The community should then seek a way to partner with a local Higher Education Institution (*ibid*.). The resulting research partnership highlights shared ownership and uses collaborative research design and processes that ultimately bring forth:

> …the development of reflective practice, the dialectic of developing theory from action, the iterative processes of action research such as planning, implementation and reflection and as a process that helps to ensure the outcomes are achieved rather than research that examines the binary question of whether or not they were met (Mullet in Munck *et al*., p. 51).

Therefore, community-based research provides a differential strategy for higher education that allows it to serve the public good in providing a resource of knowledge for the whole community that concerns an issue of social relevance. The *National Strategy for Higher Education to 2030* (Department of Education and Skills Training, 2011) stipulated that

higher education in an era of social transformation must consider aspects of the relationship that bind it to wider society. Higher education therefore needs to respond to new social, economic, demographic, and cultural change in modern Ireland. Consequently, this research goes toward fulfilling the objectives of the *National Strategy for Higher Education to 2030*, which recommends that each higher education institution, such as UCC, must 'address the full range of its responsibilities towards society including local communities, public policy and practice and engage[s] with the needs of the community for its wellbeing' (Department of Education, 2011, p. 5).

Israel *et al*. (1998, p. 177) highlight how 'community-based research is a collaborative approach…that equitably involves all partners in the research process and recognises the unique strength that each brings.' Age: Wisdom and Hope are a diverse group of professionals who contributed various unique strengths in the course of this project, such as organising meetings for planning and brainstorming with myself, the student researcher, providing input to letters and documentation needed for the research, distributing them, and scheduling appointments for certain interviews carried out. On the other hand, I, as the student researcher, brought my own skills to the project, which included academic research and writing skills, access to a wide range of documents through the UCC library, supportive supervision, access to a supportive academic network, and full-time commitment to the project. The collaborative strengths of both parties led to the development of a research framework outlined in the subsequent sections of this chapter.

2.4 Research Design

According to Denscombe (2010, p. 99), 'a research design specifies the general approach… and gives details about the methods of data collection and analysis. It also provides rationale for the choice of research strategy'. The student researcher and the community partner participated in a meeting to discuss research objectives and the design of the research. As a team we agreed that due to the apparent rarity of FII in older people in Ireland and a lack of large-scale measurable data on the topic, a qualitative approach would be more suited to this phenomenon, employing techniques of description, exploration, and explanation to gain a comprehensive insight into the experiences and concerns of

professionals regarding FII in older people (Denscombe, 2010; Savin-Baden & Major, 2013). Furthermore, the flexible nature of a qualitative approach was deemed better suited for the objectives of the research project, which were formulated as follows:

i. To establish whether FII in older people exists;
ii. To ascertain what body of literature on FII in older people is currently available;
iii. To identify what signs, symptoms. and behaviours constitute FII in older people; and
iv. To find out in what setting or context FII in older people is most likely to take place.

2.5 Sampling Technique

Sampling is a process of choosing the target population to be included in the research study. In order to choose the target population, this research study used a purposive sampling method, as outlined by Sarantakos (1988). Dezin and Lincoln (quoted in Silverman, 2010, p. 141) suggest that 'many qualitative researchers employ purposive sampling methods. They seek out groups, settings and individuals where the processes being studied were mostly likely to occur.' Therefore, considering that the topic under investigation has been underresearched and has not been recognised as a form of abuse of the elderly, the selection of the population that would be the subject of the study needed careful consideration. It was necessary to select participants who had encountered FII cases in the elderly or had information about it; hence the use of a purposive sampling technique which the research team resolved to use after their meetings (Silverman, 2010).

2.5.1 Population and sample size

The next questions the student researcher and the community partner addressed were: 'how do we choose a sample size that would answer the research questions, seeing that there is limited information on FII in older people? Will we have a sufficient sample size?' At this stage these were very challenging questions to answer. A number of brainstorming meetings were held. The team resolved that pre-interview letters and a checklist (see copies in Appendices 9 and 10, respectively) be first of all sent to potential participants, from

whom a sample size would be selected based on the responses. Furthermore, an elevator pitch (see copy in appendix 8) was carried out to inform professionals dealing with elder care about the research so that if they had information on FII in older people or if they knew someone who had, they could let the community partner and the student researcher know. This was also an effort to get professionals to start thinking about FII in older people through reading the elevator pitch. We wrote the letters and prepared the checklist to help potential participants assess whether they had come across an FII case in older people or whether they had information of such. It was agreed that the student researcher should prepare the drafts and that the partner provide input and distribute the letters, which was done. The community partner sent over 50 letters throughout the country to medical and non-medical institutions dealing with the welfare of older people.

Twenty-one responses were received and analysed by way of a meeting. The pre-interview checklist (Appendix 10) had twelve questions and we agreed that since FII in older people appears relatively rare, 6–12 ticks on the pre-interview checklist would mean 'yes', 3–5 ticks would denote 'unsure', and 0–2 ticks mean a definite 'no.' The analysis showed that out of 21 responses received eight were 'yes', eight were 'no', and five were unsure of having come across an FII case in older adults. The student researcher then summarised the resolution of the meeting in a table below, which also indicated the category of professionals who responded to the pre-interview letters:

Table 2: Consolidated pre-interview checklist outcome

Profession	Yes	No	Unsure	Total
General Practitioners (GP)	1	1	1	3
Social Workers	2	2		4
Public Health Nurses	1	4	2	7
Director of Nursing private nursing care facility or HSE facility	1		1	2
Clinical Nurse Level 2	1	1	1	3
Home Help	1			1
Elder Care Management	1			1
Total	**8**	**8**	**5**	**21**

The team then selected a sample of eight professionals who fell into the 'yes' category from one location in Ireland. We also decided to write a letter to the 21 potential

participants thanking them for their responses (see copy in Appendix 7). Subsequently, the team wrote letters to the eight participants requesting an appointment to interview them (see copy in Appendix 6). From the responses received, the community partner scheduled the interview appointments and the student researcher interviewed the participants accordingly. Therefore, the final sample comprised one General Practitioner (GP), two Social Workers (one medical and one non-medical), one Public Health Nurse, one Nursing Care (private), one Clinical Nurse Level 2, one Home Help, and one Eldercare Management, eight in total. For anonymity reasons the gender of the participants and their location were left out throughout this dissertation.

2.6 Data Collection

Although initially the team proposed to use both interviews and focus group discussions, ultimately only interviews were used. To arrive at this decision separate discussions were held, one with the supervisor and the other with the community partner, and it was resolved that due to the sensitive nature of the research, focus groups were not going to be used as they could limit individual disclosure in the group (Then *et al*., 2014) and were time-consuming (Doody *et al*., 2013). Therefore, the community partner and student researcher co-constructed a research interview guide. Bryman defined an interview guide as a list of questions to be asked in a semi structured interview, the sequence of which can vary, therefore providing latitude to ask further questions in response to what was seen as significant responses (Bryman, 2008). In this regard, the student researcher developed the initial draft interview guide and had a meeting with the community partner who provided input in line with what Age: Wisdom and Hope wanted to find out, which was added to core themes that arose in the literature. The data collection instruments used were the interview guide and a recorder. All the interviews were recorded and transcribed. The eight interviews were a maximum of 45 minutes each and were organised by the community partner at the venue suited to the participants, which was generally within their work environments. The student researcher was mostly accompanied by the community partner, as most of the venues were not familiar to the student researcher. The community partner would then leave after introducing the student researcher to the participants. The interviews provided in-depth information from individual professionals on FII in older

people that helped to answer research questions (Kumar, 2005). Data was therefore generated on expected themes and some unexpected themes. The data was then analysed using thematic analysis.

2.7 Data Analysis

Using thematic analysis, the researcher drew on evidence from the interviews to ground the claim that FII in older people may exist and professionals need to be aware of it (McNiff, 2013). Braun and Clark (2006) suggest that in thematic analysis, if one is working with verbal data such as interviews, the data needs to be transcribed into written form in order to analyse it. As such, the student researcher transcribed the interview data and coded the data into themes for analysis. Saldana states that:

> …a code in qualitative inquiry is often a word or short phrase that symbolically assigned a summative, salient or evocative attribute for a portion of data. The data could consist of transcripts, field notes, document and others (2009, p. 3).

Braun and Clarke defined thematic analysis as a method of identifying, analysing and reporting patterns (themes) within the data (2006). Having been familiarised with thematic analysis and with transcripts, the researcher began the process of identifying themes in the data. Using Braun and Clarke's approach (*ibid*.) to thematic analysis, a matrix of themes, sub-themes and notes was developed. Many themes arose from this exercise, and a table was drawn up and divided into the four main themes that emanated from the research questions. Raw data from interview transcripts was matched with the appropriate codes, drawing on the recommendations of Vaismoradi *et al*. (2013). Many codes were generated initially under each main theme, resulting in a long list of different codes. In order to refocus, the codes were then sorted into main themes and some codes of a similar nature were combined and placed under one sub-theme under the respective overarching themes (Mokhatari Nouri *et al.,* 2014). Other codes were refined and combined with similar subthemes. It was found that a few codes did not match the main themes; these were given a separate theme called 'Surprises'. After further analysing the codes under 'Surprises', some codes were discarded that seemed to be repetitions, and some that did not have enough data. Additionally, under 'Surprises', the researcher highlighted extracts from the

interviews that were considered to be 'amazing findings.' Themes were further reviewed and some reworded and reconsidered in relation to others. An analysis for each theme and respective sub themes was then carried out (Braun & Clarke, 2006), and conclusions were made in Chapters Four and Five of this report respectively

2.8 Limitations of the study

Some limitations to the study must be highlighted, one of the principal being time constraints. Due to their busy and demanding occupations, some participants were not able to share as much information as they would have liked. Another limitation was the lack of any published case report involving FII in older people from the Republic of Ireland, which could have been a starting point in terms of analysis, conclusions, and recommendations. In addition, very few cases have been published around the world which may explain why no previous research was carried out in Ireland, though it is hoped that this dissertation serves as a first step in this direction. Furthermore, one of the published cases on FII in older people was in French and not accessible in the course of this dissertation, which brought the total number of analysed cases to five instead of six. Documentation on this subject was therefore limited and may have impacted on the broad literature review.

2.9 Ethical Considerations

Punch (1998) pointed out that all social research presents ethical issues because it involves collecting data from people about people, as in the case of this research. In this regard, the researcher and the community partner wrote to participants informing them of the purpose of the study, stating why Age: Wisdom and Hope had decided to undertake the study, making it clear that any information would be treated with strict confidence and anonymity, and that no participant would be identifiable as having given information to the research (see copy of information sheet and letter in Appendices 4 and 6). In view of the sensitivity of the research and the fact that it was undertaken in one location, the names of the participants have been substituted with false names where direct quotations are used in order to maintain anonymity, as was highlighted to participants in the individual letters. Additionally, to protect the identity of a participant who was a GP, the gender of the

participants were not revealed anywhere in the research report or the chapter on presentation of findings. Also, the location of the research participants remained anonymous throughout this dissertation to protect participants. Furthermore, written consent (see copy in Appendix 5) from participants was obtained and it was agreed that the voice recorder would be destroy after 6–12 months of writing the report. As a matter of courtesy the researcher and the community partner extended their gratitude to the participants after the interviews.

2.10 Dissemination

Arising from the research findings presented in Chapter Four, the community partner and the student researcher disseminated the findings to the research participants as well as professionals in Age: Wisdom and Hope. The meeting was attended by a cross section of individuals including, professionals from Age: Wisdom and Hope, UCC lecturers and students. The community partner and the student researcher co-presented the findings at a meeting held in UCC on 21st September, 2015 (see copy of presentation in Appendix 11). In addition, the community partner and the student researcher co-developed a checklist for professionals on what to look for if they suspect FII in an older person, which the community partner is distributing, as well as an information leaflet (see copies in Appendices 2 and 3). In addition, the team wrote letters to the Ministers of Health, Education and Skills Training and the Minister of State for Primary and Social Care informing them of the study and lobbying for the possibility of incorporating FII in social policies in future.

2.11 Conclusion

As this chapter has shown, the search strategy highlighted a sparsity of previous research regarding FII in older people. As a result, a qualitative approach is suited to this study, which was designed by the student researcher in accordance with the community partner. This community-based approach brings a range of strengths to the research, and is ideally suited to the socially important topic considered here that incorporates views from a variety of professionals operating in 'real-world' situations. The sampling technique, sample size, data collection, and methods of data analysis were devised by the student

researcher with the input of the community partner, and were carried out with consideration for relevant ethical issues. Dissemination was also a vital consideration in the study, and accordingly actions were subsequently taken to ensure that all knowledge gained would be put to use in the community. The next chapter examines available literature on FII in older people, locally and internationally.

CHAPTER THREE

Review of Policy and Literature on Fabrication or Induction of Illness in Older People by Carers

3.1 Introduction

This chapter addresses the research questions and aims in presenting a review of current policy and literature regarding FII in older people by carers, focusing generally on the global context and particularly on the Irish context. While the domestic context provided highlights policies, best practice, and legal frameworks related to FII in older people, the global context examines the existence of FII internationally as well as identification, awareness, and management issues. The literature indicates that FII in children has been of far more concern internationally (Feldman & Brown, 2002); reports published on children exceeded 400 in number in 2002 (Schreier, 2002). However, less than ten reports have been published that deal with people aged 65 and above, indicating that this form of abuse has been underreported in older people, and is often only reported after someone has suffered a great deal (Davis, 2009). This scarcity of research has grave implications in light of the fact that older people are among the most vulnerable members of society and need to be protected (Boyd *et al*., 2014). The current chapter begins by highlighting the historical background related to FII around the globe and also discusses issues relating to the setting in which FII can exist, identification, and awareness. It ends by examining the policy frameworks and best practice pertinent to FII in older people in the Republic of Ireland.

3.2 FII in the global context

3.2.1 History of Fabrication or Induction of illness

Fabrication or Induction of Illness is also known as Munchausen Syndrome, having been named for a Germany cavalry officer called Baron Munchhausen born around 1720, who used to entertain his friends with exaggerated stories from his military experiences. In 1951 an English Physician, Richard Asher, first used the label 'Munchausen Syndrome' to refer

to a condition in which adults fabricated or exaggerated illnesses in themselves which resulted in numerous hospital visitations as well as unnecessary medical examinations, procedures, and treatments (Frye & Feldman, 2012). According to Meadow (1982), the Munchausen Syndrome label began to be applied to children who were presented for medical attention with fabricated and medically unverified illnesses by someone else (proxy), generally a female parent. Meadow had previously published two cases of families fabricating illness in their children in 1977. After publication of the two cases by Meadow, the term 'Munchausen Syndrome by proxy' gained recognition and was described both as a form of child abuse and parental behaviour. Since then, hundreds of Munchausen syndrome by proxy cases involving children have been reported and published (Schreirer, 2002).

When referring to cases in children Cabral (2014, p. 78) pointed out that:

> The phrase fabrication or Induction of Illness was the preferred term of reference mainly in the United Kingdom. The change of terminology from Munchausen to fabricated or induced illness was meant to help professionals to focus on the impact of FII on the welfare of the child.

Postlewaite (2010) added that the phrase 'FII' was preferred because it put focus on the children rather than perpetrators, concentrated on the harm, its cause to children and reflected on the wide range of behaviours being included in this form of abuse, while it also guarded against FII being understood as a discrete medical condition. Although literature suggests older people and persons with disabilities are equally vulnerable to carers inducing or fabricating illnesses in them, very few cases have been reported since FII began to be recognised in 1977. The first case involving an older person was reported by Smith and Arden in 1989. Cases of FII in older people by carers, as this dissertation demonstrates, remain unrecognised and underreported.

3.2.2 Ageing and FII-related issues around the globe

The *World Ageing Population Report* states that 'ageing is a dynamic process which affects everyone everywhere and reflects biological or physiological changes in individuals

over time' (United Nations, Department of Economic and Social Affairs, 2013, p. 3). Timonen argues that society in general and young adults in particular tend to find the study of ageing and older people irrelevant, yet ageing is one of the most important global phenomena: 'In the developed world everybody who is "young" today can confidently expect to be "old" in the future' (2008, p. 3). On the other hand the *European Report on Preventing Elder Maltreatment* (World Health Organisation, 2011) suggests that various countries define older adults differently; the ages of 60 and 65 are mostly adopted by most European countries as the beginning of old age to coincide with retirement. However, it has also been observed that retirement age could go beyond the age of 60 or 65 in some countries and therefore chronological age is not the sole variable when examining the ageing process. This dissertation adopted the Irish Central Statistics Office (CSO)'s definition of older adults which was 65 and above (2007). Arksey and Glendenning, when defining a carer, pointed out that although carers are not a homogenous group, women are more likely to be carers and to provide intensive support. The authors added that there is a wide range of carers and care-giving relationships, and the circumstances within which care takes place. In other words, depending on the circumstances of older people, care may be paid or unpaid and take place in a family or institution (Arksey & Glendinning, 2008).

