ARCADA

PERCEPTIONS AND PERSPECTIVES OF PRIVACY

IN

INSTITUTIONALIZED ELDERLY CARE

A Literature Review

Mbole Elsie Ngwane

DEGREE THESIS	
Arcada	
Degree Programme:	Human Ageing and Elderly Services
Identification number:	7288
Author:	Mbole Elsie Ngwane
Title:	Perceptions and Perspectives of Privacy in Institutionalized Elderly Care
Supervisor (Arcada):	Maria Gustavson
Commissioned by:	Tuula Yliknuussi, Puolarmetsan Sairaala Osasto 4E

Abstract:

The need for long-term care services in the western world is rising due to demographic change. This has more often than not implied jeopardizing the privacy of elderly people as they move from their own homes in a familiar environment into an unfamiliar institutional care setting. This study aims at examining the different perceptions and perspectives of privacy as presented by the elderly patients and nurses/caregivers. The method of this study was systematic literature review of materials relevant to the study. Results from this study revealed that both nurses and elderly patients place more importance on certain dimensions of privacy (socio-psychological and informational) with less focus on others. On the socio-psychological dimension, issues like having one's own room and personal space were mentioned, autonomy, mutual understanding and respect between nurses and patients and also friendship and attention. On the informational dimension, the focus was on issues like informed consent before handling or disseminating patient information or details and confidentiality in the keeping of patient information and diagnosis. To conclude, there exists a strong relationship between age and control (autonomy) on one side and between age and dependence on the other side. With increase in age, people face privacy loss due to a higher need for care and increased dependence on others.

Keywords:	Care, Elderly, Finland, Nurse, Privacy, Sweden
Number of pages:	56
Language:	English
Date of acceptance:	

OPINNÄYTE	
Arcada	
Koulutusohjelma:	Ihmisen ikääntyminen ja vanhustenpalvelut
Tunnistenumero:	7288
Tekijä:	Mbole Elsie Ngwane
Työn nimi:	Käsitykset ja näkökulmat yksityisyydestä vanhusten laitoshoidossa
Työn ohjaaja (Arcada):	Maria Gustavson
Toimeksiantaja:	Tuula Yliknuussi,Puolarmetsan Sairaala,Osasto 4E

Tiivistelmä:

Tarve pitkäaikaisille hoitopalveluille länsimaailmassa kasvaa väestörakenteen muutoksen takia. Yhä useammin tämä epäsuorasti vaarantaa vanhusten yksityisyyden kun he muuttavat omista kodeistaan tutusta ympäristöstä tuntemattomaan laitoshoitoon.Tämä tutkimus tähtää tarkastelemalla erilaisia käsityksiä ja näkökulmia yksityisyydestä jotka vanhukset ja hoitajat ovat esittäneet. Menetelmä tälle tutkimukselle oli systemaattine kirjallisuuden tarkastelu jotka olivat asiaankuuluvia tälle tutkimukselle.Tulokset tästä tutkimuksesta paljastavat että molemmat sekä hoitajat että vanhukset asettavat enemmän tärkeyttä tietyille yksityisyyden osa-alueille (sosiaalipsykologialle ja informaatiolle). Sosiaalipsykologisilla osa-alueilla, asioilla kuten jollakin on oma huone ja henkilökohtaista yksityisyyttä ovat mainittu, autonomia, keskinäinen yhteisymmärrys ja kunnioitus hoitajien ja asiakkaiden välillä sekä ystävyys ja huomioonottaminen. Informationaalisilla osa-alueilla keskitytään asioihin kuten tietoinen suostumus käsitellä ja levittää asiakkaan informaatiota tai yksityiskohtia ja luotettavuutta säilyttää asiakkaan informaatiota ja diagnoosia. Lopuksi, on olemassa vahvoja suhteita iän ja kontrollin(autonomian) välillä ja toisaalta iän ja riippuvuuden.

Avainsanat:	Hoito, Vanhukset, Suomi, Hoitajat, Yksityisyys, Ruotsi
Sivumäärä:	56
Kieli:	Englanti
Hyväksymispäivämäärä:	

TABLE OF CONTENTS

TABLES

FIGURES

FOREWORD

1   INTRODUCTION

Due to the fast increase in the number of aged people in the western world, the need for long-term care services cannot be over-emphasized. This has more often than not implied jeopardizing the privacy of elderly as they move from their home in a familiar environment into an unfamiliar care institution setting (Schopp et al, 2003). Privacy is the state of being free from intrusion or disturbance in one's own life or affairs. In the area of care, it usually includes not releasing medical information about clients without their consent. There is usually a discrepancy in the perceptions of privacy between nurses or caregivers on one hand and clients/relatives on the other. The expectations of the clients and their relatives are usually too high especially in care institutions where they basically have to share almost everything with fellow clients. The level of respect for privacy has been lowered most often by the lack of resources and means in care institutions which usually have a routine pattern of care. Perceptions of privacy are the most conflicting of ethical issues amongst caregivers and clients' relatives. Other ethical concerns are autonomy and self-determination. This study will concentrate more on the privacy of elderly people while being in long-term institutional care. The concept of privacy is multi-dimensional as it covers physical, social, psychological and informational issues. Maintaining the level of needed care and the respect for privacy poses one of the biggest challenges faced by nurses and caregivers, especially in the face of inadequate resources and means in relation to the amount of elderly people needing institutionalized long-term care.

1.1   Background (problem statement)

As people age, they experience privacy loss due to health care needs particularly in nursing homes. Consequently, balancing care giving of elders with respect for privacy boundaries represents a challenge to health care providers (Petronio and Kovach 1997).In order to accept the care from others, elderly people have had to give up their privacy especially as they have to move from their home to a care unit, having to share a lot with other patients or residents. Previous studies on privacy confirm that female patients always feel more violation of their privacy than males while elderly also perceived more violation than younger patients (Bauer 1994, Parrott et al.1989).On the part of the nurses and caregivers, it has been realized that

those who are part time workers compared to those who are full-time workers have a positive attitude towards the maintenance of patients' privacy. Those who are better educated also have a faster way of responding to social pressure than the less educated. Most often people think of privacy only in terms of their bodies being exposed but the lack of privacy is related to handling of patient information, residents not being able to be alone when they feel the need to do so. There have been differences in the perceptions of privacy needs between patients and caregivers as caregivers seem to overestimate the needs of the patient and have also misjudged the patients' feelings and psychosocial needs (Mowinski and Muhlenkamp 1981). Finding a suitable balance where the care is given while taking into account the privacy of the patient is usually not an easy task for the caregivers. A form of collaboration has had to be made between the nurses and the patients/relatives. This study will look at the ways in which this balance is made in providing the much needed care to the patients/residents while respecting their privacy perceptions. It will also evaluate the expectations on privacy shown by the patients and their relatives in relation to how the care process is carried out.

1.2 Objective of Study

The aim of this study was to examine different perceptions and perspectives of privacy of the elderly in nursing homes in Finland (and Sweden). The perceptions and perspectives on privacy have been thought to be affected by socio-demographic factors like age and gender and the social status of the elderly (whether the person had been living alone or with someone).Other factors like education and previous experiences also affect patients' perceptions of privacy. The educational level of the caregivers, the type of job they have, full-time or part-time also determines the way they will take issues of privacy into consideration and react to social pressure. The privacy of patients has always been assessed with stereotypes by nurses (Farrell 1991). Patients usually feel that their privacy is violated when nurses forget to close the door when the patient goes to use the lavatory or when their dignity is not respected when they are being assisted with personal hygiene. Patients usually expect that their private matters should not be discussed within the hearing of other patients and that their medical records will not be left in public places. Intimate examinations should also not be carried out in open view of others, if so they constitute a severe violation of patient's dignity. Nurses and caregivers are often caught between the conflicting interests of their patients who wish to main-

tain their privacy and caregivers who feel a legitimate right to have their privacy respected or taken into account. Therefore, the nurses have the obligation to carefully balance the interests of the patients and their relatives on one hand and the nurses/caregivers on the other.

1.3   Research Questions

The research questions guiding this study are:

- - What are the most discussed issues on privacy for the elderly patients and care givers in nursing homes?
- - What recommendations are presented in the articles when it comes to improving respect for patients' privacy?

1.4   Scope of Study

The scope of the study is such that it will cover privacy related issues in nursing homes in Finland and Sweden. How much privacy related issues are considered during the planning and provision of care and also factors in the structure of nursing homes that make it a bit difficult to maintain a high level of privacy like the living arrangements. The structure of the thesis is such that the next section will highlight the theoretical background of the work with in-depth explanation of the definition of privacy and its dimensions in health care sciences as well as issues related to the law and policy of privacy and previous research conducted in the area of privacy. Thereafter in Section 3, the methodology used in the study is outlined. Literature review is the main method used but this section will present the criteria for selecting the data, keyword and strings used in searching the Web of Science database to obtain scientific articles and a short presentation of the articles selected for systematic review and analysis for this study. Synthesised results in section 4 to capture the perspectives of both the elderly patients and the care givers- the nurse in this case and possible areas of overlapping concerns for both parties. In section 5, the results will be discussed in details. It will include further analysis of additional articles to either support, challenge or provide recommendations based on the findings of the study while the conclusions and recommendations are discussed in section 6.

1.5   Significance of Study

This study will generate information that will help care professionals improve on the respect of clients' privacy. It will also emphasize the importance that the elderly attach to their privacy as human beings in nursing homes. It will take a look at the various issues that patients/relatives consider to be a part of their privacy and when they feel it is violated or not respected. The ways in which nurses and caregivers strive to put a balance between the expectations of the patients/relatives and the caregivers will also be examined. Practices in nursing homes and institutions that do not take the privacy perceptions of the elderly patients and their relatives into consideration will also be looked into and ways of enhancing the level of privacy maintained during the care process provided .The information gotten from this study will also help nurses and caregivers in their quest of making nursing homes as hospitable as the homes of the patients themselves so as to curb the feeling of deprivation that usually arises when an elderly person has to be transferred from his or her own home to a nursing institution or home. Results from this study will help foster nursing ethics as it will enrich the already existing ethical boundaries which shape the practice of care and nursing as a whole.

1.6 Limitations of Study

This study was faced with methodological limitations. A systematic literature review should have been very vigorous if the study should have concentrated on many more articles as opposed to the limited number that has been used in the study. Also, the overlap that exists among the concepts of privacy, identity, autonomy and self-determination have made it impossible to talk strictly on privacy but other concepts or phenomena related to privacy.