Although there are few published cases on FII in older people, the cases published in children can be seen as a basis on which to study FII in older people. When defining FII in children, Ozedmir *et al.* suggest that FII is a form of abuse in which a caregiver deliberately exaggerates or induces health problems in a child under their care. The condition is difficult to characterise and diagnose because of the different ways in which it manifests (2015). In older people, the definition of FII is similar to that of children. Deimel IV *et al.* (2012) define FII in an adult as a form of abuse in which an individual deliberately produces or feigns clinical illness in a person under their care, highlighting that the phenomenon is underreported. This issue is compounded when we consider the *World Population Ageing Report* (United Nations, Department of Economic and Social Affairs, 2002), which stipulates that the older population is growing at a considerably faster rate than that of the world's total population. Their statistics show that people in all regions of the world are increasingly likely to survive to old age, and once they have

attained it they tend to live longer as the gains in life expectancy are relatively higher in old age.

An increase in the number of older people globally suggests a rise in the number of older adults dependent on others for care and support, and this would put many at risk of maltreatment of any form including FII (Momtaz *et al*., 2013), hence the need for interventions that protect older people. Spanier *et al*. (2013) note that the growing ageing population raises new questions about the protection and advancement of human rights of older people in the world; developing an awareness of the risk of FII in older people is one vital consideration in this regard. The *European Report on Preventing Elder Abuse* (World Health Organisation, 2011, p. 1) suggests that:

> The European region has a rapidly ageing population, one third of the European region will be 60 years and older in 2050…elder maltreatment will grow as a public health and societal problem. Further there is concern that the impact of the economic downturn might exacerbate the risk of elder maltreatment as pressure increases on societal and family resources. Despite this, much of elder abuse remains under reported and ignored in the World Health Organisation (WHO) European region.

Henceforth, WHO has been pushing countries to put measures in place that protect and promote the welfare of older people. As Schulze (in Liebfried,1993, p. 120) observes: 'Europe is known for a common tradition in peace, culture and above all welfare-statism'; however, some countries seem to have been drifting away from the model of a welfare state whose task is 'redistribution, social investment and intergenerational transitions' (Greve, 2015, p. 31). A study by Gunnarsson (2009) reflects that older people themselves are uncertain about whether the quality of help they will receive in the future will be acceptable. This should not only worry older people of today but also of tomorrow, seeing that the welfare state affects options available at different stages in life. Miller (2012, p. 17) pointed out that:

> A person is vulnerable if their daily existence depends on another person. In certain circumstances older people may still possess legal capacity but their physical

> capability to for instance cook, wash or clean may have diminished. Therefore the inevitable need for a carer and the possible fear of losing one would place an older person at risk of maltreatment.

The welfare of older people should therefore be a societal concern of everyone. Even though FII in older people is still underrecognised it can be considered a sub-category of elder abuse. Of equal importance to note is that the definition of elder abuse does not allude to FII, yet if older people have to be protected from all forms of abuse, this phenomenon must be highlighted to inform people. According to the *European Report on Preventing Elder Abuse* (World Health organisation, 2011, p. 1) elder abuse is:

> A single or repeated act or lack of appropriate action occurring within any relationship in which there is an expectation of trust that causes harm or distress to older people. This definition includes forms of violence such as physical, mental, emotional, neglect, sexual, economical or financial abuse.

The report recognises that elder abuse can take place anywhere, in the home or institutional settings such as nursing and residential homes and hospitals where older people find themselves. However, although the definition of elder abuse by WHO (2011) is broad, there is still room for incorporation of other forms of abuse pertinent to older people such as FII. Furthermore, there would be need for WHO to go beyond the elder abuse definition to distinguish the different forms of abuse such as FII so that they are recognisable In view of the fact that the WHO, elder abuse definition has been widely accepted, it can be argued that if FII is incorporated in this definition more people will be aware of it, considering that many nations ascribe to international agencies such as the United Nations in general and WHO in particular.

3.2.3 Does FII in older people by carers exist globally?

As the literature search shows (2.2), cases of FII in the elderly have been recorded, but no formal study exists. Whether this phenomenon can be said to be a global phenomenon, however, is very difficult to assess on the basis of the limited study that has been undertaken, though as noted above it seems that FII is generally underrecognised and

underreported. Although FII in children is globally recognised, more still needs to be done for the same to be the case in relation to older people in a variety of international contexts. Bass and Jones (2009) highlight that proof for the occurrence of FII in children normally comes from victims, perpetrators' confessions, third-party witness statements, recording of FII on video or audio, scientifically-obtained forensic information, police investigations and examination of timing; however, even in children were a large body of literature exists on FII there is debate concerning a lack of clarity on its diagnosis, and psychotherapeutic interventions for perpetrators, which may in turn contribute to the thinking that FII in older people does not exist (Mercer & Perdue, 1993). In addition, Libow, writing about victims in adulthood, argues that professionals are reluctant to intervene or investigate the victim's distress, even where suspicions exist (Libow, 1995). The situation is worse when it comes to older people, where very few cases have been published. Burton *et al.,* (2014, p. 35) highlight the issue of the elderly and disabled, pointing out that:

> The incidence and prevalence of FII in older adults is likely to increase in future because of medical technology that allowed greater survival of cognitively impaired populations, who were dependent on the care of others, henceforth, older people and persons with disabilities may be especially at risk.

Lazenbatt (2013) when discussing FII in children asserted that FII could occur more frequently than expected but the variety of presentations makes diagnosis difficult. On the other hand the few published cases on FII in older people internationally suggest that FII may exist but this is not definitive proof that the phenomenon occurs in society as a whole. More needs to be done on public and professional awareness and on undertaking formal studies on FII in older people (Singh *et al.*, 2013) to provide conclusive evidence that the phenomenon is prevalent throughout all society globally.

3.2.3.1 Summary of published case reports on FII in older people by carers globally

The search strategy (2.2) revealed that Singh *et al.* (2013)'s study identified four cases. Other cases on older adults from the age of 21 to 82 in which perpetrators were highly involved in the care of the victims were highlighted by Burton *et al.* (2014). Since the focus of this research is older people aged 65 and above, the research focuses on the six

case reports that met the criteria. However, only five are highlighted as the sixth case was published in French and was not accessible, as noted above (2.2). Below is a summary of the FII cases in older people presented for information and analysis**:**

Table 3: Published FII cases in older people

Case #	**Gender**	**Age**	**Available information on Perpetrator & relationship**	**Case summary**	**Authors**
Case 1	Male	69	55-year-old companion & ex-nurse	Victim referred to 25 different medical teams over a four-year period, saw five doctors privately for second opinion and two GPs. Despite a wide variety of tests, no positive findings were noted; there seems to be a singular lack of confirmatory evidence. The patient and the companion continually suggested new possibilities to encourage further investigations.	Smith & Arden (1989)
Case 2	Female	73	Daughter a surgical nurse (age unknown)	Victim with multiple myeloma experienced four episodes of loss of consciousness, convulsions and profuse sweating while in hospital. Medical investigations disclosed presence of serum glucose and a normal level of serum C-peptide during each attack. The patient could not inject herself due to her disability hence a search for a possible perpetrator discovered that the patient had a daughter who appeared upset whenever she was told that her mother was about to be discharged from the hospital.	Ben-Chetrit & Melmed, (1998).
Case 3	Female	80	Granddaughter (age unknown)	Admitted because of Syncope, after effective therapy a decision to discharge her was met with firm refusal by the victim's granddaughter. Clinical symptoms increased in the afternoon after visitation and decreased in the evening late at night and in the morning. After honest talk	Chodorowsk *et al*. (2003)

				with the granddaughter and reducing her contacts, there was improvement and the conscious disturbance disappeared.	
Case 4	Male	71	Wife, worked at a hospital	History of recurrent episodes of stupor and coma. Attacks occurred every three to six months, he had up to seven hospital admissions in one year. Wife was challenged and confessed to having given drugs over the period of his presentation. The clinical setting of a pleasant elderly country gentleman always accompanied by his ever-present, appropriately worried wife gave professionals no reason to suspect abuse of drugs or medication. The wife took advantage of professionals' vanity and the fact that they looked at literature instead of the patient.	Grannot *et al*. (2004)
Case 5	Female	79	Son	Suffered from dementia for three years. Victim's medical state was dominated by frequent involvement with various primary care providers, psychiatric and old age psychiatry teams and acute medical admissions in a number of localities. Previous admissions to acute medical wards were triggered by victim's worsening cognitive and behavioural problems. All attempts to regulate them through medical or behavioural management were compromised by son's involvement. Victim improved when son's visits were stopped.	Singh *et al*., (2013)

The references below relate to FII in older adults aged 19 and above and have been higlighted to show the raririty of documentation on FII in adults as well as to serve as a reference point for possible future research on FII in the elderly. Six of these are specifcally case reports on FII in older people.

References on FII cases in older people

Ben-Chetrit, E., & Melmed, R. N. (1998). Recurrent hypoglycemia in multiple myeloma: A case of munchausen syndrome by proxy in an elderly patient. *Journal of Internal Medicine, 244*(2), 175-178.

Burton, C., M,, Warren, M., B,, & Michael., B. (2014). Munchausen Syndrome by Adult Proxy: A review of the Literature. *Journal of Hospital Medicine, 2015*(10), 32-35.

Chodorowsk, Z., Anand, J. S., Porzezińska, B., & Markiewicz, A. (2003). Consciousness disturbances: a case report of Munchausen by proxy syndrome in an elderly patient. *Przeglad lekarski, 60*(4), 307-308. [in Polish].

Deime IV, G.W., Burton, C., Raza, S.S., Lehman, J.S., Lapid, M.I., & Bostwick, M. (2012). Munchausen Syndrome by Proxy: An Adult Dyad. *The Academy of Psychosomatic Medicine, 53*(3), 294-299.

Granot, R., Berkovic, S. F., Patterson, S., Hopwood, M., & Mackenzie, R. (2004). Idiopathic Recurrent Stupor: A Warning. *Journal of Neurology, Neurosurgery and Psychiatry, 75*(3), 368-369. doi: 10.1136/jnnp.2003.021691.

Kaufman-Walther, V., & Laederach-Hofmann, K. (1997). Munchausen syndrome in a 66-year-old patient. *Praxis, 86*(20), 850-855.

Singh, A, Coppock,.M, &Munkaetova-Ladinska, E.B. (2013). Munchausen Syndrome by Proxy in older adults: A case report. *Macedonian Journal of Medical Sciences,* 6(2), 178-181.

Smith, N., J,, & Ardern, M., H. (1989). More in sickness than in health: A case study of Munchausen by proxy in the elderly. *Journal of Family Therapy*(11), 321-334

Strubel, D., Docher, C., & LaPierre, M. (2003) Munchhausen syndrome by proxy in an old woman. *Revue Geriatr*., 28:425–428 [in French].

3.2.3.2 Researcher's brief analysis of case reports

As already noted, while FII in children has been relatively well-reported, FII in older people is not as well recognised (Feldman & Brown, 2002). The above six case reports show that in all incidences the suspected carer/perpetrator was a close member of the family or a companion who seemed to be genuinely concerned about the victim, which makes it more difficult for professionals to recognise and believe that the carer could hurt the victim. Additionally, female carers were overrepresented as only one of the cases involved a male perpetrator, confirming that FII is associable with females due to the fact that carers tend to be female. In the five cases, seeking attention for self and victim and assuming a sick role were the main motivating factors. The main signs and symptoms as pointed out by the respective authors included seeking medical attention from various

medical professions in a short space of time, medicating the victim, and the victim showing a worsening of symptoms after being visited by the carer. Furthermore, three out of five case reports mentioned a perpetrator with a medical background. The fact that there were carers who did not have a medical background indicates that professionals who deal with older people outside the medical institution should also be alert and aware of this phenomenon. The above cases then provide examples of FII and what characteristics professionals and the general public could look out for in order to protect older people from this form of maltreatment.

3.2.4 Context, identification, awareness, and management

Due to the key role that medical professions play in the diagnosis of FII, society has been inclined to believe that FII is a medical or health issue alone. In addition, because FII is usually seen as something that can only be recognised by medical professionals, professions in other settings are highly unlikely to identify it, despite the fact that health settings are not the only settings in which care is provided. Cabral (2014, p. 81) observes that:

> There has been a misconception that in cases of FII, the perpetrator is focused on the medical profession and therefore it is only health professionals who need to be alert to this behaviour. It is becoming more widely recognised that the perpetrator will feed information to professionals from a variety of settings including, teachers, education welfare officers, social workers not just to health professionals. While FII was often discovered by health professionals, it was also being identified by a wide range of professionals who came in contact with the victim and the carer.

Even the available literature indicates that most studies have been done by medical professionals (Parrish & Perman, 2004). However, all professionals, medical and non-medical, who deal with older people need to be well-informed and to have an awareness of common indicators such as medically and non-medically unexplained signs and symptoms, test that do not explain the reported signs and symptoms, and a carer who seeks multiple opinions from professionals. On the other hand, Cabral (2014, p. 78) argues that:

> In FII the success in drawing attention toward the situation lies in the manipulation presented by the perpetrator, the detection of such activities can be fraught with challenge. Furthermore, the motivation of carers were multiple and complex and there was no single common profile which would identify an FII perpetrator.

Although most literature shows that the intention of carers in FII is the gaining of respect and admiration for exemplary behaviour, attention seeking, or assuming a sick role by proxy with absent external incentives for the behaviour, others suggest that there could be perpetrators motivated by other factors (Levin and Sheridan, 1995). Burton *et al.* (2015, p. 34) put it this way: 'there may be some perpetrators motivated by something other than purely psychological end points such as financial reward or even sexual victimisation'. However, there seems to be limited research studies indicating financial or even sexual motivation of FII perpetrators in older people.

Discussing children, Mercer and Perdue (1993) argue that there are no easy and fast rules on presenting the diagnosis of FII to the family or other professionals. Moreover, although literature indicates that some carers may have mental or psychological disorders, situations have been recorded in which carers were seemingly able to engage in ordinary activities regardless of the harm inflicted on the victim, indicating the complexity of FII. In addition, most people would not believe that a parent or a close carer would intentionally induce illness in a child or a person under their care, for these behaviours seem shocking, as does elder abuse in general. Mercer and Perdue (1993) advised that professionals must dig for a deeper understanding of the behaviours within the family context and the societal environment, yet there are still many mysteries about FII. Nonetheless, if in older people FII continues to be undiagnosed, unrecognised and underreported, many older people may continue to experience unnecessary medical and non-medical investigations, painful medical procedures, hospitalisations, unnecessary surgeries, and even death as some authors have warned in relation to children (Gehlawat *et al*., 2015). Lazenbatt (2013, p. 72) concluded that:

> Recognition and successful management of FII in children was particularly complex and had time and resource implications for professionals and multi professionals

> working together and interagency collaboration were paramount and crucial to the diagnosis and management of any form of maltreatment.

As in relation to FII in children, where a criminal offence might have been committed the police should be involved at the earliest opportunity, and a safe place for the victim should be secured. However, none of the cases reported in older people went through the court system as has been the case in relation to various children. Nonetheless, in children, Cabral (2014) showed that FII in Britain was recognised as a criminal offence under the British Law. In older adults Smith and Ardern (1989, p. 329) argued that:

> Unlike in children where the identified patient is a child, there are no legal restraints available to break the cycle, by removing the patient from the carer. With the elderly there is a degree of compliance from the patient, that makes 'straight talking' less likely to succeed.

Not only is there a scarcity of case reports on FII in older people but no literature has been identified that recognises FII in older people as a criminal offence. Most legal documents are generic when it comes to the protection of older people. Arguably, therefore, if FII cases in older people were taken for court proceedings, general legal provisions on abuse would be used. However, these would prove a challenge as FII is not recognised in most legal frameworks in many countries around the globe, including Ireland. Meanwhile, interventions and multidisciplinary management of FII are needed to protect the best interest of the growing number of older people, as is the case with children (Wrennall, 2007).

3.3 FII in the domestic context

Having discussed FII from a global perspective, the Irish context of FII will now be discussed. The discussion includes policy, best practice and legal framework related to FII in older people. Although literature exists on FII in children, there is a lack of literature dealing with FII in older people in Ireland, and this issue goes hand-in-hand with a lack of policy, best practice, and legal framework on the issue.