2 THEORETICAL FRAMEWORK

2.1 Definition of Privacy

The word "privacy" has been defined in many different ways by a variety of authors and institutions. In some dictionaries, privacy is defined as withdrawal from public view or company and one's private life. It can also be defined as the state of being free from intrusion or disturbance in one's own life or affairs. The Oxford English dictionary refers to privacy as a state in which one is not observed or disturbed by others. Westin (1968) and Altman (1976), defined privacy as the voluntary and temporary withdrawal of a person from the general society by physical or psychological means. In the Wikipedia online dictionary, privacy is the ability of an individual or group of individuals to seclude themselves or information about themselves and thereby revealing it selectively. Privacy can also mean confidentiality, seclusion or secrecy. According to Clarke (2006), privacy is an individual's interest in sustaining a personal space, free from interference from other people or groups. The European Commission for Human Rights 1976, looked at privacy as the right of a human being to live as far as one wishes protected from publicity and to a certain degree the right to establish and develop relationships with other human beings. Privacy is the claim of individuals, groups or institutions to determine for themselves when, how and to what extent information about them is communicated to others (Westin 1968).

Privacy is an outcome of a person's wish to withhold from others certain knowledge as to his past and present experience and action and his intentions for the future. Parker (1974) defined privacy as control over when and by whom the various parts of us can be sensed by others. Altman (1975) saw privacy as selective control of access to the self or to one's group. Privacy International (2004) gave the definition of privacy as a way of drawing the line to how far the society can intrude into a person's affairs. Jourard (1966) claims that privacy is a person's wish to withhold from others certain knowledge as to his past or present experience and actions and to his intentions for the future while Bates (1964) says that privacy is a person's feelings that others should be excluded from something which is of concern to him while also recognizing that others have a right to this feeling too. Robertson (1973) on his part explains that privacy is an individual's interest to be protected against any intrusion into his intimate life and into any part of his existence which he might legitimately desire to keep to himself

including the protection against intrusion into his private affairs, public disclosure of private facts and against publicity. Mark Hughes (2004) argues that privacy does not mean a complete withdrawal from the public world but a claim to a partial and controlled withdrawal.

2.2 Basic Assumptions of Privacy

The concept of privacy is full of basic assumptions as people try to get a clear meaning of the concept in its entirety. Privacy is always assumed to mean confidentiality or vice versa (Heikkinen et al. 2005). Most people define privacy only in terms of the body forgetting about issues related to the release of information and respecting personal boundaries in interaction situations or relationships. Privacy in health care is highly subjective. It means different things to different people at different times and in different ways and places. Privacy for many people represents an ideal level of interaction with others, of how much or how little contact is desired at any given moment (Altman 1975). The privacy of an individual is a dynamic process. This dynamism changes the content and degree of privacy overtime, making people to seek an optimum balance in privacy that is neither too much nor too little (Westin 1968). We loose part of our personal defense every time we allow someone to penetrate our privacy. On the other hand, the construction of successful relationships is possible if we expose ourselves (Koller and Hantikainen 2002). London (2005) points out that the respect of privacy in occupational health services is based on the perception that health professionals are able to meet the requirements of legislation and ethical standards in professional conduct and will not misuse the power society confers on them.

2.3 Dimensions of Privacy in Nursing Homes

The concept of privacy is very broad in nature as it engulfs physical, social, informational and psychological aspects. These aspects overlap and involve social practices that need to be understood within specific contexts. Care givers and health care institutions should therefore map out the terrain of privacy by examining specific problematic situations (Solove 2002).

2.3.1 Physical Privacy

The physical dimension of privacy, according to Schopp et al. (2003), relates to an individual's need for personal space and territory. Personal space describes an area or a protection zone that separates one person from another and territory combines both the physical space and human behaviour giving people the opportunity to be alone. Lyman and Scott (1967) identified three types of territory invasion: violation, invasion and contamination. Violation refers to unwarranted use of another's territory for example entering a patient's room without permission or knocking. Invasion refers to entering the patient's territory and thereby changing the meaning of that territory for instance a nurse being a member of a patient's social group. Contamination in this case refers to rendering the territory impure for instance a nurse smoking in a patient's room.

The need for personal space differs from one individual to another depending on the age, gender or social and health status. According to Tanner, (2008), patients in nursing homes often experience a violation of the need for their own territory. In spite of the need for personal space and territory, patients are rarely able to claim an absolute area of the nursing facility to be their defined territory. At times patients succeed in mapping out a fixed area to call their own like the lounge or a dining room, though such claims usually are violated by nurses and caregivers. The interaction between the patient and the nurse in relation to space is also considered under the non-verbal communication of touch. Touch, according to Tutton (1991) is not only the outward physical contact between two people but includes the transfer of feelings and energy between two or more individuals .Touch however has particular significance in nursing practice and is a specific form of therapeutic intervention. According to Jones and Yarbough (1985), it can communicate different messages that might indicate a positive emotional effect between two people of close relationship. Touch can also communicate playfulness and in this case lightens the emotion of an interaction. On the other hand, touch can communicate control and dominance that directs the behaviour, attitude and feeling of another person.

In nursing practice, some of the touch is related to performance of functions and tasks by the nurse. Tutton (1991) further divides touch in nursing practice into; instrumental, expressive, therapeutic and systematic categories. Instrumental touch is often related to the performance of nursing related tasks. Tutton considers that there are many other forms of touch which are

associated with the enhancement of patients' wellbeing. Nurses, however have quickly socialized into using the limit of touch to the instrumental. The ward layout and furniture, the patient's condition, cultural background and the personality of the nurse and the patient are additional factors that may also limit the use of touch in nursing to the instrumental.

Expressive category of touch has a therapeutic benefit to patients. Tutton argues that touch affects people's feeling of values and worth. It communicates comfort, love and security as well as enhancing patients' self esteem and it facilitates their recovery and acceptance of a particular diagnosis. Therapeutic category refers to the use of hands to direct human energies to help or heal someone. It is based on the assumption that there is a universal life energy that sustains all living organisms. The practice of therapeutic touch involves communication between the practitioner and the patient at a fundamental level which is that of energy. Systematic category of touch is seen as being synonymous with massage. It involves the purposeful manipulation of the soft tissue of the body with the intention of enhancing the receiver's sense of wellbeing.

Despite all the positive interactive aspects of touch between the patient and the caregiver, there is a dark side to touch which grossly invades the privacy of patients in nursing homes. Touch can be one of the main ways in which sexual misconduct occurs in nursing homes. A nurse may touch the patient inappropriately or unnecessarily thereby violating or intruding into the physical privacy of the patient. According to Aucoin and Lane (2004), invading someone's personal space can be a "touchy" subject, even in spending time with patients or giving them a back rub which are essential components of care giving. Considering when you should touch, how often, whom and what you can touch will go a long way in respecting patients' physical privacy. Not only touching involving the patient's body is considered violation or intrusion of physical privacy as a patient's personal belongings which have been brought into the nursing facility also form part of his or her personal space so consent has to be sought before touching or going through them.

Touching when this is not needed is also considered intrusion of personal space and should be avoided in nursing homes. When personal space is invaded, it can give rise to violent behaviour. Residents in nursing homes usually feel that their privacy has been violated in issues connected with personal hygiene and elimination as well as when too many have to share the sleeping space or when it becomes impossible to spend time alone due to the archi-

tectural design of the nursing home building. De Vito (1991) suggested different reactions to territorial encroachment that may include withdrawal, in which case the nurse can leave the territory; turf defense where the patient will not allow the nurse to enter his or her territory and will attempt to expel the nurse. In addition to reactions to territory encroachment, personal territory can be marked out. Hickson and Stacks (1989) identified three types of markers; central, boundary and ear markers. Central markers are items placed in order to mark the territory of a patient e.g. their names on the door or on the locker to let others know that the territory belongs to a particular patient Boundary markers divide the territory of one patient from that of others e.g. the curtain between two beds while ear markers identify patient's possession of a territory or object such as the initials of a patient's name on clothing, watches and certain appliances like a hairdryer. In nursing homes, physical privacy dwells on the physical and social construction of the nursing home in general and the rooms in particular. Curtains are usually used to provide some form of visual privacy but these fall short of preventing overhearing discussions or conversations.

Physical privacy can also be the extent to which one's body is physically accessible to others and the public (Hughes 2004). Today's powerful online networks can cause high-tech challenges for hospitals and nursing homes bound by the legal and ethical duty to safeguard their patients' privacy. In a recent case that provoked public outrage, for example, three staff members at Bremerton's Kitsap Health and Rehabilitation Center in the USA were fired after swapping by cell phone nude photos of residents of the nursing home as a joke (Poterfield 2011).

2.3.2 Social Privacy

The social dimension of privacy usually involves the ability of an individual to control his or her social contacts. Elderly people usually show a need to be alone without any companion. A typical example is seen in the way meal times are arranged as everyone has to eat at the same time irrespective of one's own needs thereby other residents have had to witness the eating habits of others. Communication patterns between nurses and residents may either violate or respect a patient's privacy. Hughes (2004) also includes the management of social contacts including control over participants, length and content of the interaction. In an actual nursing home setting, social privacy is ensured by knocking on doors of patient rooms before

entering or informing the patient by phone in advance before going into the room which is considered their personal space.

The quality of relationships that exist between the nurses and their patients and also the level of trust define the extent to which social privacy is respected. Interactions in nurse-client relationships are characterized by trust, respect, intimacy, and power (CRNNS 2002). It also defines how blurred the boundary between a health care professional and the patient is. The College of Registered Nurses of Nova Scotia in Canada (CRNNS 2002) argues that in order to focus on the person or persons receiving care, and to accurately evaluate the outcomes of care, registered nurses form therapeutic relationships with clients to: a) gain an understanding of the clients' needs for care; and b) create an environment in which care can be provided safely, effectively and ethically. In any professional-client relationship there is an imbalance of power in favour of the professional. This is caused by the professional's additional knowledge base and is reinforced, in health care services, by the inherent vulnerability of a client needing care. Health professionals must appreciate that these characteristics are the basis for their relationships with clients, and guide their professional actions and behaviors accordingly (CRNNS 2002). It is expected that in nursing homes, care givers and patients will encounter each other in the course of normal daily activities. However, social contact with patients may become risky when the care giver begins to perceive that relationship as "special" and beyond the range of providing adequate medical care (e.g., becoming "intimate friends") (Texas Medical Association 2011). Making special exceptions for certain patients (e.g., offering reduced fees for services, overlooking inappropriate behaviors) may also be an early indicator of problematic boundary violations. Making friends with patients blurs professional boundaries and there is a risk that patients' confidential health information and privacy can become public.

Healthy boundaries require trust. It respects both the nurse as a professional and the patient as a client. In such a respectful relationship, the client's human dignity, autonomy and privacy are safeguarded, and the registered nurse is recognized as a professional with certain obligations and rights (CARNA 2005). A critical element for resolving boundary issues is to set limits that respect both the client and the nurse. It is possible however, to be under-involved or over-involved in a nurse-client relationship, rather than helpfully and therapeutically involved (CARNA 2005). In a study entitled "danger signals in staff/patient relationship in the therapeutic milieu" by Coltrane and Pugh (1978), warning signs that professional boundaries of the nurse-client rela-

tionship may be jeopardized were listed and include: frequently thinking of the client when away from work; frequently planning other clients' care around the client's needs; spending free time with the client; sharing personal information or work concerns with the client; feeling responsible if the client's progress is limited; noticing more physical touching than is appropriate or sexual content in interactions with the clients; favoring one client's care at the expense of another's; keeping secrets with the client; selective reporting of client's behaviour (i.e., negative or positive client behaviour); swapping client assignments; communicating in a guarded and defensive manner when questioned regarding interactions/relationships with the client; changing dress style for work when working with the client; receiving of gifts or continued contact/communication with the client after discharge; denying the fact that the client is a client; acting and/or feeling possessive about the client; giving special attention/treatment to this client, which differs from that given to other clients; and denying that you have crossed the boundary from a therapeutic to a non-therapeutic relationship.

2.3.3   Informational Privacy

Though privacy and confidentiality are most often used interchangeably, privacy in itself deals with individuals while confidentiality deals with information. Therefore, privacy entails confidentiality as an important part. Informational privacy deals with the disclosure of personal information and confidentiality relating directly to the identity of an individual. It may also include the mode of collection of such personal information (Hughes 2004). This is usually protected by legislations and regulations which must be respected in care settings. Care processes involve a lot of demographic information which makes it absolutely important to have some degree of mutual trust between nurses and patients. In a situation where patients receive information about their diagnosis in the presence of others, violation of privacy has been reported. Patients in nursing facilities need to have access to their personal information and also be informed on the confidentiality processes that are carried out in the nursing home in which they are resident let alone the dissemination of their information to the public or others. To protect the public's right to quality nursing services, the College of Nurses of Ontario (CNO 2009 p.8-10) developed "The Standard of Care" related to informational privacy. This spells out the various ways in which nurses must act to enhance informational privacy in nursing homes as outlined in Table 1 below.

Table 1. Care standards and their indicators related to informational privacy in nursing homes (College of Nurses of Ontario, 2009)

Standard	Expectation	Indicators
Personal health information practices	Nurses must explain to the client that information will be shared with the health care team whose members are obliged to maintain confidentiality	- Seeking information about issues of privacy and confidentiality of personal health information; - Maintaining confidentiality of clients' personal health information with members of the health care team who are also required to maintain confidentiality including documented or electronically stored information; - Maintaining confidentiality after the professional relationship has ended, an obligation that continues indefinitely when the nurse is no longer caring for a client or after the client's death; - Ensuring clients or substitute decision-makers are aware of the general composition of the health care team that has access to confidential information; - Collecting only information that is needed to provide care; - Not discussing client information with colleagues or the client in public places such as elevators, cafeterias and hallways; - Denying people who are not part of the health care team access to personal health information; - Safeguarding the security of computerized printed or electronically displayed or stored information against theft, loss, unauthorized access or use, disclosure, copying, modification or disposal. - Not sharing computer passwords, ensuring that explicit consent has been obtained to keep a client's personal health information in the home; - Not using standard e-mail to send personal health information; ensuring that security-enhanced e-mail is effective before sending personal health information this way; - Using confidentiality warnings on facsimile cover sheets and in e-mail to instruct those

		who receive the information in error to destroy it immediately before reading it;
		- Communicating to the recipient of the information that a particular record is incomplete;
		- Advocating for policies and practices that ensure confidentiality during storage, transmission or transfer or disposal of personal health information, whether in hard copy or electronic form like e-mails and fax;
		- Complying with retention policies or advocating for these when none exist;
		- Ensuring that personal health information is destroyed in a way that protects the confidentiality of that information and;
		- Notifying the contact person within the practice setting when he or she becomes aware that there has been a breach of confidentiality e.g. personal health information has been stolen, lost or accessed by unauthorized people.
Knowledgeable consent and substitute decision-makers	Ensuring that clients are aware of their rights concerning their personal health information and have expressly consented to the collection, use and disclosure of information outside the health care team	- Obtaining the client's express consent before disclosing his or her information outside the health team like to family members or friends of the client; - Ensuring that clients are provided with an opportunity to withhold or withdraw consent to disclose their name, location in the facility and general health status; - Ensuring clients are provided with an opportunity to withhold or withdraw consent to disclose their name to a person representing his or her religious organization and also by seeking consent from the substitute decision-maker when the client is incapable of providing knowledgeable consent; - Indicators of this standard are that the nurse ensures that the custodian has provided written notice to clients about information practices and that clients are aware of their personal health information rights; and facilitating client access to information about care and treatment.
Potential for	When the nurse learns information that if not revealed	- Nurse considers if any harm may come to a client as a result of disclosure; - Reports the information as required by law;

harm	could result in harm to the client or others, he/she must consult with the health care team and if appropriate, report the information to the person or group affected	- Informs the client as appropriate when there is a duty to report the information to another agency or facility; - Providing the client with the opportunity to take action and report information when appropriate; - Informing the appropriate authority if the client does not take action and report information; - Consulting with the health care team when there are concerns about harm resulting from sharing information with a client.
Disclosure without consent	Nurses adhere to legislation that requires them to reveal confidential information to others	- Ensuring that clients or substitute decision-makers know that information may be used for purposes other than client care, such as for research or improvements to the quality of care; - Ensuring that those seeking access to information have the requisite authority before providing information e.g. police officers who request information have a court order ; - Seeking the advice of the contact person for privacy of health information before providing information.
Client's right to access and amend his/her personal health information	Nurses respect the client's right to see/obtain a copy of his/her health information or health file and to request correction to the information	- Nurse ensures that the custodian has provided written notice to clients about information practices and that clients are aware of their personal health information rights; and - Facilitating client access to information about care and treatment.

2.3.4 Psychological Privacy

Psychologically, people need to have a space of their own be it in public places or behind closed doors and curtains. Each and everyone needs to be able to look around and make personal judgments about others and things without the intrusion of other individuals. Psychological privacy thus is the control of cognitive and affective processes, the ability to form values and the maintenance of a personal identity (Hughes 2004). Wheelis (1958) defined identity as a coherent sense of self, based on the awareness that our endeavors and life make sense, that they are meaningful in the context in which we live our lives, with stable values and actions related to these values. In her paper, clarifying the patient sense of identity, Milstein (1971) defined identity as a sense of wholeness, of integration, of knowing what is right and what is wrong and that we are capable of choosing between them. The Eriksonian framework rests on three distinctive identities (Erikson 1978, Erikson 1979). The first relates to a psychological sense of continuity known as "the self" or ego identity. The second separates one person from the next, known as the personal identity while the third relates to a collection of social roles that a person might play, known as the social or cultural identity. A deficiency of any of these identities may mean an increase in the chances of an identity crisis, confusion or erosion of psychological privacy (Cote and Levin 2002). In a nursing home, the goal of psychological privacy is to prioritize residents'/patients' independence and identity expression through participation in community life both inside and outside of the home. Individual interests, customs, beliefs and ethno-cultural backgrounds are also valued and promoted. To facilitate psychological privacy, policy makers, care providers and researchers need to examine how older people maintain a sense of identity and home and how this might be threatened.

When patients in nursing homes especially those with dementia find that their mental abilities are declining, they often feel vulnerable, threatened and in need of reassurance and support. The people closest to them - including their nurses, health and social care professionals, friends and family - need to do everything they can to help the person to retain their sense of identity and feelings of self-worth (Alzheimer's Society 2011). It's very important that dementia patients are treated with respect because they are still a unique and valuable human being, despite their illness. Our sense of identity is closely

connected to the names we call ourselves. It's important that people address the person with dementia in a way that the person recognizes and prefers. Some people may be happy for anybody to call them by their first name or nickname. Others may prefer younger people, or those who do not know them very well, to address them formally and to use courtesy titles, such as Mr. or Mrs. Elderly patients' sense of identity is also linked to respecting cultural values. Nurses, health and social care professionals from different countries, culture and religious background should behave accordingly by taking into account the patients' background and culture. Issues to be considered may include respectful forms of patients address, what patients can eat, their religious observances such as prayer and festivals, particular clothing or jewelry that the person (or those in their presence) should or should not wear, any forms of touch or gestures that are considered disrespectful, ways of undressing, ways of dressing the hair, and how the person washes or uses the toilet (Alzheimer's Society 2011).

2.4 Health Care Privacy Law and Policy

2.4.1 Finland

In Finland, as in many other countries, the privacy of patients in nursing homes is covered by laws and policies that have been put forward to control the practice of nursing and health care (Finlex 2011, Ministry of Social Affairs and Health 2011). The Ministry of Social Affairs and Health in Finland is the governing body on issues of health care which formulates the laws guiding the practice and states the rights of patients to whom health care services are offered. The National Advisory Board on Social Welfare and Health Ethics as stipulated by Section 2 a (658/2009) operates in conjunction with the Ministry of Social Affairs and Health. This advisory board has as its task to deal at the level of principle with ethical issues relating to social welfare and health care and the status of patients and clients as well as to give out recommendations concerning these issues. According to No.785/1992, the Act on the Status and Rights of Patients, chapter 2 section 5, patients have the right to be informed about his/her state of health, the significance of the treatment administered, various alternative forms of treatment and their effects and also about other factors related to his/her treatment that are significant when decisions are made on the treatment given to him/her. This information however shall

not be given against the will of the patient or when it is obvious that giving the information would cause serious hazard to the life or health of the patient. Section 6 talks about patients' right to self-determination referring to the fact that care has to be offered in mutual understanding between the caregiver and the patient thus if the patient refuses a certain treatment or measure, he/she has to be cared for, as far as possible in other medically acceptable way in a mutual understanding with him/her. In the case where the patient cannot decide on the treatment due to mental disturbance or retardation, the legal representative or a family member or other close person of the patient has to be heard before making an important decision concerning treatment to assess what kind of treatment would be in accordance with the patient's will. Section 13 (653/2000) states that information contained by patient documents shall be confidential and should not be given to outsiders without a written consent by the patient. In case the patient cannot assess the significance of the consent, his/her legal representative's consent will be sought. The secrecy obligation expected from the health care workers remains in force after termination of the employment relationship or the job.