3.3.1 FII in Ireland

The search strategy described in Chapter Two identified no literature on FII in older people in Ireland. This was, however, not surprising considering that the number of case reports published in the world on average were very few and may reflect that the phenomenon is uncommon, though as the research findings indicate (Chapter Four) suspected cases may never be formally diagnosed due to lack of knowledge and appropriate policy. Nevertheless, there have been publications done on FII in Irish children, such as that published by the *Irish Journal of Applied Social Studies* on FII in a child, a review of labels and literature using electronic libraries (Burns, 2004). Although there has been no case published in Ireland on FII in older people, statistics suggest that the number of older people in the population is increasing, which requires attention in order to devise measures to protect older people. According to the Central Statistics Office (CSO), the population of persons aged 65 and above in 2011 was 535,393, an increase of 14.4% from 467,926 in 2006. This age group therefore experienced great growth over the period (Central Statistics Office, 2011). In addition, CSO projected an upward trend from 16.4% to 25.1% of persons aged 65 and above who would depend on persons aged 15–64 years for their daily existence. Given that there is no data on FII on older adults in Ireland, there is still a chance that some older people in Ireland may experience this form of maltreatment and would not know what to do, where or whether to report, or indeed whether people would believe them (Phelan, 2005). As a result, FII in older people is an important line of inquiry that needs to be pursued.

3.3.2 Policy framework and best practice in Ireland

As in many parts of the world, old age in Ireland seems to be perceived as a societal category that everyone joins or anticipates to join, however, most people would be reluctant to accept ageing and often hold negative beliefs and attitudes towards old age, which have been perpetuated in society over time, such as the belief that 'youth' is better and older people are recipients of services and should be prepared to die gracefully. While longevity is perceived as an accomplishment, the ageing of the population is often considered a negative phenomenon (Kite & Wagner, 2004). Nonetheless, Kennedy and Quin (2008), when referring to the Irish state, point out that ageing and social policy in Ireland bring together works on areas related to the situation of older people, which in the

recent past seem to have continued to be constructed and reconstructed through policy and practice. Even so, policy alone without the active participation of older people has been viewed as an inadequate response to older people's needs. There are various reasons why older people need to be protected, for instance, their changing role in society means that they cannot access gainful employment and continue being active and independent. Timonen (2008, p. 11), argues that:

> Lack of opportunities to work, poor pensions and institutional care make older people powerless and dependent. On the other hand, the political, economic and social policy structures sometimes render older people weak and marginalised, for instance the forced or perceived need to exit work is portrayed as a major cause for older people's marginalisation. Dependence is in this perspective socially constructed by governments and the markets (capitalism) that have marginalised, dominated and weakened older people.

If we consider the assertion by the *National Economic and Social Council* (2005, P. ix) that 'in Ireland the idea of the developmental welfare state is based on the premise that social policy systems should support citizens to reach their full potential', it would follow that the state should have policies and necessary systems of laws that guarantee the protection of its citizens, especially the most vulnerable groups (Spicker, 2008), from all sorts of abuse. Nevertheless, there are a number of policy documents that promote and protect the interest of older people in Ireland, though none of them address FII in older adults. Policy documents related to older people include the *National Positive Ageing Strategy* (Department of Health, Patient First, & Health Ireland, 2013), *An Garda Síochána Strategy for Older People* (An Garda Síochána, 2010) and the commitment towards older people enshrined in the *Programme for Government, 2011–2016* (Department of the Taoiseach, 2011). These policy documents were developed through a series of consultative processes involving various government departments and non-governmental organisations (NGOs), and promote quality of life for older people. Similarly, another key policy strategy within Ireland's health reform is *Health Ireland – A framework for improved health and well-being, 2013-2025* (Department of Health, 2013). This framework is also key to the implementation of actions towards the wellbeing of older people and protection

against abuse. However, although the framework addresses abuse and wellbeing, neither this framework (*Health Ireland – A framework for improved health and well-being, 2013-2025)*, nor the above mentioned policy frameworks, address FII in older people.

In the recent past a very progressive policy, namely *Safe Guarding Vulnerable Persons at Risk of Abuse, National Policy and Procedures* (Health Service Executive, 2014), was developed and launched. The policy incorporates services for elder abuse and persons with disabilities. However, this policy, like the other available policies, does not highlight FII as a form of elder abuse, nor does it distinguish it from overall elder abuse, which could make FII more difficult to identify and classify as included in the abuses covered by these policies. Furthermore, FII in older people is not included among the main categories of abuse highlighted in the *Safe Guarding Vulnerable Persons at Risk of Abuse, National Policy and Procedures* (Health Service Executive, 2014). The categories are:

> Physical, sexual, psychological, financial or material abuse, neglect and acts of omission, discriminatory and institutional abuse. Even the psychological category which includes, emotional abuse, threats of harm or abandonment, deprivation of contact, blaming, controlling, intimidating, coercion harassment, verbal abuse, isolation or withdrawal from services, or supportive networks.
> (Health Service Executive, 2014, p. 9).

These do not clearly encompass FII in older people. Spicker (2000, 2008) argues that the social policy of a government is the set of measures and approaches it adopts in relation to social protection and provision of welfare.; policies are important as they affect the way people live, yet they should serve more purposes than just provision of welfare. Policies are supposed to protect people and make them secure. In the same vein policies on older people in Ireland should serve to ensure day to day safety from all forms of abuse including FII. The available policy documents therefore show no data on FII in older people, which suggest a gap in policy and practice. As a result, periodic review of the strategies and subsequent incorporation of emerging issues such as FII is underscored by this dissertation. The lack of policy and best practice related to FII indicates that there is no formal way of dealing with FII; there is neither assessment tool nor checklist to help

professionals who suspect it. Consequently, FII still remains unrecognised and unattended to, meaning that older people could be at risk. As a potential category of abuse, it needs to be highlighted in policy and practice on older people in Ireland.

3.3.3 Legal Framework

Begley and Mathews (2010) postulate that there is no specific statutory recognition of elder abuse in Ireland and that those who abuse older people are not subjected to special penalties, though older people are entitled to the same legal protection as other citizens. Phelan (2005) notes that the pursuant of criminal or civil trespass through generic legislation by older people may reflect the archaic nature of certain Irish laws. Likewise, the constitution is overly-generic when it comes to legal protection, article 40 (3) for instance stating that 'the state shall, in particular, by its law as best it may from unjust attack, and, in the case of injustice done, vindicate the life, person and good name and property of every citizen'; although older people may be covered under this provision, it would appear that the stage in life they may find themselves at would need more specific than generic provisions. The state of affairs at the time of the research indicated that the nation still has a long way to go in coming up with a specific legislation or statutory provision on older people.

3.4 Conclusion

This chapter has reviewed policy and literature on FII, highlighting some of the common factors identified in the five cases surveyed. These case reports show that a finite number of cases of FII in adults have been identified, but the small body of evidence makes it impossible to state categorically that it exists globally. However, the few number of published cases could indicate that many cases of FII go undiagnosed, particularly outside of health professional settings, as the phenomenon appears to be underreported internationally, including in Ireland, where no single case report was available at the time of the research. The issue of FII in older people is therefore in need of greater research internationally in order to determine the precise nature of the phenomenon. Furthermore, in contrast with the subject of FII in children, there is a serious lack of policy guidelines, sufficient best practise, and legal framework related to FII in older people. Tools to assess,

identify or even manage it if professionals suspect its existence are not available to the professionals dealing with older people in an institution, family or community, while government policies to protect the elderly are vague in this regard. Therefore, there is a clear need to disseminate knowledge of the possibility of FII in older people in order to bring about a better policy and legal framework for the protection of older people as well as raise public and professional awareness.

CHAPTER FOUR

Research Findings, Analysis and Discussion

4.1 Introduction

This chapter presents the findings from the research interviews, as well as analysis and discussion through identified themes and relationships. The research interprets and develops explanations on FII in older people by carers based on the following research questions:

i. Does fabrication or induction of illness in older people by carers exist?
ii. In what setting does it exist and what are the motivating behaviours in these contexts?
iii. How can FII in older people be identified by professionals?
iv. What policies, best practice or legal frameworks are available to protect victims or potential victims of FII by carers in Ireland?

Eight interviews were conducted with medical and social work professionals in Ireland. The professionals belonged in the following categories: Public Health Nurse, former Nurses dealing with Home Helps, Medical and Elder Care, Medical and Non-Medical Social Workers, Medical Doctor (GP), Clinical Nurse Level Two, and Elder Care Management (private). The names used in this chapter were pseudonyms rather than real names of participants; this was to ensure no participant was identifiable.

Different themes that arose from the interviews conducted will be discussed under five main areas considered relevant to the investigation's research questions or research focus (Bryman, 2012). The themes are:

i.) Fabrication or induction of illness in older people by Carers; does it exist?
ii.) Nature and context of FII
iii.) Identification and awareness

iv.) Management (policy, best practice and legal framework issues)

v.) Surprises

These themes analysed in this chapter reflect key themes generated organically through the interview process. The entire data set is therefore reflective of thematic description (Braun & Clarke, 2006) as the area under investigation was underresearched and relatively unchartered territory.

4.2 Fabrication or induction of illness in older people by carers; does it exist?

Before establishing whether or not FII in older people existed, the research sought to find out who was a carer or perpetrator, and ascertain the definition of FII in older people by professionals who work with them as well as the difference between FII and elder abuse. The findings under this topic would help the community partner establish whether FII in older people exists with a view to coming up with appropriate intervention measures such as public awareness. Although the community partner, based on the experience of working with older adults locally, felt that FII in older people exists, they had no definite evidence to show this. The focus of the research interviews was to explore participants' experiences of working on these cases and to answer the research questions.

4.2.1 Who is a perpetrator of FII in older people?

In a study on children and adults, Burton *et al.* (2014) showed that FII perpetrators were carers who included mothers, wives, husbands, daughters, granddaughters or companions. In older people the carers were a diverse group and included daughters, sons, nieces, nephews, brothers, sisters, cousins, while in a care setting they included a professional worker directly involved with the victim's care. Burton's study suggested that care was mostly being provided by females.

Similarly, this research discovered that the carers involved had a female 'face' as most of the FII cases were being perpetuated by a female member of the family, although males were also potential perpetrators. This was echoed by participants as follows:

'Her daughter who was the main carer would regularly give her sweet cake twice a day…' (Lucy)

'The daughter (carer) of the lady we were looking after was extremely overprotective of her mother.' (Joan)

'In one particular case we had a lady who was being cared for by her niece.' (Maggi)

'I suspected in a case of a woman whose elderly mother was in a nursing home.' (Julie)

'I think he thought he was being very concerned that his brother wasn't being cared for properly…' (Jane)

Of the eight interviews undertaken only two reported having come across a male perpetrator, indicating 80% of potential perpetrators were female. This was also noted in Cabral's study, which showed that FII was most commonly carried out by a female main carer of a child victim, with studies showing that males were the perpetrators in approximately 10% of cases (Cabral, 2014). Although not always the case, this research suggest that carers are likely to be females who assume the care role as a daughter, a granddaughter, sister or a niece of the older person. Having established who a potential perpetrator was, participants gave their views on the meaning of FII in older people.

4.2.2 Description of FII by professionals

When defining FII in children, Gregory asserted that it is the falsification or induction of physical and/or emotional illness by a caretaker of a dependant person (2004). In older adults Singh *et al.* (2013, p. 178) defined FII as 'a factious disorder characterised by a distinct behavioural pattern in which the caregiver exaggerates, fabricates, induces physical and/or psychological behavioural problems in people under their care'. Some indicative quotes from the interviews are highlighted below:

'I would describe it as somebody who has capacity as a carer or relative to induce illness in an older adult by either emission of drugs or their medication or by inducing …' (Jane)

'It's when another person, a carer or family member would cause an illness that isn't there by either adding something to their diet or their blood or their urine, not giving something they require, like insulin or reducing the quantity or increasing the quantity. The person themselves doesn't see the illness or doesn't feel the illness, it is just the carer who I suppose suggests that it is there.' (Mary)

'*It would be where the carer or the relative is stating that the older person has symptoms or signs which you actually don't find yourself on examination and constantly presenting the elderly complaining that this and that…'* (Hope)

From the description of FII by research participants the research discovered that the description of FII in older people, as in the case of children, seemed to be linked to behavioural patterns of perpetrators as alluded to by Singh *et al.* (2013). In this regard, potential characteristics of FII in older people can be said to include the falsifying or inducing of illness in an older adult by carers in various ways, such as reducing or increasing the quantity of something (drugs /food) they require, or presenting an older adult for medical attention even though they were not sick.

4.2.3 Difference between FII and elder abuse

Most participants stated that even though FII was not included in the elder abuse policy documentation and does not have its own subcategory in the broader elder abuse definition, FII was, in their view, a form of elder abuse and that there was a thin line between elder abuse and FII. FII has been recognised as a form of child maltreatment (Lazenbatt, 2013); Cabral (2014) observes that FII is often interrelated with emotional abuse and neglect, with such complexity that FII should be given its own category as a form of child abuse. Similarly, research participants observed as follows:

'It's a very thin line and I see it because I work in the care of the elderly.' (Lucy)

'Elder abuse is any form of mistreatment of an elderly individual that causes them any form of distress or upset and it can be anything.' (Rose)

The data from interviews and from literature suggest that FII in older people is considered a form of elder abuse. Most literature does not distinguish FII from elder abuse. It was interesting to note how certain literature sees FII as synonymous with elder abuse, as was suggested by some participants in this research, for instance Lasher (2003, p. 409) has noted that FII 'almost always manifest[s] as a combination of physical abuse, emotional abuse and neglect. It can also manifest as a sexual abuse' (Lasher, 2003). Some characteristics, however, can be identified which identify FII as distinct from general elder abuse; Furthermore, Maggi, Julie and Mary when distinguishing FII from elder abuse, indicated that:

> *'Elder abuse for me, it's usually they are hiding from an audience, it's sneaky stuff, cruel staff behind the scenes that you don't want to be found out or financial abuse that you don't want to be found out. So I think this one [FII] is where you want the light shed on what you are doing or the result of what you are doing, whereas in elder abuse you want the light turned off on what you are doing, that is just my interpretation of it.*' (Maggi)

> *'It would in my view constitute a form of elder abuse. The difference may be in the insight ability of the relative who is trying to produce symptoms if they have issues and problems, maybe their responsibility for the abuse is less because perhaps they have mental health issues and are less aware, it could be considered less deliberate as against what I might term straightforward elder abuse or neglecting and humiliating or physically abusing an elderly relative.'* (Julie)

> *'Well, you see the elder abuse is very specific, it's clear, and it's very easy to understand the signs and symptoms and to see where the physical or financial or sexual abuse has occurred. The psychological is very different but easy enough with good assessments.*' (Mary)

These quotes suggest that in elder abuse people seem to be more aware of what they are doing than in FII; the act of neglect and the physical, sexual and financial abuse of the elderly in elder abuse were considered unlikely to be a result of ignorance or mental health issues in the perpetrator in contrast with FII. While in FII most perpetrators do not hide

what they do, but may have hidden agendas, they are overprotective and can seem to do what they do for the love of the victim, though in the end they inflict pain. FII perpetrators do not usually hide their actions, but elder abusers tend to be covert. Interestingly in children, Gregory (2004) suggest that FII can be considered as the world's most hidden and dangerous form of abuse, even though it was done in broad day light when everyone was watching, insinuating that although FII in children may have an audience, the agenda of fabricating or inducing illness may be a hidden one. Participants' views in table 4 below suggest that FII can have an audience, while elder abuse is hidden from an audience. Some of the key issues that participants shared in an effort to distinguish FII from elder abuse are listed in Table 4 below:

Table 4: Difference between elder abuse and FII- participants' perspectives

Fabrication of Induction of Illness in older people	**Elder abuse**
• Has an audience, e.g. perpetrator presents signs and symptoms in an older person to a medical practitioner	• Hides from an audience • Done behind the scenes
• Need to maintain a good self-image • Attention seeking	• In rare circumstances the motive is attention seeking or maintenance of good self-image
• Most hidden form of abuse	• Identifiable
• Difficult to determine	• Relatively easy to determine
• Has light on	• Has light off
• Has a possibility of perpetrators not being fully aware of what they are doing • Perpetrators think they are doing good	• Mostly aware of their actions
• Carers' actions in some circumstances can be considered less deliberate	• Mostly deliberate
• Not straightforward	• Relatively straight forward
• Unspecific, unclear	• Specific, clear
• Unnoticeable	• Noticeable
• No shame	• Shameful

• Perpetrators may not always plan what to do • Difficult to provide evidence • Limited information, research, unpublished sources • Underreported	• May plan what to do • Proof may easily be provided • A great deal of information available • Reported

Most of the suggestions by participants in Table 4 above in relation to the differences between FII and elder abuse would benefit from research studies so as to inform literature and also professionals dealing with elder care.

4.2.5 Lack of information and expertise

Apart from observing the difference between FII and elder abuse, participants bemoaned the lack of information and expertise around FII. FII rarely came up for discussions in most of their professional meetings. This could be as a result of very few published cases existing at present as well as a lack of guidelines that could inform professionals on what to do. Singh *et al.* (2012, p. 180,) writing about FII in older adults, indicated that authors only knew of three cases preceding his own study:

> …to our knowledge there are only 3 similar Munchausen Syndrome by Proxy cases in the elderly published: a 69 year old with numerous consultations in various specialities at the request of his partner, a 73 year old woman with multiple myeloma with recurrent hypoglycaemia without any cause, and an 80 year old woman with altered consciousness.