2.4.2 Sweden

In Sweden, laws regulating the provision of health care, like in Finland are formulated by the Ministry of Health and Social Affairs under the Health and Medical Services Act (1982:763) (Privacy International 2011, Swedish Patient Center 2011). Section 2a clearly states that health and medical services shall be founded on respect for the self-determination and privacy of the patient. Care and treatment shall as far as possible be designed and conducted in consultation with the patient. The patient shall be given individualized information concerning his/her state of health and the treatment methods available. Otherwise it will be supplied to a close relative. Processing of data concerning health so called sensitive data is prohibited and may only be done with the explicit consent of the patient or if he/she publicizes the information in a clear manner. Sensitive personal data may be processed for health and hospital care purposes only if this is necessary for preventive medicine and health care, medical diagnosis or health care treatment. The Health and Medical Services Act also promulgates legislations on professional secrecy expected from health care workers and professionals. All information received during care processes are confidential until proven otherwise by the patient or

his/her family member or close person. Same goes for information about an individual's state of health or other personal conditions. Personal data here includes information of where the person is receiving medical care, his/her address and telephone number, information about his/her ability or inability to work as well as his or her physical and psychological state. The aim of this professional secrecy is to ensure protection of the individual's personal interests and also to make sure that he/she is able to influence his/her situation.

2.5   Previous Research on Privacy

The concept of privacy in health care has been discussed by various researchers with viewpoints varying from one country to another. Petronio and Kovach (1997) give a caregiver's perspective on how privacy issues are managed in nursing homes in Scotland and how patients struggle to adapt from living in their own homes to living in nursing homes where almost everything is shared with someone. Petronio identified the way caregivers and elderly patients negotiate a relational privacy boundary when managing possessions and territory. It is always the duty of the caregivers to provide a balance between providing the much needed care to the elderly and respecting their perceptions of privacy. To Scottish elders, moving into a nursing home usually implies negotiating privacy with others as they have to share a common territory and space. Usually, privacy in nursing homes are always limited to certain areas of the building like the living space, space for personal hygiene, wheelchair and dining space as those are the main places (territories) that have to be shared with other patients in the care home. Their dependence on caregivers to provide basic hygienic needs also compromises their control over privacy (Lawton and Bader, 1970). Privacy in Scottish nursing homes has usually been defined in terms of occupancy of rooms but the findings from the study indicate that there is much more to privacy in a nursing home than just the room. The interdependent relationship that exists between the nurses and their clients is also emphasized as both depend on each other for a considerable maintenance of privacy control.

In a study by Koller and Hantikainen (2002), the meaning of privacy to psychiatric patients is explored as to what obtains in a Swiss psychiatric clinic. The results demonstrated that privacy is not a question of luxury but a very basic human right. Based on the findings of this study, the need for privacy correlates with that of safety and support shown by the patients in institutions. When the level of privacy is low, patients feel vulnerable. By entrusting oneself to the much needed care of others, it implies giving up all aspects of self control and autonomy. This study also brings out how necessary it is for patients to have close relationships with people and the environment as this enhances the level of trust and respect and also helps them to respect each other's privacy expectations. Patients who took part in the study expresses the desire to be alone at certain times not however implying not sharing their space with someone but having control and security and also a feeling of invulnerable privacy without any obligations. Koller and Hantikainen show how in Switzerland, people express different privacy expectations in their study with a predominant perspective from the patient. They conclude that privacy is connected with a need for protection and includes striving for more security, the protection of the person and his/her identity is an important factor in health care as well as protection of relationships that exist between patients and their caring staff.

The caring personnel often face a tough situation as patients always have high expectations of them being their confidant in maintaining the level of control and by implication privacy. Akpan et al (2006) discuss privacy especially in older adults with fecal incontinence in England as well as the differences in perceptions between those who live in their own homes and those in nursing homes. Findings from the study demonstrated that privacy during defecation was often less achieved in patients in nursing homes when compared to those in their private homes. Elderly people who are dependent on others for their care lack privacy as they are unable to clean themselves during defecation. Privacy in such a situation is defined as being left alone in a toilet or having the curtains pulled around one's bed during defecation in a nursing home. The caring staff face the challenge of striking a balance between ensuring privacy and minimizing risks of falls during defecation. Also, it would be difficult to achieve complete privacy when dealing with patients who are unable to indicate when they require using the toilet or when they are totally dependent on others for their needs. This also depends on how

disabled the patient is, thus a compromise has to be made between the caregiver and the patient to decide on a reasonable and acceptable degree of privacy taking into consideration the risks faced by older adults. According to the findings of this study, those elderly people who had privacy during defecation were more likely to experience a resolution of their fecal incontinence, while the less dependent patients like those who could walk by themselves to the toilet were more likely to get help for their illness.

3 RESEARCH METHODOLOGY

3.1 Systematic Literature Review

In most areas of health care, there are too many studies to be identified and considered in order to make well-informed decisions. The introduction of systematic reviews of the growing tens of thousands of studies in health care is now used as a potential method to appraise, select, summarize and bring together high quality research evidence relevant to the research question under investigation (Smith et al. 2011). An understanding of systematic literature reviews and how to implement them in practice is becoming mandatory for all professionals involved in the delivery of health care services. These reviews are quite common in nursing, medicine, psychology, occupational therapy among others. They can provide reassurances that the conclusions of individual reviews are consistent, or not. The quality of individual reviews may be assessed, so that evidence can be highlighted and provide definitive summaries that could be used to inform health practices (Smith et al. 2011).

A thorough search of the literature for relevant papers represents an important initial step in a systematic literature review. The methodology section of the review will list the databases and citation indexes searched, such as Web of Science, Google Scholar and EBSCO as well as individual journals. The titles and abstracts of the identified articles are checked against predetermined criteria for eligibility and relevance. Systematic reviews may use quantitative statistical techniques such as meta-analysis or qualitative reviews which adheres to the standards for gathering, analyzing and reporting evidence. In this case, the qualitative approach will be preferable for the author due to the small sample size of the data to be reviewed and analyzed. According to Smith et al. (2011), the Cochrane Handbook outlines eight steps for preparing a systematic review. These steps include:

- Defining the review questions and developing criteria for including studies

- Searching for studies

- Selecting studies and collecting data

- Assessing risk of bias in including studies

- Analyzing data and undertaking meta-analyses

- Addressing reported biases

- Presenting results and summary of findings tables

- Interpreting results and drawing conclusions

The author adopted the steps that are suitable and rejected or modified those that are not. The steps taken by the author in the systematic literature review are presented in the next subsection below.

3.2   Search Strategy and Data Collection

Undertaking a systematic review entailed an outlined research protocol to be followed by the author. The protocol includes:

-   The scoping and screening of suitable databases for data search

-   The searching of selected database for data extraction

-   A clearly outlined criteria for data selection

-   A summary of extracted data ready for analysis

3.2.1   Scoping and Screening of Database

Articles related to privacy in health care were initially searched in Google Web to get a general overview of possible articles, their access and free availability. Most of the documents were general documents with few scientific articles. The search was further refined by exploring the Google Scholar search engine. Google scholar provided mainly scientific articles which was better. After reading the abstracts of many of the articles, the full articles could not be accessed. Moreover, Google scholar fell short of systematically sorting the articles in a suitable way for the study. For example it was difficult to get the most relevant articles first or to sort the articles in order of their year of publication, which on the other hand are the main strength of other search engines

such as the Web of Science and EBSCO database. Although the EBSCO database provides a range of library services including searching and accessing scientific articles, this author found it easier to use the Web of Science database accessed through the NELLI portal that is connected to the E-library of the University of Helsinki network.

3.2.2 Database Search

The Web of Science database was searched for data extraction. Web of Science is an online academic citation index designed for providing access to multiple databases, cross-disciplinary research and in-depth exploration of specialized subfields within an academic or scientific discipline. Key words accessed in the Web of Science for this study are related to the topic under investigation. A pre-search was conducted to test the keywords, search strings and topics with the most searched results. The pre-search yielded 122 results. It was conducted using the following keywords, search strings and topics: (i) - "institutional care?" or elderly and privacy OR (ii) – "institutional care?" or elderly home and privacy OR (iii) – "geriatric care?" or nursing and privacy. This was deemed by the author to be small and insufficient to sort out the final articles for review. So a new set of keywords, search strings and topics were used to obtain a higher search result which was then used for selecting the articles. For the actual searches after pre-searching, the database used the following sets of keywords, search strings and topics for the search:

(i) - "health services or practice?" and privacy

   OR

(ii) - elderly and privacy

   OR

(iii) - nursing and privacy

The search results found 447 articles related to the key words. The results were sorted in order of relevance to privacy of elderly patients in nursing homes. The abstract of the articles were scanned and 7 scientific articles selected. A second search was conducted

within the 447 articles using the keyword "nurse" and it resulted to 361 articles which were still too large for screening. A third search was conducted within the 361 articles using the keyword elder. This third search refined the result into 77 articles among which 5 was further selected to add to the 7 selected articles making a total of selected 12 articles for the study as shown in Table 1.

Table 2. Steps taken to access and select articles in the Web of Science database

Search levels	Activity	Total result	Selected articles
First level	keywords and string search	447	7
Second level	refined search within result	361	0
Third level	refined search within result	77	5
Total			**12**

3.2.3 Data Selection Criteria

Clearly outlined criteria were used for selecting the articles which represented the data for analysis. Since the research focuses on privacy of the elderly patients in nursing homes, studies were included if they meet the following criteria:

i- Studies that addressed the perception of elderly or and caregiver on privacy

ii-   Studies that addressed the factors affecting privacy in health practices

iii-   Studies centered on privacy in caregiving

iv-   Studies that dealt on the intrusion into patients privacy

v-   Studies that addressed privacy during interaction between patients and care givers

vi-   Studies that focused on privacy in nursing homes and not the homes of patients

vii-   Studies that addressed the management of privacy issues in nursing homes

viii-   Studies written in English and were published after 1995

ix-   Studies that are based on empirical and not theoretical research

x-   Full access to and availability of the electronic copy of the study

xi-   Studies conducted in developed countries particularly in Europe

xii-   Studies published as scientific articles and not conference proceedings

3.2.4   Data Extraction

Detail general information of the selected 12 studies is presented in Table 3+. The selected studies will be further analysed, synthesised and the findings presented in the result section.

Table 3. A summary of selected 12 studies from the Web of Science database

Author (year)	Title	Study country	Journal
Heikkinen et al. (2007a)	Privacy and dual loyalties in occupational health practice	Finland	Nursing Ethics
Heikkinen et al. (2007b)	Privacy in occupational health practice: promoting and impeding factors	Finland	Scandinavian Journal of Public Health
Akpan et al. (2006)	Privacy for defecation and fecal incontinence in older adults	England	Journal of Wounds, Ostomy & Continence Nursing
Heikkinen et al. (2005)	Privacy and occupational health services	Finland	Journal of Medical Ethics
Leino-Kilpi et al. (2003a)	Perceptions of autonomy, privacy and informed	Finland, UK, Greece, Spain,	Nursing Ethics

	consent in the care of elderly people in five European countries: general overview	& Germany	
Leino-Kilpi et al. (2003b)	Perceptions of autonomy, privacy and informed consent in the care of elderly people in five European countries: comparison and implications for the future	Finland, UK, Greece, Spain, & Germany	Nursing Ethics
Schoop et al. (2003)	Perception of privacy in the care of elderly people in five European countries	Finland, UK, Greece, Spain, & Germany	Nursing Ethics
Koller and Hantikainen (2002)	Privacy of patients in the forensic department of a psychiatric clinic: a phenomenological study	Switzerland	Nursing Ethics
Graneheim et al. (2001)	Interaction relating to privacy, identity, autonomy and security. An observational study focusing on a woman with dementia and behavioural disturbances and on her care providers	Sweden	Journal of Advanced Nursing
Magnusson and Lützén (1999)	Intrusion into patient privacy: a moral concern in the home care of persons with chronic mental illness	Sweden	Nursing Ethics
Bäck and Wikblad (1998)	Privacy in hospital	Sweden	Journal of Advanced Nursing
Petronio and Kovach (1997)	Managing privacy boundaries: health providers' perceptions of resident care in Scottish nursing homes	Scotland	Journal of Applied Communication Research

3.3 Data Analysis

The initial step for analysing the data involves a simple descriptive evaluation of each of the study, to be presented in a tabular format. The tables may include for example, information on the population under study, Study methods, and sample size of the population, the privacy issues and outcomes, the decisions about items to include in the descriptive table related to the objectives and research questions of the study. The content of the individual studies will be further analysed to highlight and summarize health care privacy-related research areas that have sufficient information as well as those areas deficient of research information. The views of elderly patients and the care givers will also be presented. Their differences and commonalities will be presented as well.

4   RESULTS

This section analyses the selected articles based on studies conducted in Finland and Sweden in relation to the research questions which are:

- What are the most discussed issues on privacy mentioned by elderly patients and care givers in nursing homes?
- What recommendations are presented in the articles when it comes to improving respect for patients' privacy?

4.1   Schopp et al. (2003)

Schopp et al. (2003) Perception of autonomy, privacy and informed consent in the care of elderly people in five European countries, Journal of Nursing Ethics. This comparative study explores issues related to autonomy, privacy and informed consent in nursing practice across Europe. It covers Finland, Spain, Greece, Germany and Scotland. Data collection was done using questionnaires for both nurses and the patients. The results show differences in perceptions of autonomy, privacy and informed consent between staff and patients within all these five countries.

Based on the findings of the above-mentioned study, both caregivers and elderly patients seemed to have similar perceptions on privacy issues in Finland, Germany and the UK. Contrarily, in Greece and Spain, the perceptions were different as nurses believed that they took account of the privacy needs of their patients more than the patients felt was the case. Both patients and nursing staff accept the fact that moving from one's own home into a nursing home presents a whole lot of changes relating to privacy and autonomy as it entails being part of some sort of community life with little or no choice. Also, the issues of architectural limitations were presented by both nurses and patients as most areas of the nursing home or facility always have to be used by most if not all the residents in the home. Using the toilet may be very challenging in a shared room as well. This was due to the lack of adequate resources which make it compulsory to share rooms between clients or patients. Another privacy issue that was raised by both nurses and patients was the difficulty they face in finding a place to spend time alone due to room sharing, no opportunities to choose roommates, restrictions in the daily exercise of

28

activities because of the presence of roommates and disturbances due to the behaviour of roommates. In this way, it was not uncommon to find residents in a nursing home being washed or using the toilet in the presence of their roommates.

On social privacy, the issue of not having a space to call one's own was raised especially as older adults always showed the need for solitude. This implied losing one's own identity which differentiates him/her from others. One major privacy issue raised was the disclosure of personal information in the presence of roommates or other persons in nursing homes. Information on personal diagnosis and other medical or demographic details are very much involved in institutionalized care but the structure and design of nursing homes may limit the level of informational privacy. Finally, both nurses and patients accept the fact that the respect for privacy while providing the much needed care will only succeed when there is a mutual respect flowing between staff and patients as well as a healthy and valuable relationship between them.

The study by Schopp et al. provided some recommendations to boost the level of social, informational, physical and psychological privacy and autonomy that exists in nursing homes. To curb the issue of having one's own space and territory, some degree of privacy can at least be maintained by using curtains while washing patients in shared bedrooms or closing the door to show respect for the person's body. Also, knocking on the doors of patients before going into their room or informing them beforehand could help them feel like they have some control over their social privacy. Nurses and caregivers should treat their patients more as friends than as objects who do not have any need for respect and privacy. When treated as friends, the nurses will always bear in mind the personal needs of the patient hence control or autonomy and privacy will be considered in their interactions. The individuality of the patients too will be acknowledged and the residents/patients will tend to feel more comfortable in their day to day relationship with nurses.

4.2 Bäck and Wikblad (1998)

Bäck and Wikblad (1998) Privacy in Hospital, Journal of Advanced Nursing. This study aims at exploring the attitudes of both patients and nurses towards privacy and to examine whether nurses' perceptions of patients' privacy needs corresponded with the pa-

tients' own reported needs. Data collection was done using questionnaires while the sample size included 120 patients and 42 nurses responsible for the care of the participating patients' individual care. Findings from the study indicate that both patients and nurses agree on the general major components of privacy in general but privacy in hospital was estimated more highly by the nurses than by patients themselves. Talking to the doctor in private was rated the highest. Patients in long term care had higher privacy preferences than those in acute care.

Overview of results: This section will present the results of the study in relation to the research questions which are:

- What are the most discussed issues on privacy for elderly patients and caregivers in nursing homes?
- What recommendations are presented in the articles when it comes to improving respect for patients' privacy?

The table below shows both issues of privacy mentioned and their ratings between nurses and patients.

Table 4. Analysis of Bäck and Wikblad (2998)

Patients	Nurses	Recommendations
Knocking on the door before entering a patient's room	Nurses estimated it higher than patients	Nurses should knock before entering the patient's room or inform in advance
Patient's desire to be cared for by a nurse of the same sex	Nurses rated higher than patients	Check the possibility of employing caregivers of both sexes as much as possible
Ability of the patient to select his/her own visitors when in hospital	Highly rated by nurses than patients	Visitors should call before hand so that consent can be sought from the patient.
Having private time with my nearest	Nurses agreed and rated it higher than patients	Space should be provided where a patient can have private time with

		family members
Possibility of being left alone at times when willing	Nurses agree with a higher rating	Patients should not be forced to sit with others against their wish and their consent should be sought before displacing them
Possibility to have meals in private	Nurses agreed and rated it highly important than patients	Ask the consent and wish of the patient during mealtimes
Possibility to do morning toilet in private	Both nurses and patients agreed and rated it high	Close the toilet doors or spread curtains to maintain privacy during toileting
Be able to talk to my nurse and physician in private	Nurses rated this aspect slightly higher than patients	Nurses and physicians should make space to talk in private with their patients
Possibility to sleep in a single room	Nurses agreed but with a lower rating than patients	Architecture should consider providing single rooms for patients who wish to have it

This study shows similarities between the perceptions of privacy by both nurses and patients though with differences in the rating of importance in the respect for patients' privacy.

4.3   Leino-Kilpi et al. (2003b)

Leino-Kilpi et al. (2003b) Perception of autonomy, privacy and informed consent in the care of elderly people in five European countries: Comparison and implications for the future, Journal of Nursing Ethics. This article which is the last of a set of five articles focuses on the perceptions of nurses and elderly patients on the realization of autonomy, privacy and informed consent in five European countries: Finland, UK, Greece, Spain and Germany. Comparisons between the concepts and countries indicate that both nurses and patients rated privacy with the highest importance and informed consent the lowest. Autonomy is best realized in Spain, privacy in the UK and informed consent in Finland. Data was collected using questionnaires for nurses on one hand and patients on the other. Nurses responded to self-completion questionnaires while the elderly participants had structured interviews. The data were analyzed statistically.

31

Overview of results: In this section, the results of the above-mentioned study will be presented as per the perceptions of various standards and their ratings by patients and nurses in various countries followed by recommendations.

Table 5. Analysis of Leino-Kilpi et al. (2003b)

Standard	Patients	Caregivers	Recommendations
Privacy	Patients view privacy as significantly maintained in nursing care. Best realized in the UK	Nurses also rated it significantly higher in nursing care. Best realized in the UK	Greater emphasis should be placed on the analysis of patients' values, what they respect, what they expect and also what they define as good quality nursing care
Autonomy	Patients agree that it was better realized in nursing care Best maintained in Spain.	Caregivers also agree that it was realized. Best attained in the UK	Continuous education programmes should be organized to help nurses gain a better understanding of ethical issues and problems
Informed Consent	Less maintained in nursing care. Best realized in Finland	Less maintained in nursing care practice. Best achieved in the UK	Attention should be paid to what is the best way of obtaining informed consent from patients.

It should be worth noting here that privacy covers issues like physical privacy, not having people see the physical bodies of patients in nursing care institutions. Autonomy on its part covers control and self-determination (social and psychological privacy) whereby the patients are able to control the level of social interaction that they get involved into and being able to maintain some degree of identity from others. Informed Consent is related more to information gotten from patients and how such information is collected and managed by caregivers (informational privacy).The study thus covers the various dimensions of privacy: physical, social psychological and informational.

4.4 Magnusson and Lützén (1999)

Magnusson and Lützén (1999) Intrusion into patient privacy: A moral concern in the home care of persons with chronic mental illness, Journal of Nursing Ethics. This study had as its objective to identify and analyse ethical decision making in the home care of persons with long-term mental illness. A focus was placed on how health care workers interpret and deal with the principle of autonomy in actual situations. Data was collected from an interactive discussion from three focus groups involving mental health nurses who were experienced in the home care of persons with chronic mental illness. The audiotaped sessions were then transcribed and analyzed comparatively. Results showed the conflict that health nurses face between their professional role and their moral role.