The lack of recorded cases coupled with the fact that FII hardly exists on professionals' agenda can account for why some professionals would never have come across it and would therefore not be in a position to know how to handle it. Participants Joan, Rose and Hope explain:

> *'It's not something that has ever come up really for discussion. It's not something that's mentioned very often.'* (Joan)

'I came across no Irish Literature on the topic at the time and this is going back two years ago.' (Rose)

'I doubt if there is any information, certainly, I have practised 30 years; we have never had information about FII in the elderly.' (Hope)

Within these quotes one can see elements of the suggestion by Deimel IV *et al*. (2012, p. 294) that FII in older adults 'was under recognised and there was insufficient documentation to inform professionals that FII can take place in an older adult with potentially devastating consequences'. Both data in the interviews and in literature therefore underscore the need for public and professional awareness to protect older people.

4.2.6 Diagnosis Issues

The problem of lack of information and expertise can be linked to difficulties in FII diagnosis. According to Lazenbatt (2013 p. 61) 'diagnosis of fabricated diseases can be especially difficult because the reported signs and symptoms cannot be confirmed (when they are being exaggerated or imagined) or may be inconsistent (when they are induced or fabricated)'. In children, the author added that confusion still remains regarding who should make the diagnosis of FII, should it be a psychiatrist or paediatrician? Should the diagnosis be applied to a parent or child? Would it be a paediatric or mental health diagnosis? This study found that these questions raised by Lazenbatt could also be raised regarding FII in older people. Consequently, would it be the geriatrician or the psychiatrist who would diagnose FII in older people? Nonetheless, it has been observed that the diagnosis of FII often presents immense clinical challenges and generally necessitates a multidisciplinary approach. In addition to the incomplete data for existing cases in the literature, it has been recognised that there are on-going difficulties in precise diagnosis of FII in older people (Burton *et al*., 2014).

In this research participants stated that there was no agreement or explanations among professionals on the suspected FII cases they came across and therefore the cases lacked a formal diagnosis due to the difficulty in coming to a diagnosis. The following is a selection

of illustrative quotes from participants describing the lack of an FII diagnosis in older people:

> '*I have never come across a case that was diagnosed…'* (Joan)
>
> *'No, there wasn't diagnosis of that [*FII] *made, no. It was more a mere suspicion that perhaps something like this was at stake…'* (Julie)
>
> *'I cannot say that I have ever seen it* [FII diagnosis] *in the care of the elderly institution or a hospital like this,'* (Rose)
>
> *'It is very difficult to prove. I mean, who would stand up and say this is it. It's to get somebody to commit to say yes this is definitely FII.'* (Jane)

From these quotes one can see that there is an absence of FII diagnosis in older people. Internationally, some authors have suggested that this is due to the deceptive nature of FII. When referring to older adults, Deimel IV *et al*. (2012) observed that given the deceptive nature of FII, medical teams can rarely be absolutely certain about the diagnosis. This is why it can be difficult to prove the existence of FII. In children, Lazenbatt (2013) pointed out that FII is a form of abuse that has been subject to debate regarding its prevalence and its very existence. The lack of clarity among professionals as to what constitutes FII, the difficulties involved in diagnosis, and the lack of research not only complicates identification and management but can also contribute to reluctance in people to categorically state that it exists. The subsequent discussion therefore analyses participants' perspectives on its existence.

4.2.7 Does FII exist?

Having established participants' perspectives on who its potential perpetrators are, how FII can be defined, aspects that differentiate FII from elder abuse, and issues related to diagnosis, the research sought to deliberate on its existence. Consequently, out of the eight research participants, five could categorically state it existed and the others were sceptical due to a lack of diagnosis, although they did not dismiss the possibility of its existence in older people.

A nurse in a private home indicated:

> *'Oh, I would absolutely say that it's a very real thing, absolutely, yeah, because I know of another case where the wife withheld tablets.'*

A public health nurse observed:

> 'O*h, it definitely exists… I think in older adults it's quite rare though.'*

A general practitioner suggested:

> *'I think it exists now for the secondary gain that the carer gets.'*

A social worker noted:

> '*….I think it's huge and I have no doubt that it exists.*'

The above opinions suggest that FII in older people could exist, though it would be rare. This confirms with Smith and Ardern's (1989) argument that, though rare, FII in older people exists more frequently than is supposed, and that professionals working with the elderly need to be alert. However, three participants in this study were sceptical of the existence of FII due to a lack of a formal diagnosis in most instances, and limited research on the subject area. In this regard, Rose, Joan and Lucy explained:

> *'I can't say for definite, I can't put a finger on it, I cannot prove it. But it would be a mere suspicion. On some occasion the suspicion would have been stronger than on other occasions.'* (Rose)

> *I don't know if it's a formal diagnosis but I think that certainly in some instances relatives will encourage their family member or next of kin to have an illness in order to access services, or to gain better treatment…'* (Joan)

> *'I haven't had time yet to do a lot of research into it…'* (Lucy)

In view of the fact that five participants were very certain that FII in older people existed and also considering that the three participants who were unsure did not completely dismiss its existence, this research suggests that FII in older people could exist but is likely to be uncommon; notwithstanding that public awareness, professional expertise, and

research studies have been limited. Nonetheless, available literature reveals that internationally professionals are increasingly becoming aware of FII, especially in children, with a very small literature focusing on older people. Lasher (2003, p. 409), put it this way:

> Since becoming involved with FII, I have been officially involved in over 400 suspected or confirmed cases and informally involved with hundreds of others…FII is no longer considered rare by most leading FII professionals but rather under-identified due to lack of public awareness and professional expertise.

In confirming Lasher's assertion that without expertise and information, it would not be easy to recognise FII in older people, a participant noted:

> *I wouldn't have any qualification to know, but there were definitely some things that were fabrication of illness for sure.* (Maggi)

4.3 Nature and context of FII

Having considered whether FII in older people exists, the research then sought to shed light regarding the context in which it could occur, as due to its nature a layperson could be inclined to link it exclusively to medical or health contexts (this was my own view prior to engaging in research). Determining the nature and context would help in devising interventions at various levels of occurrence. The subsequent discussion highlights the context, signs, and symptoms, and what could motivate perpetrators to fabricate or induce illness in older people under their care.

4.3.1 In what setting does FII take place?

This research established that FII may potentially take place anywhere, be it in a family, residential or day care setting, hospital, school or church. Nonetheless, it was noted that the family setting had the highest occurrence. Participants had the following views:

'I think in this case it was in a family, there was certainly a co-dependence there, the daughter wanted to be the carer and the mother wasn't desperately happy at being cared for 24 hours a day…' (Lucy)

'…because in a residential care setting for older people, the resident can be living in the care home for many years and yeah the potential is there for Munchausen to exist…' (Joan)

'I think it can happen anywhere. I think a general hospital, paediatric ward could show this as equally as a nursing home, geriatric ward you know, I think it can be anywhere. Perhaps we just need to educate ourselves better in what to look for, you know,' (Julie)

'I think it's possible that it's any one of them and a combination of them. I would say go back to that particular lady, it was a situation at home and that's why she ended up in nursing care and it happened in a nursing home private, it happened in HSE establishments. I have no proof, I have nothing to stand up in court with but I believe it was in all those contexts.' (Mary)

These quotes suggest that FII in older people can take place in diverse settings, especially in the family, and would not only take place in a medical or health setting. Interestingly, some authors seem to view FII as a behaviour problem and not necessarily as a medical or psychiatric problem. Wilson (2003, p. 269) stated that, FII 'is a behaviour problem to be identified, not a medical or psychiatric diagnosis.' This was an interesting observation as certain literature suggests that FII is solely a medical or health or indeed a mental health issue. Cabral (2014) argues that false impressions have been created, reflecting that in FII, the carer was focused on the medical profession, who supposedly are the only ones to be alert to FII behaviour.

Arising from the findings and available literature, this study confirms that FII could occur in any setting and may not be a purely medical or health issue (Wilson, 2003). Therefore, social policy practitioners and social workers alike have a key role to play, whether it is in influencing policy, making assessments, or to serve as a referral point; they cannot leave

diagnosis and management of FII entirely to medical and health practitioners. Bass & Glaser postulated that since FII can take place in varied settings involving workers from social work, education, legal and medical domains, the ability to recognise early signs should be included in the development of all professionals (2014).

4.3.2 Motivation of carers or perpetrators of FII in older people

This research study found that participants' perspectives on the motivation of suspected perpetrators was not straightforward; they were complex and could involve a range of factors. '*I don't think its straight forward…*' Mary noted. In some circumstances the motivation has less to do with directly causing harm to the victim even if the actions lead to harm, but is rather related to the carer's need for praise, or being seen as a wonderful carer, and drawing attention from others to themselves through access to facilities. These factors can be influenced by feelings of low self-esteem, a sense of being left out, and family conflicts. These were some of the factors that may have motivated some carers to fabricate or induce illness in older people as Joan, Rose and Mary suggest below:

> *'I think to be seen as the carer that would be it, that's the one that is doing all the hard work.'* (Lucy)

> *'They might feel left out in the family and might want to gain attention for themselves. It's a little bit intangible.'* (Joan)

> *'She seemed to need attention and she did attract personal attention from staff of the hospital, possibly her family members, by virtue of that attention was drawn to the lady herself.'* (Rose)

> *'I think that she liked telling people, how ill people were and I think she had the sense of I am so wonderful, presenting to other people as being fantastic. Maybe it's low self-esteem and low sense of value, I don't know…'* (Mary)

The study observed that financial or economic gain does not seem to be the primary motive for the behaviour. The primary motive for the behaviour rather stems from more intangible factors such as attention seeking, and assuming a sick role with the absence of any external

incentives (Trask & Sigmon, 1997). Pinto and Walsh (2015) suggested that the perpetrator's behaviour was performed in order to assume the role of being a patient by proxy and there were no external incentives such as financial gain. Ben-Chetrit and Melmed, when describing the motivation in the case of an elderly female patient, asserted that her daughter was concerned about her mother's discharge from hospital and could have staged the illness in order to prolong her admission (1998). This would have gained her mother better medical attention than she could have received in the nursing home and the fact that hypoglycaemic episodes ceased with her transfer to the nursing home would confirm that the intention of the perpetrator was not to harm the elderly person but to gain medical attention (*ibid*.). Deimel IV *et al.* (2012) added that the perpetrator's psychological needs were met through the attention they received during medical evaluations of their charge.

Tangible factors such as economic gain were not ruled out in this research as motivating FII, even though they were seen as indirect benefits. In other words, the direct FII benefit or intangible motives such as attention seeking and being seen as a good carer may result in perpetrators ultimately gaining in a more tangible way e.g. financially. Mary commented:

> *'I think it's for her own financial need, sense of gratification and how wonderful am I. I get more hours, I need more hours because I have to do this woman on my own…'.*

Therefore, the study observed that in gaining more hours the carer was directly gaining attention from colleagues, but she was also indirectly gaining extra paid hours. As a result, this research suggests that financial gain was not usually a primary motivation in FII as would be the case in more 'straightfoward' elder abuse. It could, however, depend on the setting in which the older person was. If it was in a nursing home, a carer would indirectly benefit from the extra paid hours; while in the family setting the carers could directly benefit from the older person's allowance or will. Hope maintained that:

> '*It can be long term gain in that they may not be getting immediate gain but they would gain by influencing the person to change the will*'.

Furthermore, accessing services could in certain circumstances be seen as a primary motive. Lazenbatt (2013, p. 65), when discussing FII in children, stated that 'some later examples have been noted where mothers have fabricated illness in order to claim welfare benefits.' One participant noted that:

> *'I would think possibly if you could show that a person is ill they would have access to more facilities, access to say the carer's allowance, they would have access to may be home help, public health nurses coming and they would be gaining.'* (Hope)

In Hope's opinion, therefore, FII perpetrators may not only stand to gain attention through access to facilities and professionals, but also to gain financially from fabricating or inducing illness in older people.

4.3.3 Mental state of carer (perpetrator)

This research also sought to ascertain participants' views on the mental state of a carer who fabricates or induces illness in older people. The study observed that while some participants felt perpetrators who fabricated or induced illness in older people had mental health challenges, others felt that it was not always the case. Lucy, Jane and Mary explained:

> *'No, I don't think it's a mental health issue, I think she is somebody that had worked in a nursing capacity for a number of years and she is somebody that wants to have a role.'* (Lucy)

> '*Well that fella definitely had a mental health issue. I had never got a diagnosis of him.'* (Jane)

> *'I just think that, that woman had ulterior motives and not necessarily related to mental health at all.'* (Mary)

These quotes reflect difference in participants' views due to lack of a formal diagnosis of the suspected perpetrator's mental health status in the cases they came across. It would appear that a mental health issue for the carer would be a possibility 'as in some occasions

a carer may not fulfil the criteria for compulsory psychiatric diagnosis and treatment and there was limited evidence for efficacy of psychiatric interventions for perpetrators' (Singh *et al*., 2013, p. 180). Bass and Glaser (2014, p. 1414) note that 'in view of diverse motivations, caregivers have no one profile of behaviour, personality, or psychiatric disorder and no psychiatric diagnosis exits for Munchausen Syndrome by Proxy'. Pinto and Walsh (2015, p. 1) state that the behaviour of perpetrators they considered was not due to a mental disorder. Considering participants' views, this research suggests that while the mental health status of a carer could contribute to their fabricating or inducing illness, it is also possible that the carer does not have a mental health challenge. Moreover, without a diagnosis it could be difficult to claim that they have a mental health problem; a multidisciplinary team working with the victim and the perpetrator would be key here. However, a GP commented:

> *'The problem is that the person as the carer wasn't my patient, whereas the elderly person would be a patient. So you often don't have access to their past history or sometimes it would be a personality disorder which won't be diagnosed in the first place.'*

4.4 Identification and awareness

In older to identify FII, people have to be aware of the signs and symptoms and type of behaviours that constitute it. However, FII is unknown to not only the general public but to some professionals as well. Lasher (2003, p. 409), talking about children, argued that:

> If victims are to be identified and protected there must be general public and professional awareness that FII maltreatment exists and when to suspect it. When working with suspected or confirmed cases regardless of role or discipline, requires specialised knowledge and skills. Most professionals, including many who were highly regarded within their own fields and specialities, knew little about FII, had misconceptions about it and lacked the knowledge and experience to undertake case involvement.

The next discussion focuses on participants' perspectives regarding identification and awareness of FII in older people.

4.4.1 Behaviour, signs and symptoms

In trying to identify FII, it seemed central to the research to examine the characteristics of both the victim and the carer as most of the signs and symptoms portrayed were linked to the behaviour of the carer in the presence of the victim and professionals as well as the behaviour of the victim in the presence of professionals and the carer. Lasher (2003) suggested that FII was a label for a pattern of behaviour that constitutes a specific and unique kind of maltreatment. Postlethwaite added that FII includes a wide range of behaviours from immediate life threatening to fabrication alone (2010). Participants' views regarding signs and symptoms were:

> *'The carer imposing conditions or diet, but in this case I would say it was over feeding*.' (Lucy)

> *'Behaviour of the relative/carer is important to notice. Are they kind of exceptionally attentive in a positive or negative way, are they over controlling the patient or the information about the patient, the giving of it, the getting of it, do they question everything and resist effort to help?*' (Julie)

> *'Over caring, you know what I mean, not taking professional advice and just feeling that everything they were doing was the right thing*.' (Jane)

> *'From my point of view as a GP, the signs and symptoms will be in the elderly, where the relatives are saying one thing and I don't see it as a professional or you have made some contacts where relatives are saying one thing, the nurses or the carer aren't agreeing with that and there is a total conflict.'* (Hope)

The researcher summarised participants' views in Tables 5 and 6 below on behaviour, signs, and symptoms that would help professionals suspect FII in older people and their carers:

Table 5: Participants' views on behaviour, signs and symptoms to look out for in older people

- ✓ Fear of losing carer
- ✓ Fear of nursing home
- ✓ Pretending to be ill
- ✓ Unexplained symptoms
- ✓ Having medically unverified conditions/recurrent illnesses
- ✓ Lack of cognitive capacity
- ✓ Looking to the carers for responses/reliance on carer for responses/ seeking approval from carer for responses and actions
- ✓ Behaving different in the presence of carer (acting up in carer's presence / inconsistent behaviour in presence of carer)
- ✓ Ability to do things in the absence of carer/dramatic change in behaviour in absence of carer
- ✓ Moving from one nursing home to another or one hospital to another or one institution to another
- ✓ Overdependence on carer

Table 6: Participants' views on behaviour, signs and symptoms to look out for in carers

- ✓ Imposing conditions on care
- ✓ Overmedicating victim
- ✓ Withholding medication
- ✓ Interfering with treatment/treatment alteration, giving wrong medication/tampering with quantity of medication/treatment plan adherence failure
- ✓ Overfeeding
- ✓ Underfeeding
- ✓ Direct or indirectly encouraging signs and symptoms
- ✓ Giving contradictory information
- ✓ Self-praise
- ✓ Exceptionally attentive
- ✓ Overcontrolling
- ✓ Obstructing medical process and over involvement in the process
- ✓ Questioning and resisting effort to help, not taking professional advice or ignoring advice.
- ✓ Persistent complaints
- ✓ Overcaring, overprotective, overconcerned (going beyond ordinary concern)
- ✓ Carer feeling they are always right
- ✓ Having conflict with professionals
- ✓ Aggressiveness toward professionals
- ✓ Lying about victim's health
- ✓ Always the one speaking
- ✓ May have a nursing background

Most of the behaviour, signs and symptoms highlighted above by participants have also been stressed by other authors as signals of an FII case. Smith and Arden for instance suggested that persistent and recurrent illness which cannot be adequately explained, and symptoms and signs that often do not occur in the patient when the carer is absent, are characteristic; the presence of any of these signs is more suspicious if the carer has had previous medical training (1989). In this research, however, not all the experienced suspected FII cases related by participants were perpetrated by a carer with a medical background, even though a carer with a medical background was always more easily suspected than one without it. In this research just three out of eight participants came across potential perpetrators with a medical background, demonstrating that although there was a possibility for a carer with a medical background to be the perpetrator, FII could be perpetrated by anyone who has a care role; moreover, this research suggests that there is more opportunity for FII in the family, and family members need not be professional health workers.