Overview of results: In this section, the ways in which patients who receive home care tried to maintain their privacy is outlined as well as the ways in which the nurses respond to such behaviour as they ensure that they provide the much needed care while avoiding to violate or intrude into the patients' privacy. Recommendations are also provided based on the findings of the study. Three dimensions of the theme of respect for patients' privacy were identified:

Table 6. Analysis of Magnusson and Lützén (3999)

Dimension	Patients	Caregiver	Recommendations
Intruding in the home of the patient	Not always willing to open the door to let nurses in. At times pretend not to be home.	Nurses felt like intruders but also recognized the patients' attempts to maintain his/her privacy and exercise autonomy. Nurses also found it controversial as they try to maintain a high level of professionalism by performing the required tasks while	Caregivers need to learn how to be flexible to swap roles and adapt to the customs of the patient. Wait without pressurizing the patient so as to build up the patient's trust then he/she will open the door for you or allow you into his territory.

		avoiding intrusion	
Experiencing fluctuating boundaries	Patients at times look at nurses as their friends and feel disappointed when the nurses do not meet up with their expectations	Caregivers perceive their relationship with patients as more professional and face confusion in drawing out the boundary between them. The atmosphere in care institutions are very different from home care settings as well as the relationship that exists between nurses and patients.	Professional responsibility should overshadow. The nurse should at times decide for the patient based on what is good and important for the health of the patient due to the knowledge and experience that the nurse has.
Respecting or transgressing the right to privacy	Patients always expect their self-determination and autonomy to be respected so they put boundaries that they expect their nurses to follow	Caregivers often find it weird to leave the patients to decide for themselves as their mental state is not good. Patient autonomy is respected as much as possible.	Apply the "wait and see" principle thus leaving the patient to decide then wait and see his/her reaction. Professional responsibility and accountability for he safety and health of patients should dominate the idea of self-determination.
Situating mutual vulnerability	Patients always felt vulnerable to the nurses as their caregivers who will always do what is best for the health of the patient. Patients feel powerless and outnumbered seeing more than one nurse	Caregivers felt vulnerable to irrational, aggressive or other unpredictable behaviour. Nurses saw themselves as "taking risks" by going to patients' homes alone	Assess the emotional climate at the patient's home, attempt to know who the patient was as a person. Communicate to the patient that it feels safer to be two and he/she will in turn feel safe in the company of the two nurses. Air out feelings during and after difficult encounters and receiving encouragement should be a moral obligation to caregivers.

4.5   Graneheim et al. (2001)

Graneheim et al. (2001) Interaction relating to privacy, identity, autonomy and security. An observational study focusing on a woman with dementia and 'behavioural disturbances' and on her care providers, Journal of Advanced Nursing. This study centers on the relationship that exists between the patient and her care providers and how they act in relation to each other. Data was collected through participant observations involving one woman with dementia and six care providers. This was followed by a reflective dialogue focusing on the interaction between the woman and her care givers. The observational notes were tape-recorded, the reflective dialogues fixed as a text and then a thematic content analysis done. The findings show that the interaction between the woman and her care providers relates to privacy, identity, autonomy and security which are all interrelated.

Overview of results: This section clearly states how the woman with dementia (Ruth) relates with her care givers and vice versa in relation to the various concepts: privacy, identity, autonomy and security. Recommendations are also provided as to what is mentioned in the text like what the nurses do in order not to invade the personal space of their patient.

Table 7. Analysis of Graneheim et al. (2004)

Concept	Patient	Caregivers	Recommendation
Privacy	-Fights to protect her own personal space and defends her body zone from intrusion by covering herself with a quilt, she also uses physical violence against her caregivers and slams the door between herself and the nurses to maintain her privacy and boundaries.	Ruth invades the physical space of the care providers by visiting the ward office and scattering the papers. -Nurses also invade Ruth's personal space by coming too close, using physical restraints like belts and	Nurses ask her permission before entering her room, -they knock and wait for a reply, -they ask her permission before starting to wash her,

	Ruth defends herself against closeness by withdrawal or by rejecting the care providers. Ruth corrects the nurses by saying "I shall go to the toilet not you."	making her private matters into common matters. -Nurses address Ruth as we instead of you "shall we go to the toilet?" -Care providers discuss about her rash and itch over her head while she is listening	-nurses allow her a certain degree of movement during morning toilet.
Identity	Ruth struggles to be confirmed and she confirms others. She attracts attention by throwing objects around or by using things to hammer on the door to get attention from the nurses. Ruth confirms others by saying hello and smiling at others. She appreciates the nurses, observers and fellow residents. Also shows concern about the way nurses dress e.g. adjusting their collars.	Nurses preserve Ruth's identity by orienting her to reality, being available, relating to her life history, and giving her new opportunities by avoiding conflicts. They also try to meet her in her own world. -Nurses are explicit to her so that she understands the situation at hand.	Nurses should be available for Ruth when she needs help with the toilet, if she wants breakfast. They also follow her way of talking and thinking. The nurses also avoid reacting to her when she gets violent. Being explicit and addressing her in a way that she understands for instance "Isn't this your pair of shoes?"

Auton-omy	Ruth tries to get her will respected by verbally asking, dismissing and rejecting the care providers' offers of help like asking "what are you doing here?" She rejects by saying "Get out of here". Also Ruth threatens to tell the actions of the nurses to others like "Mum and Dad, I shall tell them what you have done". She doesn't obey the nurses when put under pressure.	Nurses respect her will by asking what she wants. They also take her wishes into consideration and let her take the initiative. They ask her consent on private matters, ask her permission before starting to take care of her and also accept "no" for an answer. Nurses also disregard Ruth's wishes at times by not consulting her in private matters and acting in contradiction to her wishes.	Care providers should wait for Ruth to say "yes" before they can do anything with her. Nurses should always think of alternatives to Ruth's behaviour and also try later.
Security	Ruth's whereabout is often checked for her own security and the security of fellow residents.	They always try to know about Ruth, where she is and what she is doing. They guide her to act safely.	

It is worth mentioning that the concepts of privacy, identity, autonomy and security are interwoven and this makes it difficult to maintain a high level of all. By trying to respect the need for privacy, the need for identity can be jeopardized. In the study, it was realized that interaction relating to the intertwined phenomena of privacy-autonomy is in conflict with interaction relating to identity and security.

4.6 Heikkinen et al. (2007a)

Heikkinen et al. (2007a) Privacy and dual loyalties in occupational health practice, Journal of Nursing Ethics. This study concentrates on the course of action that occupational health professionals take in respect of privacy in a situation of dual loyalty between employees who wish to maintain their privacy and employers who have a legitimate right to know about personal issues. Data was collected using questionnaires that

were sent by post to randomly selected respondents. The sample consisted of nurses and physicians with an overall respondent rate of 64% as 140 nurses and 94 physicians returned the answered questionnaires. The results show that privacy, as an absolute value is not in the interest of either employees or employers and also that where dual loyalty is concerned, the best and most reliable course of action in dealing with drug and work community problems will be to rely on a tripartite cooperation.

Overview of results: In this overview, the various courses of action in ethically problematic situations are presented. They are laissez-passer, delegator, employee advocacy, employer advocacy, acting like a civil servant and tripartite co-operation. Laissez-passer refers in this case to a person who will not even try to tackle a dilemma but just let it go by. A delegator prefers to delegate tasks or responsibility to others while employee advocacy will weigh the dilemmas to the employee's perspective and the employer advocate will weigh them from the employer's perspective. The civil servant takes an authoritative approach instead of working with others while the tripartite cooperation refers to working together with both employers and employees. Among these courses of actions, the results showed that the most widely adopted were tripartite cooperation, employee advocacy and acting like a civil servant. Results show the differences between nurses and physicians on how they resolve ethical conflicts.

Table 8. Analysis of Heikkinen et al. (2007a)

Course of action	Nurses	Physicians
Tripartite cooperation	Nurses recommended an overall survey of the working environment	Physicians did not think of this as much as the nurses did

Employee advocacy	Nurses were more emphatic in the fact that in their capacity as health professionals, they were now allowed to provide illness-related information when needed	Less emphatic than nurses
Civil servant	Nurses were less emphatic on this course of action in solving privacy dilemmas	Physicians exercised authority in recommending this course of action as good

Here, it would be good to mention that no recommendations were provided as this study did not examine privacy but rather looked at the differences in opinion that exists between physicians on one hand and nurses on the other relating to ethically problematic matters on dealing with privacy.

4.7 Heikkinen et al. (2007b)

Heikkinen et al. (2007b) Privacy in occupational health practice: Promoting and impeding factors, Scandinavian Journal of Public Health. This article examines the views of occupational health professionals, employees and employers on the promoting and impeding factors of privacy in occupational health practice. Data was collected through theme interviews with 44 subjects and content analysis then followed. The results showed the two different roles played by occupational health professionals in Finland towards their two groups of clients: employees and employers. Factors that promote privacy were referred to as adequate behaviour such as respect, good communication, presence and adequate knowledge base (instinct, work experience, ethical thinking and knowledge of legislation).The impeding factors to the realization of privacy in caring relationships were referred to as inadequate behaviour such as untrustworthy, busy, distant and "friend". Both promoting and impeding factors were organized into two content areas which were "caregiving" (patient- caregiver relationship) and tripartite cooperation (cooperation between occupational health professionals, employees and employer).

Overview of results: In this overview, the findings will be presented according to two main categories, promoting factors on one hand and impeding factors on the other. Each group of factors will be subdivided into the various behavioural issues (subcategories) relating to the group. Recommendations will be provided also based on the findings of the study. The first table is based on the first content area: care giving while the second table is based on tripartite cooperation.

It would be good to understand that privacy, in the context of occupational health practice cannot be seen only from the employees' point of view as it also serves the interests of employers. Before an optimal level of privacy can be reached, questions concerning the diverse and often simultaneous duties and roles towards both employers and employees require a close look.

Table 9. Analysis of Heikkinen et al. (2007b): Caregiving

Factors	OH professionals	Employees	Employers	Recommendations
Promoting Factors -respect -good communication -presence -instinct -work experience -ethical thinking -knowledge of legislation	Agree that all these are important factors in promoting privacy in OH.	Employees also agreed that all except work experience and knowledge of legislation were promoting factors for the realization of privacy in OH practice.	Agreed on respect, good communication, ethical thinking and knowledge of legislation but disregarded the others as important factors.	These factors are the key to maintaining a suitable level of privacy with patients therefore need to be upheld. A good knowledge base is also good as all knowledge must be interpreted before being applied in practice. Listen to patients' wishes.
Impeding Factors -untrustworthy -busy -distant -"friend"	Oh professionals regarded all these factors as impeding the promotion of privacy in OH practice	Regarded all except "friend" as impeding factors	Regarded untrustworthy and "friend" as impeding factors but not busy and distant.	Dialectic interaction between patient and caregiver should be improved. Professionalism should be enhanced.

Table 10. Analysis of Heikkinen et al. (2007b): Tripartite cooperation5

Factors	OH professionals	Employees	Employers	Recommendations
Promoting factors -impartiality -regular contacts -Community spirit -fair play -informed consent -advocacy	Professionals agreed on all as promoting the realization of privacy in OH practice	Employees also accepted	Employers agreed	Objectivity should be encouraged between the three parties. Permission should also be gotten before disseminating sensitive information.
Impeding factors -confusions in confidentiality -confusions in duties -confusions in roles	They regarded these as impeding the realization of privacy in OH practice	Employees also saw these factors as impeding the respect for privacy	Employers did also	Preconditions for confidential cooperation must be established.

4.8 Summary of Results

This summary will look at the common issues of privacy mentioned in the articles, therefore the main themes will be listed and the articles in which the themes are mentioned put in brackets. It will be good to note that not all articles mention all the common themes as it depends on what the article focuses on. The numbers indicate the order in which the articles have been analyzed for instance (1) means the first analyzed article in the results section.

Table 11. Main privacy themes and articles in which they are mentioned6

Main themes	Articles in which they are mentioned
Own room and space	1, 2, 3, 5
Mutual respect between staff and patients	1, 5, 7
Informed consent	1, 5, 7
Autonomy	1, 2, 3, 4
Confidentiality	1, 2, 3, 5
Friendship and attention	4, 5

5   DISCUSSION

In this section, the author refers back to the research questions guiding this study which are:

- What are the most discussed issues on privacy for the elderly patients and care givers in nursing homes?
- What recommendations are presented in the articles when it comes to improving respect for patients' privacy?

5.1   Most discussed issues on privacy

5.1.1   Elderly Perspective

From the data collected during this study, it seems that the elderly people usually feel the need for privacy but have little or no choice in the care giving process which makes them tend not to value their privacy as much as they should have if they had alternatives. The most discussed issues that the elderly mention in the articles fall under the different dimensions of privacy: informational, socio-psychological and physical.

On informational privacy, the elderly people always felt that their medical results or their socio-demographic information should not be read in public or to the hearing of their room mates or passers-by. They also felt that their consent has to be sought before any form of dissemination of their information or personal details is done. Another thing that the elderly think violates their privacy is when they have to speak with their nurse or physician in the presence of other nursing home residents or to the hearing of others. Nurses were said to discuss patients' personal information during their break or over the head of the patient, the elderly usually felt disrespected in such a case.

Talking about the social and psychological dimensions of privacy, the elderly people always show the need for them to have control over their interactions with other residents and even with the nurses. They often felt that they were not given the chance to decide when they interact with whom they want and were not allowed to choose. This was in line with what the elderly referred to as lack of autonomy and control over what is done to the nursing home residents as they thought that nurses followed a routine ir-

respective of the wishes of the patient. An example was during meals when the patients have to eat all at the same time no matter whether they wish to do so at that time or not. Also, eating in the presence of other residents was usually not appreciated as some got to know the eating difficulties of fellow residents. Elderly nursing home residents also feel that they should be spoken to in a friendly manner and not treated as objects but rather as friends to the nurses. More often than not, the residents feel that things should be done according to their will and not to the wishes of the nurses and they should not be subjected to any form of routine without their consent.

Their physical bodies were usually exposed to the view of other room mates or even passers-by to the disadvantage of the residents. Some elderly patients have claimed that the curtains do not completely separate the spaces outlined for each of the residents in the room and cannot provide enough privacy. Among the elderly patients, some feel that the touch of the nurses at times is a form of intrusion especially when done without their consent or against their wish.

5.1.2 Nurses Perspective

On the part of the nurses, they also perceived privacy in the same way as the patients but they thought that the respect of privacy was limited by both architectural designs and the inadequate resources available in the care sector. Nurses and care givers also raised some issues pertaining to all the various dimensions of privacy ranging from physical, social-psychological (socio-psychological) and informational. On the physical privacy, the nurses also presented the issue of not having enough privacy while doing the morning hygiene to the patients. This was due to the fact that the rooms were often shared rooms with only curtains to use in separating the spaces and the beds. Such curtains did not always maintain the expected degree of privacy especially when taking care of the patients in their rooms. Another challenge that nurses and caregivers face was maintaining privacy when a patient is using the toilet. The nurses are quite aware of the fact that they need to maintain a high degree of privacy when an elderly goes to the toilet but this is hindered by the fact that the toilet is always used by more than one patient. Nurses often do their possible best to close the toilet doors, use the curtains to shade the patient who is using the toilet from other residents or roommates or even passers-by but this has not often helped as much as expected. For patients using a com-

mode in the bedroom, it has always been hard to maintain respect for privacy as this usually needs more space than the bedroom itself provides.

On socio-psychological privacy which has to do with interactions and the need for the patients to have control and autonomy over their social interactions, nurses understand very well the need to give the elderly some degree of autonomy but the way the work programme of the caregivers is made often submits the nursing home residents into some sort of routine. The consent of the patients has not often been sought before visitors are allowed neither have the residents been informed before hand. Nurses have always tried to maintain some level of privacy by knocking on the doors of patients and waiting for a positive response before going in or by informing the patient in time before going into his or her room. This has not often worked successfully as it still feels at times like they have not done enough especially at times when nurses have had to go in even without the consent of the patient if necessary for fear of endangering the patient. An important factor of socio-psychological privacy that nurses brought up was the lack of personal space within the nursing facility where a patient can have quiet time alone. Almost all if not all areas of the nursing homes are shared between residents which makes it hard for patients to have control over when they want to interact and when they do not. Elderly people have times when they want to be left alone but this wish is not often fulfilled as they do not have a place where they can just sit without anyone. They also lack the means to choose their roommates as the caregivers choose for them based on certain conditions. Nurses see the importance of having a quiet time alone or with close relatives but often get it hard fulfilling the patients' wishes all the time. Often times, meetings between nursing home residents are organized with little or no consent from the patients themselves as such meetings or activities are usually made based on the plan of activities drawn up by the caregivers or the administration. Nurses know that the patients expect them to have a friendly relationship with the residents but such a relationship has often been difficult to build since the staff-patient relationship only lasts for a while (during the care period) and can end so prematurely. Also, nurses perceive touching a patient against his/her wish as intrusion or violation of patient privacy.

On the informational dimension of privacy, nurses know that they have to hold the information of patients confidential and no form of dissemination whatever should be done without the consent of the resident or his or her close relative in a case where the resident cannot decide for himself due to mental disability. Caregivers also acknowledge the fact that they should not discuss the medical history or diagnosis of an elderly to the hearing of other residents or strangers as this would mean a violation of privacy. A fundamental issue raised by nurses on privacy dealing with information is when they have to give out the information of a patient to another care sector like the dentist as they think is for the good of the patient. In such a case nurses often feel that the consent of the patient may not necessarily be needed as the information is still within the care professionals. It poses a big challenge when the patient is mentally not fit to decide and there is no close relative from whom consent can be sought as it has often resulted that the nurses decide for the patient or the attending doctor decides on behalf of the patient depending on the urgency and need for the decision. For instance when a particular form of treatment which is thought to be the best for the patient has to be carried out and it is certain that if the patient is asked to decide, he/she will not be able to do so due to his/her mental state and there is no close person from whom such consent has to be gotten, the care team will only have to carry out the process if they see that it is the only way out.

Conclusively, both nurses and elderly patients have discussed the same issues on privacy though they differ in the importance they attach to the need and respect for privacy. As per the studies analyzed, nurses usually attach a lot more importance to respect for privacy than the elderly themselves. The elderly often face the challenge of adapting to life within a care facility as they find it different from their own private homes. The challenge to the nurses is how to provide the much needed care without jeopardizing the privacy of the elderly patients.

5.2 Recommendations

Based on the findings of this study, some recommendations are made to help improve on the respect for privacy in elderly care. On the side of the patients, some form of education should be done involving the elderly patients and their close relatives who are the

ones to decide in case the elderly patient cannot do so for him/herself. The main aim of such education will be to expose the patients and their relations to certain care procedures that may make it hard to maintain a high level of privacy and that may hinder the care professionals from always seeking the consent from the patient. In such procedures which have to be done in absolute urgency, the nurses may be caught up by time and may not be able to ask for the consent of either the patient or his/her relatives e.g. if the need for an urgent operation arises where the operation is much needed than the consent of the patient/relative, the best will be done for the good of the patient. Such an education will serve as an eye opener which will also help the patients or their relatives to understand why certain decisions were taken. Also, a preparatory meeting should be held with the patients and his/her family relatives before the patient starts living in a nursing home or facility. This will aim at informing them on how life in the facility takes place and get their opinions on certain aspects of the nursing home which may not be appealing to the patient/relatives. This will not only help to prepare the minds of the patient but will also help him/her adapt easily to the nursing home. The feedback that is gotten from the patient/relatives will also help the caregivers and the administration to ameliorate their services.

It will be a good idea for nurses to always have refresher courses on ethics so as to keep ethical considerations always fresh in their minds as they perform the task of providing care. Routine should be avoided as much as possible during work unless otherwise. Ethics is the basis on which the act of caring should be done especially when dealing with human beings who have dignity and are individualistic in nature. Employers will need to face the challenge of providing the resources for such educative activities to their employees so as to benefit the patients and also improve on the services provided. More resources should be allocated to provide facilities which enhance privacy and the respect for it, for instance the design of the shared rooms can be modified in a way that the curtains used between the patients are wide enough to cover as much as possible. There should be a clear demarcation between the spaces of two room mates in a nursing facility so that they both know where each of their personal spaces begins and ends. The option of providing single rooms to elderly patients who deem it necessary should be provided with a possibility of a higher fee than the shared rooms. Space can often be provided for being alone or with visitors during the design and construction of a nursing

home. Most of these recommendations will imply large amounts of financial resources but will also go a long way in avoiding ethical problems and improve on the care sector if carried out diligently.