4.4.2 Some FII prompts for professionals working with older people

Apart from behaviour, signs, and symptoms that people observed when they suspected FII in older people, participants also noted other prompts that professionals working with older people could look out for. These were mainly based on gaining a relationship of trust. Joan, Lucy and Hope suggested:

> *'I think you would have to know the person quite well and have an established relationship with them. The person would have to trust you to be able to say how they are feeling.*' (Joan)

> '*For me it's speaking with the client and family and getting an understanding.'* (Lucy)

> *'If you suspect so then you can lead on and follow on, make sure they don't appear to have illness, you look at the character of the relatives or the carer and see what's going on there…'* (Hope).

These quotes suggest that without a relationship between professionals and FII victims, it might be difficult to recognise FII. It would then appear that in certain situations victims may need to gain a relation of trust with a professional in order for them to explain what is going on (Parrish and Perman, 2004).

4.4.3 Professional and public awareness

The research suggests that some professionals were not aware of FII due to various factors including the lack of reported cases in older people and a general lack of information. Deimel IV *et al.* (2012, p. 297) argue that 'there are few reported cases of recurring unexplained illness in the elderly patients believed to represent FII which emphasises the need to identify elder abuse.' Singh *et al.* (2013, p. 180) also suggest that 'verification of FII especially in older adults poses even greater difficulties than in young children as the most common form of verification was the resolution of symptoms when the victim and the perpetrator were separated.' On identifying FII from a professional perspective, some participants indicated the following:

> *'With great difficulty, it might not be recognised sometimes; it would depend on how well professionals know the person and if there was a change in personality.'* (Joan)

> *'Unfortunately it seems you could never identify it until it is happening. I don't think I would be able to tell until something has happened and then unfortunately.'* (Maggi)

There were other participants who thought that FII was easy to identify, these were their views:

> *'It's very easy to recognise I think. It's whether people want to recognise it or want to do anything about it.'* (Jane)

> *'It's not common and I think because it's not common, it's actually quite identifiable for people who work with the elderly on* a *regular basis.'* (Hope)

On professional awareness, there were mixed viewpoints among participants. Some felt that some professionals were more aware of FII in children than in older persons; there was also a belief that FII was increasingly becoming more common. Still others suggested that although professionals may be aware, there was insufficient data written on it and others held that professionals were not aware. This was echoed as follows:

> *'Oh yeah, very aware of it, I just don't think there is enough written on it and not enough research on it, not enough information on it.'* (Jane)

> *'A lot of people would have been aware of it in children but wouldn't be aware of it in older people.'* (Mary)

> *'I would think not enough no, it doesn't seem to be discussed much.'* (Julie)

> *'No I wouldn't think professionals are very aware, it depends on each individual, their education, what they read.'* (Rose)

> *'I think that the geriatricians would be aware, a lot of GPs are becoming more aware because they are doing more and more on the elderly.'* (Hope)

The above quotes suggest that although professionals are becoming increasingly aware of FII in older people, there is limited professional and public awareness and therefore FII in older adults remains more underreported and unidentified than FII in children. When referring to FII in children, Lasher (2003) submitted that FII was no longer considered rare by most leading FII professionals but rather underrecognised due to lack of public awareness and professional expertise. Furthermore, with regard to awareness on the part of the victim, the study suggested that the victims were aware of FII but were protecting perpetrators because they were afraid of losing a carer, or that they were not aware of what was happening. Deimel IV *et al.* (2012, p. 298) showed that:

> When the victims were separated from the perpetrators, they repeatedly denied being abused; this was either because they were unable to recognise that their situations were

> potentially dangerous or the victims were aware but were protecting the perpetrators. This was in contrast to previously published cases where the adult victims were not aware the perpetrator was producing illness.

Maggi claimed that '*I don't think the patients know they are being made ill. The two patients that I am thinking of would never be aware even if it was written up in the wall*'. Hence, the research noted that, depending on the cognitive capacity of older people in a given setting, some would be aware while others would not, each circumstance was different, hence the need for public and professional awareness.

4.5 Management of FII

This section examines participants' perspective on how FII was managed and their knowledge of social policy, best practice guidance, and legal framework to deal with FII in older people by carers.

4.5.1 Policy and legal framework on FII

Participants noted that they knew of no policy or legal framework related to FII, neither was there a formal system available to assist professionals who suspected FII in older people. It was also noted that FII was not mentioned in any of the national policies that addressed the plight of older people such as the *Safe Guarding Vulnerable Persons at Risk of Abuse, National Policy and Procedures* (Health Service Executive, 2014) and the *National Positive Ageing Strategy* (Department of Health, Patient First and Health Ireland, 2013). Mary, Rose, Julie and Joan explained as follows:

> *'We have nothing legal for elder abuse locally, not to mention for FII, we have no legal rights specifically for elder abuse, the same legislation applies to older people as it does to younger people in Ireland.'* (Mary)

> *'No we have nothing like that, not that I know of in the care of the elderly.'* (Rose)

'To my knowledge FII isn't specifically mentioned in policies we have in the general sense of protecting somebody, we have various categories of elder abuse it's not specifically listed.' (Julie)

'*There isn't in my experience any formal way of dealing with it because there isn't any formal way of diagnosing it.'* (Joan)

The aforementioned participants' views chime with Begley and Mathews who also noted that Ireland still had no specific statutory recognition of elder abuse; practitioners and families rely on the same legal protection as other citizens (2010). In addition, despite the development of the progressive policy *Safeguarding Vulnerable Persons at Risk of Abuse, National Policy and Procedures* (Health Service Executive, 2014), which provided guidelines on concerns of abuse or neglect related to older people, there was nothing in the policy that identified FII as a type of maltreatment. Furthermore the definition of elder abuse in this national policy was silent on the FII type of maltreatment (Health Service Executive, 2014), which could make it difficult for professionals to identify it during policy implementation and practice.

4.5.2. Management and best practice

Participants noted that FII was very difficult to manage:

'It's a very difficult thing to manage. There is a lot of time involved in managing it and the GPs wouldn't have that time. It is very hard to manage it out of the house.' (Jane)

'It's hard to write down exactly what you are looking for, or how to recognise it or deal with it.' (Joan)

Apart from being difficult to manage in the absence of policy and legal framework, there was no best practice, national social policy, or professional guidelines that professionals could follow in an event that they suspected a case of FII in older people. Participants viewed FII as having to meet one of the targets in the policy on *Safe Guarding Vulnerable*

Persons at Risk of Abuse, National Policy and Procedures (Health Service Executive, 2014), instead of having a standalone policy on FII. Rose and Lucy commented:

> *'I have not heard of any best practice, we have no checklist and FII doesn't reach any of the targets in the elder abuse policy.*' (Rose)

> *'If you have elder abuse there is a certain formula that you can follow, outside of phoning colleagues, I wouldn't know of any process.*' (Lucy)

Although there was neither policy, legal framework, nor best practice, professionals somehow had a way of dealing with suspected FII cases in older people, however, such ways were *ad hoc* and included referral, communication, and liaison with colleagues. This was echoed by participants as follows:

> *'I think everybody manages it differently, nothing specific.'* (Jane)

> *'I suppose what there would be, would be referral pathways only.'* (Hope)

> *'Well if you know certain things on FII and I know certain things, then we work together, most of the things we do on FII will just be our opinion or something we have picked up or worked on, on that occasion and I don't see that there is any specific policy guideline.'* (Mary)

Furthermore, participants had various roles in the suspected FII cases they came across. The roles ranged from conflict resolution facilitator, situation assessment, home-help coordination, supervising nursing care, to general practice, public health and linkage with other service providers; for instance, Lucy, Julie and Hope explained:

> *'My role in that particular situation was there was a big family all who cared for their mum but didn't get on with each other, so this main carer had as some of the others had seen it, completely taken over and they felt they were not allowed any access. I went in and provided a very practical time tabling access.'* (Lucy)

'My role, I was asked by the geriatrician to give my assessment of the situation. I think they suspected the daughter of the patient had some issues and maybe overstating what was going on in the nursing home.' (Julie)

'Very little role as I found it, impossible as an isolated GP to stop what was happening.' (Hope)

Lucy, Julie and Mary's quotes suggest that professionals can play different roles in dealing with FII cases and that no one professional can effectively handle FII in isolation, hence the importance of a multidisciplinary team. Smith and Arden (1989, p. 334) argued that 'multidisciplinary teams can successfully offer 'tag therapy" to patients and families, where each professional hands on the therapeutic baton to the next colleague in a mixed medley where skills are offered in the individual professional's own particular style.'

4.6. Surprises

There were some observations made by participants which the study considered interesting for future research consideration. This section therefore highlights these surprises, and proposes that some of them could need further study to inform literature. In this regard, a participant linked FII in older people to the economic recession. The participant believed that some carers were fabricating or inducing illness in older people for financial gain due to the recession. The participant stated:

'*Greed is a terrible thing and if there is secondary gain, they may do it, especially now with the recession and the carer's allowance pays a lot so if it all helps to get the carer's allowance for a family who may not otherwise get it and if the person is out of work, it all helps…*' (Hope)

However, the study did not come across literature linking FII in older people to economic recession. Perhaps this could be a matter for future research.

Another participant noted that some older people wanted to be with the perpetrators even though they knew they were being abused and whether or not professionals suggested

separation of the victim and the carer. The relationship of love between the victim and the carer was surprising, as noted by a participant. In this case it seemed as if it was not about the fear of losing the carer. On the other hand, the perpetrators seemed to love the victim and it would not make sense for them to fabricate or induce illness in a person they claimed to love. Maggi noted:

> '*It is a love relationship, so it's hard to understand, but like this wife absolutely loved her husband, it seemed to me to be linked to a nursing role, she withheld some of his tablets, I don't understand why. But do you know the irony of the whole thing Esther? That the clients, the patients, just wanted to be with those people, that is really the saddest part of all isn't?*'

This is similar to Kumar *et al.*'s observation (2014) that professionals sometimes overlook the possibility of FII because it goes against their belief that caregivers would deliberately hurt a close family member or child. Nonetheless, professionals should not take it for granted that the person who loves the victim cannot hurt.

Still another participant described a case in which the participant felt that the victim was mistakenly placed in a mental health institution through her husband who fabricated illness in her, and convinced a medical professional to have his wife locked up in a mental institution. In this case, a spouse fabricated illness to get rid of his wife. The participant recounted:

> *'Actually, I am thinking now of another case way back that I came across whereby I was working in the mental health hospital as a student and I met a woman who appeared to be perfectly sane. She was in a psychiatric institution and I asked her what happened and she said: "I hit menopause and my husband went off me. He started an affair, wanted another woman in his life, so he got the doctor to sanction me as being kind of insane. I may have been a bit depressed, I was menopausal but I ended up in a psychiatric hospital. One doctor signed me in and I haven't been able to get out and I have been locked up ever since and he actually visits me with his new partner". And this was a very sane normal woman.'* (Julie)

In this instance, the spouse reportedly got the medical professional to believe the woman was insane or had a psychiatric condition by producing signs and symptoms of her depression and he was believed. If true, this was a deliberate act to get rid of someone and had nothing to do with attention seeking. This reveals how complex FII can be and the motivation of perpetrators. The case was similar to one of the cases outlined by Levin and Sheridan (1995) of a female perpetrator who wanted to get rid of her 48-year-old husband by having him admitted to a psychiatric hospital because of alleged violence against her. It also revealed how professionals may sometimes take cases for granted because they are presented by close family members (Kumar *et al.*, 2014).

The study revealed another potentially valuable insight when one participant stated:

> *'But you see there must be degrees of it (FII), I think that when you have Munchausen's by proxy, I don't think it is that you have a full blown, but you could have a very mild form of it.'* (Maggi)

This is similar to what Khan (2008, p. 5) suggested, when the author stated that 'the disorder may be mild where a false medical history is provided or severe where the parent actually induces symptoms in a child.' The research did not come across literature relating to older people suggesting that there are gradual degrees of FII; this is a matter that requires future research.

4.7 Conclusion

The analysis of the themes discussed in this chapter based on the data gathered from participants, and informed by the literature, suggests that FII is an underresearched area of social policy and practice in relation to older adults, and though it may be considered uncommon, anecdotal evidence of its existence suggests it is a real if not elusive issue that could affect the elderly in Irish society and would escape official notice. Certain characteristics can be identified however that would aid professionals in the diagnosis of FII in older people, and that show that FII should be considered a category of abuse in its own right, rather than simply part and parcel of what is generally termed elder abuse. Judging by the views expressed by participants, FII can take place anywhere, whether in a

family, residential or day care or hospital setting depending on the situation of older people. The discussion reflects that there is a lack of information on FII in older people that can inform professionals who work in the area of elder care, which prevents diagnosis and puts the elderly, a vulnerable as well as fast-growing social group, at risk. Furthermore, there are currently no legal frameworks, national social policies or professional guidelines that could aid and inform professionals in the event of a suspected FII case. This is coupled with a general lack of public awareness. In view of the findings and analysis of the themes in this chapter, the subsequent chapter highlights the research conclusions and recommendations.

CHAPTER FIVE

Conclusions and Recommendations

5.1 Introduction

This final chapter summarises the conclusions of the research. It then highlights the recommendations jointly developed with the community partner, before presenting a personal reflection on the researcher's experience of the research process and concluding remarks. Collaborating with the community partner, this research sought to respond to a vital but previously neglected issue that affects one of the most vulnerable groups in society. Therefore, following initial documentary research, this study set out to answer the research questions devised with the community partner (1.5), and addressed comprehensively in Chapter Four, in an effort to address the concerns of the community partner and contribute to the quality of life of older people in Ireland. These research questions are used as the chapter headings here in recapitulating the major findings.

5.2 Does FII in older people by carers exist?

Participants' description of FII in older people tended to view FII as a form of elder abuse in which a carer falsified or induced illness in an older adult in various ways such as reducing or increasing the quantity of something (drugs/food) they required; or in which a carer presented an older person for medical attention even though they were not sick. The description of FII in this regard is similar to how Deimel IV *et al*. (2012, p. 294) described FII in older adults 'as a form of abuse in which an individual produces or feigns illness in a person under their care'. Data presented in this study suggests that FII in older people could exist. Although five out of eight participants were absolutely sure that it existed, and three were unsure, this was a small exploratory study and larger national study is required to provide stronger evidence. The literature search demonstrated that there are a very finite number of cases around the world published on FII in older people. The six articles found were all case reports in medical journals and no formal studies were identified. Although this is not definite proof that FII in older people exists throughout society internationally,

the articles suggest that it is likely. Furthermore, as this study has emphasised, FII in older people may be far more common than thought, as emphasised by various authors (e.g. Ben-Chetrit and Melmed 1998; Singh *et al.* 2013); a lack of knowledge and underreporting would prevent diagnosis. Indeed, as the participants' comments showed, health professionals had diverse ways of dealing with suspected cases, none of which actually involved diagnosis of FII, while the lack of a legal framework also entails that FII might not be identified in the overall elder abuse definition, FII needed to be treated as a phenomenon in its own right. Moreover, diagnosis of FII in older people is a challenge among professionals as it is deceptive in nature, which contributes to the lack of formal studies and reported cases. Deimel IV *et al.* (2012, p. 297) referring to older adults suggested that 'given the deception at the core of FII, teams can rarely be absolutely certain about the diagnosis.' Therefore, based on participants' perspectives and the available literature, this study suggests that FII in older people is a possibility and formal studies are necessary as well as professional expertise on its diagnosis and public awareness to protect older people who are potentially at risk of this form of maltreatment.

5.3 Nature, context, and motivation

In view of the fact that FII in an older adult is a possibility as demonstrated by this study, it was vital to highlight its nature and context to ascertain the setting in which it is likely to take place and subsequently the motivation of perpetrators, with a view to creating public and professional awareness. All participants in this study stated that FII in older people can take place wherever older people are being provided with care, including a family setting, hospital, geriatric ward, day and residential care setting, depending on the situation of older people. This confirms with Bass and Glaser (2014) who suggested that FII can take place in many diverse settings involving various professionals in social services, educational, legal, and medical domains. Owing to the participants' views and available literature, this study suggests that FII should not be viewed as a health or medical issue alone as doing so could render interventions to address it as being too narrowly focused, rather than comprehensive and multidisciplinary. In addition, society would be doing a disservice to older people who could suffer in settings that are non-medical.

With regard to the motivation of perpetrators, the research ascertained that motives can be divided into two: intangible and tangible motives. The intangible motives are stronger than the tangible ones. In this regard, most of the participants (six out of eight) stated that the motivation of perpetrators was concerned with attention-seeking, self-praise and maintaining a good self-image. In this research, such motives were considered as intangible and had no external incentives as pointed out by Trask and Sigmon (1997), when defining FII in children. Khan (2008, p. 5) added that: 'the motivation of the perpetrator is to assume sick role by proxy. External incentives for the behaviour, such as economic gain, avoiding legal responsibility, or improving physical wellbeing are absent.'

However, apart from alluding to intangible motives, two out of six participants could not rule out external motives such as financial gain and other in-kind benefits. Although there was insufficient available literature on external motives of perpetrators in older people such as financial gain, in children Lazenbatt (2013) observed that there were examples indicating that some mothers fabricated illness to gain welfare benefits in light of the recession. Based on this study, the primary motivations of perpetrators have more to do with attention seeking and being seen as a good carer than with external benefits such as financial gain. However, there is a need for research to provide evidence on whether financial gain could be included as a motivating factor for perpetrators in older people and whether it could be related to economic recession. In the few reported cases on FII in older people the information did not overall suggest that financial gain was a primary or secondary motivating factor.

5.4 How can FII in older people be identified?

The data presented in this study suggests that identification of FII in older people is a challenge due to a lack of diagnosis and awareness. Although participants highlighted signs and symptoms in both perpetrators and victims (outlined in Chapter Four) they also stated that it was not easy to confirm the signs and symptoms. These concerns were echoed by many authors dealing with both children and adults such as Singh *et al.* (2013) and Lazenbatt (2013). In relation to children, Lazenbatt submitted that there was a lack of clarity among professionals with regard to what constitutes FII and its diagnosis, which

further complicated identification and management. In older adults, Singh *et al*. (2013, p. 180) argue that 'verification of FII especially in older adults poses even greater difficulties than in children, as the most common form of verification is the resolution of symptoms when the victim and the perpetrator were separated.' Furthermore, participants suggested that there was limited professional expertise on FII in older people; this was similar to Lasher's (2003) assertion that most professionals he encountered knew little if anything about FII in older people; there were misconceptions about it and some of them had insufficient experience to undertake case involvement. Therefore, the research findings presented in Chapter Four suggest that FII is not easy to identify due to a number of factors such as limited professional expertise on diagnosis and public awareness. The dissertation therefore underscores the need for professional and public awareness if older people are to be protected.

5.5 What policy, best practice, and legal framework exist?

All participants stated that there was no formal way of managing FII in older people, confirming what Begley and Mathews (2010) alluded to when the authors said that there is no specific statutory recognition to protect older people against abuse in Ireland; older people rely on generic legislation. Although suspected cases of FII were being handled in an *ad hoc* manner, some participants were of the view that the national policy on *Safeguarding Vulnerable Persons at Risk of Abuse, National Policy and Procedures* (Health Service Executive, 2014) was the right framework for managing suspected cases, as this social policy is concerned with the protection of abuse of older people. However, the policy does not mention FII in older people. Meanwhile, some participants said that this policy was the appropriate framework in which to incorporate FII as a subcategory and a form of elder abuse, instead of creating separate guidelines as the process would take too long. Therefore, the data presented in this study suggests an absence of policy guidelines, best practice, and legal framework to help professionals working in the area of elder care deal with FII in older people when they suspect it.

5.6 Recommendations

In view of the above conclusions and ideas from participants on the way forward, the student researcher and the community partner jointly developed the following recommendations:

5.6.1 Short-term recommendations

1. One participant stated that '*Awareness would be the most important thing*.' Another added: *'We need a paper that is just easy to understand and distributed to every professional in the country*.' The researcher recommends that a summary or an information leaflet be developed and distributed to relevant professionals and institutions, which can also serve as an instrument for public awareness. This process be led by social work staff in the HSE dealing with the welfare of older people, initially in collaboration with Age: Wisdom and Hope. As a result of this recommendation, the researcher and the community partner developed an information leaflet which the community partner started distributing (see copy in Appendix 3).
2. The latter participant referred to also added: '*It* (summary paper) *could be sent to the IASW to have CPD points accredited to it because people then may have more interest in it*.' The researcher recommends that the summary paper or leaflet be sent to the Irish Association of Social Workers (IASW), Nursing Board, and Medical Council to increase professional awareness. This could be done by the community partner, Age: Wisdom and Hope.

5.6.2 Long term-recommendations

1. A participant observed: '*We need a clear line of investigation available to carers, victims, and anybody who would suspect it, like we have in elder abuse*.' A clear line of investigation and identification (decision algorithms/system) should be instituted. The available line of investigation in elder abuse could be a starting point or could set as a framework for instituting one on FII in older people. This process could be led by social workers (elder care) in the HSE in consultation with other multidisciplinary professionals who work with older people.

2. One participant suggested: '*I think we need somebody who can develop and devise an assessment tool and I think that would be an evolving kind of process.*' The researcher recommends that social workers for the protection of older people should initiate the process with multidisciplinary consultations. The process could be spearheaded by social workers in the HSE responsible for elder care. It is recommended that this be an on-going process due to the emerging trends related to the subject area.
3. '*You know I think having a multidisciplinary team would deliver information on FII in different areas,'* a participant observed. The researcher recommends that where they are multidisciplinary teams these should be utilised, and where there are not they should be formed.
4. Another participant proposed *'FII would have to fit in the prevention of abuse policy.*' The researcher recommends that FII should be recognised or integrated in the policy on *Safeguarding Vulnerable Persons at Risk of Abuse, National Policy and Procedures* (Department of Health, 2014) and included as a subcategory under the definition of elder abuse. The Social Work and Social Care Division of the HSE should spearhead this process and hold consultative meetings with stakeholders on how best FII could be incorporated in the policy. In addition, Age: Wisdom and Hope could lobby for this by writing letters to the responsible government minister(s) and other key officials on the need to incorporate FII in the policies and follow up on the process until it is achieved.
5. On alleged staff perpetrators in institutions of care, a participant suggested *'some occupational health support services are needed for staff to see where they are at in their behaviour mentally.'* The researcher recommends that these institutions of care should utilise their Employee Assistance Programme (EAP) and should develop a programme of occupational health support services, specifically in relation to elder abuse, including FII. Directors of these institutions should incorporate occupational health within the institutional policies and regularly review the policies.
6. '*FII should be included as a topic in post graduate gerontology courses and undergraduate nursing courses,' a* participant advised. Therefore, the researcher

recommends that a letter be written to the Department of Education and Skills proposing the incorporation of FII into relevant post- and undergraduate curriculum, to inform students and professionals that FII in older people is a possibility. This should be spearheaded by Age: Wisdom and Hope and HSE social workers dealing with elder care and would be an on-going process of engagement.

7. A participant indicated *'I would be very interested in further training on it, if there were courses on how to recognise and deal with it*.' The research recommends that the Department of Health and Social Care could incorporate FII as an agenda item in their short courses, seminars, or workshops for staff working with older people on how to diagnose and deal with FII in the event that they suspect it. The few reported cases together with literature on children and this study could set as a reference point. Although there are no policy and formal studies, professionals would have information on it and how it can be addressed. This would ensure that older people are protected against this form of abuse.
8. Another participant recommended *'I think we need to send a tick box say to GPs' annual conferences.*' The research therefore recommends that a checklist on what to look for when professionals suspect FII in older people should be developed and reviewed regularly. It should be an agenda item at the annual conferences held by various professionals, such as GPs, Social Workers, Public Health Nurses, Geriatricians, Psychiatrists and relevant academics; the department of Health should spearhead this process. As a starting point, the checklist was developed by Age: Wisdom and Hope in collaboration with the student researcher and was being distributed to professionals by the community partner.

5.6.3 Recommendations pertaining to academic future research

The researcher recommends the following possible future research areas and questions on FII in adults:

1. Qualitative research on, 'what is the relationship between FII in older people and the economic recession? Is financial gain an FII motive, primary or secondary?
2. Are there degrees of FII in older people and how are the degrees classified? This would help to influence policy and practice related to older people.

3. Qualitative research on FII in adults aged 19-64, living with disabilities and on developing appropriate assessment tools and checklists.
4. What is the difference between elder abuse and FII in older people?

5.7 Researcher's Reflection

In the context of a research methodology, reflexivity can be used to highlight an awareness of the identity or self of the researcher within the research process. One examines, analyses, and reflects on the nature, role, and the writing of the research work (Elliott, 2005). In addition, 'responsible research and innovation is expected to contribute to meeting societal needs, instead of failing to addressee them and leaving implementation gaps. Reflection is therefore required in order to act adequately and to be open to changes in the process' (RRI Tools, 2015, p. 1). As a UCC Master of Social Science in Social Policy student researcher, I here reflect on the process of the research and my experiences in undertaking it.

This was community-based research and I therefore worked with a community partner from the beginning. Consequently, selection of participants, pre-interview letters, and interview venues were carried out with the community partner. In addition, brainstorming on aims of the study and interview guide were also negotiated and carried out with the community partner to ensure that the research reflected the aspirations of the partner. My communication skills were strengthened as a result of the brainstorming meetings.

Furthermore, this was my first ever experience of academic research with a community partner. In the process I learnt that community-based research has its pros and cons as this type of shared responsibility focuses on the research needs of the community partner, which can make a student researcher like myself sometimes forget that the research is not simply based around the student researcher but is being undertaken for the community who commissioned it and that the process is a collaborative and shared one. However, continued reflection and communication with the community partner helped me to stay focused and appreciate the power of collaborative research to have a real-life impact and contribute to a better society for older people. Overall, the process of undertaking this

research study was a fulfilling experience. Nevertheless, I still need to learn more on the process of undertaking community based research with a multicultural Civil Society Organisation, seeing that many communities around the world are becoming culturally diverse.

Being a student from Zambia and knowing absolutely nothing about FII in older people, it was a challenge to undertake this research, but a challenge I took on with enthusiasm. I had to start almost 'from scratch' in my research with virtually nothing to serve as a reference point. Although my search strategy identified six published cases on FII in older people around the world, none were identified in Ireland which made the study more interesting as well as challenging, and gave a lot of leeway for exploration and analysis. I can simply say this was one of the most exciting experiences I have ever had regarding research. I found the information participants shared moving, vast, and more enlightening than I had ever anticipated, knowing that the FII area in the elderly was underresearched. I count myself as one of the few privileged Zambians to have undertaken this research in Ireland, and as a social policy student the information from this research that Age: Wisdom and Hope commissioned will also be vital in influencing policy on older people even in my home country. Hence the benefits of the research go further than the borders of Ireland.

According to the RRI Tools document (2015) responsible research and innovation is about working collaboratively to align the outcomes of the research to values, needs and expectations of society for the betterment of future generations. The community partner, Age: Wisdom and Hope, also reflected on the outcome of this research study, the reflection contributed to a number of activities being jointly done such as the checklist and the information leaflet. Moreover, based on the outcome of the study, the community partner planned to circulate the checklist and information leaflet to professionals working with older people and to the Irish Association of Social Workers for publishing. The organisation also planned to initiate the process of developing an assessment tool on FII in older people by Carers as well as follow up with relevant institutions on a number of issues that needed to be addressed based on participants' recommendations. These activities by the community partner suggest that the outcomes of this study will be put to good use in

the community and has enhanced interaction among research outcomes and policy making (RRI Tools, 2015) and thus likely to contribute to the protection of older people in Ireland

Furthermore, the research questions which this study set out to answer provided much insight into the phenomenon of FII in older people, although there were limitations such as insufficient data on FII in older people in Ireland and internationally as well as time constraints. As such, given an opportunity to study a doctorate, I would pursue this line of inquiry on FII in older people further as this is my likely future engagement with research. Consequently, some activities would be carried out differently; the research design would be adjusted to allow more activities to be undertaken such as information sharing or public awareness, in addition the sample size would be adjusted to include one or two professionals such as geriatricians and psychiatrists. An assessment tool could also be a possibility given a longer timeframe to study this subject area in the course of a doctoral thesis.

5.8 Final research conclusion

This research study set out to answer the following research questions

i. Does fabrication or induction of illness in older people by carers exist?
ii. In what setting does it exist and what are the motivating behaviours in these contexts?
iii. How can FII in older people be identified by professionals?
iv. What policies, best practice or legal frameworks are available to protect victims or potential victims of FII by carers in Ireland?

The aforementioned research questions have all been addressed in the course of the dissertation. The findings presented in this study suggest that evidence to state that FII in older people exists is too limited to be conclusive proof; the published six articles were all medical journals and not formal studies. This study nevertheless suggests that FII in older people is a possibility that must be considered based on information gathered from participants as well as the likelihood that the phenomenon is underreported. This possibility is a grave one in light of the fact that there are no policy guidelines, or best practice, or legal framework that addresses FII in older people in the Republic of Ireland.

Furthermore, even the available policy on elder abuse in Ireland makes no mention of the FII type of abuse. Professionals dealing with suspected FII cases on the other hand were dealing with it in an *ad hoc* manner but recommended that it be highlighted in the elder abuse policy to inform professionals working with older people that it could happen. Also apparent is a general lack of public awareness and limited professional expertise on its diagnosis, which contributes to the phenomenon not being easily identified and recognised. Additionally, the research study suggests that FII can take place anywhere, in a family, day or residential care setting, in a hospital or geriatric ward and many diverse places depending on the situation in which older people are. Based on these salient findings, the recommendations made in this dissertation drew on the proposals by participants, who were professionals who worked in the area of elder care, as well as the relevant literature.

The research has been made available to the community partner for follow up with relevant institutions on some of the recommendations of the research. The community partner and the student researcher also shared the findings with the research participants at a dissemination meeting held in UCC on 21st September, 2015, attended by professionals in elder care, UCC lectures and students (see copy of presentation in appendix 11). Moreover the student researcher, in collaboration with the community partner, developed an initial checklist or tick box on what to look for when FII in older people is suspected (see Appendix 2). This was based on participants' views and recommendations. An information leaflet (see copy in Appendix 3) was also co-developed by the community partner and the student researcher and the community partner had begun the processes of circulating it to professionals working with older people. Further joint letters were done by the community partner and the student researcher to the Ministers of Health, Education and Skills Training and the Minister of State for Primary and Social Care on the findings of the research for future consideration and incorporation into relevant policies to inform professionals that FII could exist (see copies in appendix 1). This is all work in progress for the community partner. Therefore, the impact of this research is already being felt in the wider community as its findings are being disseminated. It is hoped that this continues into the future, and that as a result older people, one of the most vulnerable groups in our society, will be better protected.

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Appendices

Appendix 1: Copy of Letters to the Ministers



University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

10th September, 2015

Minister of Health
Department of Health, Hawkins House,
Hawkins St,
Dublin 2.

Dear Minister Leo Varadkar,

Re: Fabrication or Induction of Illness in Older People by Carers

Please allow us to introduce ourselves as Esther and Pauline who have worked in collaboration to produce the attached documentation.

Esther is a Master of Science (Social Policy) student at University College Cork (UCC) from Zambia. Dr Kenneth Burns, Master of Social Work Deputy Director and Research Associate with ISS21, supervised this research; he had previously carried out similar research into FII in children.

Pauline is part of a diverse group of professionals called Age: Wisdom and Hope of Cork. They are interested in older people and the problems they face. This group was devised as an education and reflective tool to promote the welfare of older people. During one of our discussions we came across a case of Fabrication or Induction of Illness in older people by carers, commonly known as Munchausen Syndrome by Proxy. Seeing that we did not find any published case related to this syndrome in Ireland, we decided to collaborate with the University College Cork to have a comprehensive policy and literature review done and also to serve as a reference guide for future research.