6 CONCLUSIONS

6.1 Key Findings

The results from this study have brought to light some important concluding relationships between increasing aging, privacy and various concepts in nursing care. One of such is the relationship between age and autonomy/control in one's life. As one starts ageing, the amount of control and privacy that a person has over his/her own life decreases as he/she starts depending more on others to provide for basic needs and care. This also takes us to the relationship that exists between age and dependence on others for assistance. As a person grows older he/she tends to depend more on others for care and basic needs of living. This is often due to the fact that the body weakens and functional capacity in general goes down, implying an absolute need for other people's help and therefore a reduction in privacy. The relationships between age and control of own life on one hand and between age and dependence for assistance on the other are represented in Figures 1 and 2 below.
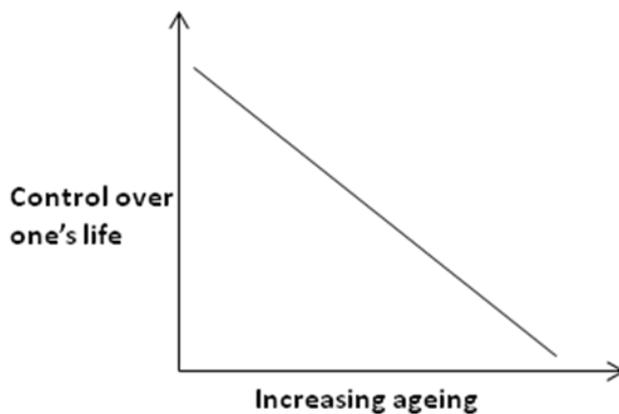

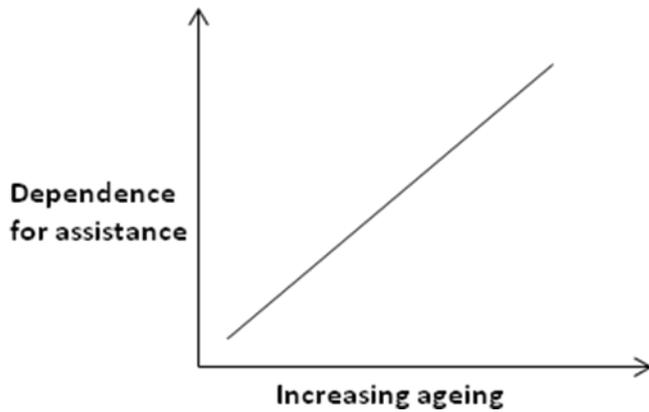*Figure 1. Relationship between age and control over one's life*

Figure 2. Relationship between age and dependence for assistance

6.2   Implications for Further Research

Further research should be done on how governments can improve on the health sector and encourage more people to be interested in working for this sector. This is due to the fact that a lot of problems which occur in nursing homes are related to the lack of human resources like shortage of workers. From personal experience, nurses are in shortage in most countries as this sector is one of the most highly hit by the fast ageing of its workforce.

Another implication would be ethical knowledge. Nurses and caregivers should be subjected to a deeper knowledge on ethics and the need for it so that they can be able to analyze problems that the elderly face from a subjective point of view. Nurses should also bear in mind the generational differences between the nurses and the elderly as they both represent different generations of persons and quite different eras of human life. More research has to be done relating to the implementation of privacy preferences during the planning and designing of nursing homes and also during the implementation of nursing services as a whole. Present day researchers should consider law as a part of nursing training so as to expose care professionals to the consequences of unethical behaviour. Due to the technical innovations of our times, deeper knowledge into the various effects that information technology has on the maintenance of privacy would be very beneficial to the nursing field.

REFERENCES

Akpan, A., Gosney, M.A., Barret, J., 2006. Privacy for defecation and fecal incontinence in older adults Journal of Wounds, Ostomy and Continence Nursing 33(5):536-540.

Aucoin, J. and Lane, P., 2004. Hospital nursing: space invasion. Nursing 34(2):32.

Altman, I. 1975. The Environment and social behaviour: privacy, personal space, territory and crowding. Monterey, California: Brooks-Coles.

Alzheimer's Society 2011. Understanding and respecting the persons with dementia. http://alzheimers.org.uk/site/scripts/home_info.php?homepageID=53 (Retrieved 21 September 2011).

Bates, A.P. 1964. Privacy - a useful concept? Social Forces 42(4):429-434.

Bauer, I. 1994. Patients'privacy: Explorative study of patients' perceptions of their privacy in a German acute care hospital. Avebury Ashgate, Aldershots.

Bäck, E., and Wikblad, K.1998. Privacy in hospital. Journal of Advanced Nursing 27:940-945.

CARNA (College and Association of Registered Nurses of Alberta) 2005. Professional boundaries for registered nurses: Guidelines for the nurse-client relationship. CARNA, Edmonton, Canada. (Retrieved 24 September 2011). http://www.nurses.ab.ca/pdf/Professional%20Boundaries%20Guidelines.pdf

Clarke, R. 2006. Introduction to dataveillance and information privacy, and definitions of terms. Xamas Consultancy Pty Ltd, Canberra.

CNO (College of Nurses of Ontario) 2009. Confidentiality and privacy – Personal health information. Practice Standards. Retrieved 10 September 2011. http://www.cno.org/Global/docs/prac/41069_privacy.pdf

CRNNS (Registered Nurses of Nova Scotia) 2002. Professional boundaries and expectations for nurse-client relationships. Retrieved 24 September 2011. http://www.crnns.ca/documents/professionalboundaries.pdf.

Coltrane, F., and Pugh, C. D. 1978. Danger signals in staff/patient relationships in the therapeutic milieu. Journal of Psychiatric Nursing and Mental Health Services, 16(6), 34-36.

Cote, J.E. and Levin, C. 2002. Identity formation, agency and culture: a social psychological synthesis. Mahwah, NJ: Erlbaum.

De Vito, J.A. 1991. Human Communication: The Basic Course. 5th edn, Harper and Collins, New York.

Erikson, E, 1979. Dimensions of a new identity. The Jefferson lectures in the Humanities. Norton and Company Inc. New York.

Erikson, E, (Ed) 1978. Adulthood. Norton and Co, Oxford, England.

Farrell, G.A. 1991. How accurately do nurses perceive patients' needs? A comparison of general and psychiatric settings. Journal of Advanced Nursing 16:1062-1070.

Finlex 2011. Finlex data bank. http://www.finlex.fi/en/ (retrieve 17 September 2011)

Graneheim, U.H.,Norberg, A., and Jansson, L. 2001. Interaction relating to privacy, identity, autonomy and security. An observational study focusing on a woman with dementia and behavioural disturbances and on her care providers. Journal of Advanced Nursing 36(2):256-265.

Heikkinen, A., Launis, V., Waiwright, P., and Leino-Kilpi, H. 2005. Privacy and occupational health services. Journal of Medical Ethics 32:522-525.

Heikkinen, A., Wickstrom, G., Leino-Kilpi, H., and Katajisto, J. 2007a. Privacy and dual loyalties in occupational health practice. Nursing Ethics 14(5):765-790.

Heikkinen, A., Wickstrom, G., Leino-Kilpi, H., 2007b. Privacy in occupational health practice: promoting and impeding factors. Scandinavian Journal of Public Health 35:116-124.

Hickson, M.L., and Stacks, D.W.1989. Nonverbal communication: studies and application. 2nd Edition, Dubuque, Iowa, Wm. C. Brown Publications.

Hughes, M. 2004. Privacy in aged care. Australasian Journal on Ageing, 23(3):110-114.

Jones, S.E., and Yarbough, A.E. 1985. A naturalistic study of the meanings of touch. Communication Monographs, 52(1):19-56.

Jourard, S.M. 1966. Some Psychological Aspects of Privacy. Law and Contemporary Problems 31(2):307-318.

Koller, K., and Hantikainen, V. 2002. Privacy of patients in the forensic department of a psychiatric clinic: a phenomenological study. Nursing Ethics 9(4):347-360.

Lawton, M.P., and Bader, J. 1970. Wish for privacy by young and old. Journal of Gerontology 25(1):48-54.

Leino-Kilpi, H., Valimaki, M., Dassen, T., Lemonidou, C., Schopp, A., Scott, A., Arndt, M., and Kaljonen, A. 2003a. Perceptions of autonomy, privacy and informed consent in the care of elderly people in five European countries: general overview. Nursing Ethics 10(1):18-27

Leino-Kilpi, H., Valimaki, M., Dassen, T., Lemonidou, C., Schopp, A., Scott, A., Arndt, M., and Kaljonen, A. 2003b. Perceptions of autonomy, privacy and informed consent in the care of elderly people in five European countries: comparison and implications for the future. Nursing Ethics 10(1):58-66.

London, L. 2005. Dual loyalties and the ethical and human rights obligations of occupational health professionals. American Journal of Industrial Medicine 47:322-332.

Lyman, S.M., and Scott, M.B. 1967. Territoriality: a neglected sociological dimension. Social Problems 15(2):236-249.

Magnusson, A., and Lützén, K. 1999. Intrusion into patient privacy: a moral concern in the home care of persons with chronic mental illness. Nursing Ethics 6(5):399-410.

Milstein, F. 1971. Clarifying the patient's sense of identity. International Journal of Offenders and Comparative Criminology 15:16-20.

Ministry of Social Affairs and Health (Finland) 2011. Legislations. Retrieved 18 September 2011. http://www.stm.fi/en/social_and_health_services/legislation

Mowinski, J., and Muhlenkamp, A.F. 1981. Systematic misperception: oncology patients' self-reported affective states and their care givers' perceptions. Cancer Nursing 4:485-489.

Parker, B., 1974. A definition of privacy, Rutgers Law Review 27: 275-296.

Parrott, R., Burgoon, J.K., Burgoon, M., and LePoire, B.A.1989. Privacy between physicians and patients: more than a matter of confidentiality. Social Science and Medicin 29(12):1381-1385.

Petronio and Kovach 1997. Managing privacy boundaries: health providers' perceptions of resident care in Scottish nursing homes. Journal of Applied Communication Research 25(2):115-131.

Poterfiled, E. 2011. Health care: social networks threaten patient privacy. Twitter, Facebook and Youtube crash into HIPAA rules. Puget Sound Business Journal.

Privacy International 2004. Overview of privacy. Retrieved 10 September 2011 https://www.privacyinternational.org/article/overview-privacy#[3].

Privacy International 2011. Sweden privacy profile.Retrieved 17th September 2011. https://www.privacyinternational.org/article/sweden-privacy-profile.

Robertson, A.H. 1973. Privacy and human rights: Report and communications presented at the third international colloquy about the European Convention on human rights. Conference Proceedings. University Press, Manchester.

Schopp, A., Leino-Kilpi, H., Valimaki, M., Dassen, T., Gasull, M., Lemonidou, C., Scott, A., Arndt, M., and Kaljonen, A. 2003. Perception of privacy in the care of elderly people in five European countries. Nursing Ethics 10(1):39-47.

Smith et al. 2011Solove, D.J. 2002. Conceptualizing privacy. California Law Review, 90:1087-155.

Swedish Patient Center 2011. Patient rights and responsibilities. retrieved 18 September 2011. http://www.swedish.org/Patient-Visitor-Info/Patient-Information/Patients-Rights---Responsibilities

Tanner, D.C 2008 The family guide to surviving stroke and communication disorders,2nd edition.London UK.

Tutton, E. 1991. An exploration of touch and its use in nursing. in McMahon R & Pearson A (eds) Nursing as Therapy. Chapman 7 Hall, London. 142–169.

Texas Medical Association 2011. Boundary problems. (Retrieved 24 September 2011) http://www.texmed.org/Template.aspx?id=4556

Westin, A. 1968. Privacy and Freedom. New York, Atheneum.

Wheelis, A. 1958. Quest for identity. Norton, New York, USA.