In 2013, Age: Wisdom and Hope submitted a research proposal to UCC via the CARL. Consequently, the research was undertaken collaboratively between Age: Wisdoms and Hope and Esther. The findings reflect a lack of professional and public awareness on the subject area, meanwhile there is a growing number of older people who depend on others for care and some are likely to experience this abuse.

Therefore on behalf of the older people of Ireland, we request you to join with us and spread this information by taking it up with your colleagues to inform the nation on it. A summary document and check list is attached for this purpose. In the long term we also encourage you to consider incorporating this type of abuse when policy or legislation related to older people are being reviewed.

Please feel free to contact either of us if you wish to discuss this further.

Yours sincerely,

Esther Ngambi
UCC Master of Social Science (Social Policy) Student
114220383@umail.ucc.ie

Pauline Glavin
Age: Wisdom and Hope
paulineglavin57@gmail.com



University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

10th September, 2015

Minister of Education and Skills Training,
Department of Education and Skills Training,
Marlborough St,
Dublin 1.

Dear Minister Jan O Sullivan,

Re: Fabrication or Induction of Illness in Older People by Carers

Please allow us to introduce ourselves as Esther and Pauline who have worked in collaboration to produce the attached documentation.

Esther is a Master of Science (Social Policy) student at University College Cork (UCC) from Zambia. Dr Kenneth Burns, Master of Social Work Deputy Director and Research Associate with ISS21, supervised this research, he had previously carried out similar research into FII in children.

Pauline is part of a diverse group of professionals called Age: Wisdom and Hope of Cork. They are interested in older people and the problems they face. This group was devised as an education and reflective tool to promote the welfare of older people. During one of our discussions we came across a case of Fabrication or Induction of Illness in older people by carers, commonly known as Munchausen Syndrome by Proxy. Seeing that we did not find any published case related to this syndrome in Ireland, we decided to collaborate with the University College Cork to have a comprehensive policy and literature review done and also to serve as a reference guide for future research.

In 2013, Age: Wisdom and Hope submitted a research proposal to UCC via the CARL. Consequently, the research was undertaken collaboratively between Age: Wisdoms and Hope and Esther. The findings reflect a lack of professional and public awareness on the subject area, meanwhile there is a growing number of older people who depend on others for care and some are likely to experience this abuse.

Therefore on behalf of the older people of Ireland, we request you to join with us and spread this information by taking it up with your colleagues to inform the nation on it. A summary document and check list is attached for this purpose. In the long term we also encourage you to consider incorporating this type of abuse when policy or legislation related to older people are being reviewed.

Please feel free to contact either of us if you wish to discuss this further.

Yours sincerely,

Esther Ngambi
UCC Master of Social Science (Social Policy) Student
114220383@umail.ucc.ie

Pauline Glavin
Age: Wisdom and Hope
paulineglavin57@gmail.com



University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

10th September, 2015

Minister of State for Primary and Social Care,
Hawkins House, Hawkins St,
Dublin 2.

Dear Minister Kathleen Lynch,

Re: Fabrication or Induction of Illness in Older People by Carers

Please allow us to introduce ourselves as Esther and Pauline who have worked in collaboration to produce the attached documentation. Esther is a Master of Science (Social Policy) student at University College Cork (UCC) from Zambia. Dr. Kenneth Burns, Master of Social Work Deputy Director and Research Associate with ISS21, supervised this research, he had previously carried out similar research into FII in children.

Pauline is part of a diverse group of professionals called Age: Wisdom and Hope of Cork. They are interested in older people and the problems they face. This group was devised as an education and reflective tool to promote the welfare of older people. During one of our discussions we came across a case of Fabrication or Induction of Illness in older people by carers, commonly known as Munchausen Syndrome by Proxy. Seeing that we did not find any published case related to this syndrome in Ireland, we decided to collaborate with the University College Cork to have a comprehensive policy and literature review done and also to serve as a reference guide for future research.

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Therefore on behalf of the older people of Ireland, we request you to join with us and spread this information by taking it up with your colleagues to inform the nation on it. A summary document and check list is attached for this purpose. In the long term we also encourage you to consider incorporating this type of abuse when policy or legislation related to older people are being reviewed.

Please feel free to contact either of us if you wish to discuss this further.

Yours sincerely,

Esther Ngambi
UCC Master of Social Science (Social Policy) Student
114220383@umail.ucc.ie

Pauline Glavin
Age: Wisdom and Hope
paulineglavin57@gmail.com

Appendix 2: Check list on FII in older people by carers (participants' perspective)

	FII Signs and Symptoms in an older person	*Tick √ / X*
1	Having medically unverified conditions/ unexplainable, persistent or recurrent illness in older people	
2	Pretending to be ill	
3	Fear of losing the carer	
4	Fear of going to a Nursing Home	
5	Lacking cognitive capacity	
6	Seeking approval of carers for responses	
7	Behaving differently in the presence of the carer	
8	Dramatic change of health in absence of the carer	
9	Ability to do things in the absence of the carer	
10	Moving from one institution to another	
11	Discrepancies in the history and clinical findings in the older person	
12	Seeking medical attention from different professions	
	FII Signs and Symptoms in a carer	***Tick √ X***
1	Overmedicating the older person	
2	Unexplainable, persistent or recurrent illness in the older person.	
3	Interfering with older person's treatment	
4	Withholding medication	
5	Imposing conditions of care	
6	Overfeeding/ inappropriate feeding	
7	Underfeeding	
8	Direct or indirect encouraging signs & symptoms	
9	Giving contradictory information	
10	Self-praise	
11	Falsifies specimen of bodily fluids	
12	Exceptionally attentive	
13	Overcontrolling	
14	Obstructing medical process/any professional process	
15	Resisting effort to help	
16	Promotes sick role in an older person	
17	Persistent complaints	
18	Overcaring, visits or calls too often	
19	Overprotective	
20	Overconcerned	
21	Having conflict with professions	
22	Aggressive towards professionals	
23	Always the one speaking	
24	Forces older person to appear disabled	
25	Carer appears more worried about treatment and staff intervention than the older person	

***Source for the table was the interviews with participants**

***If you suspect FII in an older person tick appropriately and consult other multidisciplinary professionals on the way forward.**

Appendix 3: FII information leaflet

FABRICATION OR INDUCTION OF ILLNESS IN OLDER PEOPLE BY CARERS

(Munchausen Syndrome by proxy in an elderly person)

Esther Ngambi and Pauline Glavin (2015)

What is it?

Fabrication or Induction of Illness (FII) commonly known as Munchausen Syndrome by Proxy is an exceptional form of abuse in which a person with a care role falsifies or induces illness in an older person (65 and above) under their care in order to gain attention. This form of abuse may also involve professionals, unknowingly, playing a role through carrying out unnecessary medical or non-medical procedures, assessments and tests conducted in the name of treating the feigned illness, which can lead to stress and even death of the older person (Gilbert, 2014). The phenomenon is well documented in children, more so than older adults. A group of professionals in a community group called *Age: Wisdom and Hope* worked a with University College Cork's Master of Social Science (Social Policy) student to undertook an exploratory study on this topic to establish what was known about this issue and to inform the public. Our research revealed a lack of information, public awareness, difficulty in diagnosis and under-reporting.

There are potential RISKS WITH LIFE THREATENING CONSEQUENCES FOR OLDER PEOPLE ASSOCIATED WITH FII BEING UNRECOGNISED

This short leaflet is therefore meant to share information on the topic as there are potential risks with life threatening consequences associated to FII in older people being unrecognised, unchecked and under reported (Lazenbatt, 2013). Fabrication or induction of illness can take place anywhere where older people receive long term care, be it in a family, day or residential care setting, nursing home, or community hospital (Cabral, 2014). The motivation of perpetrators are varied and complex, but can includes: attention-seeking for the carer through access to facilities and professionals, or gaining praise for helping older people, assuming a sick role by proxy and being seen as a 'wonderful' carer. Perpetrators' psychological needs are met through the attention they get during medical evaluations or involvement with various professionals (Deimel *et al*., 2012). Signs and symptoms may include:

- ✓ An older person having unverified medical conditions/unexplainable, recurrent illnesses;
- ✓ Interfering with medical or non-medical processes involving older people;
- ✓ Carer being over protective, over caring, over concerned, over feeding the older person;
- ✓ Carer being aggressive towards professionals and resisting efforts to help;
- ✓ Giving contradictory information;
- ✓ Causing an older person to appear disabled;
- ✓ Older person person's sudden health improvement in the absence of their carer;
- ✓ Older person being moved from one nursing home to another or one institution to another;
- ✓ Fear of losing a carer.

The above signs and symptoms are an indication of a *possible* FII in older people by carers (Smith & Arden, 1998). Should professionals, family members or the general public to suspect a case of FII in older adults, please inform your nearest social worker in charge of elder care or email: paulineglavin57@gmail.com for information. The full research report will be available on this link at the end of 2015: http://www.ucc.ie/en/scishop/rr/



CARL
COMMUNITY - ACADEMIC
RESEARCH LINKS
University College Cork, Ireland

Appendix 4: Information sheet for participants



University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

Fabrication or induction of illness in older people (65 and above): Does it exists?

Information Sheet

Introduction

My name is Esther Ngambi and I am pursuing a Master of Science in Social Policy at University College Cork (UCC). As part of the requirements for this Masters, I will carry out a research study in collaboration with a community based organization namely; Age, Wisdom and Hope of Cork County. The research is about fabrication or induction of illness in older people by their carers.

Context:

Fabrication or induction of illness (FII), formerly known as Munchausen by proxy, is a rare and unique type of maltreatment of older people where a carer in a given context such as family, residential care, nursing home, day care and hospital etc. either feigns illness, promotes a sick role by exaggeration, or presents made-up signs and symptoms for medical attention. This form of maltreatment can occur anywhere where care is provided to older people.

Purpose of the Study: The purpose of this research study is to protect older people from this form of maltreatment, provide more knowledge and literature to all people working with older people, and to inform policy and practice in Ireland.

What will the study involve? The study will involve you being interviewed for 45 to 60 minutes at the venue of your choice.

Why have you been asked to take part? The pre-interview letter that was sent to you showed that you are suitable to provide data for the study.

Do you have to take part? The answer is 'no'! Participation is voluntary and you have the option of withdrawing before the study commences even if you have agreed to participate. You also have a right to discontinue after data collection has started. You are also free to withdraw or ask for your data to be destroyed within two weeks of participation.

Will your participation in the study be kept confidential? Yes. I will ensure that no clues to your identity appear in the thesis. Any extracts from what you say that are quoted in the thesis will be entirely anonymous.

What will happen to the information which you give? The data will be kept confidential for the duration of the study. On completion of the thesis, they will be retained for a further twelve (12) months and then destroyed.

What will happen to the results? The thesis may be read by future students. It may also be published in a research journal and presented at conference. Your name and organization will not be identified.

What are the possible disadvantages of taking part? I do not envisage any negative consequences for you in taking part. It is possible though that talking about your experiences may cause some distress.

What if there is a problem? At the end of the interview, I will discuss with you how you found the experience and how you are feeling. If you subsequently feel distressed, I will provide information on who you can contact. However, should you feel you would like to contact someone later, my tutor and my colleague can be contacted respectively as follows:

Dr. Kenneth Burns
School of Applied Social studies
University College Cork
Crossleigh House,
O,Donovan's Road
Email: k.burns@ucc.ie

Pauline Glavin,
Senior Social Worker (Health Service Executive),
'Age: Wisdom & Hope'
Room 6 - City General
6 Infirmary Road, Cork
Email: Pauline.Glavin@hse.ie

Who has reviewed this study? The project will not involve service users hence ethical approval will not be required. However, the study has been approved by the school of Applied Social Studies and by my tutor Dr Kenneth Burns.

Any further queries? If you need any further information, you can contact me: Esther Ngambi, Mobile 0899730701 / 0894239175, email: 114220383@umail.ucc.ie

If you agree to take part in the study, please sign the consent form overleaf

Appendix 5: Consent Form

I ……..agree to participate in the research study.

The purpose and nature of the study has been explained to me in writing.

I am participating voluntarily.

I give permission for my interview with …… ……to be tape-recorded

I understand that I can withdraw from the study, without repercussions, at any time, whether before it starts or while I am participating.

I understand that I can withdraw permission to use the data within two weeks of the interview, in which case the material will be deleted.

I understand that anonymity will be ensured in the write-up by disguising my identity.

I understand that disguised extracts from my interview may be quoted in the thesis and any subsequent publications if I give permission below:

(Please tick one box:)

I agree to quotation/publication of extracts from my interview

I do not agree to quotation/publication of extracts from my interview

Signed…… Date……

Appendix 6: Interview request letter



University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

15th May, 2015

Dear Research Participant,

Request for a research interview on Fabrication or Induction of illness in older people by Carers

First and foremost we would like to extend our sincere gratitude for having responded to our pre-interview letter on fabrication or induction of illness in older people by carers.

Your response showed that you meet the criteria to be interviewed for this study and we would like to invite you to participate in an interview. We really appreciate your participation in this study as there are few people with knowledge on this topic and we would value your input. If this is acceptable, kindly let us know if you are available on 25th, 26th, 27th or 28 May 2015 and what time you could be interviewed.

We would appreciate if you could indicate your availability to:

Pauline Glavin,
Senior Social Worker,
"Age: Wisdom & Hope"
Room 6 - City General
6 Infirmary Road
Cork.
Email: Pauline.glavin@hse.ie

Attached is an information sheet on the same as well as a consent form to be signed should you accept to be interviewed.

Looking forward to your response.

Esther Ngambi
UCC Masters Student

114220383@umail.ucc.ie

Pauline Glavin
Age: Wisdom and Hope

Pauline.glavin@hse.ie

Appendix 7: Copy of gratitude letter



University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

9th May, 2015

Dear Colleague,

Responses to the questionnaire / check list on fabrication or Induction of Illness in older people by carers

This letter serves to thank you for your time and effort in responding to our recent pre-interview letter on fabrication or induction of illness in older people by carers. Your responses on the subject were much appreciated.

Thank you very much.

Esther Ngambi
UCC Masters student

114220383@umail.ucc.ie

Pauline Glavin
Age: Wisdom and Hope

Pauline.glavin@hse.ie

Appendix 8: Elevator pitch

Fabrication or Induction of Illness in Older people: Does it exist?

- My name is Esther, a UCC Masters student undertaking community-based research in collaboration with 'Age: Wisdom and Hope' on fabrication or induction of illness in older people by carers. We are looking to interview people who know something about this subject area.
- The main aims of this research are: (a) to find out whether fabrication or induction of illness in older people exists and (b) whether there is an assessment tool to protect victims or potential victims (from abuse by carers) at the hand of carers.
- The research does not necessarily involve looking at elder abuse in general but a particular maltreatment which is often difficult to identify. It(but) can include(s) falsifying illness or inducing illness, promoting sick role by exaggeration, presenting made-up signs and symptoms for medical (intervention) care, while pretending to be unaware of the cause, the use of physical restraint and over medication to control behaviour in older people.
- This research project if supported can help gather information on the (topic) situation, as well as inform policy and practice and protect older people from this form of maltreatment**.**
- **If you have any information or know someone who does, you can contact me on** 0899730701 / 0894239175, email: 114220383@umail.ucc.ie or Pauline Glavin on Pauline.glavin@hse.ie.

Thank you!

Appendix 9: Copy of pre-interview request letter



University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

9th April, 2015

Dear Colleague,

Research on Fabrication or Induction of Illness in Older People by Carers

A group of professionals called '**Age: Wisdom and Hope**' of Cork County in partnership with a Master of Science in Social Policy student at University College Cork are working together to carry out a research on fabrication or induction of illness in older people by carers. This is commonly referred to in children as Munchausen Syndrome by Proxy.

This research is about a particular maltreatment of older people which is often difficult to identify. It includes falsifying illness or inducing illness in older people, promoting sick role by exaggerating and presenting made-up signs and symptoms for medical (intervention) care, while pretending to be unaware of the cause.

As part of the requirements is to gather information on this topic, interviews will be conducted. This letter therefore, seeks to find out if you have experience of or information on fabrication or induction of illness in older people by carers. It is also a way of identifying professionals to be interviewed.

Attached is a check list of the kind of information we will be looking for. We would appreciate if you could complete the appropriate boxes on the attached table and add any comments. This will indicate your knowledge of the existence of fabrication or induction of illness in older people by carers.

Please mail to: Pauline Glavin,
Senior Social Worker,
'Age: Wisdom & Hope'
Room 6 - City General
6 Infirmary Road
Cork

By providing this information the team will structure appropriate data collection instruments for the research. The purpose of this research is to: protect older people from this form of maltreatment; provide more knowledge and literature to all people working with older people and to inform policy and practice in Ireland.

Looking forward to your response.

Esther Ngambi
UCC Masters Student
114220383@umail.ucc.ie

Pauline Glavin
Senior Social Worker
Pauline.Glavin@hse.ie

Appendix 10: Pre-interview checklist

Name: _____ **Job Title:** _____

Address: _____

_____

Phone: _____ **Email:** _____

Fabrication or induction of illness (FII) in older people (65 and above) by carers, information checklist

NO.	**Type of information being sought; are you aware of any case where the following is happening or happened?**	**Experience or knowledge of FII (score √ or X where applicable)**	
		√ / X	**Any comment?**
1.	The perpetrator (carer) intentionally produces or feigns physical or psychological signs or symptoms in the older person in his or her care		
2.	The carer promotes sick role in the older person		
3.	Unexplainable, persistent or recurrent illness in the older person		
4.	Discrepancies in the history and clinical findings in the older person		
5.	Symptoms and signs in the older person only occurs in the presence of the carer		
6.	The carer is extremely over attentive and visits or calls constantly		
7.	The carer appears more worried about treatments and staff intervention than the older person themselves		
8.	The carer falsifies specimens of bodily fluids		
9.	The carer forces the older person to appear disabled		
10.	The carer attempts to diagnose what is wrong with the older person		
11.	The carer overmedicates the older person		
12.	The carer undermedicates the older person		

Signature: _____Date: _____

Appendix 11: copy of FII presentation

Fabrication or Induction of Illness in Older People by carers.

Dissemination of findings

By Pauline Glavin (Age: Wisdom and Hope) and Esther Ngambi (UCC Master of Social Science-Social Policy) Student

Held in UCC, ORB, building, GO46

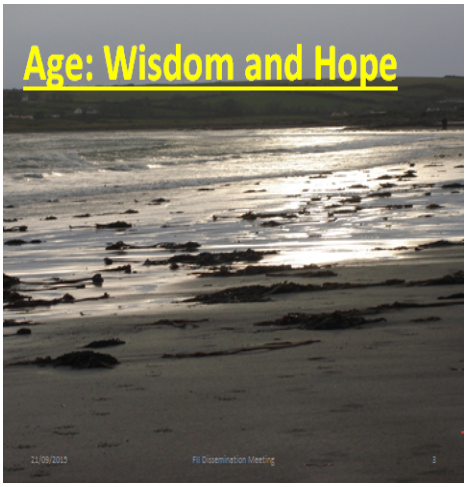
21st September, 2015

21/09/2015 FII Dissemination Meeting 1

Outline

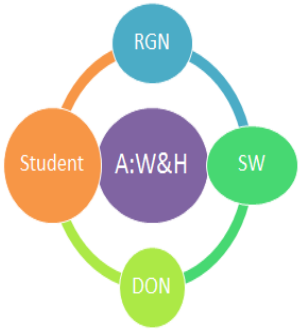
- Age: Wisdom and Hope and linkage with CARL
- What is FII in older people?
- FII background information
- Why is it important
- Aims and research questions
- Methodology
- Findings
- Limitations
- Recommendations
- What has been jointly done so far
- Way forward (What Age: Wisdom & Hope, will do)
- Conclusion

21/09/2015 FII Dissemination Meeting 2

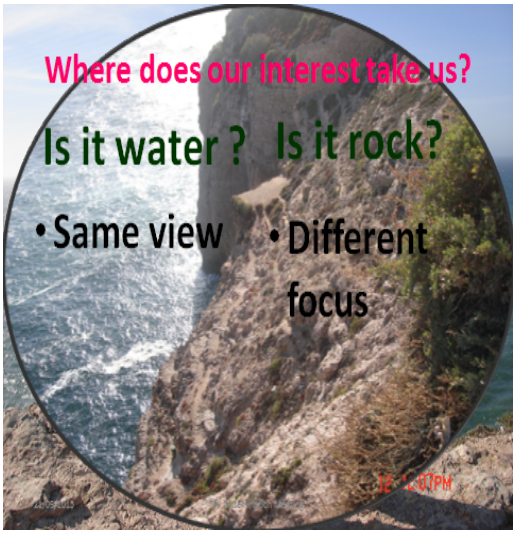


21/09/2015 FII Dissemination Meeting 3

Same interest – different perspective



21/09/2015 FII Dissemination Meeting 4



Age: Wisdom & Hope

- Questions > Frustration >Creation
- Different Views >seeking knowledge
- UCC Kenneth >CARL
- UCC >CARL >Esther
- Esther > FII Thesis
- FII Knowledge >Knowledge Explosion
- =
- Improve the life of the Vulnerable person

21/09/2015 FII Dissemination Meeting 1

What is fabrication or induction of Illness

Fabrication or Induction of Illness in Older People (65 and above) is an extraordinary type of abuse in which carers (Spouse, family, member, companion, professional or non professional worker) exaggerates, invents or induces illness in an older adult under their care in order to gain attention or praise for helping them (Bennet, 2007).

Background

FII

- Formerly & still commonly known as Munchausen Syndrome
- Devised by a Germany officer, Baron Munchhausen born in 1720
- Rekindled in 1951 by Dr Richard Asher to describe adults who fabricated illness in themselves
- In 1977 Dr Roy Meadow described 2 cases involving children
- Since then a number of reports have been published involving children (Frye & Feldman, 2012)

Aims

1. To establish whether FII in older exist.
2. To ascertain a body of literature in Ireland and Internationally.
3. To identify what signs, symptoms and behaviours constituted FII in older people.
4. To find out what setting FII was most likely to take place.

Research questions

1. Does FII in older people by carers exist in Ireland and Internationally?
2. In what setting does it exist & what are the motivating behaviours?
3. How can FII be identified by professionals?
4. What policies Best practice or legal framework are available?

Methodology



How did we arrive at the Sample Size?

- Co-developed an elevator pitch, pre interview checklist and letters.
- Over 50 letters sent throughout the country to professionals working with older people.
- 21 responses received and 8 were selected using the checklist i.e. 6 to 12 on tick list meant yes, while 3 to 5 unsure and 0 to 2 was a definite no.
- Wrote letters requesting the 8 to be interviewed and the Age: Wisdom schedule the interviews
- Co-developed interview guide and recorder used.

Population and sample size

Profession	Yes	No	Unsure	Total
General Practitioners (GP)	1	1	1	3
Social Workers	2	2	0	4
Public Health Nurses	1	4	2	7
Private nursing care facility & HSE facility	1	0	1	2
Clinical Nurse level 2	1	1	1	3
Home Help	1	0	0	1
Elder Care Management	1	0	0	1
Total	8	8	5	21

Ethical considerations

- Gender not mentioned.
- Location not mentioned.
- False names used (where direct quotations were used).
- Obtained Consent.
- Provided information sheet.

Findings

Participants views on FII and elder abuse

- ***It's a very thing line***. (Lucy)
- ***Elder abuse is any form of mistreatment of an elderly individual that cause them any form of distress and it can be anything.*** (Rose)
- ***Elder abuse for me its usually they are hiding from an audience, its sneaky stuff, cruel staff behind the scenes.*** (Maggi)
- ***It could be considered less deliberate as against what I might term straight forward elder abuse or neglecting and humiliating or physically abusing an elderly person.*** (Julie)

FII in older people (some views from participants)	Elder abuse
• Has an audience, e.g. perpetrator presents signs and symptoms in an older person to a medical practitioner	• Hides from an audience, • Done behind the scenes • Most hidden form of abuse • Identifiable
• Need to maintain a good self-image • Attention seeking	• In rare circumstances is the motive attention seeking or maintenance of good self.
• Has light on	• Has light off
• Difficult to provide evidence	Proof may easily be establish

Does FII in older people exist? Results from search strategy

- Leading and relevant data bases searched such as JSTOR, Scopus, Web Science, PubMed, Oxford Journal Search, Google Scholar and Science Direct.
- Found many articles in children.
- 13 cases of FII in adults aged 19 to 82 out of which 6 were related to FII in older people aged 65 and above.
- Of the 6 cases 2 were from UK, 1 from Israel, 1 from Australia, 1 Poland and 1 from France, which was in French and not accessible.

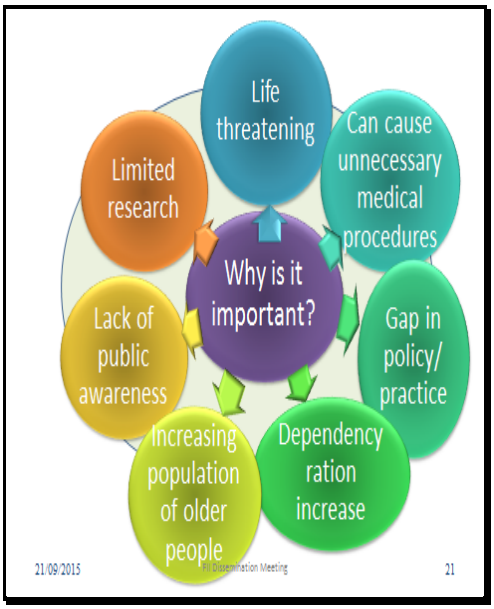
Published FII cases in Older People

1. The case of a 69 year old man referred to 25 different medical teams over a four year period (Smith& Arden (1989)
2. A 73 year old woman with multiple myeloma (Ben- Chetrit & Melmed, 1998).
3. An 80 year old woman with syncope (Chodorowsk *et al.*, 2003)
4. A case of an 82 year old woman (Strubel *et al.*, 2003) [in French].
5. A 71 year old man with a 16 year history of recurrent episode of stupor and coma (Grannot *et al.*, 2004).
6. 79 year old who suffered from dementia for 3 years (Singh *et al.*, 2013)

The case reports were in medical related journals and not formal studies.

Participants views on existence of FII

- 5 out of 8 participants were very sure it exists.
- 3 were unsure though they did not dismiss its existence.
- Based on participants views and available literature, this study suggest that FII could exist and is a possibility but the evidence is weak as no formal studies are available and there is very little information on it including how to recognise and diagnose it.



Why is it important?

FII

- Persons aged 65 in 2011 in Ireland was estimated at 535,393, an increase of 14.4% from 467,926 in 2006.
- CSO projected an upward trend from 16.4 % to 25.1% of persons aged 65 and above who would depend on persons aged 15 to 64 years for their daily existence (CSO, 2011).

Setting: what is known about the setting?

- All participants said FII in older people would happen anywhere (family, day/ residential care setting, geriatric ward, hospital) depending on the situation of individual older people.
- Therefore the study suggest that FII in older people should not be viewed as a health or medical issue alone as these were not the only settings in which older people received support.

Motivation of perpetrators

- Most participants said the motivation was, attention seeking, self praise, being seen as a good carer.
- 2 of the 8 participants could not rule out external motives such as financial gain and in-kind benefits due to the recession.
- This study suggest that motivation can be varied and complex and there is need for research on economic gain on FII in older people.

Participants views on identification of FII in older people

- Some participants thought FII was difficult to identify. ***With great difficulty, it might not be recognised sometimes; it would depend on how well professionals know the person***. (Joan), ***I don't think I could be able to tell until something has happened and then unfortunately***. (Maggi)
- Others thought it was easy: ***Its very easy, its whether people want to recognise it or want to do something about it***. (Jane). ***Its not common and I think because its not common its actually identifiable for people who work with the elderly***. (Hope)

Participants views on Signs/Symptoms in older person

- Fear of losing carer
- Fear of nursing home
- Pretending to be ill
- Having medically unverified conditions/ recurrent illnesses
- Looking to the carers for responses/ seeking approval from carer for responses and actions
- Moving from one nursing home to another or one hospital to another or one institution to another.

Behaviour, signs and symptoms in carer- participants perspective

- Imposing conditions on care.
- Over medicating victim/ withholding medication.
- Interfering with treatment or treatment plan adherence failure.
- Over feeding/ under feeding.
- Direct or indirectly encouraging signs and symptoms.
- Exceptionally attentive.

Signs in carer continued….

- Obstructing medical process and over involvement in the process
- Question and resisting effort to help, not taking professional advice or ignoring advice.
- Persistent complaints
- Over caring, over protective, over concerned (going beyond ordinary concern)
- Aggressiveness toward professionals
- Lying about victim's health
- Always the one speaking

Do perpetrators have mental health challenges

- *"No I don't think it's a mental health issue, I think she is somebody that had worked in a nursing capacity for a number of years and she is somebody that wants to have a role."* (Lucy)
- *"Well that fella definitely had a mental health issue. I had never got a diagnosis of him"* (Jane)
- *"I just think that, that woman had ulterior motives and not necessarily related to mental health at all."* (Mary).

- "In some occasions a carer may not fulfil the criteria for compulsory psychiatric diagnosis and treatment and there is limited evidence for efficacy of psychiatric interventions for perpetrators" (Singh *et al*., 2013, p. 180, talking about older people).
- In children, Bass and Glaser (2014, p.1414) said: "in view of diverse motivations, caregivers have no one profile of behaviour, personality, or psychiatric disorder and no psychiatric diagnosis exits for Munchausen Syndrome by Proxy." While Pinto and Walsh (2015, p. 1) argue that the perpetrators' behaviour was not due to another mental disorder."

Policy, best practice or legal framework- participants views

All participants said there was none related to FII in older people:

- ***We have nothing legal for elder abuse locally not to mention for FII, the same legislation applies to all.*** (Mary)
- ***We have nothing like that, not that I know of in the care of the elderly.*** (Rose)
- ***To my knowledge FII isn't specifically mentioned in policies we have in the general sense of protecting somebody. We have various categories of elder abuse and FII isn't specifically listed.*** (Julie)

So what do professionals do?

- ***I think everybody manages it differently, nothing specific.*** (Jane)
- ***I suppose what there would be, would be referral pathways only***. (Hope)
- ***If you know certain things and I know certain things, then we work together. Most of the things we do on FII will just be our opinion or something we have picked up or worked on, on that occasion and I don't see that there is any specific guideline.*** (Mary)
- No policy reflect FII and there are no guidelines to help professionals who suspected it.

'Surprises'

- "*Greed is a terrible thing and if there is secondary gain, they may do it, especially now with the recession and the carer's allowance pays a lot so if it all helps to get the carer's allowance for a family who may not otherwise get it and if the person is out of work, it all helps,*" (Hope).

'Surprises'

- "*It is a love relationship, so it's hard to understand, but like this wife absolutely loved her husband, it seemed to me to be linked to a nursing role, she withheld some of his tablets, I don't understand why. But do you know the irony of the whole thing Esther? That the patients, just wanted to be with those people, that is really the saddest part of all isn't?*" (Maggi)

'Surprises'

- *"But you see there must be degrees of it (FII), I think that when you have Munchausen's by proxy, I don't think it is that you have a full blown, but you could have a very mild form of it (Maggi).*

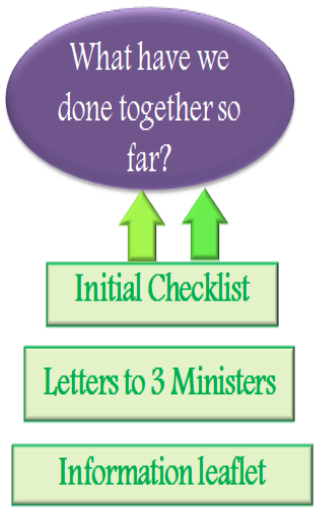
Limitations

- Time constraints. Some participants were not able to share as much information as they would have liked.
- Lack of a published case report on FII in older people in Ireland.
- Very few cases published around the world.
- No formal studies.
- One of the case reports on FII in older people was published in French and not accessible during the duration of this dissertation.

Some recommendations jointly done

- *"Awareness would be the most important thing."* Another added; *"we need a paper that is just easy to understand and distributed to every professional in the country."*
- *"I think we need to send a tick box say to GPs' annual conferences."*
- *"I would be very interested in further training on it, if there were courses on how to recognise it and deal with it."*

- *"some occupational health support services are needed for staff to see where they are at in their behaviour mentally."*
- It is recommended that institutions of care should utilised their Employee Assistance Programme (EAP) and should develop a programme of occupational health support services, specifically in relation to elder abuse including FII.





"Said a sheet of snow white paper..."

Said a sheet of snow white-paper, "pure was I created, and pure I will remain forever. I would neither be burnt and turn to white ashes than suffer darkness to touch me or the unclean to come near me"

The ink-bottle heard what the paper was saying, and it laughed in its dark heart; but it never dared to approach her. And the multicoloured pencils heard her also, and they too never came near her.

And the snow-white sheet of paper did remain pure and chaste forever- pure and chaste – and empty.

(Kahlil Gibran The Forerunner 1972)

THANK YOU ESTHER

Conclusion

- Does it exist? It is a possibility as weak evidence exists;
- In what setting? Can take place any where;
- What motivates perpetrators? Attention, seeking, self praise. A possibility of economic gain exists but insufficient evidence.
- How can FII be identified by professionals? Very difficult due to a lack of diagnosis (see back of leaflet on what to look for).
- What policies, best practice exists? None but FII could be incorporated in already existing policies as a possibility.

Thank you

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- Supervisor- Kenneth
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- Everyone who attended the dissemination meeting
- Thank you all!